Cervical Cancer Audit Report

Screening of Women with Cervical Cancer, 2000–2002
Disclaimer

Whakakahotia

This document reflects advice and recommendations to the Ministry of Health from independent auditors contracted by the Cervical Cancer Audit. It does not necessarily reflect the views or policies of the Ministry of Health.

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Mihi

Tēnā koutou katoa
E mihi ana ki te whenua, e tangi ana ki te tangata, ki o tātou tini mate e hinga
mai nei, e hinga atu nei, kua tae atu ki te Kaihanga e pūtiki mai rā i te
kāpunipuni o ngā wairua. Haere koutou; haere, haere. Koutou te hunga
wairua ki a koutou, tātou te hunga ora ki a tātou, tēnā koutou.

Kia mihi kau ake ki te rangatiratanga wahine,
Ko nga wāhine – te atamira o te ira tangata.
Tiakina, manaakitia rātou,
Te mātāpuna o te tapu.

E ngā waka, e ngā reo, ngā maramara totara o rātou mā, huihui, tui tuia.
Tēnā anō koutou katoa.
Foreword

Kupu whakataki

The death rate from cervical cancer almost halved among New Zealand women between 1988 – before the National Cervical Screening Programme (NCSP) was established – and the year 2000. As mortality rates had previously been rising, the reduction in deaths is likely to reflect the effectiveness of cervical screening and the NCSP. However, a range of monitoring and evaluation activities are necessary to further reduce the incidence of and mortality from cervical cancer for all women, and to eliminate ethnic and other disparities.

In 1997 a University of Otago team recommended an audit of screening histories of women with cervical cancer as part of an evaluation strategy for the NCSP. The implementation of an audit was endorsed by the Ministerial Inquiry into the Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region in 2001.

This document is the report of the Audit, carried out as a partnership between the University of Auckland and the Ministry of Health. The Ministry of Health was responsible for operational aspects of the Audit. The University of Auckland provided epidemiological input into the design and implementation of the study, the analysis and interpretation of the data, and in collaboration with other independent Auditors was responsible for writing the report. The completeness and quality of the information in the Audit is a tribute to the goodwill and co-operation of New Zealand women with cervical cancer, their next of kin, and the health professionals involved in their care.

This report describes the important findings of the Audit. The Audit did not identify evidence of systemic failings in New Zealand cytology laboratories but did find inadequate screening coverage and evidence of ethnic disparities in screening and follow-up. The main findings are not unique to the New Zealand cervical screening programme, nor are they new information, but they underscore the importance of ongoing efforts to increase coverage, improve the accuracy of routine data, and decrease inequalities in health for Māori women and other disadvantaged groups.

I commend this report to you and trust it will help to further improve the delivery of quality cervical screening services to New Zealand women. It will also serve as a baseline for future audits in New Zealand.

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The Auditors

*Kaiōtīta*

This project was conducted as an independent audit. It was funded by the Ministry of Health, who also managed the operational aspects. The Auditors provided independent input into the study design and conduct, analysed data, and produced this report. The final content of the report is the responsibility of the Auditors.

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Drs Sadler and Priest and Professor Jackson were contracted to the Ministry of Health through Auckland UniServices Limited.

Drs Crengle, Peters, Priest, and Sadler were involved in the design, planning, and carrying out of the project. Drs Priest and Sadler were responsible for the data analysis. Drs Peters, Priest, and Sadler wrote the report. Dr Crengle provided advice and input into Māori women’s results and disparities analysis within the report. Professor Jackson provided oversight to the Auditors.
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Executive Summary

Whakarāpopototanga Tuatahi

An audit of women with invasive cervical cancer was first planned as part of an evaluation of the New Zealand National Cervical Screening Programme (NCSP) in the late 1990s. In 2000, a Ministerial Inquiry into Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region of New Zealand was held, with the inquiry committee reporting to the Minister of Health in April 2001. The first recommendation in the report was that the planned audit be conducted, giving impetus to the existing intention to do so. This document is the report of the Cervical Cancer Audit that was carried out to fulfil this recommendation.

