



**Initial
Response to
the New
Zealand
Cervical
Cancer
Audit 2004**

**National
Screening Unit
December 2004**

INTRODUCTION

1. This report provides the initial response of the National Screening Unit (NSU) to the findings and recommendations of the New Zealand Cervical Cancer Audit 2004.

BACKGROUND INFORMATION

2. A Cervical Cancer Audit of women with invasive cervical cancer was first planned as part of a National Cervical Screening Programme (NCSP) evaluation plan put forward by the University of Otago in the late 1990s. The Ministerial Inquiry into the Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region (the Gisborne Inquiry) recommended that the Audit proceed and be completed within 6 months. The Audit was a key recommendation of the Inquiry and was aimed at determining whether the NCSP was safe for women, what improvements were required to increase its effectiveness, and whether there was evidence of systemic under-reporting of cervical abnormalities in New Zealand laboratories during the 1990s.
3. The National Screening Unit (NSU) commenced the Audit in January 2001. Late in 2001, a new independent audit team was established in partnership with the University of Auckland. The Audit was to be carried out independently of the NSU, given its national responsibility for the NCSP, and that it effectively formed part of what was being audited.
4. The goals of the Audit were to provide information to support:
 - improvements to the NCSP, and thus contribute to the ongoing reduction in the incidence and mortality from invasive cervical cancer in New Zealand
 - the elimination of disparities between Māori and non-Māori in the incidence of and mortality from invasive cervical cancer.
5. The Audit was a significant under-taking by international comparisons. It involved collecting screening histories for the seven years prior to diagnosis of 376 women diagnosed with cervical cancer (77 percent with squamous cell carcinoma¹) between January 2000 and September 2002. Three hundred and forty nine (78 percent) of women eligible for the Audit consented to all forms of data collection.² The Audit also carried out a slide review (over 4300 slides).

Key Findings

6. Overall, the auditors considered that, from a national perspective, the NCSP operates to a generally high standard for women who are having regular smears. Furthermore, women and health professionals can have confidence in the service and should be encouraged to participate in the NCSP. The

¹ Squamous cell carcinoma is the most common cervical cancer (about 80 percent of cases). Cervical screening is more effective at preventing squamous cell carcinoma than adenocarcinoma.

² The Audit was carried out under Section 74A of the Health Act 1956. The Health (National Cervical Screening Programme) Amendment Act 2004, which comes into effect March 2005, will not require consent for the collection of data for future Audits.

reduction in cervical cancer deaths and cancer cases over the past decade reflects the effectiveness of cervical screening and the NCSP.

7. The foreword to the Audit report states that: “the main findings are not unique to the New Zealand cervical screening programme, nor are they new information, but they under-score the importance of ongoing efforts to increase coverage, improve accuracy of routine data, and decrease inequalities in health for Māori women and other disadvantaged groups” (Ministry of Health, 2004).

Cancer incidence, stage and mortality

8. The Audit found that the NCSP has met its 2005 target for cervical cancer incidence for all women in 2001, although a 22 percent reduction in the incidence rate for Māori at that time would be needed to reach the 2005 target for Māori (11.0 per 100,000).
9. More than 70 percent of women with cancer were diagnosed at Stage 1, meaning that the NCSP met its target for stage of disease distribution. This is an internationally accepted measure of a good quality screening programme. In addition, women who have a high-grade abnormality detected are generally referred for investigation in a timely manner.

Achieving high levels of regular screening

10. The Audit’s major finding was that women with invasive cervical cancer had not been screened adequately; they had either not been not screened at all, or screened with inadequate frequency. Māori women were more poorly screened than non-Māori, possibly entering the programme later. Women of high deprivation, low income, lower education, and of older age were also poorly screened. The Audit found that the NCSP would be more effective in reducing the incidence of and mortality from cervical cancer if the proportion of women having regular smears at the recommended intervals increased, and if disparities between Māori and non-Māori were eliminated.

Smear reading

11. The Audit did not find evidence of systemic under-reporting of cervical smears in New Zealand laboratories. The upgrade proportion for prior negative smears for women with cervical cancer did not exceed the NCSP standard, and the Audit considered that missed high-grade smears (that is, false negatives) are currently a minor contribution to the incidence of cervical cancer in New Zealand when compared with levels of inadequate screening.

Routine data quality

12. The Audit found that the NCSP-Register and the National Cancer Registry were accurate records of screening histories and the total rates of incident cases of cervical cancer respectively. The Audit found, however, that neither register was an accurate source of ethnic specific statistics.

Summary of Recommendations

13. The Audit makes 31 recommendations for improvement of the NCSP. Responsibility for some of the recommendations is shared between the NSU,

New Zealand Health Information Service (NZHIS), and Clinical Services Directorate (CSD). Twenty-five of the recommendations fall within the responsibility of the national management and operation of the NCSP, ten with the NZHIS and one with the CSD. An analysis of the recommendations identifies that of the 31 recommendations, 26 are already underway and four are completed.

Table 1: Summary of progress against recommendations

| Issue | Recommendation | Status | Responsibility |
|---|-----------------------|-----------------------|-----------------------|
| Achieving high levels of regular screening | 1 | Underway | NSU/ NZHIS |
| | 2, 6 | Underway | NSU/ CSD |
| | 3 | Underway | NSU/ NZHIS |
| | 4 | Completed | NSU |
| | 5 | Underway | NSU |
| Smear reading | 7, 8, 9, 11 | Underway | NSU |
| | 10 | Completed and ongoing | NSU |
| Investigation of abnormal smears and bleeding | 12, 13, 14 | Underway | NSU |
| Routine data quality | 15 | Underway | NZHIS |
| | 16, 18 | Underway | NSU/ NZHIS |
| | 17 | Underway | NZHIS |
| | 19, 20 | Underway | NZHIS |
| | 21 | Completed | NZHIS |
| Monitoring the NCSP | 22, 23, 24, 27 | Underway | NSU |
| | 25 | Completed | NSU |
| | 26 | Underway - ongoing | NSU |
| | 28 | Underway | NZHIS |
| Future Audits | 29, 30 | Underway | NSU |
| | 31 | Under consideration | NSU |

14. Six recommendations relate to the need to achieve high levels of regular screening, including:
- utilising a population based database for identifying unscreened and under-screened women and inviting them for a smear
 - implementing a national recall system rather than relying upon individual primary care recall systems
 - exploring linkages between the NCSP-Register, National Health Index and PHO register to ensure women's contact details are current
 - ensuring women who cancel their enrolment are aware that they or their smear taker are responsible receiving smear results and reminders
 - reducing barriers for under-screened women to access screening
 - using targeted strategies to reduce inequalities.

15. Of the other 25 recommendations:
- one calls for improvements in the resources provided to women to ensure that women are made aware of the need for regular screening
 - four relate to the need to improve laboratory quality assurance activities
 - three relate to the need to improve colposcopy data collection and address any ethnic disparities in access to investigation and diagnosis
 - four call for improvements in ethnicity data collection
 - three call for improvements in Cancer Registry data collection and reporting
 - seven relate to improvements in NCSP indicator definition and monitoring
 - three relate to the carrying out of future audits and investigations.
16. A number of the recommendations are either complete or will be completed as part of the work to implement the Health (National Cervical Screening Programme) Amendment Act, effective from March 2005, including:
- clarification of roles and responsibilities of the NCSP and NCSP providers
 - provision of information to women to ensure they are aware that if they cancel their enrolment in the NCSP, they must depend upon their own initiative or smear-taker recall system for reminders regarding regular smears
 - an updated information booklet for women emphasising the need for regular smears
 - new colposcopy data reporting and standards,
 - improved programme monitoring and evaluation, and provision for future audits.
17. Recommendations related to laboratory quality assurance will be implemented as part of the review of the NCSP Operational Policy and Quality Standards Laboratory Services chapter, which is due to be completed in 2005/06.
18. Recommendations that require information system developments, including as part of the NHI and National Cancer Registry (NCR) upgrade work and planned NCSP-Register redevelopment, will take longer to implement.

