# Report of the Parliamentary Review Committee regarding the New Zealand Cervical Screening Programme June 2015

Pay heed to the dignity of women

**Commissioned by the New Zealand Government** 

Parliamentary Review Committee
The Minister of Health
Parliament, Wellington, New Zealand

# E ngā mana, e ngā reo, e rau rangatira mā Tuhia ki te rangi Tuhia ki te whenua Tuhia ki te ngākau o ngā tāngata Ko te mea nui Ko te aroha Tihei Mauri Ora! Tēnā koutou, tēnā koutou katoa

The first human was a female whose body was moulded out of earth by the god Tāne.

Tāne's mother Papatūānuku advised him, "Go to the soil at Kurawaka, there to go about your work. There the woman can be found, untouched, select and sacred, for she possesses the essence of humankind."

Nā Tāne, ko Hineahuone, te wahine tuatahi ki te ao. Ko Tāne tēnei e whakahā ana i a ia; ka matihe a Hineahuone, ka ora mai. Nō konā te kōrero, "*Tīhei mauri ora*".

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### **Acknowledgements**

Worldwide, cervical cancer is the fourth most common cancer affecting women, with just over half a million new cases of cervical cancer being diagnosed every year. Cervical cancer is also the fourth most common cause of cancer death in women worldwide, with 266,000 deaths in 2012 (IARC 2013). The disease strikes women around the world in their prime, with devastating impacts on those women and their families, and resultant high human, social and economic costs for their communities.

The World Health Organization states that a successful national cervical cancer prevention and control programme requires three high-quality, interdependent, preventive components: primary (human papillomavirus or HPV vaccination), secondary (screening and treatment) and tertiary (treatment and palliative care) services (WHO 2014).

Since the inception of the New Zealand National Cervical Screening Programme (NCSP) in 1990, there have been significant reductions in the incidence of and mortality from cervical cancer. The 2015 Parliamentary Review Committee acknowledges the many health professionals, individuals, organisations and governments that have contributed to the success of the cervical screening programme over the last two-and-ahalf decades. The programme would not have achieved its current success without the individual and collective dedication to delivering a quality programme, committed to reducing morbidity and mortality attributable to cervical cancer. However, there are still women who are suffering and dying from this largely preventable disease, and the Review Committee wishes to encourage the ongoing commitment to reducing the burden of this disease on New Zealand women and their families into the future.

The Review Committee acknowledges and thanks all those who provided feedback during the review process. They provided open and honest opinion, and gave freely of their time and expertise, to inform the Review Committee in its investigations and preparation of this report. The Review Committee also acknowledges the support of the National Screening Unit and the staff who have supported the Review Committee and assisted in the preparation of the report. Finally, the Review Committee thanks and acknowledges the following reviewers who provided expert advice and feedback on the report prior to publication:

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## **Executive summary**

The National Cervical Screening Programme (NCSP) has been highly successful in reducing the incidence of and mortality from cervical cancer. From 1991, when the NCSP commenced, to 2011, cervical cancer mortality declined from 6.2 to 2.4 per 100,000 for all women, and from 13.0 to 5.4 per 100,000 for Māori women<sup>1</sup>. Between 1996 and 2012, cervical cancer incidence declined from 10.5 to 6.2 per 100,000 for women of all ethnicities, and from 25.0 to 12.7 per 100,000 for Māori women (NSU 2014a).

The many high-quality achievements and initiatives of the NCSP, clinicians and staff working within the programme since its inception must be acknowledged. The NCSP is among the most successful cervical cancer screening programmes in the world, and this achievement would not have been possible without the dedication and commitment of many people. This commitment to ensuring New Zealand women have access to a high-quality cervical screening programme includes the regular, ongoing monitoring and evaluation of the programme's performance as well as open and transparent reviews such as the one delivered with this report. The New Zealand Government and all staff working within the programme are to be congratulated.

# Highest-priority key issues and recommendations identified by the 2015 Parliamentary Review Committee

- 1. The incidence of and mortality from cervical cancer in Māori women are twice the incidence and mortality for women from all ethnicities. This inequity needs to be addressed with strategies that will remove barriers to accessing screening services. Including an additional measure of socio-economic status in the regular reporting on and monitoring of participation would enable a greater understanding of the barriers to screening among ethnic groups.
- 2. Ongoing audit of the screening histories of women who develop cervical cancer is paramount. The underpinning rationale is that there are likely to be valuable lessons from these audits that would inform the implementation of quality improvement initiatives.
- 3. 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 National Cervical Screening Programme-Register (NCSP-R). It is recommended that an audit across all District Health Boards (DHBs) is undertaken by December 2015 to ensure colposcopy data is being collected successfully.

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<sup>&</sup>lt;sup>1</sup> Data provided by the NSU in 2015

- 4. High-quality screening programmes need to be supported by high-quality organisational structures, systems and processes. Continuing change processes and loss of corporate knowledge with staff turnovers have had major impacts on the organisational systems in the National Screening Unit (NSU) and NCSP. 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 the Group Manager, NSU; the Programme Manager, NCSP; and the Clinical Leader, NCSP. 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 force.
- 5. Internationally, clinical evidence has shown convincingly that primary human papillomavirus (HPV) screening can deliver greater gains in reducing morbidity and mortality from cervical cancer, and international cervical screening programmes are transitioning to new testing regimes and follow-up protocols. New Zealand must give priority to reviewing the evidence and developing recommendations to transition to a primary HPV screening protocol that will deliver a more effective and efficient programme for the investment. 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.

## All key issues and recommendations identified by the Parliamentary Review Committee 2015

#### Coverage, participation, equity and access

A well-conceived, well-managed national cancer control programme lowers cancer incidence and mortality and improves the quality of life of cancer patients. Although coverage for all women is below the national target of 80%, the NCSP is to be congratulated for enabling access to screening for 76.4% of women aged 25–69 years over the most recently reported three-year period to December 2013. Participation rates in the cervical screening programme compare very favourably with participation rates in other developed countries that have organised cervical screening programmes.

There is, however, room for improvement. The incidence of and mortality from cervical cancer in Māori women are twice the incidence and mortality for women from all ethnicities and this needs to be addressed with strategies that will remove barriers to accessing screening services. Although socio-economic status is an important determinant of health, the NCSP monitoring and annual reports do not currently capture this data. National recruitment strategies are also important and the NCSP should centrally coordinate at a national level a full range of health promotion and recruitment initiatives. A close and collaborative working relationship with the Māori Monitoring and Equity Group will be critical in achieving improved participation rates and reducing the

burden of the disease on the Māori population. This collaborative effort will include developing health promotion and recruitment strategies and working in partnership with the National Kaitiaki Group (NKG) to enable access to data in order to develop and appropriately target strategies. Providers need to offer training in cultural competency to health practitioners to support access to services by women from different cultural backgrounds.

Given the wide variation in early re-screening rates, it is important for the cervical screening programme to regularly monitor and review performance on this indicator across DHBs to determine whether the variation is due to clinical practice that is not conforming with guidelines in those areas with high re-screen rates. The variation in timely follow-up outcomes suggests there may be barriers to accessing services, particularly for Pacific and Māori women. Timely follow-up after an abnormal test result is important. Overcoming barriers will be essential to reduce inequities.

#### Monitoring and evaluation

Comprehensive monitoring reports have been produced by the NCSP since 2004. These reports are now produced biannually by the University of New South Wales, Australia, against a suite of eight groups of monitoring indicators, including coverage, first screening events, withdrawal rates, early re-screening, laboratory indicators, follow-up of women with high-grade cytology and no histology, colposcopy indicators and HPV tests. These reports provide ongoing monitoring against the programme's process measures and indicator targets.

Including an additional measure of socio-economic status in the regular reporting and monitoring of participation would enable a greater understanding of the barriers to screening. In addition, a watching brief on early re-screen rates will be important to ensure that early re-screening does not reduce the cost-effectiveness of the programme and that it does not limit access for women who are not participating in screening regularly. 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.

Data on the accuracy of negative cytology reports in the most recent Monitoring Report showed a significant variance across laboratories. Close monitoring of this indicator is essential. Discussions with pathology experts to determine whether a quality intervention is required would be highly appropriate.

The targets for timely follow-up for women with a high-grade cytology report to accepted referral and colposcopy visit have not been met. Moreover, the proportional over-representation of Māori and Pacific women who are not accessing timely follow-up for treatment and management of suspicious high-grade abnormalities indicates barriers for these women in their ability to access services. Strategies to identify and address these issues are essential.

Complete data for the timeliness of women accessing colposcopy subsequent to persistent low-grade cytology or a low-grade cytology and positive HPV test was not available from the NCSP-R for the latest Monitoring Report. The e-colposcopy project has experienced interoperability challenges, with the result that the majority of providers are unable to upload colposcopy reports. A comprehensive national intervention to resolve these information technology issues is essential.

#### **Quality assurance**

The National Screening Unit has produced a draft document, released for consultation in December 2014, entitled *National Screening Unit Quality Framework 2014: Delivering screening programmes* (NSU 2014c). The core set of six principles is intended to provide a foundation for achieving the NSU's strategic vision of high-quality, equitable and accessible screening programmes. Further, the NCSP Policies and Standards document provides agreed policies, guidelines and standards of practice for health professionals who provide cervical screening services (Ministry of Health 2014a). The NCSP also has well-established advisory group structures, including the Māori Monitoring and Equity Group, which can both support and inform the identification of issues and development of strategies that will assist in the achievement of its quality strategic vision. Engagement of these groups in the quality improvement initiatives for the programme will be critical to their success.

Performance monitoring must inform the development and implementation of strategies that become part of the continuous quality improvement cycle. Monitoring and evaluation and the implementation of quality improvement strategies must be a collaborative process between the NCSP, DHBs, laboratories and the NCSP-R so that learnings can be shared and strategies implemented consistently across the country. Regular, ongoing meetings for monitoring and quality improvement should be scheduled shortly after the release of the biannual monitoring reports, and the agenda for these meetings should be informed by the monitoring report indicators. The actions and outcomes from these meetings would inform the development of, on an ongoing basis, a Quality Improvement Plan for the NCSP.

Ongoing audit of the screening histories of women who develop cervical cancer is recommended. The underpinning rationale is that there are likely to be valuable lessons from these audits that would inform the implementation of quality improvement initiatives. It is essential that these audits occur regularly and include expert clinicians involved in the programme. Any identified system or process gaps or failures should be used to inform quality improvement strategies, and be incorporated into a quality improvement plan.

The NCSP would be enhanced by the introduction of the Plan-Do-Check-Act (PDCA) cycle, particularly during the NCSP's consideration of the biannual monitoring reports. It would likewise benefit from the implementation of a Quality Improvement Plan that informs the ongoing work plan for the programme.

#### Organisational and structural issues

This Parliamentary Review Committee (PRC) 2015 acknowledges that challenges have consistently arisen in terms of organisation and structure. Five essential components are critical to the effectiveness of the programme: a central agency to lead and coordinate the screening pathway; clinical governance; infrastructure and systems to manage a screening programme; monitoring and evaluation; and the quality cycle. Each of these components must operate to a high standard for the programme to meet its objectives of providing the screening pathway for women in New Zealand.

Currently the single most important issue facing the national screening programme in New Zealand is addressing the disparities and inequities that continue to challenge participation in the programme by Māori, Pacific and Asian women.

High-quality screening programmes need to be supported by high-quality organisational structures, systems and processes. A common element of all programmes is the necessity for information systems that meet the specific requirements of screening. Within the confines of available resources, systems should be thoughtfully developed to be as user-friendly as possible. Continuing changes have had major impacts on the organisational systems in the NSU and NCSP, with staff turnovers making change necessary for the continuation of the NCSP. 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 – the Group Manager, NSU; the Programme Manager, NCSP; and the Clinical Leader, NCSP. 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 force.

Within the organisation and structure of the NCSP, there needs to be greater focus on supporting equity in access to all elements of the screening pathway. Equity is important; in particular, achieving the target for participation by Māori women should be a priority, as should achieving the targets for Asian and Pacific women. The development of culturally appropriate information for Māori, Asian and Pacific people about HPV and screening should be a focus for the programme.

#### **Workforce** issues

The outstanding area of concern for the laboratory science workforce in the near future is the impact that HPV screening will have across this sector.

With the changes in cervical screening internationally, the loss of cytology expertise of senior scientists and laboratory personnel has been a major challenge in the transition to primary HPV screening. There needs to be a planned approach to support cytologists, pathologists and laboratory scientists in order to sustain the programme until any changes in the screening regime are implemented. Change management

strategies, including education and re-training, will be critical in ensuring the workforce can be maintained until any transition occurs.

Cultural competency is also important. The Foundation Course in Cultural Competency provides support to practitioners to build their understanding of cultural competency and health literacy in New Zealand, with a focus on improving Māori health outcomes. As the general Māori population increases, so too will the demand for a workforce that is sensitive to the needs of the Māori population.

#### **NCSP-Register**

The National Cervical Screening Programme-Register (NCSP-R) is the national database that stores screening and diagnostic test results for women who are enrolled in the NCSP. Having the ability to populate the NCSP-R with population-level data and issue invitations to all eligible women to screen would enable proactive approaches to unscreened and under-screened women. The current invitation process is dependent on general practice databases having a complete record of all women in their regions.

The majority of issues with electronic transfer of colposcopy reports to the NCSP-R appear to be due to challenges with the interoperability of the operating systems. Timely access to and reporting of colposcopy findings is critical to the outcomes of the NCSP. Consistent feedback from screening providers was that the system is unable to match local health databases with the NCSP-R data to identify unscreened or under-screened women. This was a primary concern for identifying women from ethnic groups who are at greatest risk of developing cervical cancer.

The 2011 Parliamentary Review Committee Report identified concerns that colposcopy and test results could be inconsistent with those recorded on the Register. The NCSP-R audit in 2014 did not include a random audit of coding on the NCSP-R and correlation with laboratory and colposcopy records. This quality assurance intervention should be considered for future audits.

The issue, action and outcome of complaints, regarding either the NCSP-R or the programme as a whole, must have robust follow-up processes. Complaints from consumers regarding the screening programme need to be regularly reviewed and monitored, and a summary report provided to the NCSP Advisory Group. Reports from the NCSP-R to providers are a valuable quality improvement opportunity to enable personal performance benchmarking and monitoring. Reporting back to providers on their outcome data should form part of the continuous feedback cycle for quality improvement, and should be a focus for the NCSP into the future.

Māori women are over-represented in cervical cancer statistics, and under-represented in cervical screening participation. The mechanisms for applying to NKG for data appear to be an impediment to improving the health outcomes and reducing cervical cancer incidence and mortality for Māori women.

There are currently no links with the HPV immunisation data. The full benefit of immunisation will not be realised for many years, until entire generations of girls and women have been vaccinated. However, monitoring of the vaccinated cohort and evaluating their screening results will inform any future decisions regarding both the vaccination and the screening programmes.

#### **Ethnicity data**

New Zealand holds a unique position in the international health sector arena regarding the protection of research information that belongs to its indigenous people. For the NCSP, information concerning Māori women's cervical screening data is deliberately and purposefully guarded by legislation, which has enabled the establishment of the National Kaitiaki Group. The NKG's task is to consider applications for the release of Māori women's data from the NCSP-R.

An audit of the NCSP-R confirmed that relationships and governance, quality improvement, value for money and IT systems for the Register (and therefore women's data, including that of Māori women) were well managed. The NSU and NCSP continue to voice their frustration with both the past relationship with the NKG, and the process for obtaining access to Māori women's data from the Register.

All of the Ministry of Health's monitoring reports analyse data by ethnic groups, including Māori, Pacific, Asian and European/Other. Current analysis from the NCSP-R data (at March 2014) recorded ethnicity codes for approximately 98.4% of the 1.4 million women on the NCSP-R. The NCSP is continuing work to improve the accuracy of ethnicity recording on the Register (NSU 2014b).

In New Zealand, ethnicity is an important dimension of health inequities. Māori and Pacific people experience lower life expectancy and health disadvantage across most mortality and morbidity indicators compared with Europeans, as well as socio-economic disadvantage in areas such as housing, education, income and employment. Ethnic inequalities between Māori and non-Māori are the most consistent and compelling inequities in health and need to be addressed. Planning for primary HPV screening is seen as a critical opportunity to improve cervical screening coverage for Māori women.

Independent service providers (ISPs) have found it challenging to identify unscreened women in their areas, particularly Māori women, who have a higher cervical cancer rate than the other priority groups. Strategies to enable identification of unscreened and under-screened women should be investigated in collaboration with general practices and ISPs.

#### Colposcopy

Colposcopy services in New Zealand are contracted to DHBs, where the service is usually part of a gynaecological or women's health service. Colposcopy is also provided by gynaecologists working in private practice.

Medical practitioners and nurses wanting to practice colposcopy in New Zealand must first have obtained Colposcopy Quality Improvement Program (C-QuIP) certification. Colposcopy indicators already collected in the NCSP-R colposcopy data should be included in the next C-QuIP accreditation cycle. It is important to analyse and report on complete data sets from colposcopy services to promote best practice, emphasising safety and quality.

National colposcopy meetings should take place annually to improve networking of DHBs and information sharing.

#### Human papillomavirus and cervical cancer

The New Zealand Government needs to be confident the New Zealand Cervical Screening Programme is delivering maximum benefit for New Zealand women in reducing morbidity and mortality attributable to cervical cancer. It needs to be confident that the programme's design and delivery is comparable with international best practice, and is effective, cost-effective and efficient in achieving the programme's objectives and in view of the Government's investment in the initiative.

Clinical evidence has shown convincingly that primary HPV screening can deliver greater gains in reducing morbidity and mortality from cervical cancer. Internationally, national screening programmes are transitioning to new testing regimes and follow-up protocols. New Zealand must give priority to reviewing the evidence and developing recommendations to transition to a primary HPV screening protocol that will deliver a more effective and efficient programme for the investment.

The assessment and future recommendations must include a strategy for ensuring every woman's HPV vaccination status is captured as part of her screening history. This may be achieved through data linkage with the HPV Immunisation Register, or through an alternative methodology for direct capture of the woman's HPV vaccination status on the NCSP-R.

### **Summary of recommendations**

#### 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.
- 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.
- 3. Cultural competency is vitally important and ongoing education is needed to ensure that smear takers are attuned to cultural sensitivities. ISPs play a vital role in supporting local communities and providing access to cervical screening. Any changes to funding for cervical screening for ISPs should be carefully evaluated in terms of the consequences. DHBs and primary health organisations (PHOs) should be supported to work closely with ISPs to facilitate access to screening for unscreened and under-screened women.
- 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.
- 5. It is recommended that NCSP and NKG work closely together to facilitate more timely and ongoing access to Māori data.<sup>2</sup>
- 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.

#### Monitoring and evaluation

- 7. There should be more stringent monitoring of the quality of colposcopy.
- 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.
- 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 and socio-economic status.

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<sup>&</sup>lt;sup>2</sup> See also Chapter 8: NCSP-Register and Chapter 9: Ethnicity data.

- 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.
- 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.
- 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.
- 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 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.
- 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.

#### **Quality assurance**

- 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 would inform the development of a Quality Improvement Plan for the NCSP.
- 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.
- 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.

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.

#### Organisational and structural issues

- 19. 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.
- 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 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.
- 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 force.
- 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.

#### 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.

- 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 smeartaker updates.
- 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.
- 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.<sup>3</sup>

#### **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.
- 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.
- 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.
- 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.
- 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.

<sup>&</sup>lt;sup>3</sup> See also Chapter 6: Organisational and structural issues.

- 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.
- 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.
- 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 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.
- 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.

#### **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 NCSP and NKG to continue to strive to improve relationships.<sup>4</sup>
- 39. The NSU, NCSP portfolio managers and DHB managers need to collaborate with ISPs 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.
- 40. 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.<sup>5</sup>

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See also recommendation 35.

<sup>&</sup>lt;sup>5</sup> See also recommendation 19.

#### 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 colposcopy clinics.<sup>6</sup>
- 42. The NCSP should ensure that colposcopy data submitted from the private sector fully complies with the Health Act 1956.<sup>7</sup>
- 43. Data held on the NCSP-R that is received from colposcopy services should be analysed annually to support practitioners in their quality improvement.<sup>8</sup>
- 44. The NCSP and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists will need to address the discrepancy between 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.

#### Human papillomavirus 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 employing primary HPV screening with partial HPV genotyping will result in the greatest reductions in incidence and mortality from cervical cancer.
- 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.
- 47. Within the existing programme, the benefits of HPV triage for LSIL cytology should be reviewed.
- 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 improve practice.
- 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

<sup>&</sup>lt;sup>6</sup> See also recommendation 30.

See also recommendation 37.

<sup>&</sup>lt;sup>8</sup> See also recommendation 34.

- HPV vaccination status with her screening history, or data linkage with the National Immunisation Register.<sup>9</sup>
- 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.

<sup>&</sup>lt;sup>9</sup> See also recommendation 36.

# Chapter 1: Introduction and methods

#### Overview

The National Cervical Screening Programme (NCSP) Parliamentary Review Committee is a ministerial review committee established under the Health Act 1956, as amended by the Health (National Cervical Screening Programme) Amendment Act 2004 (Part 4A).

According to the Health Amendment 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 National Cervical Screening Programme
- evaluation activities of the kind described in section 112T of the Act that have been carried out, or that are proposed to be carried out.<sup>10</sup>

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.

In November 2014, the New Zealand Minister of Health appointed Dr Jeffrey HJ Tan, MBBS, MRCOG, FRANZCOG (Australia), Ms Gail Ward, Dip App Sc (Med Rad), Dip Prac Mgt, Grad Cert PSM (Australia) and Ms Linda H Thompson, RN, ADN (New Zealand) to undertake an independent review of the New Zealand NCSP. The Minister requested that the Review Committee present a written report of this review by June 2015, which the Minister would subsequently present to the New Zealand Legislature and would later publish and distribute to interested parties. The Review Committee has summarised its findings and recommendations in this report to the Minister of Health.

Table 1.1 briefly describes the role and contributions of members of the Review Committee.

(1) For the purposes of this Part, evaluate means to monitor and assess the service delivery and outcomes of the NCSP so as to promote the fulfilment of its objectives by determining whether there are any systemic issues to address within the programme or quality improvements that may be made to it.

<sup>&</sup>lt;sup>10</sup> Section 112T: Meaning of evaluate

<sup>(2)</sup> An evaluation may, from time to time, include a review of, and an investigation into, the cases of –

<sup>(</sup>a) any woman who is enrolled in the NCSP (whether or not she has developed any cervical cancer); and

<sup>(</sup>b) any woman who has developed any cervical cancer (whether or not she is enrolled in the NCSP); and

<sup>(</sup>c) any deceased persons to whom paragraph (a) or paragraph (b) applied at the time of death.

Table 1.1: Parliamentary Review Committee responsibilities

Title	Name	Key responsibilities and lead areas	
Committee Chair	Dr Jeffrey Tan	<ul> <li>Liaise with stakeholders on the project's scope.</li> <li>Finalise the review scope.</li> <li>Develop the review framework.</li> <li>Identify key informants and other information-gathering requirements.</li> <li>Analyse and document findings and develop recommendations.</li> <li>Take responsibility for the following review areas: colposcopy, HPV and cervical cancer, future directions – technology and research.</li> </ul>	
Committee Member	Ms Gail Ward	<ul> <li>Contribute to the review's design and implementation.</li> <li>Identify key informants and other information-gathering requirements.</li> <li>Analyse and document findings and develop recommendations.</li> <li>Take responsibility for the following review areas: coverage, participation, equity and access, monitoring and evaluation, quality assurance, the NCSP-R, HPV primary screening, and future directions – screening.</li> </ul>	
Committee Member	Ms Linda Thompson	<ul> <li>Contribute to the review's design and implementation.</li> <li>Identify key informants and other information-gathering requirements.</li> <li>Analyse and document findings and develop recommendations.</li> <li>Take responsibility for the following review areas: organisational and structural issues, workforce issues, ethnicity data, and future directions – management.</li> </ul>	

#### **Background**

#### History of cervical screening in New Zealand

In June 1987, Sylvia Cartwright, an Auckland District Court Judge, was appointed by the then Minister of Health Michael Bassett to conduct an inquiry into allegations concerning the treatment of cervical cancer at the National Women's Hospital and other related matters. The report of the Committee of Inquiry was released on 5 August 1988 and provided a detailed analysis of the evidence presented, as well as the key findings and recommendations (Cartwright 1988). One of the key recommendations was to establish a National Cervical Screening Programme in New Zealand, and in 1990 the NCSP was established in 14 Area Health Boards.

The next major inquiry into cervical screening occurred in May 1999, when the then Health Funding Authority began an investigation after concerns were raised about the reading of cervical smears by a community laboratory in the Tairawhiti region. Almost 23,000 cervical cytology slides were re-read by a Sydney laboratory, and significant under-reporting of cervical smear abnormalities was found. The then Minister of Health immediately announced an inquiry, subsequently known as the Gisborne Cervical Screening Inquiry (CSI), would take place (Duffy et al 2001). The committee's report presented 46 recommendations; subsequent reviews put forward 126 recommendations for programme improvements (see Table 1.2). More information about key events in the history of cervical screening in New Zealand is presented in Appendix A.

Table 1.2: Key events in the history of cervical screening in New Zealand

1988	The Report of the Cervical Cancer Inquiry (Cartwright 1988) is published. It recommends the establishment of a National Cervical Screening Programme in New Zealand.
1990	The NCSP is established in 14 Area Health Boards and is accountable to these boards. The Department of Health provides guidance and support.
October 1999	An inquiry is launched to investigate the under-reporting of cervical smear abnormalities in the Gisborne region.
April 2001	The Gisborne Cervical Screening Inquiry report is published (Duffy et al 2001).
February 2002	The Office of the Auditor General (OAG) report is published (OAG 2002): this monitored the Gisborne recommendations.
August 2003	A final report on the review of progress to implement the recommendations of the Gisborne CSI is published (McGoogan 2003).
December 2003	The OAG's second report, comprising a review of the CSI and other recommendations, is published (OAG 2003).
July 2004	The Health (National Cervical Screening Programme) Amendment Act, section 112c, comes into force on 1 July 2004. The rest of the Act comes into force 12 months after the date on which it received royal assent.
November 2004	The Cervical Cancer Audit Report is published (Cervical Cancer Audit and the University of Auckland 2004).
May 2006	The Health and Disability Commissioner's review of colposcopy services at Waitemata DHB is published (NSU 2006).
June 2011	The Report of the Parliamentary Review Committee regarding the New Zealand Cervical Screening Programme is completed (Tan et al 2011).

#### The National Cervical Screening Programme

The National Cervical Screening Programme is part of the National Screening Unit (NSU) and is funded by the New Zealand Ministry of Health. The NCSP interfaces with District Health Boards (DHBs), with many services coordinated regionally. Cytology, histology and human papillomavirus (HPV) testing services are provided by both private and DHB laboratories across New Zealand by way of a tendering process and contracts with the NSU.

#### NCSP-Register

A key component of the programme is the National Cervical Screening Programme-Register (NCSP-R), which enables access to information by those operating or evaluating the programme. Data contained within the Register includes every result reported to the NCSP from a screening or diagnostic test. Immunisation data is held in a separate register. Data linkage with the New Zealand Cancer Registry occurs at regular intervals as part of the cancer case review process. Laboratories have access to historical screening and pathology data from their own and other laboratories.

#### NCSP networks

The NCSP Advisory Group connects the NCSP with stakeholders and partners. The NCSP also has a range of clinical networks and contracts with service providers. External monitoring is carried out by the NCSP Advisory Group with technical assistance provided by the University of New South Wales. Laboratory accreditation services are provided by International Accreditation New Zealand, a national organisation that offers accreditation services for the technical competence of laboratories and radiology services. Colposcopy audit services are provided by Health and Disability Auditing New Zealand.

#### NCSP Policies and Standards

Following the implementation of the NCSP in 1990, a series of Policies and Standards was developed for laboratories, smear takers who screen, colposcopists and information systems. Guidelines for cervical screening have also been developed. Since 1990, there has been a decrease in both the incidence and mortality rates of cancer of the cervix, while participation in cervical screening in New Zealand has increased.

#### Cervical cancer incidence and mortality in New Zealand

#### Cancer incidence

Cancer incidence is the annual rate of new registrations of invasive cervical cancer (per 100,000 women in the New Zealand resident population at the end of that year) standardised to the World Health Organization (WHO) Standard Population according to Ahmad et al (2001). Cancer incidence data is available in the latest NSU Annual Report to 2012 (NSU 2014a).

In 2012, there were 166 new diagnoses of cervical cancer, including 40 new diagnoses among Māori women. This is equivalent to an age-standardised rate (ASR) of 6.2 new diagnoses per 100,000 women in the general population and 12.7 per 100,000 for Māori women (NSU 2014a).

Most cervical cancers were squamous (116 cases; 4.5 per 100,000 women ASR), with a smaller proportion comprising adenocarcinoma (26 cases; 1.0 per 100,000 women ASR), adenosquamous (one case; < 0.05 per 100,000 women ASR) or other cervical cancers (23 cases; 0.8 per 100,000 women ASR).

Overall, between 1996 and 2012 cervical cancer incidence declined from 10.5 to 6.2 per 100,000 for women of all ethnicities, and from 25.0 to 12.7 per 100,000 for Māori women. There was some variation in the incidence rates by ethnicity, as shown in Figure 1.1a, although the 95% confidence intervals were very wide. When Māori women were compared to all women (Figure 1.1b), incidence was higher among Māori women, although again confidence intervals were comparatively wide.

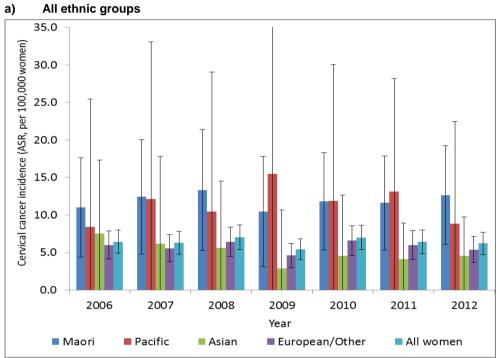
#### **Cancer mortality**

The most recent mortality data available is for 2010. In 2010, there were 52 deaths due to cervical cancer, including eight deaths in Māori women. This is equivalent to an age-standardised mortality rate of 1.7 per 100,000 women in the general population and 3.3 per 100,000 for Māori women.

Overall, between 1998 and 2010 cervical cancer mortality has declined from 3.2 to 1.7 per 100,000 for women of all ethnicities, and from 10.3 to 3.3 per 100,000 for Māori women. However, incidence and mortality rates have not changed from 2006 to 2012.

Figure 1.2 shows the age-standardised cervical cancer mortality rates from 2006 to 2010 by ethnicity. As with the incidence data, the 95% confidence intervals are very wide.

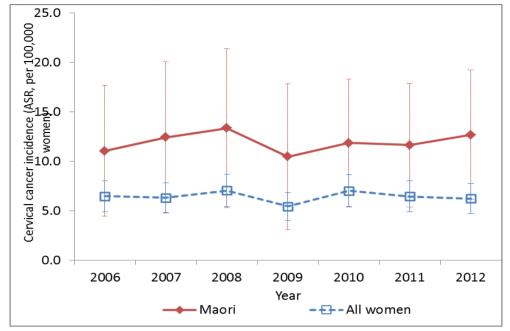
Figure 1.1: Age-standardised cervical cancer incidence rates, 2006 to 2012, by ethnicity



Note: Vertical bars represent 95% confidence intervals.

Source: NCSP Annual Report 2012 (NSU 2014a)

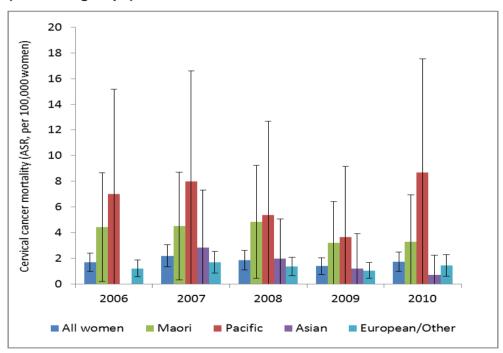
#### b) Māori women, compared with all women



Note: Vertical bars represent 95% confidence intervals.

Source: NCSP Annual Report 2012 (NSU 2014a)

Figure 1.2: Age-standardised cervical cancer mortality rates, 2006 to 2010, by ethnicity (all ethnic groups)



Note: Vertical bars represent 95% confidence intervals. No deaths were recorded for Asian women in 2006.

Source: NCSP Annual Report 2012 (NSU 2014a)

#### Performance of the National Cervical Screening Programme

Although screening coverage for all women is below the national coverage target of 80%, the NCSP is to be congratulated for enabling access to screening for 76.4% of women aged 25–69 years over the most recently reported three-year period to December 2013.

Of particular interest are the increases in coverage for Pacific and Asian women since Monitoring Report Number 34, which reports 2010 figures (NSU 2012a) – with a 7.7% improvement in coverage for Pacific women since 2010 and a 10.5% improvement for Asian women. There has been a 6.2% improvement in coverage for Māori women from 2010 to 2013. Of note, coverage for European/Other women declined by 1.9% over that same period (see Chapter 3: Coverage, participation, equity and access).

Although overall cervical cancer incidence and mortality rates have declined between 1996 and 2012, there has been a plateau since 2006. We will need to consider if further substantial improvement can be expected from improving coverage in this current programme. The NCSP will achieve further success in the future through the benefits of HPV vaccination and if primary HPV screening is introduced.

#### Methodology of the review process

#### **Review scope**

The statutory functions of the Review Committee were to:

- prepare a review plan
- ensure the plan applied the focus for continuous quality improvement referred to in section 112O(2) of the Health (National Cervical Screening Programme) Amendment Act 2004, and took into account the need for timeliness in the completion of the review
- determine which issues were to be reviewed and the expected date of completion of the review.

The review plan developed by the Review Committee was presented to the Minister of Health in November 2014. The Minister approved the plan on 10 December 2014.

Broad areas for the review included:

- coverage, participation, equity and access
- monitoring and evaluation
- · quality assurance
- · organisational and structural issues
- · workforce issues
- · the NCSP-R

- · ethnicity data
- colposcopy
- HPV.

More detail about the areas reviewed is provided in Appendix B.

#### **Review objectives**

In accordance with section 112O(2) of the Health (National Cervical Screening Programme) Amendment Act 2004, the focus of the Review Committee was the continuous quality improvement of components of the NCSP, with a view to reducing the incidence and mortality rates of cervical cancer. Specific objectives involved addressing the following questions:

- What progress has been made in implementing the previous recommendations of the Parliamentary Review Committee (Tan et al 2011)?
- What are the key issues, challenges and risks to the programme?
- How does the NCSP evaluate the programme and implement quality improvement initiatives?
- What are the future issues that need to be considered by the NCSP?

An effective cervical screening programme needs to be built on evidence-based guidelines and standards. Particular tools and resources are also needed to fulfil the requirements of the programme's mandate. Accurate knowledge and awareness among both clinicians and the public are critical to the success of cervical screening. This knowledge will help ensure that participants are well informed throughout the process and understand the rationale for screening. All of these aspects of the programme have been considered in this review.

#### **Methodology overview**

Both qualitative and quantitative research methods were used by the Review Committee to gather information for this review. More specifically, its work involved the following:

- A full literature review was carried out in relation to cervical cancer screening and related topics.
- Relevant information was evaluated from peer-reviewed scientific literature, technology assessments, specific reports, standards documents, and guidelines from other jurisdictions. Evidence was collected from both New Zealand and international sources.
- Findings from reviews, meta-analyses and randomised controlled trials were considered in the context of the entire spectrum of programme components and delivery of services.

- NCSP documentation was reviewed, including external audits, historical documents (see Table 1.2) and performance-related programme documents from the NSU and the NCSP. The NSU also facilitated access to a wide variety of documents required for key areas of the review.
- Recommendations for best practice were assessed.
- Interviews took place in February 2015 with interviewees and key informants. For the purposes of this report, an interviewee is defined as a participant interviewed by the PRC who is external to the Ministry of Health, including the advisory groups of the National Screening Unit and the National Cervical Screening Programme. A key informant is a key staff member from the Ministry of Health. Interviews took place either in person or by teleconference. A list of the individuals and groups who were interviewed is provided in Appendix C. To help identify priority themes, and to help elicit information from a variety of audiences about their experience and opinions in relation to interactions with the NCSP, a semi-structured interview guide was used. This is provided in Appendix D.
- Written submissions were also received from partners, stakeholders and the public.
   This provided the opportunity for open feedback. A copy of the form used is provided in Appendix E.
- The Parliamentary Review Committee also requested that the NCSP provide an update of progress towards the recommendations made following the previous review in 2011. This update is reported in Chapter 2 of this report.

#### **Parliamentary Review 2015**

This report follows on from a previous Parliamentary Review Committee Report (Tan et al 2011). The chapters that follow discuss in detail the various aspects of the cervical screening programme, and provide an update on progress towards achieving the recommendations made in that report. The final chapter provides suggestions on the future directions for the programme.

This report is based on data that is publicly available. A full list of references is included at the end. The latest National Cervical Screening Programme Annual Report was produced for the year 2012 (NSU 2014a), and the latest Monitoring Report (Number 40) covered July to December 2013 (NSU 2014b).

# **Chapter 2: Update from the 2011 Parliamentary Review Committee recommendations**

## 1 Coverage, participation, equity, access and disease burden

No.	Parliamentary Review recommendation June 2011	National Cervical Screening Programme (NCSP) update February 2015	Comments in Parliamentary Review Committee Report 2015
1.1	A proactive campaign is needed, with targeted interventions to address disparities among ethnic groups in terms of participation, retention, and improved follow-up after abnormal screening results.	This is ongoing, with communication campaigns targeted to Māori and Pacific women.  The National Screening Unit (NSU) has run a tender process and appointed a new communications supplier. Social marketing initiatives will target priority groups and strengthen messaging in the Ministry of Health's campaigns about human papillomavirus (HPV) immunisation.  A campaign will be run for cervical screening awareness month in September 2015.	Ongoing strategies are needed to address the disparities among priority groups in terms of participation and retention. Improved follow-up is needed after abnormal screening results. Further details are provided in Chapter 3: Coverage, participation, equity and access and Chapter 9: Ethnicity data.
1.2	The Ministry of Health must explore options to fund Pap tests at a system level to reduce disparities in access.	This has been completed. Currently the NSU contracts with District Health Boards (DHBs) and non-government organisations to provide approximately 38,600 free cervical smears per year to priority women. Priority group women can access free smears within the primary care setting or through Māori or Pacific health providers who work to help women to overcome barriers to access. Other options for provision of free cervical smears have been explored. No changes to the funding structure will be made at this time.	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 highest-need women. To improve coverage for high-priority women, the cost of smears must not be a barrier.  Further details are provided in Chapter 3: Coverage, participation, equity and access.
1.3	Improve screening participation by increasing the number of smear takers who are attuned to cultural sensitivities and the preferences of women with special needs.	This is ongoing. Smear-taker training courses include a cultural awareness component and cover some issues for women with special needs.	Cultural competency is vitally important and ongoing education is needed to ensure that smear takers are attuned to cultural sensitivities. It is important to provide local community support; it is recommended that independent service providers (ISPs) are funded to support local communities and that smear takers work closely with ISPs. Further details are provided in Chapter 3: Coverage, participation, equity and access.