Background

Te Pūtakenga

Cervical cancer was the ninth most common cancer among New Zealand women in 1999. Only provisional data are available since 1999, but they show that the age-standardised incidence of cervical cancer among all women was approximately 8.0 per 100,000 between 2000 and 2002. The incidence of cervical cancer in Māori is approximately twice that in non-Māori, whereas Māori mortality from cervical cancer is four times that of non-Māori. The reported age-standardised incidence for Māori women in 1999 was 16.0 per 100,000 and for non-Māori 8.2 per 100,000 (age-standardised mortality 8.8 and 2.1 per 100,000 respectively over 1997 to 2000). During the period 1990–1999, the population incidence of cervical cancer declined by 28%.

The NCSP commenced as a national programme in New Zealand in 1990–1991. The NCSP is aimed at women aged 20–69 years and recommends a three-yearly screening interval. Women are encouraged to have two smears 12 months apart when they reach 20 years and three-yearly smears thereafter until their 70th birthday, provided their results remain normal. More frequent screening is recommended for women with confirmed abnormalities. There is no national invitation system, so most women are invited to have a cervical smear by their primary care provider. Smear-taking is mainly provided in the primary care environment, and smears are read at contracted laboratories throughout the country. Colposcopy and biopsy services are provided at public hospitals, although women may choose to have private investigations.
The NCSP national office is part of the National Screening Unit (NSU) of the Ministry of Health and is responsible for all national activities relevant to the effective running of the NCSP, including funding and quality assurance activities. The NCSP also houses the NCSP Register (NCSP-R), which contains the smear and biopsy results for women participating in the NCSP. These data form a clinical record that is used for determining the date that each woman should have her next smear and to remind women who are overdue for a smear. They are also used for programme monitoring.

Programme ‘coverage’ is measured as the proportion of women in the population in the age range 20–69 years inclusive who have had a smear result entered onto the NCSP-R in a three-year period. Coverage may be reported as ‘adjusted for hysterectomy’ or as ‘unadjusted’. Census data are used as the denominator, which is reduced by the estimated proportion of women who have had a hysterectomy to calculate the hysterectomy-adjusted figures. During the period relevant to the Audit the NCSP coverage target was 85% adjusted and 80% unadjusted.

Monitoring and statistical reports indicate that programme coverage adjusted for hysterectomy has been approximately 73% between 1997 and 2004 (64% unadjusted). Reported coverage is much lower for Māori and Pacific women (46% for Māori and 45% for Pacific women, unadjusted). Monitoring includes reporting of cytology results, and data for 2001–2002 show the proportion of smears reported as high-grade was approximately 1% with a positive predictive value around 74%.

Audit goals

Ōtitanga

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 of and mortality from invasive cervical cancer in New Zealand women
- to provide information to support the elimination of disparities between Māori and non-Māori women in the incidence of and mortality from invasive cervical cancer.
Methods

Āhuatanga mahi

The Audit compiled the screening histories, for the seven years prior to diagnosis, of women diagnosed with histologically proven invasive cervical cancer during the period 1 January 2000 to 30 September 2002. 562 potentially eligible women were identified from the National Cancer Registry (NCR) of whom 445 met the Audit eligibility criteria. Eligible women (or their next of kin/personal representatives in the case of deceased women) were approached by the Audit first for consent for an interview and then for consent to access relevant medical records and cervical smears for re-reading.

Interviews with women or next of kin were undertaken either face-to-face or by telephone. Relevant medical records from primary care providers, hospitals and specialists were collected and information abstracted.

A smear re-read was undertaken. This was designed to mimic a normal screening environment. Between one and five cervical smears taken in the four years prior to diagnosis from Audit participants and not initially read as high-grade or above (index smears) were seeded into sets of negative smears from women without cancer enrolled in the NCSP (control smears). In addition to the index and control smears, sets of smears also contained up to five reference smears (known unsatisfactory, high-grade or low-grade smears). Each set contained 50 smears and was re-read in an Australian laboratory by three independent teams according to the laboratory’s usual practices. Smears were considered upgraded if they were given a more serious result by all three teams and the changed result would have altered the recommendation for clinical management.

