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

22 June 2011

Commissioned by the New Zealand Government

Parliamentary Review Committee
The Associate Minister of Health
Parliament, Wellington

E ngā mana, e ngā reo, e ngā karangatangamaha
E mihi atu nei ki a koutou
Tēnā koutou, tēnā koutou, tēnā koutou katoa

Ki a tātou tini mate, kua tangihia, kua wheturangitia
Rātou, ki a rātou, haere, haere, haere
Ko tātou ēnei nga kanohi ora ki a tātou
Ko tenei te kaupapa, 'Me aro koe ki te hā o Hineahuone'
Hei huarahi puta hei hāpai tahi mo tātou katoa
Hei oranga mō ngā iwi katoa
Tihei Mauri Ora!

Koru on cover:
This is a variation of the koru design within a circle
and depicts eternity, togetherness, cohesion, family (whānau).

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Christchurch

The Review Committee wishes to acknowledge the tragic events of the earthquakes in Christchurch. We extend our heartfelt concern to the residents in Christchurch and wish the residents and their extended families all the best success in their efforts to recover from this tragedy.

Acknowledgements

The Review Committee dedicates this report to the memory of New Zealand women and their families who have been affected by a diagnosis or death related to cancer of the cervix. Fully operational screening programmes are widely acknowledged as an effective way to detect precancerous lesions and/or cervical cancer at an early stage when treatment is likely to be most effective. The widespread use of Papanicolaou (Pap) tests is a success story for early identification of what has become, for the most part, a preventable cancer.

The Committee are grateful for the expert advice and feedback from three external reviewers who were kind enough to read our report prior to publication. They are:

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The Review Committee are grateful for, and have been impressed with, the forthright and consistent feedback from all those who made themselves available to meet with us. Throughout the document there are direct quotes from interviewees that are helpful in understanding the issues.

The Committee also extends their gratitude to the National Screening Unit for providing secretariat support.

Executive Summary

Coverage, participation, equity, access and disease burden

The National Cervical Screening Programme (NCSP) has achieved significant gains by decreasing the burden of disease related to cancer of the cervix. Nevertheless, increasing participation and reducing disparities – among all women – are hugely important issues that have yet to be fully appreciated and addressed.

There is room for improvement in the organised programme via improved collaboration and integration with the HPV (human papillomavirus) immunisation programme and improved alignment with New Zealand's cancer control strategy. HPV-related disease is an issue for society as a whole – men and women – and perspectives must change to provide effective education about this very common virus.

Quality assurance and monitoring

Significant programme resources have been expended on quality initiatives, largely in response to recommendations from inquiries, audits and monitoring reports. Progress in this area is commendable. However, beyond the standards and guidelines and past efforts, awareness of current NCSP quality activities is very limited. A few partners and stakeholders reported having attended a presentation, but most indicated having no awareness of the programme's efforts in this regard.

A broad range of quality activities is in place, but consultation and collaboration between the NCSP and key stakeholders require significant improvement. Stakeholders report they have a limited voice with the National Screening Unit (NSU) and NCSP regarding limits, volumes and targets that sometimes do not make sense in the current environment.

Organisational and structural issues

The Ministry of Health has restructured many times in this past decade, inevitably affecting the NSU and the NCSP. In this report, both internal and external impacts from the change management processes have been highlighted. Although the critical situation of the vacancy for a Chief Advisor Screening (now National Clinical Director Screening) role has been recognised and position now approved, other potential gaps in provider contracting and advisory areas of the NSU have been reported. For example, NSU contracts with providers could be improved by better linkages and consultation with the primary care division of the Ministry of Health regarding funding allocations in primary and community health services. Also, better cohesion between the NCSP Advisory Group and the NSU would realise the full advantages of the expertise represented in this group.

The NSU needs to consider how best to enhance its organisational structure and future development in order to realise better alignment and cohesion with the National Cancer Control Strategy. This would enhance both clinical leadership and overall strategy implementation for all cancer screening services.

Workforce issues

Enhanced leadership capacity – including population health, public health and screening expertise – is urgently required within the NCSP to improve the depth and breadth of expertise and experience within the NSU and NCSP.

NCSP smear takers must complete a recognised educational course outlined in *NCSP Competencies for Smear Taker Training*. Colposcopists will commence an accreditation/re-accreditation programme with the Royal Australian and New Zealand College of Obstetricians and Gynaecologists Colposcopy Quality Improvement Programme (RANZCOG C-QuIP). Laboratories have expressed concerns with recruitment and retention of their experienced scientific workforce.

The National Gynaecological Cytology Training School will be broadened to include cervical histology and HPV testing. A new tender process is underway for ongoing provision of the training services.

Ethnicity and inequalities

There is strong consumer advocacy for cultural appropriateness in terms of the Treaty of Waitangi and the State's special responsibility to protect and promote the health of Māori and address their health inequalities. High-quality screening services need to follow the Treaty of Waitangi principles and consider culturally sensitive (whānau ora) approaches to cervical screening.

Continued monitoring of progress is necessary to improve the collection and collation of Māori women's data on the National Cervical Screening Register, and the reporting on this. Effective strategies must be implemented by the NSU to reduce disparities between Māori, Pacific and Asian populations, vulnerable women and those with special needs compared to European/other ethnic groups.

Challenges remain for the NCSP in the area of screening coverage for Māori, Pacific and Asian women. The NSU and NCSP must develop improved communications and streamlined arrangements with the National Kaitiaki Group to enable periodic access to aggregate data. Without data, the NCSP cannot carry out its reporting functions on a monthly, quarterly and annual basis. The anomaly of compartmentalised or ambiguous legislation is untenable because it negates both parties' ability to fulfil their responsibilities.

National Cervical Screening Programme (NCSP) Register

NCSP Register management and accountability remain within the Ministry of Health, although its administrative and technical support functions have been transferred to DATAM, a subsidiary of New Zealand Post. The integrity and timeliness of data transfer to the NCSP Register are well established across laboratories. Collection of colposcopy data is still incomplete, however, and is affecting the ability to monitor outcomes.

The NCSP Register facilitates processes to recall those who are overdue for screening and follow up those with abnormal results. Access to on-line screening histories is available for laboratories and colposcopy services. Plans are underway to allow electronic access to the NCSP Register for those who collect screening specimens.

Complaints to the NCSP have highlighted the need for ongoing public education efforts to inform participants that their screening information is included in the NCSP Register and to advise them of their withdrawal options.

The NCSP (through the NSU) must apply each time to the National Kaitiaki Group for Māori women's aggregate data from the NCSP Register to meet its routine monitoring functions. Data facilitates the production of statistical reports to inform policy, monitor programme functions and evaluate programme effectiveness. The National Immunisation Register will be an important link to the NCSP Register and Cancer Registry in monitoring the effectiveness of HPV vaccination in New Zealand.

Colposcopy

'Periodic and ongoing review of screening guidelines are required, eg, initiation, screening intervals and follow-up; and need to develop evidence-based follow-up algorithms within the context of the HPV immunisation programme.' (Interviewee)

To the best of our knowledge, New Zealand is the only country in the world that enshrines the duty of those performing colposcopic procedure in its health legislations. Colposcopy services and providers receive an *Operational Policy and Quality Standards Manual* from the NCSP. All colposcopy service providers contracted to the NCSP are assessed by an independent monitoring group, which compares colposcopy-specific indicators with targets on a biannual basis.

Colposcopy data collected on the NCSP Register are reported to be incomplete, and colposcopy indicators have not been able to be included in the monitoring reports. Following a number of reviews and audits, recommendations were made to improve the District Health Board (DHB) colposcopy services and data collection. Regular audits are done to ensure compliance with the Operational Policy and Quality Standards. A new round of DHB colposcopy audits began in June 2010, but the new colposcopy audit provider has not yet completed the monitoring reports.

Nurses performing colposcopy procedures have undergone training in accordance with the training standards developed by the New Zealand Nurses Organisation, but the NSU currently does not support their accreditation and employment.

An RANZCOG C-QuIP Programme, presently in development, aims to improve the care of women who are referred for colposcopy and treatment of screen-detected abnormalities through education, accreditation/re-accreditation and audit programmes for all health professionals performing colposcopies in Australia and New Zealand.

HPV vaccine and testing

An HPV vaccine programme was introduced in 2009 using a quadrivalent vaccine. Uptake has been modest, except there was better uptake among Māori and Pacific women.

HPV testing is used as a reflex triage mechanism and to assess the efficacy of treatment for abnormalities. This report makes recommendations for adapting to the new prevention paradigm for HPV-related disease as well as preparing for an integrated approach to cervical cancer prevention that will assess evolving technologies in the future.

Summary of recommendations

Coverage, participation, equity, access and disease burden

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.

2. The Ministry of Health must explore options to fund Pap tests at a system level to reduce disparities in access.

3. Screening participation needs to be improved by increasing the number of smear takers who are attuned to cultural sensitivities and the preferences of women with special needs.

4. An HPV education campaign should be undertaken to increase awareness and accurate knowledge among the general population. (See also the two sections relating to HPV.)

5. Continuity of monitoring, evaluation and reporting needs to be assured. This is best achieved through collaboration and improved partnerships with the academic community and/or the NCSP Advisory Group. The NCSP must make concerted efforts to consult with partners and stakeholders and to complete and report overall programme activities on a more regular basis, whether annually or biennially.

6. Long reporting delays contribute to a loss of confidence in the programme and must be prevented in the future.

Quality assurance and monitoring

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.

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.

   (This change is of paramount importance since the Christchurch earthquakes, which have severely limited the operations of two key laboratory facilities. Negotiations for all lab services should be conducted on the basis of input from relevant regional, national, laboratory and screening contacts.)

3. The NCSP should continue to conduct ongoing review of the screening histories of women who develop cervical cancer.

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.

5. External expert review is recommended every five years, rather than every three years.

6. Secretariat support for future external reviews should be provided by MoH staff outside the NSU, and should have experience in providing executive assistance.

Organisational and structural issues

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.

2. Regional co-ordination 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 co-ordination 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.

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.)

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 co-ordination of all cancer screening programmes to achieve better alignment of strategies and services across the entire cancer continuum.

Workforce issues

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.

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.

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.

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.

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.)

6. Laboratories must maintain the experience and expertise of their scientific workforce.

Ethnicity data: quality, completeness and use

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 'HPV Testing'.)

2. The following recommendations relate to the National Kaitiaki Group.

   - 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'.

NCSP Register

1. The NCSP must work with DHBs to ensure the integrity of colposcopy data supplied to the NCSP Register. This is an urgent priority.

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.

3. Colposcopy services must be supported to facilitate efficient electronic transfer of data.

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.

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.

6. Linkages between the National Immunisation Register and the NCSP Register and Cancer Registry to monitor the effectiveness of HPV vaccination are essential for ongoing integrated evaluation of screening and prevention efforts.

Colposcopy

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 non-compliant in several, or many, areas.

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.

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.

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.

HPV vaccination

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.

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.

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.

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.

HPV testing

1. The 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.

Introduction

Overview

Opportunistic cervical cancer screening by Papanicolaou (Pap) tests has been underway in New Zealand for many decades. As a result of significant screening failures and the publicity related to unethical research several inquiries have been undertaken to investigate these anomalies. Details of these issues have been well documented (see Table 1).

The National Cervical Screening Programme (NCSP) was introduced in 1990 and has resulted in lower incidence of and mortality from cervical cancer. In general, a high priority has been placed on monitoring and evaluation in the screening programme. Subsequently, several other reports have been completed since the original inquiries and the New Zealand Government committed to regular reviews of NCSP. Table 1 provides a brief outline and timeline of some key events related to cervical cancer screening in New Zealand.

Table 1. History of screening in New Zealand

1988	The Cartwright Inquiry Report (1) is completed (Cervical Cancer Inquiry at National Women's Hospital). It recommends establishing the NCSP.
1990	The NCSP is established in 14 Area Health Boards (AHBs) and is accountable to these boards. The Department of Health provides guidance and support.
October 1999	An inquiry is launched to investigate under-reporting of cervical smear abnormalities in the Gisborne region.
April 2001	The Gisborne inquiry report is published.(2)
February 2002	The Office of the Auditor General (OAG) report (3), which monitored the Gisborne recommendations, is published.
August 2003	A final report (4) on the review of progress to implement recommendations of the Gisborne cervical screening inquiry (CSI) is produced by Dr Euphemia McGoogan.
December 2003	The OAG's second report (5), comprising a review of the CSI and other recommendations, is published.

March 2004	The Health (National Cervical Screening Programme) Amendment Act 2004, 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 receives royal assent.
November 2004	The Cervical Cancer Audit Report is published.
May 2006	The Health and Disability Commissioner's review of colposcopy services at Waitemata DHB is published.

Chronology prepared by the NSU, 2011.

In January 2011 the New Zealand Associate Minister of Health appointed Jeffrey HJ Tan, MBBS, MRCOG, FRANZCOG (Australia), Roberta I Howlett, PhD, MASc (Canada) and Linda Thompson, RN, ADN (New Zealand), to undertake an independent review of the NCSP. The Minister requested that the Committee present a written report of this review by 17 June 2011 (the draft report was received on 22 June), which the Minister would subsequently present to the New Zealand House of Representatives and later attend to publication and distribution of the review report.

The NCSP Review Committee is a ministerial review committee established under Part 4A, Section 112O, of the Health Act 1956 ('the Act'). The Committee's statutory functions were to review:

- the operation of the NCSP
- evaluation activities of the kind described in section 112T of the Act that had been carried out or are proposed to be carried out.[1]

The Review Committee focused on the continuous quality improvement of the overall screening programme and relevant NCSP components to reduce the burden of disease related to cancer of the cervix and early precursors. The Committee has summarised its findings and recommendations in this report to the Associate Minister of Health, including a recommendation for future reviews.

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[1] **Section 112T states:** 'Meaning of evaluate:

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.

(2) An evaluation may, from time to time, include a review of, and an investigation into, the cases of:

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

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

(c) any deceased persons to whom paragraph (a) or paragraph (b) applied at the time of death.'

The following table briefly describes the role and contributions of the members of the Review Committee.

Table 2. Review Committee responsibilities

Title	Name	Key responsibilities and lead areas
Committee Chair	Dr Jeffrey Tan	• Liaise with stakeholders on the project's scope • Finalise the review's scope • Develop the review framework • Identify key informants and other information-gathering requirements • Lead the analysis, documentation of findings and development of recommendations • Take responsibility for the following review areas: quality, workforce, colposcopy, HPV, Register, future directions
Committee member	Dr Roberta Howlett	• Contribute to the review's design and implementation • Identify key informants • Lead the report writing and complete substantive editing of the final report • Take responsibility for the following review areas: coverage, quality, Register, organisational structure, workforce, HPV, future directions, HPV testing and immunisation
Committee member	Ms Linda Thompson	• Contribute to the review's design and implementation • Identify key informants • Contribute to report writing and act as technical background editor • Take responsibility for the following review areas: organisational structure, ethnicity, workforce

Background

A key recommendation of the 1988 Cartwright Inquiry was to establish a national cervical screening programme in New Zealand. Quality issues were noted in the reading of screening specimens in Gisborne region, which resulted in the appointment of a Committee of Inquiry in 1999. The Committee's report, published in 2001, presented 46 recommendations. Subsequent reviews (see Table 1) put forward 126 recommendations for programme improvements.

Aspects relating to previous recommendations are the subject of this report and will be addressed in greater detail in the sections that follow. Many matters noted in the recommendations related to efficient and effective programme organisation as well as the need for improved quality assurance, monitoring, evaluation and audits. An effective programme is predicated on evidence-based standards and guidelines, as well as having the necessary tools and resources to fulfil the programme's mandate. Public and clinician awareness and accurate knowledge among both groups are critical to the success of screening to ensure that participants are well informed and understand the rationale for screening.

Organisationally and administratively the NCSP is part of the National Screening Unit (NSU) and is funded by the Ministry of Health. The NCSP is connected with partners and stakeholders via the NCSP Advisory Group and through a variety of mechanisms ranging from contracts to clinical networks. NCSP undertakes internal monitoring against evaluation indicators. External monitoring is carried out by the NCSP Advisory Group, with technical assistance provided by the Cancer Council of New South Wales. International Accreditation New Zealand (IANZ), a national organisation offering accreditation services for the technical competence of laboratories and radiology services, provides audit services. The programme is subject to parliamentary review every three years.

Since implementation of the NCSP in 1990 it has developed standards for laboratories, colposcopy, clinicians who screen, information systems (the NCSP Register) as well as guidelines for cervical screening. The NCSP reports increased participation rates and a decrease in incidence and mortality related to cancer of the cervix.

The NCSP interfaces with District Health Boards (DHBs), and many services are co-ordinated regionally. Private and DHB laboratories across New Zealand provide cytology and histology services by way of tendering processes and contracts with the NSU. The NCSP Register is a database that contains cytology, histology, colposcopy and human papillomavirus (HPV) testing data. Immunisation data are held in a separate register. Data linkage with the 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.

Please refer to the relevant sections of this report for more detailed discussion of past recommendations, current status and recommendations from this Review Committee.

Methodology of the review process

Review scope

The NCSP Review Committee's statutory functions were 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.

As required by legislation, the Review Committee developed a plan to articulate the scope and process of the review, and consulted partners and stakeholders[2] about the proposed areas for review. Based on this feedback, additional items were incorporated and the final plan was presented to the Minister of Health in early March 2011. The Minister approved the plan on 16 March 2011.

Broad areas for review included:

- coverage, participation, equity, access and disease burden
- quality (including laboratory processes)
- organisational and structural issues
- workforce issues
- ethnicity data, including quality, completeness and use
- the NCSP Register
- colposcopy
- HPV testing
- HPV vaccination
- future directions (including technology, screening, management and research).

More detail on the areas of review is given in Appendix A.

Review objectives

As required by legislation, the Review Committee focused on the continuous quality improvement of the various components of the NCSP. Specific objectives included addressing the following questions:

[2] These included the NCSP Advisory Group Chair, NCSP Advisory Group members representing the RCPA, the RNZCGP, the Society of Cytology, the RANZCOG, the lead pathologist from cytology laboratories, a selection of seven lead colposcopists from the 20 DHBs, and a selection of four lead scientists from laboratories.

- What progress has been made in implementing recommendations from previous reviews of the NCSP?
- What (evaluative / continuous quality improvement) activity has the NCSP undertaken and what do they plan for the future?
- What, if any, are the key issues, challenges and risks to the programme?
- What future issues should the NCSP consider?

Methodology overview

The Review Committee used both qualitative and quantitative methods to elicit information to conduct its review of the NCSP. Specific methods included:

- a review of NCSP documentation, including external audits and programme documents
- a scan of peer-reviewed evidence relating to cervical cancer screening and related topics
- key informant interviews, facilitated by a semi-structured interview guide (this approach aimed to identify priority themes that relate to the experience and opinions of those who interact with the NCSP in a variety of contexts)
- a written submission process from partners, stakeholders and the public, which provided opportunities for open feedback from interested parties
- attendance/observation at a forum of health promoters, where the Committee also conducted group interviews.

Review of documentation

The Review Committee looked at relevant historical documents from the Cervical Cancer Inquiry 2001 onwards (including Dr McGoogan's report), as well as reports to monitor progress against recommendations from the Cervical Screening Inquiry. The Committee also examined relevant documents and reports from the NSU and NCSP that related to programme performance. The NSU facilitated the Committee's access to a wide variety of documentation related to background information on activities in each of the key areas for review.

Finally, the Committee requested an update on the status of recommendations made since the 2001 Inquiry. Appendix B outlines this information.

Literature review

The Committee reviewed relevant evidence published in peer-reviewed literature, technology assessments and related reports, and standards and guidelines from other jurisdictions. These included publications relating specifically to New Zealand, as well as other jurisdictions that provide cervical screening services in a variety of ways. Current findings from various reviews, meta-analyses and randomised control trials were considered in the context of the entire spectrum of programme components and delivery, as well as best practice recommendations.

Interviews

The Review Committee selected key informants for interviews, either in person or by teleconference. Interviews occurred between 22 March and 15 April 2011. In total about 60 interviews were scheduled and 55 were completed.

Key informants included:

- NSU senior management
- NCSP staff
- advisory groups (NSCP group, Māori group, Pacific contact)
- a Register provider
- representative laboratory personnel
- colposcopists
- regional co-ordinators from DHBs
- independent service providers, including Māori and Pacific
- government agencies
- non-government organisations[3] (NGOs)
- clinicians who collect screening specimens[4] and are affiliated to NGOs and primary health organisations[5] (PHOs)
- professional bodies
- public health and clinical experts
- women's and consumer groups.

Please refer to Appendix C for more detail on the representation of individuals, agencies and organisations contacted by the Review Committee.

[3] NGOs are provider organisations that may receive funding from government but are not a government agency in the same way as, for instance, the Ministry of Health or the Disability Commissioner. Smear takers and health promoters, etc, are employed by NGOs. Independent service providers (ISPs and PHOs) are non-government organisations.

[4] In New Zealand clinicians who take Pap test specimens are known as 'smear takers'.

[5] PHOs are collectives of general practice services that have centralised entities to administer and manage funds and data for primary health care.

Prior to the interview, each interviewee received the generic semi-structured interview guide (see Appendix D), which was developed by the Review Committee to elicit information related to the matters under consideration. At the time of interview each interviewee responded to specific questions related to their main areas of expertise and experience. Each interviewer made additional inquiries to supplement the basic questions.

Written submissions

The Review Committee requested additional feedback from other partners and stakeholders via written responses to general questions in a submission form (see Appendix E). This form was distributed to selected stakeholders in mid-March 2011. The form was also posted on the NSU website to facilitate ad hoc representations to the Review Committee.

The following groups were contacted (individuals who were interviewed in person may have been excluded):

- DHB chief executives
- DHB funding and planning managers
- PHOs
- laboratory chief executives, a laboratory manager and a clinical director
- laboratory pathologists and charge scientists
- colposcopy service managers at DHBs
- colposcopy nurses at DHBs
- lead colposcopists at DHBs
- NCSP regional programme managers at DHBs
- independent service providers
- the National Screening Advisory Committee
- smear-taker trainers
- professional bodies
- government agencies.

Report of the Review Committee

In most instances, this report will reference only data that is publicly available. The last annual NCSP Report was produced for the year 2007. More recent data references are from Monitoring Report 32, finalised in June 2011.

Coverage, Participation, Equity, Access and Disease Burden

Overview

Population-based cancer screening differs from other health programmes insofar as the target population is generally healthy. The aim of cancer screening is to encourage healthy people to undertake a screening test in an effort to find and treat precancerous lesions, or to detect cancer in the earliest possible stage so that treatment outcomes are optimal.

The essential components for organised cancer screening have been well articulated (6,7). A fully organised population-based screening programme should be comprised of *all* these elements, which include:

- education and communication
- recruitment of the screen-eligible population
- recall of those who are overdue for screening
- follow-up of those with abnormal screening results
- quality assurance and improvement
- monitoring and evaluation, and
- research.

If all components are not in place, the screening programme is not fully organised and there is a risk that some part of the intended population will not benefit, or that some aspect of the screening programme is prone to error, missed opportunities or ineffective and inefficient efforts to reach the screen-eligible population.

Most components rely on an effective and complete population-based information system. Such a system facilitates recruitment of the target population, recall of those who are overdue for screening, and follow-up of those with abnormal test results. Other elements include a supporting laboratory network, quality assurance programmes, methods for monitoring and evaluation, as well as health promotion (8).

The latter element must include education of both the public and health care providers. It is essential that the target population has access to all components of screening, as well as diagnostic and treatment procedures. All elements must be supported by evidence-based guidelines and promotion of best practice. Once established, an organised cancer screening programme must continuously monitor and modify standards, guidelines, reporting terminology and best practices as new evidence emerges (6).

Current status

Since implementation in 1990, the NCSP has developed standards for laboratories, colposcopy, those who take screening specimens (known as smear takers in New Zealand), the NCSP information system (NCSP Register), as well as updated guidelines for cervical screening and guidance for HPV testing. NCSP reports increased participation rates and a decrease in incidence and mortality related to cancer of the cervix (9, 10).

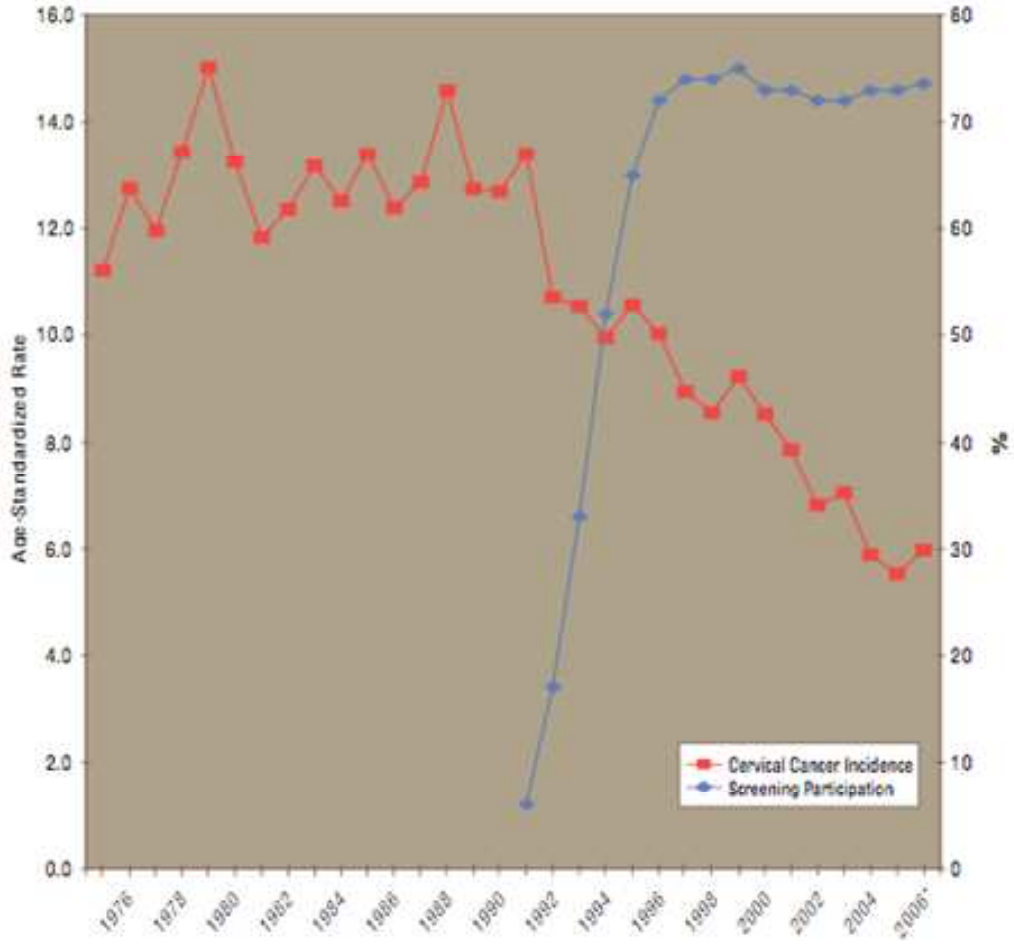
Primary care organisations issue screening invitations to screen-eligible women consistent with NCSP screening guidelines. About 1.4 million women are enrolled on the NCSP Register, which represents approximately 96%[6] of eligible women.

The NCSP reported an increase from 2006 to 2007 in overall rates for enrolment, participation and coverage (see Figure 1 for a 30-year comparison). Nevertheless, there have been significant historical disparities in participation and coverage rates. Women from ethnic groups (Māori, Pacific and Asian) have been less likely to participate in screening. Unadjusted[7] participation rates were 20% lower, and adjusted rates 30% lower than European/other women (about 93%) (9).