Programme Developments

19. The period covered by the Audit pre-dates the implementation of NCSP improvements made since the Gisborne Inquiry. Information gathered by the Audit regarding any part of the NCSP relates to past rather than current practices. Since the period the Audit investigates, 1996 to 2002, the NSU has undertaken and implemented a number of initiatives to strengthen the NCSP. Many of these have or are addressing the areas for improvements identified by the Audit. These are given the table below.

Table 2: Initiatives to strengthen the NCSP

| | |
|-------------------|--|
| July 2001 | Community and hospital laboratories and DHB colposcopy providers required to meet new standards NSU assumes direct contractual relationships with NCSP DHB providers |
| December 2001 | Dr McGoogan Report on progress to implement the CSI recommendations |
| February 2002 | Office of the Auditor General Report on progress to implement the CSI recommendations |
| March 2002 | 1996-98 NCSP Statistical Report published and distributed to stakeholders |
| June 2002 | The detailed booklet for women regarding the NCSP published |
| July 2002 | Migration of the NCSP-Register onto the Health Intranet to help enable the New Zealand Cancer Registry to establish a read-only link to the NCSP-Register |
| Commenced in 2002 | Independent monitoring reports produced quarterly Liaison with Colleges and other professional organisations strengthened NCSP sponsorship of the New Zealand Society of Cytology Annual Conference and Scientific Meeting NCSP-Register and the New Zealand Cancer Registry data assurance processes implemented |
| June 2003 | Second Dr McGoogan Report on progress to implement the CSI recommendations |
| July 2003 | Reconfiguration of NCSP-Regional office register operations |
| December 2003 | Study grants provided to 13 fourth year Bachelor of Medical Science students Second Office of the Auditor General Report on progress to implement the CSI recommendations |
| February 2004 | New laboratory agreement implemented for laboratories providing cervical cytology |
| March 2004 | Health (National Cervical Screening Programme) Amendment Bill passed in Parliament 7 March 2004 for implementation in March 2005 |
| April 2004 | Three "Challenges in Cytology" one-day workshops held nationally Consultation undertaken on NSU's Improving Quality: a Framework for Screening Programmes in New Zealand |
| May 2004 | Publication of the National Screening Unit's Cervical and Breast Screening Programmes Workforce Development Strategy and Action Plan 2002 to 2007 |
| June 2004 | The NCSP sponsorship of two pre exam cervical cytology study days |
| July 2004 | Commencement of NCSP provider compliance audit New Colposcopy standards implemented New Regional services standards implemented |
| October 2004 | Three new Māori Independent Service Providers contracted |
| December 2004 | Vocational Registration Programme in Cervical Cytology implemented |
| December 2004 | Work commenced on implementing an individual external quality assurance programme for pathologists in 2005. Massey University appointed as the new Independent Monitoring Group for the NCSP New Health Promotion Framework published |

Response From NSU Advisory Groups and Professional Colleges

20. The NSU has sought initial responses to the Audit findings from the NCSP Advisory Group, the Consumer Reference Group (CRG) and Māori Advisory Group. The NSU will continue to work with its advisory groups, including the Pacific Advisory Group, on the further consideration of the recommendations and how they will be implemented.

NCSP Advisory Group

21. The NCSP Advisory Group is preparing a detailed response to the Audit. In the interim, the group concurs that overall the Audit provides confidence for women that participating in a 3 yearly cervical screening programme reduces the risk from either developing or dying from cervical cancer. The Audit's key message is that women are failing to participate in the NCSP (either by not having smears or not utilising treatment services) and this is particularly so for Māori women. The Group recognises that some strategies have been put in place since 2002 to address discrepancies in the NCSP. The Group suggests that consideration be given to offering free smears to women similar to the breast screening programme, BreastScreen Aotearoa (Appendix 1 refers).

Consumer Reference Group

22. The CRG considers that the recommendation to implement a national population-based database for identifying women who have not been screened, are under screened, or who are eligible for their first screen may be an excessive tool for capturing women eligible for a screening programme. There are plenty of systems in place to recall women and the emphasis on primary care belongs with PHOs. The Group believes that it would be more optimal to use scarce resources to strengthen screening incentives for PHOs and explore other options before developing a database, for example, more information could be found out as to why women are not having regular smears and health promotion activities could be strengthened to raise women's awareness of cervical screening. The Group recommends that free cervical screening be piloted. The group also feels that should the development of a population-based database commence, it needs to be preceded by public debate (Appendix 2 refers).

Māori Advisory Group

23. The Māori Advisory Group (MAG) supports the development of a national population-based database together with the NCSP-Register to identify women as they reach the eligible age and directly invite them for their first smear. The MAG recommends that:
- smear takers should be required to record ethnicity accurately
 - smear takers should be trained and undertake refresher courses to ask ethnicity questions and to be able to explain the importance of ethnicity questions
 - the provision of free smears to women in target groups

- the population-based database and the NCSP-Register be used to keep track of women being screened regularly and invite directly those women who show overdue for a smear, and that the responsibility for recall should remain with the individual woman's smear taker
- the provision information about the programme in appropriate ways to Māori
- promotion of NCSP messages should to go beyond the individual woman, but show responsibility for other women and for future generations
- more Māori be involved in the screening workforce
- research be undertaken as to why it takes longer for Māori women with an abnormal smear to receive treatment.

23. The full response of the MAG is attached as Appendix 3.

The Royal New Zealand College of General Practitioners

24. The Royal New Zealand College of General Practitioners, in a media statement in response to the Audit, supports the need to increase the screening rates for Māori women, those on low incomes and the elderly. The College feels that recall issues and the collection of accurate ethnicity data could be strengthened by integrating the various Primary Care information technology systems. It also considers that having to pay for a cervical smear is a barrier to screening.

The New Zealand Medical Association

25. The New Zealand Medical Association (NZMA), in a media statement following release of the Audit, supports ensuring that more women, particularly Māori, can take part in the NCSP. It feels that resources should be prioritised to improving Māori rates for regular screening and referral and investigation processes. The challenge is to find ways of reaching out to women not currently enrolled, or who do not have regular smears. The NZMA considers the current general practice recall system is working well for many women, and any changes to the NCSP should build on this.

COMMENT

26. The NSU's response to key recommendations of the Audit is provided below.

Achieving high levels of regular screening

27. The main Audit findings and recommendations highlight the need to improve coverage (that is the number of women who have had a smear recorded on the NCSP-Register within the last 3 years) in the NCSP, particularly for Māori and Pacific women. The Audit reinforces one of the NCSP's most important programme messages – regular three yearly screening is a woman's best protection against cervical cancer. In addition, the Audit findings have suggested that current primary care responsibility for invitation and recall on its own may not be achieving the programme coverage required to meet targets for the reduction in cervical cancer incidence and mortality.