No.	Parliamentary Review recommendation June 2011	National Cervical Screening Programme (NCSP) update February 2015	Comments in Parliamentary Review Committee Report 2015
1.4	Undertake an HPV education campaign to increase awareness and accurate knowledge among the general population. (See also the two sections relating to HPV.)	This is ongoing. The NCSP communication campaigns include education and awareness messages about HPV and this is being strengthened on the NSU website and as NSU goes forward with new social marketing initiatives. The NSU sees ongoing education as essential for new providers and women entering the cervical screening pathway.	Ongoing HPV education campaigns are important to ensure increased awareness and knowledge among the general population and among health care providers.  Further details are provided in Chapter 3: Coverage, participation, equity and access.
1.5	Ensure continuity of monitoring, evaluation and reporting. This is best achieved through collaboration and improved partnerships with the academic community and/or the NCSP Advisory Group. NCSP must make concerted efforts to consult with partners and stakeholders and to complete and report on overall programme activities on a more regular basis, whether annually or biannually.	This has been completed. The NCSP Advisory Group reviews and provides recommendations to the National Screening Unit in the NCSP monitoring reports. NCSP monitoring reports are sent to NCSP providers in draft for comment on errors or omissions. Continuity of monitoring, evaluation and reporting is essential for the clinical safety of participating women. The NCSP consults extensively with partners and stakeholders to ensure the delivery of a high-quality cervical screening programme.	Since the last Parliamentary Review Committee Report (Tan et al 2011), comprehensive external monitoring reports have been produced biannually against a suite of eight groups of monitoring indicators.
1.6	Extended reporting delays contribute to a loss of confidence in the programme and must be prevented in the future.	This is ongoing. A business case and funding to establish NSU datamarts in the Ministry of Heath's data warehouse have been approved. The NCSP datamart is expected to be operational towards the end of 2015 and will enable timelier reporting.  An interim solution has been put in place to ensure data is extracted from the National Cervical Screening Programme-Register (NCSP-R) in a timely way so that ongoing biannual and annual monitoring is achievable.	The biannual monitoring reports are addressing this issue. The challenge is ensuring that information gained through the monitoring reports is used for continuous quality improvement for the programme.

# 2 Quality assurance and monitoring

No.	Barliamentary Baylow	NCSP update	Comments in Parliamentary
NO.	Parliamentary Review recommendation June 2011	February 2015	Comments in Parliamentary Review Committee Report 2015
2.1	The NSU should explore options for consolidating services related to cytology, histology and HPV-DNA testing, which will ideally be centralised with, at most, one or two laboratories. Several laboratories have expressed a preference for a centralised national model. Others were not happy with the current regional structure because they were subsidising cytology services and this is not a sustainable business model.	This has been completed. The NSU has explored options for consolidation of laboratory services. While HPV primary testing is being considered in the New Zealand context, the NSU considers it is not prudent to implement significant service change, which would be a short-to medium-term solution. This decision has been approved by the NSU Senior Management team.	The NSU and NCSP have commenced policy work for a potentially major change to HPV primary testing in the National Cervical Screening Programme.
2.2	It would be beneficial for the Ministry of Health to consolidate laboratory negotiations in one department external to the NSU. It makes sense for one Ministry section to assume responsibility for all discussions with laboratory executives/representatives regarding all lab services. Although the Ministry contact would need to seek input from clinical and lab experts within the NCSP about specific tests, contract and funding negotiations should be conducted outside the screening programme.	It is not feasible at this time to move responsibility for laboratory negotiations into another part of the Ministry. No other area of the Ministry has the capability or capacity, as no other area in the Ministry is directly responsible for laboratory contracts. This decision has been approved by the NSU Senior Management team.  NCSP laboratory contracts were successfully renegotiated by the NSU during 2014.	This has been noted by the Parliamentary Review Committee (PRC) 2015.
2.3	The NCSP should continue to conduct ongoing review of the screening histories of women who develop cervical cancer.	This is ongoing. Reviews of cervical cancer cases are being undertaken and will continue as part of the NCSP work programme.	Ongoing audit of the screening histories of women who develop cervical cancer is recommended. The underpinning rationale is that there are likely to be valuable lessons from these audits that would inform the implementation of quality improvement initiatives. Further details are provided in Chapter 5: Quality assurance.
2.4	It is difficult to adopt a proactive approach in a programme when there are delays in the production of monitoring and evaluation efforts. The NCSP Annual Report has been delayed by more than three years. Since that delay, semi-annual monitoring reports have been produced by an Australian group. Numerous interviewees expressed concerns regarding unexplained delays and dissolution of the Independent Monitoring Group. Not everyone agrees that sourcing this function outside of New Zealand is the best approach, as many believe there is sufficient expertise within the country to perform this function.	This has been completed. External monitoring reports are now up to date. The 2012 Annual Report has been published on the NSU website (NSU 2014a). This is now business as usual.	This has been noted by the Parliamentary Review Committee 2015.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
2.5	External expert review is recommended every five years, rather than every three years.	The proposal to move to a five- year review was declined, and therefore the review will stay at three years at this time.	This can be re-visited if five- yearly screening comes in with primary HPV screening. It is noted the three-yearly review is a legislative requirement. Ongoing review of the programme is an important element of quality improvement.
2.6	Secretariat support for future external reviews should be provided by Ministry of Health staff outside the NSU, and should have experience in providing executive assistance.	The NSU has engaged contractors with experience in providing executive assistance to help coordinate the 2015 NCSP Parliamentary Review Committee. This review will be completed by June 2015.	Secretariat support was provided by contracted staff. Due to difficulty securing contracted staff who were suitably qualified, the report-writing support for PRC was provided by an NSU staff member, but her work on the review was independent of the Ministry of Health.

# 3 Organisational and structural issues

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
3.1	The NSU and NCSP must supplement clinical leadership capacity to include population health, public health and screening expertise as a matter of urgent priority.	This has been completed. In January 2013 an NSU Clinical Director was appointed. The position of NCSP Clinical Leader has also been retained. Both postholders are public health physicians with population health, public health and screening expertise. A public health physician with applied epidemiology skills has also been appointed to lead the monitoring and evaluation analysis within the NSU's Information, Quality and Equity team. An additional public health physician with a lead role in promoting achievement of equity for all NSU screening programmes has also been appointed.  Additionally, a Clinical Governance Group was established in 2010. This group provides clinical, public health and strategic advice on screening practice, including monitoring and resourcing.	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 crucial that the new incumbents, including the appointment to the clinical leadership position, are promptly oriented in their positions and that the new leadership team establishes strong regional coordination and communication across the national screening sector.  Further details are provided in Chapter 6: Organisational and structural issues.

No.	Parliamentary Review	NCSP update	Comments in Parliamentary
	recommendation June 2011	February 2015	Review Committee Report 2015
3.2	Regional coordination and communications need to be improved. The NSU and NCSP must provide the lead collaboratively for performance management and monitoring across all sectors to strengthen coordination and integration. Examples of key areas for collaborative discussions are contracting arrangements and incentives to improve delivery through funding innovation (eg, for coverage, screening, assessment and treatment services, and change management). Interviewees expressed significant concerns regarding the apparent isolation of the NCSP from other Ministry departments as well as from other partners and stakeholders, and also within the NSU itself. Such isolation has been manifested in a lack of appropriate consultation and limited communications with partners and stakeholders, combined with decision making that has excluded key partners. This is of great concern as communication and collaboration are essential for a successful screening programme, not only to ensure feedback and representation from all partners and stakeholders, but also to optimise the benefit of scarce resources, avoid duplication and provide meaningful services.	This has been completed. The NSU continues to communicate with its stakeholders with the regular <i>Screening Matters</i> newsletter and an additional quarterly update to the sector with NCSP highlights and monitoring information. The NCSP has a quarterly teleconference attended by regional coordination services and non-government organisations. This teleconference focuses on sharing successes (eg, initiatives that increase coverage in priority groups), discussing current issues and developments, and connecting providers with each other.  The NCSP became fully staffed in 2013, and both senior portfolio managers have been undertaking a programme of visiting providers. The NCSP team has been supporting a number of quality improvement initiatives (eg, improving methods to identify unscreened women through a data matching process) being undertaken by DHBs and primary health organisations.  The regional coordination section of the Policy and Quality Standards has been reviewed and updated standards were published in July 2014. Consultation with the sector has been an important part of the review of all NCSP Policies and Standards. This recommendation will continue under business as usual.  NCSP and NSU have ongoing relationships with other areas of the Ministry, for example, with the Cancer team (and cancer networks) about the Cancer Control Strategy. The NCSP and the Immunisation team are building a strong relationship around HPV immunisation and cervical screening. An important focus of this relationship is to ensure messaging is consistent between and supportive of both programmes.  NSU's breast screening and cervical screening clinical leaders have a professional reporting line through the NSU's Clinical Director to the Ministry's Chief Medical Officer.	While steps have been taken to improve regional coordination with providers, further strategies must be identified to rectify remaining issues of coordination and communication with regional providers.  NCSP regional portfolio managers must continue to demonstrate improvements in regional coordination with providers through at least one planned national meeting per year and ongoing regional face-to-face meetings with local service leaders for the cervical screening programme in the regions.  Further details are provided in Chapter 6: Organisational and structural issues.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
3.3	A whānau ora approach should be adopted. The NSU and NCSP need to broaden their scope of contract modelling to include the emerging whānau ora collectives, along with the primary/community health care independent service providers. These networks incorporate essential health initiatives that are already integrated with other social and educational programmes to demonstrate inclusiveness of whānau/family. The NCSP should drive this initiative with whānau ora and primary health care providers to increase opportunities for coverage and participation. (See also the 'Ethnicity data' section.)	This has been completed. The NSU is working closely across the Ministry's integration programme, with a particular focus on primary care.  The Clinical Director, along with the NCSP and BreastScreen Aotearoa programme managers, has worked with the Māori Health Business Unit to establish regular meetings. This allows participants to review progress against the Māori Health Plans and the whānau ora collective reports, and to discuss initiatives or policy developments.	Addressing equity is important. In particular, the variable achievement of the 80% target for Māori, Pacific and Asian women is an outstanding disparity of this programme that must be eliminated.  Information and appropriate messaging about HPV and changes to the NCSP are important to achieving effective and ongoing engagement of the priority groups for this programme.
3.4	The NSU and NCSP must align their initiatives and work plan with the priorities and planning of the New Zealand Cancer Control Strategy. This will require improved consultation and coordination of all cancer screening programmes to achieve better alignment of strategies and services across the entire cancer continuum.	This has been completed. Development of NSU work plans, initiatives and programmes is aligned to the Cancer Control Strategy, and its associated work plans.	The NCSP is to be commended for having an 80% participation rate included as a target within the cancer control work plan. Ongoing strategies to achieve these targets across all DHBs for all cultural groups are essential.

## 4 Workforce issues

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
4.1	As in other jurisdictions, professional associations that are linked to the Royal College of Pathologists of Australasia (RCPA) may be best positioned to administer quality standards for cytotechnicians, pathologists and screeners. Quality is closely aligned with professional education and can potentially be very difficult to ensure. It may not be appropriate for any one laboratory to assume responsibility. Professional colleges and associations tend to have greater credibility among their members and are more likely to require adherence to professional standards and a scope of practice.	This has been completed. The laboratory training service is in place, and is being delivered to laboratories.  The RCPA Quality Assurance Programme now administers the individual external quality assurance programme for all cytopathologists, cytoscientists and cytotechnicians screening and reporting cervical cytology samples. This commenced on 1 July 2012.	This has been noted by the Parliamentary Review Committee 2015.

No.	Parliamentary Review recommendation	NCSP update	Comments in Parliamentary Review Committee Report
	June 2011	February 2015	2015
4.2	To ensure equitable access in outlying, rural and under-serviced areas, the NSU and allied professional staff should consider alternative options for service delivery to improve screening access for vulnerable populations. Such options might include:  • train-the-trainer approaches, or  • training local health professionals to coach such populations in the use of self-collected specimens.	This is ongoing. The Ministry of Health has developed an online learning tool on HPV to support training opportunities for health professionals. This was released in January 2015.  The introduction of self-collected specimens will be considered as part of any future policy development on HPV primary screening testing.  Cervical screening information on the NSU website is regularly reviewed and updated.	NCSP must ensure regular updates to online courses and improved access to online training for primary care workers such as practice nurses, midwives, registered nurses, enrolled nurses and general practitioners.  Further details are provided in Chapter 7: Workforce issues.
4.3	As cervical screening technology evolves, professional requirements will also change. Planning and strategies for such change are best achieved by participation and collaboration across all disciplines involved in the screening process. Given that there are significant financial and training implications of converting to any new standard or process, this type of collaboration and consultation is essential to map out the most efficient, efficacious and cost-effective screening programme.	This is ongoing. The NSU, Health Workforce New Zealand and provider representatives meet to consider future planning, and how systems and technology will impact the screening workforce. Working groups are established as required to inform new standards or processes.  The NSU recognises that there may be workforce impacts, particularly for the laboratory sector, if HPV primary screening is introduced. The NSU will work with the sector to ensure clear communication of any changes and will support a planned transition for providers and their workforce.	The introduction of primary HPV screening is likely to have a significant impact on the laboratory workforce. This will precipitate the need to have a planned approach to support cytologists, pathologists and laboratory scientists to move or relocate to areas where their expertise is not lost to the sector. Well-designed and integrated education and training, together with ongoing competency assurance, will be vital to support change. It will also be important to ensure that service specifications, purchase agreements, funding arrangements and industrial arrangements do not unnecessarily impede this.
4.4	Until such discussions and long- term plans have been addressed at a system level, it is difficult to predict workforce demands, because the health system must first decide on the best approach for their population and existing infrastructure.	This is ongoing, as above.	See PRC comments in section 4.3.
4.5	The HPV vaccination programme will decrease the burden of HPV-related disease, in particular cervical abnormalities. This will have an impact on all elements of the collective prevention and screening workforce. Strategic planning and an integrated evaluation plan are essential to cope with this transition. (See also the 'HPV vaccination' section.)	This is ongoing. Strategic workforce issues will be considered as part of the policy work on primary HPV screening.	See PRC comments in section 4.3.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
4.6	Laboratories must maintain the experience and expertise of their scientific workforce.	This has been completed. The current laboratory training school contract for the gynaecological cytology, histology and HPV screening laboratory sector has been extended to December 2017 to support the experience and expertise of the pathology and scientific workforce.	This has been noted by the Parliamentary Review Committee 2015.

# 5 Ethnicity data: quality, completeness and use

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
5.1	The following strategies aim to increase and improve participation and retention.  The NCSP has implemented a range of strategies to increase coverage for Māori, Pacific and other priority group women.  These should be advanced and identified in a Priority Action Plan for increasing screening participation of the seldom and never screened. Evaluation of these efforts is essential.  Provider contributions and innovations need to be explored through community consultation and collaboration to engage a range of Māori, Pacific and Asian providers in both primary health care and whānau ora collective arrangements.  The NCSP needs to explore options for implementing commercially available options for self-collected specimens for HPV-DNA testing (see also the section on HPV screening).	This is ongoing. The NCSP DHB contract reporting templates have included reporting against actions in the Māori Health Plans from July 2014.  See also recommendations 1.1, 1.3, 3.2 and 3.3 above.  The NSU is revising its Quality Framework and has consulted with a wide range of stakeholders as part of this process.  The NSU is undertaking analysis to examine the issues in ethnicity data collection, and any potential solutions, across all screening programmes.  Self-collected samples will be explored when work is undertaken to consider the role of HPV screening as the primary screening test in New Zealand.	Current analysis from the NCSP-R data (at March 2014) recorded ethnicity codes for approximately 98.4% of the 1.4 million women on the NCSP-R. The NCSP should monitor the completeness and accuracy of ethnicity data on the NCSP-R.  The data shows persisting inequities in participation rates for cervical screening among Māori, Asian and Pacific women. This is considered a major concern for the NCSP and the sector, particularly in regard to Māori women. Planning for primary HPV screening is seen as a critical opportunity to improve cervical screening coverage for Māori women.  Further details are provided in Chapter 9: Ethnicity data.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
5.2	The following recommendations relate to the National Kaitiaki Group (NKG).  In line with the recommendations of the legal reviewers, we believe this review is an opportunity to amend the Kaitiaki Regulations to achieve supportive and enhancing actions that uphold the respective roles and responsibilities of the National Kaitiaki Group and the NSU and NCSP.  All major parties (ie, the NKG, and units of the Ministry of Health: the Māori Health Directorate, NSU and NCSP) must be involved in consultation to produce mutually agreeable protocols that clarify the relationship between the NKG and NCSP to access, use and disclose 'protected information'.	This is ongoing. The NKG Regulations have not been amended. However, the Māori Business Unit at the Ministry of Health, the NSU and the NKG are working together, to make the NKG process appropriate for allowing access to data and for protecting data that relates to Māori women. The NSU has undertaken a review of the process for NKG applications for Māori women's data. Process improvements have been discussed and agreed with the NKG. The NKG is leading the work to develop a combined NSU and NKG application form for accessing and using Māori women's cervical screening data.	Issues encountered in regard to data access have highlighted that the process of obtaining information from NCSP-R is slow. This is mainly influenced by relationships between the NCSP and the NKG, which need to improve to bring about a process that ensures timely, ongoing access to important data and in this way enables ongoing monitoring and quality improvement of the programme. Further details are provided in Chapter 9: Ethnicity data.

# 6 NCSP-Register

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
6.1	The NCSP must work with DHBs to ensure the integrity of colposcopy data supplied to the NCSP-Register. This is an urgent priority.	This is ongoing. A large-scale project is underway to ensure that all DHB colposcopy clinics capture the required colposcopy data in a database, and that data is then transferred electronically to the NCSP-Register. This project is well underway with all DHBs working towards updating their databases and establishing electronic messaging to the NCSP-Register. All DHBs should have completed implementation within the 2015/16 financial year. See also recommendation 7.2 below.	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. Further details are provided in Chapter 8: NCSP-Register.
6.2	Longer wait times for colposcopy must be closely monitored by the NCSP, and efforts to resolve wait time issues with local service providers must be proactive for the preventive benefit of women with high-grade lesions. Timely assessment by clinicians and colposcopy is essential.	This has been completed. Colposcopy wait times continue to be monitored using service monitoring data. The updated (July 2013) colposcopy standards have been implemented. These standards contain clear wait time indicators, which colposcopy providers will be measured against.	Timely access to colposcopy for all women continues to be an unmet target. Strategies to eliminate barriers to accessing colposcopy services, particularly for Māori and Pacific women, must be an ongoing priority.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
6.3	Colposcopy services must be supported to facilitate efficient electronic transfer of data.	This has been completed. The NSU and DHBs are working closely together to support the electronic transfer of colposcopy data. This recommendation is business as usual. See also recommendation 6.1 above.	It has been noted by the Parliamentary Review Committee 2015 that this project is not complete. See recommendations in Chapter 8: NCSP-Register.
6.4	Smear takers and NCSP service providers should continue to inform the public that screening data are included in the NCSP-Register and advise them of their withdrawal options.	This has been completed. The information to support this message by smear takers and NCSP providers is available on the NSU website.	This has been noted by the Parliamentary Review Committee 2015.
6.5	Continuing dialogue is essential between the NCSP and NKG to resolve the persistent issue of access to Māori women's aggregate data from the NCSP-Register. This will facilitate monitoring and evaluation; a standing agreement would be the preferred option.	This is ongoing. See also recommendation 5.2 above.	It is strongly recommended the NCSP seeks the advice of, and works in partnership with, the NKG to identify more streamlined processes that minimise the burdens the current processes for accessing data place on both parties.  Further information is provided in Chapter 8: NCSP-Register.

# 7 Colposcopy

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
7.1	The current round of 2010 audits should be made available to ensure that DHBs have addressed the shortcomings in the findings of the 2008 audit, when all DHBs were noncompliant in several, or many, areas.	This has been completed; the 2010 audit findings were made available in a meeting held with DHB colposcopy providers in June 2012. All audit corrective actions and evidence provided by DHB colposcopy clinics to close out corrective actions are monitored by the NCSP portfolio managers, with input from the NCSP Clinical Leader.	A new round of audits commenced in 2015 for all 20 DHBs.
7.2	There is an urgent need to ensure that colposcopy data in the NCSP-Register are complete and that colposcopy indicators are included in monitoring reports.	This is ongoing. A project is well underway for all data in the 2013 colposcopy standards to be electronically sent to the NCSP-Register. Full implementation is due to be completed in 2015/16. Colposcopy indicators have been included in monitoring reports since 2011. See also recommendations 6.1 and 6.2 above.	Electronic reporting from DHBs would reduce the likelihood of incomplete reporting of colposcopy to the NCSP-R. It is important to ensure e-colposcopy is functioning well in all DHB colposcopy clinics.  Further details are provided in Chapter 4: Monitoring and evaluation, Chapter 8: NCSP-Register and Chapter 10: Colposcopy.

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
7.3	National colposcopy meetings should be re-convened to improve the networking of DHBs and information sharing, as the last meeting held was in 2008.	This has been completed. The NCSP held national DHB colposcopy meetings in June 2012 and November 2014. Also, the Australian Society for Colposcopy and Cervical Pathology Scientific Meeting in 2013 was held in New Zealand.	This has been noted by the Parliamentary Review Committee 2015.
7.4	New Zealand supports the RANZCOG C-QuIP programme and ensures all health professionals performing colposcopy in New Zealand undergo a common pathway for accreditation/re-accreditation and participate in the audit programme.	This recommendation has been implemented by including the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) Quality Improvement Programme in the NCSP colposcopy standards, and data being collected in the NCSP-Register.	There is discrepancy between the C-QuIP and NCSP colposcopy standards that will need to be addressed by NCSP and RANZCOG. Further details are provided in Chapter 10: Colposcopy.

## 8 HPV vaccination

No	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
8.1	Effective, intensive and broad-reaching education strategies are essential for the general public as well as health care providers to ensure awareness and accurate knowledge about this very common virus – human papillomavirus (HPV). The benefits from such a strategy are likely to translate to improved screening participation as well as vaccine uptake.	This is ongoing. The 2012/13 advertising campaign included a focus on HPV and this focus will remain in future education strategies. See also recommendations 1.1 and 5.1 above.  To support training opportunities, the Ministry of Health has developed an HPV online learning tool for health professionals. This tool was released in January 2015.	This has been noted by the Parliamentary Review Committee 2015.
8.2	Ongoing linkage among all immunisation, screening and cancer databases is essential to move forward with the integrated evaluation of primary and secondary prevention of HPV-related cancers.	This is ongoing, with the process of reporting new cases of cervical cancer to the NCSP from the Cancer Registry continuing.  Further work will be explored to improve data sharing between the NCSP-Register and the National Immunisation Register as part of the HPV primary screening policy work.	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 to link data with the Immunisation Register.
8.3	All Ministry of Health departments responsible for education, prevention (immunisation), screening and cancer control strategies must be in regular communication with each other to develop consistent messages for effective planning and evaluation strategies. Working in isolation is not an option.	This has been completed. Integration across the Ministry of Health has been incorporated into the NCSP work plan. See also recommendations 3.2, 3.3 and 3.4 above.	This has been noted by the Parliamentary Review Committee 2015.

No	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
8.4	All stakeholders need to embrace this new paradigm for the control of cervical and other HPV-related infections and cancers. It is apparent that many are still embedded in the old paradigm of singular screening, with little regard for the overall impact of HPV-related disease across the entire population. Both men and women are affected by HPV: this is truly an issue that affects society as a whole.	This is ongoing. The NSU and the Immunisation teams are working with stakeholders to discuss all the evidence and alignment of the programme's priorities in relation to HPV.  New DHB reporting templates include the need for reporting on how regional coordination activities involve HPV immunisation providers.	The current three-dose coverage in girls aged 12–13 years in New Zealand is 48–56%. The coverage is higher among the Māori and Pacific population. Efforts are needed to increase this coverage to levels achieved in countries like Australia and United Kingdom.  Further details are provided in Chapter 11: Human papillomavirus (HPV) and cervical cancer.

# 9 HPV screening

No.	Parliamentary Review recommendation June 2011	NCSP update February 2015	Comments in Parliamentary Review Committee Report 2015
9.1	NSU and NCSP need to more actively engage with, and broaden the scope of expertise on, their advisory boards. Given current and future challenges, advisory groups must be involved in the consultation processes noted above, with representation that is knowledgeable about traditional aspects of the screening pathway as well as immunisation and other HPV-related cancers. The NCSP should position their programme in the context of the broader cancer control strategies.	This has been completed. The NCSP has additional expertise on the NCSP Advisory Group with the appointment of a molecular scientist / biologist (with expertise in HPV) representative for the New Zealand Institute of Medical Laboratory Science.	This has been noted by the Parliamentary Review Committee 2015.

## Ongoing issues from recommendations identified in previous reviews

The table below lists some of the recommendations from past reviews that were indicated as ongoing in the 2011 Parliamentary Review Committee Report (Tan et al 2011). These are highlighted as they are issues spanning over a decade and have been reviewed by the PRC in 2015.

#### 1 Status of the Cervical Screening Inquiry (CSI) recommendations

Ref	Recommendation	Status: January 2011	Further work required?
1.12	Management of the National Cervical Screening Programme within the Ministry of Health  The National Cervical Screening Programme must be managed within the Ministry of Health as a separate unit by a manager who has the power to contract directly with the providers of the programme on behalf of the Ministry. The programme's delivery should not be reliant of the generic funding agreements the Ministry makes with providers of health services. For this purpose the unit will require its own budget.	The NSU was established in July 2001 as a separate business unit with the delegated power to contract directly with providers of the programme.  The NSU has subsequently been reintegrated into the Ministry of Health. The NSU continues to contract directly with providers.  The NSU has been part of the National Health Board since its introduction in November 2009.	Yes – ongoing
1.13	Manager of the National Cervical Screening Programme The National Cervical Screening Programme should be under the control of a second or third tier manager within the Ministry. The Manager of the unit should as a minimum hold specialist medical qualifications in public health or epidemiology. As a consequence of the programme's link with the Cartwright Report it has always had a female national co-ordinator.	In 2002 the NSU appointed a Programme Manager and Clinical Leader to jointly manage the programme at fourth tier. The Clinical Leader has specialist medical qualifications in public health.  Restructuring the Ministry of Health placed the NSU into an operational group under National Services Purchasing. At this time the title of Clinical Leader was downgraded to Clinical Advisor. The change in title was not supported by the Group Manager of NSU. The subsequent restructuring of the Ministry of Health brought the NSU in under the National Health Board.	Yes – ongoing

## 2 Status of Dr McGoogan's recommendations

Ref	Recommendation (McGoogan 2001)	Status/date	Further work required?
2.8	National Screening Unit organisational development (para 100) In addition to addressing the manpower resource issue in the NSU, consideration should be given to organisational development.	The NSU was restructured in 2007 with the aim of providing greater leadership, clarity around decision making and increasing capacity for lateral teamwork and research and development.  A subsequent review in 2009, resulted in additional performance management analysts joining the NCSP team, with the responsibility for managing the NCSP provider contracts with regional services, independent service providers, laboratories and DHB colposcopy services.  At the same time, clinical leadership has been downgraded with the NCSP Clinical Leader now being a tier 6 (whereas the CSI recommendation was that the position be a second or third tier; see recommendation 1.13). Work is currently underway to restore the position to Clinical Director at a higher tier.	Yes – ongoing
2.10	Clinical audit  More work must be done to develop and promote an understanding of clinical audit as an integral part of good quality healthcare delivery. Regular critical review of how well clinical care is being delivered is vital to improving the quality of health care. I suspect that the external audit suggested for the retrospective cancer audit has mistakenly been portrayed as similar to financial auditors checking up on one's income tax returns and snooping into private matters.  The retrospective cancer audit is not 'external' in that sense. It simply means that experts will be commissioned to investigate and evaluate the information collected on behalf of the NSU. Women will be approached by nurses or trained healthcare professionals who will be sensitive to the local customs and cultural needs so that the full information about screening histories can be gathered, They are in effect functioning as part of the NCSP. As with all healthcare records, all information gathered will be handled with great sensitivity and kept confidential (para 105).	There is no intention to repeat the audit published in 2004. However, audits of parts of the screening pathway are regularly undertaken (eg, laboratory and colposcopy units). Audits of individual cancer cases are also ongoing. An analysis of cases for 2003 to 2006 has been published. It is intended to undertake further analysis as more cases accumulate.	Yes – ongoing

### 3 Status of Dr McGoogan's further recommendations

Ref	Recommendation (McGoogan 2003)	Status/date	Further work required?
3.1	New cases of cervical cancer should not just be reviewed but be fully audited as soon as they arise (paragraph 27).  I am also concerned that a decision has been made not to carry out a full audit of all new cases of cervical cancer as they are diagnosed. I highlighted this in my first report and on each of my subsequent visits. I understand that each case is now being 'reviewed' but not fully audited. I find the decision not to audit new cases as they arise, with the consent of women, incomprehensible. The woman's gynaecologist could request her consent soon after diagnosis and the audit carried out contemporaneously. The results could be combined into anonymised annual reports or three yearly reports but any specific deficiencies identified could be remedied immediately. It is not best practice to carry out only periodic audits of women who develop cervical cancer.	New cases of cervical cancer are reported to the NCSP on a monthly basis once they have been confirmed by the Cancer Registry. Cases have been reviewed over the four years 2003–2006. Case reviews include reviewing the entire screen history of each case and the histology report. Data are entered onto a spreadsheet and analysed after sufficient cases accumulate. These data have been published in the New Zealand Medical Journal.  Periodic audit appears to be sufficient. However, even this has been criticised by some commentators as unnecessary. In spite of this, a decision was made to continue this work.	Yes – ongoing
3.7	The NSU, its clinical leadership, management structure and location within the Ministry of Health should be kept under critical review (main recommendation).	See CSI recommendation 1.13.	Yes – ongoing

### 4 Status of the Auditor-General's recommendations

Ref	Recommendation (OAG 2002, 2003)	Status/date	Further work required?
4.2	Clinical Leader role  Noted that Dr McGoogan highlights that the Clinical Director has a direct line management relationship to the National Screening Unit's Manager who is not medically qualified. The Clinical Director is also not the direct line manager of any permanent staff. This structure runs the risk that the clinical input into the National Screening Unit could be sidelined and the Clinical Director excluded from decision making. Consider that it is important that this risk is acknowledged and appropriately managed.	See also CSI recommendation 1.13.  A review of the Clinical Advisor's position is being undertaken, including a change of title to Clinical Director and positioning to align with the restructured Ministry of Health. This will acknowledge the accountability and responsibilities of the role.	Yes – ongoing

### 5 Status of the Cervical Cancer Audit recommendations

Ref	Recommendation (Cervical Cancer Audit)	Status/date	Further work required?
5.28	Future audits Prior to further audits of women with invasive cervical cancer, priority be given to implementation of other Audit recommendations described above.	Implementation of the audit recommendations has been prioritised.	Yes – ongoing
5.29	Independent audits of women with cervical cancer.  Following the implementation of changes in the National Cervical Screening Programme, further independent audits of women with cervical cancer should occur, although not more frequently than once every 10 years. This interval could be reviewed if there was compelling reason to do so.	The data accumulated for the years 2003–2006 produced through linkage with the Cancer Registry have been analysed and published.	Yes – ongoing

## Chapter 3: Coverage, participation, equity and access

#### Overview

A well-conceived, well-managed national cancer control programme lowers cancer incidence and mortality and improves the quality of life of cancer patients. An organised population-based national cancer screening programme is a public health intervention designed to prevent and reduce the number of cancer cases and deaths attributable to the disease, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis and treatment. A comprehensive national cancer screening programme aims to reduce the burden of a disease in the community, evaluates the various ways for prevention and early detection of the disease and implements those that are the most cost-effective and beneficial for the largest part of the population. Its emphasis is on preventing cancers or detecting cases early so that they can be cured. An effective cancer screening programme targets the identified 'at risk' population as a whole, while seeking to address the needs of the different subgroups at risk (WHO 2006a).

The principles for implementation and management of a successful national screening programme include the following (Australian Population Health Development Principal Committee, Screening Subcommittee 2008):

- The programme has a detailed national management policy framework that defines
  the screening age range and screening interval, the follow-up tests for those with a
  positive screening test, clinical guidelines for treatment and management, and
  identification and management of high-risk groups.
- The screening pathway must be clearly defined and based on the best available evidence.
- The pathway must be efficient and cost-effective and maximise the utilisation of resources.
- Screening to diagnosis must be delivered in a timely manner, minimising any harms of delayed diagnosis and treatment.
- The resources required, including funding, workforce and supporting workforce infrastructure, must be sufficient to sustain the programme.
- The governance and coordination of the programme, including data capture, invitation and follow-up protocols, must be clearly defined.
- There must be high levels of participation by the target population and evidencebased strategies for ensuring ongoing participation in the programme – including high levels of participation by 'at risk' and disadvantaged groups.
- There must be equity in access to all elements of the screening pathway for all
  participants, and information to support participants in making informed choices
  about their participation, management and treatment.

- Stakeholders (including consumers) must be engaged in the ongoing oversight of the programme to ensure support for and 'ownership' of the programme by those involved in its delivery.
- There must be a quality management framework that continually reviews and assesses the programme's performance.
- Governance and management, including clinical leadership, must be robust.
- A formal approach to the ongoing monitoring and evaluation of the programme must be undertaken.

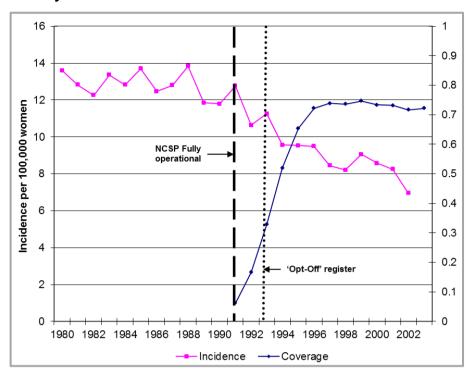
Without an end-to-end systematic, organised approach, screening programmes will not be able to achieve significant reductions in morbidity and mortality from the identified disease, and will consequently not realise the community and population benefits.

#### **Current status**

For the purpose of this report, 'coverage' considers the capacity of the cervical screening programme to ensure equitable, timely, access to all elements of the screening pathway for eligible women (regardless of their socio-economic, cultural, ethnic, disability, rural or remote status) in order for the programme to achieve its stated objectives and performance indicators. Generally, coverage refers to the extent to which the screening programme covers the eligible population equitably. Participation rates describe the proportion of women in the eligible population attending screening.

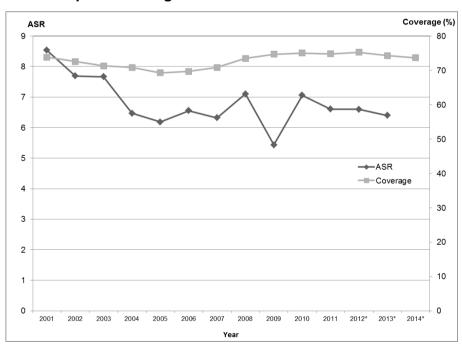
Although coverage for all women, and each priority group is below the national target of 80%, the National Cervical Screening Programme (NCSP) is to be congratulated for enabling access to screening for 76.4% of women aged 25–69 years over the most recently reported three-year period to December 2013 (see Table 3.1). Over a five-year period, 90.4% of women in the target age group accessed cervical screening. Participation rates for the cervical screening programme compare very favourably with participation rates in other developed countries with organised cervical screening programmes. Cervical cancer incidence and screening participation from 1980 to 2003 are shown in Figure 3.1. Figure 3.2 shows an updated analysis of cervical cancer incidence and coverage from 2001 to 2014.

Figure 3.1: Cervical cancer incidence and screening participation among women aged 20–69 years from 1980 to 2003



Source: NZHIS and NCSP-R, National Cervical Screening Programme, 2005

Figure 3.2: Age-standardised cervical cancer incidence rates of women aged 20–69 years for 2001 to 2013\* and NCSP rolling coverage of women aged 20–69 years in each 36-month period ending 31 December from 2001 to 2014\*\*



Notes: ASR = age-standardised rate per 100,000 population standardised to the World Health Organization (WHO) World Standard Population.

- \* 2012 and 2013 cancer data is provisional. 2014 cancer data is not yet available.
- \*\* Coverage is for each three-year period ending 31 December of the year indicated.

Source: Cervical cancer data - the New Zealand Cancer Registry; coverage data - National Screening Unit

International participation rates for organised cervical cancer screening programmes vary widely for many reasons, including differences in target age groups, screening intervals and eligibility criteria. Although any comparisons should be undertaken with caution, in a 2009 Canadian report comparing international participation in cervical screening programmes, three-year participation rates of over 80% were reported for Finland, New Zealand and Denmark (Funen County). Participation rates of between 70% and 80% were observed in Iceland, Norway, the United Kingdom, Belgium and Denmark (Copenhagen). Participation rates of between 60% and 70% were seen in the Netherlands, Australia and Chile. In Sweden, participation rates ranged between 50% and 70%, and in Italy 36.7% of women were screened (Public Health Agency of Canada 2009).

In the *National Cervical Screening Programme Monitoring Report Number 40* (NSU 2014b), the hysterectomy-adjusted participation rate for women aged 25–69 years for the three years ending December 2013 was 76.4%. This was a slight increase of 1.2% on Monitoring Report Number 34; the 2010 rate was 75.2% (NSU 2012a), which was also the rate at the time of the 2011 Parliamentary Review (Tan et al 2011). The coverage for Māori, Pacific and Asian women has increased since the previous Parliamentary Review; however, participation by ethnic groups continues to fall well short of the 80% targets. Table 3.1 shows the three-year participation rates by ethnicity.

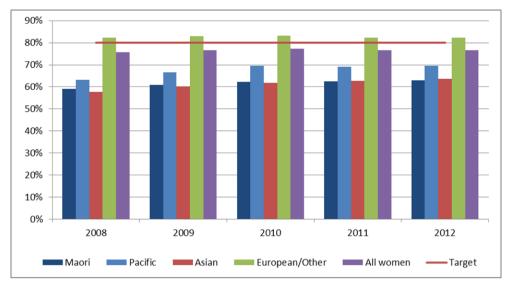
Table 3.1: Percentage of women screened by ethnicity

Ethnicity	% screened in 3 years to 2013	% screened in 3 years to 2010
Māori	62.6	56.4
Pacific	68.6	60.9
Asian	64.8	54.3
European/Other	81.9	83.8
Total	76.4	75.2

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Figure 3.3 below shows the percentage of women aged 25–69 years screened in the previous three years, by year and ethnicity. Figure 3.4 shows the percentage of women screened by ethnicity for each year.

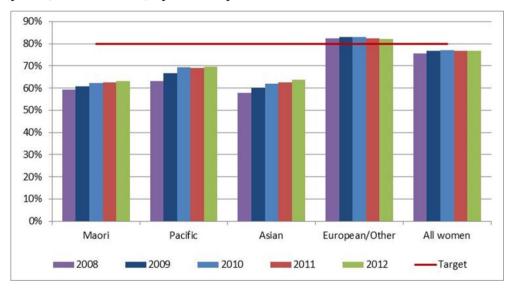
Figure 3.3: Percentage\* of women aged 25–69 years screened in the previous three years, 2008 to 2012, by year and ethnicity



Note: Attendance is within the three year period ending on 31 December of the year Note: Attendance is within the three-year period ending on 31 December of the year indicated.\* As a percentage of the hysterectomy-adjusted population in that age group and year, based on projections from 2006 Census population to the end of the relevant calendar year and hysterectomy prevalence estimates relating to the end of the relevant calendar year.

Source: NCSP Annual Report 2012 (NSU 2014a)

Figure 3.4: Percentage\* of women aged 25–69 years screened in the previous three years, 2008 to 2012, by ethnicity



Note: \* As a percentage of the hysterectomy-adjusted population in that age group and year, based on projections from 2006 Census population to the end of the relevant calendar year and hysterectomy prevalence estimates relating to the end of the relevant calendar year.