[6] This estimate is based on a comparison of the number of women on the Register with the number of women in New Zealand in the same age range, as provided by Statistics New Zealand (SNZ) through its population estimates and projections. These are based on New Zealand's five-yearly census, updated using the Registers of Births and Deaths and SNZ's calculations of migration (in turn based on sampling the arrival and departure cards) (Dr H Lewis, personal communication, 25 May 2011).

[7] Adjusted for hysterectomy: if a woman has had a total hysterectomy she is no longer part of the screen-eligible population as the cervix has been removed. If only a partial hysterectomy has been done, she should still be screened because the cervix is likely still intact.

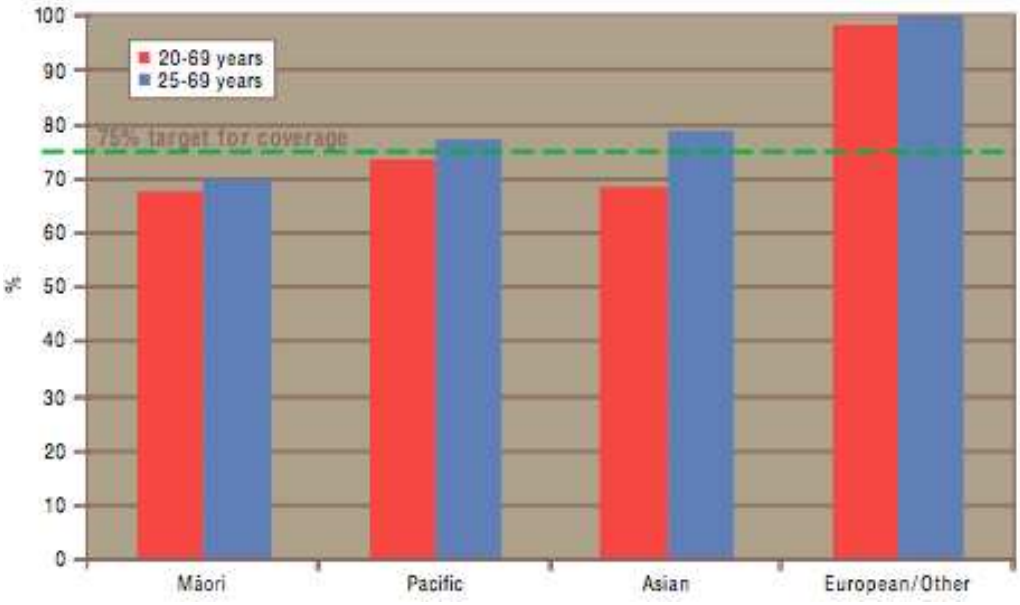
Figure 1. Cervical cancer incidence and screening participation from 1976 to 2006



Similarly, after adjustment for hysterectomy, three-year coverage (retention or regular screening in the past three years) rates among women in Maori, Pacific or Asian were less than 50%, compared to European/other women (77%). The overall coverage target is 75% after correction for hysterectomy (9). There was some regional variance in participation and coverage, but the disparities for women from the defined ethnic groups are fairly consistent across all New Zealand regions.

The most recent Monitoring Report (up to the end of 2009) indicates that the national target for coverage (75%) has been exceeded, with almost 80% of women having been screened in the preceding three-year period (10). Compared to the three years ending June 30, 2009, this represents an increase at a national level, especially among Pacific and Asian women (62.2% to 64.7% for Pacific women and 64.3% to 67.8% for Asian women) (10). Nevertheless, disparities among ethnic groups were maintained (10). (See Figure 2 for five-year coverage data.)

Figure 2. Five-year coverage by ethnicity (women screened in the five years prior to 31 December 2009, as a proportion of hysterectomy-adjusted 2006 female population)



Note: Coverage is calculated using the population projection for 2006 based on 2001 Census data. The target (green line) of 75% refers to three-yearly coverage.

More recently, a widespread social marketing campaign was launched by NCSP with the intent of increasing awareness and participation among Māori women and to some extent among Pacific women. Women from other ethnic groups seem not to have been included in these health promotion efforts. Similarly, women from other vulnerable groups – those of low literacy, women who live in poverty and women with special needs[8] – seem not to have received the benefit of public education efforts purposely directed to recruit and encourage their screening participation.

Generally in New Zealand, loss to follow-up rates after abnormal screening tests are low, at less than 10%; however, there are higher rates in certain regions and among ethnic groups. This suggests improved processes since programme implementation, since rates in earlier years were higher (11). Nevertheless, in some regions, very low rates of loss to follow-up have deteriorated (9). By comparison, in many other jurisdictions, up to 20–40% of women with abnormal Pap tests are lost to follow-up assessment and treatment (12–18). In these same jurisdictions, wait times for assessment and treatment are closely related issues that reportedly contribute to high rates of loss to follow-up. Another related factor is that women may not understand the importance of timely follow-up after an abnormal screen; this concern must be addressed via public education efforts and patient/physician discussion.

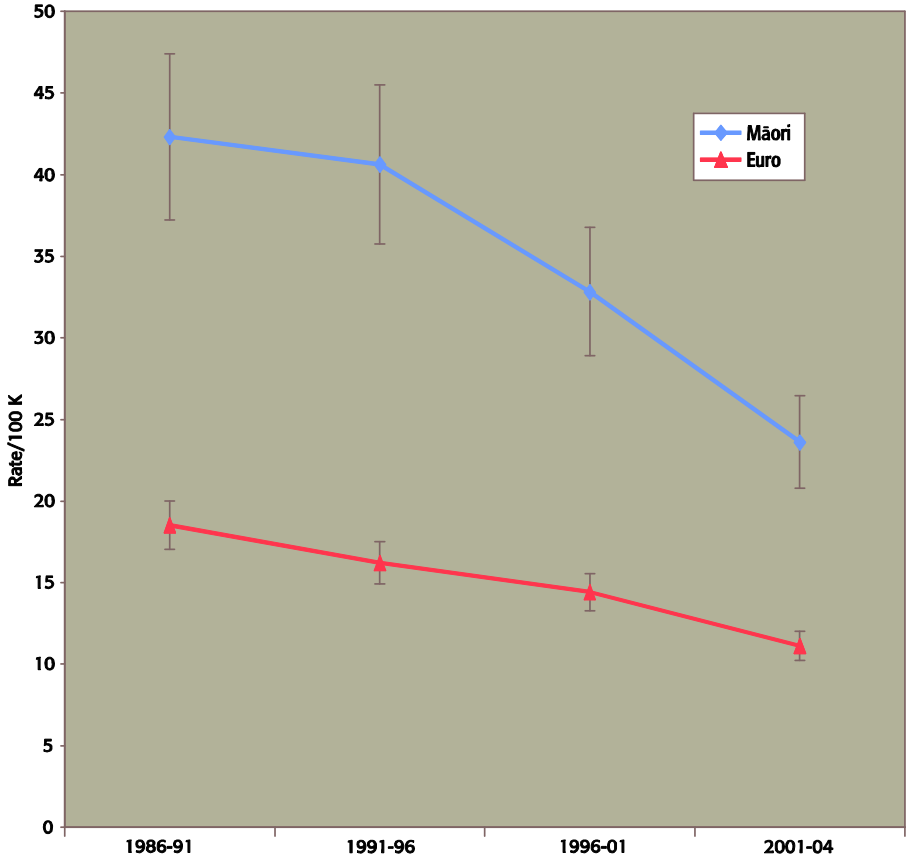
[8] This may include, but not be limited to, women with physical and/or cognitive challenges.

The NCSP advises that recruitment efforts have been maximised since New Zealand's primary health organisations assumed responsibility for screening invitations to screen-eligible women who are included in primary care rosters. While enrolment is reportedly high (Dr H Lewis, personal communication, 25 May 2011), the fact remains that some screen-eligible women are seldom or never screened. This is reflected in incidence data, given that about 80% of new diagnoses occur in women who are seldom or never screened (19).

Furthermore, these disparities are also evident in other ways. Mortality rates are significantly higher – more than twice as high – among women who are Māori or Pacific (9). Nevertheless, across all women, mortality rates have decreased. (See also the section 'Ethnicity Data: Quality, Completeness and Use'.)

While the burden of cervical cancer is low compared to other cancers, it is important to remember that this is essentially a preventable cancer if effective screening is available. The fact that most new cases and deaths occur in women from ethnic and vulnerable groups represents inequitable access to service – an urgent issue that must be addressed. Incidence and mortality are declining across all groups, but women from ethnic and vulnerable groups still bear a disproportionate burden and concerted efforts are required to address this inequity (see Figure 3).

Figure 3. Cervical cancer incidence of Māori and European women by five-year time periods from 1986 to 2004



As reported in many other jurisdictions, and as acknowledged by the World Health Organization (7), the NCSP has achieved significant gains by decreasing the burden of disease related to cancer of the cervix. This is due, in part, to the implementation of an organised screening programme. Other factors may very well have played a role in this successful decline in incidence and mortality. Such factors may have included increased awareness among clinicians – primary care providers, colposcopists, pathologists and oncologists – as well as in the general population.

Key issues

- While impressive progress has been realised with cervical screening efforts since implementation, there is room for improvement in the organised programme. (See also the section 'NCSP Register'.) Intensive local research is urgently needed to understand the underlying reasons for poor participation, retention and loss to follow-up among ethnic women and the most vulnerable women. It is essential to obtain clear information on the knowledge, attitudes and behaviours of the New Zealand population. Without such evidence, future health promotion efforts may not be effective or efficient. Although the NCSP commissioned an assessment of the 2010 social marketing campaign, it is not clear how the programme plans to apply the findings to improve knowledge and access.
- Many stakeholders cited the cost of Pap tests as a significant barrier to screening participation, especially among the most vulnerable groups.
- Awareness and accurate knowledge of the role that HPV plays in cancer of the cervix and other cancers is generally low. This topic must be a primary focus of all education efforts.
- Customised and targeted interventions are needed to increase awareness, knowledge and participation in *all* components of screening by all ethnic groups and women from vulnerable populations. It is essential that such efforts are customised and targeted, with input from relevant community sectors, as 'one size does not fit all'. Public education must be customised and streamlined to take into account the specific needs of women from all ethnic groups and women who may not understand the importance of screening and prevention. Feedback indicates that women from other ethnic groups – such as Asian populations – have not been the focus of health promotion efforts. While the number of women in these groups may be lower than Māori women, a truly inclusive approach must reach all women.

'There is also still confusion among the general public as to what cervical screening is testing for. Many women assume it is testing for all gynaecological cancers. This lack of clarity needs to be more clearly addressed in the information provided by NSU.' (Interviewee)

Recommendations

1. A proactive campaign is needed, with targeted interventions to address disparities among ethnic groups as to participation, retention, and improved follow-up after abnormal screening results.
2. The Ministry of Health must explore options to fund Pap tests at a system level to reduce disparities in access.
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.
4. Undertake an HPV education campaign to increase awareness and accurate knowledge among the general population. (See also the two sections relating to HPV.)
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 overall programme activities[9] on a more regular basis, whether annually or biennially.[10]
6. Extended reporting delays contribute to a loss of confidence in the programme and must be prevented in the future.

[9] For example, larger programme reports that summarise achievements; challenges; monthly and semi-annual monitoring; internal evaluation; age-, time- and period- cohort analyses; and longer term trends.

[10] Given that significant resources are needed to complete data analyses and produce programme reports annually, publishing this information every two years may be satisfactory, assuming that other established monitoring is completed as per current recommendations and requirements, eg, quarterly or semi-annually.

Quality Assurance and Monitoring

Overview

Evaluating NCSP performance 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
- ongoing monitoring of smear takers, laboratories and colposcopy services against the programme's own quality standards
- investigation of complaints
- monitoring trends in programme outcomes – cervical cancer incidence and mortality (20–27).

Historical inquiries and reviews are summarised in Table 1 in the Introduction. The most recent information relating to laboratory performance is detailed in numerous reports (28–31).

Current status

New Zealand Cervical Cancer Audit

Women who are enrolled in the NCSP have their screening histories – laboratory cytology and histology (biopsy) and HPV test results – recorded in a centralised database, the National Cervical Screening Programme Register. All tissue diagnoses of cancer (including cervical cancers, by stage and histological type) are notified to the New Zealand Cancer Registry under the Cancer Registry Act 1993 (32). Also, both databases identify individuals by their National Health Index (NHI) number, a unique personal identifier assigned to all persons at first contact with the health system. It is thus possible to link a woman's cervical cancer diagnosis (recorded on the Cancer Registry) to her screening history (recorded on the NCSP Register) via her NHI.

Since 2000 the NHI completion rate has been very high (close to 100% on both databases). Problems were experienced earlier (prior to 1997) involving multiple NHIs being assigned to the same woman, but this has been greatly reduced due to more active detection and resolution of duplicates on the NHI database.

The New Zealand Cervical Cancer Audit (33), published in November 2004, was carried out following the Ministerial Inquiry into the Under-reporting of Cervical Smear Abnormalities in the Gisborne Region (2). One recommendation following the Gisborne Inquiry was that the NCSP should implement a process for ongoing review of the screening histories of women who develop cervical cancer. Such case reviews are conducted by several countries with organised cervical screening programmes (34–40) and should be distinguished from periodic full-scale programme audits.

Lewis et al have described the method developed by the NCSP for reviewing cases of cervical cancer (19). They presented the results from linking new cervical cancer cases (from the Cancer Registry) with screening histories from the NCSP Register via the NHI for the four-year period 2003–06 and compared these results with those of the earlier New Zealand Cervical Cancer Audit. Linkage to screening history revealed that 202 of the 438 women (46%) had never been enrolled in the NCSP; 137 (31%) were enrolled but were infrequently or irregularly screened; and 85 (20%) developed cancer despite regular screening (data were missing for three women). These results were similar to those found in the New Zealand Cervical Cancer Audit, covering the period 2000–2002.

Lewis et al concluded that ongoing linkage of cancer and screening data is useful for monitoring programme performance. Confirming that 80% of potentially preventable cervical cancers involve women who are seldom or never screened provided confirmation that improving coverage (then around 72%) was a priority. Further investigation (phase two) needs to investigate those few cases where cervical cancer developed despite regular screening (an average of 21 per year, or approximately 20% of eligible cases) to distinguish interval cancers from potential programme quality issues.

Ongoing review of the screening histories of women diagnosed with cervical cancer provides a complementary approach to auditing the overall performance of the NCSP. It could also potentially lead to the identification of specific problems that need more detailed investigation and possible corrective action. The Health (National Cervical Screening Programme) Amendment Act 2004 (section 112T–112Z) provides the legal basis for these reviews.

Independent monitoring

Ongoing systematic monitoring is a requirement of an organised screening programme. Such monitoring allows for the evaluation of programme performance and corrective action, as required. Monitoring is carried out using a set of key indicators, which cover all aspects of the screening pathway, including participation by women, their clinical outcomes, NCSP provider performance and the programme overall.

Monitoring reports were produced quarterly from December 2000 to June 2007 (Report 27), and bi-annually thereafter.[11] These monitoring reports were intended for the general public, NCSP providers and the programme itself.

The NSU, under contract with the University of Otago, established an Independent Monitoring Group to provide independent quantitative monitoring of the NCSP in 2000.[12] This was the first time the NCSP was monitored; the first report of the Independent Monitoring Group of the NCSP was for the quarter October–December 2000.

The main purpose of the report was to assist the NSU and service providers to improve the quality of the NCSP. National indicators for the NCSP were established by the NSU in 2000. These provide the basis for the monitoring reports produced by the Independent Monitoring Group. Some national indicators will be reported quarterly and others will only be included in six-monthly and annual reports. The reports are distributed to providers and are publicly available on the NSU website, and provide statistical data on the performance of the NCSP and NCSP providers. They show that the national indicators of performance are largely being met; where there are recommendations to follow up with providers, the NSU addresses these directly with the service provider concerned.

The Independent Monitoring Group, based at the University of Otago, published quarterly monitoring reports on NCSP Register data from October 2000 to March 2003. Reports from April 2003 were taken over by the Centre for Public Health Research, Massey University, Wellington. The raw data from which the indicators included in these reports (with the exception of the colposcopy indicators) are calculated were provided to the Centre by the NSU in the form of an anonymised extract from the NCSP Register. The data extract was taken six weeks after the end of the period to which the report relates. The colposcopy data were provided by the NSU and reformatted by the Centre. Their first report was for April to June 2003, prepared in May 2004. Their last was the six-monthly report covering January to June 2008, prepared in November 2008.

Following a hiatus of two years, the next monitoring report was completed by the Cancer Epidemiology Unit, Cancer Council NSW, Sydney, Australia. Their first report was Monitoring Report 30, covering July to December 2008 and published in February 2011 (41). The next two six-monthly reports for 2009 were finalised in March 2011. This coincided with the use of a new reporting format, incorporating more explicit definitions and utilising data from the newly developed NCSP Register, so earlier reports are not fully comparable with Report 30 onwards.

[11] See http://www.nsu.govt.nz/health-professionals/1063.asp for list of all reports.

[12] See http://www.nsu.govt.nz/files/NCSP/NCSP_QR_1.pdf for the first report.

The development of these reports is ongoing. In particular, colposcopy indicators are not calculated due to the incompleteness of colposcopy data on the NCSP Register relating to this time period. These indicators will be included in reports when the data have improved. Work is also underway to improve the accuracy and completeness of ethnicity data on the register and to update denominator population data. Other indicators, such as the accuracy of negative cytology reports, are in development and will be reported on in future. Technical information on the indicators is available in a separate report (*Technical Specification for Monitoring Reports*), available at www.cervicalscreening.govt.nz.

Approval was sought and received from the National Kaitiaki Group for access to Māori women's data from the NCSP Register in order to calculate various programme indicators by ethnicity. NCSP biannual monitoring reports are reviewed by the NCSP Advisory Group,[13] a multidisciplinary advisory and monitoring group representing NCSP providers and consumers. The group may make recommendations to the NSU for follow-up actions.

Laboratories: Provision of cytology and histology – reporting rates and monitoring of continuing competence in laboratory staff

The laboratory network that supports cancer screening 'is essential to cancer screening and is inclusive of physical facilities, human resources, safety issues and procedures specific to the screening test itself .... Laboratory professionals and services have been, and will continue to be, an important part of the screening process' (42).

'Periodic and ongoing review of screening guidelines are required, eg, initiation, screening intervals and follow-up; and need to develop evidence-based follow-up algorithms within the context of the HPV immunisation programme.' (Interviewee)

There are more than 23 laboratories in New Zealand that carry out cytology, histology and HPV testing. In the past there were even more, but the total has diminished since reorganisation. Laboratories may collect and process specimens from anywhere in the country. There are six private laboratories and two public laboratories associated with hospitals; the latter two are administered by the government. Laboratories have a longstanding relationship with the NCSP.

New Zealand's laboratory services have been the subject of detailed investigation in previous inquiries, audits and evaluations, some of which are referenced here (2–5). Based on findings from these various reports, there has been significant improvement in laboratory services and quality assurance processes. NCSP Operational Policy and Quality Standards are in place for providing 'a smear taking service' (22) and a 'laboratory service' (23).

[13] For more information, see http://www.nsu.govt.nz/health-professionals/1072.asp

Quality standards across the laboratories are reviewed by IANZ, with an annual cycle for review (in Australia the review occurs every three years). Operational Policy and Quality Standards are an internal laboratory process for monthly performance review of individual cytotechnologists. Since implementation of automated screening, standards are reported to require some revision, as current standards have too many categories for screening that are not consistent with international standards.

Several lab contacts reported 'dissatisfaction amongst pathologists and scientists with respect to the NCSP's laboratory strategic planning and operational management'. Specific concerns from one interviewee described an organisation with 'new layers of managers and acting managers with ill-defined roles and poor communication skills. The NCSP was dictatorial and high handed in its management style. Responses to questions from our laboratory were in some cases either ignored or replied to so slowly that the issue faded into neglect.' (Interviewee)

Since conversion to liquid-based cytology (LBC), the proportion of cytology specimens processed by this method has increased to almost 90% (10). The recommended NCSP targets for unsatisfactory cytology specimens are from 1 to 8% for conventional cytology and from 1 to 5% for LBC. The former target was met at a national level and the latter by three out of nine laboratories. There has been no change in the rate of unsatisfactory LBC specimens (10).

Since these targets are very generous compared to other jurisdictions and laboratory experience (43), such a high rate of unsatisfactory samples may reflect relatively low volumes in laboratories that function within a regional structure. In Ontario, Canada, the implementation of LBC resulted in a significant decline in unsatisfactory cytology specimens, even in an environment where these rates were already very low due to comprehensive quality assurance mechanisms across the entire screening spectrum (43).

There is no guarantee in New Zealand that cytology and histology specimens for cervical cancer screening will be processed in the same laboratory. This relates to a regional funding structure that seems to be based on lower costs among competing laboratories – a structure that may not be the most efficient, cost-effective or reliable. Clinicians who provide assessment and treatment for women with abnormal screening results often consult the reading laboratory to discuss specific cytology and histology results. If either one of these services is located outside the clinician's region, the clinician is less likely to contact that laboratory for clarification as those conversations are based on clinician–laboratory communications and trust that are well established.

Key issues

NCSP Register

Feedback indicates continuous problems with respect to the Register. There are questions as to whether the Register is robust, given the frequent system failures – either with or without advance notification. These concerns are not reflected in the Register outages reports. (See the 'NCSP Register' section for more detail.)

Impact of HPV immunisation

Laboratories have expressed concerns about the impact of implementing HPV vaccination. These concerns relate to the public's limited understanding of HPV. The first is the potential for vaccinated females to believe that screening is no longer required. The second relates to the less than optimal uptake of the HPV vaccine and the future changes to screening algorithms that will be required in this new environment. The third relates to the impact of immunisation on HPV testing and the potential for reduced performance of cytology as a screening test.

Laboratory infrastructure

Historical inquiry and audit reports have recommended a national laboratory structure. Such an approach would improve consistency, efficacy and coherent application of quality assurance measures, and would simplify negotiations with laboratories regarding the fee structure and adhering to required volumes. New Zealand is a relatively small country, so laboratory infrastructure could easily be adapted to increase capacity to deal with screening and histology volumes. Communications would be improved with clinicians and with NCSP staff, with a focus on adherence to established standards and guidelines.

A tendering process was reported to have been completed in recent years and a successful bidder was selected. The tendering process was withdrawn but no laboratory staff we spoke to could inform us of the reasons for not proceeding with this approach once there was a change in government in 2008. NSU indicated they had sent the following communication to all the laboratories: "There have been a number of changes in the wider laboratory sector over recent times; the changes are on-going. There is also uncertainty about the availability of funding for the introduction of LBC and HPV testing. It has been decided that it was not in the best interests of the NCSP, laboratories or the wider health sector, to proceed with implementing the RFP (request for proposal) at this time".

Laboratories have noted their enthusiasm for such an approach, as the current tendering, funding and negotiation processes are tedious, time-consuming and inefficient – all of which results in laboratories experiencing difficulty in workforce planning, maintaining infrastructure and recruiting/retaining experienced and expert staff. (See also the section 'Workforce Issues'.) The current tendering and funding shortages have aggravated intermittent shortages of qualified and experienced cytotechnologists and pathologists.

As noted earlier, in spite of the conversion to LBC, the rate of unsatisfactory specimens remains higher than one would expect with this form of specimen collection and preparation. Furthermore, a high volume of LBC warrants centralisation, because the kind of automatic reading that is enabled by LBC can easily accommodate throughput and increase capacity. This is also true for the use of high-risk HPV (hrHPV) testing as a triage mechanism. When, and if, cervical screening converts to the use of hrHPV testing as the primary screening tool, centralisation could easily accommodate this transition. It

would require consolidated and collaborative planning among all key partners (internal and external) to effect this change to a national laboratory structure.

Such an approach would provide an opportunity to move towards a more proactive, rather than a reactive, screening programme. The programme's history is such that the Ministry and NSU have been in the position of reacting to a series of crises. Now that the NCSP is well established, a paradigm shift based on proactive planning is in order. (See also the Committee's comments in the sections on 'Organisational and Structural Issues' and 'Workforce Issues'.)

Relationship with the NSU and NCSP

The Committee received numerous comments from parties within and outside the NSU regarding the apparent lack of communication and cohesion between clinical and quality staff within the NSU, and the resulting impact on communication with laboratories and others. Comments also pointed to a lack of staff experience and expertise with respect to cancer screening and how best to apply quality assurance within a screening environment.

In general, partners and stakeholders applauded the success in reducing the incidence and mortality due to cervical cancer, but had reservations about the current status of the programme. Some feedback alluded to the inconsistent application of quality standards, which may have reflected either a misunderstanding of the standard or a bias towards some laboratories over others.

Even though laboratories have a vested interest in maintaining their share of services, the Committee was impressed with their feedback, which focused on providing a high-quality screening programme for the women of New Zealand.

Recommendations

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.

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.

(This change is of paramount importance since the Christchurch earthquakes, which have severely limited the operations of two key laboratory facilities. Negotiations for all lab services should be conducted on the basis of input from relevant regional, national, laboratory and screening contacts.)

3. The NCSP should continue to conduct ongoing review of the screening histories of women who develop cervical cancer.

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.

5. External expert review is recommended every five years, rather than every three years.

6. Secretariat support for future external reviews should be provided by MoH staff outside the NSU, and should have experience in providing executive assistance.

Organisational and Structural Issues

Current status

Ministry of Health restructuring

From 2001 to 2011 reports and inquiries on cervical screening highlighted concerns and recommended change in the development, management, autonomy and leadership of the NSU and NCSP. The Cervical Screening Inquiry (CSI) (2000–01) noted the need to 'preserve and encourage' the culture fostered by the Health Funding Authority (44). The CSI also proposed that the NSU be a separate unit within the Ministry of Health, with its own budget and manager, who would have delegated powers to contract for screening services directly with providers on behalf of the Ministry (44). Since that time the Ministry, along with both the NSU and NCSP, have restructured many times. These changes are summarised in the following sections.

NCSP moves influenced by sector changes

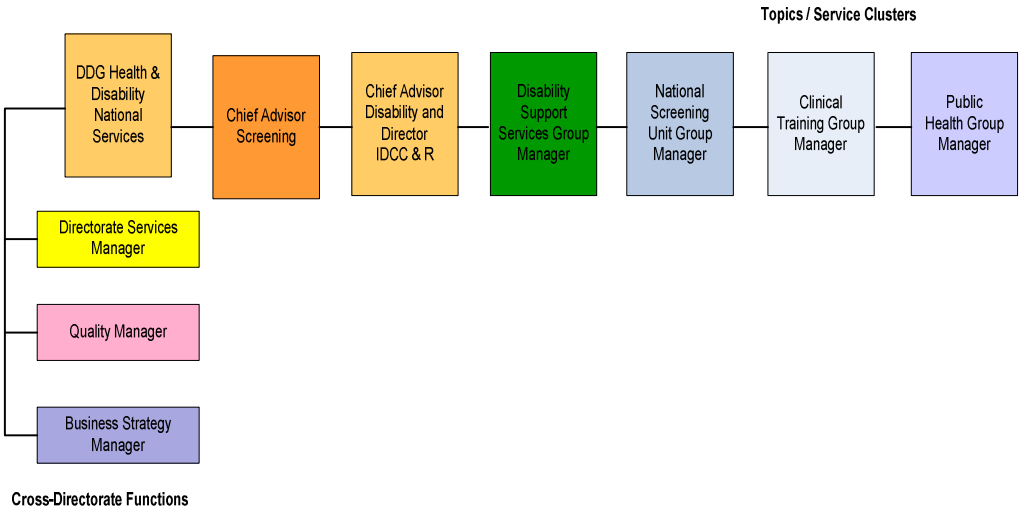
From 1988 to 1993 the NCSP was dispersed among the 14 Area Health Boards), then the Regional Health Authorities including (Ministry of Health, Public Health Commission and four Regional (purchasing) Health Authorities) of New Zealand. The NCSP commenced a single national focus, with national co-ordination managed from the Public Health Directorate of the Ministry of Health from 1998. (See Appendix F for a more detailed chronology of significant events.)