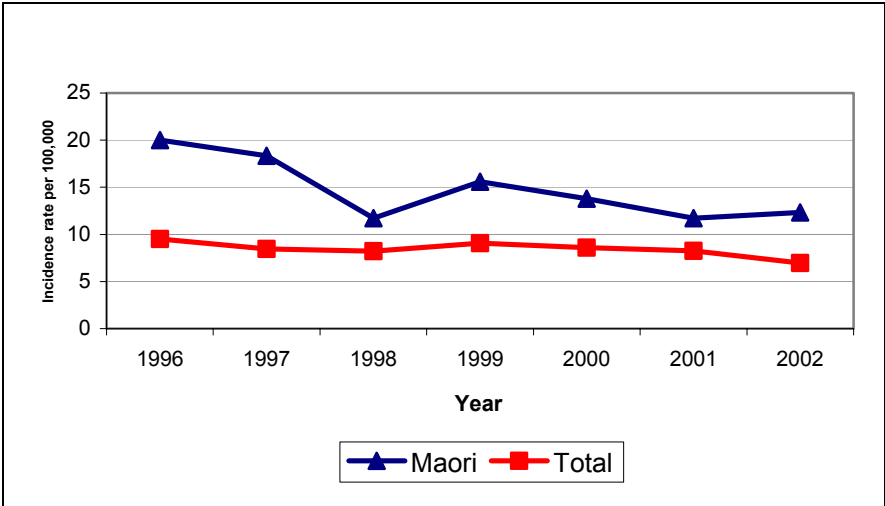
28. Only 50 percent of women with cervical cancer had a smear in the 6 to 42 months prior to diagnosis. Eighty percent of women had not had regular smears, and 20 percent of women had had regular smears. The Audit did not ask these women as to why they had insufficient smears as it felt this to be insensitive and would have introduced a bias into the Audit methodology. Almost all women had a regular GP during the seven years the Audit reviewed. Māori women, women on low income and women with high deprivation indices were inadequately screened.

Cervical cancer incidence and mortality

29. The primary aim of the NCSP is to reduce the number of people dying or affected by cervical cancer. Increasing coverage and participation is key to achieving this aim. The Audit reported cervical cancer incidence data for all women for the period 1990 to 1999, showing a decline of 27 percent during this period.

30. More recent epidemiological data summarising the impact of the NCSP over the last decade shows that the incidence of cervical cancer in the total population has decreased by about 40 percent since the NCSP began in 1991 from 12 per 100,000 in 1991 to below 7 per 100,000 in 2002.³ Cervical cancer mortality for the total population has been declining since the 1970s. However, the rate of mortality decline accelerated by about 60 percent from the early 1990s (from 5 per 100,000 in 1990 to 2 per 100,000 in 2001).

Figure 1: Cervical cancer incidence for Māori and the Total population: age standardised (Segi) per 100,000 women



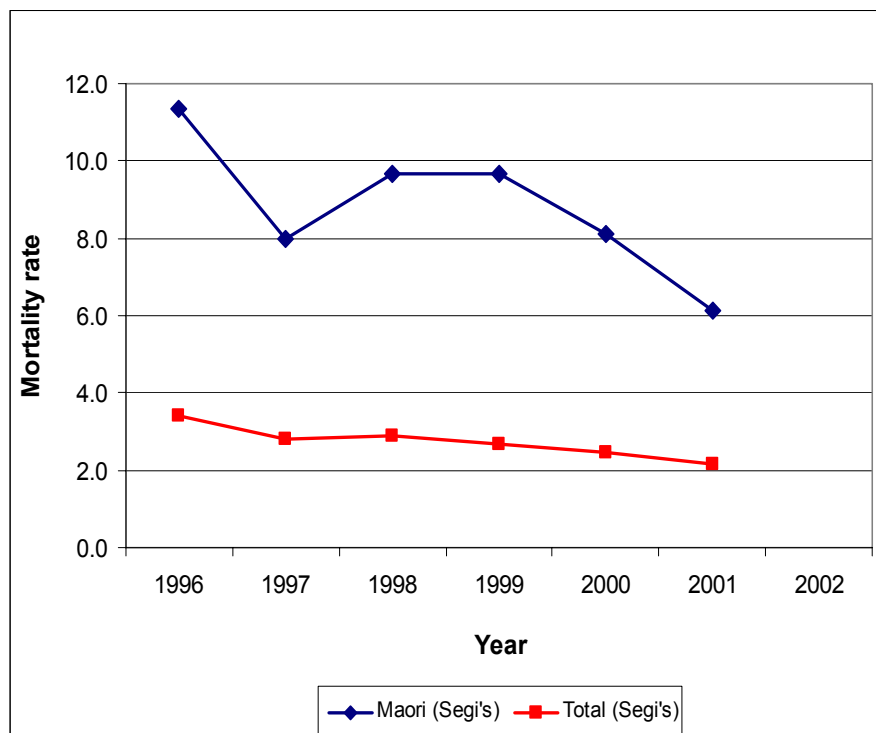
31. While the incidence of cervical cancer is higher among Māori women than the general population, NZHIS data indicates that the gap is closing, as illustrated by Figure 1. In 1996, the first year for which reliable ethnic data is available, the difference between Māori and total rates was 10.5 per 100,000 women (adjusting for age). By 2001, this difference had fallen to only 5.4 per 100,000.

³ Ministry of Health, *Cervical screening in new Zealand: the first decade*, unpublished as at December 2004.

The Audit was only able to report incidence data for Māori for the period 1996 to 1999.

32. Māori have higher mortality from cervical cancer than the general population, as illustrated by Figure 2. As with incidence, however, the gap is closing. From 1996 to 2001 mortality among Māori women fell from 11 per 100,000 to 6 per 100,000 (a 46 percent decrease), whereas over the same period mortality among all women fell by 35 percent (adjusted for age).

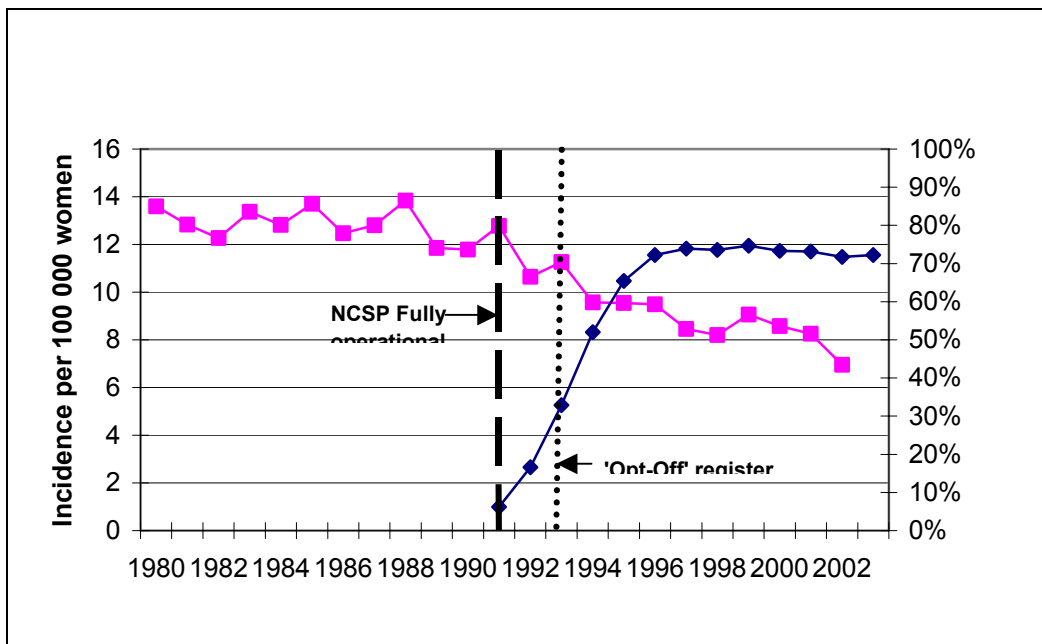
Figure 2: Cervical cancer mortality for Māori and the Total population: age standardised (Segi) per 100,000 women