Results

Ngā hua

Response rates

376 (85%) of the eligible women consented to at least one form of data collection and 349 (78%) consented to all forms of data collection. Consent rates for Māori women were the same as those for non-Māori. However, next of kin and legal representatives were significantly less likely to consent to interview and access to medical records than the women themselves. These results indicate that, with appropriate resources and processes, it is possible to obtain high consent rates from both Māori and non-Māori women for interview and access to medical records.
Screening

The major finding from the Audit was that women with invasive cervical cancer had not been screened with sufficient frequency by all definitions used to measure this. The NCSP has a three-year screening interval for women with normal screening histories, yet only 50% of women with invasive cervical cancer had had a smear in the six to 42 months prior to diagnosis (a three-year period) and only 20% had an adequate screening history (defined by the Audit as no interval of more than three years between screening smears, during the six months to seven years before diagnosis).

Māori women were more poorly screened than non-Māori women. In addition, among the Audit population, women with high deprivation indices, low income, lower education, and of older age were also less well screened. Women with lower-stage disease were more likely to have had screening. This supports the evidence that screening is beneficial in downstaging cervical cancer.

As noted above, New Zealand NCSP monitoring data also indicate that, overall, New Zealand women are not being screened optimally and Māori and Pacific women in particular experience low levels of screening. The NCSP routinely reports ‘coverage’ (women who have had a smear in three years) as a measure of participation in screening. The Audit results suggest this measure probably does not capture the extent to which New Zealand women are under-screened because it does not measure whether or not women are being regularly screened: because of the low sensitivity of a single smear, this is necessary to obtain maximum benefit from the programme.

Māori women

Consent to any data collection was given for 77 of the 95 eligible Māori women (of whom 78 were living and 17 deceased).

The Audit found inaccurate recording of ethnicity on the NCSP-R and the NCR in about 20% of Māori women. Satisfactory monitoring of Māori women’s health is affected by these inaccuracies.

When the younger age at diagnosis of Māori women is taken into account, a greater proportion of Māori than non-Māori women have later-stage disease (FIGO stage 2+) at diagnosis.

Māori women were less well screened than non-Māori women. For example, the age-standardised proportion of women who had a smear in the six to 42 months prior to diagnosis was significantly lower for Māori women (42% compared with 54%). In addition, Māori women were more likely to wait longer for investigation and diagnosis. While not all differences between Māori and non-Māori women reached statistical significance, there was an impression that at all steps of the screening pathway, Māori women were less well served.
The data collected by the Audit, however, do not explain the much greater disparity between Māori and non-Māori in mortality compared with incidence for cervical cancer.

**Cytology reporting**

The upgrade proportion of 18% for prior negative smears from women with squamous cell carcinoma did not exceed the standard of 20% established by the Audit. The Audit concluded that it did not find evidence of systemic under-reporting of cervical smears although it could not completely exclude it.

**Cancer incidence and stage**

The NCSP incidence target for all women in New Zealand for 2005 (8.6 per 100,000) was met in 2001. However, a 22% reduction from the 2000/2001 incidence rate would be required to meet the NCSP incidence target for Māori women for 2005 (11.0 per 100,000).

The NCSP also met the target for stage distribution (fewer than 30% of women diagnosed with invasive cervical cancer are beyond stage 1 at diagnosis) for all women, Māori women and non-Māori women in the Audit.

**Routine data sources**

The NCR is an accurate source of total rates of incident cases of invasive cervical cancer, but approximately 25% of women in the Audit had no stage recorded on the NCR (50% for women with stage 1A disease). The lack of staging information on the NCR is an impediment to the routine measurement of NCSP effectiveness.

Although the Audit found records of some smears that were not recorded on the NCSP-R, it is an accurate source for calculating the proportion of women who have been screened, at least among women with cancer.

Neither the NCR nor the NCSP-R is an accurate source of ethnic-specific statistics for women with invasive cervical cancer. The incidence of cervical cancer in Māori is worse than suggested by routinely reported statistics, while the proportion of Māori women who have been screened is likely to be better than that reported by the NCSP.
Conclusions

Ngā whakaotinga

The aim of the Audit was to take a systems view of the NCSP and determine where systemic issues might exist and what improvements are required to increase the effectiveness of the programme. The Audit also looked specifically at issues relating to Māori women, because of their relatively high incidence of and mortality from cervical cancer.