NSU reviews influenced by Ministry restructuring

In 2000 the Ministry of Health established the NSU as a separate unit with a Clinical Director and Group Manager, in line with CSI Recommendation 1.12 (44). The first structural review of the NSU in 2002 resulted in increased clinical leadership positions. Additional internal restructuring over 2002 and 2003 led to the termination of the quality group, with quality functions incorporated within the NCSP and BreastScreen Aotearoa teams. (See Appendix F for a more detailed chronology of significant events.)

Over 2007/08 Ministry of Health restructuring resulted in the NSU moving to the Health and Disability National Services Directorate of the National Health Board within the Ministry of Health (see Figure 4 below).

Figure 4. Health and Disability National Services Directorate structure, 2009 (45)



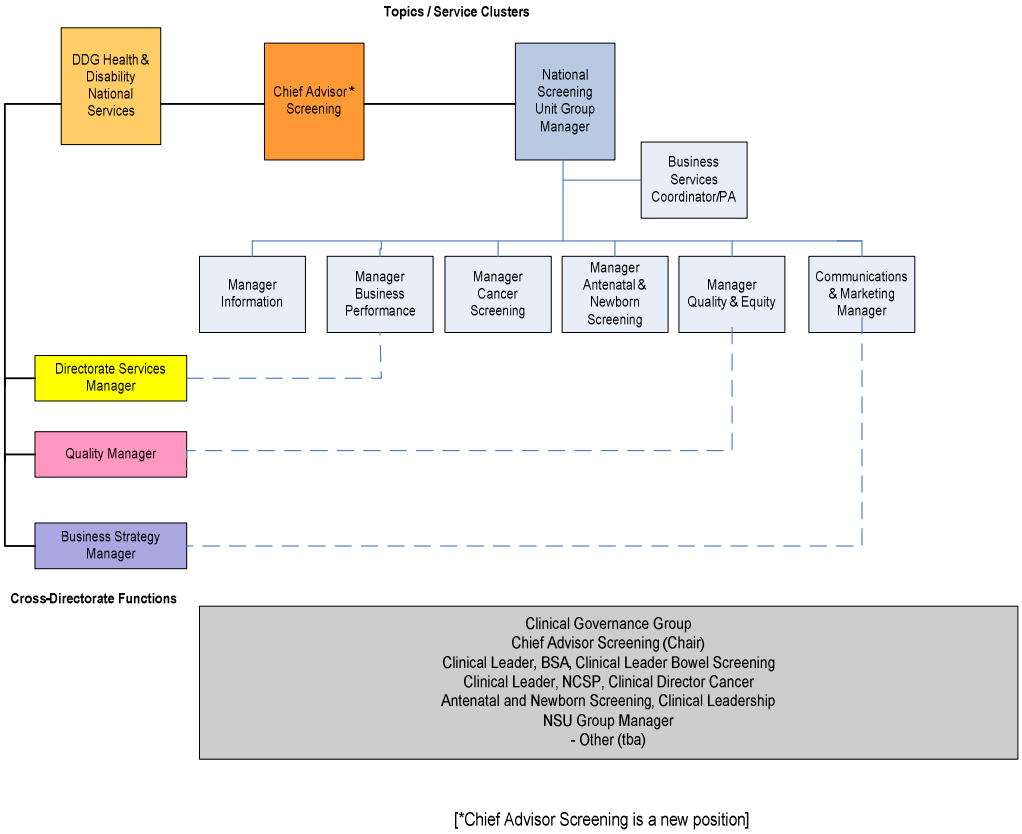
Ref: National Screening Unit Structural Review, 2009

Simultaneously, the NSU included a new initiative for antenatal and newborn screening. The NSU then re-established its quality team as a quality assurance team and retained its 'direct service purchasing' role.

In 2009/10 the Ministry of Health restructured and established the National Health Board. This moved the NSU into the National Services Purchasing division of the National Health Board.

The NSU lost two senior positions in management and advisory roles and the Strategy and Policy Team was moved out of the NSU. Internal changes included: a new group manager; a clinical governance group; the senior leadership team became the management team (excluding programme clinical leaders); and additional performance management analysts were appointed to cervical and breast screening programmes. (See Appendix F for a more detailed chronology of significant events.)

Figure 5. NSU structure, 2009



Ref: National Screening Unit Structural Review, 2009

From 2001 to 2011, reports and inquiries on cervical screening highlighted concerns and recommended change in the development, management, autonomy and leadership of the NSU.

A more detailed chronology is appended to this report (see Appendix F). Ministry of Health change management processes are ongoing under the current management.

Key issues

NCSP management (CSI Recommendation 1.13)

The NCSP management structure was recommended as senior level (second or third tier) within the Ministry of Health, with clinical leadership and part of a national cancer control strategy. In 2002 the NSU was jointly managed by a programme manager and clinical leader, at fourth tier. In 2009 the Clinical Leader position was changed to Clinical Advisor, sitting at tier 6 within the NSU. The latter change has compromised the credibility of the Clinical Leader externally among clinical peers and wider stakeholder groups. The absence of a senior clinical position was perceived as posing risks to clinical safety and robustness and was not consistent with the intent of CSI Recommendation 1.13.

NSU senior management reported that such risks are 'multi-layered'. For example, the absence of a senior clinical voice across all six national screening programmes undermines the NSU's clinical credibility with both the sector and the Minister of Health. Furthermore, the loss of a senior clinician leaves operational clinicians without support for professional practice and development. Having no senior clinical interface between the National Health Board and related divisions of Ministry of Health weakens vital linkages among programmes for medical, research and academic robustness (ref: National Screening Unit Structural Review, 2009). The intention of CSI Recommendation 3.7 was that the NSU clinical leadership and management structure would be located within the Ministry of Health.

Progress on recommendations from the Office of the Auditor-General, 2002–03

Clinical leader role (5, 44)

The NSU had concerns that the Clinical Director position at the time (2000–2002) did not have direct responsibility for any permanent staff and felt it was important to include the position in decision-making. These risks needed to be acknowledged and managed appropriately. Nevertheless, Ministry of Health restructuring over time has confirmed a management structure within the organisation that may have had the effect of compromising clinical leadership. Clinical experts and advisors must remain as the linchpin in any clinical programme, but they need not be encumbered with management roles for leading sector or agency divisions.

Recruiting key positions

The NSU is reported to have experienced difficulties recruiting key staff. The NSU previously contracted epidemiological support from the Public Health Intelligence group within the Ministry of Health, and currently contracts with a team of epidemiologists who have significant expertise in cervical screening. A manager of the Quality Assurance team was appointed on 29 October 2007.

Since 2008/09 a clinical governance group and performance management analysts have been in place for the screening programmes. In 2011 the senior clinical position at the fourth tier was approved for the NSU and will be recruited as National Clinical Director for Screening. This role is at the same level as the Group Manager within the National Health Board of the Ministry of Health. The Clinical Advisor roles remain at tier 6 within this structure. In this respect, the NSU's development is progressing as part of the change management process.

Impacts of infrastructure change on providers and women

Impacts of screening programme infrastructure changes have been felt externally. DHBs noted concerns about the compromised clinical roles within the NSU, and these concerns are supported by other clinical and public health experts. Multiple changes within the Ministry of Health carry the risk of loss of institutional knowledge and screening experience. High staff turnover has translated to lost expertise. The impact on providers and screening participants has been noted with respect to limited or no communication about changes, with the loss of continuity and key contacts.

Among women in vulnerable or high-priority groups, the loss relates to key contacts (staff) who led vital networks and relationship development and maintenance. Staff turnover has left gaps for screening participants and/or providers, which has interfered with reliable access to information, data or other related services. New people may take longer to rebuild these networks, and in the process misinformation may result.

Impact of change on NSU culture

Provider feedback suggests that the pace and nature of changes within the NSU have had an impact on the NCSP by lessening screening knowledge and robustness. Externally there is a perception of a general 'dumbing down' of both the NSU and NCSP. Feedback has indicated an impression externally of a pervasively disorganised and reactive culture, disconnected relationships with stakeholders and poor co-ordination.

Such concerns could not be confirmed with the NSU, which has made efforts to improve co-ordination and strategic planning. For example, new service specifications for future purchasing are underway to improve co-ordination between primary health care and NSU provider activities.

Funding and contracting

The Ministry of Health is the chief health and disability advisor to the Government. The Ministry of Health's roles include:

- policy advice for strategic direction through internal and external advisory mechanisms
- arranging purchasing and funding with providers
- co-ordination and monitoring of key functions to achieve optimal health outcomes for the New Zealand public.

DHBs are the regional health authorities reporting directly to the Ministry of Health. These boards have funding and purchasing responsibilities for regional activities across their boundaries and they report on national health targets to the Ministry of Health.

Primary health organisations (PHOs) were established under the national Primary Health Care Strategy and are charged with managing health care services for New Zealanders enrolled with general practitioners (GPs). PHOs (through the GP services) hold registers for enrolled patients and must provide regular updates and reports on general and targeted health activities.

Ministry of Health divisions/directorates, DHBs and PHOs may purchase and/or provide health services in their regions, including contracts with NGOs (eg, independent service providers or laboratories).

Many providers report intermittent difficulties with NSU contract negotiations but still wish to retain contract funding. As service providers they believe their current networks and co-ordinating abilities across each other's services enable better regional co-ordination than deferring to the planning and funding divisions of the DHBs.

A balanced approach for the NSU

NSU staff report a more balanced approach aimed at maintenance and continuous improvement of quality processes across all components of the screening pathway. Linkages are apparent among information (registers) and planning (strategic, business and divisional work plans) across the Ministry of Health, but this is not always clear or translated into practice with NSU stakeholders.

Significant feedback refers to disconnectedness within and external to the NSU. Some examples include:

- two DHBs have been part of a quality improvement process where they found information was not well distributed or co-ordinated
- regional co-ordination is lacking, which impedes cost and time efficiency and services may be duplicated – communication and structure are essential to maintain past achievements
- dissatisfaction with management and interaction with consumers and multidisciplinary groups, including those for kaimahi (in the ISPs), processes for performance management audits and developing monitoring standards.

Overall, the feedback suggests disjointed operations and structural issues within the NSU and NCSP.

NCSP management

CSI recommendation 1.13 required the NCSP to be treated as 'part of a national cancer control strategy as this has sometimes been perceived as being compromised for non-medical reasons'. The NSU has highlighted the impact of Ministry of Health restructuring on its management, clinical and advisory roles and pending staff recruitment efforts. Planning documents for the New Zealand Cancer Control Strategy and Action Plan are aligned with and include the work of the national screening programmes. At least five out of the six goals for the Cancer Control Strategy have direct links to the NSU and NCSP. In particular, Goal 2 is to 'ensure effective screening and early detection to reduce cancer incidence and mortality'. The NSU National Clinical Director role is designed to be equivalent to the current National Cancer Control Programme's Clinical Director. Better clinical co-ordination for screening programmes is expected with this organisational change in clinical leadership (46).

Recommendations

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.

2. Regional co-ordination 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 co-ordination 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.

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 ISPs. 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.)

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 co-ordination of all cancer screening programmes to achieve better alignment of strategies and services across the entire cancer continuum.

Future considerations

Representation for consumer and priority women's groups

The two remaining NCSP advisory groups must have a stronger role and function to ensure an adequate voice and presence for consumer and women's groups. These include the NCSP Advisory Group and the Māori Monitoring & Equity Group, formerly known as the Māori Advisory Group. A Pacific group advises all NSU programmes and meets twice a year. The NSU has also looked at merging Māori, Pacific and other health promoters into one hui, and the National Leadership & Workforce Development Forum in March 2011 was the first attempt to implement this strategy. The NSU still needs to consider whether other priority women's groups are sufficiently covered by these arrangements.

Regional co-ordination

Regional co-ordination is still lacking in some areas despite this being a strategic priority. Providers emphasise that there is an urgent need to ensure collaboration among DHBs, PHOs and ISPs, with appropriate strategic and leadership capacity in all screening programmes.

Whānau ora approach

Cervical screening must be integrated with other health programmes, particularly those that are able to demonstrate inclusiveness of whānau/family. An increased emphasis on health promotion rather than health education has been recommended. The whānau ora approach needs to be given priority and should be driven from the screening programme to primary health care providers to improve screening participation and retention. (See also the 'Ethnicity Data' and 'Coverage, Participation, Equity, Access and Disease Burden' sections.)

Workforce Issues

Current status

Smear takers

The Cervical Screening Inquiry (CSI) recommended that only health professionals who have undergone specific formal training and who participate in continuing professional development should collect Pap test specimens. The lack of free training and easily accessible update courses is a barrier to safe practice. Smear-taker training and update courses should be provided free for practice nurses and should be more broadly available.

The NCSP *Operational Policy and Quality Standards* (22) require that all smear takers complete a recognised educational course in specimen collection through one of the following training programmes:

- a New Zealand Qualifications Authority (NZQA)-accredited course for non-medical smear takers
- training as part of a medical degree
- through an NZQA midwifery training programme.

The 2009 *NCSP Competencies for Smear Taker Training* (24) were developed to provide detailed requirements for the skills, knowledge and attributes for smear takers. They replaced the *NCSP Training Standards for Smear Takers 2002*. Competencies are intended for trainees, supervisors and accredited providers of NZQA Unit Standard 1098, which is most commonly used by non-medical smear takers.

Entry to smear-taker training is restricted to individuals who meet the following criteria. Individuals must be either:

- a New Zealand-registered nurse, midwife, nurse practitioner or doctor; or
- an enrolled nurse or nurse assistant.

Completion of this training programme should normally take no more than one year. Entry for lay people to the NZQA unit standard for smear-taker training was discontinued when the NZQA-accredited course was updated with NSU input in 2008.

The proportion of cytology specimens taken by non-medical smear takers is increasing. In 2008 nurses took approximately 38% of smears within the NCSP, compared with 34% in 2006 and 31% in 2005. These competencies help to ensure that smear takers provide a consistently high standard for specimen collection.

The Cervical Screening Inquiry (2000/01) noted that free training and courses for updating smear takers were not sufficiently accessible for these providers. In response, the NSU implemented strategies to address this concern.

- The NSU, NCSP and laboratories began to provide updates to smear takers (medical and nursing) through methods such as professional development (training), newsletters and emails/reminders.
- NCSP competencies for smear-taker training were revised in June 2009.
- The NCSP introduced a smear-taker training fund in 2002, allowing reimbursement of those who completed the course; this fund was increased in 2008. Providers in primary and community health care (PHOs, ISPs) have suggested direct funding of organisations for training fees, instead of through individual reimbursements.

Colposcopy

The *Report on the Findings of a Review of District Health Board Colposcopy Services* (2006) (47) noted that the NSU recognises that some DHBs experience difficulties recruiting and retaining experienced colposcopists. It also noted that the sustainability of 21 DHB colposcopy service providers may need to be discussed and consideration given to a lead regional service model. All DHBs completed an NCSP template for assessing work force capacity as part of that review. Approximately 123 permanent consultants or long-term locums were employed across the DHBs that performed colposcopies, and four vacancies were reported at the time of data collection.

It is difficult to determine if this is sufficient for a national workforce, as colposcopy is only one component of Obstetrics and Gynaecology consultants' work, and at times lack of availability can be due to competing priorities. Some rural services occasionally have difficulty recruiting, but there is no indication that there is a 'shortage' of qualified staff available for colposcopy.

RANZCOG C-QuIP[14] has commenced registration of colposcopists in Australia and New Zealand based on their current practices and experiences. This will be a preliminary requirement towards eventual certification/ re-certification. The NCSP policies and standards currently under revision (including section 6 for colposcopy services) will plan to include the requirement that colposcopists be obliged to meet the standards that will eventually be outlined by RANZCOG C-QuIP. As the number of overseas-trained colposcopists working in New Zealand increases, it is important to ensure they are well versed in NCSP policies and standards and the New Zealand guidelines to reduce any risk to programme quality functions.

[14] See http://www.ranzcog.edu.au/cquip/index.shtml for more detail.

Laboratories

NCSP *Operational Policy and Quality Standards*, Section 5, 'Providing a Laboratory Service' (23), relates to the provision of gynaecological cytology and/or histology services, including high-risk human papillomavirus (hrHPV) testing for NCSP. The term 'laboratory' applies to each individual fixed laboratory site and includes all community and hospital laboratories providing gynaecological cytology and/or histology services.

'... the intended outcome of this tender process was to reduce the number of labs operating in New Zealand. Of course the opposite happened with large labs like our own no longer able to offer job security to new or even incumbent staff. For the first time in 30 years we had difficulty maintaining our workforce. Individual case load, overtime and lab cost had to increase to compensate.'

'Our scientific staff were made redundant and our highly experienced gynaecological pathologists are no longer allowed by the NCSP to report cervical biopsies.' (Interviewee)

All pathologists, scientists and technicians reporting gynaecological cytology or histology, along with histo-scientists and histo-technicians preparing histology specimens for the NCSP, must have appropriate qualifications and be competent, as defined in the Health Practitioners Competency Assurance Act 2003. All professionals who interpret LBC specimens must complete an appropriate training course. Continuing education is mandatory for all staff who report gynaecological cytology and/or histology.

This section of the NCSP *Operational Policy and Quality Standards* aims to provide health professionals with policies, guidelines and standards to enable them to provide an appropriate level of laboratory service. This ensures that all aspects of the screening pathway relevant to gynaecological cytology and/or histology meet NCSP standards and are reviewed to maintain continuous quality improvements.

To ensure that NCSP standards are met and laboratory services are provided as per the tender process, feedback from the laboratories to this Review Committee highlighted specific concerns regarding recruitment and retention of their scientific workforce.

National Gynaecological Cytology Training School

Since 2005 the NSU has funded a National Gynaecological Cytology Training School, previously contracted to Canterbury Health Laboratories. This provides update courses for all practitioners. With the expiry of this contract, a tender process is (or will soon be) underway for continuation of the training services, expanded to include cervical histology and HPV testing. The new tender process has been based on laboratory responses to an NCSP survey. Detailed recommendations are outlined in a discussion paper (48). Based on laboratory feedback to this Committee, such training may not be the optimal approach given the changing role of cytotechnology. There is concern about maintaining workforce capacity in future years.

Key issues and recommendations

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.

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.

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.

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.

5. The HPV vaccine 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.)

6. Laboratories must maintain the experience and expertise of their scientific workforce.

Ethnicity Data: Quality, Completeness and Use

Current status

Ethnicity data and reporting

Regular monitoring and reporting of progress on the collection and collation of Māori ethnicity data for cervical screening is an important issue, which the NCSP must address. Since 2001 the NSU has completed annual (and other) statistical reports (44). Because Māori women are significantly undercounted on the NCSP Register (33), these reports must examine disparity statistics and data to enable specific monitoring of the gap in screening coverage between Māori and non-Māori women (49).

One report (50) outlines strategies to improve the accuracy and completeness of ethnicity data on the NCSP Register. Smear takers are educated about collecting self-identified ethnicity information and processes for matching NCSP Register data with NHI data where no information is recorded on a woman's ethnicity. The NSU continues to explore the use of ethnicity adjustors in monthly and annual monitoring reports. These processes must continue, along with the system that tracks progress to improve the collection and collation of Māori women's data.

The National Kaitiaki Group (NKG) reviews applications for access to Māori women's (aggregate) data for monitoring and reporting (44). However, issues persist that must be addressed to eliminate reporting delays.

Whānau ora approaches

The Whānau Ora strategy in the Māori health sector has seen collaborations of hauora providers with combined social, educational, economic and environmental interests. It also allows the larger integrated and iwi (tribal) based organisations to deliver improved whānau outcomes across their constituencies and to have much broader indicators for measuring their achievements. These are important sector movements for embracing the much-needed alternative approaches to reducing disparities, particularly for Māori women and their whānau (51).

Screening inequalities

There have been significant historical disparities in participation and coverage rates. Women from ethnic groups (Māori, Pacific and Asian) have been less likely to participate in screening (10, 33, 52). Although there has been improved participation and coverage, as well as a decreased incidence of and mortality from cancer of the cervix among ethnic groups, such improvements have not been significant enough to eradicate the disparate burden of disease compared to the general population. (See the 'Coverage, Participation, Equity, Access and Disease Burden' section for more detail.)

Key issues

Barriers to access

Recurring themes revealed in the review were equal access, cost, location and cultural barriers. A multi-pronged approach for improved access for vulnerable groups must be considered, including health groups, health promoters, health educators, school programmes, family development initiatives and whānau ora collectives such as community-based mobile and after-hours screening services.

Coverage for priority women

Disparities in coverage rates need to be reduced by continually increasing access for all priority women's groups. Consumer groups would prefer a broader definition of high priority in the future – one that includes Asian women, migrant and refugee women, women in same-sex relationships, those who have suffered sexual abuse and women with disabilities. Other vulnerable groups are:

- women who have been seldom or never screened
- women aged 50 years of age and older
- low socioeconomic and rural women
- women of low literacy
- women with physical and cognitive challenges
- transient women (eg, female shearing workers).

Informed decision-making

Women's consumer groups reported a failure to adequately inform women about aspects of their health care that involve:

- the Pap test and its limitations
- the benefits and risks of the cervical screening programme
- eligibility for free screening among high-priority populations
- greater access to another clinician who is more sensitive to an individual's needs, for those who have had a negative experience with screening in the past.

Women who are adequately informed are more likely to participate in screening.

Health promotion providers report feeling "disempowered, poorly managed and poorly funded. They consider that lack of equity of funding is clearly evident although providers stated that NCSP management has indicated the need to rectify this situation". (Interviewee)

Funding for community engagement

Direct funding that enables communities to promote screening is true collaboration because it supports customised public education efforts that are best suited to each community. Women's services reportedly experience inconsistencies from NCSP managers. Mixed messages have confused and disrupted service continuity and credibility within the primary health care sector.

National Kaitiaki Group (NKG) processes

This review has found that disheartening commentary still abounds inside and outside the Ministry of Health. This relates to ongoing challenges that limit regular access to aggregate data on Māori women enrolled with the NCSP Register, as well as the NKG's role in granting data access. Both the NSU and the NCSP experience frustration in trying to comply with the NKG's changing requirements for accessing aggregate data to perform routine monitoring. Non-approval affects timely reporting and unnecessarily increases workload. The NKG's rejections for data access have delayed routine monitoring efforts.

Over-extended authority

Some interviewees questioned the role and authority of the NKG, suggesting that their actions have gone beyond the original scope intended for the group. It seems the NKG believes they have the authority to review NSU and NCSP activities. Those outside the NKG do not regard this as a legitimate role, given that there are other legitimate monitoring, evaluation and review processes in place that appraise the programme's benefits to Māori and all other women.

The programme's outcomes are reported at appropriate intervals and are supplied to the Ministry. All details on the programme's achievements and benefits to Māori are known, as are the gaps and various strategies to reduce these.

Providers (DHBs and ISPs) advise that NKG processes that question and refute applicants' requests for data are no longer useful. Data access to complete evaluations must improve. NKG application processes require streamlining and updating so that there is no interference with routine monitoring functions, otherwise, it presents an unnecessary barrier that impedes improvements in women's health.

Support for the NKG

Others have expressed support for the NKG and for maintaining the Kaitiaki Regulations. For example:

- there is still belief in the concept of protecting Māori women's data
- some stakeholders are not sure, or not in favour of, getting rid of the NKG altogether
- others said it was timely for this review to address remaining issues for access to Māori women's aggregate data and are relying on future analysis to 'iron out' current access difficulties.

NKG Regulations review

A review of the Health (Cervical Screening (Kaitiaki)) Regulations was undertaken in 2002 and Cabinet decided to maintain the status quo. This had the effect of retaining and perpetuating the difficulties noted above. These included delays with:

- reporting coverage for Māori women – monthly coverage rates must be assessed as part of NCSP monitoring for programme effectiveness; coverage for Māori (as well as Pacific and Asian) women remains well below the 75% target for New Zealand
- formulating and monitoring initiatives – monthly baseline data on coverage rates inform the NCSP in developing appropriate strategies with providers to increase Māori women's screening participation and retention
- providing timely reports to the Minister.

Data destruction

The NKG has required the NCSP to destroy all data after six months, including all electronic copies and paper copies distributed to parties outside the NSU. The impact of this has included:

- destroying essential coverage reports needed for time-series reporting (tracking trends)
- prohibiting appropriate follow-up of issues that affect Māori women's participation.

These continuing difficulties have prompted the NCSP to seek a legal opinion (53) regarding how best to streamline processes for accessing Māori women's data. The report's Recommendation 5.1 states:

> If the opportunity arises to amend the Kaitiaki Regulations the opportunity should be taken to clarify the relationship between the NKG and the ability of the NCSP to access use and disclose 'protected information' without the consent of the NKG.

Recommendation 6.1 states:

> There may be some value in issuing a document setting out what the NSU sees as the routine uses of 'protected information' and other information from the register, and Programme that employees are entitled to under section 112ZE, and the circumstances in which NKG approval would be sought prior to undertaking any use or analysis of such information.

Recommendations

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 'HPV Testing'.)
2. The following recommendations relate to the National Kaitiaki Group.
    - 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'.

Future considerations

There is ongoing concern about providers' understanding of how to treat tangata whenua for screening and specimen collection. Women's experiences are important for sustaining their participation in screening. It only takes one bad experience for a woman to withdraw and never participate again. Strategies have to be multi-faceted, targeted and rolled out in consultation and collaboration with a wide range of providers and utilising their specific models of care, such as whānau ora (family wellbeing). (See also the 'Coverage, Participation, Equity, Access and Disease Burden' section of this report.)

The programme needs to demonstrate the capability to accommodate a whānau ora approach. Focus group(s) and other qualitative methods are required to understand and address barriers and implement facilitators for women from all ethnic groups, those with special needs and the most vulnerable. For instance, women's consumer groups and other providers want more suitable and appropriate venues for screening priority women, such as marae-based community health clinics and other community-based clinics that provide culturally specific and appropriate services to these populations. Some have suggested more 'suitcase' smear takers for home-based services. A whānau ora nurse would also be ideal for at-risk and high-priority groups.

We encourage major primary care medical and nursing practitioners to show more evidence of working together. There is still a need to place funding in primary health care education and health promotion with independent service providers, hauora Māori providers and whānau ora collectives. PHOs, both Māori and Pacific, have said they want to work with providers to influence better service integration, thus increasing participation among Māori and Pacific women. Some have advocated incentives for these providers, as well as for doctors and nurses.

For women who will not attend for specimen collection, self-collected specimens for HPV testing are a realistic option – one that would suit this group as well as offering more options for rural or under-serviced areas.

The NCSP Register

Current status

The National Cervical Screening Programme Register (NCSP Register) is an important management tool for the NCSP.

(See www.nsu.govt.nz/nationalscreeningunit for more detail.)

The Register is a database for storing and maintaining screening details and it supports new service delivery as well as the management of participants with abnormal screening tests.

The Register holds the details of all participants enrolled in the NCSP (54). This information includes:

- participants' demographic data (name, address, age and ethnicity)
- National Health Index number
- participants' Pap test and histology results
- HPV test results
- clinician demographic data
- details regarding health facilities and laboratories.