Coverage and Participation

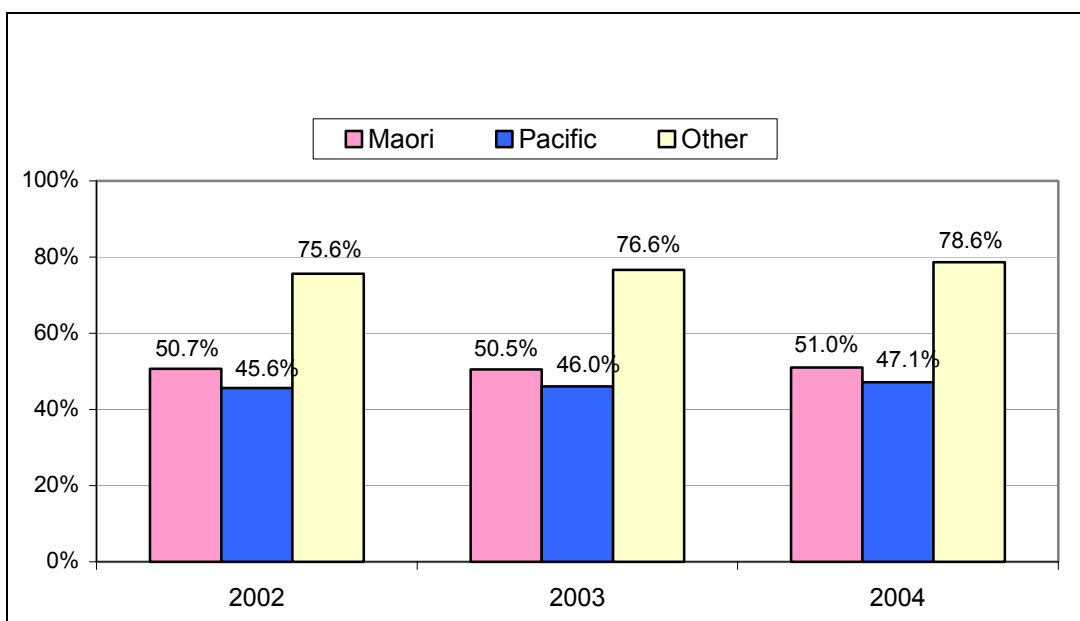
33. The Audit concluded that the NCSP would be more effective in reducing the incidence and mortality from cervical cancer if it increased the proportion of women aged 20 to 69 years having regular smears at the recommended intervals and if disparities between Māori and non Māori were eliminated in terms of participation in regular screening, referral and investigation.
34. Cervical screening coverage for the total population increased markedly between 1991 and 1996 but has since levelled off, as illustrated by Figure 3. About 73 percent of eligible women (women aged 20 to 69 years who have not had a hysterectomy) have had a cervical smear in the last three years.

Figure 3: Incidence of cervical cancer and NCSP coverage in New Zealand



35. Unequal participation in screening programmes is an international problem that can lead to widening ethnic inequalities in health. In countries, such as United Kingdom or Sweden, special efforts are made to promote screening in population groups that are less responsive to invitation and recall processes. Both Māori and Pacific women have lower participation in the NCSP and higher rates of incidence and mortality than the general population, as illustrated by Figure 4. Using data from the NCSP-Register as at November 2004, coverage amongst non-Māori, non Pacific was 78.6 percent, whilst for Māori it was only 51 percent and for Pacific only 47 percent.

Figure 4: NCSP coverage of New Zealand female population by ethnicity from 2002 to 2004 (adjusted for hysterectomy)



36. These coverage figures in Figure 4 are compared with survey data collected as part of the NZ Health Survey 2003 and Commonwealth Fund Survey 2004 in Figure 5. These data suggest that coverage for Māori may be underestimated given the difficulties with ethnicity data recording on the NCSP-Register.

Figure 5: Comparison of New Zealand 3-yearly cervical screening coverage rates

| | NZ Health Survey: 2003 | Commonwealth Fund Survey: 2004 | NCSP-Register November 2004 |
|---------|-----------------------------------|---|--|
| Total | 74.0 | 81 | 71.3 |
| Other | 77.5 | Not reported | 78.6 |
| Māori | 72.8 | Not reported | 51.0 |
| Pacific | 54.4 | Not reported | 47.1 |
| Asian | 43.1 | Not reported | Not reported |

Efforts to increase participation in NCSP

37. At the commencement of the NCSP in the early 1990s, 14 Regional Services were established to maintain the NCSP-Register, co-ordinate communications with primary care practitioners and laboratories, provide regional health promotion services, and target under-screened population sub-groups. Over the last two to three years the NSU has worked with the Regional Services to improve NCSP-Register operations and re-orientate health promotion activities more towards target population groups.
38. The NSU has also worked to improve the capacity and capability of Independent Service Providers who carry out regional health promotion activities targeting under screened populations, including community and marae-based activities aimed at educating women on the benefits of cervical screening and the need for regular smears. In 2004/05, the number of these providers contracted to the NSU increased from three to six. A new funding model has also been introduced along with new service specifications and a new Health Promotion Framework.
39. Since 2003 the majority of the 13 NCSP Regions have shown an overall improvement in coverage for Māori, Pacific and other women. Of the 13 Regions, all of the North Island regions have higher than 51 percent coverage for Māori (the national average), with the exception of Auckland and Waikato. None of the South Island Regions reached the national coverage figure for Māori.
40. In addition, 11 NCSP-Regional Services and the six Independent Service Providers are contracted to provide funded smear-taking for under-screened populations. In 2003/04, a total of 5607 smears were funded at a cost of \$112,140. This figure is expected to increase to 6200 smears for 2004/05. The NSU also provides funding for Independent Service Providers to offer support services for Māori and Pacific women accessing smear taking, assessment and treatment services.
41. Further initiatives aimed at increasing awareness of the need for regular cervical screening are planned by the NSU for 2004/05 and 2005/06, including:

- an awareness raising campaign to coincide with the introduction of the Health (National Cervical Screening Programme) Amendment Act
 - a letter and question and answer sheet to be sent to over 1,000,000 women on the NCSP-Register to coincide with the introduction of the Health (National Cervical Screening Programme) Amendment Act
 - updating the detailed booklet and general pamphlet
 - improving the smear-taker information sheets
 - providing health centres with an NCSP information pack
 - developing new resources for Pacific women
 - reviewing and developing new resources for Māori women.
42. The NSU has recently commissioned a nationwide survey of women to better understand:
- the social context and cultural norms of current health-related behaviour
 - women's perceptions of the NCSP and the new legislation
 - appropriate communication messages and vehicles in relation to the programme and cervical screening.
43. This work will inform the development of health education material and awareness raising campaigns planned for 2005.
44. The Audit recommends that the NCSP, 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. This is in the current booklet, however, the emphasis of this message will be included in the review of NCSP health education material by the end of March 2005.
45. This year the NSU has also commenced a research project to identify and evaluate inequalities that may exist for Māori women along the screening pathway.
46. In addition the NSU work programme includes a range of initiatives to strengthen the role of primary care and linkages with the NCSP-Register, which is discussed in detail below.

The Role of Primary Care

47. Currently participation in the NCSP is supported by a woman's primary care practitioner. A woman may be invited for screening opportunistically as part of another health visit, or she may be proactively invited from a GP age/sex register. Primary care practitioners also have prime responsibility for recall.
48. The Audit's findings suggest that primary care invitation and recall systems, together with NCSP back-up recall, may not be fully successful in ensuring that women are regularly screened. The Audit findings and NCSP coverage figures, particularly for Māori and Pacific, highlight that some women are not being

screened regularly despite having a regular GP and, possibly also, back-up reminders from the NCSP for those enrolled. The Audit was not designed to determine what prevented these women from being screened regularly.