The Auditors consider that from a national perspective the NCSP operates to a generally high standard and in some areas operates to a very high standard. For example, the aim of the NCSP to reduce the overall incidence of cervical cancer was met and the aim to detect at least 70% of disease at stage 1 was met for women in the Audit. Almost all smears are on the NCSP-R, making it a reliable source of screening histories and monitoring information, and women who have a high-grade abnormality detected on a cervical smear are generally referred for investigation in a timely manner. In particular, the Audit has not found evidence of systemic issues in laboratory reading and reporting of cervical smears. Overall, women and health professionals can have confidence in the services that are provided and should be encouraged to participate in the NCSP.

However, the Audit also demonstrated that 50% of women with invasive cervical cancer had not been screened within the six to 42 months prior to diagnosis and 80% had not had regular smears. Importantly, given the ethnic disparities in the incidence and mortality from cervical cancer, the Audit also found that Māori women are less well served by the NCSP than non-Māori women.

The NCSP would be more effective in reducing the incidence of and mortality from cervical cancer if it increased the proportion of women aged 20–69 years having regular cervical smears at the recommended intervals, and if disparities between Māori and non-Māori were eliminated in terms of participation in regular screening and in referral and investigation processes. Attention to other groups of women who are less likely to be regularly screened is also required. In addition, more accurate recording of ethnicity on the NCR and NCSP-R, and cancer stage on the NCR, is required to enable greater accuracy in programme monitoring. The recommendations that follow suggest ways in which these systemic issues might be addressed.
Recommendations

Ngā tūtohutanga

These recommendations are grouped according to the issue addressed. However, priority for implementation should be given to recommendations 1 to 6, (achieving high levels of regular screening), 8 (review of prior negative smears), 19 (cancer registration), and 31 (investigation of the greater disparity between Māori and non-Māori in mortality than in incidence).

Achieving high levels of regular screening

E taea ai ngā taumata tiketike o te ārai rite tonu

The Audit recommends that the NCSP develops and implements strategies to increase the proportion of women who are regularly screened and that these strategies should:

- include systems to identify and invite unscreened women for screening
- include systems to ensure that women are recalled proactively so that most women have their smears at the recommended interval
- prioritise Māori women
- not increase disparities between Māori and non-Māori women
- prioritise other groups of women at risk of not being screened
- be evidence-based and consider measures to improve individual access to screening, such as the removal of financial and practical barriers.

Identification and invitation

The Audit recommends that:

1. the NCSP utilises a national, population-based database along with the NCSP-R for identifying unscreened and under-screened women aged 20–69 years and inviting them to have a smear. Along with the introduction of the new legislation, a staged process of identifying and inviting all women who have not had a smear for more than three years would help to give every New Zealand woman the opportunity to be enrolled in the NCSP. In addition, as women reach the eligible age for screening, this population-based system should be used to invite them for their first smear. It could also be used to identify unscreened or under-screened groups to inform the design of interventions to improve screening in those groups.
The process for establishing this system should take into account other potential successful models, utilise a database that most women nationally are listed on, and be acceptable, effective and appropriate for Māori women and other women who are currently less screened. The National Health Index (NHI) is likely to be the most appropriate population database, and impediments to its utilisation need to be resolved as soon as possible.

**Recall**

The Audit recommends that:

2. the NCSP 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 NCSP/NCSP-R and smear-takers
   - clearly identify the organisation responsible for determining the recall interval for women. (For women who are enrolled in the NCSP, the NCSP-R 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 NCSP, 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 NCSP screening interval. (In addition the NCSP-R may still provide a fail-safe mechanism for women who do not respond to the proactive system.)

3. the NCSP explores how linkages between the NCSP-R, NHI, and primary health organisation registers can be made to ensure that those responsible for recalling women have their most up-to-date contact details.

4. the NCSP ensures that women who cancel their enrolment in the NCSP 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.
Reducing barriers to screening

The Audit recommends that:

5. the NCSP 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.

Reducing disparities

The Audit recommends that:

6. the NCSP 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.