The NCSP Register's function is prescribed under Part 4A, Section 112F (2), of the Health Act.[15] Every result that is reported to the NCSP from a screening test, or from a diagnostic test, must be recorded on the Register if that result relates to a woman who is enrolled in the NCSP. As such, the Register operates on the basis of implied consent and women must submit a written request to exclude their screening results from the Register. The proportion of those who choose to withdraw from the Register is extremely small: 48 women (0.003%) during one reporting period of 6 months.

The NCSP Register supports the NCSP by:

- supplying screening histories to support clinicians, laboratories and colposcopists to provide screening to women
- generating confirmation notices to women who have enrolled in, or withdrawn from, the programme
- providing a back-up service to GPs by generating letters to women regarding test results and overdue screening notices
- providing statistical data to fulfil monitoring and evaluation functions.

[15] Health Act 1956, Public Act 1956 No 65, date of assent 25 October 1956.

Under Part 4A of the Health Act, as amended in 2004, information can only be provided outside the programme (under s 112J) to health practitioner(s), and/or evaluators, or to a review committee appointed by the Minister of Health to evaluate the programme, and to others for the purpose of follow-up after a screening or diagnostic test.

History

In 2010 the administrative and technical support functions of the NCSP Register were transferred to DATAM,[16] a subsidiary of the NZ Post Group, although the management and accountability for the Register remained with the Ministry of Health. In 1991 the Register was first introduced in 14 Area Health Boards (AHBs) as stand-alone systems. In 1994 the Register became a national database operating out of the 14 AHBs. Data input was maintained at the AHB level. In 1996 the Register was centralised in Wellington, with the operational teams remaining in AHBs. In 2000, the Government initiated changes which led to community-focused District Health Boards (DHBs). In 2002 data input to the Register was reduced from 14 to 6 DHBs.

In 2006 NCSP providers were consulted about the preferred service delivery model for the operation of the NCSP Register. The Ministry of Health assumed responsibility for Register operations and the NSU re-developed the Register; the changes were implemented in September 2008. In July 2010 administrative and technical support functions of the Register were transferred to DATAM. Management and accountability for the Register remained with the Ministry through a rigorous governance regime of monitoring and audit.

The Ministry of Health anticipates a number of efficiency gains from the new arrangements, including technology enhancements, improvements in programme monitoring and the interface with primary care. The NSU has communicated these changes to the sector over the course of the project through published documents and workshops. Based on the feedback, all personal information is stored securely and confidentially. The new provider is charged with complying with all relevant health legislation.

Management and accountability

The NCSP Register services with DATAM are managed under a governance framework.[17] Regular meetings occur with designated Ministry representatives. They are:

- weekly – operations review
- monthly – services delivery review
- quarterly – quality and audit, register governance review
- annually – strategic review.

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[16] See https://www.datam.co.nz/ for more information.

[17] 491092/334000/00 Provider No/Contract No NCSP-R Governance and Relationship Management.

The monthly service delivery report highlights the:

- performance overview
- business operations services
- information system application support & maintenance and development services
- information system hosting and infrastructure services
- event, incident and problem management content
- changes and continual service improvement programme report.

Accessibility of the NCSP Register

The NCSP Register is available on-line to DHB laboratories and colposcopy services. This includes data on any individual whose screening and/or histology results may have been completed at other laboratories. Screening history must be available at each stage of the screening process and for clinical interpretation and analysis (23). Recommendations for recall or referral must be based on the cytological findings of the most current screening test, combined with the woman's complete gynaecological history, in accordance with the NCSP Guidelines.

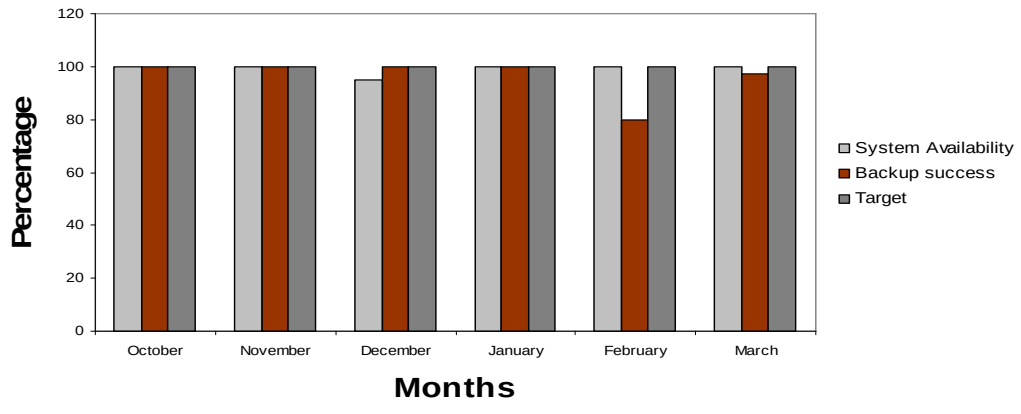
Laboratory staff must seek information from the NCSP Register (available electronically) if the laboratory does not have the screening history of a woman who is enrolled on the NCSP Register, or if the full history is uncertain. This also applies to colposcopy services.

Key issues

Outages

After the initial transition of the NCSP Register to DATAM there were problems with access on-line by users because of outages. This has improved, and by the early part of 2011 unplanned outages during core hours for the month of February totalled just three hours (see Figure 6).

Figure 6. Information system hosting and infrastructure services – service levels (55)



Integrity and timeliness of data transfer

Since mid-2009 the NCSP Register has received data electronically, including colposcopy data. Laboratories and colposcopy services send data on a regular basis. For laboratories this is possible with electronic data transfer to the Register. Electronic access to the Register and direct electronic reporting are still in development at the DHB level for colposcopy units; private colposcopists will need to modify their own systems. For colposcopy services, three DHBs enter data electronically. All other colposcopy data are sent manually on forms to the Register Central Team for manual entry.

Some DHB colposcopy clinics (about half) have software that enables them to perform electronic data extraction from their systems, download this onto the required forms and send these to the Register Central Team for manual data entry. Other DHB colposcopy services do not have a computerised clinical database system, and these forms have to be filled in manually. This reporting activity is time consuming and could be assisted by a uniform computerised system for all colposcopy services that would also ensure integrity and timeliness of data and transfer. There are plans to move to weekly reporting for more timely data collection.

Laboratory cytology

Since July 1 2010, over 10,000 cytology results could not be processed and were rejected when HL7 was introduced. These results had to be uploaded to the NCSP Register. Processes are underway to ensure that these outstanding results are resolved expeditiously via collaboration between the NCSP Register and laboratories (February 2011 teleconference notes).

The volume of rejected results has decreased markedly for most of the laboratories. As of 11 April 2011, there were 7333 rejected results still needing to be resubmitted to the NCSP Register. Over half of these (3827) were from one laboratory due to a technical issue, which they are addressing.

Some missing results have resulted in sending incorrect reminder letters. Regional services had to field calls from smear takers and women who had previously advised that a Pap test had been completed and that the report or generated letter was incorrect. Communications were sent to smear takers advising them of this, and efforts to rectify the situation are reported to be under way.

Colposcopy services

There are outstanding problems with the collection and uploading of colposcopy data to the NCSP Register. The NSU has notified all DHBs of colposcopy service issues concerning the quality of colposcopy reporting to the NSCP. The NSU has ongoing concerns with the quality of colposcopy data and has requested that all DHB colposcopy services urgently review their processes for completing the forms. Reporting to the NCSP is both a contractual and

legislative requirement of colposcopy services (section 112M of the Health [National Cervical Screening Programme] Amendment Act 2004).

As evidence of these concerns, when the NSU undertook a data review of the NCSP Register it uncovered a significant amount of missing or incomplete information on colposcopy forms, including:

- colposcopy visit reporting form – missing data rate estimated to be 30% ± 10%
- colposcopy referral reporting form – missing data rate estimated to be 40% ± 10%
- colposcopy DNA reporting form – missing data rate estimated to be 40% ± 10%.

CDs were sent to each DHB colposcopy unit with all data relating to that unit on the NCSP Register from 1 July 2009 to 31 December 2010. This enabled them to audit their own information systems and identify missing information that had not been sent in, and to provide corrections. These corrections were due to come back to the NCSP by the end of June 2011.

This review by DHBs of the processes relating to their collection and forwarding of colposcopy visit, referral and DNA form information to the NCSP Register is time-consuming, and efforts to rectify this situation require wide collaboration to identify the problems. The NCSP Register does not feel there is an issue with their ability to correctly read data submissions, except for one field relating to discharges. This is scheduled in the work plan for correction.

Complete colposcopy data are essential to ensure:

- a complete screening, assessment and treatment history in the NCSP Register
- the availability of accurate data to facilitate the monitoring and evaluation of provider performance against national standards, indicators and targets
- tracking of individual women to facilitate timely recall and follow-up consistent with the recommended guidelines
- the ability to produce meaningful and accurate reports.

To date, monitoring reports have not been possible for colposcopy performance and standards.

Accuracy of coding results

There are inconsistencies in colposcopy and test results compared with those in the NCSP Register. There is no fail-safe mechanism to ensure that laboratories and the Register are correctly coding the results. The NCSP Register does not employ medical records coders and does not code anything, unlike the Cancer Registry. All data that require coding are coded at source. However, problems (outliers) are usually picked up through routine programme monitoring and, if found, checks are made with the laboratory concerned. In addition, the NCSP has now implemented routine monitoring as a contractual requirement of laboratories, which are also required to report any deviations to the programme.

The NCSP Register Service Delivery Report for January 2011 indicated that:

- 100% of colposcopy referral visits or DNA information are recorded in the NCSP Register Information System within 10 working days of receipt
- 100% of result processing errors are resolved within 10 working days of identification
- 100% of requested screening histories are provided within eight working hours.

Invitation and recall for screening

The NCSP Register has the capacity to issue recall notices to screening participants who are overdue for repeat screens, plus follow-up notifications for those with abnormal results who did not attend for assessment. The NCSP intends to work with the Register team to undertake data matching with primary care to enable appropriate targeting of communities with low coverage. It will actively engage with the health sector and primary care to encourage collaborative approaches for recruitment and retention strategies to engage priority groups in the screening programme and to support women who are referred to colposcopy. However, access to a population register was part of the CSI's recommendations to be more inclusive and to ensure that seldom- and never-screened groups can be invited to participate in screening. Without a population-based recruitment strategy, an essential component of organised screening is missing from the NCSP.

Advances in primary care registers and systems for invitation and recall have addressed some of the issues that could be resolved by access to a population register (see Appendix G.) Invitations for screening participation are issued by primary health organisations to women who are included in their patient registers. Nevertheless, a significant proportion of screen-eligible women, typically the most vulnerable, have not been invited to participate in screening for cervical cancer. Given that cervical cancer is almost entirely preventable, this is a priority equity issue that must be urgently addressed by the programme.

Complaints to the NCSP

The NCSP maintains a register of complaints received from service providers, as well as from women who are invited to enrol, or are already enrolled, in the NCSP Register. A review of the log of 100 complaints over six months in 2009 revealed that 25% of complaints were related to enrolment and withdrawal processes. It is imperative that smear takers and NCSP service providers continue to advise women that screening data are included in the NCSP Register and that participants have a right to opt out, as long as they are fully informed of the consequences of choosing to withdraw from organised screening. If a woman withdraws, she will no longer receive recall or follow-up notices, and there are implications that women must fully understand prior to making such a decision.

Feedback suggests that it would be helpful for providers' competency to have a performance indicator for the informed consent process. Requesting an appointment should not be seen as giving explicit consent (56). Some degree of demonstrated competency by providers is necessary to present both the risks and benefits of screening that enable an informed choice. This is mandated through the Health and Disability Commissioner Code of Rights,[18] but at this time is not adequately assessed as part of the smear taker's quality performance standards. This would also help women better understand the NCSP Register.

National Kaitiaki Group

The NCSP, through the NSU, has to apply to the NKG for Māori women's aggregate data from the NCSP Register each time in order to complete routine monitoring. Delays in approval often result in not meeting deadlines to complete monitoring reports. Failure to provide timely approvals for data access requests puts huge pressure on the workload of the NCSP. The NKG is reported to have no provision for prospective (or standing) applications for data access, based on a strict interpretation of the Health (Cervical Screening (Kaitiaki)) Regulations 1995, which specifically refer to protected information that is already on the Register (section 2[1]).

The Health Act was specifically amended in 2004 to facilitate improved monitoring of the NCSP (following the Gisborne Inquiry). The purpose of the Act is to reduce the incidence of and mortality from cervical cancer by providing for the continuity of the NCSP, and to facilitate the operation and evaluation of the NCSP by enabling access to information. Section 112D specifically sets out the NCSP's objectives. Monitoring is not only a statutory responsibility to ensure the safety of women in the programme, but specifically enables the NCSP to assess progress in reducing inequalities (ie, closing the gaps in screening participation between Māori and non-Māori – a core programme objective). Continuing productive dialogue between the NCSP and NKG is essential to resolve this ongoing issue and develop a better solution.

Recommendations

1. The NCSP must work with DHBs to ensure the integrity of colposcopy data supplied to the NCSP Register. This is an urgent priority.

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.

3. Colposcopy services must be supported to facilitate efficient electronic transfer of data.

[18] See http://www.hdc.org.nz/media/2223/english-leaflet.pdf for more information.

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.

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.

6. Linkages between the National Immunisation Register and the NCSP Register and Cancer Registry to monitor the effectiveness of HPV vaccination are essential for ongoing integrated evaluation of screening and prevention efforts.

Future considerations

A phase two plan will allow electronic access to the NCSP Register by agencies that provide specimen collection (eg, smear takers). This facility will depend on the technological readiness of those agencies and funding in the NSU. As yet there is no specific timeframe for this work, but it is expected to start some time in the next financial year.

With the introduction of the HPV vaccine in New Zealand, the National Immunisation Register is a required data set that must be available for linkage to the NCSP Register and Cancer Registry. Information from school-based consent forms and details of each vaccine dose offered, given or declined at school or in primary care are recorded on either the School-Based Vaccination System (or similar) or the General Practice Management System, and some of it will be posted on the National Immunisation Register. The linkage of immunisation, screening, cytology, histology, diagnostic and treatment data is vital to facilitate monitoring of the effectiveness of HPV vaccination in New Zealand.

Colposcopy

New Zealand is the only country that has the duty of persons performing colposcopic procedure enshrined in its health legislation.

Current status

The Health (National Cervical Screening Programme) Amendment Act 2004 defines the duty of persons performing colposcopic procedures as follows.

(1) Every person who performs a colposcopic procedure on a woman must –

  (a) explain the procedure to the woman; and

  (b) provide information, to the extent that is reasonable in the circumstances, about the objectives of the NCSP and the NCSP register, the importance of having regular screening tests, who has access to information on the NCSP register, and the uses to which that information may be put; and

  (c) if he or she believes that the woman is not enrolled in the NCSP, advise her that she will be enrolled but that she may prevent or cancel that enrolment by notifying the NCSP manager under section 112G; and

  (d) cause a report in relation to that colposcopic procedure to be forwarded to the NCSP manager.

(2) A report under subsection (1)(d) must –

  (a) be provided free of charge; and

  (b) contain the information specified by the Director-General; and

  (c) be provided in the manner and form specified by the Director-General.

Colposcopy services and providers

Colposcopy services and providers receive an *Operational Policy and Quality Standard Manual* (21) from the NCSP. Guidelines for cervical screening in New Zealand (57) incorporate a section headed 'The Management of Women with Abnormal Cervical Smears'.

Colposcopy services staff must be appropriately qualified and experienced. Colposcopy clinics are directed/led by a designated, appropriately skilled medical specialist responsible for ensuring the delivery of services in accordance with the policy and standards. In each facility one lead clinic nurse who has gynaecology skills and experience is dedicated to colposcopy and has no concurrent duties in other clinics. Colposcopy must be performed by a trained colposcopist, who works closely with other health professionals, and may include an experienced gynaecology or sexual health nurse and a pathologist.

All colposcopy service providers contracted to the NCSP are monitored by an independent monitoring group, which reviews colposcopy-specific indicators with targets on a biannual basis. The NCSP follows up on any issues arising from the reports. Colposcopists have guidance on their responsibilities to the woman attending for colposcopy, her GP or primary care provider, and the smear taker (if this is not the woman's regular GP or primary care provider). The colposcopist should have cytology reports and screening history available during colposcopy examination and advise the pathologist and laboratory of any required history and findings of the examination.

The urgency of colposcopic examination depends on the degree of abnormality indicated by the Pap test result or by clinical examination. If treatments are recommended, there are targets for timeliness of treatment. Colposcopy services are monitored to ensure they meet the prescribed target dates.

Colposcopy services should be culturally safe, ensuring that an individual woman's needs are met. The service should ensure that staff undertake training on the Treaty of Waitangi and are able to apply these concepts when working with Māori women. Māori, as tangata whenua (people of the land), have a special relationship with the Crown. The Crown has duties and responsibilities under the Treaty of Waitangi to ensure improved health outcomes for Māori people. As agents of the Crown, service providers are obliged to fulfil these responsibilities.

Colposcopy services are also required to be appropriate for and supportive of Pacific and Asian women and those from other ethnic groups, and to acknowledge their culture and ensure cultural competence throughout the service. Colposcopy services must also meet the diverse needs of women of all ages and sexual orientation.

Māori support services

Māori support services will be utilised, where available, to assist in locating, supporting and providing follow-up of women referred for colposcopy.

Guidelines for loss to follow-up (failure or refusal to attend)

A reasonable effort should be made to ensure women attend colposcopy, including an offer of other appointment times. Colposcopy services have written protocols, with prescribed targets, for the management of women who do not attend (DNA) for follow-up care after referral to colposcopy. The purpose of these guidelines is to ensure attendance and manage non-attendance.

District Health Board colposcopy services

In October 2005 the Health and Disability Commissioner found that Waitemata DHB had breached Right 4(1) of the Health and Disability Services Code of Consumer Rights in respect of the care of a woman with invasive cancer. In response, the NSU requested that all DHBs undertake a review of their colposcopy services. The analysis of review responses, in addition to the outcomes from routine provider compliance audits and contract monitoring, indicated that, to a greater or lesser extent, all DHBs were experiencing difficulties in achieving compliance with the *Operational Policy and Quality Standards*.

Report on the findings of a review of District Health Board Colposcopy Services (47)

The 2006 review of DHB colposcopy services, the nine routine colposcopy service audits and the analysis of colposcopy data generated the following findings and recommendations.

Findings

The NSU received an uneven response from DHBs to the review's questions. Some DHBs provided comprehensive information, while others provided insufficient information to support a detailed analysis and further follow-up was necessary. DHBs provided sufficient information to allow meaningful analysis of:

- triage and classification of colposcopy referrals
- information provided to referring clinicians
- information provided to women regarding referral, diagnosis and treatment
- clinical leadership/oversight to ensure adherence to professional requirements
- quality assurance activities.

Insufficient information was provided to support the analysis of responses relating to:

- wait list data
- clerical and booking system processes
- documentation
- multidisciplinary team meetings for colposcopy case review.

The following areas were highlighted in the review.

- The lack of standardisation of assessment and grading of referrals is an important issue that needs to be addressed.
- Wait-time data may not be accurately reported due to inconsistency in data generated from colposcopy databases and patient management systems, and the variation in triaging, classification of referrals, clerical and booking system processes.

- Checking processes are important to ensure that all women who are assessed and/or treated by colposcopy services receive appropriate follow-up care.
- DHBs need to maintain an audit and to reconcile their clinical files. Some DHBs are using manual systems to report data to the NCSP, and issues of data completeness and inaccuracy are common. Clinicians in the services have identified this as an area for improvement so that greater consistency within and between services is achieved.
- Services appreciate the importance of ensuring that correspondence is sent to smear takers, GPs, referring health professionals and women.
- DHBs are providing women with the NCSP pamphlet when the appointment letter is sent, and DHB-specific information is conveyed either at the time of the colposcopy appointment or when the colposcopy results are communicated.
- Multidisciplinary meetings for colposcopy case review were recommended in the 1999 *Guidelines for the Management of Women with Abnormal Cervical Smears*. However, attendance at, and the frequency of, multidisciplinary team meetings is variable, and documentation of meetings and outcomes of case reviews is incomplete.
- DHBs have often not identified a formalised lead colposcopist role. This finding has significant implications for the services' ability to achieve the required organisation for regular multidisciplinary colposcopy case reviews, as this forum requires dedicated clinical leadership and co-ordination.
- All DHBs have processes in place to manage incident reports, and a number of DHBs have internal audit plans.

Recommendations from the review

- The NSU continue to follow up with each DHB colposcopy service to support the development of plans to address the issues identified during audit.
- The DHBs be encouraged and supported to identify key performance indicators and to establish a programme of internal monitoring against the NCSP *Operational Policy and Quality Standards (OPQS).*
- The NSU engage with the DHB managers of women's services to identify areas where the development of infrastructure support for colposcopy units is needed to ensure that contractual requirements are met.
- The DHBs address the infrastructure requirements to support clinicians in their quality assurance processes.
- The NSU undertakes a scoping exercise to determine whether additional resources are required for DHBs to achieve compliance with the NCSP OPQS.

- The NSU collaborates with lead colposcopists to support the development of services and educational opportunities for staff which could include assistance with the development of specifications for the lead colposcopist and nurse roles.
- The NSU reprioritises the routine colposcopy service audits within the NCSP audit programme.
- The NSU undertakes a process to monitor the progress of DHB colposcopy services in quarter one 2007/08.

All DHB colposcopy services have undergone audit since the 2006 report. Three reports are referenced for further information:

a) *Progress against Colposcopy Review Recommendations Made from the 'Report on the Findings of a Review of District Health Board Colposcopy Services'*, December 2006

b) *Compliance on the First Round of NCSP Colposcopy Compliance Audits*, August 2008

c) *National Audit Programme: NCSP, Audit Report, Colposcopy Services 2006–2008*.

Progress against Colposcopy Review Recommendations Made from the 'Report on the Findings of a Review of District Health Board Colposcopy Services' (47)

This draft in August 2008 discussed progress in areas identified in the 2006 review report. There had been improvement in most areas, but in two areas, although showing progress at that stage, some DHBs needed further improvement:

- compliance with the NCSP Operational Policy and Quality Standards for managing women who fail to attend appointments
- establishing documented, regular, multidisciplinary case review meetings.

(See Appendix H for more detail.)

DHB colposcopy audits

The first round of colposcopy audits of all 21 DHBs was completed between March 2006 and April 2008 (58). An audit team, comprising a lead auditor from International Accreditation New Zealand (IANZ) and a multidisciplinary team of specialist advisors, conducted on-site examination of documentation and records, discussions with relevant staff members and direct observation of some activities. The fundamental purpose of the audit was to provide an objective assessment of compliance by DHB colposcopy services with the Operational Policy and Quality Standards and contractual obligations for service delivery.

The audits addressed many concerns highlighted in the review report, and other concerns have been addressed outside of or in conjunction with audits. The audit report recommended that any departures from the Operational Policy and Quality Standards or contractual obligations should be addressed through corrective action requests.

All DHBs were non-compliant in several, or many, areas and the audit process helped to inform DHBs and the NSU of how to better meet standards and requirements for service delivery. An NSU representative followed up with all DHBs following the audit to discuss corrective actions and DHB plans to resolve and negotiate timeframes for resolution.

This process has taken considerably more time for DHBs than the NSU anticipated; priority was given to high-risk corrective action requests. National colposcopy meetings for key people in colposcopy have contributed to improved networking and information-sharing across DHBs, thereby contributing to a better understanding of, and a more consistent approach to, applying the Operational Policy and Quality Standards to colposcopy services.

Recommendations from Progress against Colposcopy Review Recommendations and 2008 DHBs colposcopy audits (58, 59)

The following recommendations were made.

1. Close performance management by the NSU to oversee resolution of the outstanding audit corrective action requests continues, with issues of non-compliance of resolution being escalated in consultation at the monthly Quality Meeting and/or monthly Senior Management Team (SMT) meeting.

2. The NSU finalises the process for reporting on the completion of corrective action requests, escalation of issues and audit follow-up for the second round of audits.

3. The audit process is reviewed and refined for the second round, taking into account feedback received from key people involved.

4. National colposcopy meetings continue to keep the networking of DHBs and information sharing alive.

5. Review of the funding/pricing for colposcopy services in the future is to be considered in the 2009/10 NSU work plan.

6. Workforce development is further considered, after the outcome of the Cabinet Workforce Development Paper to bring all workforce development under one umbrella has been considered.

Current round of DHB colposcopy audits

A new round of DHB colposcopy audits began in June 2010, following a new process for provider appointments. The new colposcopy auditor has not yet completed DHB monitoring reports. This delay has restricted the Review Committee's ability to provide the latest appraisal of the colposcopy services.

Current monitoring of colposcopy services

Monitoring of colposcopy services occurs monthly through assessment against contractual requirements. Monitoring has not been reported in the biannual monitoring reports as yet. This is due to start following completion of a project undertaken to improve colposcopy data collection on the NCSP Register.

The NSU has ongoing concerns with the quality of colposcopy service data in the NCSP Register (60, 61), with missing data in reporting forms varying from 30% to 40%, ± 10%. The colposcopy services, in turn, are concerned about the timely management of data audit within the NCSP Register. They also find it difficult to meet the demand on resources at a DHB level to review their processes relating to the collection and forwarding of information to the NCSP Register.

NCSP six-monthly Monitoring Report 32, July–December 2009 (10)

This is the latest monitoring report available, but unfortunately it does not report on these colposcopy indicators. The calculation of these indicators is under development and will include measures such as:

- wait times for colposcopic assessment of abnormal cytology results
- adequacy of recording at colposcopy
- minimum colposcopy volumes
- correlation between colposcopy and histology
- adequacy of treatment.

Some of these measures are still being defined. Colposcopy data are collected on the NCSP Register, but data relating to the time period of this report are believed to be incomplete. As a result, measures were not calculated for the current reporting period. Data completeness is improving, and it is anticipated that these colposcopy indicators will be reported upon in future.

DHB colposcopy services have expressed disappointment with the delay for including colposcopy indicators in monitoring reports and in receiving reports from the recent DHB colposcopy audits.

Nurses providing colposcopy

The NSU has been made aware of nurses undertaking colposcopy procedures in two DHBs. NCSP Operational Policy and Quality Standards for colposcopy services were developed with RANZCOG representatives for medically trained College Fellows. Standards will be reviewed to incorporate RANZCOG recommendations once a common training pathway is developed for all professional groups interested in performing colposcopy procedures.

Until this pathway for nurses is established, the NSU does not support the accreditation and employment of nurses as colposcopists. The NSU recognises that the nurse colposcopist role has potential for enhanced choices for women and reducing wait times, while providing clinically effective care. The NSU is also aware that work has gone into the development of training standards by the New Zealand Nurses Organisation, and that the two nurses who perform colposcopy procedures have undergone training in accordance with those standards.

Regarding these two nurses, the NSU does require assurance that there are adequate systems in place within DHBs to ensure the safety of women and clarity around the services that will be provided. It is imperative that women are fully informed of the type and extent of the service provided by the nurse colposcopist, and, in particular, its limitations and boundaries, and the medical supervision, oversight and accountability that are provided. The NSU intends to liaise with RANZCOG, the Ministry's Chief Nursing Advisor and the Nursing Council of New Zealand to further develop this role, and will inform colposcopy units regarding developments.

Note: The Nursing Council of New Zealand authorized the training standards for nurse colposcopists (62), which were developed by the New Zealand Nurses' Organisation Women's Health Section in consultation with key stakeholders. These standards established that registered nurses trained to these standards are able to undertake colposcopy, as are nurse practitioners where it is part of their role.