Source: NCSP Annual Report 2012 (NSU 2014a)

Hysterectomy-adjusted five-year participation rates were 90.4% for all women aged 25–69 years, compared with 87.8% in 2010. Five-year participation was 77.2% for Māori women, 86.7% for Pacific women, 76.4% for Asian women, and 95.9% for European/Other women. Figure 3.5 shows five-year coverage by ethnicity.

Of particular interest are the increases in coverage for Pacific and Asian women since Monitoring Report Number 34, which reports 2010 figures (NSU 2012a): coverage for Pacific women improved by 7.7% and for Asian women by 10.5% since 2010. There has been a 6.2% improvement in coverage for Māori women from 2010–2013. Of note, coverage for European/Other women declined by 1.9% over that same period (2010–2013).

There are no readily available explanations, supporting data or rationale for these significant changes in participation coverage, particularly for Pacific and Asian women. However, feedback and interviews with stakeholders and National Screening Unit (NSU) staff during this Parliamentary Review provided some anecdotal insight that may enable the development of some hypotheses to help understand these improvements for participation among three ethnic groups and the slight decline among European/Other women.

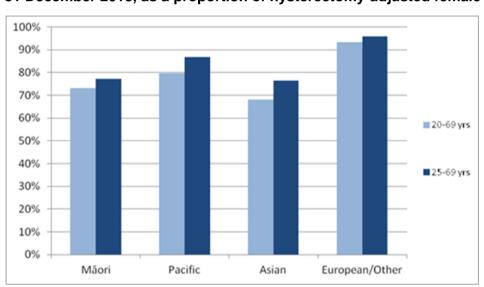


Figure 3.5: Five-year coverage by ethnicity (women screened in the five years prior to 31 December 2013, as a proportion of hysterectomy-adjusted female population)

Note: Coverage calculated using population projection for 31 December 2013 based on 2006 Census data. Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Anecdotal evidence from District Health Board (DHB) cervical screening providers suggests that marketing campaigns and the incentives implemented to encourage providers to achieve the 80% coverage targets for all demographic groups in their region may have played a significant role in the improvements in participation. Four DHBs have exceeded the overall 80% target for the three-year period ending December 2013 – Hawke's Bay (81.4%), Marlborough (81.7%), Taranaki (86.6%) and Wairarapa (82.5%). Two further DHBs – Capital & Coast (79.3%) and Southern (79.8%) – fell only marginally short of achieving the 80% target. Although the numbers of women within some ethnic groups are very small in some DHBs, it is worth noting that Wairarapa was the only DHB to have achieved the target of 80% coverage for Māori women, and indeed across all cultural groups. Six DHBs achieved the 80% target for Pacific women and nine achieved the target for Asian women.

It has also been suggested that the 1.9% decline in coverage for European/Other women may relate to a belief among young women who have had a human papillomavirus (HPV) vaccination that they do not need to screen (HPV vaccination and the interdependency with participation are covered in Chapter 11: Human papillomavirus and cervical cancer). The percentage of women aged under 30 years who participate in the programme has declined slightly between the 2011 and 2013 monitoring reports; however, this factor alone is unlikely to explain the drop in coverage for European/Other women. Figure 3.6 shows the trends in three-year coverage by DHB. Table 3.2 shows coverage by DHB.

Figure 3.6: Trends in three-year coverage by DHB (women aged 25-69 years screened in

the previous three years, as a proportion of hysterectomy-adjusted female population) 100% 90% 80% 70%

60% 50% 40% 30% 20% 10% To 31 Dec 2012 To 30 Jun 2013 To 31 Dec 2013

Note: Coverage calculated using population projection at the end date shown, based on 2006 Census data. Target 80%.

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Table 3.2: Coverage by DHB (women aged 25–69 years screened in the three years prior to 31 December 2013, hysterectomy-adjusted)

DHB	Hysterectomy- adjusted population	Women screened in the last 3 years		
		Number	Percentage	
Auckland	133,680	101,910	76.2	
Bay of Plenty	54,372	42,768	78.7	
Canterbury	132,874	98,219	73.9	
Capital & Coast	82,231	65,188	79.3	
Counties Manukau	129,590	90,073	69.5	
Hawke's Bay	38,617	31,439	81.4	
Hutt Valley	36,629	28,574	78.0	
Lakes	25,929	20,355	78.5	
Mid Central	41,262	31,127	75.4	
Nelson Marlborough	36,265	29,627	81.7	
Northland	39,546	29,703	75.1	
South Canterbury	13,641	10,585	77.6	
Southern	76,446	60,967	79.8	
Tairawhiti	11,455	8,822	77.0	
Taranaki	26,979	23,355	86.6	
Waikato	91,231	70,213	77.0	
Wairarapa	9,832	8,113	82.5	
Waitemata	147,023	110,997	75.5	
West Coast	8,238	6,382	77.5	
Whanganui	15,076	11,349	75.3	
Total	1,150,916	879,766	76.4	

Note: Excludes 33 women for whom DHB could not be determined.

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Screening programmes require an organised, systematic approach to recruitment to ensure all population groups have equitable access to screening. This may require targeted interventions for groups at highest risk and/or greatest disadvantage. The recent 'Support to Screening Services Review' undertaken by the NSU may consider changes to the funding arrangements for support to services for disadvantaged women. Concern has been expressed by Māori independent service providers (ISPs), who are currently funded directly by the NSU to deliver screening services, that changes to funding arrangements may create barriers to participation in the screening programme for Māori women. Some of the many issues raised in feedback and during interviews with stakeholders were: concerns that women who owe money to primary health care providers for other services may be too embarrassed to attend for a free screening; the risks of losing 'outreach' services currently provided by ISPs; and the need for culturally competent providers.

The incidence of and mortality rates from cervical cancer in Māori women are twice the figures for women of all ethnicities. The age-standardised incidence rate in 2012 was 6.2 new diagnoses per 100,000 women in the population as a whole and 12.7 per 100,000 for Māori women. The age-standardised mortality rate in 2010 was 1.7 per 100,000 women in the population and 3.3 per 100,000 for Māori women.

A 2012 Statistics New Zealand report (Milne et al 2013) states that "socio-economic status (SES) is an important determinant of health". Generally, more affluent groups have better health outcomes than less affluent groups. The reasons for this are multifactorial and cannot be easily distilled. Lower health literacy, lower education levels and lifestyles are just some of the factors that can contribute to higher disease incidence among lower socio-economic groups. The NCSP monitoring and annual reports capture data by ethnicity, but do not report participation by socio-economic groups. Understanding the interplay (if there is any) between ethnicity and socio-economic factors may help the NCSP more appropriately identify and develop strategies for improving participation for all women.

DHBs and primary health organisations (PHOs) develop and deliver their own recruitment strategies to encourage participation in the screening programme at a local level. These initiatives are supported by incidental marketing campaigns and funding arrangements through the National Screening Unit. However, there is no nationally led, strategic recruitment plan that provides leadership, guidance and a coordinated approach to improving participation. To address the inequities in cervical cancer screening participation to ensure equity in access not only for Māori women but for all women, a nationally coordinated and consistent recruitment strategy is essential.

A key factor in achieving improved outcomes for Māori women is the cervical screening programme's ability to regularly access contemporary participation and outcome data. One specific need is the ability to match data from the National Cervical Screening Programme-Register (NCSP-R) on a regular and continuing basis with PHO databases so that unscreened and under-screened women can be identified and strategies implemented, where appropriate, to enable access to screening. It is essential that a close and collaborative working relationship is forged between the National Kaitiaki Group and NCSP, with a shared understanding that access to Māori data is critical to reducing cervical cancer incidence and mortality among Māori women. Access to this data will assist in developing strategies to improve participation rates and reducing the burden of the disease on the Māori population.

Capacity and resource availability are key factors in ensuring all women are able to access screening. The Review Committee has not identified a shortage in the workforce that may reduce accessibility for women. The one exception relates to the concerns expressed by some stakeholders that there is a lack of providers who are culturally competent, and that this may be limiting participation, particularly among Māori women. Ensuring all providers are aware of their own cultural competency and are trained regularly will be important in enabling and supporting access to the programme by women from different cultural backgrounds.

Early re-screening (more frequently than the three-year screening interval) by women who had a previously normal screen and were recommended for the routine re-screen interval can place an unnecessary burden on the system, and consequently limit access for women who are either unscreened or under-screened. The December 2013 Monitoring Report (NSU 2014b) calculated a national early re-screen rate of 18.5%, as shown in Table 3.3. This rate varied considerably by DHB – from 26.7% to 9.5%. For some of these women, early re-screening would be entirely appropriate, if the woman became symptomatic subsequent to a 'normal' screen. However, given the wide variance in early re-screening rates, consideration must be given to whether clinical practice has an influence in those areas where there are high re-screen rates. It is important for the cervical screening programme to understand and address, where necessary, these variations in early re-screening.

Table 3.3: Early re-screening by DHB, 1 July to 31 December 2013

DHB	Women recommended to	Women with ≥ 1 subsequent test		
	return in 3 years	Number	%	
Auckland	4,758	1,216	25.6	
Bay of Plenty	2,186	484	22.1	
Canterbury	3,557	654	18.4	
Capital & Coast	3,584	515	14.4	
Counties Manukau	4,053	751	18.5	
Hawke's Bay	1,494	232	15.5	
Hutt Valley	1,542	184	11.9	
Lakes	1,035	237	22.9	
Mid Central	1,532	146	9.5	
Nelson Marlborough	1,291	176	13.6	
Northland	1,383	231	16.7	
South Canterbury	546	106	19.4	
Southern	2,830	417	14.7	
Tairawhiti	432	58	13.4	
Taranaki	1,118	132	11.8	
Waikato	3,456	490	14.2	
Wairarapa	432	89	20.6	
Waitemata	5,514	1,471	26.7	
West Coast	270	50	18.5	
Whanganui	522	59	11.3	
Total	41,535	7,698	18.5	

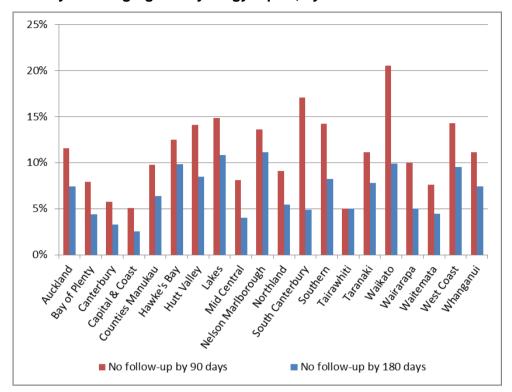
Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Providing timely results and promptly following up women with a cytological abnormality are other measures of equity and access for a screening programme. Laboratories have targets for turnaround times to ensure women are provided their results within an acceptable timeframe. Overall, 95% of cytology samples were reported on within seven working days and 99.3% within 15 working days. Both these outcomes surpass the national targets.

To ensure women with an abnormality receive timely management and treatment, the target is for 90% of women with a high-grade cytology result to have been seen by a specialist and have had a histology report within 90 days of their cytology report date. Nationally, 82.3% of women had a histology report within 90 days of their cytology report, which is below the 90% target. In some instances, women may not have had a biopsy performed at colposcopy, and so there would be no histology report. However, for the reported period, 2,490 women required follow-up. There were 280 women (11.2%) who had no record of any subsequent follow-up within 90 days of their cytology report, and 167 women (6.7%) who had no record of any follow-up within 180 days. There was significant variation across DHBs (as shown in Figure 3.7) and also by ethnicity, with 24.4% of Pacific women and 14.8% of Māori women not having a follow-up test reported within 90 days after a high-grade cytological abnormality (see Figure 3.8). Asian women were the most likely to have had follow-up tests within 90 days of an abnormal cytology report.

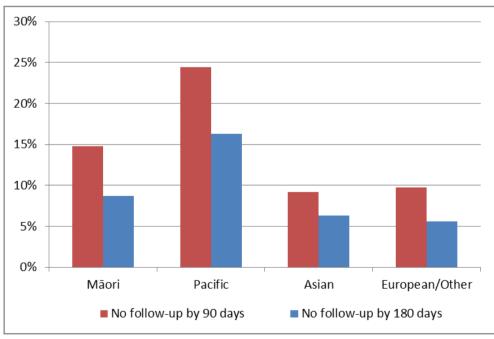
These variations in outcomes indicate there may be inequities in access or barriers particularly for Pacific and Māori women that make it more difficult for them to access, or understand the need for, timely follow-up after an abnormal test result. Understanding what these barriers and inequities might be will be essential in order for the programme and service providers to implement strategies that will remove these barriers and inequities in access to timely follow-up.

Figure 3.7: Proportion of women without any follow-up test within 90 days and within 180 days of a high-grade cytology report, by DHB



Source: NCSP Monitoring Report Number 40 (NSU 2014b)

Figure 3.8: Proportion of women without any follow-up test within 90 days and within 180 days of a high-grade cytology report, by ethnicity



Source: NCSP Monitoring Report Number 40 (NSU 2014b)

### **Key issues**

- Socio-economic status is recognised as an important determinant of health (Milne et al 2013), with more affluent groups having better health than less affluent groups. The NCSP monitoring and annual reports capture data by ethnicity, but do not report participation by socio-economic group. Understanding the interplay (if there is any) between ethnicity and socio-economic factors may help the NCSP more appropriately identify and develop strategies for improving participation for all women.
- The incidence of and rates of mortality from cervical cancer in Māori women are twice the figures for women from all ethnicities. The age-standardised incidence rate in 2012 was 6.2 new diagnoses per 100,000 women in the population as a whole and 12.7 per 100,000 for Māori women. The age-standardised mortality rate in 2010 was 1.7 per 100,000 women in the population and 3.3 per 100,000 for Māori women. Tailored and well-coordinated national strategies that remove barriers to screening and timely follow-up for Māori women are essential so that these inequities in health outcomes can be addressed.
- A nationally coordinated and consistent recruitment strategy is essential to address
  the inequities in cervical cancer screening participation to ensure equity in access not
  only for Māori women but for all women. The NCSP should centrally coordinate at a
  national level a full range of health promotion and recruitment initiatives.
- A critical part of achieving improved participation rates and reducing the burden of the disease on the Māori population will be having a close and collaborative working relationship with the Māori Monitoring and Equity Group to work on the development of health promotion and recruitment strategies and in partnership with the National Kaitiaki Group (NKG) to enable access to data in order to develop and appropriately target strategies.
- It is important to ensure all providers are aware of their own cultural competency and are trained regularly to support access to the cervical screening programme by women from different cultural backgrounds.
- Given the wide variation in early re-screening rates among DHBs (see Table 3.3), it is
  important for the cervical screening programme to regularly monitor and review
  performance across DHBs for this indicator. The purpose of this activity is to
  determine whether the variation is due to clinical practice that is not conforming with
  guidelines in those areas where there are high early re-screen rates.
- The variation in timely follow-up outcomes suggests there may be barriers to accessing services, particularly for Pacific and Māori women. Timely follow-up after an abnormal test result is important. Overcoming barriers will be essential to reduce inequities and ensure timely follow-up.

#### Recommendations

- Ongoing strategies are needed to address the disparities among priority groups in terms of participation and retention. Improved follow-up is needed after abnormal screening results.
- 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 with the highest need. To improve coverage for high-priority women, the cost of smears must not be a barrier.
- 3. Cultural competency is vitally important and ongoing education is needed to ensure that smear takers are attuned to cultural sensitivities. ISPs play a vital role in supporting local communities and providing access to cervical screening. Any changes to funding for ISPs for cervical screening should be carefully evaluated in terms of their consequences. DHBs and PHOs should be supported to work closely with ISPs to facilitate access to screening for unscreened and underscreened women.
- 4. Ongoing HPV education campaigns are important to ensure increased awareness and knowledge among the general population and among health care providers. This is of particular importance prior to any introduction of primary HPV screening.
- 5. It is recommended that NCSP and NKG work closely together to facilitate more timely and ongoing access to Māori data.<sup>11</sup>
- 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.

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<sup>&</sup>lt;sup>11</sup> See also Chapter 8: NCSP-Register and Chapter 9: Ethnicity data.

## **Chapter 4: Monitoring and evaluation**

#### Overview

Historical enquiries and reviews are summarised in Table 1.2 (Chapter 1: Introduction and methods). Evaluating the performance of the National Cervical Screening Programme (NCSP) currently involves:

- independent monitoring of a range of performance indicators against agreed targets
- regular independent audits of specific programme components
- three-yearly reviews of the programme as a whole, in accordance with the Health (National Cervical Screening Programme) Amendment Act 2004. The last review took place three years ago (Tan et al 2011)
- ongoing monitoring of smear takers, laboratories and colposcopy services against the programme's own quality standards
- · investigation of complaints
- monitoring of trends in programme outcomes, including cervical cancer incidence and mortality.

#### **Current status**

The World Health Organization (WHO 2002), in its policy and managerial guidelines for cancer control programmes, advises that monitoring and evaluation must be built into a programme's design. The implementation and delivery of a cancer control plan need to be evaluated. Evaluation is a means of monitoring the programme design and effectiveness so that it can be improved. At the development level, evaluation can help answer questions about how well the processes and systems are working and whether the goals and objectives are being met. Evaluation can show whether the strategies are being implemented, and whether the anticipated outcomes are being realised.

Both outcome and process measures need to be monitored. Process evaluation is critical for ensuring the ongoing success of the programme. Gathering feedback from key partners on their satisfaction with the programme, then making corrections as necessary so that concerns are addressed, is an important part of ensuring trust in, and credibility of, the programme within the targeted population. To determine whether a screening programme is achieving its designed purpose, it is also necessary to monitor process measures. For example, in a cytology cervical screening programme, it is important to ensure that women who are at risk of cervical cancer are being screened by good-quality Pap smears (process measures) and to monitor trends in incidence and mortality from cervical cancer (outcome measures), rather than simply focusing on the number of women being screened.

For successful programme monitoring and evaluation, it is important to:

- allocate resources and staff to conduct evaluation activities of all elements of the programme
- identify emerging challenges, develop solutions and conduct ongoing planning for improvement (the Plan-Do-Check-Act (PDCA) cycle)
- appoint the responsible people and set deadlines for remediation or implementation of revised processes.

Comprehensive monitoring reports have been produced by the NCSP since 2004. Since the last Parliamentary Review Committee Report (Tan et al 2011), external monitoring reports have been produced biannually by a team at the Lowy Cancer Research Centre, University of New South Wales, Australia, against a suite of eight groups of monitoring indicators as follows:

- Indicator 1: Coverage
- Indicator 2: First screening events
- Indicator 3: Withdrawal rates
- Indicator 4: Early re-screening
- Indicator 5: Laboratory indicators
- Indicator 6: Follow-up of women with high-grade cytology and no histology
- Indicator 7: Colposcopy indicators
- Indicator 8: Human papillomavirus (HPV) tests.

These reports provide ongoing monitoring against the programme's process measures and indicator targets, where targets are set. Full copies of the reports are available on the National Screening Unit (NSU) website at www.nsu.govt.nz including the latest report (NSU 2014b).

#### **Indicator 1: Coverage**

The population distribution of women by ethnicity is shown in Table 4.1. Coverage has been discussed in detail in Chapter 3: Coverage, participation, equity and access. There is, however, an element of population coverage currently not monitored. A New Zealand report on *Decades of Disparity* (Ministry of Health and University of Otago 2006) suggests that inequalities in health exist between ethnic groups and social classes in New Zealand, as they do anywhere else, and that the inequalities are not accidental in that for most countries, "socially disadvantaged and marginalised groups have poorer health, greater exposure to health hazards, and lesser access to high quality health services than their more privileged counterparts". The report finds that the extent of inequalities in New Zealand is unacceptable. The authors also state that, where health is concerned, ethnicity is not confined to 'socio-economic position'. Hence, both socio-economic position and ethnicity (as a marker of differential experience and exposure) matter in terms of health. These two factors jointly and independently influence mortality through multiple pathways and require integrated social and health policy to reduce and eliminate inequalities and inequities (Ministry of Health and University of Otago 2006).

Regular reporting and monitoring of participation by an additional measure of socioeconomic status would add a valuable dimension to enable greater understanding of the barriers to screening, and to inform the development of further, coordinated national strategies to ensure equitable access to all elements of the screening pathway by all disadvantaged groups.

Table 4.1: Population distribution of women aged 20-69 years

Ethnicity	Hysterectomy-adjusted population		
Māori	177,735		
Pacific	78,228		
Asian	174,165		
European/Other	881,008		
Total	1,311,136		

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

#### **Indicator 2: First screening events**

This indicator enables the programme to monitor the numbers and proportion of women entering the programme, by ethnicity and age. Ideally, and to ensure screening equity, the proportion of women undertaking their first screening event should be reflective of population demographics and distribution. First screening events should also be concordant with screening guidelines, with the majority of New Zealand women screening for the first time being in the age group of 20–24 years. Monitoring Report Number 40 (NSU 2014b) shows conclusively that the overwhelming majority of women entering the programme are, as would be expected, in the age range of 20–35 years. Of particular interest is the distribution by ethnicity of first screening events. Although the Monitoring Report does not enable absolute conclusions to be drawn, it would appear that Māori and Pacific women are significantly under-represented in first screening events (based on population distribution data from Indicator 1 – see Table 4.2).

The ethnic group with the highest number of women with first screening events, as would be expected given the population distribution, was European/Other women (13,142). Asian women were the next highest (5,178), then Māori (2,242) and Pacific women (1,628). Māori women had the lowest proportion of their eligible population being screened for the first time and Asian women had the highest proportion.

Monitoring Indicator 2 has no monitoring target at this time. To support WHO's doctrine of translating 'knowledge into action' to enable continuous quality improvement for the programme, 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 and socio-economic status.

Table 4.2: Women (aged 20–69 years) with first screening events as a proportion of i) total number of women with screening events, and ii) eligible women, by ethnicity, for the period 1 July–31 December 2013

Ethnicity	Women with first events	As a proportion of women with a screening event <sup>i</sup>		As a proportion of eligible population <sup>ii</sup>	
		n	%	n	%
Māori	2,242	23,093	9.7	177,735	1.3
Pacific	1,628	10,914	14.9	78,228	2.1
Asian	5,178	23,644	21.9	174,165	3.0
European/Other	13,142	155,711	8.4	881,008	1.5
Total	22,190	213,362	10.4	1,311,136	1.7

Note: Proportions shown are women with first screening event within a DHB, divided by i) all women with a screening event within that DHB (first or subsequent events) and ii) the hysterectomy-adjusted 2006 Census population projected to 31 December 2013 for that DHB, as a percentage.

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

#### Indicator 3: Withdrawal rates

All women who have a cervical screening test have the results of those tests recorded on the National Cervical Screening Programme-Register (NCSP-R), unless they elect to withdraw from the programme. The NCSP website, under Frequently Asked Questions, provides the following information (NCSP 2014a).

#### Q: Does a woman have to take part in the programme?

A: No, a woman can decide at any time she does not want to take part in the programme and withdraw. When a woman withdraws, she and her smear taker are responsible for her own screening.

This means the programme will not:

- make sure a complete record of your cervical screening history exists, even if you change your doctor or smear taker
- send reminder letters if you are overdue for a smear
- make sure you get the right tests and treatment if you have an abnormal result.

To ensure the programme is able to effectively monitor the cervical screening programme's effectiveness and outcomes, it is important that 'withdrawal rates' are zero or negligible. The NCSP Monitoring Report Number 40 (NSU 2014b) reports the number of women who have actively elected to withdraw from the programme has increased from 41 women in the previous Monitoring Report to 53 women for the latest reporting period. This represents just 0.004% of women on the Register. The data completeness to enable appropriate monitoring and evaluation of the programme is considered acceptable, and certainly comparable with organised cervical screening programmes in other countries.

#### Indicator 4: Early re-screening

Early re-screening has been discussed in Chapter 3: Coverage, participation, equity and access. It is noted that there is no target set for this indicator; however, the objective would be to ensure 'early re-screening' is maintained at 'as low as reasonably achievable' levels.

In reviewing 'early re-screen' rates by District Health Board (DHB), there is significant variance – ranging from the lowest rate of 10% of women (who were recommended to return at the routine screening interval (three years) and were re-screened early) to the highest rate of 27%. The median early re-screen rate is 16.5% and the mean is 17%. It is important for the programme to translate knowledge into action and investigate further to understand whether this is a chance anomaly and women are re-screening early for symptomatic reasons, or whether quality improvement interventions are necessary and work is required to ensure clinical compliance with NCSP screening guidelines.

A watching brief on this indicator will be important to ensure that early re-screening does not reduce the cost-effectiveness of the programme and that it does not also limit access for women who are not screening regularly.

#### **Indicator 5: Laboratory indicators**

There is a suite of indicators to enable regular monitoring of laboratory performance, the quality of samples, positive predictive values and timeliness of reporting. The seven pathology laboratories in New Zealand are all meeting performance targets for liquid-based cytology (LBC) samples reported as unsatisfactory, and the proportion of satisfactory samples reported as negative. The number of LBC samples reported as unsatisfactory also enables monitoring of the quality of smear-taking technique by providers, which is important given that one of the factors contributing to an 'unsatisfactory sample' is inadequate cells being collected due to poor technique.

Performance targets for 'satisfactory samples reported as abnormalities and as high-grade squamous intraepithelial lesions (HSIL) by laboratory' have not been met by all laboratories. However, the significant variance for one laboratory may well be explained by its case mix, where a significant proportion of samples are from colposcopy clinics, and it is to be expected that there would be a higher abnormality rate with these samples.

Of particular note is the significant decline in the proportion of samples reported as HSIL for women in the age cohorts of < 20 and 20–24 years. Women in these age groups were eligible for HPV vaccination (the oldest cohort would have been aged up to 23 years at the time of the latest Monitoring Report). As the NCSP-R does not capture vaccination status, it is not possible to determine whether this decline is consistent with an effect of HPV vaccination. It will be essential to monitor whether the decline in high grade abnormalities is sustained, as anticipated. Achieving 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.

Indicator 5.3, which monitors the accuracy of negative cytology reports, showed a significant variance across some laboratories (NSU 2014b, p 63). Close monitoring of this indicator is essential and discussions with pathology experts to determine whether a quality intervention is required would be highly appropriate.

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

This indicator, which monitors the follow-up of women with high-grade cytology, has been discussed in Chapter 3: Coverage, participation, equity and access. It showed significant variation across DHBs and also by ethnicity: 24.4% of Pacific women and 14.5% of Māori women did not have a follow-up test reported within 90 days after a high-grade cytological abnormality. Asian women were the most likely to have had follow-up tests within 90 days of an abnormal cytology report.

These variations in outcomes indicate there may be inequities in access or barriers particularly for Pacific and Māori women that make it more difficult for them to access, or understand the need for, timely follow-up after an abnormal test result. Understanding what these barriers and inequities might be will be essential in order for the programme and service providers to implement strategies that will remove these barriers and inequities in access to timely follow-up.

#### **Indicator 7: Colposcopy indicators**

This suite of indicators monitors timeliness of access to colposcopy and treatment and the adequacy of documentation of colposcopy assessment. The indicators to monitor the minimum colposcopy volumes for providers to maintain competency (against the NCSP Policies and Standards) are not yet being reported.

The targets for timely follow-up for women with a high-grade cytology report (both those with suspicion of invasive disease and those with no suspicion of invasive disease) to accepted referral and colposcopy visit have not been met. As previously identified, the proportional over-representation of Māori and Pacific women who are not accessing timely follow-up for treatment and management of suspicious high-grade abnormalities indicates these women face barriers to accessing services. Strategies to identify and address these issues are essential.

Complete data for the timeliness of women accessing colposcopy subsequent to persistent low-grade cytology or a low-grade cytology and positive HPV test was not available from the NCSP-R for the latest Monitoring Report. Because the e-colposcopy project has experienced interoperability challenges, the majority of providers have been unable to upload colposcopy reports. A comprehensive national intervention to resolve these information technology (IT) issues is essential. For more information on colposcopy, refer to Chapter 10: Colposcopy.

#### **Indicator 8: HPV tests**

This indicator monitors the use of HPV testing. Currently two indicators are reported (no targets have been set), while further work is to be undertaken to identify other measures that will enable monitoring of the use of HPV testing. For more information on HPV and further discussion of HPV screening, refer to Chapter 11: Human papillomavirus and cervical cancer.

#### Cost-effectiveness

Determining the priorities for a health system draws on a variety of technical, political and ethical criteria. Cost-effectiveness is never the only criterion to be considered, but it is the one that must be met most often when deciding which interventions to choose (WHO 2006a).

All countries have to make difficult choices on how best to allocate resources for health and health care. Cost-effectiveness summarises the efficiency with which an intervention produces health outcomes. A 'highly cost-effective' intervention is defined as one that generates an extra year of healthy life (equivalent to averting one disability-adjusted life year – DALY) for a cost that falls below the average annual income or gross domestic product per person. In 2011, the *First Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control* (WHO 2011) found that cervical cancer screening and treatment of pre-cancerous lesions to prevent cervical cancer are very cost-effective and very low cost, averting a current global disease burden of five million DALYs.

#### What is a disability-adjusted life year?

The World Health Organization (WHO 2015a) explains that one disability-adjusted life year (DALY) can be thought of as one lost year of 'healthy' life. The sum of these DALYs across the population, or the burden of disease, can be thought of as a measurement of the gap between current health status and an ideal health situation, where the entire population lives to an advanced age, free of disease and disability. DALYs for a disease or health condition are calculated as follows.

The sum of the years of life lost (YLL) due to premature mortality in the population and the years lost due to disability (YLD) for people living with the health condition or its consequences (DALY = YLL + YLD).

A QALY, the 'quality-adjusted life year', is a measure of disease burden, including both the quality and the quantity of life lived. It is used in assessing the value for money of a medical intervention.

# **Key issues**

- Including an additional measure of socio-economic status in the regular reporting and monitoring of participation would enable a greater understanding of the barriers to screening, and would inform the development of further national strategies to ensure equitable access to the screening pathway by all disadvantaged groups.
- 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 and
  socio-economic status.
- Review of 'early re-screen' rates shows significant variance among DHBs. It is
  important for the programme to understand whether these are chance anomalies and
  women are re-screening early for symptomatic reasons, or whether quality
  improvement interventions are necessary to ensure clinical compliance with NCSP
  screening guidelines. A watching brief on this indicator will be important to ensure
  that early re-screening does not reduce the cost-effectiveness of the programme and
  that it does not also limit access for women who are not screening regularly.
- The number of smears reported as HSIL for women in the age cohorts of < 20 and 20–24 years has declined significantly. Women in these age groups were eligible for HPV vaccination. However, as the NCSP-R does not capture vaccination status, it is not possible to determine whether this decline is consistent with an effect of HPV vaccination. It will be essential to monitor whether the decline in high-grade abnormalities is sustained, as anticipated. Achieving 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.</p>
- 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.
- The targets for timely accepted referral and colposcopy visit for women with a highgrade cytology report have not been met. As previously identified, the proportional over-representation of Māori and Pacific women who are not accessing timely followup for treatment and management of suspicious high-grade abnormalities indicates these women face barriers to accessing services. Strategies to identify and address these issues are essential.
- Complete data for the timeliness of women accessing colposcopy subsequent to
  persistent low-grade cytology or a low-grade cytology and positive HPV test was not
  available from the NCSP-R for the latest Monitoring Report. Because the
  e-colposcopy project has experienced interoperability challenges, the majority of
  providers have been unable to upload colposcopy reports. A comprehensive national
  intervention to resolve these information technology issues is essential.

# Recommendations

- 7. There should be more stringent monitoring of the quality of colposcopy.
- 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.
- 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 and socio-economic status.
- 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.
- 11. It will be important for the NCSP to determine if the decline in the proportion of samples reported as 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.
- 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 discussions these findings with pathology experts to determine whether a quality intervention is required.
- 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 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.
- 14. A comprehensive national intervention to resolve the barriers to the successful implementation of the e-colposcopy project is essential to ensure complete data for women referred for colposcopy is captured on the Register.

# **Chapter 5: Quality assurance**

# Overview

'Quality assurance' has been an approach applied in health service delivery for many years. Duke University Medical Centre (2014), in a document considering the terms 'quality assurance' and 'quality improvement', states that some perceive 'quality assurance' as having negative connotations and associate it with a reactive, retrospective and sometimes punitive approach. For the purposes of this report, the chapter title of 'Quality assurance' is referring to the strategies and practices employed within the National Cervical Screening Programme (NCSP) to assure the quality of services provided to women accessing the programme. This is otherwise known as a philosophy of continuous quality improvement.

The World Health Organization (WHO), in its document *Quality of Care. A process for making strategic choices in health systems* (WHO 2006b), notes that medical science and technology have advanced at a rapid pace, and that health care systems have floundered in their ability to provide consistently high-quality care to all. The document notes that the scientific and technological advances will not, in and of themselves, lead to the high-quality health care that populations and individuals rightly have come to expect. Taking a systems perspective and orienting systems to the delivery and improvement of quality services are fundamental to meeting the expectations of the population.

WHO's report *Comprehensive Cervical Cancer Control: A guide to essential practice* (WHO 2014) states that quality assurance and a quality control approach are essential for cervical cancer prevention and control programmes. One risk of screening, which applies to all screening tests described, is a variable rate of over-detection of pre-cancer (i.e. false-positive results), which leads to overtreatment of women who are in fact not at increased risk of invasive cancer at that time. Another, more significant risk of screening is the risk of obtaining a false-negative result, which may result in missing signs of disease and thus a missed opportunity for treatment of pre-cancer or early cancer. Another risk to the success of the screening programme is represented by women who do not screen, or do not screen regularly.

#### **Current status**

The National Screening Unit (NSU) has produced a draft document, released for consultation in December 2014, titled *National Screening Unit Quality Framework 2014: Delivering screening programmes* (NSU 2014c). The core set of six principles is intended to provide a foundation for achieving the NSU's strategic vision for achieving high-quality, equitable and accessible screening programmes.

NCSP Policies and Standards documents provide agreed policies, guidelines and standards of practice for health professionals who provide cervical screening services (Ministry of Health 2014a). Their purpose is to support all those involved in the NCSP to achieve the programme's aims and objectives, by ensuring a high standard and national consistency of service at each step of the screening pathway. These Policies and Standards establish the baseline for the programme's delivery. Regular monitoring and evaluation of the programme's performance against key indicators should inform and facilitate continuous quality improvement by identifying areas where performance is not to the expected standard, or where gaps in programme design or service delivery are identified.

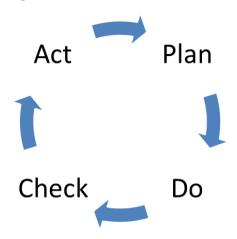
The NCSP also has well-established advisory group structures, including the NCSP Advisory Group and the Māori Monitoring and Equity Group, which can both support and inform the identification of issues and development of strategies that will assist in the achievement of its quality strategic vision. In addition to these groups will be the reformed National Screening Advisory Committee, which will provide overall governance to the roll-out of human papillomavirus (HPV) screening as the primary screening test. Engaging these groups in the quality improvement initiatives for the programme will be critical to the success of the initiatives.

The United Kingdom's Health Foundation has instituted a broad research agenda into quality services and quality improvement initiatives (Health Foundation 2009). The so-called 'quality enhancing interventions' offer a resource to inform health services on similar quality issues and improvements implemented. When monitoring and evaluation data shows areas for improvement, the next step is to identify the most effective actions.

In *Comprehensive Cervical Cancer Control*, the WHO (2014) advises that all screening programmes require a well-functioning quality control and quality assurance programme. According to its *Health Systems Strengthening Glossary* (WHO 2015b), 'monitoring' is the continuous oversight of an activity to assist in the programme's supervision and to see that it proceeds according to plan. It involves the specification of methods to measure activity, the use of resources, and the performance by services against agreed criteria.

Programme performance monitoring and continuous quality improvement initiatives developed as a result of monitoring are critical to the ongoing success of screening. The Plan-Do-Study-Act (PDSA) cycle or Plan-Do-Check-Act (PDCA) cycle, otherwise known as the 'Deming cycle', is a model for continuous quality improvement that is particularly pertinent for screening programmes (see Figure 5.1). The cycle begins with a 'Planning' phase in which the issue to be addressed is clearly identified and understood. A critical element in identifying the issue is to ask – over and over again – 'Why is this occurring?' Potential solutions can then be generated and tested in the 'Do' phase, and the outcome of this testing is evaluated during the 'Check' phase. 'Do' and 'Check' phases can be iterated as many times as is necessary before the full, polished solution is implemented in the 'Act' phase. The cycle is perpetual and based on continual monitoring and evaluation of performance.

Figure 5.1: The Plan-Do-Check-Act cycle



The National Screening Unit is taking a proactive approach by developing a draft Quality Framework for delivering screening programmes. Once endorsed, the next stage will be to identify areas where there is a need to develop actions or interventions. The biannual monitoring reports have been developed to monitor the effectiveness of the screening programme. It is essential that the knowledge gained through these reports is used for the ongoing quality improvement of the programme through the development of a Quality Improvement Plan – based on the PDCA cycle. Where monitoring targets have not been met, or when performance across any of the measures falls outside of the expected norms, the proactive development of strategies to improve performance is an essential element of a successful screening programme.

For example, this approach could be applied to address the variations in Indicator 4 (Early re-screening) identified in Chapter 4: Monitoring and evaluation. The first phase of the planning cycle for quality improvement in outcomes for Indicator 4 would be to recruit experienced clinicians and engage them in reviewing variations across District Health Boards (DHBs). This could include case study reviews or audits.

If unexplained deviations from clinical guidelines were identified, the 'Planning' phase would see the development of strategies such as training or education interventions for clinicians to encourage compliance with guidelines. The 'Do' phase of the cycle would be implementing these strategies and the 'Check' phase would be ensuring clinicians understand and feel confident with the screening guidelines. Finally, the 'Act' phase would involve the ongoing monitoring of 'early re-screening' rates, ensuring that clinicians are complying with the guidelines and that early re-screening rates fall within expected margins. Ongoing monitoring will identify if or when further interventions may be needed.

Monitoring and evaluation are neither static nor stand-alone elements of the screening system and processes. Performance monitoring must inform the development and implementation of strategies that become part of the continuous quality improvement cycle.

Quality improvement of service provision by providers should be carried out continually, with any quality improvement strategies instituted in a timely manner. Improving quality is a responsibility of all stakeholders, and may include:

- self-assessment and local problem-solving, as participatory methods that should involve all providers as well as representative members of the community
- supportive supervision, which is particularly pertinent to service providers at the
  primary health organisation (PHO) level who are performing cervical screening tests,
  and also staff in laboratories. This process should be facilitated by trained
  supervisors, and may include mentoring and updating the skills of health workers and
  working with them to solve any issues noted
- seeking feedback from consumers of the service to identify shortfalls or gaps in service delivery.

Process evaluation is critical for ensuring the ongoing success of the programme. Gathering feedback from key partners (including providers and consumers of the services) on their satisfaction with the programme, then making corrections as necessary so that concerns are addressed, is an important part of ensuring trust in, and credibility of, the programme within the targeted population.

The Parliamentary Review Committee has reviewed a report on complaints relating to cervical screening submitted to the Health and Disability Commissioner (HDC) for the period 23 June 2011 to 26 March 2015. In all, 15 complaints were received by the HDC during this period. Most (eight) complaints were from women who had experienced delays in communication of results or in diagnosis of abnormalities, or failure to refer appropriately or in a timely manner. Six complaints were about inappropriate conduct, inadequate communication or incorrect information being provided by the health care provider/s. One complaint was regarding a perception of inappropriate cervical screening posters in general practices and coercion by doctors of women to be screened. Two complaints (one from July 2013 and the other from July 2014) are still under investigation by the HDC.