Smear reading

Pānui i ngā ūkuikui

Laboratory quality assurance

The Audit recommends that:

7. the NCSP continues to ensure laboratory operational policies and quality standards are current and regular provider audits occur and the NCSP continues to support cytology workforce development initiatives.

8. the NCSP and laboratories collaborate to review the approach to the review of negative smears taken within the previous 42 months from 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.

9. the NCSP reviews the upper limit for the prior negative review target, in the 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.
10. while acknowledging that the NCSP was established to detect the precursors of squamous cell carcinoma, the NCSP and laboratories continue educational activities to improve the detection of glandular abnormalities in cervical smears within New Zealand laboratories.

Information for women

The Audit recommends that:

11. 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.

Investigation of abnormal smears and bleeding

Āta titiro i ngā ākuikui me ngā toto rereke

The Audit recommends that:

12. when defining the colposcopy data elements that the NCSP 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 the colposcopy, the colposcopic impression and biopsy result and plans for follow-up.

13. the NCSP 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.

14. where significant ethnic disparities in times to investigation or diagnosis are found, either between or within clinics, the NCSP works with clinic staff to establish reasons for the disparities and strategies for addressing them.
Routine data quality

Raraunga pai mai i ngā tikanga mahi

Ethnicity information

The Audit recommends that:

15. the New Zealand Health Information Service (NZHIS) 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,¹ published by the Ministry of Health in 2004.

16. 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 NCR and NCSP-R.

17. if evaluation shows that Māori cervical cancer incidence and mortality remain underestimated by the NCR data, the NCR should consider other avenues than the NHI 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 NCR).

18. the NCSP reviews its processes for obtaining ethnicity data (if the NCSP cytology request form requires smear-takers to collect this information from women, then the NCSP needs to liaise with the NZHIS and make use of their training package to actively inform smear-takers as to the best practice for doing so). In the meantime, the NCSP could consider using a definition of ‘Māori on any routine data source’ for reporting Māori data, although screening targets would need to be revised to take account of the higher estimates thus obtained.

Cancer registration

The Audit recommends that the NCR:

19. 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 reconsideration of her case, this information is routinely provided to the NCR.
20. 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.

21. ensures that it consistently adheres to international standards for assigning date of diagnosis and for determining eligibility for registration.

**Monitoring the NCSP**

*Rarangi me te tātari o te NCSP*

**NCSP**

The Audit recommends that:

22. the NCSP 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.

23. the NCSP ensures 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.

24. screening indicators, such as coverage and ‘adequate frequency of screening’, reported for different ethnic groups are age-standardised.

25. the NCSP continues to report both hysterectomy adjusted and unadjusted screening indicators.

26. 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 and also reports screening indicators both as numbers and proportions of enrolled women and of all eligible women.

27. the NCSP considers ways of ensuring that annual monitoring data, including screening indicators can be available in a timely way.
NCR

The Audit recommends that:

28. the NZHIS provides more timely cervical cancer incidence data for all women, Māori women and non-Māori women (at present these data are available only up until 1999). In the meantime, provisional data reported on the NZHIS website should include ethnic-specific rates.

Future audits

Ngā ētita ā mua

The Audit recommends that:

29. prior to further audits of women with invasive cervical cancer, priority be given to implementation of the other Audit recommendations described above.

30. following the implementation of changes in the NCSP, 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 were compelling reason to do so. 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.

31. 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.
1 Introduction

Timatanga

This document constitutes the report from The New Zealand Cervical Cancer Audit 2000–2002 (the ‘Audit’).

1.1 Structure of the document

Te hanga o te tuhinga

The report is written as a series of chapters covering:

- executive summary
- recommendations
- introduction
- background to the project, including the goals, aims, and objectives
- methods
- results: a descriptive analysis of the audit population
- results: pathways to diagnosis in audit participants
- results: smear re-read
- results: the accuracy of routine data sources
- discussion and recommendations
- tables showing details of the data and analytical methods.