RANZCOG C-QuIP Programme

(See http://www.ranzcog.edu.au/cquip/index.shtml for more detail.)

In August 2009 the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) were successful in securing a grant from the Department of Health and Aging to develop an education, accreditation/re-accreditation and audit programme for all health professionals performing colposcopy in Australia and New Zealand over a period of three years.

The Colposcopy Quality Improvement Programme (C-QuIP) will improve the care of women who are referred for colposcopy and treatment of screen-detected abnormalities. This will be achieved by:

- developing certification and recertification programmes in colposcopy
- promoting best practice in colposcopy, with an emphasis on safety and quality
- developing audit for all health professionals and centres performing colposcopy
- supporting practitioners in their efforts to improve their performance in colposcopy
- providing a comprehensive on-line education programme for all professionals performing colposcopy.

Colposcopists in Australia and New Zealand have commenced registration with RANZCOG C-QuIP, detailing their practice and experience in colposcopy. The Pap test registries around Australia collect data relevant to the proposed quality standards, such as screening history, date and outcome of histology. They receive some information on colposcopy, although this is not systematically collected.

A small pilot in the state of Victoria, Australia, is underway to determine the feasibility and most effective method of collecting colposcopy data. Colposcopy services in New Zealand, on the other hand, are well ahead in this process as colposcopy data are already collected in the NCSP Register, awaiting only the inclusion of colposcopy indicators in their monitoring reports.

Recommendations

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 non-compliant in several, or many, areas.

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.

3. National colposcopy meetings should be re-convened to improve networking of DHBs and information sharing, as the last meeting was held in 2008.

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.

HPV Vaccination

About 13 high-risk HPV types are strongly associated with cervical cancer, and another six are also likely to be carcinogenic (63). HPV is also associated with other cancers, including cancer of the penis, anus, vagina, vulva and some oral cancers (64–68), although the evidence is not yet as strong as for cervical cancer. It will therefore be important to assess the HPV vaccine's potential role in the prevention of these other cancers (69). Primary and secondary prevention of HPV-related cancers requires an integrated and cohesive strategy to maximise the benefits of immunisation and screening. This is unlikely to transpire efficiently and effectively without collaboration.

Fully integrated screening and vaccine programmes are needed because each alone will not reach all women (70, 71). To achieve the maximum impact of cervical cancer control (primary and secondary prevention), all eligible women should be encouraged to receive the preventive HPV vaccine and should also have access to and participate in cervical screening, regardless of immunisation status. In particular, more effective strategies are needed to reach vulnerable populations. Promotion and social marketing efforts must be multi-focal, targeted, community-based and culturally sensitive to increase screening among the seldom- or never-screened population.

Current situation

New Zealand implemented an HPV immunisation programme in 2009 using Gardasil® for 12-year-old females, with an additional 'catch-up' component for older females up to 20 years of age. As of December 2010, vaccine uptake had not been optimal, with about 50% of the eligible population receiving at least the first two of three required doses and only 46% receiving all three doses (53). Among ethnic groups that received all three doses, coverage was highest among Pacific females (70%), followed by Māori females at 56%; these levels reached the projected targets (53). To achieve maximum benefit and cost effectiveness of the vaccine programme, coverage must be high, due to the costs of the vaccine itself and programme delivery. Since Gardasil® is a quadrivalent vaccine that also prevents infection from HPV types 6 and 11, those who receive the vaccine will also likely be protected from ano-genital warts, as a secondary benefit.

Accurate knowledge of the link between HPV and related cancers in the general population is essential to ensure that vaccine recipients and/or their parents understand the causal relationship between HPV and related cancers. HPV is a very common virus and current evidence must be available for clinicians and the public (via appropriate resources) to ensure a full understanding of the benefits and risks of any intervention. Improved knowledge of HPV, combined with targeted interventions to reach those who decided against immunisation, may help to increase vaccine coverage.

NCSP has demonstrated forward thinking by commissioning a study of the impact of immunisation on cervical screening, cancer incidence and the NCSP (72).

Recommendations

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). Benefits from such a strategy will likely translate to improved screening participation as well as vaccine uptake.

2. Ongoing linkage among all immunisation, screening and cancer databases is essential to move forward with integrated evaluation of primary and secondary prevention of HPV-related cancers.

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.

4. All stakeholders need to embrace this new paradigm for 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 impacted by HPV – this is truly an issue that affects society as a whole.

HPV Testing

Current status

Since conversion to liquid-based cytology (LBC), NCSP and affiliated laboratories have had the capacity, from 2009, to perform HPV-DNA testing as a triage mechanism when mild Pap test abnormalities are noted while reading cervical cytology. The programme has also recommended HPV testing for management after treatment of abnormalities to assess the success of treatment. New Zealand has been forward thinking in making use of these new technologies.

Guidance (but not guidelines) for using HPV testing for these two approaches is provided in the most recent NCSP cervical screening guidelines (73, 74).

Furthermore, a significant proportion of laboratories are converting to automated cytology reading. Use of all these technologies move towards increased efficiency and capacity. (See also the section on Laboratories in Quality Assurance and Monitoring.)

Recommendation

1. NSU and NCSP need to more actively engage 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. NCSP should position their programme in the context of the broader cancer control strategies.

Future considerations

With publications from large randomised clinical trials in several jurisdictions (75–79), convincing evidence is emerging to support the use of HPV testing as a primary screening test. While there are still practical programme issues and algorithms to sort out, it is timely for any cervical screening programme to initiate the planning and strategy processes for moving to this new paradigm (80). Preparing for this change and implementing a co-ordinated evaluation strategy necessitates broad consultation across stakeholders and service providers, including those parts of the health sector that have typically not required ongoing communication and collaboration (69).

Furthermore, new screening tests are under assessment.[19] NCSP and stakeholders will have to consider each in the context of their current screening and immunisation programmes and how, or if, they may be suitable for implementation. Additional challenges face the programmed as it is not always clear or straightforward what impact will transpire, and what resources will be required, to adapt to the changing landscape. One thing is certain – any change process will depend on consultation and collaboration with all relevant stakeholders and service providers. A cancer screening programme cannot function in isolation.

Modifying standards and guidelines in the context of current and emerging evidence will be an ongoing need. This will similarly be the case with quality assurance programmes at all levels of the immunisation and screening continuum.

[19] 15 That will not be outlined in this report.

Future Directions

Lower screening participation has been noted among younger women in other jurisdictions. Consequently, public education efforts will need to reinforce the importance of cervical cancer screening in this age group to avoid potential complacency after immunisation. Given the causal relationship between HPV and other genital and non-genital cancers, public and professional education must include information on the role of hrHPV in cancers other than cervical (as described earlier in this report).

The focus for the prevention of HPV-related disease must be broadened to include both men and women to ensure better awareness and accurate knowledge in the entire population. In the new era of HPV vaccination, most (but not all) persistent HPV infections will decrease, with a subsequent reduction in high-grade squamous intra-epithelial abnormalities of the cervix. This will, in turn, result in fewer colposcopies and treatment of cervical abnormalities. As the prevalence of abnormalities falls, this will have an impact on the performance characteristics of cytology as a screening test due to a lower positive predictive value.

As international evidence strengthens about the use of HPV testing as a primary screening test, many researchers and stakeholders in the screening programme are increasingly supportive of moving forward to replace cytology with HPV testing as the primary screen, and reserving cytology as a triage to ascertain referral to colposcopy. This would have a major impact on the organised cervical screening programme, with the likely scenario of delaying initial screens until 25 years of age or later, and extending screening intervals (by HPV testing) to six years. This may reduce over-treatment of women less than 25 years of age, as colposcopy is the current recommendation for women of any age with high-grade abnormalities.

Potential consequences for screening providers will impact on their workforce and require a review of quality assurance in the areas of cytology and colposcopy. NCSP will need to collaborate with, and seek expert advice from, service providers, clinicians, public and population health experts, epidemiologists, researchers, vaccine experts and community groups to meet these new challenges and continue to provide the high quality service that New Zealanders have come to expect and deserve.

At times there is confusion regarding the respective roles of NCSP and NSU. It appears that the original intent for NCSP was to provide a service that would reduce the burden of disease from cancer of the cervix. This would encompass the women who participate, health promotion activities, smear takers and assessment services, laboratories and related staff, treatment services, monitoring agents and evaluation teams. The NCSP would provide cohesiveness and co-ordination for all these initiatives.

The NSU is the primary, but not the only, agency responsible for facilitating the organisation of all these activities, but for some, NSU should not have direct control. NCSP is larger than the NSU. Some organisational, accountability and leadership problems are apparently related to a contrary NSU philosophy that the NCSP is merely one of several screening programmes. NSU's intended role was to facilitate and support NCSP, and it should operate accordingly.

NSU is a major stakeholder regarding successful implementation and maintenance of a cervical screening programme, with a role to facilitate the organisation and cooperation of all the stakeholders and partners.

Yet the main stakeholders have to be the women of New Zealand; without that focus, participation and effectiveness may be reduced.

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Glossary

AHB	Area Health Board
ASCCP	Australian Society for Colposcopy and Cervical Pathology
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.
BSA	BreastScreen Aotearoa
Cervical Cancer Audit	*The New Zealand Cervical Cancer Audit: Screening of Women with Cervical Cancer (2000–02)* was published , with 31 recommendations, in November 2004.
CIN	cervical intra-epithelial 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 'Cancer Screening Inquiry' (CSI), released its report containing 46 recommendations in 2001.
C-QuIP	Colposcopy Quality Improvement Programme
DD-G	Deputy Director-General
DHB	District Health Board
DNA	Did not attend
H&DC	Health and Disability Commissioner
hauora Māori providers	Māori health (service) provider/s
HPCA Act	Health Practitioners Competence Assurance Act 2003
HPV	human papillomavirus
HPV-DNA	human papillomavirus – deoxyribonucleic acid
hrHPV	high-risk HPV
hui	meeting or large gathering
IANZ	International Accreditation New Zealand
IDCC & R	Intellectual Disability Compulsory Care and Rehabilitation
ISP	independent service provider
kaimahi	health worker/s
NCSP	National Cervical Screening Programme: the national programme for cervical screening in the National Screening Unit

NCSP–R	National Cervical Screening Programme Register, or the 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.
NGO	non-government organisation
NHB	National Health Board: the national services, purchasing, and strategic planning division of the Ministry of Health.
NHI	National Health Index
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 Service (disbanded in 2008)
NZNO	New Zealand Nurses Organisation
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.
Pacifica	of/belonging to the Pacific region: an inclusive term for the Pacific Island nations of the Pacific region
PHC	primary health care
PHO	primary health organisation
RCPA	The Royal College of Pathologists of Australasia
RNZCGP	The Royal New Zealand College of General Practitioners
RANZCOG	The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
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)
Whānau Ora	family health and wellbeing: the name of the national Māori health strategy led by the current Associate Minister of Health 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.
WHO	World Health Organization

Appendices

Appendix A: Areas of review defined by the Review Committee (from the Final Plan to the Minister of Health)

1.5.1 Coverage, participation, equity, access and disease burden

- Coverage and screening participation by region, age, ethnicity and socioeconomic status.
- Adherence to screening guidelines.
- Retention rates and loss to follow-up rates.
- Historical trends in rates and processes related to these measures.
- Impact of access, coverage and participation on overall morbidity and mortality over time and across various population sectors.
- Work undertaken to improve data and measurement, and impact (if any) of these activities.
- Are there differences in access that vary by ethnicity and/or socioeconomic status?
- What mechanisms are in place to ensure equitable access to screening and treatment services by all populations that are eligible for screening?
- Key facilitators and barriers to future improvements.
- Work undertaken (or proposed) by the NSU or its providers to evaluate its activities in these areas.

1.5.2 Quality

- Review Independent Monitoring Group (IMG) reports and other documentations held by the NSU or relevant groups in relation to quality across the Programme and in laboratory facilities.
- Work undertaken (or proposed) by the NSU or its providers to evaluate its activities in these areas.
- New Zealand Cervical Cancer Audit.
- Laboratories: provision of cytology and histology – reporting rates. Monitoring of continuing competence in laboratory staff.

1.5.3 Organisational and structural issues

- Are there structural (ie, NCSP structure) and infrastructural issues that have an impact on the quality of the NCSP and services it delivers?
- Work undertaken (or proposed) by the NSU or its providers to evaluate its activities in these areas.
- Role and performance of the NCSP Advisory Group.

1.5.4 Workforce issues

- Current issues for workforce.
- Possible issues for the future.
- NCSP planning and actions around current and future workforce issues.

1.5.5 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?

1.5.6 NCSP Register

- Integrity and timeliness of data, integration with and across laboratories.
- Processes for invitation of those who are seldom or never screened, recall of those overdue for screening and follow-up of those with abnormal results.
- Access to on-line screening histories.
- Support to regional services and any possible issues.
- Collection of colposcopy data and any possible issues.

1.5.7 Colposcopy

- Colposcopists (medical) – RANZCOG C-QuIP Programme.
- Nurse colposcopists – accreditation and practice improvement.

1.5.8 HPV vaccination

- Impact of HPV immunisation on the NCSP.
- Assess impact from the evaluation of the Immunisation Programme on how well the programme has achieved coverage and met goals, objectives and implementation priorities.

1.5.9 HPV testing

- Guidance on using HPV testing by detecting high-risk type HPV.
- Criteria for approving HPV tests that meet WHO international standards.

1.6 Future directions

1.6.1 Technology

- Liquid-based cytology.

1.6.2 Screening

- Using HPV testing as primary screening.

1.6.3 Management

- CIN 2 in young women.

1.6.4 Research

- Future research to be undertaken.

Appendix B: Recommendations arising from the Cervical Screening Inquiry 2001 and follow-up reports

(Prepared by the NSU for the Parliamentary Review Committee 2011)

In the early 2000s a number of reviews of the National Cervical Screening Programme (NCSP) were undertaken by external agencies. In 2001 the Ministerial Inquiry into the Under-reporting of Cervical Smear Abnormalities in the Gisborne Region, known as the 'Cancer Screening Inquiry' (CSI), released a report containing 46 recommendations. At the request of the Minister of Health, Dr Euphemia McGoogan, an independent cytopathology expert, visited New Zealand in October and November 2001 to carry out a review of progress over the first six months. A written report summarising her findings was provided to the Minister of Health in December 2001.

In October 2001 the Office of the Auditor General (OAG) also carried out a review to determine what action had been undertaken to implement the CSI's recommendations. The OAG released its first report in February 2002. In addition, the OAG advised the Minister of Health that it intended to keep the progress made in implementing the CSI's recommendations under review. The OAG undertook this by maintaining contact with Dr McGoogan and reviewing the Ministry's monthly and quarterly reports to the Minister of Health.

Dr McGoogan revisited New Zealand in January 2003 and in June produced her second and final report on the progress of the implementation of the recommendations. In July 2003, at the Minister of Health's request following issues raised in Dr McGoogan's report, the OAG undertook a follow-up review of the progress made in implementing the 46 recommendations. The OAG released its second report in December 2003. The OAG looked at:

- what progress had been made by the Ministry since Dr McGoogan's review (in January 2003)
- the issues relating to, and reasons why, the Ministry had not progressed as quickly as recommended with the implementation of some recommendations
- how and when the Ministry intended to address other issues raised in Dr McGoogan's reports.

Recommendation 1 of the CSI required a review of the cervical screening history of women with cervical cancer. The Ministry and the University of Auckland completed a review of 371 women who had developed cervical cancer between 1 January 2000 and 30 September 2002. The findings were published in November 2004. The audit found that from a national perspective the NCSP operates to a generally high standard for women who are having regular cervical smears. The audit did not find systemic issues in the laboratory reading and reporting of cervical smears. The audit made 31 recommendations, which the Ministry has been addressing.

The above reports have resulted in over a hundred recommendations, the vast majority of which have either been implemented or have become an ongoing part of NCSP business. This appendix works through all of these recommendations and comments on their status as follows:

1 Status of the CSI Recommendations

2 Status of Dr McGoogan's Recommendations

3 Status of Dr McGoogan's Further Recommendations

4 Status of the Auditor-General's Recommendations

5 Status of the Cervical Cancer Audit Recommendations

1 Status of the Cervical Screening Inquiry (CSI) recommendations

Ref	Recommendation	Status: January 2011	Further work required?
1.1	**Evaluation of National Cervical Screening Programme** The remaining two phases of the national evaluation designed by the Otago University Team must proceed. Until those phases are completed the programme's safety for women cannot be known. It is imperative that this exercise is completed within the next six months. Particular attention should be given to the discrepancy between the average reporting rate of high-grade abnormalities of Douglass Hanly Moir Pathology (2.5%–3.7%) for the re-read of the Gisborne women's smear tests and the current New Zealand national average for reporting high-grade abnormalities (0.8%). Unless this exercise is carried out the possibility that the national average is flawed and that there is a systematic problem of under-reporting in New Zealand laboratories cannot be excluded.	The Ministry of Health and the University of Auckland completed a review of 371 women who had developed cervical cancer between 1 January 2000 and 30 September 2002. The *New Zealand Cervical Cancer Audit: Screening of Women with Cervical Cancer: 2000–2002* (referred to as the Cervical Cancer Audit) was published in November 2004. The audit found that the programme operated to a generally high standard for women who had regular cervical smears. It did not find systemic issues in the laboratory reading and reporting of cervical smears. The audit made 31 recommendations, which the Ministry of Health has been addressing.	No

Ref	Recommendation	Status: January 2011	Further work required?
1.2	**Re-enrolment and re-screening of women** If the national evaluation throws doubt on the accuracy of the current national average then the Committee recommends that all women who are or who have participated in the programme should be invited to re-enrol and offered two smear tests 12 months apart. Women who have never enrolled on the Register or who have had their names removed from the Register should be invited through notices in the print media to also go through the process of having two smear tests twelve months apart.	This recommendation will not be implemented, as there was no indication from the Cervical Cancer Audit that recommendation 1.2 needs to be responded to.	No
1.3	**Evaluation of National Cervical Screening Programme** A comprehensive evaluation of all aspects of the National Cervical Screening Programme, which reflects the 1997 Draft Evaluation Plan developed by Doctors Cox and Richardson, should be commenced within 18 months. This exercise should build upon the three-phase evaluation referred to in recommendation 1.1.	Parts 5, 6 and 8 have been included within the scope of Part 3 (Cancer Audit) – see recommendation 1.1 above. Parts 4, 7 and 10 are included within the scope of the programme's statistical reporting. *See also recommendation 1.7 below.*	No
1.4	**Operational Policy and Quality Standards, and Evaluation and Monitoring Plan** The Policy and Quality Standards for the National Cervical Screening Programme and the Evaluation and Monitoring Plan for the National Cervical Screening Programme prepared by Dr Julia Peters and her team must be implemented fully within the next 12 months.	The standards were implemented in October 2000 and a number of sections have been revised since. There are ongoing periodic reviews of the standards. The Health (National Cervical Screening Programme) Amendment Act 2004 enabled regulations to be made if needed that set standards for screening services. In accordance with the Evaluation and Monitoring Plan, an independent monitoring group was contracted to provide quarterly and annual monitoring reports.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.4	(Continued)	Since January 2009 monitoring reports have been published six-monthly, prepared by the Cancer Council NSW in collaboration with the NSU. Expert review is undertaken by the NCSP Advisory Group. The NSU also undertakes quarterly reporting of the NCSP.	
1.5	**Full legal assessment of Operational Policy and Quality Standards** There needs to be a full legal assessment of the Policy & Quality Standards for the National Cervical Screening Programme and the Evaluation and Monitoring Plan for the National Cervical Screening Programme to ensure that the requisite legal authority to carry out these plans is in place.	A report from Kim Murray (Barrister) was provided to the NSU in December 2001.	No
1.6	**Legal assessment of National Cervical Screening Programme authority** The National Cervical Screening Programme should be thoroughly evaluated by lawyers to determine whether or not those persons charged with tasks under the programme have the necessary legal authority to discharge them.	This issue was also included in the report from Kim Murray (Barrister) provided to the NSU in December 2001.	No
1.7	**Statistical reporting.** The National Cervical Screening Programme should issue annual statistical reports. These reports should provide statistical analysis to indicate the quality of laboratory performance. They should also provide statistical analysis of all other aspects of the programme. They must be critically evaluated to identify areas of deficiency or weakness in the programme. These must be remedied in a timely manner.	Independent monitoring against a range of programme indicators and targets has taken place quarterly and, from 2008, six-monthly. These reports are available at www.nsu.govt.nz/health-professionals/1063.asp. Independent review and recommendations on these reports has been provided to the NSU by a contracted independent monitoring group, and since 2008 by the NCSP Advisory Group. The NSU reports on actions taken in response to this advice.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.7	(Continued)	The following statistical reviews are also available on the NSU website: • annual statistical reports since 2001 • *Cervical Screening in New Zealand: A Brief Statistical Review of the First Decade* (2005) • Lewis H, Li-Chia Yeh, Almendral B, Neal H. Monitoring the performance of New Zealand's National Cervical Screening Programme though data linkage. NZ Med J 2009; 122: 1305.	
1.8	**Regular statistical information** Meaningful statistical information should be generated from both the National Cervical Screening Register and the Cancer Registry on a regular basis. Attention must be paid not only to laboratory reporting rates but also trends and the incidence of disease, assessed by regions that are meaningful to allow some correlation between reporting profiles of laboratories and the incidence of cancer. Because cervical smear tests may be read outside the region in which the smear test is taken, a recording system needs to be devised which identifies the region where smears are taken.	Monitoring against programme indicators is undertaken regularly using data generated by the NCSP Register (see recommendation 1.7). Work is in progress to improve the quality of colposcopy data on the Register. It has been the considered opinion of the NSU and the University of Otago that it is not possible to correlate laboratory reporting with the regional incidence of cervical cancer in New Zealand.	Yes – ongoing
1.9	**Minimum standards for cytology laboratories** The compulsory setting of a minimum number of smears that should be read by laboratories each year must be put in place. The proposal to impose three minimum volume standards on laboratories must be implemented.	NCSP laboratory agreements began incorporating minimum volume standards from July 2001. Almost all laboratories have been meeting the minimum volume standards since December 2005. However, one laboratory did not meet the minimum volume requirement of 15,000 per annum to June 2010. The NSU is monitoring this laboratory closely to see that it meets the standards. It has a one-year contract, and the contract will only be renewed for another year.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.9	(Continued) These are: each fixed site will process a minimum of 15,000 gynaecology cytology cases, each pathologist will report at least 500 abnormal gynaecological cytology cases, cytotechnical staff must primary screen a minimum of 3000 gynaecological cytology cases per annum. This should be implemented within 12 months.	Minimum standards for staff were reviewed in consultation with the sector and updated in 2008, as follows. • Pathologists: 500 cases (any interpretation); for mixed LBC/conventional samples, a minimum of 100 cases of the lesser sample type were reviewed. • Non-medical staff: – senior staff: a minimum of 3000 cases, which may include up to 1200 full re-screen cases – charge scientists: 1000 primary/full re-screen cases • Mixed conventional/LBC samples: a minimum of 500 LBC cases if the majority of cases are conventional; a minimum of 500 conventional cases if the majority of cases are LBC. In 2009 additional standards and policy were incorporated, including minimum volumes in an automated screening environment. In 2010 the programme converted to 100% LBC (SurePath or ThinPrep).	
1.10	**Balanced approach for National Cervical Screening Programme** There needs to be a balanced approach, which recognises the importance of all aspects of the National Cervical Screening Programme. The emphasis on smear-taking and increasing the numbers of women enrolled on the programme needs to be adjusted.	The programme now has a more balanced approach, with a strong focus on increasing coverage among under-screened groups as well as continuously improving quality across all components of the screening pathway.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.11	**Culture of the National Screening Unit** The culture which was developing in the Health Funding Authority regarding the management of the National Cervical Screening Programme under the management of Dr Julia Peters needs to be preserved and encouraged now the Health Funding Authority has merged into the new Ministry of Health.	NSU strategic planning supports the continuous quality improvement of its programmes through comprehensive monitoring and evaluation systems. Note that in recent years both the Ministry of Health and the NSU have undergone a number of restructures.	Yes – ongoing
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 on 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 re-integrated 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 the fourth tier. The Clinical Leader has specialist medical qualifications in public health. Restructuring of the Ministry of Health placed the NSU into an operational group under National Services Purchasing. At this time the title Clinical Leader was downgraded to Clinical Advisor. The change in title was not supported by the Group Manager, NSU. The subsequent restructuring of the Ministry of Health brought the NSU in under the National Health Board.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.13	(Continued) While there are understandable reasons for having the programme managed by a woman it is not necessary for cervical screening programmes to have female managers. The cervical screening programme in New South Wales is managed by a male medical practitioner. The time has arrived for the National Screening Programme to be treated as a medical programme which is part of a national cancer control strategy. In the past its link with the Cartwright report has at times resulted in its purpose as a cancer control strategy being compromised for non-medical reasons.	A parallel review of the NSU's internal structure moved the clinical positions into the relevant operational screening programmes. The net effect of these processes resulted in the clinical positions sitting at tier 6 and the role of the Clinical Advisor in the NSU being compromised. These changes also risk compromising the credibility of the position to external clinical directors in the sector and wider stakeholder interest groups. Overall it has become clear that the role of the Clinical Advisor has been downgraded. This poses risks to the clinical safety of women in the programme (in terms of the perceived role) and is not consistent with the intent of the recommendations made by the Gisborne Inquiry. The Group Manager is preparing papers to propose a change of the Clinical Advisor position to that of Clinical Director overseeing the NCSP. This aligns the role with other national clinical positions and clinical positions in the sector.	
1.14	**Amend section 74 of the Health Act 1956** The Health Act 1956 should be amended to permit the National Cervical Screening Programme to be effectively audited, monitored and evaluated by any appropriately qualified persons irrespective of their legal relationship with the Ministry. This requires an amendment to section 74A of the Health Act to permit such persons to have ready access to all information on the National Cervical Screening Register.	The Health (National Cervical Screening Programme) Amendment Act 2004 contains provisions to permit the effective monitoring, audit and evaluation of the programme.	No

Ref	Recommendation	Status: January 2011	Further work required?
1.15	**Kaitiaki Regulations** There needs to be reconsideration of the Kaitiaki Regulations, and the manner in which those regulations currently affect the Ministry of Health gaining access to aggregate data of Māori women enrolled on the National Cervical Screening Register. The Ministry of Health and any appropriately qualified persons engaged by it (be they independent contractors, agents or employees) require ready access to the information currently protected by the Kaitiaki Regulations in order to carry out any audit, monitoring or evaluation of the programme.	A review of the Health (Cervical Screening (Kaitiaki)) Regulations was undertaken in 2002 and the decision of Cabinet was to retain the status quo. However, the NCSP continues to have difficulties in gaining timely access to Māori women's data on the Register to be able to fulfil its legislative functions. This has resulted in delays with: • assessing monthly NCSP coverage among Māori women (and other women) • providing NCSP providers with baseline monthly coverage information to help them to formulate and monitor initiatives aimed at increasing Māori women's participation in the NCSP • providing monthly information to update the communications strategy • reporting approved summary monthly coverage of Māori women to the Minister or other key stakeholders. Because of these difficulties, legal advice was sought in 2010 regarding the application of the Kaitiaki Regulations. In summary, the advice was that amendments in Health Act in 2004 (Section 112ZE) make it clear that NCSP staff should have unimpeded access to register information to carry out their functions, and this prevails over the restrictions in the Kaitiaki Regulations. It was suggested that it would be timely to consider amending the regulations to clarify this point. The NCSP continues to work closely with the National Kaitiaki Group to try to resolve these issues.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.16	**Legal right to access information from the Cancer Register** The present legal rights of access to information held on the Cancer Registry need to be clarified. The Ministry and any appropriately qualified persons it engages to carry out (external or internal) audits, monitoring or evaluation of cervical cancer incidence and mortality require ready access to all information stored on the Cancer Registry about persons registered as having cervical cancer.	The amendment to the Health Act 1956 contains provisions to permit screening programme evaluators to access all information on the Cancer Registry that relates to a relevant woman.	No
1.17	**Amend Health Act 1956 to enable access to medical files** The Health Act 1956 requires amendment to enable Ministry of Health and any appropriately qualified persons it engages to carry out (external or internal) audits, monitoring or evaluation of cervical cancer incidence and mortality, to have ready access to all medical files recording the treatment of the cervical cancer by all health providers who had a role in such treatment.	The amendment to the Health Act 1956 contains provisions to permit the effective monitoring, audit and evaluation of the programme, including access for evaluators to health information and specimens relating to a relevant woman.	No
1.18	**Change guidelines under which ethics committees operate** There needs to be change to guidelines under which ethics committees operate to make it clear that any (external and internal) audit, monitoring and evaluation of past and current medical treatment does not require the approval of ethics committees.	The operational standards for ethics committees have been amended.	No
1.19	**Review of operations of ethics committees** There should also be a review of the operation of ethics committees and the impact their decisions are having on independently funded evaluation exercises and on medical research generally in New Zealand.	Ethics committees have been reviewed and a new ethics committee structure put in place. The National Ethics Advisory Committee undertook this work in 2002/03, culminating in the presentation of advice to the Minister of Health in December 2003 and implementation of the National Ethics Advisory Committee's recommendations.	No