It is important to note that the 15 complaints are only those that have reached the level of submission by consumers to the Health and Disability Commissioner. It is not known what complaint management processes are in place within DHBs and general practices, nor what the quantum or scope of those complaints might be. Around 270 complaints have been received over the last four years by the NSU regarding a range of issues relating to cervical screening services.

Core principles of a successful screening programme are that the test/s are acceptable to the population being screened, and that the screening programme is safe for participants, both physically and psychosocially. Monitoring and acting on (where appropriate) feedback on the delivery and acceptability of screening services is a critical element of programme continuous quality improvement. It is important that the NCSP continually seeks and monitors feedback on the acceptability of the programme to participants, and implements remedial strategies where required.

For successful programme monitoring, evaluation and continuous quality improvement, it is important to:

- allocate resources and staff to conduct evaluation activities of all elements of the programme
- identify emerging challenges, develop solutions and conduct ongoing planning for improvement as shown in the PDCA (see Figure 5.1)
- appoint the responsible people and set deadlines for remediation or implementation of revised processes
- have ready access to timely data.

Monitoring and evaluation and the implementation of quality improvement strategies must be a collaborative process between the NCSP, DHBs, laboratories and the National Cervical Screening Programme-Register (NCSP-R) so that lessons can be shared and strategies implemented consistently across the country. Regular, ongoing monitoring and quality improvement meetings should be scheduled shortly after the release of the biannual monitoring reports, and the agenda for these meetings should be informed by the monitoring report indicators. The actions and outcomes from these meetings would inform the development of, on an ongoing basis, a Quality Improvement Plan for the NCSP.

Canada's cervical screening programme has also led to significant reductions in cervical cancer incidence and mortality (Canadian Partnership Against Cancer 2013). Despite this success, over 1,400 Canadian women are diagnosed with invasive cervical cancer each year. Canadian studies have found that women diagnosed with invasive cervical cancer were not screened in the five years before diagnosis, were not followed appropriately after an abnormal Pap test result, or had a Pap test that failed to detect their cancer. The Canadian Cervical Screening Program states that the continuous monitoring and evaluation of cervical cancer screening is critical to ensure that Canadian women have access to and receive high-quality cancer prevention services.

The 2011 NCSP Parliamentary Review Committee (Tan et al 2011) recommended ongoing audit of the screening histories of women who develop cervical cancer. The underpinning rationale is that there are likely to be valuable lessons from these audits that would inform the implementation of quality improvement initiatives. It is essential that these audits occur regularly and involve expert clinicians involved in the programme. Any identified system or process gaps or failures should be used to inform quality improvement strategies, and be incorporated into a quality improvement plan.

Other opportunities for quality improvement have been identified under other sections in this report – including Chapter 3: Coverage, participation, equity and access, and Chapter 4: Monitoring and Evaluation. The NCSP would be enhanced with the introduction of the PDCA cycle, particularly during the NCSP's consideration of the biannual monitoring reports, and the institution of a Quality Improvement Plan that informs the ongoing work plan for the programme.

# **Key issues**

- Monitoring and evaluation are neither static nor stand-alone elements of the screening system and processes. Performance monitoring must inform the development and implementation of strategies that become part of the continuous quality improvement cycle.
- Monitoring and evaluation and the implementation of quality improvement strategies
  must be a collaborative process between the NCSP, DHBs, laboratories and the
  Register so that learnings can be shared and strategies implemented consistently
  across the country.
- Regular, ongoing meetings for monitoring and quality improvement should be scheduled shortly after the release of the biannual monitoring reports, and the agenda for these meetings should be informed by the monitoring report indicators. The actions and outcomes from these meetings would inform a Quality Improvement Plan for the NCSP both during its development and on an ongoing basis.
- Ongoing audit of the screening histories of women who develop cervical cancer is recommended. The underpinning rationale is that there are likely to be valuable lessons from these audits that would inform the implementation of quality improvement initiatives. It is essential that these audits occur regularly and involve expert clinicians involved in the programme. Any identified system or process gaps or failures should be used to inform quality improvement strategies, and be incorporated into a quality improvement plan.
- The NCSP would be enhanced with the introduction of the PDCA cycle, particularly during the NCSP's consideration of the biannual monitoring reports, and the institution of a Quality Improvement Plan that informs the ongoing work plan for the programme.
- Other opportunities for quality improvement have been identified under other sections in this report – including Chapter 3: Coverage, participation, equity and access; Chapter 4: Monitoring and evaluation; and Chapter 8: NCSP-Register.

#### Recommendations

- 15. Regular, ongoing meetings for monitoring and quality improvement should be scheduled shortly after the release 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 would inform the development of a Quality Improvement Plan for the NCSP.
- 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.

- 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.
- 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.

# Chapter 6: Organisational and structural issues

#### Overview

Each year in New Zealand around 170 women are diagnosed with cervical cancer (in 2010 the figure was 180) and around 60 women die from the disease. In 2010 cervical cancer accounted for 1.8% of all female cancer registrations and 1.3% of all deaths from cancer in women (National Health Committee 2015).

In the three years ending December 2013, 879,862 women were screened in New Zealand, with an overall coverage rate of 77% of eligible women aged 25–69 years. The National Cervical Screening Programme (NCSP) 2013/14 budget was \$40.4 million. This amount comprised:

laboratory costs: \$16.2 million

· colposcopy costs: \$9.3 million

· regional services: \$7.0 million

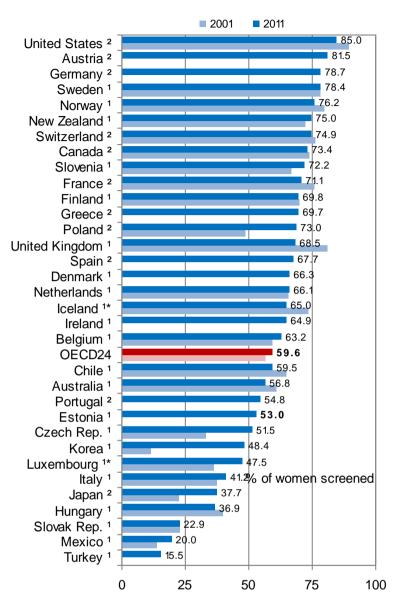
• other funding: \$7.9 million.

Regional services include promotion and coordination, some smear taking and supporting women through screening. Other funding includes monitoring, audits, the National Cervical Screening Programme-Register (NCSP-R) (including invitation and recall and social marketing) and programme resources (National Health Committee 2015).

Figure 6.1 shows coverage rates for a number of international programmes. Although the ethnic mix, and focus on achieving equity across all ethnic groups in New Zealand, mean figures across different countries are not directly comparable, it does provide a general idea of New Zealand's position in relation to other countries.

New Zealand continues to have one of the highest coverage rates in the Organisation for Economic Co-operation and Development (OECD) with resources distributed to ensure a high-quality and well-organised screening system for the early detection of cervical cancer.

Figure 6.1: Cervical cancer screening in women aged 20–69 years in OECD countries from 2001 to 2011 (or nearest year)



#### Note:

- 1. Programme.
- 2. Survey \* Three-year average.

Source: OECD (2013)

# **Current status**

# A high-quality, organised screening system

Five essential components of a high-quality, organised screening system are identified in the Quality Framework of the National Screening Unit (NSU 2014c) as critical to the safe and effective practice of organised screening (adapted from Hale 2012). These are:

- 1. a central agency to lead and coordinate the screening pathway
- 2. clinical governance
- 3. infrastructure and systems to manage a screening programme
- 4. monitoring and evaluation
- 5. quality cycle.

The National Health Committee (NHC) affirms that a screening programme displaying these characteristics "lifts the screening game" for the programme concerned. Therefore the challenge to national screening programmes is to maintain this quality by working more closely with the wider health sector especially in times of fiscal constraint (National Health Committee 2015).

The NHC also notes that many screening programmes are underperforming for Māori, Pacific, Asian and economically deprived populations.<sup>12</sup>

Therefore, unless carefully planned, health interventions tend to increase inequalities. In undertaking assessments, the NHC is required to consider both existing and potential disparities in health in relation to a proposal. Another critical role of the NHC is to maintain a continuing interest in emerging screening technologies and significant extensions and/or modifications to existing screening programmes, such as in the NCSP's human papillomavirus (HPV) primary screening (NSU 2014d).

This Parliamentary Review Committee (PRC) 2015 acknowledges that challenges have consistently arisen from many of the interviewees and key informants whose collective commentary spanned the five essential components that are critical to the effectiveness of the programme (NSU 2014c). For the purpose of this report, an interviewee is defined as a participant interviewed by the PRC who is external to the Ministry of Health, including the advisory groups of the National Screening Unit and the National Cervical Screening Programme. A key informant is a key staff member from the Ministry of Health. More information about the interview process is available in Chapter 1: Introduction and methods. More of the detail provided in the interviews is given in Appendix F.

In addressing the organisational and structural issues of the NCSP, the first three components in the NSU Quality Framework as listed above are most pertinent.

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<sup>12</sup> http://www.nhc.health.govt.nz

<sup>&</sup>lt;sup>13</sup> Ibid 12.

Each of the components of the NCSP screening pathway must operate to a high standard for the programme to meet its objectives for providing the screening pathway for women in New Zealand (Ministry of Health 2014b). This pathway includes invitation and recall of women through smear taking, laboratory testing, colposcopy and information systems that support these processes. The screening pathway is further supported through the scope of the NCSP's service provision, which includes:

- national services for management, coordination, monitoring and information management through the NCSP-R
- regional/local services for rollout and effective programme coordination. Many of the components of the screening pathway are at this level, contracted and subcontracted to major sector providers such as: District Health Boards (DHBs), Primary Health Organisations and Independent Service Providers.

# Clinical governance

Clinical governance as a system of accountability for continuous improvement in the quality of the (screening) services and guarding high standards of care is essential for creating an environment in which excellence in clinical care will flourish (Scally and Donaldson 1998). This definition embodies three attributes: recognisable high standards of care; transparent responsibility and accountability for those standards; and a constant dynamic of improvement (NSU 2014c).

# **Advisory groups**

The National Screening Unit seeks external advice from a range of sources to support its work. The groups that have particular relevance and importance to the NSU and NCSP at governance level are the:

- Māori Monitoring and Equity Group (MMEG)
- National Screening Advisory Group
- National Cervical Screening Programme Advisory Group.

# Māori Monitoring and Equity Group

Up to 12 members are appointed to the MMEG for their particular expertise in matters relating to Māori health and screening programmes. The group provides Māori leadership on strategic issues for planned screening programmes that are clinically and technically sound, and is using an equity assessment framework for monitoring reductions in inequalities in health for Māori.

# National Screening Advisory Committee

Up to 12 members are appointed for their particular expertise in matters relating to a wide range of screening policies, practices and research. This group provides advice on the Ministry of Health's screening policy work programme, which covers screening in health and disability practice and research, including cancer and genetic screening.

# National Cervical Screening Programme Advisory Group

The group is composed of members who collectively have wide knowledge and experience of the NCSP screening pathway. It includes: obstetricians and gynaecologists, pathologists, cytologists and laboratory scientists, primary care plus medical and nursing experts in screening. Māori, Pacific and consumer representatives are also members of the group.

# Clinical leadership

The NSU and NCSP were challenged in the 2011 Parliamentary Review on the variable balance of clinical leadership skills and capacity demonstrated over time within these units of the Ministry of Health. In response, the NSU appointed a new Clinical Director in January 2013; the position of NCSP Clinical Leader was retained. Both post-holders are public health physicians with population health, public health and screening expertise. A public health physician with applied epidemiology skills was appointed to lead the monitoring and evaluation analysis within the NSU's Information, Quality and Equity team and an additional public health physician with a lead role in promoting achievement of equity for all NSU screening programmes was appointed. A Clinical Governance Group was established in 2010 to provide clinical, public health and strategic advice on screening practice, including monitoring and resourcing.

The National Cervical Screening Programme is essentially a clinical programme; therefore, having high-quality clinical competence across the screening pathway remains the central focus of its success. Clinical competence must also embrace the future developments for the programme as it moves towards a screening route of HPV primary testing.

Sustaining the clinical competency of the programme requires a fine balance between consumer and stakeholder opinions of clinical competence at governance and programme leadership levels, and the reality for the programme to be continually striving to meet these demands through appointments of key skilled personnel. Achieving this balance is important to maintain the programme's clinical integrity.

The National Screening Advisory Group reported that the NSU and the NCSP are engaging with it more and are providing improved insights into programme planning at this governance level in a timelier manner.

There have not been in-depth discussions within the group regarding the National Kaitiaki Group, apart from receiving informal expressions of frustration about not getting timely access or timely permission to commission for data. However, the last Monitoring Report (NSU 2014b) raised no further issues relating to data access.

#### The National Health Committee

The National Health Committee (NHC)<sup>14</sup> is an independent statutory body charged with prioritising new and existing health technologies and making recommendations to the Minister of Health. It was reformed in 2011 to establish evaluation systems that would provide the New Zealand people and the health sector with greater value for money invested in health.

Section 13 of the New Zealand Public Health and Disability Act 2000 specifies the NHC's purpose is to provide advice to the Minister of Health on:

- the kinds, and relative priorities, of public health services, personal health services, and disability support services that should, in the NHC's opinion, be publicly funded
- b) other matters relating to public health, including
  - i) personal health matters relating to public health; and
  - ii) regulatory matters relating to public health
- c) any other matters that the Minister specifies by notice to the NHC.

The NSU and NCSP will have a future role and referral process with the NHC regarding the development and rollout of primary HPV screening, a major project advancement that is in the early stages of investigation and policy framework expansion in cervical screening. For more information on HPV screening, see Chapter 11: Human papillomavirus and cervical cancer.

# **Equity**

Currently the single most important issue facing the national screening programme in New Zealand is addressing the disparities and inequities that continue to challenge all levels and component parts of the programme.

There is a need to continue to make improvements for Māori, Asian and Pacific women and consider what the opportunities are from an equity perspective. The NSU and NCSP need to make sure there are strong relationships with the sector, there is good dialogue, and the sector is much more involved with decision making.

Two key examples of what did work and what should be considered as necessary to improve performance for reaching priority women – especially Māori women – are the television advertisements promoting cervical screening and the education of women about the importance of having smears:

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http://www.nhc.health.govt.nz

- "The TV adverts were a great way of addressing (this) promoting cervical screening – as they highlighted that it isn't just the woman herself who matters but the whole whānau ... whānau ora strategies are needed.
- Very disappointing that the TV adverts are no longer being broadcast, these were impressive and had a great deal of impact.
- The other issue is that the priority women do not consider cervical screening a priority in their lives. Education is important."

Interviewee

Social marketing programmes were also viewed as important by those interviewed by the Parliamentary Review Committee:

"Having social marketing programmes that make women visible is highly beneficial. Social media and web-based culture should be considered as a means to disseminate information. Health promotion and literacy is essential for quality assurance and data access. It is important that the results from programmes are easily accessible to consumers and understandable in layman terms. This is seen as improving engagement. If people trust programmes, they are more likely to be engaged."

Key informant

These issues have not gone unnoticed by the National Screening Unit, which has made it clear in its Quality Framework document (NSU 2014c) that:

"Achieving equitable coverage is the emphasis and the NSU must lead the screening sector to achieve equity; this is the absolute focus for the future."

Key informant

The intent must now be followed through by improvements in engagement with the priority women's groups and innovative ways to execute this. The foundations are now in place to increase coverage according to another key informant:

"An internal operational group (Equity Forum) is in place, as well as the Māori Monitoring and Equity Group (MMEG). There is now a need to get to the target rate of 80% for Māori. While there are many initiatives, there is still a need for a 'real plan' to have improved progress."

Key informant

Another current concern was the lack of plans in place to promote screening to Asian women, who are another priority group in the NCSP, but the Parliamentary Review Committee was informed that Asian advisors are to be engaged in the future.

# Regional coordination issues

Following the previous Parliamentary Review (Tan et al 2011), the NSU and NCSP have responded to the recommendations made and have provided a system of consultation and reporting to progress these.

The responses from the NSU and NCSP were as follows:

- A newsletter *Screening Matters* is produced and provides quarterly updates to the sector with highlights and monitoring information.
- Policy and quality standards have been reviewed and relationships with the Cancer team and cancer networks about the Cancer Control Strategy are ongoing.
- Work plans are developed with initiatives and programmes aligned to the Cancer Control Strategy and the associated work plans.
- The NCSP and the Immunisation team within the Ministry of Health are building a strong relationship around HPV immunisation and cervical screening, especially to ensure messaging is consistent and supportive of both programmes.
- Close collaboration occurs across the Ministry integration programme, with a
  particular focus on primary care. There is consultation with the Māori Health Business
  Unit to monitor progress against the Māori Health Plans, and the whānau ora
  collectives' reports, and to discuss initiatives or policy developments.

It was also reported to the Parliamentary Review Committee that over the last three years there has been limited regional coordination and consultation. However, since 2013, two senior portfolio managers have undertaken a programme of visiting providers.

A quarterly teleconference with regional coordination services and non-government organisations takes place to share successes and discuss current issues and developments concerning providers. Interviewees stated that these meeting points are for the "higher level managers" only and they would prefer to see a different approach:

"A national meeting and regular regional face-to-face meetings would be useful to help fit together the pieces of the jigsaw."

Interviewee

#### Infrastructure and systems issues

High-quality screening programmes need to be supported by high-quality infrastructure. A common element of all programmes is the necessity for information systems that meet the specific requirements of screening. Within the confines of available resources, systems should be thoughtfully developed to be as user-friendly as possible. This helps to make doing the right thing easy to do (NSU 2014c).

Continuing change processes have had major impacts on the organisational systems in the NSU and NCSP in the past three years, with staff turnovers making change necessary for the continuation of the NCSP. Many of the stakeholders interviewed brought this issue to the forefront throughout the review. In 2012, following the past reviews of both the NCSP and the BreastScreen Aotearoa (BSA) programme, the NSU undertook a change management process affecting the configuration of positions across these two programmes at a national level, and within the Ministry of Health itself (NSU 2012b). The changes made by NSU were:

- dually arranging reporting lines of senior clinical leaders in the programme for operational and clinical accountabilities
- changing the Clinical Advisor title to Clinical Leader, NCSP and retaining the role
- disestablishing roles for the two management and leadership positions of the NSU and the NCSP
- establishing a dedicated reporting line for two analysts; one administration role, and one management role for the NCSP.

While it was acknowledged that in the previous two years the team had been relatively stable, there had been recent staff losses prior to this review in 2015. These vacancies comprised senior staff within the NSU and NCSP. The NSU Group Manager, NCSP Programme Manager and NCSP Clinical Leader all resigned in the two months prior to or at the commencement of this review.

These sudden changes have implications for the institutional knowledge and ongoing functioning of the programme. 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.

The remaining position to be filled is Clinical Leader for the NCSP. There is a need to seek strong leadership skills in areas of clinical knowledge and experience such as colposcopy, pathology and cervical screening nationally, and substantial capability in quality management and research.

This role will require an ability to work as a team leader with colleagues of complementary ability – operationally such as with the NCSP Programme Manager; regionally with the portfolio managers working directly with DHBs; and nationally with the Clinical Director and Group Manager across the NSU.

The Clinical Leader must also demonstrate energy and passion for their area of expertise. The Clinical Leader will have a critical role in future HPV developments and changes within the NCSP.

It is crucial that the new incumbents, including the new Clinical Leader, are promptly oriented in their positions and that the new leadership team establishes strong regional coordination and communication across the national screening sector.

Much effort for the programmes has been focused on business as usual, the NCSP-R and the Quality Framework (for the NSU).

The following organisation charts show the National Health Board structure (Figure 6.2) and the structure of National Services Purchasing (Figure 6.3). The NSU senior management team is shown in Figure 6.4 and the NCSP organisational structure is shown in Figure 6.5.

Figure 6.2: National Health Board structure 2015

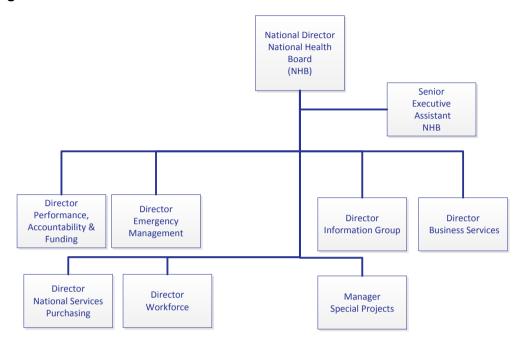
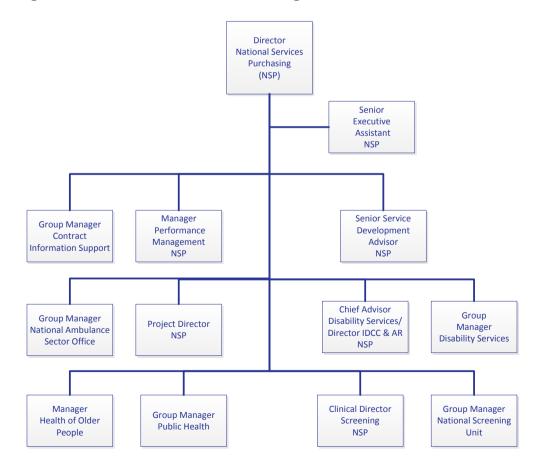


Figure 6.3: National Services Purchasing structure 2015



Ministry of Health Chief Medical Director National Services Officer Purchasing Clinical Director **National Screening** Group Manager National Screening Unit Unit Analyst Executive Planning & Assistant Reporting Programme Manager Antenatal and Clinical Programme Programme Leader Manager Manager Leader Manager Manager Business National Cervical National Cervical BreastScreen BreastScreen Newborn Information, Performance Screening Programme Screening Programme Aotearoa Aotearoa Screening Quallity & Equity

Figure 6.4: National Screening Unit senior management structure 2015

Ministry of Health Director Chief Medical National Services Officer **Purchasing** Clinical Director **Group Manager National Screening** National Screening Unit Unit Programme **NCSP Clinical Lead** Manager Executive Assistant Senior Analyst Senior Analyst Senior Portfolio Senior Portfolio Service Service Manager Manager Development Development

Figure 6.5: National Cervical Screening Programme organisational structure 2015

# Leadership

Despite the impact of high staff turnovers being felt at all levels internally and externally in work related to regional coordination, the infrastructure support systems for both the NSU and NCSP, including for senior management, have provided sound decision making and well-considered resolution for human resource management issues internally.

The management position for the Information Quality and Equity Unit has recently been filled after being in abeyance as an 'acting' position for the last 18 months.

The Clinical Director position is in the NSU and is spread over five organised national screening programmes that the NSU manages. As described to the PRC, an estimated 20% of the workload for this role is dedicated to the NCSP Strategic and operational work is ongoing and engaging with staff is seen as very important. HPV planning takes up to 50% of the role at the time of this review (2015). The broad responsibilities of the Clinical Director are ensuring the safety and high quality of national screening programmes; providing professional leadership and guidance to Clinical Leaders in the national screening programmes; and providing risk

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<sup>&</sup>lt;sup>15</sup> JD NSU Clinical Director revised 03.05.12, Ministry of Health.

management advice and direction on issues relating to the screening programmes. In regard to the NCSP specifically, some of the Clinical Director leadership functions involve the oversight of:

- improvements to systems and links to primary care and with women
- increased and improved relationship building by the NCSP with providers regionally, through the portfolio management roles that are dedicated to this area and with planning and funding activities of the DHBs for distribution modelling on investment in the screening programme.

This strategic and clinical leadership from the NSU strengthens opportunities for provision of a good programme overall for the future.

The improvements in the programme also extend to the information needs of the priority groups of the NCSP. Attention must be appropriately given to Māori, Pacific and Asian people in regard to HPV vaccination and primary screening, just as these groups have been considered in the past in regard to cervical screening and treatment.

Past studies have reported key areas that have to be taken into consideration when promoting and raising awareness of important health programmes and treatments that require involvement and participation, especially by priority population groups such as those for the cervical screening programme. <sup>16</sup> This has covered areas including the use of the person's (or group's) first language (Cartwright 1988); addressing the personal barriers of the women – then encouraging their participation and implementing a multifaceted advertising strategy. <sup>17</sup>

Other areas covered are the use of easy-to-understand language<sup>18</sup> and finding the best messenger.<sup>19</sup>

Important to this issue are NCSP efforts in working collaboratively with the HPV Immunisation team within the Ministry of Health. A critical focus of this relationship is to ensure messaging is consistent and supportive for both the HPV vaccination and primary screening programmes. Screening services and health information are both activities used to improve individual and population health (Ministry of Health 2003).

http://www.moh.govt.nz/notebook/nbbooks.nsf/\$FILE/kiawhaitemaramatanga. Cited in Ministry of Health (1994), p 58. From Lynch (1989), quoting Cartwright Report (1988).

<sup>&</sup>lt;sup>17</sup> Ibid 16, p 63.

<sup>&</sup>lt;sup>18</sup> Ibid 16, p 64.

<sup>&</sup>lt;sup>19</sup> Ibid 16, pp 64–65.

"The health promotion messages are important; we need to ensure that we talk about the importance of family, we need to help people feel they are strong and we need to help encourage people to feel good about themselves and to be happy and confident to seek medical help. These strategies will help to overcome fears as keeping people engaged is essential to keeping them healthy."

Interviewee

# **Key issues**

- Addressing equity is important. In particular, the variable achievement of the 80% target for Māori, Pacific and Asian women must be eliminated as an outstanding disparity of this programme.
- While steps have been taken to improve regional coordination with providers, further strategies must be identified to rectify remaining issues of coordination and communication with them.
- It is essential to sustain the infrastructure and systems within the programme.
   Therefore the orientation of the new incumbents to their positions in the NCSP needs to be prompt and thorough.
- Information and appropriate messaging about HPV and changes to the NCSP are important to achieving effective and ongoing engagement of the priority groups for this programme.

# Recommendations

- 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.
- 20. NCSP regional portfolio managers must continue to demonstrate improvements in coordination with providers through at least one planned national meeting each year and ongoing regional face-to-face meetings with local service leaders for the cervical screening programme in the 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 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.

- 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 force.
- 23. Information about HPV must be appropriately provided to the NCSP priority groups: Māori, Pacific and Asian people. The NCSP must also 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.

# **Chapter 7: Workforce issues**

#### Overview

The outstanding area of concern in the near future for the laboratory science workforce is the impact that human papillomavirus (HPV) screening will have across this sector, particularly on its workforce.

#### **Current status**

#### Laboratories

The National Screening Unit (NSU) and National Cervical Screening Programme (NCSP) responded to the 2011 Parliamentary Review workforce development recommendations by suggesting that professional colleges and associations are best positioned to administer the Individual External Quality Assurance Programme and training (as opposed to quality standards more generally).

# Contract for the national cervical pathology training service

The Ministry of Health has contracted for a national cervical pathology training service since October 2011. The service is currently provided through a contract with Southern Community Laboratories Ltd<sup>20</sup> (see Appendix G).

There is an allowance in this contract for continuing professional development for the laboratory workforce. The NCSP encourages the workforce to keep updated, and attend conferences and meetings for continuing professional development.

Contract outputs (NCPTS 2014) included:

- · providing comprehensive training in up to eight regions to all laboratory sector groups
- establishing an independent training committee
- completing a national laboratory workforce training needs assessment
- circulating an informative annual newsletter
- establishing a scholarship fund
- developing eight specific training plans for each of the laboratory sector groups
- providing a plan for the HPV screening programme.

New training initiatives to December 2014 have been reported to the NCSP and are comprehensive (see Appendix G).

Agreement: NZ Govt. and Southern Community Laboratories Ltd. Laboratory Training Services Provider No: 420619 / Contract No: 347182/00. 28.06.2013 – see Appendix G.

# Contract for NCSP Individual External Quality Assurance Programme Training:<sup>21</sup> Royal College of Pathologist Associates Proprietary Limited, RCPA QAP Pty Ltd

This contract ensures the training for cytoscientists provides evidence and further development of competence at an individual level – a key requirement of the Cervical Screening Inquiry.

The NSU and NCSP have committed to consult with the provider on the strategy to transition from the current contract to new arrangements, should the current contract be affected by developments as the programme moves towards primary HPV screening. Progress is being made in providing guidelines for managing underperformance of programme participants, and there is intent to continue with (liquid-based) cytology as part of the screening pathway as the programme is developed to move to primary HPV screening.

The National Health Board, NSU and NCSP agreed in November 2014 to also renew the existing contracts to roll forward to 2017 for cytology pathology training and for Individual External Quality Assurance for Pathologists and Scientists competencies. This ameliorates the concerns in 2011 that indicated future impact on the workforce.

#### Smear takers

A smear taker must be a registered health professional, such as a medical practitioner, a registered nurse, an enrolled nurse or a registered midwife. All smear takers are required to complete cervical screening training through one of the following training programmes:

- training as part of a medical degree
- New Zealand Qualifications Authority (NZQA) midwifery training programmes
- NZQA accredited courses for non-medical smear takers.

The main regulations that surround the practice and competency of smear takers are:

- the Health Practitioners Competency Assurance Act 2003<sup>22</sup> (HPCA Act)
- section 112L of the Health Act 1956, Part 4A<sup>23</sup>
- section 4 of the NCSP Policies and Standards.<sup>24</sup>

<sup>&</sup>lt;sup>21</sup> Procurement Plan for NCSP Cytology Individual External Quality Assurance Programme 1 July 2012.

<sup>&</sup>lt;sup>22</sup> HPCA Act http://www.legislation.govt.nz/act/public/2003/0048/latest/DLM203312.html

Health Act 1956 http://www.legislation.govt.nz/act/public/1956/0065/latest/whole.html

https://www.nsu.govt.nz/system/files/page/ncsp\_policies\_and\_standards\_section\_4\_providing\_a \_smear\_taking\_service\_july\_2011.pdf

# Professional development for smear takers

The NCSP expects smear takers to have an up-to-date knowledge of smear-taking techniques, screening issues and the NCSP, including its benefits and limitations. Smear takers are expected to maintain their competence and those who have persistently high rates of unsatisfactory smears are required to seek further training in smear-taking techniques.

# Smear Taking Training Grant

Smear takers are supported by the Smear Taking Training Grant, which is a reimbursement of course fees and is paid on successful completion of smear taker training at a recognised course.

The NSU provides the following resources for cervical screening and smear taker training:

- education and professional updates for smear takers<sup>25</sup>
- NCSP Guidelines for Cervical Screening (NSU 2008)
- Responsibilities of Smear Takers<sup>26</sup>
- Competencies for Smear Taker Training.<sup>27</sup>

# HPV testing: smear-taker responsibilities

Smear takers also have responsibilities for the provision of HPV screening/testing, as shown in Table 7.1.

# Table 7.1: The role of the smear taker in the screening pathway

#### Role of the smear taker

• Informs women about the role of high-risk HPV testing in the pathogenesis of cervical cancer and the use of HPV testing as an adjunctive test.

- Explains the meaning of a positive/negative HPV test result to the woman (referring to HPV testing fact sheet).<sup>28</sup>
- Every woman aged 30 years or over without a recent abnormal smear is informed that on the slight chance her smear result is mildly abnormal (ASC-US or LSIL), the laboratory will do an HPV test using some liquid taken from the same liquid-based cytology sample (this is called 'reflex testing').
- Informs women that all HPV testing results will be sent to the NCSP-Register (unless the woman has withdrawn from the NCSP).

https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/ncsp-workforce/smear-takershttps://

https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/ncsp-workforce/smear-takers

https://www.nsu.govt.nz/system/files/page/competencies\_for\_smear\_taker\_training\_-\_final\_-\_july\_09.pdf

https://www.nsu.govt.nz/system/files/page/hpv\_and\_hpv\_testing\_fact\_sheet\_for\_women.pdf

# HPV testing for women following treatment of high-grade lesions

The smear taker has a responsibility to identify if a woman has previously been treated for CIN 2/3 and is on annual smears, and to offer her an HPV test with her smear. HPV testing will mean it may be possible for her to return to a normal three-yearly screening interval, if her test results are negative for both cytology and high-risk HPV on two consecutive occasions, 12 months apart.<sup>29</sup> The same regime applies to historical testing where prior high-grade squamous abnormalities more than three years ago (treated or not treated) are identified.

# HPV online learning tool

Following the 2011 review, the NSU was advised to ensure equitable access in outlying, rural and under-serviced areas, and to consider options such as:

- train-the-trainer approaches
- training local health professionals to coach such populations in the use of selfcollected specimens.

In response, the NSU and NCSP have placed an HPV online learning tool on their website for health professionals. This has been available since February 2015<sup>30</sup> for smear takers to maintain their competencies. Cervical screening information on the website is regularly reviewed and updated. LearnOnline.Health.nz is a vocational training resource hub for New Zealand's community of health practitioners, providing a collaborative approach to educational resources for the health sector. There is a growing number of courses available, provided by different organisations for health workers either studying or working in different fields of practice.

# HPV training course for health professionals<sup>31</sup>

The training is aimed at cervical smear takers in primary care, and focuses on the use of HPV testing in the NCSP. The training also includes information on HPV immunisation for girls. The module is designed to support existing knowledge of HPV and the HPV vaccine. It will assist with knowing when to order an HPV test as part of regular cervical screening, and discussing the results of those tests with women. The NCSP has advised that the introduction of self-collected specimens will be considered as part of any future policy development on HPV primary screening.

Refer to Flowchart HPV testing Guidance 2 in the *Guidelines for Cervical Screening in New Zealand* (NSU 2008): https://www.health.govt.nz/system/files/documents/publications/cervical-screening-guidelines-aug08.pdf

http://learnonline.health.nz/login/index.php

https://www.nsu.govt.nz/news/human-papillomavirus-hpv-training-course-now-available-health-professionals

Commentary from regional providers revealed that the HPV online course has its limitations; it is "very slow" and not designed for the primary care setting. Providers stated they needed updated information in primary care and that this should be available online. The Clinical Leader role was seen as addressing the education and facilities that are needed for staff. Having to pay for their training courses and then being reimbursed was also a limitation. According to one interviewee (external to the Ministry of Health), "if the practice nurse has to pay and do it in her own time, they won't do it".

# Family Planning Association training courses

The Family Planning Association of New Zealand provides an average of up to 20,000 smears annually and is not funded to provide free smears. The organisation provides cervical smear training and other related courses can be found on its website.<sup>32</sup>

#### **Health Workforce New Zealand**

Health Workforce New Zealand (HWNZ) is part of the Ministry of Health, has its own governance board and advises the Minister and Director General of Health. It has a budget of \$76 million, all of which is directed towards training the New Zealand health workforce. The focus groups of HWNZ are the regulated and non-regulated workforces.

The national screening workforce (including cervical screening), while making up both focus groups for HWNZ, is considered in the broader context of workforce groups. HWNZ invests very heavily NZ in medical training, allocating far less to the allied health categories.

Health workforce planning is executed through a set of service reviews in principal areas (eg, aged care and mental health) and completed by experts. A recent report, *Health of the Health Workforce*, gives a direction about available workforce data (Health Workforce New Zealand 2014).

HWNZ advised that professions should be mindful of changing technology and changing needs. "Retraining workforces should be done in a way where they aren't starting from the bottom." There is commitment from HWNZ to work with professions to find a balance in this respect.

Within the professions that the NCSP relies on, there is a large number of nurse (Pap) smear takers and colposcopists (providers). A focus has been to move services closer to the women and HWNZ has reported that some of its funds are used on the employment and training for first-year trainee general practitioners (GPs) (Health Workforce New Zealand 2014, p 6), and for Nurse Entry to Practice (NETP) training programmes for nursing graduates in their first year of employment (p 9).

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<sup>32</sup> http://www.familyplanning.org.nz/courses

# Advancing primary HPV screening

The NSU reported that policy work has commenced. HPV primary screening could be achieved in the New Zealand NCSP. The NSU will lead the project through the NSU Clinical Director, and technical experts from across areas relevant to cervical screening have been solicited for membership of a Technical Reference Group to provide advice and expert guidance. Various other aspects of implementation will be considered with appropriate experts as part of constituted working groups to collaborate on designing the future model for the NCSP. Strong linkages with the Australian NCSP are enabling NSU to build on its work but contextualise it for the New Zealand environment.

Part 1 of this policy work includes modelling the testing methodologies and developing high-level implementation ideas for consultation. Two pieces of work are nearing completion:

- Finalising the policy question to guide the assessment of HPV primary screening in the New Zealand NCSP
- 2. Modelling the testing methodologies (being undertaken by the University of New South Wales, which undertook the modelling for the Australian NCSP renewal project).

The technical reference group will consider the testing methodologies and associated high-level implementation options. This will lead to the development of a paper for sector consultation, which will include the public. The high-level implementation considerations will include:

- · impact on the workforce
- service delivery options, including the feasibility of self-testing
- impact of HPV vaccination
- achieving equity.

# Anticipated impacts on the workforce of introducing primary HPV screening

In 2011 the Parliamentary Review Committee advised that, as cervical screening technology evolves, professional requirements will also change. It recommended that the health system must first decide on the best approach for its population and existing infrastructure. Since 2011 the NSU, Health Workforce New Zealand and provider representatives have continued to meet to consider future planning, and the impact that systems and technology will have on the screening workforce. Working groups are established as required to inform new standards or processes. The NSU recognises that there may be workforce impacts, particularly for the laboratory sector, should HPV primary screening be introduced. The NSU will work with the sector to ensure clear communication of any changes and will support a planned transition for providers and their workforce.

# Impacts of primary HPV screening on the laboratory workforce

During this 2015 review, stakeholders expressed opinions in regard to HPV screening impacts. Impending developments towards introducing primary HPV screening will dramatically reduce cytology and this will impact on the laboratory workforce.

Concerns were expressed for senior scientists, who are a small number, working at a national level. Loss of the workforce will be felt dramatically as the level of expertise drops. The NCSP has indicated it is in the early stages of having plans in place to develop workforce standards and guidelines to provide greater certainty around workforce impacts. This will include working with the sector and the health workforce in New Zealand generally to ensure implementation of the standards is feasible.

However, there should also be a planned approach that supports cytologists, pathologists and laboratory scientists to move or relocate to appropriate areas where their expertise is not lost to the sector. This can include working with employees to set up structured career pathways and professional development programmes, supporting staff through transition into other areas of work or other career pathways, and exploring ways in which career pathways could be established to further develop this workforce.

Well-designed and integrated education and training, together with ongoing competency assurance, will be vital to support change. It will also be important to ensure that service specifications, purchase agreements, funding arrangements and industrial arrangements do not unnecessarily impede this kind of development and work redesign (Ministry of Health 2006).

#### Addressing disparities for NCSP priority groups

Three-yearly coverage overall varied by ethnicity and the target of 80% was not met for Māori, Pacific, or Asian women across all District Health Boards (DHBs). Coverage in these groups for women aged 25–69 years was 62.6%, 68.6% and 64.8% respectively (NSU 2014b).

One of four DHBs that demonstrated some success in getting closer to Māori women's participation targets for the NCSP cited the following as key factors for success:

- working in a more integrated way with stakeholders and utilising targeted funding schemes (support to screening services and the Very Low Cost Access funds) to facilitate community workers' activities in accessing women and overcoming barriers for them, such as outstanding bills at general practices
- setting an example three senior Māori women in health leadership positions have made it their business to make the systems work for them
- standardising the systems in the Ministry of Health, with a focused prioritisation for Māori, Pacific and Asian populations

- having key people in strategic places who possess certain attributes such as:
  - cultural competency
  - knowing how to talk to Māori communities
  - achieving health literacy by breaking down complicated issues
  - demonstrating cultural understanding.