1.2 The Audit

Te Ōtitanga

Regular quality assurance activities are a fundamental part of well-organised screening programmes. In cervical screening, regular audit of the screening histories of women with invasive cervical cancer is one of these activities. The overall aim of such an exercise in New Zealand is to provide information to support programme improvement so that ongoing reductions in incidence and mortality are achieved and disparities between Māori and non-Māori women are reduced and removed.
This Audit of women with invasive cervical cancer is the first to be undertaken in New Zealand at a programme level. The Ministry of Health had identified the need for an audit in 1997. The Report of the Ministerial Inquiry into the Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region\(^2\) underlined the importance of the Audit. The inquiry committee stated in its first recommendation that an audit must go ahead. The project has been conducted as a partnership between the University of Auckland and the Ministry of Health, with ultimate editorial control residing with the Auditors.

The goals of the Audit were to provide information: to support improvements to the National Cervical Screening Programme (NCSP) and thus the ongoing reduction in the incidence of and mortality from invasive cervical cancer in New Zealand women; and to support the elimination of disparities between Māori and non-Māori women in the incidence of and mortality from invasive cervical cancer. The Audit project formally commenced in 2001. Ethics approval was obtained in May 2002. Data collection, including face-to-face interviews with over 360 women or their next of kin, was completed in December 2003.

1.3 Links with other documents

**Hōnonga ki ētahi atu tuhinga**

A number of other documents were created during the conduct of the Audit. These were primarily methodological documents and operational manuals. They will be available on:

http://www.moh.govt.nz/cervicalcanceraudit

A summary of the report has been prepared for distribution to those women who participated in the Audit. It is available to others who request it and can also be accessed on:

http://www.moh.govt.nz/cervicalcanceraudit
2 Background

Te Pūtakenga

2.1 Cervical cancer

Mate pukupuku taiawa

Cervical cancer arises most commonly from the squamous epithelial cells of the transformation zone of the uterine cervix (squamous cell carcinoma) or the glandular cells of the endocervix (adenocarcinoma). These two types make up around 90% of cases of cervical cancer, and squamous is the most common (about 80% of cases).

Squamous cell carcinoma is caused by infection with one of a number of high risk (oncogenic) strains of human papillomavirus (HPV). HPV is very common in sexually active women and in most cases resolves without causing obvious signs of disease, although it may be apparent as low-grade changes (cervical intraepithelial neoplasia (CIN) grade 1) on a cervical smear. These low-grade changes resolve in the majority of cases. However, for a few women, infection persists and may cause high-grade disease (CIN2 or CIN3). In some women these high-grade abnormalities progress to cancer. This process of progression from HPV infection to cancer, where it occurs, generally takes many years, and the aim of cervical screening is to detect the abnormal, precancerous cells before they have progressed to cancer.

In countries with organised cervical screening, the proportion of adenocarcinoma is increasing as the incidence of squamous cell carcinoma declines. This is in part because cervical screening is more effective at preventing squamous cell carcinoma than adenocarcinoma.

2.2 Screening and cervical screening

Ārai me te taiawa ārai

2.2.1 Screening

Screening is a health service in which members of a defined population – who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications – are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatments to reduce the risk of disease or its complications.
The screening test does not definitively determine who has the disease but aims to categorise those tested into two main groups: those who are at higher risk of the disease and those who are at lower risk. Those identified as being at greater risk are referred for further tests to confirm their disease state. Inevitably, some of those who undergo further tests will be found not to have the disease (false positives)* and some of those who tested negative on the original screening test will later be found to have the disease (false negatives).† It is never possible to eliminate false positives and false negatives but these can be minimised in organised programmes by ensuring that the service is properly structured and that comprehensive quality assurance processes are in place.

### 2.2.2 Cervical screening

The cervical screening test aims to detect precancerous change in the cervical cells (specifically CIN3) so that the cervix can be treated, on the assumption that a proportion of women with CIN3 will progress to cancer and that treatment of the CIN3 will prevent this progression. Where cancer does occur, regular cervical screening assists with its detection at an early stage when treatment is most effective. Cervical screening is less successful in the detection of pre-invasive lesions of adenocarcinoma than of squamous cell carcinoma.⁵

A cervical smear test involves a qualified smear-taker (usually a medical doctor or nurse) inserting a speculum into the woman’s vagina so that the cervix can be seen and then taking a sample of cells from the surface with a spatula or brush. These cells are placed on a glass slide and fixed with preservative. The slide is then transported to a laboratory where it is stained and read by qualified laboratory technologists and cytopathologists. Over recent years a range of new technologies has become available for the preparation and reading of cervical smear tests, including liquid-based preparations and computer-based screening. Testing for HPV is also being developed.