49. The NCSP provides a back-up to the primary care recall, but does not provide a direct invitation for a first smear. The NCSP (via the Regional Services) sends a back-up reminder letter to a woman recalling her for a smear 6 months after she is due (or 3 months for an abnormal smear). The Audit recommends that the NCSP develop a nationally consistent system for recalling women at the appropriate interval.
50. In 2004, the NCSP sent approximately 243,923 letters to women reminding them that they are due for a smear. Of the 1,274,576 women on the NCSP-Register, 503,245 women, or 40 percent, have full screening histories where their smears have been taken on time in accordance with programme policies. These women would not have needed a NCSP back-up reminder. The remaining 60 percent of women who did not have their smears taken on time would have been sent a reminder letter. Around 7.8 percent (99,388) of women on the NCSP-Register remain overdue by 1 to 3 years, and 8.7 percent (110,641) are overdue more than 3 years. This data is available by ethnicity and the NSU is submitting a request to the National Kaitiaki Group and Pacific Women's Data Advisory Group to seek access to Māori and Pacific women's data in order to examine potential inequalities in relation to recall.
51. The NCSP Regional Services communicate with primary care practitioners regarding women overdue for a smear. This may also act as a reminder to GPs to initiate their recall systems, and/or provide an update for the NCSP-Register on new contact details for women. Some women may be recorded on the Register as GNA (gone no address) based upon the return of either result or recall letters and that they are no longer in the care of a GP. Currently around 45,283 women are recorded as GNA. These women would not receive repeat reminders until their details are updated again should they have a smear sometime in the future. The NCSP Regional Services use a combination of phoning the smear-taker, looking through the telephone book and electoral role, and the NHI to try and track these GNA women. Three attempts at tracking these women and those overdue for a smear is considered reasonable.
52. The NCSP already effectively offers a national recall system for those women enrolled on the NCSP-Register, although as a back-up to recall by a woman's GP, six months after the woman is due for a smear. The Audit recommends that this back-up recall process is changed to proactively recall women 3 months prior to the date their next smear is due.
53. The NSU supports the need for improvements in the ability to recall women to the NCSP for regular screening. The NSU has concentrated its efforts on improving primary care recall systems and is currently carrying out a pilot project to review and trial improvements to the recall systems between Medtech 32, the leading primary care Patient Management System (PMS) and the NCSP-Register. The pilot aims to improve the connectivity between these systems in order to improve recall in line with national standards and improve the follow-up of abnormal smears. This project will be evaluated in 2005 and

depending upon the outcome the NSU plans to offer the improvements more widely.

54. The NSU believes that further consultation is needed with the sector before the NCSP implements a national recall system to replace current primary care recall and NCSP back-up recall.
55. An important consideration will be whether a change in the recall approach would address the 7.8 percent of women overdue by 1 to 3 years or 8.7 percent of women overdue by more than 3 years, or whether the 60 percent of women currently sent a reminder letter would respond more quickly to a smear being due, if the letter was sent 3 months prior.
56. In addition, maintaining the role of the primary care practitioner with prime responsibility for recall is also consistent with developments in Primary Care towards a more population health focus where the ability to invite and recall enrolled primary care populations will improve. This role is also consistent with recent developments to measure PHO performance in relation to screening coverage and to eventually provide performance payments. The NSU's CRG has commented that the emphasis on primary care belongs with PHOs and the Royal New Zealand College of GPs and NZMA have suggested that changes in recall should build upon current primary care systems.

Barriers to cervical screening

57. The Audit was not designed to determine what barriers prevented women with cervical cancer from being screened. The Audit did recommend, however, that the NSU pilot and evaluate evidence-based, sustainable strategies for increasing coverage of women at risk of under screening.
58. Access to screening has three components: opportunity, accessibility, and affordability. In practice, the degree of coverage depends on the quality of the invitation and recall system, the level of demand from the eligible population and interest amongst health professionals.
59. The NSU has examined a large amount of literature in this area and has identified that there is a complex range of barriers that may prevent women from being screened. A number of commentators have focused on one particular barrier – cost.
60. Within organised screening programmes internationally, screening typically is free or else individuals are largely reimbursed, so affordability is not a significant barrier to access.⁴ In New Zealand cervical screening is not entirely free. Women are still required to meet the costs of the primary care smear-taking, whilst the NSU funds laboratory and public sector colposcopy services and other programme operations.
61. In New Zealand the current breast screening programme, BreastScreen Aotearoa, offers free mammography and follow-up services. Even where this

⁴ Miles et al, *A Perspective from Countries Using Organised Screening Programmes*, American Cancer Society, Cancer supplement, September 2004, vol 101 no 5.

service is fully funded obtaining high levels of programme coverage is still a challenge.

62. The recent Commonwealth Fund Survey reported coverage rates for cervical and breast screening. As Figure 6 illustrates the coverage rates for women self reporting a smear in the last 5 years did not differ between New Zealand and the United Kingdom (UK), even where in the UK smear taking is fully funded.

Figure 6: Percentage of women aged 25 to 64 self reporting a cervical smear within the previous 3 years by country

| Country | Australia | Canada | NZ | UK | USA |
|-------------------------------|-----------|--------|----|----|-----|
| Smear in the last 3 years (%) | 78 | 77 | 81 | 77 | 89 |
| Smear in the last 5 years (%) | 82 | 83 | 85 | 85 | 92 |

Source: 2004 Commonwealth Fund

63. However, cost is acknowledged as a barrier to accessing primary care services, and reducing the cost of access to health care, particularly for those people on low incomes is a priority in New Zealand with the development of PHOs. PHOs now cover 3.7 million New Zealanders, more than 2 million of whom will benefit from cheaper primary care visits, including for screening services. These developments in primary care since the period of the Audit offer new opportunities for increasing the number of women participating regularly in the NCSP.
64. Currently a woman accessing a non-Access funded PHO can expect to pay on average \$48.05 for a consultation. This average varies from \$43.11 to \$53.87 between District Health Boards (DHBs). As Access funding rolls out to those PHOs currently funded on the Interim formula the fees will drop. This has already happened for the over 65s (from 1 July 2004). Average fees for this age group are \$24.65, ranging from \$19.36 to \$28.15. A similar reduction is expected for 18 to 24 year-olds from 1 July 2005, for 45 to 64 year-olds 1 July 2006, and for 25 to 44 year-olds from 1 July 2007. By 2007 all eligible women will be entitled to receive cheaper smears, however, this can still be perceived as a barrier to screening.
65. In addition, PHOs will also be measured against a range of performance indicators, including cervical screening coverage and participation. PHOs will eventually receive a per capita performance payment for their achievements on a number of indicators. PHO agreements also offer the opportunity to stipulate performance requirements for the invitation and recall of women for cervical screening.
66. The NSU will closely monitor the impact of PHO development on the NCSP and will work with the other Ministry directorates responsible for primary care in order to identify opportunities to improve screening service delivery and population coverage.
67. The NSU has identified that increasing the use of practice nurses to take smears, similar to other organised cervical screening programmes

internationally, may be an opportunity to improve accessibility and affordability of smear taking services. As payment is no longer tied to either a doctor seeing the patient or to the number of services provided, PHO development encourages more services to be provided by practice nurses. Of the total number of 6,126 registered smear-takers in the NCSP, 1,706 (28 percent) are practice nurses. The NSU has implemented initiatives over the last 2 years to increase the number of nurse smear-takers as a way of offering further choice for women and reducing the financial burden.

68. Irrespective of funding, practical barriers to screening remain an issue in both organised and opportunistic settings. In countries with organised programmes, coverage rarely exceeds 85 percent. Low socio-economic status may be a barrier to participation in screening even where screening is free or heavily reimbursed (Miles et al 2004).
69. Attitudes, beliefs and knowledge are consistently associated with screening use. A lack of belief that cancer screening is personally relevant or important, a patient's perception that she is at risk, procedural barriers (embarrassment, discomfort) and other negative attitudes regarding screening, such as the belief that screening will not reduce cancer related morbidity or mortality, have all been linked with lower levels of participation. In contrast, screening rates are consistently higher among those who have a preventative orientation and participate in other preventative activities.⁵
70. The NSU is carrying out a nationwide survey of women to better understand the social context and cultural norms of current health-related behaviour and women's perceptions of the NCSP. This work will further assist the NSU to identify barriers to screening, whether they are cost related, or other practical or attitudinal barriers.
71. In addition, the NSU has also commenced a research project to identify and evaluate inequalities that may exist for Māori women along the screening pathway, and which also present barriers for Māori women accessing screening.
72. Further work would need to be carried out to determine the extent to which the remaining co-payment represents a barrier for women obtaining a smear and whether incentive payments to primary care result in increased invitation and better recall to screening.
73. The CRG recommends piloting free smears to women. The NSU will consider the policy implications of this proposal and, in the first instance, undertake an evaluation of the efficacy of smear taking that is already currently funded.