# Factors influencing demand for health and disability support services

Demographic change and consumer demand across the health sector are also influenced by factors beyond the control of the health care sector. It is well established that policy and the social, cultural, economic and physical environments in which people live their lives affect health outcomes (Public Health Advisory Committee 2004). This is depicted graphically in Figure 7.1.

Gender and culture

Juing and working conditions

Juing and community influences

Gocial and community influences

Age, sex and hereditary factors

Figure 7.1: Environmental factors that influence health outcomes

Source: Ministry of Health (2002)

In most Organisation of Economic Co-operation and Development (OECD) countries, education and health policy, legislative and economic developments and growth, coupled with technological and medical advances, have led to an overall improvement in health treatment, longer life expectancy and greater expectations about health care.

Since 2000, one of two major Government responses to trends influencing requirements placed on health and disability support services in New Zealand is an overarching strategy aimed at improving population health outcomes and reducing disparities (Ministry of Health 2002).

#### Customer-centred service models

Service delivery models should be consumer-centred and focused on primary care public health (population health) rather than secondary and tertiary health care. These models of care are based on higher cognitive and higher generalist skills rather than specialist skills, and emphasise collaboration and teamwork over individual work, as well as integration across health, disability and social services.

These service models require changes in service practice. For example, there is a need to expand the roles of primary care nurses, practice nurses, GPs and community providers (urban and rural) to increase the range of services they can provide and to encourage early intervention.

# Focus on the non-regulated workforce

Specific workforce strategies focused on service changes have been developed in some priority areas, including Māori health, Pacific health and mental health. Others are under development.

It has long been recognised that, as the general Māori population increases, it is likely that the demand for the Māori non-regulated workforce will also increase (Robson and Harris 2007). According to a report by Lehmann and Sanders (WHO 2007), the credibility of Māori community health workers, (kaimahi/community health workers), kaiarahi/coordinators and team leaders depends primarily on:

- · their community credentials
- being members of the communities with which they work
- · an understanding of Māori cultural norms
- utilisation of kaupapa Māori approaches to their work
- unwavering commitment to supporting those communities in need.

This workforce provides added value to their services because they improve the Māori community's access to, delivery of, compliance with and self-management of health care, disability support and social services. Interviews with key contacts in the regions gave the following examples of how these success factors look in practice:

- working with a local Māori independent service provider
- building a good reputation
- prompting many first-time smear event through word of mouth or health promoters (community health workers)
- providing good health promotion.

# Successful strategies

Further success factors in working with Pacific and Māori women, identified since the 2011 Parliamentary Review, include training Pacific providers to take smears and telling Pacific communities what providers do. A workforce that has the ability to engage with the people/ communities is what makes a difference, as does having essential workforce positions, particularly at the front line and in colposcopy.

The Ministry of Health is aware that the priority groups for the NCSP, in particular Pacific and Māori women, need things done differently (equity focus). For example, there is a need to ensure interaction with key Pacific people and to use media campaigns to increase awareness.

# Health literacy

Health literacy is defined as the ability to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions (Ministry of Health 2010). In May 2014 the Ministry of Health held a roundtable discussion<sup>33</sup> with Pacific and Māori health sector participants who provided broad views and opinions on the importance of both health literacy and cultural competency in addressing participation in health services and developments for priority groups.

# The views highlighted:

- strong support for both health literacy and cultural competency, and how these two
  concepts cannot be addressed in isolation and instead should be recognised as
  complementary to each other
- the consistent view that both health literacy and cultural competency require a wholeof-system response. This includes making sure there is organisational and systemic cultural competency along with sound health literacy practices
- a theme emerged that health professionals need to "know the person well" before
  they focus on conditions and treatment. This was a call to understand a person's
  background, avoid making assumptions, take time to get to know the person (and,
  where appropriate, their whānau) and change practice if necessary
- the need to think about how to build the competence of families and communities around health literacy and engender cultural competency and cultural confidence
- Pacific interviewees reported that health literacy should be considered within a
  systems approach where the key message is about family and not just the women.
  Once women are aware about how they can access services, they respond well. All
  DHBs should be required to produce a Pacific Action Plan.

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<sup>&</sup>lt;sup>33</sup> Health Literacy & Cultural Competency Roundtable Discussion, Ministry of Health, Wellington, 16 May 2014.

# Workforce cultural competencies

A number of professional groups, such as the Health Promotion Forum, have developed competencies to provide advice on workforce development (Auckland Regional Public Health Service 2014). These competencies have also been used in the employment of staff and in salary negotiations.

Interviews from across the screening sector in this review regularly identified the need for cultural competency in the screening workforce.

# Why is it important for health professionals to be culturally competent?<sup>34</sup>

All health professionals should have the ability and knowledge to communicate and understand health behaviours influenced by culture. Health professionals who have this level of cultural competency will find ways to better communicate with people from different cultures who use health services. A culturally competent health workforce can make a positive difference to patient experiences and their health outcomes.

# Cultural competency training tool

New Zealand's first online Foundation Course in Cultural Competency,<sup>35</sup> designed specifically for health workforce professionals, was released on 3 July 2012.

The Foundation Course in Cultural Competency provides support to practitioners to build their understanding of cultural competency and health literacy in New Zealand, with a focus on improving Māori health outcomes. The multimedia interactive course is a voluntary programme spread across four modules and is available for all people working in the health sector. Each training module is supported by videos, video transcripts, additional reading resources and library references.

Cultural competency training has been found effective in updating health workers' knowledge, skills and attitudes, allowing them to be more 'in tune' with their patients or clients. The training tool also addresses the need for a nationally consistent online Foundation Course in Cultural Competency and health literacy for the regulated and non-regulated health workforces.

http://learnonline.health.nz/

<sup>35</sup> http://www.health.govt.nz/news-media/news-items/cultural-competency-training-tool-available

# **Key issues**

- The introduction of primary HPV screening is likely to have a significant impact on the laboratory workforce. This will precipitate the need to have a planned approach to support cytologists, pathologists and laboratory scientists to move or relocate to areas where their expertise is not lost to the sector.
- Well-designed and well-integrated education and training, together with ongoing competency assurance, will be vital to support change. It will also be important to ensure that service specifications, purchase agreements, funding arrangements and industrial arrangements do not unnecessarily impede this.
- The NCSP expects smear takers to have an up-to-date knowledge of smear-taking techniques, screening issues and NCSP standards and guidelines. They are expected to maintain their competence and those who persistently have high rates of unsatisfactory smears are required to seek further training in smear-taking techniques.
- Cultural competency is important. The coverage target was not met for Māori, Pacific or Asian women (with a coverage rate of 62.6%, 68.6% and 64.8% respectively) screened within the previous three years. New Zealand's first online Foundation Course in Cultural Competency, designed specifically for health workforce professionals, was released on 3 July 2012. The Foundation Course provides support to practitioners to build their understanding of cultural competency and health literacy in New Zealand, with a focus on improving Māori health outcomes.
- Specific workforce strategies focused on service changes have been developed in some priority areas, including Māori health, Pacific health and mental health, and others are under development. As the general Māori population increases, it is likely that the demand for the Māori non-regulated workforce will increase as well. This workforce has a critical role in the promotion and provision of health messages to all the priority groups of the NCSP.
- It is important to address disparities in the NCSP for all of its priority groups. For more information, see Chapter 3: Coverage, participation, equity and access.

# Recommendations

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.

- 25. The NCSP must ensure online courses are regularly updated and access is improved access 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.
- 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.
- 27. The NCSP must ensure that, for 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.<sup>36</sup>

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<sup>&</sup>lt;sup>36</sup> See also Chapter 6: Organisational and structural issues.

# **Chapter 8: The NCSP-Register**

## Overview

The National Cervical Screening Programme-Register (NCSP-R) is the national database that stores screening and diagnostic test results for women who are enrolled in the National Cervical Screening Programme (NCSP). The Health Act 1956, section 112F(2), requires that every cervical screening and diagnostic follow-up test must be recorded on the NCSP-R.

The role and functions of the NCSP-R also include the following (NCSP 2014b):

- providing screening histories to inform smear takers, laboratories and colposcopists in their management of women
- providing smear-taker recall and overdue reports to women's health care providers
- sending letters to women with an overdue reminder and/or to provide their screening history
- sending women letters confirming their enrolment on the NCSP-R or advising of their withdrawal if they have elected to do so
- collecting and providing statistical data for the purpose of monitoring and evaluating the NCSP.

Monitoring quality and outcomes in any health programme ensures that the programme maximises the benefits to the target population. Quality assurance refers to an overall management plan (the 'system') that guarantees the provision of good-quality service. Quality control refers to the application of a series of measurements (the 'tools') used to assess the quality of the services and facilities.

Quality assurance of a cervical screening programme involves the systematic monitoring and evaluation of the various aspects of screening to maximise the probability that the programme is achieving its goals. The expected benefits of a screening programme, in terms of significant reductions in morbidity and mortality from cervical cancer, can only be achieved if quality is optimal at every step in the screening process, from identifying the target population to ensuring appropriate follow-up and treatment of women with screen-detected abnormalities.

Quality control activities of a cervical screening programme include the use of standardised procedures for collecting data from different levels of service delivery, and the preparation of reports in an approved format at regular intervals.

Critical information required to assess the above-mentioned indicators should be collected on a regular basis, generated in a timely manner and analysed to inform ongoing programme implementation. It is crucial that the denominators and numerators used are as accurate as possible.

A fully computerised register is the most effective way to monitor and evaluate a screening programme. The ideal register links with health facilities, laboratories and population-based cancer registries (WHO and PAHO 2013).

## **History**

In 1991 the NCSP-R was introduced in 14 Area Health Boards (AHBs) as a stand-alone system. In 1994 the NCSP-R became a national database operating out of the 14 AHBs. Data input was maintained at the AHB level, and in 1996 the NCSP-R was centralised in Wellington, with the operational teams remaining in AHBs. After the formation of District Health Boards (DHBs) in 2001, data input to the NCSP-R was reduced in 2002 from 14 to 6 DHBs.

After consultation with stakeholders in 2006, the Ministry of Health assumed responsibility for NCSP-R operations and the upgraded national NCSP-R was implemented in September 2008. From July 2010, the administrative and technical support functions of the NCSP-R were transferred to New Zealand Post. The day-to-day management of the NCSP-R is currently provided by New Zealand Post Health Services (NZPHS). Overall management of and accountability for the NCSP-R remain with the Ministry of Health (Tan et al 2011).

## **Current status**

The Ministry of Health retains ownership of the hardware on which the Register operates and is responsible for ensuring the NCSP-R software licences are current. The day-to-day management of the NCSP-R is the responsibility of NZPHS. The current contract is due to expire in 2017.

In April 2014 the NCSP submitted the *Stack Upgrade Project Business Case* for the upgrade of expired versions of the operating system for the NCSP-R to ensure the system is fully supported by vendors and that 'bug fixes' and security upgrades occur when necessary (NCSP 2014b). The Project Plan agreed between the National Screening Unit (NSU) and NZPHS was signed in November 2014, and the upgrade project is expected to take 17 months.

In October 2014 the NSU undertook the first audit of the NCSP-R's operations to assess whether the Register is being managed efficiently, effectively and in accordance with best practice and the requirements of the NCSP.

Overall, the audit made 22 recommendations for improvement and found that the NZPHS has good governance and a strong focus on continuous quality improvement. The audit identified the need for strong strategic governance and also information technology (IT) expertise within the Ministry as decisions are made regarding changes to the clinical service delivery of the NCSP and the redesign of the NCSP-R and its functions.

## Management and accountability

The contract for the formal governance and reporting structure for the NCSP-R includes:

- · weekly operational meetings
- · monthly service delivery meetings
- quarterly quality and audit meetings
- · change control meetings
- · quarterly governance meetings
- · annual strategic review.

The October 2014 audit found that the meetings are run formally and professionally, and that NZPHS completes action items in a timely manner. Monthly and quarterly reports by NZPHS were also found to be delivered on time and to a high standard. The audit recommended streamlining reports to eliminate duplication between monthly and quarterly reports.

The audit found the NZPHS team has a sound knowledge of the NCSP pathway and their roles and responsibilities in the delivery of the programme. The team's knowledge has been developed over a number of years, and is not easily replaceable. There is a team of 20 people who undertake day-to-day tasks of the NCSP-R. Complex business rules align to the screening guidelines.

The NZPHS operational team has a schedule for providing the services of the NCSP-R. The services provided include:

- · business services
- printing services and letter mail-outs
- hosting and infrastructure looking after the NCSP-R platform
- development and support from an IT perspective
- reporting to NSU as per contractual arrangements.

Operationally, when results are received by the NCSP-R, demographics information is analysed to match date of birth, address, first name and last name in the Register, and checked against the equivalent information in the National Health Index, and any duplicates on the Register are merged. The NCSP-R advises challenges with ethnicity data in determining which source is correct in cases where the sources differ. The NCSP Monitoring Report Number 40 reports that ethnicity coding follows the classification used by the Ministry of Health, and the current data analysis contained ethnicity codes for 98.4% of women on the NCSP-R (NSU 2014b).

Robust systems are in place for managing the security and confidentiality of the data on the NCSP-R, as well as operational processes to ensure back-up of data, business continuity systems and disaster recovery.

## **Accessibility of the NCSP-Register**

The NCSP-R is available online for laboratories and at DHBs to access women's screening histories. Screening histories must be available at each stage of the screening process to inform recommendations for recall, referral or treatment in accordance with the NCSP guidelines. The contract between the NCSP and NZPHS sets a 100% availability target for the NCSP-R during working hours (8 am to 6 pm Monday to Friday), with a minimum acceptable performance of 99%. During the 12-month period from February 2014 to January 2015, there were five outages totalling 4.5 hours. This is a 'downtime' of 0.18% for the 12 months, as shown in Figure 8.1.

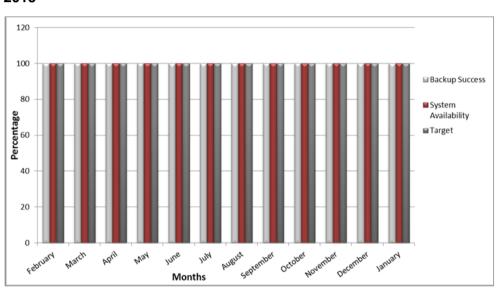


Figure 8.1: Information system hosting and infrastructure service levels from 2014 to 2015

Source: Data provided by NZPHS 2015

Direct online access to the NCSP-R is not available to smear takers and direct access for colposcopists is, at times, limited. To ensure a woman's complete screening history is available to the clinician at the time of appointment, health care providers rely on DHB staff employed to download the screening histories of women due to attend for screening or to receive their results. Ongoing issues – identified by Tan et al (2011) in the previous Parliamentary Review Committee Report – exist with the completeness of colposcopy data on the NCSP-R.

## Colposcopy data

The 2015 Parliamentary Review Committee's interviews with key personnel across all services and IT areas revealed that the majority of issues with electronic transfer of colposcopy reports are due to operating system interoperability challenges. However, other reasons contributing to the incompleteness of the required data fields may be difficulties in completing the e-colposcopy form, and the competing priorities for clinicians' time. The NCSP Monitoring Report Number 40, Indicator 7.3, requires 100% of medical notes to accurately record colposcopic findings, the colposcopic opinion regarding the nature of the abnormality, and the type of and timeframe for recommended follow-up (NSU 2014b). No DHB, nor the aggregate of colposcopy visits

to private practice, meets the target of 100%. Completion of most recommended fields has decreased since Monitoring Report Number 39, and overall completion (89.8%) is also lower than the previous report (91.8%).

Timely access to and reporting of colposcopy findings is critical to the outcomes of the NCSP. 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 Register. It is recommended that an audit across all DHBs should be undertaken by December 2015 to ensure colposcopy data is successfully being uploaded to the Register.

## Invitation and recall for screening

Consistent feedback from screening providers was that the system could not match local health databases with the NCSP-R data to identify unscreened or under-screened women. This gap was identified as a primary concern for identifying women from ethnic groups who are at greatest risk of developing cervical cancer. Having the ability to populate the NCSP-R with population level data and issue invitations to all eligible women to screen would enable proactive approaches to unscreened and under-screened women, and should be a strategic priority for the NCSP to investigate.

Currently, invitations to screen are only generated by primary health organisations (PHOs). Sending an invitation is obviously contingent on a woman actually being registered with a PHO. Data shows that a significant proportion of women in the target age group, particularly those who are at greatest risk, are not screening. Cervical cancer is almost entirely preventable, and the inequities in the screening programme could be significantly reduced through the introduction of an invitation system for all eligible women.

## Data accuracy/integrity

The previous Parliamentary Review Committee Report (Tan et al 2011) identified inconsistencies in colposcopy and test results in comparison with results on the NCSP-R. The Parliamentary Review Committee Report identified the lack of any fail-safe mechanism to ensure that laboratories and the NCSP-R are coding correctly. 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 and colposcopy records. This quality assurance intervention should be considered for future audits.

## **Complaints and incidents**

The NCSP-R management advises there is a 0800 telephone number for any complaints regarding the NCSP-R, and that most of the complaints relate to administrative issues. Issues that have arisen include the use of a Māori salutation, or a letter going to the wrong address, or addressed to the wrong person. The NCSP-R management advises that around 80% of complaints are administrative. The remaining 20% relate to clinical issues and these are sent to the Ministry of Health.

A review of the approximately 270 records of feedback to the NCSP from consumers from 2011 to 2015 (mostly complaints, and many issues not relating to the NCSP-R) showed that most were from women requesting removal of their data from the NCSP-R, or complaining about letters sent to the wrong address, incompleteness of data on the NCSP-R and delays in follow-up. 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. A summary report should also be provided to the NCSP Advisory Group and, where relevant, to the NCSP-R, so that any trends can be identified and addressed.

## **NCSP-Register reports to providers**

The NCSP-R provides regular standard reports for:

- smear taker recall reports women due for a smear
- overdue reports Pap smear providers of women overdue by up to 90 days
- quality of smear reports adequacy of specimen
- cytology/histology correlation for laboratories to identify slides for review where there is discordance (part of laboratory quality assurance processes).

DHB regional staff advise that the routine reports to providers are well received, and they are a valuable quality improvement opportunity for providers to enable personal performance benchmarking and monitoring.

The NCSP-R advised that it has little interaction on a daily basis with the end user (Pap smear provider), but regional services at a DHB level are in regular contact. Smear takers may get in touch in regard to screening history. The NCSP-R identified that providing data for monitoring to the monitoring report authors is a priority for the NCSP. A focus for the NCSP into the future should be reporting back to providers and reviewing, in collaboration with providers, the data and outcomes as part of the continuous feedback cycle for quality improvement.

## **National Kaitiaki Group**

The inequities in coverage, particularly for Māori women, have been identified in previous chapters. Māori women are over-represented in cervical cancer statistics, and under-represented in cervical screening participation. The NCSP, through the NSU, must apply to the National Kaitiaki Group (NKG) every time Māori women's data is required to monitor the programme. The mechanisms currently in place appear to be an impediment to improving the health outcomes and reducing cervical cancer incidence and mortality for Māori women. 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 place on both parties.

#### **Future directions**

Decisions regarding the future directions of cervical screening must be strategically planned, with realistic and achievable timeframes and resourcing so that robust registry systems can be developed to support any revised screening pathway. The NCSP-R understands human papillomavirus (HPV) screening is on the horizon. It needs timely advance notice and clearly defined timeframes to manage its business and to ensure that business continuity for any transition is achievable. The Register currently has no links with the HPV immunisation data and there has been no discussion with the NCSP-R regarding this.

## **NCSP** staffing

The NCSP-R identified concerns regarding the high staff turnover at the NSU and NCSP over the last six months, particularly at senior levels. This has led to a loss of corporate knowledge for the NCSP, in their relationships with the NCSP-R and for the programme as a whole.

## HPV vaccination and cervical screening – NCSP-Register linkages

HPV immunisation programmes are being implemented worldwide, with the aim of reducing the incidence of, and deaths from, cervical cancer. Significant resourcing is being invested by governments, including the New Zealand Government, in introducing these immunisation programmes.

The single most important element of monitoring the success of New Zealand's Immunisation Programme is evaluating whether its objective is being achieved. To make this assessment, the screening histories of women being screened, combined with their vaccination status, must be monitored and evaluated. The full benefit of immunisation will not be realised for many years, until entire generations of girls and women have been vaccinated. However, monitoring of the vaccinated cohort and evaluating their screening results will inform any future decisions regarding both the immunisation and the screening programmes.

A very early study on the impact of HPV vaccination (Brotherton et al 2011) reported on the introduction of the Australian HPV vaccination programme with the quadrivalent HPV vaccine for all women aged 12–26 years between 2007 and 2009, and the impact on women's cervical screening results. Trends in cervical abnormalities in women in Victoria, Australia, before and after introduction of the vaccination programme, were analysed by linking vaccination programme data with those women's data on the Victorian Cervical Cytology Registry between 2003 and 2009. The study compared the incidence of histopathologically defined high-grade cervical abnormalities (HGAs, lesions coded as cervical intraepithelial neoplasia of grade 2 or worse or adenocarcinoma in situ; primary outcome) and low-grade cytological abnormalities (LGAs) in five age groups before (1 January 2003 to 31 March 2007) and after (1 April 2007 to 31 December 2009) the vaccination programme began.

The study found that, after the introduction of the vaccination programme, incidence of HGAs decreased by 0.38% (95% confidence interval 0.61–0.16) in girls younger than 18 years. This decrease was progressive and significantly different to the linear trend in incidence before the introduction of the vaccination (incident rate ratio 1.14, 1.00–1.30, p = 0.05). No similar temporal decline was recorded for LGAs or in older age groups.

This very early study linking cervical screening results with women's vaccination status identified the importance of linkage between vaccination and screening registers to confirm that the decrease in HGAs continues as expected subsequent to the introduction of the HPV immunisation programme; and to enable ongoing monitoring of participation in screening, and screening results, among vaccinated women.

The Brotherton et al (2011) findings reinforce the need for cervical screening programmes to adapt and respond to a post-vaccination environment and the requirement to define workable screening algorithms, especially in vaccinated populations. For this to occur, HPV vaccination status must be captured and recorded with the woman's screening history, or both registers must be linked to enable confirmation of vaccination status.

Any future planning for the NCSP-R must include options for linking the HPV Immunisation Register with the NCSP-R, so that a woman's vaccination status forms part of her cervical screening history.

## Key issues

 Having the ability to populate the NCSP-R with population-level data and issue invitations to all eligible women to screen would enable proactive approaches to unscreened and under-screened women, and should be a strategic priority for the NCSP to investigate.

- The majority of issues with electronic transfer of colposcopy reports to the NCSP-R
  appear to be due to operating system incompatibilities. However, other reasons
  contributing to the incompleteness of the required data fields may be the competing
  priorities of clinicians' time, and difficulties in completing the e-colposcopy form.
  Timely access to and timely reporting of colposcopy findings are critical to the
  outcomes of the NCSP.
- Consistent feedback from screening providers was that the system could not match local health databases with the NCSP-R data to identify unscreened or underscreened women. This was a primary concern for identifying women from ethnic groups who are at greatest risk of developing cervical cancer.
- The 2011 Parliamentary Review Committee Report identified concerns that some colposcopy and test results were inconsistent with those recorded on the Register. The NCSP-R audit in 2014 did not include a random audit of coding on the NCSP-R and correlation with laboratory and colposcopy records. This quality assurance intervention should be considered for future audits.
- The issue, action and outcome of complaints, regarding either the NCSP-R or the
  programme as a whole, must have robust follow-up processes. Complaints from
  consumers regarding the screening programme need to be regularly reviewed and
  monitored, and a summary report provided to the NCSP Advisory Group (and where
  relevant to the NCSP-R), so that any trends can be identified and addressed.
- The routine reports from the NCSP-R to providers are well received and they are a
  valuable quality improvement opportunity for providers to enable personal
  performance benchmarking and monitoring. Reporting back to providers on their
  outcome data and reviewing the data and outcomes, in collaboration with lead clinical
  providers, should form part of the continuous feedback cycle for quality improvement,
  and should be a focus for the NCSP into the future.
- Māori women are over-represented in cervical cancer statistics, and underrepresented in cervical screening participation. The mechanisms for applying to NKG for data appear to be an impediment to improving the health outcomes and reducing cervical cancer incidence and mortality for Māori women.
- The NCSP-R understands HPV screening is on the horizon. It needs timely advance
  notice and clearly defined timeframes to manage its business and to ensure that
  business continuity for any transition is achievable. The NCSP-R currently has no
  links with the HPV immunisation data and there has been no discussion with the
  NCSP-R regarding this.
- The NCSP-R identified concerns regarding the high staff turnover over the last six months at the NSU and NCSP, particularly at senior levels. This has led to a loss of corporate knowledge for the NCSP, in relationships with the NCSP-R and for the programme as a whole.
- The full benefit of immunisation will not be realised for many years, until entire
  generations of girls and women have been vaccinated. However, monitoring of the
  vaccinated cohort and evaluating their screening results will inform any future
  decisions regarding both the immunisation and the screening programmes.

## Recommendations

- 28. Strong strategic governance and also 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.
- 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.
- 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.
- 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.
- 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.
- 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.
- 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.
- 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 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.

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.

# **Chapter 9: Ethnicity data**

## Overview

This chapter reviews the quality and use of ethnicity data (particularly access to and use of Māori women's data), the nature of efforts employed to gauge the accuracy of ethnicity data and to bring about improvements in this data, and the completeness of ethnicity data.

## **Current status**

## **Data access and the National Kaitiaki Group**

New Zealand holds a unique position in the international health sector regarding the protection of research information that belongs to its indigenous people. In regard to the National Cervical Screening Programme (NCSP), Māori women's cervical screening data is deliberately and purposefully guarded by a specific regulation – the Health (Cervical Screening [Kaitiaki]) Regulations 1995, Regulation 4 – and by the Health Act 1956, section 112J(h).

The legislation enabled the establishment of the National Kaitiaki Group (NKG), which is accountable to the Minister of Health. The NKG's task is to consider applications for the release of Māori women's data from the National Cervical Screening Programme-Register (NCSP-R).

In 2011 the Parliamentary Review Committee Report (Tan et al 2011) recommended that the NCSP take that review as an opportunity to amend the Kaitiaki Regulations. This recommendation was not upheld in its entirety. Instead, the Māori Business Unit (formerly the Māori Health Directorate) at the Ministry of Health, the National Screening Unit (NSU) and the NKG upheld the intent of the recommendation, which was to resolve to work together to make the NKG process appropriate for allowing access to data and, at the same time, assuring protection of Māori women's data. This action is a continuing process that was confirmed in review discussions in 2015, with all parties involved.

The NKG continues to approve (or not) the release of Māori women's information. Frustrations abound with data analysts who through this role are also charged with monitoring the performance of the programme. A key informant commented:

"It is frustrating that we have to apply to use the data that we collect for the purposes that we are employed to do, as enabled by section 112" (ie, section 112J(h) of the Health Act 1956).

The NKG meets quarterly and accepts applications electronically. However, these arrangements do not mitigate the issue for analysts who are under time constraints to use the data and produce the monitoring reports within Ministry of Health guidelines and timeframes, and before they must meet the NKG's routine requirement to destroy the data after six months falls due. Should the NSU wish to retain the data beyond six months, it must make a further application to the NKG. The NSU has clarified that, while there is no stand-alone legal requirement to destroy data after six months, the NKG routinely places a condition, on all applications to access data, that the data be deleted after six months has elapsed.

## Ethnicity data and addressing the equity gap<sup>37</sup>

- District Health Boards (DHBs) are required to report on cervical screening coverage and develop plans to improve this.
- Cervical screening activities are monitored for inclusion in DHB Māori Health Plans.
  The NCSP team has reviewed all Māori Health Plans and provided feedback. Māori
  Health Plans are a good lever within DHBs to inform the Boards on cervical
  screening and to help them address the equity gap.
- The NCSP has strengthened its connections with the Māori Health Business Unit within the Ministry of Health. Quarterly meetings are held to review progress against Māori Health Plans and whānau ora collective reports, and to discuss initiatives or policy developments.
- Equity Our Focus, an internal steering group, has been set up. Members include NSU staff and Māori and Pacific advisors from across the Ministry. This group provides operational advice and oversight to contribute toward achieving equitable national screening programmes.
- The NSU has met with Tumu Whakarae, the collective of DHB Māori Health General Managers, to build relationships and discuss improving access to services. There was agreement to provide information to assist DHBs with their monitoring and reporting.

## Quality

Data in the NCSP-R is safe. The first audit of the NCSP-R<sup>38</sup> was conducted by senior managers in the NCSP in July-August 2014. The Register is a database containing secure cervical screening information for more than 1.4 million women. The management of the Register has been the responsibility of New Zealand Post Health Services (NZPHS) since 2010.

Information provided by the NCSP for the Parliamentary Review Committee: What the NCSP has been doing to increase coverage in the last three years.

<sup>&</sup>lt;sup>38</sup> Performance Audit report: National Cervical Screening Programme, Register Management October 2014.

The audit of the NCSP-R aimed to provide assurance that the Register is being managed efficiently, effectively, and in line with best practice and the needs of the Ministry of Health's National Screening Unit and the NCSP. Findings from the audit confirmed that relationships and governance, quality improvement, value for money, and IT systems management of the Register (and therefore women's data, including that of Māori women) are well managed. The relationships between the Ministry and NZPHS are strong and working effectively for the benefit of New Zealand women.

## **Ethnicity analysis**

All of the Ministry of Health's monitoring reports explain (among other extrapolations) their process of analysis by ethnicity, which is considered in four groups – Māori, Pacific, Asian and European/Other – based on women's priority two ethnicity codes recorded on the NCSP-R. Current analysis from the NCSP-R data (at March 2014) recorded ethnicity codes for approximately 98.4% of the 1.4 million women on the NCSP-R.

The data is collected during encounters with the health system, such as when a woman is registering with primary care services, during an admission to hospital, or during surveys. The Ministry engages in a number of activities to improve the quality of ethnicity data, including by developing in 2004 protocols for the collection and recording of ethnicity data. Coding of ethnicity on the NCSP-R follows the classification used by the Ministry of Health (Ministry of Health 2004).

The NCSP undertakes continuing work to improve the accuracy of ethnicity recording on the Register (NSU 2014b).

In New Zealand, ethnic identity is an important dimension of health inequities. Māori and Pacific people experience lower life expectancy and health disadvantage across most mortality and morbidity indicators compared with Europeans, as well as socio-economic disadvantage in areas such as housing, education, income and employment (Harris et al 2012).

Ethnic inequalities between Māori and non-Māori are the most consistent and compelling inequities in health (Robson and Harris 2007). An analysis of socioeconomic position and health status data identifies three distinct types of ethnic inequalities in health in New Zealand. These have been described as the distribution gap, the outcome gap and the gradient gap. New Zealand research suggests life expectancy and other measures of health status are similar in rural and urban areas.<sup>39</sup>

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<sup>39</sup> https://www.rnzcqp.org.nz/assets/documents/Standards--Policy/Health-inequities-position-statement.pdf

## **Data matching**

At the regional level, DHBs have their own databases for more localised and timely access to data on their screened populations and for results from their screening efforts. NCSP has regular contact with DHBs regarding their processes for data matching and tracing women for their screening participation.

## The NCSP reports the following:

- PHOs can request data matching against the NCSP-R every six months to identify women who are overdue or who have been screened elsewhere and information from the other provider has not been provided to them.
- An automated data matching pilot is underway with a large PHO in Auckland (ProCare) to identify PHO-enrolled women who are unscreened. This will inform further data matching for other PHOs.
- Most DHBs are manually data matching with general practices to identify women who
  are overdue for a cervical smear and facilitating opportunities for them to be screened.<sup>40</sup>

## Use of ethnicity data

Complexities proliferate where aggregated data is evidenced in coverage reporting but not in the biannually reported data. There are demands on the time limits for other provider functions to produce timely data to meet targets that are aligned to funding incentives. For example, PHO funding is tied to the Integrated Performance and Incentive Framework (IPIF), which relies on disaggregated data that can only be supplied twice per year (biannual reportage quotient) from the analysts in the NCSP and NSU. The NSU has confirmed that this data is being supplied on a monthly basis from May 2015.

The NSU and NCSP continue to identify improvements in the relationship with the NKG. Applications have recently been written that make sense from an NKG perspective as well as not compromising the NCSP's intent to obtain the data in a respectful manner. The NCSP has made efforts to present applications that adequately answer the key questions that NKG asks about the use of Māori women's data. The NCSP ensures that the people who attend the meetings with the NKG understand the Health Act 1956 and related regulations and can respond to the NKG's questions about the use of the data and how this aligns with this legislation. In the last round of applications for information, the NKG acknowledged an improvement in the manner in which applications are filled out.

The Review Committee is encouraged to find that the NSU has undertaken a review to improve the process for the NKG applications for Māori women's data, and has agreed that the NKG lead the work to develop a combined NSU and NKG application form for accessing and using Māori women's cervical screening data. Questions and responses for access to Māori women's data on the NCSP-R continue to follow the standard set by

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Information provided by the NCSP for the Parliamentary Review Committee: What the NCSP has been doing to increase coverage in the last three years.

the NKG. Applications to access Māori women's data are made for monthly monitoring, and quarterly and biannual coverage reports.

## The function of the NCSP-Register

Part 4A, section 112F(2) of the Health Act 1956 prescribes that every screening or diagnostic test result that is reported to the NCSP must be recorded on the NCSP-R if that result relates to a woman who is enrolled in the NCSP.

Once screening records are stored within the Register, they can be used to provide:

- screening histories to support smear takers, laboratories and colposcopists in their provision of screening services to women
- a back-up service for women by generating overdue screening test letters and screening test result letters
- statistical data for monitoring and evaluation of the programme.<sup>41</sup>

To complete the NKG and NSU process for accessing Māori women's data, the NCSP diligently provides its responses to six NKG queries on the Report Back template. The NKG asks for reports on how the data will be used to improve Māori women's health and for confirmation that the data will be or has been destroyed. All NCSP monitoring reports are placed on the Ministry of Health website and are available publicly.<sup>42</sup>

The NCSP response to the NKG requests includes the following points:

- The NKG's approval of NCSP requests to access Māori women's data as part of routine monitoring of the programme is seen as invaluable.
- Māori women are a priority group for the NCSP.
- Māori women's data:
  - helps to reduce inequities health for Māori women
  - enables complete analysis specifically in relation to participation rates for Māori women
  - informs the planning, funding and decision-making processes of government and providers (DHBs) to shape policy and drive initiatives to improve and increase coverage rates for Māori women at national and regional/district levels.
- The findings show how specific initiatives to maintain Māori coverage rates within the regions (DHBs) achieve equitable coverage at or above the 80% NCSP target for Māori, Pacific, Asian, European/Other and overall. Individual DHBs can be identified as high performers in contributing to Māori coverage rates.
- Coverage information is another key tool in the development and review of DHB Māori Health Plans, as these are used to monitor the performance of DHBs in providing cervical screening to the Māori population.

<sup>&</sup>lt;sup>41</sup> Performance audit report: National Cervical Screening Programme – Register Management October 2014, p6.

<sup>&</sup>lt;sup>42</sup> NKG Application, 5 January 2015.

• NCSP biannual reports are able to show timeliness for further referrals and tests such as colposcopies for Māori women with high-grade results from their smears. For example, 49.4% of Māori high-grade women were seen within the standard time of 20 working days, compared with 65.0% for European/Other high-grade women. These statistics show the need for colposcopy services to improve their methods for seeing Māori women within the timeframe set by the Colposcopy Policies and Standards. The NCSP can then follow a process of consultation with colposcopy clinics and monitor progress for those women within the programme.

## Accuracy of ethnicity data

The NCSP team works directly with providers to improve their service delivery models, with a focus on increasing coverage for women in priority groups. Included in this is information about the importance of correctly documenting ethnicity.

A more intensive investigation was instigated to address reasons why the laboratories omitted recording accurate ethnicity data from their processes for handling women's smears. The NCSP has worked with laboratories to discuss this and provide information on the importance of accurately recording ethnicity information in laboratory systems. The ethnicity recorded on laboratory systems is the same as the ethnicity that is recorded on the NCSP-R.

## Ethnicity adjusters for NCSP-Register

The NSU also undertook a review to examine the issues with ethnicity data collection and potential solutions. A previous set of adjusters was developed in 2008 and used for a number of years to compensate for inaccuracies in ethnicity data on the NCSP-R, particularly the undercounting of Māori, Pacific and Asian women.<sup>43</sup>

The NCSP has worked on developing the new set of ethnicity adjusters for the Register. Previously, adjusters were used to better estimate coverage for Māori women because using the ethnicity data held in the NCSP-R results in an undercount. It is likely that some, but not all, of the disparity between Māori and non-Māori is due to undercounting. Also noted were the new denominator counts from Census 2013, which means that coverage data is now more accurate, but there has been an apparent decrease in coverage for Māori women.<sup>44</sup> NCSP-R management reports that there are issues with ethnicity data in terms of what is the most accurate.

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<sup>&</sup>lt;sup>43</sup> Information provided by NCSP – Equity Current Initiatives.

<sup>&</sup>lt;sup>44</sup> Ibid 43.

## Data completeness<sup>45</sup>

Stakeholder comments have identified that the data shows persistent inequity or disparities in participation rates for cervical screening among Māori, Asian and Pacific women. This is considered a major concern for the NCSP and the sector, particularly in relation to Māori. The NSU and NCSP engage in a wide range of activities that support and enhance the completeness of ethnicity data and encourage broad-based approaches to data accuracy and data sharing that contribute to achieving this completeness. The following are some instances of such activities.

#### NCSP are aware that:

- there is a need to have greater scrutiny on the inequalities, similar to the provision and the process used by BreastScreen Aotearoa<sup>46</sup>
- it is important for Māori to be part of any discussion and that the NCSP has ownership of any implementation processes.

## The NCSP-Register

Management for the NCSP-R is unsure of how complete the data is if there is limited or no referral information provided. The NCSP is continuing with work to improve the accuracy of ethnicity recording on the Register. 47

## Support to screening services funding review

The model of this funding is being updated. The key goals of funding support to screening services were to:

- provide funding that achieved intensive one-to-one support for priority women who are hard-to-reach
- make a big difference to a small number of women and increase their access to cervical smears
- support Māori and Pacific providers, who were well placed to offer culturally safe kanohi ki te kanohi (face-to-face) services.

## Social marketing

According to a key informant, social marketing for NSU-wide activities will focus on Māori women. Qualitative research (focus groups and individual interviews) will be planned to understand women's motivations for and barriers to participation in screening programmes.

<sup>&</sup>lt;sup>45</sup> Ibid 43.

http://www.pha.org.nz/conference2013/presentations/130918-new-wahine.pdf

Ibid 41.

- Māori representation is on the Social Marketing Governance Group.
- Advice from the Māori Monitoring and Equity Group and contracted Māori advisors with communications experience will also inform the social marketing work.

## Data access and reducing disparities

Issues encountered in regard to data access have highlighted that the process to obtain information from the Register is slow. This process is mainly influenced by:

- the need for a correctly functioning database that would also help to access information in real time
- concerns about obtaining up-to-date data and the need to have information, technology and reporting systems working more efficiently
- the need to improve relationships between the NCSP and the NKG.

The latest Monitoring Report (NSU 2014b) showed that the coverage target was met for European/Other women (81.9% screened within the previous three years), but was not met for Māori, Pacific or Asian women (62.6%, 68.6% and 64.8% respectively screened within the previous three years).

## Data access and sharing information

Independent service providers (ISPs) have found it challenging to identify who the unscreened women are in their areas, particularly Māori women, who have a higher cervical cancer rate than the other priority groups.