Broadly, smear test results may be reported as negative, mildly abnormal (low-grade, CIN 1, or HPV and seriously abnormal (high-grade, CIN 2 or more serious). A small number of smears are inadequate for reading (unsatisfactory) and need to be repeated. Women with a high-grade result are at greatest risk of having precancerous abnormalities of the cervix and are referred immediately for further investigation, usually a colposcopy and biopsy. Women with a negative result are recalled for screening at an agreed interval (provided their previous history is also normal). Between and within these major results

* A ‘false positive’ result in cervical screening arises where a pathological abnormality is not present but a woman receives a smear report indicating that an abnormality may be present and that follow-up is required.
† A ‘false negative’ result in cervical screening arises where a woman who does have a pathological lesion receives a negative cervical smear report. A ‘false negative’ can occur because the abnormal cells were not present on the slide or, they were present but were misinterpreted or not detected by the laboratory.
categories there are a number of refinements that determine the recommendation for repeat screening and/or referral.

An isolated cervical smear test has a relatively low sensitivity, and up to 40–50% of women who have CIN3 or worse cervical disease will not have a high-grade smear result. This occurs for a number of reasons, including the lesion not shedding abnormal cells, the smear-taker not sampling the abnormal area or the abnormal cells not being interpreted as such by the laboratory. The low sensitivity of the test is one reason for the importance of regular smears. Although false negative smear results occur, regular screening increases the chance of a true positive result.

Whilst there has never been a randomised controlled trial of cervical screening, patterns of disease in countries with organised approaches to cervical screening have shown that it is effective in reducing the incidence and mortality from cervical cancer. Variable estimates exist as to the potential impact of organised cervical screening on the burden of disease, although it appears that well-structured, high-quality cervical screening programmes have the potential to reduce the population incidence and mortality from cervical cancer by 75–80%.

2.2.3 Organised cervical screening programmes

There is an important difference between screening tests that are offered to well individuals by health practitioners when the opportunity arises and the organisational and ethical requirements of organised screening programmes that aim to provide health benefits to a defined population. To achieve their aims, organised cervical screening programmes establish systems to ensure that women in the target population are invited for screening, receive screening tests at the appropriate interval and receive appropriate investigation and follow-up for abnormalities detected. Organised programmes also set standards and undertake various monitoring and evaluation activities.

Organised programmes require resources dedicated to ongoing policy development, information management, attention to funding arrangements, workforce development, awareness of new technologies, and ongoing comprehensive quality assurance processes, including annual statistical reporting.

A number of countries have organised cervical screening programmes. In addition to New Zealand, examples include the United Kingdom, parts of Canada, Finland, Sweden, Australia and Iceland.
2.3 International incidence and mortality

Ātaiao pupūtanga me te mate

Cervical cancer is the second most common cancer among women worldwide, and the most common in developing countries. Global estimates predicted 452,000 new cases and more than 234,000 deaths from cervical cancer in the year 2000. Almost 80% of cases occur in developing countries. The disease is less common in economically developed countries, where it accounts for 2–4% of cancers in women.

Where organised approaches to cervical screening have been introduced, a decline in the incidence and mortality from cervical cancer has occurred. For example, in England and Wales the incidence of cervical cancer fell by 42% between 1988 and 1997, and between 1971 and 2000 mortality rates declined by 60%. In Finland between 1970 and 2001, the age-adjusted incidence rate for invasive cervical cancer fell by 57% and mortality fell by 72%. Similarly, in Australia between 1989 and 2000 the age-standardised incidence of cervical cancer fell by 45% per 100,000 women, and between 1982 and 2001 mortality declined by 53%.

Where adequate mortality data are collected for the Australian indigenous population, age-standardised death rates are more than four times those of the non-indigenous population.