Population Based Database and National Recall Systems

74. The Audit recommends further efforts to improve the means of identification, invitation and recall through the use of a population based database and a national recall system. The Audit considers that this is necessary in order to

⁵ Ibid.

reach higher levels of population participation and regular screening, particularly amongst Māori and Pacific populations.

75. The development of population registers has also been supported in previous reports by Dr Euphemia McGoogan on the NCSP and in the report of the international independent expert review of BSA by Dr Jocelyn Chamberlain.^{6 7}
76. An organised call-recall system, with targets for population uptake, typically leads to greater and more regular coverage than is achieved by circumstances dependent entirely upon individual motivation. Centralised registers can also lead to more accurate estimates of screening coverage and facilitate the identification of under screened groups. Population registers are considered the ideal and exist in Nordic countries such as Sweden. However, most other countries have less complete registries. In Australia, for example, there is no invitation system and recall is based upon their equivalent NCSP-Register (state based). The UK uses general practitioner lists, which are often inaccurate, particularly in urban areas where the level of population mobility is high.⁸
77. The Audit suggests that the most appropriate population database is likely to be the NHI. Although the NHI will record basic demographic details of women aged 20 to 69 who have been in contact with the health system, it is not a population register in itself. The principle purpose of the NHI is to provide unique personal identifiers for use in the health sector. The NHI, which is currently being upgraded, can provide a “master index” from which population register extracts can be made available for purposes such as screening and immunisations.
78. In order for the NCSP to benefit from the creation of a population register, an extract from the NHI would need to record details of:
 - all women aged 20 to 69, their demographics, ethnicity and enough information to match with them with their screening history if held on the NCSP-Register, or match them with their decision to opt out of the NCSP
 - all women about to turn 20 and who may be invited for their first smear
 - all women who had changed their name details, for example, through marriage
 - all women who have died and would not receive an invitation or recall for a smear
 - all women who have immigrated
 - all women who have returned from overseas
 - timely update of address details when women change address.

⁶ Chamberlain, J., (2002). *Breastscreen Aotearoa – an Independent Review*. May 2002.

⁷ McGoogan, E., (2003). *Report on the National Cervical Screening Programme and progress towards Implementation of the Gisborne Inquiry Recommendations*. June 2003.

⁸ Miles et al. *A Perspective from Countries Using Organised Screening Programmes*. American Cancer Society, Cancer supplement, September 2004, vol 101 no 5.

79. In addition, policies would need to be developed as to how women would be compelled to update the NHI (in the absence of contact with the NHI) and the frequency of the extract for use by the NCSP.
80. Assuming these details are able to be provided using the NHI, in addition to details held on, for example, the Births, Deaths and Marriages Register and the New Zealand Immigration Service's computer database, the NCSP would know at any point in time the exact number of women eligible for cervical screening, where they currently reside, and their screening histories. This would enable the NCSP to monitor more accurately coverage and participation, send invites directly without the intervention of primary care, and recall women due for screening again without the involvement of primary care.
81. This may represent an ideal scenario for public health interventions such as cervical screening but it is likely that further public discussion would be required, including consideration of:
- the impact on primary care developments towards a more population health focus and enrolled populations on local registers which may be used for invitation and recall for preventative health measures
 - individual privacy implications and whether New Zealand consumers can accept this type of intervention
 - the feasibility of such an intervention into a health system that is a mix of private and public health provision
 - practical considerations associated with compelling persons to update a population based database
 - the extent to which such an investment is able to achieve high participation in public health interventions compared with other more targeted initiatives
 - the acceptability of such an intervention to Māori and Pacific communities.
82. The NSU's CRG felt that the development of a population-based database should be publicly consulted. The NHI upgrade project has a Consumer Advisory Group and a consumer awareness campaign is planned. The NSU will take into account any consumer concerns raised when adopting the NHI Upgrade as part of the new NCSP-Register developments. A diagram depicting the NCSP Register redevelopment and link with the NHI upgrade project is appended (Appendix 4 refers).
83. The Audit recommends the NCSP explore how linkages can be made between the NCSP-Register, NHI and PHO registers to ensure that those who recall women into the NCSP have a woman's most up-to-date contact details. This recommendation is underway and is being considered as part of a range of primary care projects and linkages. In addition, the development of a new NCSP-Register planned for the end of 2007 will further facilitate these linkages.

Routine data quality

84. Seventeen percent of women who identified as Māori in the Audit were not identified as Māori by the NCSP.

85. The voluntary collection of ethnicity information has long been a feature of New Zealand health information systems. Improving the way ethnicity information is recorded by the Ministry of Health was one of the recommendations of the WAVE Report. NHI ethnicity data are derived from individual encounters with the health sector (both at DHB facilities and primary care) and it is expected when these encounters occur, individuals will be asked to update their ethnicity information.
86. The Audit recommends that NZHIS ensure 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 in 2004. This recommendation is underway. All ethnicity collection, apart from death certificates, is consistent with the ethnicity data protocols. Births, Deaths and Marriages (BDM) supply the NZHIS with death registrations and medical certificates that use the 1996 census ethnicity question. NZHIS intends to discuss updating the certificate with BDM when Statistics New Zealand has advised on any changes to the ethnicity question for the 2006 census.
87. The Audit recommends that Ministry evaluate the impact of the proposed initiatives to improve ethnicity coding in routine data on the accuracy of ethnic-specific data reported by the NCSP and NCSP Register. This recommendation is underway. A project has commenced to quantify accuracy of ethnicity recording on the NCSP-Register with recommendations for action. Planned NCSP-Register developments include improvement capture of three levels of ethnicity coding. Further, the NZHIS has begun a national wide training programme for DHBs and PHOs to improve the quality of ethnicity data collected and captured within the NHI.
88. It also recommends that if evaluation shows that Māori cervical cancer incidence and mortality remain underestimated by the National Cancer Registry (NCR) data, the NCR should consider other avenues than the NHI for obtaining ethnicity information. This recommendation is underway. The NZHIS makes every effort to obtain the correct ethnicity information from all sources available to NCR. Data quality is monitored and other measures will be looked at if data quality falls below an acceptable level.
89. Further, the Audit recommends the NCSP to review its processes for obtaining ethnicity data. (If the NCSP cytology request form requires smear-takers to collect this information from women, then the NCSP will need to liaise with NZHIS and make use of their training package to actively inform smear-takers as to the best practice for doing so.) This recommendation is underway. The importance of accurate ethnicity data collection is included in NCSP presentations to smear takers. The NCSP Regional Service staff also regularly communicate this message to smear takers.
90. The NSU notes that Ministry survey data also shows higher coverage of eligible Māori women than that obtained by the NCSP-Register. The new NCSP-Register will facilitate improved data collection through an interface with primary care. A variety of matching is undertaken between the NHI and the NCSP-

Register to ensure demographic information on the NHI and the NCSP register is kept up to date.