The 2012 NCSP Annual Report (NSU 2014a) reports that in 2010, there were 52 women who died from cervical cancer, including 8 Māori women. The agestandardised mortality rate was 1.7 per 100,000 women in the general population and 3.3 per 100,000 for Māori women. This is after a reduction in the number of deaths from 10.3 per 100,000 in 1998 for Māori women.

Difficulties in screening are encountered where general practitioners (GPs) are not sharing information or data with ISPs. Information need to be shared more freely and transparently between GPs and other providers. This issue could be ameliorated by better communication between the DHB managers and the NSU. Given that the NCSP can only report on women who have been screened and a PHO can only report on patients who are enrolled with that PHO, there should be proactive planning and coordination between GPs and ISPs locally, supported by DHB managers and NSU nationally, to have strategies in place to assist with the identification of the unscreened women. Access to and identification of this information can be directly related to reducing disparities for priority women – and Māori women in particular.

## Data accuracy and laboratory recording of ethnicity<sup>48</sup>

The NCSP screening coverage data is taken from the NCSP-R, and the ethnicity recorded on the NCSP-R is the same as that entered by laboratories. The NCSP explained in its June 2014 newsletter that, while any person can have multiple ethnicities, the person's ethnicity is self-identified and can change over time. Smear takers are responsible for providing accurate ethnicity data on laboratory request forms.

The NCSP has provided two ways in which laboratories can improve the quality of ethnicity data on the NCSP-R:

- Ensure that ethnicity is entered and/or updated at the laboratory, and the ethnicity recorded matches that on the latest laboratory request form.
- If more than one ethnicity is listed on the laboratory request form, prioritise ethnicity according to the Ethnicity Data Protocol.<sup>49</sup>

The NCSP ensures that sound systems are in place so that some ethnic groups are not undercounted. In addition, through these systems, quality ethnicity data is provided to measure how health services are working for specific (priority) populations and to assist in improving access to health services for people who need them.

#### For instance:

- coding of ethnicity on the NCSP-R follows the classification used by the Ministry of Health (Ministry of Health 2004)
- work is continuing to improve the accuracy of ethnicity recording on the Register (NSU 2014b).

Ethnicity data protocols for the health and disability sector require ethnicity to be recorded at Level two as the minimum level of specificity (Ministry of Health 2004). The category of Māori stands alone at all levels of the classification. This is in recognition of Māori as the tangata whenua (original inhabitants) of New Zealand and New Zealand's unique position as the only country where there is a commitment to the status, preservation and continuity of Māori cultural traditions, including language (Ministry of Health 2004).

Figure 9.1 shows the ethnicity data quality-improvement cycle. Collecting good-quality ethnicity data in the health and disability sector is important for many reasons, including the following:

 Ethnicity data is part of a set of routinely collected administrative data used by health sector planners, funders and providers to design and deliver better policies, services and programmes. Better information helps improve every New Zealander's health by providing a sound basis for decision making.

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<sup>&</sup>lt;sup>48</sup> NCSP Laboratory Update. Newsletter June 2014.

<sup>49</sup> http://www.health.govt.nz/publication/ethnicity-data-protocols-health-and-disability-sector

• In New Zealand, ethnic identity is recognised as an important dimension of health inequalities. The impact of those factors is particularly evident among Māori and Pacific peoples, whose health status is lower on average than that of other New Zealanders (Ministry of Health 2004).

Step 1:
Collecting

Step 2: Recording, classifying, storing

Training and education

Process improvement

The three steps covered by these protocols

Step 3:
Outputting

Data quality monitoring

Figure 9.1: Ethnicity data quality-improvement cycle

Source: Ministry of Health (2004)

The NCSP has produced for this 2015 review a range of strategies to increase coverage and reduce disparities between priority women – Māori, Pacific and Asian – and European/Others. Evaluation of these efforts will undoubtedly need to continue as part of the essential business for the NCSP.

- The NCSP has included in its DHB contract reporting templates a requirement to report against actions in the DHB Māori Health Plans, since July 2014.
- Some work has looked at funding free smears for more people but equally there is now a need to consider developments with primary human papillomavirus (HPV) screening and funding HPV development, as against whether or not a focus should remain on funding free smears.
- Feedback regarding ISPs providing screening interventions was that they are very creative. Some are combined with breast screening promotion and some involve smears being taken in the home.

## Key issues

 New Zealand holds a unique position in the international health sector arena regarding the protection of research information that belongs to its indigenous people. The NKG is accountable to the Minister of Health and considers applications for the release of Māori women's data from the NCSP-R. The NSU and NCSP continue to voice their frustration with both the past relationship with the NKG and the process for obtaining access to Māori women's data from the NCSP-R.

- Current analysis of the NCSP-R data (at March 2014) recorded ethnicity codes for approximately 98.4% of the 1.4 million women on the NCSP-R. The NCSP has continuing work to improve the accuracy of ethnicity recording on the Register.
- In New Zealand, ethnic identity is an important dimension of health inequities. Māori
  and Pacific people experience lower life expectancy and health disadvantage across
  most mortality and morbidity indicators compared with Europeans, as well as socioeconomic disadvantage in areas such as housing, education, income and
  employment. Ethnic inequalities between Māori and non-Māori are the most
  consistent and compelling inequities in health.
- The NCSP has worked with laboratories to provide information on the importance of accurately recording ethnicity information in laboratory systems. The ethnicity recorded on laboratory systems is the same as the ethnicity that is recorded on the NCSP-R.
- Stakeholder comments have identified that the data shows persistent inequities in participation rates for cervical screening among Māori, Asian and Pacific women.
   This is considered a major concern for the NCSP and the sector, particularly in regard to Māori. Planning for primary HPV screening is seen as a critical opportunity to improve cervical screening coverage for Māori women.
- Issues encountered with regard to data access have highlighted that the process to
  obtain information from the Register is slow. This process is mainly influenced by the
  need to improve relationships between NCSP and the NKG so that a process of
  obtaining information quickly can be established. A correctly functioning database is
  also important.
- Independent service providers have found it challenging to identify the unscreened women in their areas, particularly Māori women, who have a higher cervical cancer rate than the other priority groups.
- Difficulties in screening are encountered where GPs are not sharing information or data with ISPs. Information needs to be shared more freely and transparently between GPs and other providers.
- Pacific interviewees reported that health literacy should be considered within a systems approach where the key message is about family and not just the women.
   Once women are aware about how they can access services, they respond well. All DHBs should be required to produce a Pacific Action Plan.

## Recommendations

38. The Parliamentary Review Committee 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 the NCSP and NKG to continue to strive to improve relationships.<sup>50</sup>

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<sup>&</sup>lt;sup>50</sup> See also recommendation 35.

- 39. The NSU, NCSP portfolio managers and DHB managers need to collaborate with ISPs 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, the NCSP and NSU should issue clear national guidelines on sharing client data between agencies.
- 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 the priority groups.<sup>51</sup>

<sup>&</sup>lt;sup>51</sup> See also recommendation 19.

# **Chapter 10: Colposcopy**

## Overview

Colposcopy is a medical procedure where the cervix is visually examined. It is carried out using a colposcope, which is a low-powered microscope that provides an enlarged view of the cervix, enabling the diagnosis and treatment of cervical abnormalities. The colposcope can help guide the taking of biopsies for histological diagnoses, and can help visualise the cervix while using a range of treatment methods.

Colposcopy is central to the successful diagnosis and treatment of cervical abnormalities. It allows a comprehensive visual examination of the cervix, and enables the location of possible lesions that may require treatment, in women referred with any of the following conditions:

- cytological abnormalities detected on cervical sampling
- visible abnormalities of the cervix
- symptoms and signs of cervical cancer.

## **Current status**

## Colposcopy services

Colposcopy services in New Zealand are contracted to District Health Boards (DHBs), where the service is usually part of a gynaecological or women's health service. Colposcopy is also provided by gynaecologists working in private practice.

Colposcopy service providers must comply with "duties of persons performing colposcopy procedures" as specified in section 112M of the Health Act 1956, as amended by Part 4A in 2004. Compliance with this Act includes providing data to the National Cervical Screening Programme (NCSP) as specified.

## Monitoring colposcopy services – compliance with legislation

According to the Health (National Cervical Screening Programme) Amendment Act 2004 (Part 4A, section 112D), the NCSP has a statutory obligation to:

- a) promote high-quality cervical screening, assessment and treatment services, while recognising and managing the differences between the various types of cervical cancer, with a view to reducing the incidence and mortality rate of cervical cancer
- b) inform women and the community of the risks, benefits and expected population health gains from participation in the NCSP
- c) promote the regular recall of women who are enrolled in the NCSP for screening tests
- facilitate continuous quality improvement by allowing and performing regular evaluations of the NCSP

- e) ensure that information that is collected for the purposes of the NCSP is:
  - i. available, in a reliable, accurate and timely manner, to persons authorised under this Part, or any other enactment, to have access to it
  - ii. safely stored, including on the NCSP-Register
- f) provide information to women about the quality and effectiveness of the NCSP including, if it is appropriate, information based on the results of evaluations.

To fulfil its statutory functions, the NCSP must collect and analyse data on colposcopy services.

## The National Cervical Screening Programme Policies and Standards

The NCSP has produced a Policies and Standards document with agreed policies, guidelines and standards of practice for health professionals who provide cervical screening services (Ministry of Health 2013). The purpose of these Policies and Standards is to support all those involved in the NCSP to achieve the programme's aims and objectives, by ensuring a high standard and national consistency of service at each step of the screening pathway.

## **Colposcopy Quality Improvement Programme**

In 2009 the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) led the development of Colposcopy Quality Improvement Program (C-QuIP), an education, certification, re-certification and audit programme for all health professionals performing colposcopy in Australia and New Zealand. The aim of C-QuIP is to improve the care of women who are referred for colposcopy and treatment of screen-detected abnormalities. A comprehensive online education programme is provided for all professionals performing colposcopy (C-QuIP 2015).

## **District Health Board colposcopy services**

The colposcopy services within DHBs are audited every three years. The most recent audit revealed a number of high-risk Corrective Action Requests (CARs), as shown in Table 10.1. The most frequently reported high-risk CARs were in relation to timeliness of diagnosis and treatment, documenting colposcopy assessment, work practices policy, internal quality control policies and quality assurance activities. All CARs have now been closed (see Appendix H for more detail).

Table 10.1: Frequency of high-risk CARS

Standard/policy	Number of DHBs with high-risk CARs		
602 – Timeliness of diagnosis	10		
603 – Documenting colposcopy assessment	7		
605 – Timeliness of treatment	6		
Internal quality control policy / quality assurance activities	5		
609 – Managing women who do not attend / failure to attend guidelines	4		
611 – Maintaining staff skill levels	4		
610 – Ensuring services are adequately staffed	1		
607 – Delivering appropriate outpatient treatment	1		
Work practices policy	6		
Referral for colposcopy policy	1		
Data collection for the development of new targets and reports	2		
Service components	1		

Source: Data provided by NCSP 2015

A third round of audits commenced in 2015 for all 20 DHBs. The audit provider is Health and Disability Auditing New Zealand Limited and the audit team consists of a lead auditor, a colposcopist and a colposcopy nurse.

All colposcopy service providers contracted to the NCSP are monitored using National Cervical Screening Programme-Register (NCSP-R) data against a range of indicators, including:

- · wait times for assessment for high- and low-grade abnormalities and urgent referrals
- rates of women who do not attend appointments
- total volumes of new assessments undertaken
- rates of women with high-grade lesions who have had a biopsy
- rates of biopsies suitable for histological interpretation
- positive predictive value (PPV) of colposcopy for high-grade lesions
- · rates of high-grade treatment failures
- · use of high-risk HPV (hrHPV) testing to manage discordant results
- follow-up of women with high-grade cytology, no histology.

Colposcopy units must ensure the maintenance of skill levels of staff performing colposcopy through:

- attaining at least the minimum volume of new cases (see Standard 610, Appendix I)
- participating once every three years in an activity recognised by C-QuIP (see Standard 610, Appendix I)
- for nursing staff, participating in continuing education activities appropriate to their practice.

For a summary of the National Cervical Screening Programme Policies and Standards, Section 6: Providing a Colposcopy Service, see Appendix I.

## Colposcopists

Colposcopists should be certified by C-QuIP or be practising under the supervision of a certified colposcopist, while working towards certification by C-QuIP.

## Colposcopists must:

- be registered to practise in New Zealand and hold a current annual practising certificate with the New Zealand Medical Council or Nursing Council of New Zealand
- practise according to the Guidelines for Cervical Screening in New Zealand (NSU 2008) and subsequent updates
- maintain a minimum volume and spectrum of new referrals as per the standards
- work closely with other health professionals and participate in multidisciplinary meetings in accordance with New Zealand guidelines.

## Nurse colposcopists

There are three practising nurse colposcopists and one treating colposcopist in New Zealand. Plans are in place for nurse colposcopists to practise in the community, rather than only in the DHB colposcopy clinics; this approach will allow access by women who have difficulty attending DHB clinics.

Results from this approach will help to decide if training more nurse colposcopists will help to address the challenging issues for the NCSP in some ethnic communities in New Zealand.

#### National colposcopy meetings

National colposcopy meetings have been re-convened since the last Parliamentary Review in 2011 in order to improve the networking of DHBs and information sharing. The NCSP held national colposcopy meetings in June 2012 and November 2014.

In addition, the Australian Society for Colposcopy and Cervical Pathology (ASCCP) held its Annual Scientific Meeting in 2013 in Wellington, and an ASCCP course in 2014 in Auckland. These educational meetings provide a professional update on all aspects of cervical screening and management of screened abnormalities.

## Follow-up after high-grade cytology

Compared with other ethnic groups, there is a higher proportion of women from the Pacific community (16.3%), followed by women from the Māori population (8.8%), for whom there is no evidence that they received follow-up tests after a high-grade cytology report. Table 10.2 shows the number of women who did not receive any follow-up within 90 days and within 180 days of a high-grade cytology report, by ethnicity.

Table 10.2: Women without any follow-up test within 180 days of a high-grade cytology report, by ethnicity

Ethnicity	High-grade cytology	Without follow-up by 90 days		Without follow-up by 180 days	
	n	n	%	n	%
Māori	400	59	14.8	35	8.8
Pacific	123	30	24.4	20	16.3
Asian	174	16	9.2	11	6.3
European/Other	1,793	175	9.8	101	5.6
Total	2,490	280	11.2	167	6.7

Source: NCSP Monitoring Report Number 40 (NSU 2014b)

## Colposcopy data

Currently, colposcopy data is sent to the NCSP-R (\*see page 112) by various modalities: by completing paper forms, electronically and, since late 2014, by ecolposcopy.

Colposcopy indicators are an important quality measure of the NCSP, and reporting on them should not be unduly delayed. The 2011 Parliamentary Review into the NCSP identified an urgent need to ensure colposcopy data in the NCSP-R was complete and to include colposcopy indicators in the monitoring reports (Tan et al 2011). It is anticipated that completeness of colposcopy data on the NCSP-R will continue to improve over time.

Colposcopy data has been recorded on the NCSP-R for a short time relative to cytology and histology data. It is possible that reporting of colposcopy data to the NCSP-R is incomplete and therefore results for these indicators may need to be interpreted with some caution (NSU 2014b). Electronic reporting from DHBs would reduce the likelihood of incomplete reporting in the future. Colposcopy data from the private sector will need to be monitored to ensure these colposcopists are complying with the Health Act 1956. The NCSP has a responsibility to assist the private sector colposcopists in this process, and to provide feedback of clinical indicators to them rather than just to the DHBs. The issue of completeness of colposcopy data is a high priority for the NCSP to address.

\* The National Cervical Screening Programme-Register (NCSP-R) is the national repository for information relating to cervical screening events and is a key component of the National Cervical Screening Programme. The purpose of the Register is to support the NCSP to reduce the incidence of and mortality rate from cervical cancer, and to enable access to information by those operating or evaluating the programme. The requirements and functions of the Register are prescribed in Part 4A of the Health Act 1956. Under this legislation, every result that is reported to the NCSP from a screening test, or from a diagnostic test, must be recorded on the NCSP-R, if that result relates to a woman who is enrolled in the NCSP. This information is stored securely by the Register in Wellington and can be accessed only by those authorised to do so. Information can only be provided outside the programme to health practitioners and/or evaluators or a review committee appointed by the Minister of Health to evaluate the programme. The NCSP-R is operated by New Zealand Post, with some Register duties carried out by DHBs.

Almost all the DHBs now utilise colposcopy software in their colposcopy clinics. By the end of 2015, it is planned that all DHBs will be utilising the Gynaecology Plus colposcopy software (proprietor Solutions Plus). The need to collect important data means that there are more mandatory fields that the colposcopist must input. There is a need to ensure this task is not too onerous to distract from clinical activities. There should be periodic reviews of what mandatory data is necessary to ensure colposcopists are meeting the NCSP standards.

For more information on how colposcopy data is managed, see Chapter 8: NCSP-Register.

## e-colposcopy

The electronic transfer of colposcopy data to the NCSP-Register is known as e-colposcopy. Colposcopy software is used by DHBs colposcopy clinics. The key stakeholders behind electronic reporting are the NCSP, DHB colposcopy clinics, NCSP-R, SolutionsPlus, clinicians and IT departments.

Conversion to e-colposcopy commenced in July 2014, but it has involved delays as a result of problems encountered with software and linkage from DHBs to the NCSP-R. These problems are being overcome with support from the NCSP team, and with governance and reporting through the Screening Information Governance Group. In March 2015 the NCSP undertook a re-scoping project to ensure the e-colposcopy project had the appropriate level of senior oversight within the Ministry of Health and linkages back to the Information Group within the Ministry.

Two DHB clinics were using e-colposcopy by March 2015. The NCSP team, together with its stakeholders, will work through the challenges and will support users in DHB colposcopy clinics as they familiarise themselves with the smooth operation of the software. The goal will be to ensure all 20 DHBs are using e-colposcopy in the near future. The importance of e-colposcopy is also discussed in Chapter 8: NCSP-Register.

#### C-QuIP

Since December 2012, medical practitioners and nurses wanting to practise colposcopy in New Zealand must have obtained C-QuIP certification (under the auspices of RANZCOG) as a practising colposcopist (or be working towards this certification).

There are two certification streams:

- diagnostic
- therapeutic.

## Diagnostic colposcopists

Diagnostic colposcopists are required to undertake 75 colposcopies in each three-year period, from commencement of audit, in women who have not been treated in the last 12 months. The practitioner is required to provide evidence of a minimum number of colposcopies annually, with 25 being the minimum level required to maintain skill to a satisfactory standard. Audit for this standard is mandatory.

## Therapeutic colposcopists

Therapeutic colposcopists are required to lodge all treatments with histology in each three-year period from commencement of audit. The practitioner should aim to have histological evidence of high-grade changes (punch biopsy and/or loop specimen) in 80% of cases. Audit for this standard is mandatory.

#### **NCSP Policies and Standards**

In addition to the C-QuIP standards, colposcopists in New Zealand need to meet more stringent criteria and colposcopy indicators outlined in the NCSP Policies and Standards (see Appendix I).

Under the NCSP Policies and Standards, colposcopists need to:

 maintain a minimum of 50 new cases per annum in New Zealand (the ideal number is 100 per annum), or a minimum of 150 cases over a three-year period (note: this total differs from the minimum C-QuIP volumes required for certification, and has been discussed with RANZCOG; case volumes can be a combination of cases from different practices (eg, combined DHB and private) but evidence is required for each practice)

- maintain a minimum number of 10 treatments per year, as per C-QuIP guidance (or 30 treatments in each three-year period)
- Maintain certification and demonstrate participation in the C-QuIP Professional Development Programme (recertification and audit) as per the C-QuIP website (www.cquip.edu.au).

It was determined that New Zealand maintains a higher number of cases and that colposcopy audits by International Accreditation New Zealand did request and include cases from both DHB and private practice.

The last RANZCOG C-QuIP accreditation cycle has been extended until the end of 2015 for New Zealand colposcopists seeking re-accreditation. The first accreditation cycle involved collecting numbers of colposcopy and treatment performed over three years from 2012. It is important that the next accreditation cycle after 2015 involves more than documenting the number of procedures. Colposcopy indicators already collected in the NCSP-R colposcopy data should be included in the next C-QuIP accreditation cycle. The NCSP will need to discuss the accreditation process with RANZCOG.

## Data collection for promoting best practice in colposcopy

## **Purpose**

It is important to analyse and report on complete data sets from colposcopy services to promote best practice, emphasising safety and quality.

## **Quality improvement**

Data held on the NCSP-R that has been received from colposcopy services is analysed to support practitioners with quality improvement. For example, analyses may include:

- correlation for high-grade lesions (CIN2 or worse) between colposcopy findings and histology results (in order to calculate the positive predictive value of colposcopy for high-grade abnormalities)
- the proportion of biopsies suitable for histological interpretation
- the number of residual high-grade abnormalities, 12 months after treatment
- the reason no biopsy was taken, when a woman with a high-grade abnormal smear has been referred
- the outcome for women who had a high-grade abnormal smear but no biopsy taken.

Feedback from the DHBs' colposcopy clinics suggests that most of the colposcopists do not have difficulties achieving the number of colposcopy required each year by the NCSP. Most of the clinics now have colposcopy software that allows them to generate the above analyses. However, it is not routine for these analyses to be generated for individual colposcopists annually. Feedback on the quality of colposcopy performance is not provided to colposcopists by the NCSP either. Feedback on colposcopy performance annually is important to assist the colposcopists in maintaining their skills.

It is vital for the private colposcopists as most do not have colposcopy software in their practice to generate these analyses. They submit their colposcopy data to the NCSP-R by paper format; the NCSP should take responsibility for providing them with the analyses of it.

## Colposcopy in population with an HPV vaccination programme

As HPV infection decreases in a HPV-vaccinated population, the need for colposcopy will decrease and the number of high-grade abnormalities will also drop, as early observations in Australia show (Brotherton et al 2011). In addition, positive predictive value of colposcopy will drop as the prevalence of high-grade disease falls.

Primary HPV screening is being introduced into countries with an HPV vaccination programme and New Zealand has started the process of evaluating the introduction of primary HPV screening. It is expected that, although the number of colposcopies is likely to increase in the initial change-over to HPV screening, it will drop by the second round of HPV screening as the incidence of high-grade disease will be substantially lower (Ronco et al 2014). The initial increase in the number of colposcopies will also be limited if the initial age of screening is moved to 25 years of age.

## **Key issues**

- Electronic reporting from DHBs would reduce the likelihood of incomplete reporting of colposcopy to the NCSP-R. It is important to ensure e-colposcopy is functioning well in all DHB colposcopy clinics in the near future.
- Colposcopy data submitted from the private sector will need to be monitored to ensure these colposcopists are complying with the Health Act 1956.
- Medical practitioners and nurses wanting to practise colposcopy in New Zealand must have obtained C-QuIP certification. Colposcopy indicators already collected in the NCSP-R colposcopy data should be included in the next C-QuIP accreditation cycle.
- It is important to analyse and report on complete data sets from colposcopy services to promote best practice, emphasising safety and quality.
- National colposcopy meetings should take place on an annual basis to improve networking of DHBs and information sharing.

## Recommendations

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 colposcopy clinics.

- 42. The NCSP should ensure that colposcopy data submitted from the private sector fully complies with the Health Act 1956. 52
- 43. Data held on the NCSP-R that is received from colposcopy services should be analysed annually to support practitioners in their quality improvement.<sup>53</sup>
- 44. The NCSP and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists will need to address the discrepancy between 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.

<sup>&</sup>lt;sup>52</sup> See also recommendation 37

<sup>&</sup>lt;sup>53</sup> See also recommendation 34

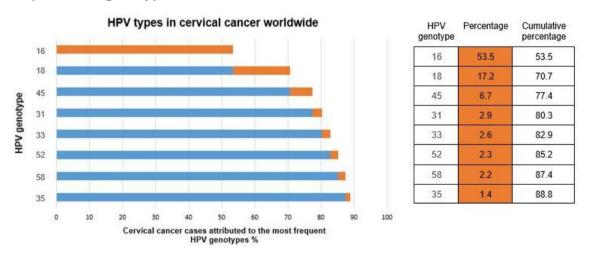
# Chapter 11: Human papillomavirus (HPV) and cervical cancer

#### Overview

Human papillomavirus (HPV) is one of the most common causes of sexually transmitted disease worldwide. HPV belongs to the *Papovaviridae* family of deoxyribonucleic acid (DNA) viruses, many of which are oncogenic or potentially oncogenic. HPV is a relatively small virus consisting of a 72-capsomere capsid, which contains the viral genome, a double-stranded DNA.

Over 200 papillomavirus types have been described, around 100 of which infect humans and are, therefore, classified as HPV (Burd 2003). Types HPV 6 and HPV 11 cause around 90% of the anogenital warts diagnosed and are not associated with cancer, but have been linked to 10% of low-grade squamous intraepithelial lesions (LSIL). They are considered as low-risk types. Fifteen subtypes (16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 68, 73, 82).are recognised as potentially oncogenic and are considered as high-risk types. Types HPV 16 and HPV 18 are responsible for approximately 70% of cervical cancers worldwide (Muñoz et al 2003; Bosch et al 2008) (see Figure 11.1). Information about cervical cancer incidence and mortality can be found in Chapter 1: Introduction and methods.

Figure 11.1: Cumulative percentages of cervical cancer cases attributable to the most frequent HPV genotypes



Source: Muñoz et al (2003)

#### HPV-attributable disease in humans

HPV is one of the most important infectious agents in cancer causation. With respect to cancer of the cervix, it is generally accepted that HPV is necessary for the development of cancer, and all cases of this type of cancer can be attributed to the infection (Parkin 2006). However, although HPV infection is necessary, it is not sufficient alone to cause cervical cancer, and other factors may also play a part. For anal cancer, it has been estimated around 90% are positive for oncogenic HPV, as shown in Table 11.1, and approximate estimates suggest that prevalence of HPV in cancers of the vulva, vagina and penis is around 40%. HPV also plays a role in a fraction of cancers of the oral cavity and pharynx.

Table 11.1: Cancers attributable to infection with oncogenic types of HPV, 2002

Site	% attributable to HPV	Developed countries			Developing countries		
		Total cancers	Attributable to HPV	% all cancer	Total cancers	Attributable to HPV	% all cancer
Cervix	100	83,400	83,400	1.7	409,400	409,400	7.0
Penis	40	5,200	2,100	0.04	21,100	8,400	0.14
Vulva/vagina	40	18,300	7,300	0.2	21,700	8,700	0.2
Anus	90	14,500	13,100	0.3	15,900	14,300	0.2
Mouth	3	91,100	2,700	0.1	183,000	5,500	0.1
Oro pharynx	12	24,400	2,900	0.1	27,700	3,300	0.1
All sites		5,016,100	111,500	2.2	5,827,500	449,600	7.7

Source: Parkin (2006)

There is compelling evidence to suggest that cervical HPV infection is acquired as a result of sexual intercourse and that, for many women, infection occurs shortly after beginning their first sexual relationship (Collins et al 2002). Lifetime number of male partners is a major risk factor (Karlsson et al 1995). One study, using longitudinal data from 242 women who had had only one sexual partner, found that the risk of acquiring cervical HPV infection was 46% (95% confidence interval (CI) 28–64) at three years after intercourse. The median time from first intercourse to first detection of HPV was only three months (Collins et al 2002).

The vast majority of HPV infections are transient, with only a small proportion becoming persistent (Karlsson et al 1995; Burk et al 1996; Strauss et al 2002). Among asymptomatic women in the general population, the prevalence of HPV infection ranges from 2% to 44%. The adjusted global prevalence, from a meta-analysis of 78 studies, was estimated to be 10.41% (95%Cl 10.2–10.7), with considerable variation by region (Burchell et al 2006). Progression of HPV infection to invasive disease is rare (less than 2% in most series). However, the data emphasises the importance of follow-up surveillance in treated patients (Burd 2003).

The high-risk HPV types 16 and 18 are the most persistent types of HPV infection and can last many times longer than low-risk types, such as HPV 6 (Ho et al 1998; Woodman et al 2001; Richardson et al 2003, Muňoz et al 2004).

# HPV and pathogenesis of cervical disease

Cervical cancer is one of the best understood examples of how viral infection can lead to malignancy (Burd 2003). After the cervix is infected with HPV, infection may cause mild Pap cytology abnormalities and/or mild cervical intraepithelial neoplasia (CIN1) or LSIL. This usually clears spontaneously.

It has become apparent that persistence of high-risk HPV (hrHPV) is a key factor in the progression to precancerous lesions (CIN2 or CIN3) or high-grade squamous intraepithelial lesions (HSIL). These lesions have a greater likelihood of progressing to invasive cancer (Solomon et al 2002; Burd 2003). The progressive development of cellular changes from HPV infection to cervical cancer generally takes 10 to 20 years, although, in very few cases, it may only take one to two years. CIN1 changes can arise within three months of infection, CIN2 within six months, and CIN3 within one to two years.

An Australian study assessed the HPV genotype prevalence among a cohort of 1,676 women who had been referred due to cytological abnormalities (Stevens et al 2009). Overall, 83.9% of women were HPV positive. Of those with histological diagnosis at the time of treatment (n = 899), HPV positivity increased significantly with disease severity. Results showed: 62.4% (normal), 77.6% (CIN1), 92.6% (CIN2) and 97.9% ( $\geq$  CIN3) (p < 0.006). The five most prevalent genotypes were HPV 16 (35.1%), 31 (12.6%), 51 (11.1%), 52 (9.9%) and 18 (8.5%). Multiple HPV infections, including multiple hrHPV infections, declined significantly with age.

A New Zealand study of 594 women with high-grade abnormal cytology and a valid HPV test showed that, of those recruited, 356 (60%) had confirmed CIN2/3 and 6 (1%) had confirmed adenocarcinoma-in-situ (AIS) or glandular dysplasia. Positivity rates for any oncogenic HPV infection and for HPV16 and/or 18 within confirmed CIN2/3-AIS were 95% (95%CI 92–97%) and 60% (95%CI 54–65%) respectively; in all women with ASC-H/HSIL+/AGC/AIS cytology it was 87% (95%CI 84–89%) and 53% (95%CI 49–57%), respectively. The most common reported HPV types in women with CIN 2/3 were 16 (51%), 52 (19%), 31 (17%), 33 (13%) and 18 (12%). A trend for higher rates of HPV 16/18 infection compared with other oncogenic types was observed in younger women (p = 0.0006) (Simonella et al 2013).

# Co-factors that increase the risk of progression to cervical cancer

Persistent HPV infection is necessary, but insufficient alone, to cause cervical cancer (Bosch et al 2002). Other factors are associated with the development of cervical cancer following oncogenic HPV infection (Burd 2003; Baseman and Koutsky 2005) including:

- environmental factors such as smoking
- sexual exposure, for example, age at first intercourse or first marriage, parity, number of sexual partners
- hormonal factors, such as long-term use of oral contraceptives

- immunosuppressive factors, such as human immunodeficiency virus (HIV) infection, or being a transplant recipient
- long-term systemic use of steroids.

Although these co-factors are well described, it is still not possible to predict who will develop cervical cancer.

# Guidance on appropriate HPV testing

HPV testing is recommended for:

- 1. women aged 30 years or older who have not had an abnormal cytology report in the previous five years following atypical squamous cells of unknown significance (ASC-US) or LSIL cytology
- 2. management after treatment for HSIL includes 'historical testing' for women on annual smears for previous high-grade lesions and with negative smears since, to assess whether they can return to routine three-yearly screening
- 3. women where colposcopy has shown discordant results from cytology, to help interpret these results.

According to NCSP Monitoring Report Number 40 (NSU 2014b), among women aged 30 years or older with valid HPV triage test results, 26.2% of women with ASC-US results and 60.1% of women with LSIL results were positive for high-risk HPV. There is a need to determine whether there is any benefit in continuing HPV triage in women with LSIL results, if more than 60% of women with LSIL results are positive for HPV.

# **Test accuracy**

A recent evidence review by the Australian Medical Services Advisory Committee (MSAC 2013) drew the following conclusions:

- The HPV triage test is more sensitive than a single repeat cytology test for the detection of CIN2+ and CIN3+ lesions in women with possible LSIL and has similar specificity.
- The HPV triage test is more sensitive than a single repeat cytology test for the detection of CIN2+ lesions (but not CIN3+) in women with LSIL and has lower specificity.
- A significant proportion of additional CIN2+ lesions that would be detected by HPV triage of LSIL and possible LSIL are likely to regress when a strategy of repeat cytology is used.
- The colposcopy rate following HPV triage is higher in women aged < 35 years than in women aged ≥ 35 years.

Specific monitoring of the other uses of HPV testing is not yet included. These other uses include:

- management of women previously treated for CIN2/3
- management of women with a high-grade squamous cytology result in the past, followed by negative cytology
- resolution of discordant cytology, colposcopy and histology.

In New Zealand, it was estimated that 3,126 (15.5%) HPV tests were for triage of low-grade cytology in women aged 30 years or older; 2,247 (11.2%) were for post-treatment management for women treated in the past four years; 7,744 (38.5%) were for follow-up management of women with high-grade squamous cytology or histology more than three years previously (historical testing); and 1,090 (5.4%) were on samples collected at a colposcopy visit that did not fit into a previous category (possibly for resolution of discordant results). Another 5,904 (29.4%) HPV tests did not fit into any of the previously described categories (NSU 2014b).

# hrHPV testing policy

hrHPV testing of liquid-based cytology (LBC) samples must be carried out using approved and validated processes and in accordance with manufacturer instructions.

The test procedure must be endorsed by an internationally recognised accreditation agency, such as the United States Food and Drug Administration (FDA), or must be Conformité Européenne (CE) marked and/or internally clinically validated to meet at least the performance of internationally validated tests. The sensitivity of the test for the detection of CIN2 or worse in women aged 30 years or older must be at least 90%. The hrHPV test must test for a minimum of the 14 most common hrHPV subtypes. More detailed criteria are in the NCSP Policies and Standards – Section 5: Providing a laboratory service.

# **Accreditation of HPV laboratories**

The NCSP has a memorandum of understanding with International Accreditation New Zealand (IANZ) for accrediting NCSP laboratory service providers.

Seven laboratories currently provide combined cytology screening and HPV testing. NCSP policy and quality standards dictate that hrHPV testing is only permitted at a laboratory where gynaecological cytology is reported.

IANZ accredits medical laboratories against ISO15189 and the NCSP audits against NCSP Policies and Standards – Section 5: Providing a laboratory service.

Accreditation involves a site visit to each laboratory annually, which consists of an IANZ assessor and a National Screening Unit (NSU) representative (surveillance visit). Every four years there is a peer review assessment, which also includes both a scientist and a pathologist technical expert for each discipline. The annual round is January to December.

A laboratory section assessment takes place over the duration of one day, and the report is subsequently issued by IANZ, with input from the NSU representative. IANZ is also responsible for follow up of Corrective Action Requests (CAR) and Strong Recommendations (SR). The NCSP also undertakes follow-up as part of its contractual meetings with service providers.

The assessments of each laboratory section can occur on the same day, or be spread across a week, so the NSU representative always attends the cytology section assessment. The relevant sections of the NCSP Policies and Standards are provided to the IANZ assessors (and peer reviewers if present) for the laboratory section that undertakes HPV testing. The outcome of the HPV laboratory section is fed back by IANZ to the NSU representative and any issues that arise against the NCSP Policies and Standards are discussed.

From the 2014 round, four CAR/SR arose from two laboratories for HPV testing, which related to aliquoting and cross-contamination checks.

The rate of HPV testing will vary between laboratories for a number of reasons. One reason is that laboratories differ in their general volume of work. Another reason may be differences in the population that laboratories serve, because HPV testing is performed in specific subgroups of women. For example ,HPV triage testing is performed in women with low-grade (ASC-US/LSIL) cytology results (but without recent abnormalities), therefore laboratories reporting higher rates of low-grade abnormalities may also have higher rates of triage testing. Conversely, laboratories reporting on a larger proportion of cytology from colposcopy clinics may be less likely to perform HPV triage testing, because women attending colposcopy have generally had a recent abnormality. These issues may, for example, partly explain differences in rates between Canterbury Health Laboratories (where rates of low-grade cytology results are comparatively high) and LabPLUS (where a larger proportion of cytology comes from colposcopy clinics) (NSU 2014b).

# **HPV** vaccination

Most developed countries have now implemented an HPV vaccination programme for pre-adolescent girls. This development has been supported by a recent cost-effectiveness analysis, which concluded that vaccination of girls is cost-effective in the vast majority of countries in the world (Jit et al 2014). In this analysis, vaccination of a cohort of 58 million 12-year-old girls, in 179 countries, prevented 690,000 cases of cervical cancer and 420,000 deaths during their lifetime. HPV vaccination was very cost-effective in 156 (87%) of the 179 countries.

HPV immunisation was first implemented in New Zealand in 2008 and is currently available to females under the age of 20 years. The HPV vaccine does not offer complete protection against cervical cancer, as the vaccine does not include all genotypes of the virus, and not all women receive or respond to the vaccine. The current three-dose coverage level in girls aged 12–13 years in New Zealand is 48–56%. The coverage is higher among the Māori and Pacific populations.

Table 11.2 provides a comparison of HPV immunisation coverage at each eligible cohort since the start of the programme on 1 September 2008 through to 28 February 2014, using the Census estimated population projection as denominator to assist in assessing the progress towards the targets for HPV immunisation. Girls have up to their 20th birthday to commence the publicly funded programme. Girls born from 1991 to 1993 will have now passed their 20th birthday and are no longer eligible for the funded HPV programme.

Modelling results suggest that, in countries like New Zealand, the health sector would achieve the best value for money in reducing incidence of cervical cancer by further improving HPV vaccination coverage for girls, rather than adding in the vaccination of boys (Pearson et al 2014). Nevertheless, vaccination of boys could become cost-effective, and could help reduce incidence of other cancers caused by HPV, if the vaccine was supplied at very low prices and administration costs were minimised.

A strategy is needed to ensure every woman's HPV vaccination status is captured as part of her screening history. This may be achieved through data linkage with the HPV Immunisation Register. This information can then be used to help assess the success of the Immunisation Programme in preventing cervical cancer.

For discussion regarding linking the HPV Immunisation Register to the National Cervical Screening Programme-Register (NCSP-R), see Chapter 8: NCSP-Register.

Table 11.2: HPV immunisation coverage by ethnicity, vaccination and eligible birth cohort, 1991 to 2000

			Immunisation	coverage (%)	
HPV birth cohort (born during the year)	Vaccination	Māori	Pacific	Other*	All
2000	HPV-1 Quadrivalent	69	77	55	60
	HPV-2 Quadrivalent	66	76	53	58
	HPV-3 Quadrivalent	60	69	50	54
1999	HPV-1 Quadrivalent	71	84	54	61
	HPV-2 Quadrivalent	69	83	53	59
	HPV-3 Quadrivalent	64	77	51	56
1998	HPV-1 Quadrivalent	67	77	50	56
	HPV-2 Quadrivalent	65	76	49	55
	HPV-3 Quadrivalent	60	72	47	52
1997	HPV-1 Quadrivalent	69	79	51	58
	HPV-2 Quadrivalent	67	77	50	56
	HPV-3 Quadrivalent	63	74	48	54
1996	HPV-1 Quadrivalent	70	79	54	60
	HPV-2 Quadrivalent	68	77	53	58
	HPV-3 Quadrivalent	64	73	51	56
1995	HPV-1 Quadrivalent	63	75	51	56
	HPV-2 Quadrivalent	60	73	50	54
	HPV-3 Quadrivalent	55	66	48	51
1994	HPV-1 Quadrivalent	63	74	54	57
	HPV-2 Quadrivalent	59	71	52	55
	HPV-3 Quadrivalent	53	64	50	52
1993	HPV-1 Quadrivalent	62	76	55	58
	HPV-2 Quadrivalent	57	72	53	56
	HPV-3 Quadrivalent	50	66	50	52
1992	HPV-1 Quadrivalent	55	74	57	58
	HPV-2 Quadrivalent	50	69	55	55
	HPV-3 Quadrivalent	44	64	52	51
1991	HPV-1 Quadrivalent	50	64	56	56
	HPV-2 Quadrivalent	45	57	54	52
	HPV-3 Quadrivalent	38	50	51	48

Note: Estimated HPV eligible population includes females only and is based on the selected denominator.