Ref	Recommendation	Status: January 2011	Further work required?
1.20	**Provide guidelines to ethics committees regarding Privacy Act & Code** Ethics committees require guidance regarding the application of the Privacy Act and the Privacy Health Information Code. Ethics committees need to be informed that the interpretation of legislation relating to personal privacy is for the agency holding a patient's data to decide. They would, therefore, benefit from having at least one legally qualified person on each regional committee.	The operational standards for ethics committees have been updated. *See also recommendation 1.18 above.*	No
1.21	**Guidelines to ethics committees for observational studies** Ethics committees require guidance regarding the weighing up of harms and benefits in assessing the ethics of observational studies.	The guidelines were released in December 2006.	No
1.22	**National ethics committee – multi-centre studies** A national ethics committee should be established for the assessment of multi-centre or national studies.	A national multi-region ethics committee was established in December 2004.	No
1.23	**Appeal process for ethics committee decisions** The procedures under which ethics committees operate need to be re-examined. Consideration should be given to processes to allow their decisions to be appealed to an independent body.	In March 2009 the Health Research Council (HRC) undertook consultation on the document *A New Appeals Process for Ethical Review in New Zealand*, which contained draft terms of reference and an appeals process for a Health Research Council Ethics Committee on Appeal (HRC ECA). The appeals process gained Ministerial approval in 2010 and it is anticipated that the final appeals process and terms of reference will be finalised shortly.	Yes (near complete)

Ref	Recommendation	Status: January 2011	Further work required?
1.24	**National Cervical Screening Programme complaints system** The National Cervical Screening Programme requires its own system to deal with complaints regarding the programme's delivery. It also needs to have in place a user-friendly system which can respond to complaints of programme failures, such as under-reporting. The difficulty that witness A experienced in having her medical misadventure recognised as a failure of the programme and a failure of Gisborne Laboratories must be avoided in the future.	The NSU complaints process has been implemented. *See also recommendation 1.45.*	Yes – ongoing
1.25	**Electronic link Cancer Registry & National Cervical Screening Programme Register** The National Cervical Screening Register needs to be electronically linked with the Cancer Registry.	A process for linking and matching data has been implemented. Cancer Registry records are uploaded and matched manually to the NCSP Register. This process is sufficient given that the data set is very small. *See also recommendation 1.26 below.*	Yes – ongoing
1.26	**Performance standards for National Cervical Screening Programme Register and Cancer Registry** Performance standards should be put in place for the National Cervical Screening Register and the Cancer Registry. The currency of the data on both registers needs to be improved. The Cancer Registry should be funded in a way that enables it to provide timely and accurate data that is meaningful.	A redeveloped NCSP Register went live on 29 September 2008. While generally working according to data entry turnaround times stipulated in the OPQS, there have been ongoing technical issues that have resulted in delays in the ability to access monitoring data and reports. These issues are recorded in the NSU JIRA system. There have also been unplanned outages, during which the Register service is disrupted and either slows down or providers are unable to connect to the Register.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.26	(Continued)	In June 2010 the NCSP Register administration and technical and support functions were transferred to an external agency (DATAM, a subsidiary of New Zealand Post). The management and accountability for the NCSP Register and the programme remains with the Ministry (ie, the NSU Manager, Information). Standards for the NCSP Register are currently under revision. In February 2011 the Government announced a plan to upgrade the Cancer Registry to enable data to be available to clinicians online.	
1.27	**Standards for the National Cervical Screening Programme should be reviewed every two years** Standards for the National Cervical Screening Programme should be reviewed every two years and more frequently if monitoring indicates that some of the standards are inappropriate.	Review and updating of the NCSP Operational Policy and Quality Standards (OPQS) is an ongoing process, reflecting changes to the programme and best practice. This process is now well established and considered routine business. The NCSP OPQS are available at www.nsu.govt.nz.	Yes – ongoing
1.28	**The Government must ensure sufficient cytotechnologists and cytopathologists and training sites** The Government in consultation with other bodies or agencies needs to ensure that there are sufficient trained cytotechnologists and cytopathologists and that there are appropriate training sites for them. There should also be a review of training requirements and maintenance of competence of smear test readers and cytopathologists.	The Vocational Registration Programme in Cervical Cytology (VRPCC) for BMLSc graduates and cytotechnicians was implemented in 2004/05. This has been embedded in the NCSP OPQS as compulsory for all new practitioners. Training and education for the NCSP laboratory cytology workforce has been provided since 2005 by a contracted laboratory, and in 2011 it is being extended to include histology and human papillomavirus (HPV) testing. Staff workload is included in the OPQS and is also audited on-site annually.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.29	**Amend Medical Laboratory Technologists Regulations 1989** The Medical Laboratory Regulations 1989 should be amended to permit only registered medical practitioners with specialist qualifications in pathology and appropriate training in cytopathology or appropriately trained cytoscreeners to read cervical smear tests.	The Health Practitioners Competence Assurance Act 2003 was passed and replaced the older regulations. The Act contains provisions that give effect to the intent of the recommendations from the inquiry, including the establishment of new registration authorities and the development of gazetted scopes of practice. The registration authority is now the Medical Laboratory Science Board (MLSB). The Act is common to all health practitioners and includes technicians. It includes continuing professional development activity as a requirement for issue of annual practising certificates from the MLSB.	No
1.30	**Impose legal obligations on storage of slides** Legal obligations in addition to those mandated by IANZ must be imposed on all laboratories reading cervical cytology requiring them to retain records of patients' cytology and histology results (including slides, reports and any other material relating to the patient) in safe storage for a period of no less than five years from the date on which the results were reported. Secondly all laboratory owners must be made legally responsible for ensuring that a patient's records are readily accessible and properly archived during the five-year storage period irrespective of changes in the laboratory's ownership through a sale of shares or a sale of the laboratory's business.	The NCSP OPQS require laboratories to keep slides and tissue in accordance with current guidelines recognised by IANZ (aligned with Australian guidelines). Storage of slides is also further specified in the NCSP Laboratory Service Agreement. Routine diagnostic testing has been excluded from the Standard for the Non-Therapeutic Use of Tissue.	No

Ref	Recommendation	Status: January 2011	Further work required?
1.30	(Continued) The vendor of the shares or the laboratory's business should carry a primary legal responsibility to store the records, though the option to transfer this legal responsibility as a condition of the sale to the purchaser should be permitted. Similar provisions should apply to laboratory amalgamations. In this case the newly merged entity should be responsible for storing the records.		
1.31	**Ensure electronic linkage between National Cervical Screening Register and cytology labs** The cervical smear test and histology histories of women enrolled on the National Cervical Screening Register should be made electronically available online to all laboratories reading cervical cytology.	All laboratories now have immediate access to online screening histories. This includes HPV test results. Access by practitioners is mandated in the NCSP OPQS and the system is checked during an annual audit.	No
1.32	**Develop standards for accuracy of laboratory coding** Standards must be developed for ensuring the accuracy of laboratory coding and this aspect of the National Cervical Screening Register must be subject to an appropriate quality assurance process.	Laboratory coding is standardised throughout the country and will be updated as part of some Ministry of Health projects. All cytology laboratory coding was revised and updated on 1 July 2005, as *Bethesda 2001 NZ Modified*, in conjunction with a sector working group. The NCSP Register was advised to accept all new codes and to retain former Bethesda codes. All laboratories use this coding. Coding is mandated in the NCSP OPQS. Histology coding uses outdated SNOMED codes, which require updating and standardisation to align with SNOMED CT, for which the Ministry of Health holds a licence. *See also recommendation 1.27.*	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.33	**The National Cervical Screening Programme should develop a population-based register** The National Cervical Screening Programme should work towards developing a population-based register and move away from being the utility-based register that it is now.	This recommendation has been overtaken by progress. Advances made in primary care registers and systems of invitation and recall have addressed many of the issues that were intended to be resolved by a population register.	No
1.34	**Legal mechanisms should be in place to allow the ACC, Medical Council and the Health & Disability Commissioner to share relevant information with the National Cervical Screening Programme** There should be a legal obligation on the Accident Compensation Corporation, the Medical Council and the Health and Disability Commissioner to advise the National Cervical Screening Programme's manager of complaints about the professional performance of providers to the programme when complaints are made to those various organisations about the treatment of a patient in relation to the programme.	The Accident Compensation Corporation is required to report complaints to the Medical Council under the Injury Prevention, Rehabilitation, and Compensation Act 2001. Under the Health and Disability Commissioner Amendment Act 2003, the Health and Disability Commissioner may refer a complaint to the Director-General of Health if it appears that the complaint is a result of inadequacies of the health care provider that may harm the health and safety of the public. Under the Health Practitioners Competence Assurance Act 2003, the Health and Disability Commissioner is required to raise with the Medical Council matters where there is a potential risk of harm to the public from a health practitioner's practice. In addition, under the Act, the Medical Council must inform the Director-General of Health of possible harm posed by the health practitioner.	No

Ref	Recommendation	Status: January 2011	Further work required?
1.35	**Medical Tribunal to supply information to National Cervical Screening Programme** Consideration should be given to the addition of an express requirement in the provisions governing medical disciplinary proceedings which would oblige the Tribunal seized of the facts of any given case specifically to consider whether there are any grounds for concern that there may be a public health risk involved. If that concern is present the Tribunal should be required to inform the Minster of Health.	This recommendation is covered by the comments on recommendation 34 above.	No
1.36	**The Accident Compensation Corporation and the Medical Council should exchange relevant information regarding claims for medical misadventure** There should be an exchange of information between the Accident Compensation Corporation and Medical Council regarding claims for medical misadventure and disciplinary actions against medical practitioners.	Implemented through the Injury Prevention and Rehabilitation Act 2001.	No
1.37	**Liaison with the College of Pathologists** It is recommended that the programme liaise with the Royal College of Pathologists of Australia. In its submissions the Royal College advised that it believed that the collaborative relationship the College had with the Federal Government in Australia might be a model worth consideration by the Inquiry. It was suggested that it was appropriate to use medical colleges as an over-arching body to provide advice on issues. The benefit of this is, if the College is asked to provide an opinion on issues such as professional practice, quality or standards, it has access to the views from multiple professionals and also a critical evaluation of current literature in contemporary standard practices.	College members are represented on the NCSP Advisory Group and on guidelines development working groups, and are regularly included in consultations on NCSP policy and strategic planning.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.37	(Continued) It is suggested that the National Cervical Screening Programme, which has achieved a great deal, would benefit from greater professional input at a College level. In particular, it is suggested that a National Cervical Cancer Register and a Cervical Cancer Mortality Review process be a means of continually evaluating the Programme's effectiveness. The Committee supports the College's submission and recommends that it be acted upon.		
1.38	**Information to women** The programme must provide women with information to enable them to make informed decisions about screening and provide them with information regarding potential risks and benefits. Until the programme has been monitored and evaluated in accordance with the current three phase national evaluation the programme has an obligation to inform women that the quality of the performance of some of its parts has not been tested. Women should also be informed that screening will not necessarily detect cervical cancer.	The Health (National Cervical Screening Programme) Amendment Act 2004 requires all smear takers to provide information to women on the benefits and risks of screening. Women are advised that screening is not 100% risk free. They are also advised of issues of false negatives and false positives. NCSP resources to inform women of the benefits and limitations of screening are actively made available to women. The programme is monitored and evaluated monthly, quarterly, six-monthly and annually in order to minimise problems with screening.	Yes – ongoing
1.39	**Letters to medical practitioners** Medical practitioners need to be reminded that cervical smear tests are not a means of diagnosing cervical cancer. They need to be alert to signs of cervical cancer, and they should not place too much reliance on a patient's smear test results to discount the possibility of cervical cancer being present.	A letter was sent in December 2001. Clinicians are frequently reminded to be alert to signs and symptoms and to exercise clinical judgment (eg, through clinical guidelines and smear-taker operational policy).	No

Ref	Recommendation	Status: January 2011	Further work required?
1.40	**Appropriately trained personnel should do cervical screening** Primary screening of cervical smears should only be performed by individuals who are appropriately trained for that task. Consideration should be given to requiring pathologists to train as cytoscreeners if they want to function as primary screeners.	Primary screening policies and standards are covered in the NCSP OPQS. Screening is limited to appropriately qualified and trained cyto-scientists and cyto-technicians. Pathologists are not permitted to screen. The OPQS was revised in 2008 to include screening of LBC samples and standards for use of automated screening devices. *See also recommendation 1.28 above.*	Yes – ongoing auditing
1.41	**All pathologists undertaking cytology should be appropriately trained** If cytology is a significant component of a pathologist's practice then he or she must participate in continuing medical education in that subject.	Pathologist qualifications and continuing education requirements are covered in the NCSP OPQS. Participation is audited annually. There are also continuing medical education requirements within the Health Practitioners Competence Assurance Act 2003 for maintaining an annual practising certificate.	No
1.42	**Cytopathologists must participate in continuing education in cytopathology** If cytology is a major component of a pathologist's practice, it is desirable that he or she should have added qualifications in cytopathology; either a fellowship slanted towards cytopathology or a diploma in cytopathology. Consideration should be given to making this a mandatory requirement.	Pathologist qualification requirements are covered in the NCSP OPQS. These policies and standards are made mandatory through the agreements with the laboratories. The Health Practitioners Competency Assurance Act 2003 also enforces qualification requirements.	Yes – ongoing
1.43	**Pathologists ought to be more open-minded** Pathologists should be more open minded and critical of laboratory performance. They should be alert to the possibility that their practice or the practice of their colleagues may be sub-optimal.	Pathologists have demonstrated their open-mindedness through participation in advisory and working groups, and participation in external quality assurance programmes.	Yes – ongoing

Ref	Recommendation	Status: January 2011	Further work required?
1.44	**The Medical Council should ensure that systems are in place to support the early reporting of errant medical practitioners by their colleagues** The Medical Council should ensure that systems are in place whereby medical practitioners are not deterred from reporting to it their concerns about the practice of an individual medical practitioner. Complainants should be assured that their reports will not result in them being penalised in any way.	The recommendation has been given effect by the Health Practitioners Competence Assurance Act 2003. Section 34 of the Act protects health practitioners who report concerns about other health practitioners from civil or disciplinary proceeding, unless the reporting was done in bad faith.	No
1.45	**National Cervical Screening Programme should have a system for identifying deficiencies** The screening programme should have in place a system over and above the audit of monitoring reports, to identify deficiencies in the process. A form of survey of users so that they can be proactive rather than reactive in the delivery of the programme would be useful.	An NSU complaints process has been implemented. User feedback is received through advisory and working groups. *See also recommendation 1.24.*	Yes – ongoing
1.46	**There should be a process for monitoring the implementation of the Committee's recommendations** A process to ensure that the recommendations made by the Committee are implemented should be put in place.	Reports on the Ministry's progress in implementing the recommendations include: • Dr McGoogan's six-month report (December 2001) • Dr McGoogan's second and final report (June 2003) • the Office of the Controller and Auditor-General's first report (14 February 2002) • the Office of the Controller and Auditor-General's second report (8 December 2003). Section 112O of the Amendment to the Health Act 1956 requires that the programme be independently reviewed at least once every three years. A Parliamentary Review is currently being undertaken. The Ministry of Health also provides the Minister of Health with regular updates detailing progress made on the recommendations.	Yes – ongoing

2 Status of Dr McGoogan's recommendations

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.1	**Regional Offices (para 129)** I must question the need for the numbers of NCSP Register offices. Data entry occurs at 14 register sites throughout New Zealand although almost 33% of the data is processed in one of these offices (the Auckland office). Some sites have experienced rapid turnover of staff and the quality of training of new staff is variable. The number of sufficiently qualified individuals in New Zealand is limited.	A redeveloped, centralised NCSP Register went live on 29 September 2008. The new Register enables strengthened quality assurance for the Programme and secure real-time communications with service providers and other key stakeholders. In 2010 DATAM was contracted to manage the Register, including day-to-day management of data input from laboratories and colposcopy services as well as technical expertise. All laboratories now submit results to the Register using Health Level 7 (HL7) Ver 2.4 messaging, which is an international standard for electronic healthcare-specific data exchange between computer applications. Colposcopy services are currently developing the capacity to submit results using HL7 messaging. A final date for this to occur has not been agreed. Regional register services also have a role to play in the management of information on the Register through updating of women's details, liaising with smear takers, updating information about health facilities and general enquiries from women and health professionals. *Refer also CSI recommendation 1.26.*	Yes – ongoing
2.2	**Smear takers (paras 89, 90)** Smears should only be taken by health professionals who have undergone specific formal training in smear taking and who participate in continuing professional development in the area of cervical screening.	**Standard 401 of the NCSP OPQS states that** 'All smear takers will complete a recognised educational course in smear-taking practice prior to providing a smear-taking service for women'. Medical practitioners and midwives obtain this through their professional training.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.2	(Continued) The lack of free training and easily accessible update courses is a barrier to safe practice. Smear taking training and update courses should be provided free for practice nurses and lay smear takers and be more geographically available.	Non-medical smear takers undertake an NZQA-accredited course, which was updated with NSU input in 2008. Note that entry for lay persons to the NZQA unit standard for smear-taker training was discontinued in this revision. Monitoring/encouraging completion of non-medical smear-taker training is ongoing. Continued professional development is provided in the form of regional smear-taker updates by NCSP staff. Regular updates/reminders to smear takers are also provided through a range of NSU communication mechanisms, including newsletters. NCSP-contracted laboratories also play an important role in providing updates/reminders to smear takers. Revised *NCSP Competencies for Smear Taker Training* were completed in June 2009. The NCSP introduced a smear-taker training fund in 2002, allowing smear takers who complete the course to be reimbursed their training fees. In 2008 the system was reviewed and the value of the grant increased from $500 to $700.	
2.3	**Cervical Screening Inquiry Report published in hard copy form (para 2)** I recommend that the CSI Report be published in hard copy form so that the public can purchase a copy in bookstores or borrow it from the library.	Completed: the *Report of the Ministerial Inquiry into the Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region* was printed and distributed in April 2002: • ISBN 0-478-24354-5 (book) • ISBN 0-478-24355-3 (web)	No
2.4	**Clinical Director input to teleconferences (para 8)** Dr Julia Peters, Clinical Director, NSU has not participated in these monthly teleconferences but I believe her input would prove useful in the future.	N/A	

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.5	**Training programme and quality standards for staff reading liquid based cervical preparations (para 92)** The NCSP needs to design an appropriate training programme and quality standards for staff reading and reporting liquid based cervical preparations.	Section 5 of the OPQS (released as 'interim' in Sept 2009) has specific policy and standards requiring pathologists, scientists and technicians who read LBC samples to read a minimum volume per annum. The same situation applies to those who read both conventional and LBC samples. All staff must have attended and satisfactorily passed a manufacturer's conversion course. The HPCA Act would require any practitioner to be competent to read LBC, and proof would be required, with the practitioner's training and competency records held by laboratories. All new graduate and technician practitioners must undergo the VRPCC training programme, which is practically focused. *See also recommendation 1.27 of the CSI recommendations*.	Yes – ongoing
2.6	**Development of New Zealand external quality assurance scheme (para 95)** NCSP needs to consider developing a New Zealand EQA scheme in collaboration with the professional bodies for individual technical and medical laboratory staff with a facility to break anonymity if there is a persistent poor performance. The format, protocols and criteria of the EQA scheme should meet NCSP standards.	A Workforce Development Project initiative with an external quality assurance (EQA) sector working group was set up and a pilot and full trial programmes were completed in December 2007. Exploration of providing an ongoing programme was undertaken in 2008. Participation in EQA schemes is compulsory for all staff reading cervical cytology (revised Section 5 OPQS). The scoping and development of an EQA programme for the gynaecological cytology and histology workforce is included in a tender process currently being undertaken for an NCSP laboratory training service. *See also recommendation 2.7 below and 1.27 of the CSI recommendations.*	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.7	**Regular cytology update courses (para 98)** Consideration should be given to providing regular cytology update courses within New Zealand for all grades of laboratory staff.	The NSU has sponsored the Annual Society of Cytology Conference since 2004. Until 30 June 2010 Canterbury Health Laboratories were contracted to provide a training service for NCSP laboratories. The provision of regular cytology update courses was part of this contract. Sixteen cases from the Cervical Cancer Audit were photographed and all laboratories were sent a CD (*Lessons from the Past*) with an interactive educational case assessment. This was suitable for both individual and group self-assessment. A tender process is currently being undertaken for the provision of these training services, which is being broadened to include the cervical histology and HPV testing workforce. *See also CSI recommendation 1.27.*	Yes – ongoing
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 this position be 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

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.9	**Information for women (paras 101–106)** ... it remains an urgent necessity to provide accurate basic information about the NCSP in brochure or pamphlet for general practitioners, practice nurses, lay smear takers and women. Similarly information about the significance of abnormal smear results and what colposcopic examination entails must be readily available for women who are referred for colposcopy. This includes information for immigrant non-English speaking minority groups. ... It is important that the NCSP is acceptable to women. Greater understanding of the fact that the cervical smear is a screening test and not a diagnostic test and of the benefits of participating in a screening programme with comprehensive audit built in must be promoted among women. The safety checks built into the NCSP are there to protect women who should be demanding, not merely consenting to these processes. It is important for women to feel safe so the risks of 'opting-off' must be explained fully to them. Some women are badly informed and opt-off the NCSP-Register without fully understanding the risks incurred by doing so.	*See also CSI recommendation 1.38.* Section 112L of the Health (National Cervical Screening Programme) Amendment Act 2004 outlines requirements for the provision of information to women. New NCSP pamphlets were developed/revised in December 2007, with ongoing updates. *Cervical Screening: What Wahine Need to Know: Atawhaitia Te Wharetanga* (Code 1837) is an informational pamphlet for Māori women with both Māori and English text. *Cervical Screening: What Pacific Women Need to Know* (Code 1831) is an informational pamphlet for Pacific women, with English text only. *Cervical Smear Tests: What Women Need to Know* (Code HE1256) is a generic resource for all women. English text only. *Cervical Screening: Understanding Cervical Smear Results* (Code HE4598) covers the entire NCSP pathway. Currently there are no NCSP-produced informational pamphlets for non-English-speaking immigrant groups. *Cervical Screening: A Guide for Women in New Zealand* is a detailed booklet for women providing basic information regarding the cervical screening pathway. This resource was redeveloped in 2009, including information on HPV testing and immunisation. The NSU website has comprehensive information for women on cervical screening and cervical cancer.	Yes – ongoing updates

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.9	(Continued)	The *Guidelines for Cervical Screening in New Zealand* (2008) contains basic information about the NCSP and the management of women with normal and abnormal cervical smears. This has been distributed to all health professionals providing services to the NCSP.	
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 healthcare. 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 other 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 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 analyses as more cases accumulate.	Yes – ongoing
2.11	**Send interim National Cervical Screening Programme information leaflet pads to providers (para 106)** I understand the dilemma between getting a simple easily read pamphlet out immediately and getting it 'right'.	This was sent to providers in May 2002. *See recommendation 2.9 above.* In addition, the *Public Health Services Handbook* provides information about the NCSP for DHBs. This information was updated in November 2008.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.11	(Continued) However, I believe that information about cervical screening is needed now, even if it has to be revised in a year's time when the legislation has changed. I commend the NSU to proceed quickly with their plan to send interim cervical screening information leaflet pads to every general practitioner, practice nurse, District Health Authority, colposcopy clinic, regional office and cytology laboratory, and for similar information to be posted on all relevant websites.		
2.12	**Standardised criteria for reporting unsatisfactory smears (para 108)** There needs to be more standardised criteria for reporting unsatisfactory smears.	*Bethesda 2001 NZ Modified* contains standards for assessing a sample as satisfactory (for conventional and LBC). All practitioners have a copy of *Bethesda*, with supporting diagrams for assessment of cellularity. The NCSP provided all labs with update sessions and a training CD prior to going live. Unsatisfactory targets were reviewed in 2009, with external consultation. *See also recommendation 1.32 of the CSI recommendations.*	No
2.13	**Issue guidance to laboratories about the implementation of *Bethesda 2001* (paras 109–111)** In order to prevent distortion of the data gathered in the monthly statistics, it is necessary to ensure that laboratories do not implement *Bethesda 2001* but continue to use the previous version of the Bethesda system until such time as the NCSP agrees that implementation of *Bethesda 2001* is desirable and a specific date is set for such a change. The NSU should issue guidance to laboratories about the implementation of *Bethesda 2001*.	*Bethesda 2001 New Zealand modified* was developed in conjunction with a sector working group. In 2005 an update package was issued to all practitioners containing old and new Bethesda, along with educational and supporting documents. The NCSP visited all labs prior to implementation to provide training to staff. Each lab was also given an educational CD with test scenarios and follow-up answers. Changes were also printed in *Screening Matters*, sent to all smear takers, on the web, and presented at appropriate conferences. *See also recommendation 1.32 of the CSI recommendations.*	No