Laboratory Performance

91. Smears from 178 women were re-read by the Auditors. The Audit did not find evidence of systemic under-reporting of cervical smears in New Zealand laboratories.
92. The Audit recommends that the NCSP continue to ensure laboratory operational policy and quality standards are current, that regular provider audits occur, and support the cytology workforce development initiatives. The NCSP completed five provider compliance audits in November 2004, while laboratory workforce projects are being developed and implemented (Table 1 refers). A review of laboratory standards is planned to begin in 2005.
93. The Audit also recommends that the NCSP and laboratories co-operate 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. It further recommends that the NCSP review the upper limit for the prior negative review target in the light of any new methodology developed for the review. These recommendations are underway and will be included in the review of laboratory standards beginning in 2005.
94. While acknowledging that the NCSP was established to detect the precursors of squamous cell carcinoma, the Audit recommends that laboratories continue educational activities to improve the detection of glandular abnormalities in cervical smears. This has been completed in the 2004 laboratory workforce workshops funded by the NSU. Further, a review of laboratory standards beginning in 2005 will include a literature review to identify feasibility and strategies for detecting glandular abnormalities.

Management of women with abnormal smears and symptoms

95. In the Audit 17 percent of women who had had smears in the 6 to 42 months prior to diagnoses had had a high-grade smear and a further 4 percent had at least two low grade smears. The Audit found that these cases represent delays in the management of abnormal smears. Māori women were significantly more likely to have a high-grade smear in this period than non-Māori suggesting inadequate follow-up of abnormal smears.
96. The Audit recommends that where significant ethnic disparities in referral times to investigations or diagnosis are found, either between or within clinics, the NCSP works with clinic staff to establish reasons for disparities and strategies for addressing these. The NSU has commenced a research project to identify and evaluate inequalities that may exist for Māori women along the screening pathway, including treatment services. This aspect of treatment services will also be examined as part of upcoming audits of colposcopy services.
97. The most common pathway to diagnosis (59 percent of women) included a high-grade smear followed by histological diagnosis. One hundred and twenty

two women had bleeding prior to diagnosis, of whom 13 percent experienced symptoms in the absence of a high-grade smear. Of the women who had a high-grade smear, 94 percent had colposcopy within 12 weeks, as per national policy and quality standards.

98. The Audit recommends certain data elements are collected from colposcopists as part of the implementation of the Health (National Cervical Screening Programme) Amendment Act. This recommendation is already underway and new colposcopy data requirements have been specified in collaboration with the College of Gynaecologists and Obstetricians. A new colposcopy database linked to the NCSP-Register is also under development.
99. The Audit also recommends that the NCSP ensure that colposcopists improve documentation and that these services are audited as for other NCSP providers. A new national database of practising colposcopists is planned and the audit of colposcopy services will commence in 2005.

Future Evaluations

100. Evaluation of the NCSP includes routine planned and ongoing activities as well as independent programme reviews, audits or reports. Current NCSP evaluation activities include:
 - routine monitoring and follow up, such as quarterly and six monthly reporting against national indicators, for example, Independent Monitoring Group Reports, and provider reports against agreements
 - NCSP-Register performance reports relating to laboratory and smear taker performance
 - national statistical reports
 - provider compliance audits against NCSP Operational Policy and Quality Standards and Agreements
 - issue based compliance audits
 - complaint monitoring and investigations as required.
101. The Audit recommends that prior to further audits of women with invasive cervical cancer, priority be given to implementation of the audit recommendations described above. All recommendations except one are either underway or have been implemented. The NSU and NZHIS will support future audits as required within current resources.
102. The Audit also recommends that following the implementation of its recommendations, further independent audits of women with cervical cancer should occur, although not more frequently than every ten years. As part of this, a period of prospective collection of screening history and clinical management data as cases are notified should occur. This recommendation is underway. Individual case review of women with invasive cervical cancer has already started (that is, the collection of screening histories) and will include clinical management data following implementation of the Health (National

Cervical Screening Programme) Amendment Act 2004. An analysis will be carried out once sufficient cases have accumulated to enable significant results to be produced. The implementation of the new NCSP legislation will provide further opportunities for evaluation of the NCSP and for case review.

103. The Audit also recommends that the Ministry of Health consider undertaking an audit of cervical cancer management to determine reasons for the much greater disparity between Māori and non-Māori women in mortality from cervical cancer than in incidence. This recommendation is under consideration.

Monitoring

104. The Audit recommends that the NCSP develop definitions and targets for the “adequate frequency of screening” (that is, regular smears at the appropriate interval), and to monitor 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 to 69 years. Implementation of this recommendation is underway. A method will be developed to link results longitudinally for each woman to see if she has had all scheduled recommended smears. Development of this initiative will be discussed with the new NCSP Independent Monitoring Group.
105. The Audit also recommends that, from the implementation of the new Health (National Cervical Screening Programme) Amendment Act 2004, the NCSP reports age-specific numbers and proportions of women who have cancelled their enrolment in the NCSP, as well as reporting screening indicators both as numbers and proportions of enrolled women and of all eligible women. This is underway and will be ongoing. The NCSP will be monitoring these trends via the NCSP-Register and mechanisms for monitoring will be in place by early 2005.
106. The Audit recommends that the NCSP ensure that targets for screening, incidence and mortality continue to aim at reduction of disparities between Māori and non-Māori and that these disparities are specifically monitored. This recommendation is underway. The Public Health Intelligence Unit of the Ministry of Health has developed a report regarding monitoring indicators for Māori women participating in the NCSP, which has been endorsed by the NCSP Advisory Group, and is being finalised following recommendations from the Māori Advisory Group. These monitoring indicators will be independently monitored alongside indicators for the entire programme.
107. The Audit also recommends that cervical screening indicators, such as coverage and “adequate frequency of screening”, that are reported for different ethnic groups be age-standardised. This recommendation is underway and will be reviewed in 2005 with the NCSP Independent Monitoring Group. The NSU also submits regular requests to the National Kaitiaki Group for ethnic breakdown of coverage data.
108. In addition the Audit recommends that the NCSP report both hysterectomy adjusted and unadjusted screening indicators. This recommendation has been completed. The NCSP routinely reports statistics as hysterectomy adjusted and

unadjusted. The adjuster is currently being reviewed in accordance with new data on hysterectomy rates.

109. The Audit recommends that the NCSP consider ways of ensuring that annual monitoring data, including screening indicators, can be available in a timely way. This is underway. The NCSP Annual Monitoring Reports for 2002 and 2003 will be available in early 2005. 2004 will then be commenced. The NSU has recently appointed a new provider of the Independent Monitoring Group service.

National Cancer Registry

110. The Audit recommends that the NZHIS provide more timely cervical cancer incidence data for all women, and for Māori and non-Māori women. This recommendation is underway and ongoing. Cervical cancer incidence data for all women is on the NZHIS website to 2002. Ethnic-specific rates will be added to this as well. The NZHIS will continue to look for ways to improve the currency of data available subject to current resources.
111. The Audit also recommends that National Cancer Registry (NCR) fully utilise the powers conferred by the Cancer Registry Act 1993 and the Cancer Registry Regulations 1994. This recommendation is underway. The NCR makes every reasonable attempt to obtain this information from the clinicians involved in the care of the patient, including personal visits to the relevant hospitals. The NZHIS will review current processes as to how this can be further improved within current resources.
112. A further recommendation is that the NCR obtain 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. This recommendation is underway. Every reasonable effort is made by NCR to follow-up suspicious histology results, including talking to relevant clinicians. The NZHIS will review current processes as to how this can be further improved within the current resources.
113. Finally, the Audit recommends that NCR consistently adhere to international standards for assigning date of diagnosis and for determining eligibility for registration. This recommendation has been completed. With respect to comments on the date of diagnosis, the NCR uses a consistent process for allocating an incidence date (or date of diagnosis), which is used by all cancer registries worldwide based on admission date, histology, cytology or death certificate.