Source: National Immunisation Register database

<sup>\*</sup> Other includes all ethnicities except Māori or Pacific.

Currently in New Zealand, three doses of the vaccine are given, as shown in Table 11.2, although there is some drop-off in coverage after the first dose. This dosage is different to the United Kingdom, where since 2014 just two doses of the vaccine have been administered (Public Health England 2014). The United States FDA (2014) has also approved a human papillomavirus 9-valent vaccine, recombinant for the prevention of certain diseases caused by nine types of HPV. Covering nine HPV types, five more HPV types than Gardasil® (previously approved by the FDA), Gardasil® has the potential to prevent approximately 90% of cervical, vulvar, vaginal and anal cancers.

Within the Ministry of Health, the NCSP needs to work closely with the Immunisation team, who are part of the Sector Capability and Implementation Business Unit, to enhance the benefit of the HPV Immunisation Programme in cervical cancer prevention. An ongoing dialogue between the NCSP and New Zealand Immunisation focused on ways of increasing vaccination coverage is important.

# **Primary HPV screening**

When the Papanicolaou (Pap) test was first introduced in the 1940s, cervical cancer was the number one cause of death among women. Since the introduction of cervical screening programmes using the Pap test in the 1970s and 1980s, much has been achieved in reducing the incidence of and mortality from cervical cancer. Scientific understanding of the natural history of cancer of the cervix and its relationship with the human papillomavirus has led to even further improvements in the prevention of cervical cancer. Recent population interventions in developed countries with the introduction of HPV immunisation programmes for 12- and 13-year-old girls will, over the coming decades, see cervical cancer incidence and the prevalence of cervical high-grade abnormalities decline even further. Science is now telling us that there are different ways to prevent, test for and manage the precursors to cervical cancer.

The following information provides some background context, as well as evidence from two recent international reports (USA and Australia) regarding the introduction of primary HPV screening for cervical cancer. The evidence for a transition to primary HPV screening is compelling.

In September 2010, the External Review Group of the World Health Organization (WHO) met to decide on the update of *Comprehensive Cervical Cancer Control:* A guide to essential practice,. One of the major conclusions of the External Review Group was that the chapter on screening and treatment of precancerous lesions for cervical cancer prevention needed to be updated. In 2013, WHO released the updated WHO Guidelines for Screening and Treatment of Precancerous Lesions for Cervical Cancer Prevention (WHO 2013).

# The guidelines state that:

"Cervical intraepithelial neoplasia (CIN) is a premalignant lesion that may exist at any one of three stages: CIN1, CIN2, or CIN3. If left untreated, CIN2 or CIN3 (collectively referred to as CIN2+) can progress to cervical cancer. Instead of screening and diagnosis by the standard sequence of cytology, colposcopy, biopsy, and histological confirmation of CIN, an alternative method is to use a 'screen-and-treat' approach in which the treatment decision is based on a screening test and treatment is provided soon or, ideally, immediately after a positive screening test. Available screening tests include a human papillomavirus (HPV) test, visual inspection with acetic acid (VIA), and cytology (Pap test). Available treatments include cryotherapy, large loop excision of the transformation zone (LEEP/LLETZ), and cold knife conization (CKC)."

The document provides recommendations for strategies for a screen-and-treat programme, and it is intended primarily for policy makers, managers, programme officers, and other professionals in the health sector who have responsibility for choosing strategies for cervical cancer prevention. For countries that already have a cervical cancer prevention and control programme, the recommendations were developed to assist decision makers in determining which screening test or tests and treatment to provide (WHO 2013).

A number of countries, including Australia and the Netherlands, are moving to modify their cervical screening programmes – or, as in the USA, to modify their cervical screening guidelines – to implement a primary HPV screening test.

On 14 April 2014 the United States FDA approved the use of one HPV DNA test (cobas HPV test, Roche Molecular Systems, Inc.) as a first-line primary screening test for use alone for women aged 25 years or older. This test detects each of HPV types 16 and 18 and gives pooled results for 12 additional high-risk HPV types.

The new approval was based on long-term findings from ATHENA, a clinical trial that included more than 47,000 women. The results showed that the HPV test used in the study performed better than the Pap test in identifying women at risk of developing severe cervical cell abnormalities.

The greater assurance against future cervical cancer risk with HPV screening has also been demonstrated by a cohort study of more than a million women(Gage et al 2014). This study found that, after three years, women who tested negative on the HPV test had an extremely low risk of developing cervical cancer – about half the already low risk of women who tested negative on the Pap test.

First-line HPV screening has not yet been incorporated into the current professional cervical cancer screening guidelines. Professional societies are developing interim guidance documents, and some medical practices may incorporate primary HPV screening (National Cancer Institute 2014).

In Australia, after an extensive review of global evidence and modelling of a range of screening pathways that commenced in 2011, the Australian Health Ministers Advisory Council (AHMAC) endorsed in early 2014 the recommendation of the Medical Services Advisory Committee (MSAC) that a new 'cervical screening test' should replace the current Pap smear (AHMAC 2014).

Cervical cancer is the 12th most common cancer affecting Australian women (excluding basal and squamous cell carcinoma of the skin). There were 682 new cases of cervical cancer diagnosed in 2010, and 152 women died from cervical cancer in 2011. This is equivalent to 9.6 new cases and 2.0 deaths per 100,000 women, respectively. Incidence of cervical cancer and mortality rates are much higher in Aboriginal and Torres Strait Islander women, with incidence at 22.3 cases and deaths at 10.6 per 100,000 women in the period 2004 to 2008 (AIHW 2014a).

# **Evaluating new cervical screening options in Australia**

# The evidence assessment

The MSAC evidence review provided a systematic review of available literature addressing the primary and secondary questions outlined in a Decision Analytic Protocol as follows.

A modelled evaluation was undertaken of the effectiveness and cost-effectiveness of six different primary screening approaches, using different technologies or technology combinations, as described in the Decision Analytic Protocol, compared with the current screening pathway. The approaches evaluated were:

- conventional cytology with International Agency for Research on Cancer (IARC) age range and intervals
- 2. manually read LBC with IARC age range and intervals
- 3. automated image-read LBC with IARC age range and intervals
- HPV primary testing with cytology (LBC) triaging of all oncogenic HPV-positive women
- 5. HPV primary testing with partial HPV genotyping (ie, differential identification and subsequent management of HPV 16/18 positive women [colposcopy] compared with women with other oncogenic HPV genotype infections [reflex LBC])
- 6. HPV primary testing with adjunctive co-testing with LBC (ie, performing both LBC and HPV testing at the primary screening stage and managing on the basis of both tests for all women).

For each of these six potential primary screening approaches, the effects of a number of possible variants, based on differences in screening behaviour and compliance assumptions and accounting for the secondary evaluation questions, were also evaluated. These included:

- (i) moving from the current reminder-based screening system in which reminders are sent to eligible women who have not attended for screening at the recommended interval, to a call-and-recall system in which invitations are sent before the re-screening due date (two different sets of attendance assumptions were used for future compliance in the context of longer intervals for reminder-based strategies and alternate assumptions were used for call-and-recall strategies)
- (ii) moving from an assumed 'slower uptake' scenario for screening initiation after age 25 years (if the recommended age of starting was changed without issuing invitations to women on their 25th birthday) to a 'faster uptake' scenario which assumed women were sent invitations on their 25th birthday
- (iii) for LBC options, use of reflex HPV triage testing for low-grade cytology instead of management according to current National Health and Medical Research Council recommendations (which involve either cytology follow-up or immediate colposcopy depending on the age and screening history of the woman)
- (iv) for LBC options using HPV triage and for primary HPV screening options involving cytology triage, two different alternatives for managing triage-test-positive women thereafter (via either recommended 12-month follow-up or direct colposcopy referral)
- (v) introducing HPV 'exit testing' for women attending screening at age 64 years or older, to assess and manage the group of women at very low risk of subsequent disease with a view to potential discharge of this group from screening.

In total, over 130 specific potential cervical screening strategies were evaluated and compared with current practice for cervical screening.

The MSAC report found that cervical screening using a primary HPV test with partial HPV genotyping will detect HPV infections that are associated with abnormal cellular changes at risk of progressing to cervical cancer. Differential management of women who test positive for HPV genotypes 16,  $18 \pm 45$  will allow more intensive management of HPV infections that are at a higher risk of progressing to cervical cancer.

# The screening interval

In regard to the screening interval, the evidence review found longer screening intervals would be appropriate for HPV screening due to its high negative predictive value. In addition to the randomised controlled trial evidence (range of three- and five-yearly intervals), two cohort studies suggested screening intervals of up to five years may be appropriate (Katki et al 2011; Kitchener et al 2011). In their recent study, Ronco et al (2014) recommended extending screening intervals to at least five years for HPV screening to avoid over-diagnosis of regressive CIN.

Elfström et al (2014) analysed 13 years of follow-up from a randomised controlled trial on HPV screening in Sweden and found the longitudinal sensitivity of cytology for CIN2+ in the control arm at three years (85.9%, 95%CI 76.9–91.8%) was similar to the sensitivity of HPV screening in the intervention arm at five years (86.4%, 95%CI 79.2–91.4%). They concluded that the increased sensitivity of screening for HPV reflects earlier detection rather than over-diagnosis, and the low long-term risk of CIN3+ among women who tested negative in HPV screening supports an HPV screening interval of five years.

The evidence review found that increasing the interval for conventional cytology to three years did not result in any change in effectiveness in a pooled analysis by an IARC working group in 1986 and two recent modelling studies (Creighton et al 2010; Kulasingam et al 2011).

# Colposcopy referral rates

The evidence review found that while HPV screening resulted in increased referral rates to colposcopy compared with conventional cytology, this increased referral rate is higher in women ≤ 35 years of age (HPV arm: 13.1% vs conventional cytology arm: 3.6%; relative risk 3.29, 95%Cl 2.88–3.75) (Vesco et al 2011). The difference in referral rates among women > 35 years of age between conventional cytology and HPV screening was not as great (HPV arm: 5.8% vs conventional cytology arm: 2.5%; relative risk 2.37, 95%Cl 2.13–2.65) (Vesco et al 2011). Referral rates to colposcopy were expected to decrease as the size of the HPV-vaccinated cohort increases and subsequent treatment rates were not expected to increase.

Similarly, the colposcopy referral rate was higher among women younger than 35 years of age compared with older women when HPV screening was used to triage women with LSIL or possible LSIL from a primary LBC test (Dillner et al 2011; ALTS 2003a, 2003b; Bjerre et al 2008) (HPV triage age < 35 years: 70.9%, 95%CI 63.6–77.3% versus HPV triage age > 35 years: 52.9%, 95%CI 45.5–60.2%).

All scenarios lacked evidence for vaccinated populations.

## **Cost-effectiveness**

- The MSAC modelled evaluation found a number of potential new screening strategies that were predicted to reduce cervical cancer incidence and mortality rates further than the current levels. These all involved replacing conventional cytology with newer technologies as the primary screening test.
- Modelling of the HPV screening strategies predicted an 8% to 18% decrease in cervical cancer mortality and savings of \$33.8 to \$52.8 million to the health system.
- Modelling projected that the volumes of cytology tests undertaken would fall from 2.4 million to 340,000 annually.

The University of New South Wales Cancer Modelling Group also undertook a sensitivity analysis for the primary HPV (with partial HPV genotyping) screening pathway to assess the threshold cost at which HPV screening would remain a cost saving:

- For both unvaccinated and vaccinated cohorts, the preferred pathway remained a cost saving when compared with current practice for all likely levels of HPV test cost.
- The overall costs decreased further as the test cost was reduced.
- The cost-effectiveness ratio of the preferred pathway did not exceed \$30,000 per Life
   Year Saved until the HPV test cost was well above likely levels.

The modelled evaluation found that, compared with current practice, primary HPV screening with partial HPV genotyping reduced cervical cancer incidence by 18% (95%CI 13–21%) and cervical cancer mortality by 18% (95%CI 14–21%) in an unvaccinated population. Of all the strategies modelled, partial HPV genotyping resulted in the greatest reductions in incidence and mortality.

Primary HPV strategies with partial HPV genotyping resulted in cost savings compared with current practice, ranging from \$33.8 to \$52.8 million, and from \$41.7 to \$58.5 million, in unvaccinated and vaccinated populations respectively. It is assumed these savings are inclusive of general practitioner (GP) and specialist visits as well as the costs of HPV partial genotyping and LBC triage. To provide some perspective, in 2012–13 an estimated \$89.3 million was spent in Australia on cervical screening pathology tests alone, excluding the costs of GP and specialist visits (AIHW 2015).

MSAC supported reflex LBC testing to triage women with positive HPV test results. In supporting reflex LBC testing, MSAC noted that, for women with HPV genotypes other than 16/18 (or possibly 45), the results of LBC would determine the need for referral for colposcopy. For individuals with HPV16/18 (or possibly 45), referral for colposcopy is required, and must be accompanied by LBC results. MSAC did not support HPV and LBC co-testing.

New Zealand is currently undertaking some modelling work with the University of New South Wales in relation to primary HPV screening for women aged 25–69 years. Results should be available in late 2015.

#### **Under-screened strategy**

There was strong evidence that self-collected HPV tests for under-screened or never-screened women would be feasible and effective for supplementing an organised screening programme that uses clinician-collected samples and examination of the cervix. Facilitation by or on behalf of a medical practitioner who also offers mainstream testing is important to provide appropriate counselling and interpretation, a safe environment for collection, timely sending of samples to a pathology laboratory and follow-up when required. Women who test positive for HPV would need to return to the clinician to obtain a new sample for LBC triage.

MSAC supported the self-collection of an HPV sample, for an under-screened or neverscreened woman, which has been facilitated by a medical or nurse practitioner (or on behalf of a medical practitioner) who also offers mainstream cervical screening.

The information above has been obtained from the Australian Government Medical Services Advisory Committee's Outcomes Report on Application No. 1276 – Renewal of the National Cervical Screening Program. Further detail on the MSAC recommendations may be found at: www.msac.gov.au.

In summary, the following points outline the key recommendations for the 'renewed' cervical screening programme, which will commence in Australia from May 2017:

- Five-yearly cervical screening should be conducted using an HPV test with partial HPV genotyping and reflex LBC triage, for HPV vaccinated and unvaccinated women aged 25–69 years, with exit testing of women aged 70–74 years.
- Self-collection of an HPV sample, for an under-screened or never-screened woman, should be facilitated by a medical or nurse practitioner (or on behalf of a medical practitioner) who also offers mainstream cervical screening.
- Invitations and reminders should be sent to women aged 25–69 years, and exit letters sent to women aged 70–74 years, to ensure the effectiveness of the programme.
- An HPV test every five years is more effective than, and just as safe as, screening with a Pap test every two years.
- An HPV test every five years can save more lives and women would need fewer tests than in the current two-yearly Pap test programme.
- HPV-vaccinated women would still require cervical screening as the HPV vaccine does not protect against all the types of HPV that cause cervical cancer.
- The recommendation to commence cervical screening at 25 years of age is based on evidence that shows:
  - cervical cancer in young women is rare
  - screening women younger than 25 years of age has not changed the number of cases of cervical cancer or deaths from cervical cancer in this age group
  - commencing screening at 25 years of age would prevent investigation and overtreatment of common cervical abnormalities in young women that usually resolve spontaneously
  - HPV vaccination has already been shown to reduce cervical abnormalities among women younger than 25 years and will continue to reduce the risk of cervical abnormalities in this age group.

Over the next two years, until the 'renewed' screening programme is implemented in Australia, the Steering Committee for the Renewal Implementation Project will be overseeing the development of the revised screening pathways and programme redesign. This will include the establishment of a new Cervical Screening Register, which will issue invitations and reminders to all eligible women in the target age group, as well as receiving screening test results, HPV immunisation status and colposcopy

reports (± histology). Negotiations are also underway for the approval of the HPV test/s with partial genotyping that will ensure the sensitivity and specificity required for the programme to achieve the predicted improvements in cervical cancer prevention.

With many countries moving to modify their cervical screening programmes, New Zealand with the advantage of having transitioned to liquid based cytology, is also in a position to consider primary HPV screening in combination with its existing HPV Immunisation Programme. The following are potential benefits to New Zealand women:

- The screening interval is longer without any loss of benefit. The low long-term risk of CIN3+ among women who tested negative in HPV screening supports an HPV screening interval of five years compared with the current three years.
- Commencement of screening from 25 years of age, rather than from 21 years as
  under the current system, will realise benefits for the health system as a whole, as
  well as for young women, who could be considered to be 'over-treated' in the current
  regime, with resultant morbidity effects such as incompetent cervices.
- Women gain psychosocial benefits with this new screening paradigm.
- International evidence suggests a primary HPV screening protocol is more costeffective and can realise savings for the NCSP relative to the current regime.

# **Key issues**

- The current three-dose coverage level in girls aged 12–13 years in New Zealand is 48–56%. The coverage is higher among the Māori and Pacific population. Efforts are needed to increase this coverage to levels achieved in countries like Australia and the United Kingdom.
  - As part of New Zealand's progress towards assessing the feasibility of implementing a new screening regime, it will be vital to have strong collaboration, communication, partnerships and change management processes with stakeholders from across government departments (including immunisation stakeholders), screening providers, District Health Board representatives, laboratories, colposcopists and consumers to enable the successful development and implementation of a revised screening programme. A key partner in the development of the best model of care for the New Zealand Cervical Screening Programme should be the National Health Committee.
- Linkage with the National Immunisation Register and/or the ability to accurately record women's HPV vaccination status with the screening history are essential for the New Zealand Government to be able to determine whether HPV immunisation is achieving its objectives, and to monitor the effectiveness and cost-effectiveness of the HPV Immunisation Programme.
  - According to NCSP Monitoring Report Number 40 (NSU 2014b), among women aged 30 years or older with valid HPV triage test results, the proportion who were positive for high-risk HPV was 26.4% for women with ASC-US results, and 60.1% for women with LSIL results. There is a need to see if there is any benefit in continuing HPV triage in women with LSIL results, if more than 60% of women with LSIL results are positive for HPV.

- There were 5,904 (29.4%) HPV tests that did not fit into any of the described categories (NSU 2014b), situations that warrant HPV testing. Appropriate use of HPV tests need to be monitored to educate clinicians.
- There is strong evidence that self-collected HPV tests for under-screened or never-screened women would be feasible and effective for supplementing an organised screening programme that uses clinician-collected samples and examination of the cervix.

# **HPV** summary

The New Zealand Government needs to be confident that the New Zealand Cervical Screening Programme is delivering maximum benefit for New Zealand women in reducing morbidity and mortality attributable to cervical cancer. It needs to be confident that the programme design and delivery are comparable with international best practice, and are effective, cost-effective and efficient in achieving the programme's objectives and in view of the Government's investment in the initiative.

Internationally, clinical evidence has shown convincingly that primary HPV testing can deliver greater gains in reducing morbidity and mortality from cervical cancer, and national screening programmes are transitioning to new testing regimes and follow-up protocols. New Zealand must give priority to reviewing the evidence and developing recommendations to transition to a primary HPV screening protocol that will deliver a more effective and efficient programme for the investment.

The assessment and future recommendations must include a strategy for ensuring every woman's HPV vaccination status is captured as part of her screening history. This may be achieved through data linkage with the HPV Immunisation Register, or through an alternative methodology for direct capture of the woman's HPV vaccination status.

# Recommendations

- 45. New Zealand must give priority to reviewing international evidence and developing a process for the introduction and implementation of a revised contemporary bestpractice 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 employing primary HPV screening with partial HPV genotyping will result in the greatest reductions in incidence and mortality from cervical cancer.
- 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.

- 47. Within the existing programme, the benefits of HPV triage for LSIL cytology should be reviewed.
- 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 improve practice.
- 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 link data with the National Immunisation Register.<sup>54</sup>
- 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.

<sup>&</sup>lt;sup>54</sup> See also recommendation 36.

# Chapter 12: Future directions for the National Cervical Screening Programme

# **Technology**

# Molecular markers for cervical screening

Human papillomavirus (HPV) testing is available based on a number of technologies. The technology for which most clinical evidence is available is Qiagen's Hybrid Capture®. Research has shown that testing based on the Hybrid Capture® technology is capable of specifically detecting the most important carcinogenic HPV types: 16, 18 and 45 (Thai et al 2009).

Other HPV testing platforms include the COBAS 4800 technology (Roche Molecular Systems Inc, Pleasanton, California, USA) and the Abbott RealTime PCR (Abbot Molecular Inc, Des Plaines, Illinois, USA).

The United States-based ATHENA trial of COBAS 4800 technology among HPV positive women has found that in women who had colposcopy, the COBAS HPV test was more sensitive than liquid-based cytology for detection of CIN3 or worse; 92.0% (95% CI 88.1–94.6) versus 53.3% (95% CI 47.4–59.1), a difference of 38.7% (95% CI 31.9–45.5; p < 0.0001) (Castle et al 2011). The authors conclude that HPV testing with separate HPV16 and HPV18 detection could provide an alternative, more sensitive and efficient strategy for cervical cancer screening than methods based solely on cytology.

The Abbott RealTime PCR high-risk HPV (hrHPV) test is also highly sensitive for detection of high-grade cervical disease and cancer. One study using this test to determine its clinical sensitivity showed that this test detected 97.2% of CIN3 specimens and 98.5% of cancer specimens (Tang et al 2009).

One project, which the National Cervical Screening Programme (NCSP) has recently endorsed, is being undertaken in the Auckland region to align with testing technologies being used in Australia. Conducted in collaboration with the Victorian cytology service and the University of New South Wales, the study is evaluating whether testing for certain types of HPV is a more effective cervical cancer screening test than the Pap smear test. In Australia, this is known as the Compass study, a three-armed randomised controlled trial of image-read cytology screening versus primary HPV deoxyribonucleic acid (DNA) testing in Australian women aged 25–64 years (Canfell et al 2014). This project in Auckland has completed the recruitment of 500 participants (aged 25–64 years) who presented for routine cervical smears from local practices. The women were randomised to three study arms, two of which will use HPV screening as the primary screening test and either HPV 16/18 or dual stained cytology with p16/Ki67 as management options. The next phase is qualitative focus group activity plus analysis of study data. The results will be pooled with Australian data as well as being analysed separately.

Few HPV tests are approved for clinical use and it is important that clinicians understand which test can be utilised, in what circumstances, with which specimens, and the meaning of the report issued. An overview of HPV tests is available in Appendix J (Cubie and Cuschieri 2013).

# Management of screened abnormalities

Two adjunctive colposcopy technologies for examination of the uterine cervix were recently examined by the National Institute for Health and Care Excellence (NICE 2012). The systems evaluated were DySIS (DySIS Medical) and the Niris Imaging System (Imalux Corporation).

DySIS comprises a digital video colposcope and dynamic spectral imaging (DSI) technology that are used in combination with each other during clinical examination. This technology evaluates the blanching effect of applying acetic acid to the epithelium (acetowhitening). It produces a quantitative measurement of the rate, extent and duration of the acetowhitening. The dynamic map (DySISmap) produced can be overlaid on a colour image of the tissue to help the clinician determine the presence and grade of any lesion.

The Niris Imaging System uses optical coherence tomography as an adjunct to a standard colposcope. It is a non-invasive device, designed to aid in the detection and diagnosis of early-stage disease. It is used for guidance of biopsy and surgery, and in post-treatment surveillance in various clinical applications, one of which is as an adjunct to colposcopy. It uses optical coherence tomography, with near-infrared light to produce real-time, high-resolution, cross-sectional imaging of tissue microstructure.

The aim of the NICE evaluation was to determine whether using adjunctive colposcopy technologies such as these is cost-effective and whether the health outcomes and quality of life in women referred for colposcopy are improved, compared with the outcomes when using conventional colposcopy.

Soutter et al (2009) found DySIS is more sensitive than colposcopy in detecting high-grade lesions and can provide improved guidance for biopsy. A further study by Louwers et al (2011) found that the sensitivity of DSI colposcopy to identify women with high-grade (CIN2+) lesions was 79% (95%CI 70–88%) and the sensitivity of conventional colposcopy was 55% (95%CI 44–65%) (p = 0.0006, asymptotic McNemar test). When the DSI colour-coded map was combined with conventional colposcopy, the sensitivity was 88% (95%CI 82–95%).

NICE concluded that the modelling of DySIS colposcopy showed that it is robustly costeffective (possibly even cost saving) compared with conventional colposcopy. However, no reliable estimates of the sensitivity and specificity of the Niris Imaging System for CIN 2+ were identified in the assessment, and a full economic analysis was therefore not possible. NICE has also developed a Medtech Innovation Briefing on ZedScan as an adjunct to colposcopy in women with suspected cervical intraepithelial neoplasia (NICE 2015). ZedScan uses electrical impedance spectroscopy (EIS) to detect pre-cancerous and cancerous cells in the cervix of women who have suspected cervical intraepithelial neoplasia. It is a diagnostic tool intended as an adjunct to colposcopy in women who are referred for colposcopy by the National Health Service's Cervical Screening Programme in the United Kingdom because of an abnormal cervical cytology result. A study by Tidy et al (2013) indicates EIS used as an adjunct to colposcopy improves colposcopic performance. The addition of EIS could lead to more appropriate patient management with lower intervention rates. The use of the ZedScan is not currently planned for any NICE guidance programme.

# Other adjunct technologies

Spectroscopy is a non-invasive method in which light or electric current is used to study the biochemical composition as well as the metabolic and structural features of tissue. Components of the electromagnetic spectrum relevant to diagnostic spectroscopy include the ultraviolet A range (315–400 nm), the visible light range (400–700 nm) and the near infrared range (700–900 nm). When light strikes tissue, it will be absorbed with or without re-emission of the light or it is scattered by (sub)surface interactions (Parker 2005).

In 1999 Mitchell et al presented a review concluding that fluorescence spectroscopy performs better than colposcopy and other techniques, including cervicography, speculoscopy, cytology and HPV testing (Mitchell et al 1999).

A comprehensive review by Louwers et al (2009) indicated some larger trials performed in the field of spectroscopy have demonstrated relatively high sensitivities in the diagnosis of squamous intraepithelial lesions. The authors believe that of all currently available objective-data-producing alternatives or adjuncts to colposcopy, spectroscopy has the potential to emerge as the technique of choice and that one day it might become incorporated into routine clinical practice.

A summary of the various modalities of spectroscopy and their efficacy has been adapted from Louwers et al's publication (Tan and Wrede 2011), as shown in Table 12.1.

Table 12.1: Description of various modalities of spectroscopy

Modalities of	Features	Sensitivity (%)	Specificity (%)	References
spectroscopy	Use of light to study the features of the tissue  Low-grade vs high-grade vs high-grad		high-grade CIN	
Multimodal hyper-spectral imaging	Fluorescence and reflectance spectra from the cervix in vivo	95	55–83	Ferris et al 2001 DeSantis et al 2007
LUMA	Combination of fluorescence, white light back scattered spectroscopy and video imaging	92	50	Huh et al 2004
DySIS	Measures spectroscopically the acetowhitening effect	79 88*	76 -	Soutter et al 2009 Louwers et al 2011
Trimodal	Combination of fluorescence, diffuse reflectance and light scattering spectroscopy	92**	71**	Georgakoudi et al 2002
Impedance	Impedance spectrum is measured through a contact probe that uses electrical current	74	53	Abdul et al 2006
Truscreen®	A probe in contact with the cervix collects spectrometric data	70	-	Singer et al 2003

#### Note:

- DySIS + conventional colposcopy
- \*\* Normal versus abnormal cervix

Source: Adapted from Louwers et al (2011)

# **Summary**

New technologies are being evaluated continuously, and the NCSP will need to keep abreast of these ongoing developments.

#### Research

The NCSP has an ethical obligation to ensure the National Cervical Screening Programme is meeting its aims and objectives. Research is an important discipline and screening programmes should be involved in ongoing research to support the quality improvement culture. Research and evaluation activities within the NCSP include:

- cost-effectiveness and cost-benefit evaluations
- · feasibility studies
- · outcome studies and evaluations
- programme evaluations.

Areas outside the scope of the research strategy include auditing and monitoring, literature reviews and policy development based on scientific literature. However, the results from the six-monthly monitoring reports and annual reports do form the basis of evaluation and help to inform research endeavours.

The NCSP, as a centre of excellence, strives to meet international obligations by publishing work that has international relevance. The research needs of the existing programme are prioritised and outcome-based research that focuses on ensuring equity and informed consent is promoted. A fair and transparent process ensures researchers can access screening data.

Research that is underway, or proposed, is reviewed on a quarterly basis by the NCSP. An internal clinical group prioritises research, accesses requests for data, identifies areas in which NCSP should publish and reviews the literature. The NCSP has a relationship with the Health Research Council in New Zealand, which also helps to inform funding decisions. In addition, annual meetings between the NCSP and the research community help to identify areas that would benefit from research.

# Current research on cervical screening and management of screened abnormalities in New Zealand

One recently published study looked at type-specific oncogenic human papillomavirus infection in high-grade cervical disease in New Zealand (Simonella et al 2013). Women on the National Cervical Screening Programme-Register (NCSP-R), aged 20–69 years between August 2009 and February 2011 with a cytology record of ASC-H/HSIL+/AGC/AIS, were invited to participate in the study. A total of 594 women were recruited; of these, 356 (60%) had confirmed CIN2/3 and 6 (1%) had confirmed AIS or glandular dysplasia. The most commonly reported HPV types in women with CIN 2/3 were 16 (51%), 52 (19%), 31 (17%), 33 (13%) and 18 (12%). A trend for higher rates of HPV 16/18 infection compared with other oncogenic types was observed in younger women (p = 0.0006). The prevalence of HPV 16/18 in New Zealand was comparable with that observed in Australia and Europe.

A further study, which is still in progress, is the PRINCess study. This is a prospective multicentre trial of conservative management of CIN2 among women who are under 25 years of age (Simcock and Sykes 2014). The objective of this trial is to provide clinically relevant information on the practicality of conservative management of CIN2. The safety of observational conservative management will be evaluated and clinical and biological markers predictive of outcome will be identified. The trial is being undertaken in large colposcopy centres in New Zealand and Australia; patients are being monitored by the local centre, with data collated and analysed centrally at the University of Otago's Department of Obstetrics and Gynaecology in Christchurch.

Further, two projects have been commissioned by the New Zealand Ministry of Health that will inform future policy change to primary HPV screening. The work is being undertaken by an expert modelling team based at the University of New South Wales, who are part of a wider research group led by Associate Professor Karen Canfell. See 'Molecular markers for cervical screening' above for more detail.

# Screening

Over the last 40 years, the implementation of organised cervical screening programmes using conventional Pap smear cytology screening has delivered significant reductions in the burden of cervical cancer across western countries. New Zealand has been one of the more successful countries in reducing the incidence of and mortality from cervical cancer. Between 1996 and 2012 cervical cancer incidence declined from 10.5 to 6.2 per 100,000 for women of all ethnicities. Between 1998 and 2010 cervical cancer mortality declined from 3.2 to 1.7 per 100,000 women of all ethnicities (NSU 2014a).

The New Zealand mortality rates from cervical cancer are lower than those in the United Kingdom (3 deaths per 100,000 women in 2010), and USA (approximately 2.4 deaths per 100,000 women in 2010). New Zealand and Australia have the lowest rates of cervical cancer incidence in the world (Cancer Research UK 2014).

However, cervical cancer is a largely preventable disease, and it is the responsibility of governments and health experts to ensure that any screening programme is able to achieve maximum benefits, in accordance with contemporary evidence, for the population it serves.

# **HPV** vaccination and screening

Much has been learned about the natural history of cervical cancer and its causative factors over recent years. This knowledge has led to the implementation of HPV immunisation programmes across most of the western world, as well as in many second and third world countries, over the last 10 years in efforts to prevent the development of cervical cancer from the main causative HPV strains. There is also high-level evidence of the benefits of different screening methodologies (including HPV primary screening) that will deliver even better outcomes than the current Pap-smear-based programmes.

The World Health Organization (WHO), in its report *Comprehensive Cervical Cancer Control: A guide to essential practice* (WHO 2014), states that new technological developments offer the potential to tackle cervical cancer in a more comprehensive way and build a healthier future for girls and women. As HPV vaccination programmes target girls between the ages of 9 and 13, before they become sexually active, there is the opportunity to launch a life-course approach to cervical cancer prevention and control, starting from childhood and continuing through adulthood.

Essential information for future screening directions will come from the ability to identify and record both vaccinated and unvaccinated women as they are screened. This information will enable appropriate monitoring, so it is possible to confirm whether the decreases in high-grade abnormalities continue as expected subsequent to the introduction of the HPV Immunisation Programme.

WHO states that it will monitor how many countries change their national screening guidelines based on the publication of the new (2014) WHO guidelines. It anticipates that in approximately five years after the publication of the 2014 recommendations, sufficient new evidence will be available to update these guidelines and potentially add new ones.

Internationally, some countries have already moved to guidelines that recommend, or are in the planning stages for, the implementation of HPV primary screening. Commencement age and screening intervals vary across countries. The new Netherlands screening programme will have a commencement age of 30 years and screen women for hrHPV to the age of 60 years at five-yearly intervals (Meijer 2015). The Australian programme will change to become an invitation and recall process commencing at the age of 25 years, with exit between the ages of 70–74 years, and screening at five-yearly intervals.

In a United States study of more than one million women (Gage et al 2014), the estimated cervical cancer risks among women who tested HPV-negative alone, Pap-negative alone and co-test-negative were compared with the risk estimates of Pap testing every three years and co-testing every five years.

The researchers found that the risk of developing cervical cancer within three years following a negative HPV test result was about half of the already low risk following a negative Pap test. Cervical cancer risk within three years of a negative HPV test was similar to the risk of developing cancer within five years following a negative co-test. The researchers estimated that the following number of women would go on to develop cervical cancer after a negative test:

- Pap-negative: 20 per 100,000 women over three years
- HPV-negative: 11 per 100,000 women over three years
- co-test-negative: 14 per 100,000 women over five years.

# Self-testing

Some countries are also considering the benefits and merits of primary HPV self-testing. The Australian Medical Services Advisory Committee report (MSAC 2014) found that the acceptability of a screening test for people having the test should be considered (issues such as convenience, ease of use, discomfort, embarrassment, cost and real and perceived risks) and that another important consideration should be equity of access to the test regardless of rurality, ethnicity, socio-economic status or disadvantage status. The report found strong evidence that self-collected HPV tests for under-screened or never-screened women would be feasible and effective for supplementing an organised screening programme that uses clinician-collected samples and examination of the cervix. The Netherlands is also implementing a self-testing alternative for unscreened or under-screened women (Meijer 2015).

Although not specifically discussed or considered in any published documents to date, it is a subject of more general discussion and highly conceivable that the future directions for cervical screening could move towards a primary HPV self-test for all women. Those found to have a positive test would then be advised to attend their health care provider for a clinician-administered follow-up test. This pathway could realise benefits for both women and the health system.

# **Urine testing**

One recent study combined the results of 14 clinical trials of urine testing and compared the results with those from the cervical HPV DNA test (Pathak et al 2014). Urine tests correctly identified 87 per cent of HPV positive samples and 94 per cent of negative samples. A *New Scientist* report on the research suggests that, as cervical HPV DNA testing is already known to be more sensitive than microscope-based methods, it may be that the urinary HPV test is as good as a cytology sample (Geddes 2014). However, there are no other studies at this time that might support this early research.

### **Genetics**

In a paper in the WHO *Bulletin*, 'Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years', authors Andermann et al (2008) note that governments are faced with the difficult task of managing the use of new genetic information and technologies while balancing the many different perspectives and needs of society. With the recent sequencing of the entire human genome, genetic screening is being proposed as a major vehicle for translating genetic and genomic advances into population health gains. However, what is technologically possible is creating pressure to introduce or expand screening programmes, often before adequate safeguards and regulatory frameworks are in place. Even beyond the field of genetics and genomics, there is a growing understanding that population-level policy decisions should be based both on high-quality evidence and on the values of the population, as well as contextual considerations.

# Management

# The screening pathway

The NCSP is one of five nationally organised screening programmes in New Zealand, where all activities along the screening pathway are planned, coordinated, monitored and evaluated. The National Screening Unit (NSU) is the coordination centre responsible for managing the country's national screening programmes, including the NCSP. The NCSP is responsible for delivering the programme. The vision of the NSU is for high-quality, equitable and accessible national screening programmes. Planning over the past five years has included a range of specifically focused strategies and actions to achieve this vision (NSU 2010).

The National Cervical Screening Programme Strategic Plan 2009–2014 identified a key management issue of the NCSP and, therefore, a remaining challenge for the National Screening Unit. Namely, the work ahead must focus on reducing the disproportionate number of Māori women developing and/or dying from cervical cancers (NCSP 2009).

In the context of screening, equity requires that all people within the target population have a fair opportunity to participate in the programme. The NCSP identifies four groups in the target population as requiring equitable access to quality services: Māori, Pacific, Asian and European/Others. Screening providers have a responsibility to ensure that all barriers to screening are minimised for participants.

Since its establishment, the NSU has demonstrated its management contributions to health outcomes for New Zealanders (NSU 2010) through a cervical screening focus for:

- increasing the coverage of cancer screening programmes
- implementing the new NCSP-R, which has centralised data entry, includes colposcopy reporting and provides online access for stakeholders
- implementing the new NCSP *Guidelines for Cervical Screening in New Zealand* (NSU 2008), including HPV testing and liquid-based cytology technology
- establishing quality and performance management systems
- raising awareness of screening through a range of health promotion initiatives
- implementing a number of workforce initiatives, including development of training for smear takers and cytology laboratories.

In the United Kingdom and elsewhere in Europe, findings on and experiences of the lower socio-economic population groups are similar to those for the priority groups of the NCSP in New Zealand, in that awareness and uptake of health services has shown a range of harder-to-reach groups have unmet need relating to information, support and cancer services. There is evidence of inequalities at each stage of the patient pathway, from information provision through to palliative care.

In the United Kingdom, appropriate and targeted service provision has been shown to be central to the reduction of cancer inequalities (Gordon-Dseagu 2006). It is, therefore, essential to provide information and support that effectively meet the needs of harder-to-reach groups.

Baker and Middleton (2003) found reduced uptake of cervical screening among lower socio-economic groups and those living in deprived areas in England from 1991 to 1999. Target levels of 80% uptake were reached by a higher proportion of providers in wealthy areas than providers in deprived areas.

A study in Belgium (Lorant et al 2002) found that women from lower socio-economic groups were less likely to have had a test for cervical cancer. Reasons for these differing uptake rates were felt to be related to:

- cost (financial and psychological)
- beliefs (attitudes of both patients and physicians)
- · behaviours (support and information seeking).

It is important that screening programmes are not exacerbating health inequalities by being less accessible to groups with poorer health status while at the same time depriving those groups of resources for other services that would improve their health. In practice, a service can be judged to be equitable when people are treated in as fair a manner as possible by ignoring irrelevant differences between them, but taking into account relevant differences (Cabell et al 1992). In New Zealand there is a diverse range of cultural groups, and cultural factors can be relevant differences. Thus a screening programme needs to operate from a cultural context that makes sense to participants (Te Manawa Hauora 1993).