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.14	**Identify duplicate additional smears at colposcopy (para 113)** No attempt is being made to identify duplicate additional smears taken at colposcopy from women referred with HSIL. If colposcopy clinics repeat the 29 smear tests on these women prior to treatment, this will artificially increase the high-grade reporting rate for the laboratory compared to another laboratory that does not receive such colposcopy smears.	This issue has been discussed in detail at NCSP Advisory Group meetings. It has been difficult to exclude clinic samples in data extracted from the Register. All eight cytology labs are now undertaking a bigger mix of screening and diagnostic cytology cases so that there is less variance in case mix between labs, which means the effect of colposcopy work may be less significant in relation to reporting rates. Options are being investigated (eg, to search per woman, for a time period, and exclude any biopsy taken within a five-day timeframe of a colposcopy event).	Yes – ongoing
2.15	**Screening interval** Both smear takers and gynaecologists fail to understand the health economics of the screening interval and advocate early recall at great expense but little benefit to many women ... (para 103)	Independent monitoring reports for 2005–2007 indicate that short interval re-screening consistently accounts for approximately 11% of all smears. Education of smear takers and colposcopists on avoiding short-interval re-screening is ongoing. The *Guidelines for Cervical Screening in New Zealand* (2008) contain a section on screening intervals. Training sessions on the new guidelines have stressed the importance of avoiding early re-screening. Notification has been sent to DHBs with consistently high short-interval re-screening rates and to professional bodies. From July 2008 (Monitoring Report 30) a revised method of calculating early re-screening using a cohort approach indicates a higher level of early re-screening (approximately 29%). Early re-screening has been extensively discussed by the NCSP Advisory Group.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.16	**Short-interval re-screening: important to define who is being screened by each laboratory and how often (para 114)** Similarly the denominator for the calculation of reporting rates (total numbers of smears) will be artificially increased if a substantial proportion of normal women return for routine smears earlier than the recommended interval. This will result in an artificial reduction in the percentage of HSIL reported compared to other laboratories. It is important to define who is being screened by each laboratory and how often.	There is currently no evidence that the rates of short-interval re-screening are substantially different between laboratories. It is currently not possible to reflect the numbers of short-interval re-screens in the denominator.	Yes – ongoing
2.17	**Audit of laboratory returns including 'opt-off' (para 115)** There is no audit of the laboratory returns. These will include smears 'opted off' the NCSP Register and thus NCSP Register data cannot be used for verification or sanity checks on the laboratory data.	New legislation changed the ability to 'opt off' or withdraw individual results. Women no longer opt off but withdraw from the register. Laboratories therefore no longer determine opt-off status. Withdrawal rates are very low (.004% January–June 2009). NCSP laboratories are monitored against the standards set out in the NCSP OPQS. An annual on-site assessment/audit is undertaken by IANZ/NCSP, which includes data analysis. *See also recommendations 1.14, 1.16, 1.17 and 1.30 of the CSI recommendations.*	Yes – ongoing
2.18	**Recording of conventional smears and thin prep samples on National Cervical Screening Programme Register (para 117)** The change to liquid based cytology needs to be monitored. Laboratory monthly returns should record results for conventional smears and ThinPrep samples separately.	The NCSP Register was updated in 2005 to accept the *Bethesda 2001* and included a requirement for labs to include sample type when reporting to the NCSP Register. Sample types are: LBC, conventional, combined LBC and conventional. The programme became 100% LBC in July 2009 and this shift is reflected in NCSP monitoring reports.	No

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.19	**Additional SNOMED codes on National Cervical Screening Programme Register (para 118)** The SNOMED system used for coding cervical biopsy histological diagnoses is also due for review. The NSU must take similar action when the revised system is published.	SNOMED coding is due for review and updating. The Ministry of Health now holds the licence for SNOMED CT, and a working group (including a pathologist) was set up in late 2009. However, this work was put on hold during NSU and Ministry of Health restructuring. There has been a recent drive from the Government to review and improve information systems, databases and clinical coding across the health sector. *See also CSI recommendation 1.32.*	Yes – ongoing
2.20	**Inclusion of colposcopy data on the NCSP Register (para 121)** Registry staff have a problem resulting from women who have been referred for colposcopy and have attended but who have not had a biopsy taken. If the regional site does not receive a histology result they do not know if this is because no sample was taken or if the result has not arrived from the laboratory. If the Register received and held information from colposcopy clinics this could be avoided.	The redeveloped NCSP Register provides an improved mechanism to closely monitor women with high-grade cytology for whom there is no histology. These events come up as a work list task and are followed up by the Register Central Team. The follow-up of women with high-grade cytology and no histology is prioritised by NSU performance management analysts with colposcopy units to ensure women receive treatment as required. The proportion of women with no follow-up of any kind at 180 days is also now monitored. *See also CSI recommendations 1.14, 1.16, 1.17 and 1.30.*	Yes – ongoing
2.21	**Improved communication between IMG, providers and National Screening Unit (para 124)** I am concerned that there is not yet a smooth and straightforward communication between the IMG, the providers and the NSU. Providers are very anxious. This situation must be improved as soon as possible. A better understanding of the reasons behind the data gathering must be promoted between all three groups to help bring about a better understanding of each other's needs.	Since 2008 the monitoring reports have been reviewed by the NCSP Advisory Group, which has representation from all provider groups and consumers. NSU members are ex officio at these meetings. This collaborative and transparent approach to monitoring has helped to maintain positive relationships with providers. Where providers do not meet NCSP targets, a collaborative approach to identifying issues and improving performance is taken. Monitoring reports are available on the NSU website.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.22	**Direct access to National Cervical Screening Programme Register for Laboratories (para 135)** Currently most exchange of information about smear histories is by telephone or fax. Electronic access to the NCSP Register should be extended to all laboratories and smear takers.	*See CSI recommendation 1.31.* All laboratories now have immediate access to online screening histories. All NCSP laboratories now submit results to the Register using Health Level 7 (HL7) Ver 2.4 messaging, an international standard for electronic healthcare-specific data exchange between computer applications. Online access for smear takers is included in Phase Two of the Register redevelopment. Phase Two has not begun as there is still some functionality development required for Phase One. This will depend, to some extent at least, on the technological readiness of smear-taking agencies. Also, electronic access to the Register and direct electronic reporting is still in progress for colposcopy units and private colposcopists.	Yes – ongoing
2.23	**Improved information on NCSP laboratory referral form from smear-takers to laboratories (para 133)** Greater attention is needed in the area of the quality of patient identification data given by smear takers to laboratories. An immense volume of phone calls result from errors or inconsistencies in patient identification. There are a variety of different cervical smear request forms in use some of which do not collect all the relevant patient demographic or clinical information. This may lead to inappropriate recall times on laboratory reports, unnecessary reminder letters and failure of failsafe follow up systems for women with abnormal smears.	Regrettably, an NHI is often not provided by smear takers although there is a requirement for them to do so in OPQS. The burden then lies with the laboratory. The laboratory undertakes a request for an NCSP Register screening event history and has to cross-correlate the woman's current demographics with the history demographics for all cases. There is sometimes a mismatch between specifications built into the Register and smear-taker recall systems for ongoing recommendations in the management of women with abnormal smears. The above will continue to be an issue until smear takers are electronically linked with the NCSP Register to make test requests. Alternatively, recall systems built into the Register will need changing to allow flexibility in the management of women.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.23	(Continued)	With the introduction of HL7 messaging in July 2010, NHI and other identifying data are a compulsory requirement for transferring laboratory results to the Register. This is included in the updated OPQS, Section 5, and communications that have been sent to smear takers. Smear takers continue to use a wide range of requisition form formats. As long as these contain the required fields there is no problem. Ongoing mismatches between the Register and smear-taker recall systems continue to create confusion among smear takers and women who receive letters requesting recall at inappropriate intervals. Delays in correcting Register problems have created confusion and concerns among smear takers.	
2.24	**Role of regional office in relation to repeat smears for individual women (para 131)** I have concerns about some of the roles undertaken particularly in relation to advice about the need for repeat smears for individual women. There is not sufficient clinical oversight at many sites to ensure that inappropriate decisions are not made.	The NCSP regional services should have minimal input in relation to repeat smears for individual women. With the new NCSP Register, Smear Taker Recall Reports and Overdue for Cervical Smear Reports are sent out by the NCSP Register Central Team. Responsibility for the ongoing management of a woman rests with her smear taker, not the NCSP. *See also CSI recommendations 1.5 and 1.6.*	No
2.25	**14 regional offices is an inefficient use of resources (para 132)** I do not believe that maintaining 14 Register office sites is an efficient use of resource. Consideration must be given to a more appropriate number and location of Register data entry sites and to the roles and responsibilities of Register office staff.	Responsibility for the management of the NCSP Register is at one site – the Register Central Team (RCT) at DATAM. All laboratory and colposcopy results going onto the register are the responsibility of the RCT. There are still 13 regional services, which provide some Register capability, and they are important for receiving and providing information to women, smear takers and other health professionals within their regions. They have an important liaison role.	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.26	**Standards for smear takers and cost issues for GPs (para 138)** While more recently there has been a change in culture and primary care sees a clear role working with the NCSP, many of the previous obstacles still remain. Since there is no contractual relationship with the NSU, it is difficult to implement standards for smear taking and failsafe follow-up among GPs. There is a significant cost that is being carried by GPs which needs to be taken into account.	A lack of a contractual relationship with most smear takers means that standards for smear takers still cannot be strictly enforced. The HPCA Act 2003 has requirements for registered health professionals to maintain competence. In general, smear takers, over a third of whom are nurses, engage closely with the NCSP by: • requesting a woman's screening history • receiving Overdue Cervical Smear Reports and Smear taker Recall Reports from the Register • making general enquiries about the NCSP Standards and Guidelines • participating in regional smear-taker updates organised by NCSP regional services. NCSP training standards for smear takers were updated in 2009 and, with the NZQA unit standard, form the basis of the training courses. Since 2002 the NCSP has funded a smear-taker training grant for nurses, which in most cases covers the cost of the smear-taker training courses run throughout the country. *See also recommendation 2.2.*	Yes – ongoing
2.27	While there must be a balanced approach that recognises the importance of all aspects of the NCSP, it is clear that New Zealand cannot be complacent about its population compliance in cervical screening. Participation in the NCSP must be further improved. The cost of the smear test consultation is undoubtedly a barrier in some areas (para 141).	A communication campaign aiming to increase coverage began in 2007 and is ongoing. There has been a steady, positive impact of the campaign on screening coverage, particularly with Māori, Pacific and Asian women, and a significant impact on the attitudes, awareness and understanding of women. There have been ongoing initiatives to implement free/low-cost smears for under-screened groups of women. *See also recommendation 5.5.*	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.27	(Continued)	Unlike comparable screening programmes, however, most women still pay to have a smear taken, and this is undoubtedly a barrier to increasing coverage.	
2.28	**Participation in the National Cervical Screening Programme must be further improved (para 139)** The support of women from all ethnic groups is necessary for the NCSP to be a success. As data is cleaned up the population coverage looks like it is less than previously thought at under 70% across New Zealand. Coverage is higher in the Tairawhiti region following the programme of repeat smears instituted after the CSI Report and this may artificially inflate the figures.	The overall programme coverage rate as at 31 December 2010 is 76%. Coverage for Māori, Pacific and Asian women remains well below both the 75% target, but the coverage for the total population continues to increase. The NCSP has a range of strategies to increase coverage for Māori, Pacific and other priority group women, including: • continuation and refreshing of the successful NCSP awareness and educational campaign • strengthening of regional co-ordination, collaboration with primary health care providers and refinement of health promotion, recruitment and retention initiatives • continuation of limited funding through the NSU for free smears targeted at Māori, Pacific, Asian, unscreened and under-screened women. Under-reporting of some ethnicities on the NCSP Register is known to contribute to the disparity in ethnicity-specific coverage, and this is being further explored. Work is underway to take account of this underestimate and to improve the accuracy and completeness of ethnicity data on the NCSP Register. Future reporting of coverage will also be affected by improved calculation methods, including updated denominator population data. *See also recommendation 2.27 above.*	Yes – ongoing

Ref	Recommendation (McGoogan 2001)	Status / date	Further work required?
2.29	**IMR frequency** While quarterly reporting is reasonable at the moment, it should be possible to reduce the frequency of publication of the IMG Reports to six monthly and eventually annually once the system is well established (para 127).	From 2008 NCSP Monitoring Reports have been six-monthly. Quarterly reports are produced internally.	No

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 the woman, 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 of the entire screening history of each case and the histology report. Data are entered onto a spreadsheet and analyzed 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

Ref	Recommendation (McGoogan 2003)	Status / date	Further work required?
3.2	**In view of the absence of explicit evidence that the National Cervical Screening Programme was safe and effective in the late 1990s, consideration should be given to implementing recommendation 11.2 at least in part (paragraphs 29–31)** At the time of my first visit in April 2002 and despite the delays to the Cancer Audit that were apparent even then, I was reluctant to push for immediate implementation of recommendation 11.2 (if there is doubt about systemic under-reporting then all women should be offered two smear tests 12 months apart). ... In the meantime, it may be that particular consideration should be given to women who had been screened prior to 2002 before the laboratory quality assurance programme was fully implemented and who will not return for repeat testing (eg, have reached the upper age limit for recall). If the results of the Cancer Audit throw any doubt there had been an unacceptable level of under-reporting then recommendation 11.2 must be implemented either in full or in part. Since there is potential for a false negative result due to sampling during smear taking, I would recommend that women have their smear test repeated under the present quality assurance conditions rather than have their previous slides reviewed. I note that the Ministry of Health asserts that they must await the outcome of the Cancer Audit before considering what to do about Recommendation 11.2. However, in my view, the Ministry must be held responsible for choosing to do nothing as regards this recommendation at this point in time.	As at June 2003 over 758,585 women had one or more smears on the NCSP Register, equating to around 70% of the eligible population, since the introduction of NCSP laboratory OPQS in October 2000. Since the routine screening interval is three years, by 2005 most women on routine screening will have had a smear test that has been read by laboratories meeting the current quality standards. A letter from Dr Karen Poutasi, dated 24/06/03, was sent to Dr McGoogan seeking her clarification on this recommendation. Based on that response, a decision was made not to implement recommendation 1.2.	No

Ref	Recommendation (McGoogan 2003)	Status / date	Further work required?
3.3	**Great care must be taken when interpreting and publishing the results of the re-read of slides as part of the Cancer Audit particularly with respect to those slides considered equivocal or atypical (main recommendation)**	This was implemented as part of the Cancer Audit Protocol.	No
3.4	**Since the National Cervical Screening Programme is a public health programme, I recommend that consideration be given to finding a way of directing National Cervical Screening Programme smear tests to appropriate laboratories irrespective of commercial interests so that comparison of laboratory reporting rates can be evaluated with respect to geographic areas, and the training of medical and technical staff can be facilitated (para 34)** The Independent Monitoring Group produces statistical reports on laboratory activity at regular intervals. Unfortunately smears are often sent to a community laboratory outside the geographic area. Thus laboratory profiles cannot be compared to the regional incidence of disease. However, since the NCSP is a public health programme I suggest that consideration be given to finding a way of directing NCSP smear tests to appropriate laboratories irrespective of commercial interests.	The NSU and University of Otago (the monitoring group at the start of the Programme) considered that it was not possible to correlate laboratory reporting with the regional incidence of cervical cancer in New Zealand. A tender process aimed at establishing laboratory contracts based on a four-region model with regional boundaries for the collection of slides commenced in 2008; however, a decision was made by the Ministry not to proceed with the outcomes of the RFP.	No
3.5	**A national external quality assurance scheme should be established for laboratory staff to monitor continuing competence (main recommendation)**	*See also recommendation 2.6.*	Yes – ongoing

Ref	Recommendation (McGoogan 2003)	Status / date	Further work required?
3.6	**More work needs to be done on the development of Information Technology systems to allow easier transfer of information between smear takers, laboratories and colposcopy clinics and the Screening Register (paragraph 42)** While laboratories receive printouts of previous histories of women whose smears are being processed, this information is not yet available electronically in real time. Work has begun but much more work needs to be done on Information Technology systems to allow easier transfer of information between smear takers, laboratories and colposcopy clinics and the Screening Register.	The redeveloped NCSP Register aimed to facilitate electronic data exchange between laboratories and colposcopy clinics. All NCSP laboratories now communicate with the Register using Health Level 7 Ver 2.4 messaging. All laboratories have immediate access to online screening histories. This includes HPV test results. Colposcopy services are in the process of developing the capacity to submit results using HL7 messaging. It is not certain when this will be implemented. Consideration has recently been given to looking at how smear takers could access screening histories from the Register.	Yes – ongoing
3.7	**The National Screening Unit, 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
3.8	**In implementing recommendation 1.10, much attention has rightly been placed on standards for laboratories and colposcopy services. However, the quality of smear taking and enrolment of women into the National Cervical Screening Programme still merit equal attention. The advice and direction of senior medical personnel is crucial to achieving a balanced approach to all aspects of the National Cervical Screening Programme (para 35 as above)**	A balanced approach to all aspects of the screening pathway has been achieved, as evidenced by the NCSP Strategic Plan 2009–14 and annual work plan. Significant attention is given to smear-taker standards, continuing education and feedback on the quality of smears. Recruitment and retention of women into the NCSP is a major focus. *See also recommendations 2.27 and 2.28 for initiatives to increase participation and coverage.* The advice of senior medical officers is frequently sought via consultation documents, working groups and the NCSP Advisory Group.	Yes – ongoing

Ref	Recommendation (McGoogan 2003)	Status / date	Further work required?
3.9	**Aggregated ethnicity data** While I understand the sensitivities about selecting out the epidemiological data for ethnic groups, I believe that all women require the same protection as Māori women. There may also be a need to protect the aggregated data for immigrant women and other minority groups (paragraph 39). I understand that following a period of consultation, Cabinet decided in June 2002 to remain with the status quo as far as Kaitiaki Regulations are concerned. I must accept this decision but again I have concerns about how this impacts on monitoring and evaluation of the NSCP and the ability to ensure it meets the needs of Māori women.	The NCSP works closely with the National Kaitiaki Group to enable timely access to Māori women's data for monitoring. The process is frequently resource intensive in terms of staff time and has at times resulted in a delay in monitoring reporting. *See also recommendation 1.15.*	Yes – ongoing
3.10	**Workforce development** A workforce development strategy for the NCSP has been agreed and is in the process of being implemented. This recognises the continuing problems attracting trained staff to New Zealand. A good start to delivery of training within New Zealand has been made with the training day attached to the National Cytology Meeting in 2002 which was a great success. However, the availability of appropriate training and development courses within New Zealand for all groups of health professionals involved in cervical screening is still inadequate. Much more needs to be offered to staff of all disciplines and within reasonable geographic distance to their normal places of work. Fees should be waived or at least affordable so that they do not become a barrier to participation (para 41).	A grant for smear-taker training has been in place since 2002. Smear-taker updates are delivered regionally via the 13 regional services. The NSU funds a National Gynaecological Cytology Training School, which commenced in 2005 and was contracted to Canterbury Health Laboratories. This provides update courses for all practitioners and also oversees the VRPCC. With expiry of this contract, a tender process is now being undertaken for continued provision of the training services, which are being broadened to include the cervical histology and HPV testing workforce. *See also recommendation 2.7 and CSI recommendation 1.28.* Cancer screening orientation for new health promoters has also been regularly provided by the NSU.	Yes – ongoing

4 Status of the Auditor-General's recommendations

Ref	Recommendation (OAG 2002, 2003)	Status / date	Further work required?
4.1	**Response to recommendations** Onus is on the Ministry of Health to address the issues raised in both reports (Dr Euphemia McGoogan, and Office of the Controller and Auditor-General) and to act upon their recommendations (intro para 4).	The NSU is monitoring the ongoing response to these recommendations, which are being implemented as part of the National Cervical Screening Programme Annual Workplan.	Yes – ongoing
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 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 (para 3.4).	*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
4.3	**Autonomy of the NSU** Noted Dr McGoogan had raised similar concerns in her report about whether the National Screening Unit has sufficient authority and independence to perform its functions. Noted that in their view there should be a review of the operation of the present arrangements to examine these concerns – the review would need to take into account the public sector governance issues that would arise from increasing the National Screening Unit's autonomy (para 3.7).	*See CSI recommendation 1.12.*	Yes – ongoing as part of Ministry of Health reviews

Ref	Recommendation (OAG 2002, 2003)	Status / date	Further work required?
4.4	**Recruitment for key positions** National Screening Unit has not yet successfully recruited for two key posts, that is a permanent Epidemiologist and a Manager Quality Monitoring Analysis and Audit Team. Concerned by the difficulties the National Screening Unit is experiencing recruiting key staff (para 3.13).	The NSU previously purchased epidemiological support from Public Health Intelligence group within the Ministry of Health, and currently contracts with a team of epidemiologists who have significant expertise in cervical screening. A manager of the Quality and Equity team was appointed in mid-2008.	Yes – ongoing
4.5	**Reporting on progress** The National Screening Unit has previously reported progress on the implementation of the recommendations by way of a table, identifying which recommendations are complete or underway and of those recommendations that are underway which recommendations are on track or have revised delivery dates. This sort of reporting is both problematic and valuable. So long as progress is being independently evaluated, see that value in continuing with the kind of analysis provided in the table (para 3.19).	Regular update reports on progress to implement the recommendations of the Gisborne Screening Inquiry have been provided to the Minister of Health.	Yes – ongoing
4.6	**National Ethics Committee** Although the Ministry funds ethics committees to provide independent ethical review of proposals for health research and innovative practice, it has no jurisdiction over them. They are by nature independent. However we consider that the NSU will need to monitor the work undertaken by the National Ethics Committee and report to the Minister on whether the Committee of Inquiry's recommendations in relation to ethics committees are being implemented (para 6.7).	The National Ethics Advisory Committee (NEAC) is responsible for the implementation of CSI recommendations 19, 21, 22 and 23.	No
4.7	**Resources for women** In order to ensure that in future all major communications about the programme contain clear messages, we recommend that they are 'piloted' with a number of women's groups before they are published in final form (para 8.14).	Contracted providers that update and review NSU resources are responsible for ensuring pre-testing of resources to ensure they are user friendly. This includes pre-testing with 'priority groups'. Feedback is then given to the NSU to either amend or progress with updating and distribution of the resource.	No

Ref	Recommendation (OAG 2002, 2003)	Status / date	Further work required?
4.8	**Independent programme reviews** Monitoring by independent expert/s needs to continue and to be expanded to focus on the effectiveness of the programme as a whole. We suggest that independent reviews of the programme be undertaken at the end of 2004, 2006, and 2011 (paras 4.13 to 4.17).	Section 112O of the Health (National Cervical Screening Programme) Amendment Act 2004 provides for the ongoing review of the NCSP at least once every three years.	No
4.9	**Colposcopy data** The NSU needs to find some way of ensuring that DHBs forward the required information needed to monitor waiting times for colposcopic assessment. The NSU should look at whether its regulatory powers as intended under the Health Screening Programmes Amendment Bill can be can be used to cover private colposcopy clinics for the collection of waiting time data (paras 5.53 to 5.55).	Colposcopists are required by the Health Act (National Cervical Screening Programme Amendment) to report on procedures to the NCSP. All DHBs submit monthly information to the NSU as well as filing regular reports to the NCSP Register. There is currently a process whereby all DHBs are requested to review their processes for forwarding to the Register to ensure its completeness. HL7 messaging with DHB colposcopy units is being developed. Electronic reporting from colposcopists in private practice has yet to be explored.	Yes – ongoing
4.10	**Introducing new technologies** No system for introducing new technologies (eg, LBC/ HPV). LBC has been introduced but this is not covered by the quality standards. This is a significant omission (paras 6.35 to 6.51).	Section 5 of the 2009 update of the OPQS contains standards for LBC and conventional smears, as well as for automated imaging devices and HPV testing. Indicators for the number and proportion of smears reported as unsatisfactory were revised in 2008 and are in place for both LBC and conventional smears. The introduction of new technologies, policy, guidelines and standards has been done in direct consultation with the laboratory sector and smear takers. Education and communications have been delivered to users by both the NCSP and laboratories.	Yes – ongoing

5 Status of the Cervical Cancer Audit recommendations

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.1	**Identification and invitation** The Audit recommends that the National Cervical Screening Programme utilises a national, population-based database along with the National Cervical Screening Programme Register for identifying unscreened and under-screened women aged 20–69 years and inviting them to have a smear.	*See CSI recommendation 1.33.*	No
5.2	**Recall** The Audit recommends that the National Cervical Screening Programme ensures there is a nationally consistent system for recalling women for screening at appropriate intervals. The system that is developed should have the following key features: • be acceptable and workable for Māori women • be acceptable and workable for other groups of women at risk of not being regularly screened • clearly identify all roles and responsibilities within the call and recall system, particularly between the National Cervical Screening Programme / National Cervical Screening Programme Register and smear-takers	NCSP expectations regarding proactive recall of women by smear takers are outlined in OPQS section 4. The process must include: • if a woman is on a normal screening interval, there must be a minimum of two attempts within six months of the recall date • if a woman requires a recall within or at 12 months, there must be a minimum of three attempts within three months of the recall date. Smear-taker recall systems are backed up by the NCSP Register, which generates overdue reminder letters for women as well as reporting to smear takers on women with upcoming and overdue smears.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.2	(Continued) • clearly identify the organisation responsible for determining the recall interval for women (for women who are enrolled in the National Cervical Screening Programme, the National Cervical Screening Programme Register will have complete smear history information and should calculate the recall interval and communicate it to individual women and smear-takers [who may decide to vary the interval on clinical grounds]. For women who decide to cancel their enrolment in the National Cervical Screening Programme, the smear-taker will be responsible for determining the recall interval and communicating it to the women) • be as administratively simple as possible • be designed to *proactively* recall women three months prior to the date their next smear is due so that most women are screened *within* the appropriate National Cervical Screening Programme screening interval (in addition the National Cervical Screening Programme Register may still provide a fail-safe mechanism for women who do not respond to the proactive system).		