Appendix 1: Interim response of the NCSP Advisory Group to the Cervical Cancer Audit

The NCSP Advisory Group would like to develop a more detailed considered response to the Cervical Cancer Audit (CAA) after having an opportunity to read the report in detail. However, members concur that overall the CCA report does provide confidence for women that participating in a 3 yearly cervical screening programme reduces risk from either developing or dying from cervical cancer. Their key message is that women failing to participate in the Programme (either by not having smears or not utilising treatment services) is the main concern and this is particularly so for Māori women. Members also recognise that some strategies have been put in place since 2002 to address Programme discrepancies.

The Group suggests that consideration be given to offering free smears for women on a par with the breast cancer screening programme. The costs of such a programme could be offset by discouraging screening more often than 3 yearly and only screening women between the ages of 20 and 69 years.

The Group looks forward to changes in the NCSP-Register in the future which will allow smear takers to access smear histories electronically and by so doing reduce the number of unnecessary smears, which could potentially lead to harmful interventions.

In relation to a recommendation for a national call/recall register, the Committee chair, Dr Helen Rodenburg commented that existing primary care systems were currently working well, were responsive to local communities and could be developed to work even more effectively with 'hard to reach' groups.

The Group is keen to work with the Programme to achieve desired outcomes for women.

Appendix 2: Minutes of the Consumer Reference Group Teleconference on the Cervical Cancer Audit

The Audit recommends the utilisation of a national, population based database for identifying women who have not been screened, are under-screened, or who are eligible for their first screen. Following this identification, the Audit recommends that the NCSP directly invite these women for screening, and that the NCSP employ specific strategies targeting these women to improve screening coverage and participation.

The CRG felt that this would be an excessive step in the first instance for reaching women who are eligible for voluntary enrolment in a screening programme. It is not clear whether women would find this acceptable or respond to an invitation from a source which is remote and unknown. The emphasis on primary care belongs with the PHOs in this new environment so it's better to strengthen incentives for PHOs who already have a relationship with women. However, it is important that incentives do not lead to an 'uptake mentality' where GPs simply focus on their performance targets. The focus should be on providing all women with information to enable them to make an informed decision about screening. GPs also have to make sure their services are accessible and acceptable. We need to try and look at other things before we start saying yes to a population-based database.

It was believed that the biggest barriers may be access and price and that these could be addressed as a first step.

There is plenty of evidence that an active invitation is better than waiting for women to come forward.

- The pilot breast screening programmes used the electoral roll to invite women but this is only available for research purposes,. The MOH could explore a change in legislation to use the electoral roll to invite women but women would have to be consulted first about this using this option. Change in legislation is a big step and presidents are set by doing this.
- Active invitations could be PHO driven.
- The cost implications of developing the population database need to be balanced against other uses and these dollars could be put towards, e.g., prioritisation of other cancer services or other health demands.

If we are to have a population based register, it has to be piloted and evaluated to see that it is effective and acceptable. Despite NZHIS being advised through a number of reviews to consult with the New Zealand public on the acceptability of extending the use of the NHI, this has never occurred. Consequently, the public does not know about the NHI or uses to which it is being put. If they want to use the NHI they need to examine questions of privacy and the implications of matching data through personal health numbers.

The Audit recommends a nationally consistent system for recalling women for screening. Currently the primary responsibility for recall rests with the individual

woman smear-taker. The NCSP provides guidelines on recall intervals and acts as a back-up to the smear-taker recall system.

There is no information in the audit regarding what the smear takers were doing to recall women, therefore conclusions cannot be reached as to why women were not having regular smears. It may be possible that the audit holds further information as to why women were not having regular smears. Qualitative research on case reviews of women diagnosed with cervical cancer could reveal key factors, i.e., reasons are likely to be multi-factorial.

The Group thought that different pilots should be tried, before the decision was made to move to a national population-based register. Some ideas were:

- active recall from the register rather than the register acting as a back-up
- it was suggested that the research that Keri Ratima has done in relation to Māori and smear recalls should be used to inform
- increased reminders rather than the single reminder under the current system
- phone reminder after the letter reminder, and
- piloting a number of different strategies to see if any of these strategies were effective, e.g., refugee migrant population and disabled women.

If women are under screened then they are at risk. If pilots are run, then they must be accessible for all, including disabled women.

The Audit highlights inequalities in the NCSP. The Audit recommends the NCSP pilot and evaluate evidence-based strategies for reducing barriers to screening amongst women at risk of under-screening and that any system-wide or targeted strategies do not increase disparities. The strategies currently employed in the NCSP include:

NCSP regional health promotion activities targeting under-screened population

- Independent Service Providers targeting health promotion activities for Māori and Pacific women; also refugee migrant women and disabled women
- funded smear-taking for targeted groups, and
- funded support services for Māori and Pacific women accessing follow-up services; example, transport assistance.

The NSU is also currently researching Māori women's access to the screening pathway and is evaluating health promotion activities carried out by Regional Services and Independent Service Providers. Focus on low socio-economic areas. Relying on self identification for ethnicity may not be meaningful given that ethnicity does not have to be race based. This could be open to abuse. Health promotion activities need to be demonstrated to raise women's awareness. There is a whole range of good resources around the NCSP, and the PHOs should always be able to display what they have on offer to women.

Recommendation: pilot free screening.

Appendix 3: Response from the Māori Advisory Group to the New Zealand Cervical Cancer Audit

The MAG discussed at length the findings of the Cervical Cancer Audit - screening of women with Cervical cancer: 2000-2002. The audit clearly showed that despite the systems in place:

- the NCSP had not engaged Māori women effectively in the programme
- Māori women were not taking up the opportunity for regular screening
- not only were Māori women under screened but that when a problem was revealed, they waited longer for treatment
- ethnicity data showed recorded inaccuracies on both the NCR and NCSP-R.

The MAG understands the importance of regular screening for the well-being of our whānau, and the need for accurate data to be recorded to ensure accurate planning and monitoring of services for Māori women.

Following the discussion the following recommendations and comments to the NCSP are made:

1. Utilise a national, population-based database together with the NCSP-Register to:
 - identify unscreened and under screened women aged 20 to 69
 - directly invite such identified women to have a smear.
2. Continue to use this database to identify women as they reach the eligible age and directly invite them for their first smear.
3. Ensure that all smear-takers (GPs and practice nurses as well) record ethnicity accurately, that is ask the women directly, tick box on the form for women to complete themselves. If Māori recorded as one of multi-choice, ensure that Māori is recorded. If the ethnicity section is not completed, can funding be withheld from the smear-taker until the error is corrected?
4. Train smear takers (and have refresher courses) to ask ethnicity questions and explain its importance.
5. Provide free smears to women in target group, that is those groups at risk of not being screened as identified in the audit. It is of major concern that older women, women on low incomes and those with little secondary education are included in this at risk section.
6. Continue to use the population-based database and the NCSP-Register to keep track of women being screened regularly, and invite directly those women who show as overdue for a smear, that is the NCSP continues as a back-up system.

7. Responsibility for recall should remain with the individual woman's smear taker. The relationship between the smear taker and the woman is important to maintain. The smear taker is the one who can build the woman's confidence and knowledge about the programme. If a woman is overdue then the backup system as in recommendation 6 should take over.
8. Provide information about the programme in appropriate ways to Māori, that is older women who have been treated or on the programme assisting smear takers with stories of their own experiences and its importance to their lives and that of their whānau.
9. Promotion of NCSP: messages to go beyond the individual woman, but show responsibility for other women and for future generations. Regular smears to be seen as an integral part of family health not just a woman's health.
10. There is a need for more Māori involvement in the workforce, especially at this time when more promotion is needed to attract Māori on to the programme. This means more trained Māori smear takers but also more Māori workers in the treatment areas as well. Can this be targeted as well with scholarships?
11. There needs to be research as to why it takes longer for Māori women with an abnormal smear to receive treatment. Māori need to feel confident that if they do participate in the programme, and if there is something wrong, they will receive treatment. The current statistics are not encouraging.

Appendix 4: Link between the NHI upgrade project and the NCSP-Register redevelopment