Māori and Pacific populations have poorer health outcomes for breast and cervical cancer. These outcomes result from both under-screening of the population and higher mortality statistics for these particular diseases within these populations. Inconsistent practice and variable access to some screening activities reduce the efficacy of national screening programmes. Finding ways to realise Māori and Pacific potential to help improve screening outcomes will be key in addressing these inequities (NSU 2010).

# **Current and future challenges**

To maximise value for money and to ensure the maximum benefits from screening accrue to the populations served, the NSU must recognise there are expectations of an increasing range of patient-centric and tailored services and treatments, and that efficient and effective purchase and delivery of screening will be required. The contributions that are essential to achieving the maximum benefits from screening include: reducing cancer incidence, ensuring priority groups have access to the information they need and reducing cancer inequalities (NSU 2010).

## Leadership of screening

The NSU Strategic Plan (NSU 2010) identifies that a whole-of-screening view is needed for the ongoing development of national screening. This would incorporate further infrastructure planning and workforce development, account for screening in the wider sector and population, and have strong clinical governance and leadership at a national level. To support an improved focus on clinical and cultural safety, quality and competent performance, there would also need to be a greater emphasis on cervical screening and health literacy where the onus is on health professionals to remove the barriers to priority groups participating in the programme. The whole-of-screening approach must recognise the complex processes involved along the screening pathway and integrate health literacy practices into strategic and operational planning, service delivery, and leadership and management. These efforts need to ensure priority groups are involved in planning and monitoring the (cervical) screening programme.

As set out in its Strategic Framework to address these challenges while working towards the NSU vision of *high-quality, equitable and accessible national screening programmes*, the NSU plans to focus its work over the next five years on the five strategic objectives shown in Table 12.2 (NSU 2014c).

Table 12.2: Strategic objectives for the NSU

Awareness and access	Information and knowledge	Equitable screening	Sector leadership	Standards and quality
80% coverage for Māori and Pacific women	Research to inform existing and future programmes	No significant variations in: coverage, ethnicity,	A screening workforce that reflects the	Implementing state- of-the-art screening practice and
Key performance indicators for whānau ora in screening	Communicating and sharing data and knowledge effectively with stakeholders	residence Involve Māori, Pacific and Asian peoples in programme	Strong regional coordination that provides leadership	technologies Effective NCSP-R acting as a key monitoring tool

# **NSU: New and future developments**

Recent years have also seen significant developments in cervical cancer prevention. The advent of the cervical cancer vaccine as a primary prevention strategy, as well as new technologies in cytology and high-risk human papillomavirus detection are changing the face of cervical screening by improving efficiency and effectiveness as well as our ability to categorise each woman's risk. The programme will continue to refine existing services as well as to adapt to incorporate the benefits of newer technologies to improve cost-effectiveness and further reduce the burden of cervical cancer for New Zealand women (NSU 2009e).

# Glossary of terms and abbreviations

AHB	Area Health Board
AGC	Atypical glandular cells
AIS	Adenocarcinoma-in-situ
ASCCP	Australian Society for Colposcopy and Cervical Pathology
ASC-H	Atypical squamous cells, cannot rule out high-grade squamous intraepithelial lesion
ASC-US	Atypical squamous cells of unknown significance
Asian	The definition of 'Asian' by Statistics New Zealand 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
BSA	BreastScreen Aotearoa
CAR	Corrective Action Request
Cervical Cancer Audit	Cervical Cancer Audit Report: Screening of Women with Cervical Cancer, 2000–2002 was published, with 31 recommendations, in November 2004.
CI	Confidence interval
CIN	Cervical intraepithelial neoplasia
CSI	Cancer Screening Inquiry. The Ministerial Inquiry into the Under-reporting of Cervical Smear Abnormalities in the Gisborne Region (2000-01), known as the 'Cervical Screening Inquiry' (CSI), released its report containing 46 recommendations in 2001.
C-QuIP	Colposcopy Quality Improvement Program
DALY	disability-adjusted life year
DHB	District Health Board
DNA	Deoxyribonucleic acid
DSI	Dynamic spectral imaging
e-colposcopy	The electronic transfer of colposcopy data to the NCSP-Register
EIS	Electrical impedance spectroscopy
FDA	Food and Drug Administration
GP	general practitioner
HDC	Health and Disability Commissioner
HGA	High-grade cervical abnormalities
HPCA Act	Health Practitioners Competence Assurance Act 2003
HPV	Human papillomavirus
hrHPV	High-risk HPV
HSIL	High-grade squamous intraepithelial lesions
HWNZ	Health Workforce New Zealand
IANZ	International Accreditation New Zealand
IARC	International Agency for Research on Cancer
Ibid	(Latin, short for ibidem, meaning the same place) In a footnote or endnote, means the same source as the one cited in the preceding footnote or endnote.
ISP	Independent service provider
IT	Information technology
LBC	Liquid-based cytology
	•

LGA	Low-grade abnormalities
LSIL	Low-grade squamous intraepithelial lesions
MMEG	Māori Monitoring and Equity Group
NCSP	National Cervical Screening Programme. The national programme for cervical screening in the National Screening Unit
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
NHB	National Health Board. The national services, purchasing and strategic planning division of the Ministry of Health
NHC	National Health Committee
NICE	National Institute for Health and Care Excellence
NKG	National Kaitiaki Group
NSU	National Screening Unit. The national unit for all cancer screening programmes within the Ministry of Health
NZHIS	New Zealand Health Information Services
NZPHS	New Zealand Post Health Services
OAG	Office of the Auditor General. The first review was undertaken in October 2001 on progress to implement the CSI recommendations, and the report was released in February 2002. The second follow-up review on progress to implement Dr McGoogan's recommendations, and the second report with 10 recommendations, were released in December 2003.
OECD	Organisation for Economic Co-operation and Development
PDCA cycle	Plan-Do-Check-Act cycle
PHO	Primary health organisation
PRC	Parliamentary Review Committee. The parliamentary or ministerial review committee established under Part 4A section 112O of the Health Act 1956
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
WHO	World Health Organization

# Glossary of Māori words and sayings

Hauora Māori providers	Māori health (service) providers
Kaimahi	Health worker or helper
Wahine	Woman
Whakapapa	The recitation of genealogies or stories which create a base or foundation of meaning for people.
whānau ora	Family health and wellbeing. Also the name of the national Māori health strategy, Whānau Ora, led by the Associate Minister of Health from 2010 to 2014 to address health, social, cultural and economic disparities between Māori and non-Māori in New Zealand. It complements the Ministry of Health's Māori Health Strategy, He Korowai Oranga, which also has whānau ora as its conceptual basis
whānau ora collectives	Groupings of whānau or family health and wellbeing service providers (usually a combination of Hauora Māori providers who also deliver a mix of social, educational, media, housing, justice services etc)

# **Appendix A: Timeline of significant events for the National Screening Unit and the NCSP**

1988	The Cartwright Inquiry (Cervical Cancer Inquiry at National Women's Hospital) recommends the National Cervical Screening Programme (NCSP) be established. Prior to this, there was only ad hoc cervical screening in New Zealand (Cartwright 1988).
1988	The NCSP is established in 14 Area Health Boards (AHBs). The Department of Health provides guidance and support.
1991	The National Cervical Screening Programme-Register (NCSP-R) is introduced into 14 AHBs.
1993	The NCSP is divided between the Ministry of Health, Public Health Commission and the purchasing units of four Regional Health Authorities (RHAs).
1994	The NCSP-R operates out of 14 AHBs, which input data.
1996–1997	The NCSP-R is reconfigured to a national database, but operations remain in AHBs.
1997	The NCSP (including the Register) is moved into the Health Funding Authority (HFA), which replaces the four RHAs.
1998	NCSP national coordination role is transferred from HFA to Auckland, Public Health Directorate.
1998	The NCSP-R team is located in Information Directorate in HFA.
October 1999	The Gisborne Inquiry into Under-reporting of Cervical Smear Abnormalities in the Gisborne Region is established.
July 2000	The National Screening Unit (NSU) is established in the Ministry of Health as a separate unit with a Clinical Director and a Group Manager. The Clinical Director reports to the Group Manager – at Tier 3.
April 2001	The Gisborne Inquiry report is published (Duffy et al 2001).
December 2001	Dr Euphemia McGoogan reports on progress in implementing the CSI recommendations and makes further recommendations on clinical improvements. She noted a serious risk of clinical exclusion from decisions and of clinical input being sidelined (McGoogan 2001).
2002	The Office of Auditor General (OAG) reports on action undertaken to implement the Cervical Screening Inquiry's 46 recommendations (OAG 2002).
June 2003	Dr McGoogan produces a second report on progress in implementing the CSI recommendations and makes further recommendations (McGoogan 2003).
2002	In an NSU structural review, the Clinical Director position is disestablished following the incumbent's resignation. Under the restructure there are three Clinical Leaders, for breast and cervical screening and public health. The Clinical Leaders for breast and cervical screening report to the Group Manager. The public health leader reports to the Director of Public Health, with dotted line reporting to the Group Manager.
2002	The new Health Bill is developed to address safety and effectiveness of the NCSP. This subsequently becomes the Health (National Cervical Screening Programme) Amendment Act 2004.
2002	Data input to the NCSP-R is reduced from 14 to 6 District Health Boards (DHBs).
2002–2003	Further NSU structural changes are made. The QMAA (a separate quality group in the NSU) is disestablished and its quality functions are incorporated within NCSP and BreastScreen Aotearoa (BSA) teams.
Dec 2003	The OAG publishes a second report, which includes a review of CSI and makes 126 other recommendations.
July 2004	The Health (National Cervical Screening Programme) Amendment Act 2004: section 112C comes into force 1 July 2004. The rest of the Act comes into force 12 months later.
November 2004	The Cervical Cancer Audit Report, on screening of women with cervical cancer from 2000 to 2002, is published (Cervical Cancer Audit and University of Auckland 2004).
July 2005	The Bethesda 2001 coding system is integrated into the NCSP-R.
2006	Redevelopment of new NCSP-R begins.

May 2006	The Health and Disability Commissioner report reviews colposcopy services at Waitemata DHB (NSU 2006).
2006	A review and audits of all DHB colposcopy services take place.
2007	In further Ministry restructuring, the NSU moves to the Health and Disability National Services Directorate.
2007–2008	A further NSU restructure aimed at "strengthening foundations" takes place. New screening initiatives (antenatal and newborn) are coordinated. A separate Quality and Equity team is reestablished in NSU. The NSU also reintegrates with the Ministry, but retains direct purchasing of services.
July 2008	The NCSP-R is centralised in the Ministry of Health. A new Register Central team is formed. All data input is central, with 13 regional Register services.
September 2008	The newly developed NCSP-R is implemented with the <i>Guidelines for Cervical Screening in New Zealand</i> (NSU 2008).
2008–2009	A Ministerial review of the health system is undertaken, resulting in the Ministerial Review Group's Report, also known as <i>The Horn Report</i> (Ministry of Health 2009).
2009–2010	The Ministry of Health is restructured. A National Health Board (NHB) is established in the Ministry of Health. The NSU is under the National Services Purchasing of the NHB. Some NSU positions are affected. The Māori Advisor role is moved from the NSU to the Māori Health Directorate.
2009	A further NSU restructure takes place following the appointment of a new Group Manager. As a result:
	the 'equity' oversight becomes a Quality team function
	clinical leadership drops to Tier 6
	a Clinical Governance Group for the NSU is established
	the Senior Leadership team becomes the Management team with fewer members. Clinical leaders are not included as clinical input is to be achieved prior to management meetings
	additional performance management analysts are appointed to NCSP and BSA
	some reporting lines change.
September 2009	The NSU Strategy and Policy team, which provides advice on wider screening issues, is moved out of the NSU.
March 2010	Ministry of Health restructuring occurs.
July 2010	NCSP-R is outsourced to DATAM (a New Zealand Post subsidiary with approximately 28 staff).
July 2010	The NCSP-R implements HL7 messaging, so that laboratory results go directly to the Register.
February 2011	Further Ministry of Health restructuring is undertaken. The NHB and NSU are not directly affected.
June 2011	The report of the Parliamentary Review Committee regarding the National Cervical Screening Programme is completed (Tan et al 2011).
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# **Appendix B: Areas for review**

# 1.1 Coverage, participation, equity, access and disease burden

- Coverage and participation by region, age, ethnicity and socio-economic status.
- · Adherence to screening guidelines.
- · Retention rates and loss to follow-up rates.
- Trends in rates and processes related to these measures.
- Work undertaken to improve these measures and impact of these activities.
- Key facilitators and barriers to future improvements.
- Work undertaken (or proposed) by the NSU or its providers to evaluate its activities in these areas.

# 1.2 Quality and monitoring

- Review Independent Monitoring Group reports and other documentations held by NSU or relevant groups in relation to quality across the programme.
- Work undertaken (or proposed) by NSU or its providers to evaluate its activities in these areas.
- New Zealand Cervical Cancer Audit.

## 1.3 Organisational and structural issues

- Structural (ie, National Cervical Screening Programme (NCSP) structure) and infrastructural issues that may impact on the quality of the NCSP and services it delivers.
- Work undertaken (or proposed) by NSU or its providers to evaluate its activities in these areas.
- Role and performance of NCSP Advisory Group.

### 1.4 Workforce issues

- · Current and possible issues for the future.
- NCSP planning and actions around current and future workforce issues.

# 1.5 Ethnicity data – quality, completeness and use

- Includes access to and use of Māori data.
- What work has been done to assess the accuracy and completeness of ethnicity data and to bring about improvements in this data?

# 1.6 NCSP-Register

- · Integrity of data, integration with laboratories.
- Processes for invitation, recall of those overdue for screening and follow-up of those with abnormal results.
- · Access to online screening histories.
- Support to regional services and any possible issues.
- Collection of colposcopy data and any possible issues.

# 1.7 Colposcopy

- Colposcopists (medical) Royal Australian and New Zealand College of Obstetricians and Gynaecologists' Colposcopy Quality Improvement Program (C-QuIP).
- Nurse colposcopists accreditation and practice improvement.

# 1.8 Human papillomavirus (HPV) vaccination

- Impact of HPV immunisation on the NCSP.
- Assess impact from the evaluation of the HPV Immunisation Programme on how well the programme has achieved its goals, objectives and implementation priorities.

# 1.9 HPV screening

- Guidance on using HPV screening by detecting high-risk type HPV.
- Criteria for approving HPV tests that meet World Health Organization International Standards.

# **Future directions**

## Technology

Adjunct technology to improve colposcopy performance.

### Screening

Using HPV screening as primary screening.

## Management

Outcomes on conservative management of screened abnormalities.

#### Research

Future research to be undertaken.

# Appendix C: Individuals, agencies and organisations contacted by the Parliamentary Review Committee

National Cervical Screening Programme (NCSP) Senior Management team

National Screening Unit Senior Management team

NCSP team

National Screening Advisory Committee

Office of the Health and Disability Commissioner

Register Central Team DATAM / New Zealand Post

NCSP Advisory Group

Māori Advisory Group

Māori Monitoring and Equity Group

Pacifica (Pacific Advisory Group)

Women's groups:

- · Women's Health Action Group
- · Federation of Women's Health Councils

Other government groups

· Health and Disability Commissioner Office

Lead pathologist and lead scientists

• Six laboratories reporting cytology and human papillomavirus (HPV) screening

Regional service managers / coordinators

Independent service providers

Pacific providers

Public health representatives/services

Other groups

- Cancer Control Council
- Cancer Control Council (New South Wales monitoring)
- Cancer Society of New Zealand

Research scientist, University of Otago

District Health Board (DHB) lead colposcopists, nurses and managers

Public health physicians

Immunisation and HPV experts

Mainstream primary health organisations

Pacific primary health organisations

Family Planning Association

Extra interviews requested with:

- · Ministry of Health
- University of Otago
- Kaitiaki Group
- Retired individuals
- Waikato DHB
- University of Auckland, Population Health, Māori and Pacific Department
- National Health Committee

# Appendix D: Semi-structured interview guide

(Adapted from Tan et al 2011)

# Review Committee of the New Zealand Cervical Screening Programme 2015

#### 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:

- Dr Jeffrey Tan (Chair)
- Ms Linda Thompson
- Ms Gail Ward.

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 General Practice Colposcopy		

hat do you know about quality improvements that have been e Screening Programme?	n underway wi
hat is your opinion as to the success of these efforts?	
No ease explain your reasons.	
your opinion, what has been the biggest single challenge trogramme faces?	hat the Screeni
your opinion, what has been the most significant accomplist creening Programme?	shment of the
''h'	an overall level, do you believe that the Screening Programuable and high-quality service for New Zealand women?  Yes No ease explain your reasons.

ther issues th	e Review (	Committee	should be awa
n that you wis	sh to share	with the R	eview Commit

please feel free to notify us by contacting:

Dr Jeffrey Tan

## **Appendix E: Parliamentary Review Committee submission form**



## NATIONAL CERVICAL SCREENING PROGRAMME (NCSP) 2014/15 REVIEW

January 2015

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 is an independent body appointed by the Minister of Health, whose 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.

Dr Jeffrey Tan (Australia) has been appointed to chair the committee and the other members are Ms Linda Thompson (New Zealand) and Ms Gail Ward (Australia).

Name
Organisation/Affiliation
As key stakeholders in the Programme, we very much appreciate receiving your input regarding functions of and any issues relating to the NCSP.
Within your area of expertise, we would like to hear your initial response regarding key issues that you think the Review Committee should consider.
Strengths of the NCSP
1.
2.
3.
Weaknesses or challenges in the NCSP
1.
2.
3.
If possible, please submit details of the weaknesses or challenges as attachments.
Please forward to:
Dr Jeffrey Tan
NCSP Review
Further information if required
Are you willing to be contacted by the Review Committee for further information if required?
☐ Yes
□ No
If yes, please supply contact details:
Address:
Phone:
Email:

#### Confidentiality

This form will remain confidential to the Ministry of Health and the 2014 NCSP Parliamentary Review Committee.

#### **Appendix F: Feedback**

Following are some views of participants external to the Ministry of Health, including the advisory groups of the National Screening Unit (NSU) and the National Cervical Screening Programme (NCSP); and staff members from the Ministry of Health. These views come through submissions and Parliamentary Review Committee interviews.

#### **Chapter 1: Introduction and methods**

"In the first instance we would like to comment on the structure of the feedback form. Its format of encouraging three comments only into issues, which have been considerably condensed in the accompanying NATIONAL CERVICAL SCREENING PROGRAMME (NCSP) 2014/15 REVIEW, Areas for review. It does not encourage comprehensive feedback, particularly from consumers, who may believe they are constrained to comment briefly and only on the issues described. Inclusion of the full review would have been more helpful as would an explanation of the roles of the NCSP and the NSU."

#### Chapter 3: Coverage, participation, equity and access

"While we note recent research indicates improved rates of cervical screening amongst Māori and Pacific, there are still significant disparities in screening participation between Māori, Pacific and Asian women compared to the rest of the population. We believe there are still concerns about women being lost to follow-up and that responses to this need to be community specific. We also believe that not enough effort has been made to identify populations or communities, which have low screening participation rates such as new migrant or refugee communities or groups such as lesbian or transgender people or women with disabilities. We agree it is particularly important that the number of smear takers who are attuned to cultural sensitivities and the preferences of diverse groups of women are extremely important."

"Currently the funding for 'free' cervical screens to the DHBs [District Health Boards] is insufficient to cover the additional primary care work to reach unscreened or under-screened women. Whilst the volume of the screens has increased which is a positive move, the funding per screen has not. The DHBs' fund to the PHOs [primary health organisations] per screen needs to be 'topped up' by the DHBs; this is putting pressure on financially constrained DHBs."

"The Ministry of Health should explore options for providing a fully funded screening programme for cervical cancer, as all other national screening programmes are. This would negate the issues of DHBs having to fund the PHOs and would help reduce the disparities that exist in access for women."

#### **Chapter 4: Monitoring and evaluation**

"The monitoring reports that are currently provided by the UNSW [University of New South Wales] Australia has caused concern particularly for Māori. It would be more useful to have a greater scrutiny on the inequalities, similar to the provision and the process used by the BSA [BreastScreen Aotearoa], for the BSA Māori Monitoring Report and including consultation on recommendations for addressing disparities. It is important for Māori to be part of the discussion and to be able, where possible, to take ownership of implementing solutions."

"The monitoring reports lack Māori input. It is important to create a picture so people understand what the issues are and to have more context. More anecdotal commentary rather than just an analysis of the data would be useful."

"I find the 'Cervical Screening Guidelines' and the associated documents 'NCSP Best Practice Guidance on HPV Testing' and 'Guidance on HPV Testing Update 1: April 2010' poorly organised and not integrated, which makes them difficult to use. I consider them in need of review and updating."

#### **Chapter 5: Quality assurance**

"We should be conducting clinical audits of women who do get invasive cervical cancer in New Zealand, not in the hugely expensive way that the last Audit was conducted around 2000, but more as a data-gathering rolling audit of cases as they occur. The numbers are small enough in New Zealand to do this. We would see a lot of the same lessons gleaned from audits overseas (unscreened, under-screened women) but there may be particular issues unique to New Zealand."

#### Chapter 6: Organisational and structural issues

#### Equity issues

"Overall it is obvious in the last three years things haven't moved much. The rates for Māori and Pacific (priority) groups have not made significant change. Participation numbers show complacency (regarding low rates demonstrated in DHB figures).

"This may show that they've lost momentum, leadership, or need a push."

"There needs to be a halt on continuing to do the same thing if it has not made any difference over the last five years. Many of the public health units (within DHBs and PHOs) who have accountability over this area are not doing anything to excite the interests of the priority (women's) communities".

"Māori health units and public health need to work together – take the lead from other successful programmes such as Suicide Prevention and have better engagement of Māori community organisations (eg, the iwi)."

"Very disappointing that the TV adverts are no longer being broadcast, these were impressive and had a great deal of impact."

"Education is important. The TV adverts were a great way of addressing this as they highlighted that it isn't just the woman herself who matters but the whole whānau (whānau ora strategies are needed)."

"Apart from difficulties in accessing services, the other issue is that the priority women do not consider cervical screening a priority in their lives."

#### Risks to the screening programme

"Māori and Pacific are not able to access the programme at the same rates as other ethnicities – this is a risk."

"Introduction of HPV [human papillomavirus] – there is a risk of public confusion if timing and messaging are not well coordinated and aligned with excellent social marketing strategies for instance."

"High turnover of staff in the NSU leads to loss of continuity and experience within the team."

"There has been a loss of identity, networking opportunities with the cessation of regular face to face NCSP Programme Managers meetings. Teleconferences just do not do it. National meetings were not an issue if given at least 6–12 months' advanced notice."

"Within the NCSP there has been a high turnover of staff and this has created difficulties, communications is not very good with regional sites and ISPs [independent service providers] especially for kaimahi. There are regular steering meetings but this is for the high level managers only."

#### Successes at regional level with ISPs and DHBs

"Good communication and encouraging women as well as workers to 'continue on this journey and keep over-delivering'."

"Staff don't give up, they keep looking for women who have moved. Fetch and find – talk to family members, ask where they are."

"Accountability of the DHBs – depends on good people. Where there are good people, there are good service delivery models."

#### Clinical leadership

"Renewed or more effective clinical leadership is essential to drive appropriate changes in the NCSP and to ensure the programme remains in line with current evidence."

"Most importantly the new Clinical Leader needs to drive a significant change with Primary HPV screening – this includes the relevant policy work, sector collaboration across the pathway including priority groups and consumers, communicating with smeartakers and women and working in a transparent (and visible) way across the Ministry and relevant other departments (Imms/NIR [National Immunisation Register] (just getting the NIR permissions to be able to routinely update the NCSP register with accurate HPV vaccination data will require a significant amount of work), HPV vaccination programme, primary care, ISPs, cancer control, women's health, pathology, laboratories etc)."

#### Cervical screening

"We believe that a more diverse range of consumer and women's organisations must be afforded more opportunities to provide both feedback and guidance at all levels of policy development and service provision. Screening is an important and sometimes life saving activity. However, screening programmes must take into account emerging research, consumer concerns, and unintended negative effects as well as consider the important issues of confidentiality and informed consent."

"A one stop shop for BSA and NCSP would be useful. There are barriers to accessing services including difficulties with travel and financial difficulties."

#### Advisory group appraisal

"The NCSP Advisory Group performs a vital role and functions relatively well, for the purposes of reviewing Monitoring Reports and providing a place for professionals to raise issues and receive feedback about developments in the NCSP. The committee largely operates as an Advisory Group ie, members provide advice about issues raised. It is not a powerhouse of clinical leadership."

"A Professional Board which has some relationship to the screening programme, where key people can provide leadership. We can raise things but it doesn't go anywhere particularly."

#### Social marketing programmes

"Having social marketing programmes that make women visible – is highly beneficial."

"Social media and web-based culture should be considered as a means to disseminate information."

"Health promotion and literacy is essential for quality assurance and data access. It is important that the results from programmes are easily accessible to consumers and understandable in layman terms. This is seen as improving engagement. If people trust programmes, they are more likely to be engaged."

#### **Chapter 7: Workforce issues**

#### Addressing disparities for NCSP priority groups, particularly Māori

"Trying to work in a more integrated way with stakeholders such as PHOs is important and encouraging the use of the support to screening services contract so community workers can talk to women and health to overcome barriers."

"In order to engage Māori stakeholders, and put them (strategies) in the community, they seem to work when you have people in strategic places who can make it work for them/you: Cultural competence; How you talk to Māori community; Health literacy – How you break down complicated issues; Cultural understandings."

"There have been many staff leave the NSU which has resulted in a huge loss of knowledge, experience and the relationships that have been built of the years. There has been no Māori portfolio manager for many years and most recently 2013 the Pacific portfolio manager left and neither of these positions has been replaced."

"Important to maintain relationships with ISPs; provide timely information to all providers i.e. ensure data is continually updated and available; support and value the work that ISPs do to contribute to engaging Priority Women (PW) into the screening programme."

"They need to retain the ISP contracts as it is the ISPs who are the only ones who can reach the really hard Priority Women (PW) and engage them into screening. Other services are more restricted."

#### Pacific comments

"Support more Pacific people coming into senior leadership roles, either within the Ministry or in positions; and those who are not Pacific who are in leadership roles, also are aware of the discrepancy in the Pacific population."

"Training around Pacific providers to take smears."

"You can set up strategies and policies, but unless you have the workforce to engage with the people/communities, it doesn't make a difference."

"The Ministry of Health is now aware that the Pacific/Māori audience needs things done differently (equity focus) eg, interaction with key Pacific people."

"For Pacific, get everyone who was involved in any sort of screening, to make sure there was cultural competency delivery. Knowing how to best engage with Pacific."

#### Impacts of primary HPV screening on the laboratory workforce

"Cytology will probably drop by 85% – even if reflex cytology are done for HPV positive tests."

"Fearful of the cytology (workforce) group, not getting graduates taking cytology because they don't see a career in it. The expertise will be 'lost'."

"Cytology: This is a small (workforce) pool of key individuals who make a huge difference."

"Labs are going to close, and where will they be? If you close a whole lab, the best screeners will go."

#### **Training**

"HPV online course is very slow, got to be designed for primary care to be able to do it in their own environment. Designed for their needs."

"We need updated information in primary care – it should be available online. Role of the clinical leader should be to address the education and facilities that are needed for staff. There's no regulation, and if the practice nurse has to pay and do it in her own time, they won't do it."

#### **Chapter 8: NCSP-Register**

"There are long reporting delays on coverage rates which can lead to a loss of confidence and frustration for health professionals when working to increase coverage rates. This applies particularly to PHOs who now have cervical screening as a target in their Integrated Performance Incentive Framework, and are working with DHBs to use data-matched lists to target women for screening invitation and recall. The largest PHOs need these lists monthly."

"Data is not extracted from the NCSP-Register in a timely manner (currently only six-monthly), therefore ongoing monitoring is difficult to achieve."

"Smear takers cannot access the Register electronically, therefore limiting their ability to access current information on the woman's screening history."

"The lack of a population register limits the effectiveness in targeting women who have never been screened or who are not enrolled in primary care. This may be up to 20–30% of women in high-risk groups."

"We are building a data warehouse at the moment, working with the IT Board to look at the cancer IT screening pathway for the future and how this looks. Modelling what this looks like in 2025 and working backwards from that."

"Dubious data quality and lack of response to data requests from DHBs. Ongoing issues with data collection/warehouse ... national data does not compare well with our local data." "There is a wealth of information on the NCSP-Register. It is a huge resource which we are not maximising. If new technologies and new techniques are to be introduced to New Zealand, relatively small nationally directed research projects would be highly useful to determine an appropriate role in the New Zealand context."

#### **Chapter 9: Ethnicity data**

#### NSU and NCSP relationship with the National Kaitiaki Group

"It is frustrating that we have to apply to use the data that we collect for the purposes that we are employed to do, as enabled by section 112 ... [section 112J(h) of the Health Act 1956]."

"It has not been a good relationship ... we have tried to strengthen that relationship. It is getting better. We want to share the information in a way that is helpful and want to ensure that information is open and transparent."

#### Social marketing

"... qualitative research (focus groups and individual interviews) will be planned to understand women's motivations and barriers to participation in screening programmes."

"The only way women will be picked up if they have not been screened is by a community initiative. Some of the ISPs face the complexity of the women they've tried to contact for smears. They've had to sort out other issues; such as domestic violence because it's not until a woman is in a stable situation that a smear is a possibility."

"To increase coverage and improve health literacy for women and their whānau a national proactive campaign needs to be reinstated, with targeted interventions to address disparities among ethnic groups in terms of participation and retention. This could include the use of social media."

#### **Chapter 10: Colposcopy**

"Most of our colposcopists have no trouble maintaining the minimal numbers [colposcopy numbers as per NCSP Standards]."

"I don't think absolute numbers are very reflective on quality, maybe it needs to be considered only when there are concerns in terms of quality??"

"Analyses of colposcopy data to support quality improvement are produced for the department as a whole annually for the annual clinical report.

Individuals can pull their own data if wished."

"Analyses of colposcopy data to support quality improvement could be obtained by audit of Gynae-Plus data – but audit and time to do this has been an issue in our department. We certainly are not provided this info by the NCSP-Register."

"Increasing nursing colposcopies would be good and increasing access."

#### Chapter 11: Human papillomavirus (HPV) and cervical cancer Primary HPV screening

"The introduction of any such programmes must be preceded by information and education for both the public and health professionals. The evidence for such a programme and the support or treatment that can be provided to those testing positive should also be considered. We agree this will have workforce implications and such a programme should not proceed without attention to there being an adequate workforce in place both in laboratories and in health professionals who are trained to give information and support to those being tested and those who test positive."

#### **HPV** immunisation

"I am unsure which agencies are the key stakeholders for implementation of HPV vaccination, but uptake in New Zealand has been disappointing compared to Australia. I have heard all sorts of reasons given why the New Zealand rate is lower than that in Australia, but I wonder if New Zealand agencies are doing enough to learn from successful strategies used in Australia."

# Appendix G: Agreement between the New Zealand Government and Southern Community Laboratories Ltd for Laboratory Training Services

Provider No: 420619 / Contract No: 347182/00. 28.06.2013

#### Section C Service Specification to:

- develop and maintain a well-informed quality workforce for the cervical screening laboratory services
- · provide comprehensive training in four to eight regions to all laboratory sector groups
- · establish an Independent Training Committee
- scope a national laboratory workforce training needs assessment
- · provide an informative annual newsletter
- provide a scholarship fund
- provide training plans for each of the laboratory sector groups
- provide a plan for the HPV screening programme.

Agreement: NZ Govt. and Southern Community Laboratories Ltd. Laboratory Training Services. Provider No: 420619 / Contract No: 347182/00. 30.04.14

#### Section C Service Specification:

C.1.1. To enable histoscientists, molecular scientists and cytoscientists/technicians attend the 2014 New Zealand Institute of Medical Laboratory Science (NZIMLS) annual scientific meeting in Dunedin on 14 August 2014

### **Appendix H: Colposcopy audit status**

#### Corrective Action Request (CAR) status 1 April 2015

District Health Boards	Date final report	Corrective Action Requests			Corrective Action
audited in current round (by audit date)	received	Total	High	CARs closed	Request status
Waitemata	2 June 2011	7	5	7	All CARs cleared
Counties Manukau	13 June 2011	10	2	10	All CARs cleared
Auckland	15 July 2011	4	2	4	All CARs cleared
Waikato	1 August 2011	14	6	14	All CARs cleared
Hutt Valley	9 February 2012	13	6	13	All CARs cleared
Lakes	9 February 2012	18	6	17	All CARs cleared
Bay of Plenty	8 March 2012	13	9	11	All CARs cleared
West Coast	26 March 2012	8	3	8	All CARs cleared
Capital & Coast	26 March 2012	12	6	0	All CARs cleared
Wairarapa	26 March 2012	15	6	15	All CARs cleared
Hawke's Bay	4 July 2012	9	3	9	All CARs cleared
Canterbury	5 July 2012	9	1	9	All CARs cleared
Southern (Southland)	9 July 2012	6	2	5	All CARs cleared
MidCentral	15 November 2012	11	1	11	All CARs cleared
Taranaki	2 November 2012	8	3	8	All CARs cleared
Southern (Otago)	26 November 2012	4	1	4	All CARs cleared
Tairawhiti	5 February 2013	5	2	5	All CARs cleared
Whanganui	7 March 2013	6	1	6	All CARs cleared
Northland	12 June 2013	11	2	5	All CARs cleared
South Canterbury	3 July 2013	10	2	10	All CARs cleared
Nelson Marlborough	29 July 2013	12	9	11	All CARs cleared

## Appendix I: Summary of Standards in Section 6: Providing a Colposcopy Service, of NCSP Policies and Standards

Source: Ministry of Health (2013)

**Standard 603**: One hundred percent of medical notes accurately record colposcopic findings at first and subsequent assessments (as per the data requirements listed in Appendix 2 of Section 6), and these are sent electronically to the National Cervical Screening Programme-Register (NCSP-R).

**Standard 604:** Ninety percent or more of women will have been sent, and/or will have had discussed with them, their definitive diagnosis within 30 working days of their colposcopy visit.

**Standard 606:** Eighty percent of women receiving large loop excision of the transformation zone (LLETZ) treatment are managed as outpatients/day patients under local analgesia.

**Standard 607:** One hundred percent of women who have ablative treatment have had an adequate biopsy taken for histological diagnosis.

**Standard 608:** Ninety percent or more of women treated for CIN2-3 should:

- have a colposcopy and smear within the nine-month period post-treatment
- be discharged back to the smear taker as appropriate.

**Standard 610**: One hundred percent of colposcopy clinics and colposcopists participating in the NCSP must meet the requirements outlined in this standard to ensure colposcopy services are adequately staffed.

**Standard 611**: One hundred percent of colposcopists:

- maintain a minimum of 50 new cases per annum in New Zealand (the ideal number is 100 per annum), or a minimum of 150 cases over a three-year period
- participate in continuing education activities, including peer review (including MDMs, audits, collegial review, Royal Australian and New Zealand College of Obstetricians and Gynaecologists requirements, case presentations) and attendance at a national or international colposcopy meeting at least every three years.

The following standards apply to the provision of colposcopy services by District Health Boards, and colposcopists should be aware of these:

- Standard 601: Recording referrals and informing women about colposcopy.
- Standard 602: Ensuring timeliness of colposcopic assessment.
- Standard 605: Ensuring the timeliness of, and appropriate selection for, treatment.
- Standard 609: Managing women who did not attend.
- Standard 612: Providing an adequate clinical environment.
- Standard 613: Provision of colposcopy data to the NCSP-R.

Typically all of the above Standards are monitored through audits undertaken by the NCSP and some regular reporting through the contract monitoring process.

# Appendix J: Overview of HPV tests (a) signal and (b) target amplification

Sub-division	Technology	Supplier	Comments and applications
(a) Hybridisation	In situ hybridisation	INFORM HPV III (Roche)	Kits with cocktails of HPV Family 6 or HPV Family 16 probes for both cytology and tissue applications
	Solution hybridisation and capture of RNA probes complementary to L1 DNA sequences	hc2 (Qiagen)	Detects 13 hrHPV types in aggregate. Well-established assay for cervical screening and disease management
	As above	Care HPV (Qiagen)	Simplified version of hc2 suitable for field testing in low-resourced countries
	Solution hybridisation with probe oligo and 'Invader' oligo	Cervista HPV HR (Hologic)	Novel approach using cleavase enzyme; detects 14 hrHPV types across three species-specific wells. Approved for cervical screening an disease management
		Cervista HPV 16/1	Reflex test giving additional typing information
(b) Amplification Consensus DNA PCR	Degenerate / multiplex / consensus primers	MY09/11; PGMY	Generalised amplification against L1 sequences
		GP5+/6+	GP5+/6+used extensively clinically for cervical screening especially in the Netherlands
Consensus DNA real-time PCR with limited genotyping	As above, but also incorporating limited type specific amplification	RealTime HR HPV (Abbott Molecular, IL, USA); Cobas 4800 HPV (Roche)	Detect HPV 16 and 18 individually and other hrHPVs in aggregate; suitable for cervical screening with risk stratification beyond presence/absence of HPV
Consensus RNA amplification	Transcription mediated amplification (RNA)	Aptima HPV (GenProbe now Hologic)	Detection of E6/E7 HPV mRNA (14 hrHPV types); evidence for increased specificity, particularly in triage contexts
RNA amplification with limited typing	NASBA and type specific resolution using molecular beacons for 5 hrHPV types	HPV Proofer (Norchip, Klokkarstua, Norway)	High specificity but lower sensitivity due to limited type range (HPV 16, 18, 31, 33, 45)
		Nuclisens HPV (Biomerieux, Marcy L'Etoile, France)	Note: HPV Proofer is available in Scandinavia and UK; Nuclisens HPV is a similar test in mainland Europe
Full genotyping	CR with hybridisation using enzyme immunoassay (EIA)	GP5+/6+-PCR-EIA	As with all full genotyping assays – suitable for epidemiology and surveillance; R&D including detection in new conditions
	PCR with reverse hybridisation of amplicons on nylon strips with immobilised probes	Linear Array (Roche)	Line blot based on PGMY primers 33
		InnoLiPA (Innogenetics, Gent, Belgium)	Line blot based on SPF10 primers; validated on FFPE sections and can be automated

Sub-division	Technology	Supplier	Comments and applications
	Microarray	Papillocheck HPV (Greiner Bio-one, Frickenhausen, Germany)	PCR with microarray reverse hybridisation; targets 1 gene and involves simultaneous detection and genotyping of 24 low-risk and high- risk types
		CLART Â HPV2 (Genomica, Coslada, Spain)	Hybridisation to each probe in array in triplicate; detecting up to 35 types with visualisation using low-density arrays
	Luminex technology	Multimetrix HPV Genotyping Test (DiaMex, Heidelberg, Germany)	Sensitive, can be used to detect up to 100 different targets
Mid range typing	Multiplex real-time PCR	BD Viper Assay (BD, NJ, USA)	Recently developed by BD; offers consensus test result plus individual typing of 16, 18, 45, 31, 51 52, 33/58, 59/56/66, 35/39/68

Note: DNA = deoxyribonucleic acid; FFPE = formalin-fixed, paraffin-embedded; HPV = human papillomavirus; hrHPV = high-risk human papillomavirus; PCR = polymerase chain reaction; R&D = research and development; RNA = ribonucleic acid.

Source: Cubie and Cuschieri (2013)

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