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.3	**Recall – data** The National Cervical Screening Programme explores how linkages between the National Cervical Screening Programme Register, National Health Index, and primary health organisation registers can be made to ensure that those responsible for recalling women have their most up-to-date contact details.	Some NCSP regional services are working with primary care organisations to encourage matching of NCSP Register data with clinic/PHO data. This enables women who are either not enrolled or are well overdue for a smear to be identified and invited to attend. With new regional service specifications due to be implemented from 1 July 2011, it is expected that relationships between the NCSP and PHOs will be developed and there will be greater opportunities for data linkage between registers. *See also CSI recommendation 1.33.*	Yes – ongoing
5.4	**Cancelled enrolments** The National Cervical Screening Programme ensures that women who cancel their enrolment in the National Cervical Screening Programme are aware that they are then dependent on either their own initiative or their smear-taker's recall system for receiving smear results and reminders regarding regular smears.	Under Section 112H of the Health (National Cervical Screening Programme) Amendment Act 2004, women must be sent a notice confirming cancellation of enrolment in the NCSP. The withdrawal form provides clear information for women cancelling enrolment in the programme, including that the woman and her smear taker are responsible for her subsequent cervical screening.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.5	**Reducing barriers to screening** The National Cervical Screening pilot and evaluate evidence-based, sustainable strategies for increasing screening amongst women at risk of under-screening, including Māori women, older women and women on low incomes and with little secondary school education.	NCSP regional service providers employ and evaluate a range of strategies for increasing coverage in under-screened groups of women. These activities will be supported and enhanced from 2011 by revised service specifications, which are based on a review of evidence-based strategies to increase coverage. A communication campaign, targeted at Māori, Pacific and Asian women, has been highly successful in increasing coverage among these groups. The NCSP provides some funding for smear-taking services for 'priority groups' of women most at risk of cervical cancer. This includes: • Māori women • Pacific women • Asian women • women over 30 years who have never had a smear • women over 30 years who have not had a smear for five years.	Yes – ongoing
5.6	**Reducing disparities** The National Cervical Screening Programme ensures that any system-wide or targeted strategies to increase the proportion of women having regular smears do not increase disparities between Māori and non-Māori.	The steadily narrowing gap between Māori and non-Māori in cervical cancer incidence, mortality and screening coverage indicates that strategies targeted at 'priority group' women (see above) are being successful in reducing inequalities.	Yes – ongoing
5.7	**Laboratory quality assurance** The National Cervical Screening Programme continues to ensure laboratory operational policies and quality standards are current and regular provider audits occur, and to support cytology workforce development initiatives.	Section 5 of the OPQS, 'Providing a Laboratory Service', underwent a full review with a sector working group and was released in September 2009 (as an interim for finalisation in June 2011). All laboratories are audited on an annual basis under a memorandum of agreement with IANZ. Each laboratory has a full assessment every four years, with follow-up visits annually.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.8	**Laboratory quality assurance – review of negative smears prior to HG** The National Cervical Screening Programme and laboratories collaborate to review the approach to the review of negative smears taken within the previous 42 months for women with a high-grade or more serious histology. A standard methodology should be developed and some external input included, involving collaborative review of smears so that maximum benefit is obtained from the process. The option of laboratory accreditation assessors re-reviewing prior negative smears in laboratories where there is any quality concern should be considered.	Some changes have been made to the review process in the revised OPQS. This includes mandatory and education review recommendations, including potentially false negative glandular cytology. Any abnormality identified as high-grade on review of a prior reported negative smear must be reviewed by a senior cyto-scientist or senior cyto-technician (qualified for full review). If there is lack of consensus on an agreed false negative, the case must be reviewed by a pathologist. The laboratory is requested to return the number of cases upgraded to the NCSP on a 6-monthly basis. Accreditation assessors have the option to review cases during accreditation. A working group is planned with an international expert cytopathologist to review and develop more consistent processes for all types of case review. This should be completed by the end of 2011.	Yes – ongoing
5.9	**Laboratory quality assurance – negative review target** The National Cervical Screening Programme reviews the upper limit for the prior negative review target, in light of any new methodology developed for the review. In view of the fact that it is to be expected that some prior negative smears should be upgraded on review, consideration should be given to establishing a lower limit (as well as an upper limit) for the standard.	There is an upper limit of not greater than 20% (OPQS indicators and targets). (*Also see recommendation 5.8 above regarding case review processes.)* A standardised process will enable better assessment for revising targets.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.10	**Laboratory quality assurance – glandular abnormalities** While acknowledging that the National Cervical Screening Programme was established to detect the precursors of squamous cell carcinoma, the National Cervical Screening Programme and laboratories continue educational activities to improve the detection of glandular abnormalities in cervical smears within New Zealand laboratories.	OPQS section 5 (2009) includes glandular abnormalities for review. Various external courses targeting glandular abnormalities are available from time to time. The *Lessons from the Past* CD (*see recommendation 2.8*) included false negative glandular cytology cases. The 2008 *Guidelines for Cervical Screening* contain a significant section on glandular abnormalities.	Yes – ongoing
5.11	**Information for women** The National Cervical Screening Programme, when revising relevant health education material, provides information that ensures that women reading it are made aware of the limited protection conferred by a single cervical smear test and therefore the importance and benefit of *regular* smears.	Website, pamphlet and booklet resources for women stress the importance of regular smear tests every three years.	Yes – ongoing
5.12	**Colposcopy data** When defining the colposcopy data elements that the National Cervical Screening Programme will be collecting under the powers conferred upon it by the Health (National Cervical Screening Programme) Amendment Act 2004, information is included on self-identified ethnicity, the date of the smear, bleeding, or other symptoms or signs leading to referral, the date of the referral letter, and any reasons for delay in investigation as well as the completeness of colposcopy, the colposcopic impression and biopsy result and plans for follow-up.	Colposcopy reporting forms collect information on self-identified ethnicity, referral details, adequacy of the colposcopy, colposcopic impression, actions during the visit and recommended follow-up. Electronic reporting of colposcopy data to the Register is still in development. *Refer also recommendation 5.12 below.*	No

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.13	**Colposcopy documentation** The National Cervical Screening Programme uses the opportunity presented by the collection of colposcopy information to emphasise to colposcopists the importance of good quality documentation to enable measurement of the quality of colposcopy services and to establish the limitations of the role of colposcopy in the diagnostic process for cervical cancer and pre-cancer.	Colposcopists are required by the Health (National Cervical Screening Programme) Amendment Act 2004 to provide information to the NCSP. This information is then used to generate reports that monitor colposcopy activities against the programme standards and indicators. This can be done from an individual colposcopist perspective or from a colposcopy service perspective. Colposcopy data on the NCSP Register are not yet robust enough to include these indicators in monitoring reporting; however, work is underway to improve this. All DHBs will have received spreadsheets from the NCSP by March 18, 2011 which show all of the information they have submitted to the Register since July 2009. They will be required to audit their own information system against the spreadsheets from the Register and submit any data that are in their system but which haven't been submitted to the Register. Once the NCSP is confident that the information on the Register is robust, reports will be able to be generated to enable monitoring against the indicators to resume.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.14	**Ethnic disparities in times to investigation or diagnosis** Where significant ethnic disparities in times to investigation or diagnosis are found, either between or within clinics, the National Cervical Screening Programme works with clinic staff to establish reasons for the disparities and strategies for addressing them.	Ethnic disparities in times to investigation or diagnosis are reported in the six-monthly monitoring reports and recommendations are made on any disparities to the NSU.	Yes – ongoing
5.15 – 5.18	**Ethnicity information** The New Zealand Health Information Service ensures that all official ethnicity data collection tools (including the ethnicity on the death certificate) are consistent with the *Ethnicity Data Protocols for the Health and Disability Sector*, published by the Ministry of Health in 2004. The Ministry of Health evaluates the impact of the proposed initiatives to improve ethnicity coding in routine data on the accuracy of ethnic-specific data reported by the National Cancer Registry and the National Cervical Screening Programme Register. If the evaluation shows that Māori cervical cancer incidence and mortality remain underestimated by the National Cancer Registry data, the National Cancer Registry should consider other avenues than the National Health Index for obtaining ethnicity information (eg, it would be possible under the Cancer Registry Act 1993 to require treating gynaecologists to request this information from women directly, as part of registration information provided to the National Cancer Registry).	There remains a significant undercount of Māori women on the NCSP Register. The NSU commissioned work to estimate the ethnicity undercounts on the Register.[20]* Further work is being undertaken to assess the current appropriateness of the ethnicity adjustors that were developed by Public Health Intelligence. This is being undertaken by matching all records on the Register against the NHI. Work is under way to take account of this underestimate and to improve the accuracy and completeness of ethnicity data on the NCSP Register. This includes: • educating smear takers to collect self-identified ethnicity information • where no ethnicity data are recorded on the NCSP, a proposed matching of NCSP Register data with NHI data • exploring the use of ethnicity adjustors in monitoring reports.	Yes – ongoing

[20] Wright C. Accuracy of Ethnicity Data in the National Cervical Screening Programme Register (NCSP-R). Health & Disability Intelligence Unit. Report Number 2. September 2008.

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.15 – 5.18	(Continued) The New Zealand Health Information Service provides more timely cervical cancer incidence data for all Māori and non-Māori women (at present these data are available only up until 1999). In the meantime, provisional data reported on the New Zealand Health Information Service website should include ethnic-specific rates. The National Cervical Screening Programme reviews its processes for obtaining ethnicity data (if the National Cervical Screening Programme cytology request form requires smear-takers to collect this information from women, then the National Cervical Screening Programme needs to liaise with the New Zealand Health Information Service and make use of their training package to actively inform smear-takers as to the best practice for doing so). In the mean-time the National Cervical Screening Programme could consider using a definition of 'Māori on any routine source' for reporting Māori data, although screening targets would need to be revised to take account of the higher estimates thus obtained.		
5.19 – 5.21	**Cancer registration** The National Cancer Registry fully utilises the powers conferred by the Cancer Registry Act 1993 and the Cancer Registry Regulations 1994 to obtain all the information necessary to gain as complete information as possible on registration of cervical cancer. This includes requesting stage information and developing systems to ensure that where a woman's status is altered as a result of a subsequent multidisciplinary meeting, review of histology specimens or other reconsiderations of her case, this information is routinely provided to the National Cancer Registry.	The National Cancer Registry has recently been targeted by the Government for major review.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.19 – 5.21	(Continued) The National Cancer Registry obtains appropriate clinical advice to determine where more information is required to confirm a registration, including following up 'suspicious' histology results to determine whether a clinical non-cancerous diagnosis has been made and to identify women with probable stage 1A disease, for confirmation by their clinician. The National Cancer Registry ensures that it consistently adheres to international standards for assigning date of diagnosis and for determining eligibility for registration.		
5.22	**Monitoring frequency of screening** The National Cervical Screening Programme develops definitions and targets for 'adequate frequency of screening' (ie, regular smears at the appropriate interval) and monitors these, in addition to monitoring women who have had a smear in the last three years, for all women and by ethnic group and other high-priority groups of women aged 20–69 years.	Work has been commissioned to examine the monitoring of the 'regularity of screening'. This work is in progress.	Yes – ongoing
5.23	**Monitoring disparities** The National Cervical Screening Programme ensures that targets for screening, incidence and mortality continue to aim at reducing of disparities between Māori and non-Māori and that these disparities are specifically monitored.	Disparities in coverage, mortality and incidence rates between Māori, Pacific, Asian and Other women are regularly monitored.	Yes – ongoing
5.24	**Screening indicators – age standardisation** Screening indicators, such as coverage and 'adequate frequency of screening', reported for different ethnic groups are age-standardised.	Age standardisation of indicators is being undertaken by the new monitoring group.	Yes – ongoing

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.25	**Hysterectomy adjustment** The National Cervical Screening Programme continues to report both hysterectomy adjusted and unadjusted screening indicators.	Indicators are reported with hysterectomy adjustment in line with international reporting of coverage. Work to update New Zealand hysterectomy adjustments is in progress.	Yes – ongoing updates
5.26	**Reporting of cancelled enrolment/ enrolled vs all eligible women** From the implementation of the new Health (National Cervical Screening Programme) Amendment Act 2004, the National Cervical Screening Programme reports age-specific numbers and proportions of women who have cancelled their enrolment in the National Cervical Screening Programme and also reports screening indicators both as numbers and proportions of enrolled women and of all eligible women.	The 'opt-off rate', which since 2008 has been called the 'withdrawal' rate, is reported in the monthly, six-monthly and biannual monitoring reports. The withdrawal rate is very low. Screening indicators are reported both as numbers and as proportions of enrolled women and of all eligible women.	Yes – ongoing
5.27	**Timeliness of annual monitoring data** The National Cervical Screening Programme considers ways of ensuring that annual monitoring data, including screening indicators, can be available in a timely way.	The NSU has reviewed the content and format of NCSP annual monitoring reports from 2008 onwards. The NSU acknowledges delays in reporting which took place over the years 2007–2009. A catch-up of monitoring is currently underway, and by December 2011 it is expected that monitoring will be up to date.	Yes – ongoing
5.28	**Future audits** Prior to further audits of women with invasive cervical cancer, priority be given to implementation of the 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

Ref	Recommendation (Cervical Cancer Audit)	Status / date	Further work required?
5.29	(Continued) A period of prospective collection of screening history and clinical management data as cases are notified should occur (eg, beginning in 2010), with collation and analysis of data performed once sufficient cases have been accumulated to enable significant results to be produced. The number of cases should be defined to include sufficient Māori women to enable robust comparisons with the results of the current audit. As the ethnic composition of the population changes, it may be possible to include sufficient Pacific or Asian women to enable ethnic-specific analyses for those groups.		
5.30	**Māori/non-Māori disparity in mortality – reasons** The Ministry of Health investigates reasons for the much greater disparity between Māori and non-Māori women in mortality from cervical cancer than in incidence. The investigation may include audit of the accuracy of ethnic-specific mortality data and audit of cervical cancer management.	Research on this topic has been carried out by the Ministry of Health, University of Otago (Eru Pomare Centre) and published in peer review journals, eg, *Am J Public Health* and other reports. Authors include Ricci Harris, Carolyn Shaw, Diana Sarfati, Tony Blakely, Gordon Purdie, Mona Jefferies.	No

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Sadler L, Priest P, Peters, Crengle S, Jackson R. New Zealand Cervical Cancer Audit: Screening of Women with Cervical Cancer: 2000-2002 [the Cervical Cancer Audit]. 2004

Appendix C: Agencies and organisations contacted by the Review Committee

District Health Board (DHB) lead colposcopist and nurses and managers

Family Planning Association of New Zealand

Immunisation and HPV experts

ISPs (independent service providers) interviewed at the Auckland Workforce Development and Leadership Forum (AK Forum):

- lead pathologist and lead scientists
- six laboratories reporting cytology and HPV testing

Mainstream primary health organisations (PHOs)

Māori Monitoring & Equity Group (formerly Advisory Group) (AK Forum)

Māori primary health organisations (MPHOs)

National Screening Advisory Committee

National Cervical Screening Programme (NCSP) Advisory Group

NCSP Senior Management Team

NCSP Team

National Screening Unit (NSU) Senior Management Team (SMT)

Office of the Health and Disability Commissioner (H&DC)

Other government groups:

- H&DC Office

Other groups:

- Cancer Control Council
- Cancer Control Council (NSW – monitoring)
- Cancer Society of NZ

Pacific primary health organisations (PPHOs)

Pacific providers (AK Forum)

Pacifica (Pacific Advisory Group)

Public health physician

Public health representatives/services

Regional service managers/co-ordinators (AK Forum)

Register Central Team DATAM / New Zealand Post

Research scientist, University of Otago

Women's groups:

- Federation of Women's Health Councils
- Women's Health Action Trust

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

Appendix D: Semi-structured interview guide (developed by Parliamentary Review Committee 2011)

Review Committee of the New Zealand Cervical Screening Programme, March/April 2011

Introduction

The Review Committee has been selected by the Minister of Health to assess and review functions and outcomes of the New Zealand Cervical Screening Programme. Committee members have been appointed by the New Zealand Legislature to carry out this mandate for the benefit of New Zealand women.

One way the Committee wishes to elicit feedback is by semi-structured interviews. This will involve a series of questions that will be followed by an opportunity 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.

Members of the Review Committee will keep your feedback in confidence. If the information you provide is included in the Committee's Report to the Minister, the source of the information will not be provided and you will not be personally identified.

Name..... Date .....

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

Advisory Committee..... Please specify Committee name.....

Physicians: General practice ..... OB/GYN..... Colposcopy.....

Laboratory ..... Nurse practitioner ..... Health promotion.....

Public health..... Scientist..... Screening participant.....

Other (please specify).....

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

What do you know about quality improvements that have been under way within the Screening Programme?

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

At an overall level, do you believe that the Screening Programme is providing a valuable and high quality service for New Zealand women?

If yes, please explain why

.....

.....

If no, please explain why

.....

.....

In your opinion, what has been the single biggest challenge that the Screening Programme faces?

In your opinion, what has been the most significant accomplishment of the Screening Programme?

In your opinion, what, if any has been the most significant negative impact of the Screening Programme?

In your opinion, what is the most important issue that the Screening Programme must address and resolve:

in the next year? .....

in the next 5 years?.....

in the next 10 years?.....

Please identify of what, if any, other issues the Review Committee should be aware?

Is there any other information that you wish to share with the Review Committee for their consideration?

Thank you so much for your time and contribution.

If you have other issues after this interview that you wish to share with the Review Committee, please submit in writing to:

Dr Jeffrey Tan
Chair, Review Committee of NCSP
jeff.tan@thewomens.org.au

Appendix E: Parliamentary Review Committee submission form

National Cervical Screening Programme (NCSP) Parliamentary Review

March 2011

Please describe any issue/s that you would like to submit to the NCSP Parliamentary Review Committee to consider in their review including why you consider these to be important. (Use additional sheets if required.)

Name..... Organisation/Affiliation .....

Issues for review

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

   At an overall level, do you believe that the Screening Programme is providing a valuable and high quality service for New Zealand women? Yes No

Please explain why

2. In your opinion, what is the biggest single challenge that the Screening Programme faces?
3. In your opinion, what has been the most significant accomplishment of the Screening Programme?
4. In your opinion, what has been the most significant negative impact on the Screening Programme?
5. In your opinion, what is the most important issue that the Screening Programme must address:

   in the next year?

   in the next 5 years?

Thank you. Please email this form to:

The Committee Chair
Dr Jeff Tan
jeff.tan@thewomens.org.au

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 2011 NCSP Parliamentary Review Committee.

Appendix F: Chronology (Timeline) of significant events for NSU and NCSP

1988	The Cartwright Inquiry (Cervical Cancer Inquiry at National Women's Hospital) recommends the NCSP be established. Prior to this, ad hoc cervical screening in New Zealand.
1988	The NCSP is established in 14 Area Health Boards (AHBs). Department of Health provided guidance and support.
1991	The NCSP Register is introduced into 14 AHBs as standalone systems.
1993	The NCSP is divided between the Ministry of Health, Public Health Commission and four Regional Health Authority (RHA) purchasing units.
1994	NCSP Register operates out of 14 AHBs which input data.
1996/97	The NCSP Register 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 co-ordination in the HFA is transferred to Auckland, Public Health Directorate.
1998	The NCSP Register team is located in the Information Directorate of the HFA.
October 1999	The Gisborne Inquiry into Under-reporting of Cervical Smear Abnormalities in Gisborne Region is established.
July 2000	The NSU is established in the Ministry of Health as a separate unit, with a Clinical Director and Group Manager. The Clinical Director reports to the Group Manager – at tier 3.
April 2001	The Gisborne Inquiry report is published.
2001+	Implementation of 46 recommendations from the CSI.
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.
2002	The Office of Auditor General (OAG) reports on action undertaken to implement the Cervical Screening Inquiry's 46 recommendations.
June 2002/03	Dr E McGoogan produces a second report on progress in implementing the CSI recommendations and makes further recommendations.

2002	In the NSU structural review (#1) the Clinical Director position is disestablished following the incumbent's resignation. Under the restructure there are three Clinical Leaders: for breast screening, cervical screening and public health. The Clinical Leaders of breast and cervical screening report to the Group Manager and the Public Health Leader reports to Director Public Health, with dotted line reporting to Group Manager.
2002	The new Health Bill is developed to address the safety and effectiveness of the NCSP. (It became the Health (National Cervical Screening Programme) Amendment Act 2004.)
2002	Data input to the NCSP Register is reduced from 14 to six DHBs.
2002/03	Further NSU structural changes are made (#2): the QMAA (a separate quality group within the NSU) is disestablished and its quality functions are incorporated within the NCSP and BSA teams.
December 2003	OAG – the second report, a review of the CSI and other recommendations is published.
7 March 2004	Health (National Cervical Screening Programme) Amendment Act 2004: section 112C comes into force on 1 July 2004; the rest of the Act comes into force 12 months later.
November 2004	The Cervical Cancer Audit report published on the screening of women with invasive cervical cancer 2000–2002.
July 2005	NCSP Register: implementation of the Bethesda 2001 coding system occurs.
2006	NCSP Register: redevelopment of a new register begins.
May 2006	The Health and Disability Commissioner report reviews colposcopy services at Waitemata DHB.
2006	Review/audits of all DHB colposcopy services are carried out.
2007	In further Ministry restructuring the NSU is moved to the Health and Disability National Services Directorate.
2007/08	A further NSU restructure (#3) occurs: 'Strengthening Foundations' – co-ordination of new screening initiatives (antenatal and newborn). This re-establishes a separate quality team (Quality and Equity) in the NSU. NSU also re-integrates into the Ministry but retains direct purchasing of services.
July 2008	The NCSP Register is centralised in the Ministry of Health. A new Register Central Team is formed. All data input is central, with 13 regional register support services.
September 2008	NCSP Register: 'Go live', a newly developed Register, is implemented with the 2008 *Guidelines for Cervical Screening.*

2008/09	A Ministerial review of the health system is undertaken, resulting in the Ministerial Review Group's Report.
2009/10	The Ministry of Health is restructured. A National Health Board (NHB) is established in the Ministry of Health. 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	Further NSU restructuring (#4) results are: • 'equity' oversight becomes a Quality Team function • clinical leadership is dropped 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 the NCSP and BSA • there are changes in some reporting lines.
September 2009	The NSU Strategy and Policy Team, providing advice on wider screening issues, is moved out of the NSU.
March 2010	Ministry of Health restructuring occurs.
July 2010	The NCSP Register is outsourced to DATAM (a NZ Post subsidiary), with approximately 28 staff.
July 2010	NCSP Register: HL7 messaging is implemented, so that laboratory results go directly to the Register.
February 2011	Further Ministry of Health restructuring is undertaken.

Appendix G: Population register compared with primary health organisation registers

What is a population register?

The United Nations Statistics Division defines a population register as 'a mechanism for the continuous recording of selected information pertaining to each member of the resident population of a country'. This makes it possible to determine up-to-date information about the size and characteristics of the population. A population register comprises a complete and up-to-date list of the name, date of birth, gender, ethnicity and addresses of individuals.

No such centralised list exists in New Zealand. Instead, New Zealand uses a five-yearly Census of Population and Dwellings as the major source of population statistics. Nordic countries have developed population registers, which link with an address register to birth and death registers, and to other administrative registers such as tax, health and education data. These registers have replaced the traditional census.

Statistics New Zealand is looking at ways to meet information needs for social and population statistics. The establishment and operation of a population-based register for New Zealand is being considered as part of this work. A recent paper published in February 2011 by Statistics New Zealand noted that a population register would be expensive to create and (more importantly) to maintain. Public acceptability is also a major factor that would require debate prior to the establishment of a population register. Most concerns are likely to relate to the misuse of data for purposes for which they were not intended.

The establishment of a population register, as recommended by the Cervical Screening Inquiry, is part of a large project under consideration by Statistics New Zealand relating to work looking at the overall system of official social and population statistics. However, the NCSP has looked at other ways to improve the accuracy of data on the NCSP Register, utilising other administrative health registers, specifically the PHO register.

PHO registers

Primary health organisations (PHOs) have been very successful in developing registers. The PHO enrolment collection was established in 2005. These registers are used by PHOs and at a national level for multiple purposes. Although no national register exists, a high proportion of the population is registered with a PHO. Enrolment in a PHO is voluntary, but people are encouraged to join in order to gain the benefits.

As a result, the set of PHO registers comprises a regularly updated register, which can be used in the same way as a centralised register. Each PHO submits its register of enrolled patients to the Ministry of Health on a quarterly basis, for payment purposes. A limitation of the PHO registers is that about 96% of the population are registered (not 100%), and a lower proportion of Māori are registered, but enrolments overall are improving.

The only practical way to establish a population register for screening or other purposes would be to capture the remaining proportion of the population (not on the NCSP Register) through primary care. Primary care is also better placed to send screening invitation letters to women.

The NCSP Register acts as the backup system for primary care and women, providing reminders for women who have not been screened and reminders to smear takers to recall women who are overdue for screening.

Appendix H: Progress against Colposcopy Review Recommendations made from the 'Report on the Findings of a Review of District Health Board Colposcopy Services' (2006) (47)

Review Report: Areas identified for improvement and progress

Area for improvement	Progress with improvement
Clinical leadership and oversight	Twenty DHBs currently have a lead colposcopist in place and 19 DHBs have a lead colposcopy nurse in place. The two DHBs not complying are working towards this.
Consistent triaging and classification of colposcopy referrals	This has been addressed in each audit and is being resolved through corrective action request (CAR) resolution. Four DHBs were identified with deficits here and all four have resolved this.
Processes in place to ensure that women receive timely initial and follow-up appointments in accordance with the NCSP OPQS	This has been addressed in each audit and is being resolved through CAR resolution. Thirteen DHBs had mention of this in their CARs and were required to address timeliness in order to sign off the CARs; 12 have resolved this. Continual monitoring of contractual monthly reporting is usual business at the NSU to identify any DHBs that fall outside of the timeframes, from month to month.
Compliance with the NCSP OPQS for the management of women who fail to attend appointments	This has been addressed in each audit and is being resolved through CAR resolution. Fourteen DHBs were identified as needing improved processes, and nine DHBs have resolved this.
Establishment of documented, regular multidisciplinary case review meetings	This has been addressed in each audit and is being resolved through CAR resolution. Fourteen DHBs were identified as not complying with this either partially or fully, and eight DHBs have resolved this.
DHB infrastructure to support the delivery of high-quality colposcopy services and meeting contractual requirements	This has been addressed in each audit and is being resolved through CAR resolution, although not with 'specific' CARs. For example, part of CAR resolution for some DHBs has been ensuring that appropriate staffing levels exist to provide the delivery of high-quality colposcopy services. Additional issues-based meetings arranged by the NSU following audits have involved DHB Senior Management to ensure the colposcopy services are supported in their actions to comply with CARs and OPQS.

Area for improvement	Progress with improvement
Develop further guidelines to support DHBs to fully implement programme standards	The audit process has provided all DHBs with guidance and guidelines on fully implementing programme standards. Audit CARs required the resolution of aspects that did not meet the programme standards
Development of specifications for the establishment of DHB clinical leadership (including nursing) positions and assisting DHBs to understand the requirements for the clinical leadership of colposcopy services	A working group was established with colposcopy nurses as part of the colposcopy enhancement project, which resulted in specifications for a job description for the Lead Colposcopy Nurse role, covering the tasks needing to be included.
Working in collaboration with lead colposcopists to further develop and stabilise the services	A national meeting for lead colposcopists and lead colposcopy nurses was facilitated by the NSU in June 2007, and was repeated in 2008. This promoted information sharing, networking and discussion around matters specific to colposcopy, audit and staff structures. Lead colposcopists are consulted regarding issues to hand, input into changes to service specifications and standards.
Supporting the colposcopy services to meet their legislated obligation to provide accurate colposcopy data, and to provide regular and timely data analysis and feedbacks to DHBs	Through the process of being audited, many DHBs recognised the inadequacy of the systems they were using to manage colposcopy data. In response to CARs relating to this, they have found solutions allowing them to meet their legislative obligations. At present, all DHBs are complying with forwarding contractual data reporting, as requested by the NSU. The NSU, from November 2007, has been reporting back to DHBs monthly with nationwide data on colposcopy waiting times and did not attend (DNA) rates. With the full implementation of the new NCSP Register in September 2008, it is planned to distribute further feedback from the new reporting capacity that will be available.
Referring concerns to senior DHB management, where necessary, to ensure that compliance requirements for colposcopy service are well understood	As part of performance management required with DHBs not in compliance, senior DHB management are informed and participate in site meetings to discuss concerns and agree on the corrective action required.

Area for improvement	Progress with improvement
Proactively engaging with those DHBs that require the most assistance to achieve compliance with the NCSP OPQS	The NCSP Relationship Manager has been actively involved in engaging with all DHBs and paying close attention to those that require the most assistance. The NSU has become actively involved with DHBs where concerns around service safety have arisen and has been proactive in organising meetings to discuss these concerns and in assisting to ensure that appropriate clinical reviews are undertaken.
Giving the highest priority to completing the schedule of colposcopy service audits	This has been completed, and all 20 DHBs have been audited.
Working with the Independent Monitoring Group to continue the development of colposcopy service indicators	This has been ongoing. As from January 2008 the Independent Monitoring Group (IMG) has taken a new format as it has been merged with the NCSP Advisory Group.
Seeking further advice from the NCSP Advisory Group and other stakeholders on additional activities to support DHBs to achieve compliance	The NCSP Advisory Group merged with the Independent Monitoring Group from January 2008 and are an integral part of the NSU seeking advice around activities concerning DHBs need for compliance. This position ended in July 2008 and the NCSP Performance Manager returned from secondment to the new NCSP Register, to continue this work.
The Review Report also noted that the NSU recognises that some DHBs experience difficulties recruiting and retaining experienced colposcopists. It noted that the sustainability of 21 DHB colposcopy service providers may need to be discussed and consideration given to a lead regional service model.	The NSU undertook a small project, as part of the colposcopy enhancement project, to gather data on the national workforce in colposcopy and as at January 2008 there were 123 permanent consultants or long-term locums working in colposcopy services. In addition, all lead colposcopy nurses are appropriately qualified and have adequate cover for when they are absent.
No further consideration has been given to a lead regional service model. Solutions have been implemented with DHBs temporarily having difficulty providing a colposcopy service due to staffing shortages through closer performance management activities by the NSU.	This has included locum cover from other DHBs or managing their referral system so that women are seen at neighbouring DHBs within the OPQS guidelines.