2.4 Cervical cancer in New Zealand

Mate pukupuku taiawa i Aotearoa

2.4.1 Incidence of invasive cervical cancer in New Zealand

All women

Cervical cancer accounts for approximately 3% of cancer registrations in women in New Zealand and was the ninth most common cancer registered for New Zealand women in 1999. The incidence of cervical cancer is declining: the New Zealand Health Information Service (NZHIS) reports a decline of 27.6% during the period 1990–1999.
Māori and non-Māori women

For Māori women, cervical cancer was the third most common cancer registered between 1996 and 2001.* Māori women are registered on the NCR with cervical cancer at approximately twice the rate of non-Māori women. For example, in 1999 the age-standardised incidence rate for Māori women was 16 per 100,000 whereas the non-Māori age-standardised rate was 8.2 per 100,000. The accuracy of published ethnic-specific rates will be affected by the small number of registered women whose ethnicity is ‘not stated’ and by misclassification of ethnicity (in particular, Māori women misclassified as non-Māori).

Table 1 provides data on cervical cancer incidence for all women for the period 1995–2002. As cancer reporting has been mandatory since the latter part of 1994, data are provided for 1995 onwards as these are the most reliable figures. **Table 1** also provides numbers and ethnic-specific cervical cancer rates for Māori and non-Māori women for the years 1996–1999. Due to missing ethnicity data, the raw numbers for Māori and non-Māori may not equal those for ‘All’ women. Rates are per 100,000 female population and age-standardised to Segi’s world population. Data for 2000, 2001 and 2002 are provisional.

---

* Personal communication Bridget Robson, October 2004.
Table 1  Numbers and age-standardised incidence rates of invasive cervical cancer per 100,000 Māori, non-Māori, and all women for the years 1995–2002

<table>
<thead>
<tr>
<th>Year</th>
<th>Māori</th>
<th></th>
<th>Non-Māori</th>
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<td>7.6</td>
<td>210</td>
<td>8.5</td>
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<td>8.5</td>
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<tr>
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<td>222</td>
<td>9.2</td>
<td>222</td>
<td>9.2</td>
</tr>
<tr>
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<td>8.7</td>
<td>191</td>
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<td>7.1</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

2.4.2 Mortality from cervical cancer in New Zealand

Mortality amongst all women

The NZHIS reports a 45.7% reduction in mortality from cervical cancer in New Zealand for the period 1991–2000.20

Māori and non-Māori mortality

Despite the decline in overall mortality, published death rates from cervical cancer for Māori women are at least four times those of non-Māori. For example, in 2000 the Māori mortality rate was 8.1 per 100,000, whilst the non-Māori rate was 1.9.

Table 2 provides the available numbers and age-standardised mortality rates for cervical cancer for Māori, non-Māori and all women for the years 1990–2000. Note that ethnic-specific data are available only for later years.
### Table 2  
Numbers and age-standardised mortality rates for invasive cervical cancer per 100,000 for Māori, non-Māori and all women for the years 1991–2000\(^{20, 21, 22}\)

<table>
<thead>
<tr>
<th>Year</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
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<tr>
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<tr>
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<td>3.2</td>
<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>2000</td>
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<td>8.1</td>
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</tr>
</tbody>
</table>

#### 2.4.3 National Cancer Registry

The New Zealand National Cancer Registry (NCR) is sited within the NZHIS, a division of the Ministry of Health. The New Zealand NCR is a register of malignant disease cases diagnosed in New Zealand. Cancers are registered once in their year of first known diagnosis.\(^{16}\)

The NCR operates in accordance with the provisions of the Cancer Registry Act 1993 and Cancer Registry Regulations 1994, which came into force on 1 July 1994. The passage of this legislation resulted in fundamental changes to the collection of cancer data in New Zealand, essentially because the legislation introduced mandatory reporting of cancers. Data from midway through 1994 were affected by the new legislation. The Act stipulates the duties of laboratories and those conducting post-mortem examinations to report cancers to the NCR and specifies that the Director-General of Health may require the supply of further information from additional sources to enable complete registrations to be made. The Cancer Registry Regulations 1994\(^{23}\) stipulate that reports shall be made no later than 21 days after the end of the calendar month in which the cancer test to which the report relates was made. In addition, the Regulations outline the information that should be contained in the registration report to the NCR.

Most information received by the NCR about incident cancer cases is received on the basis of laboratory reports. However, information regarding some incident cases is obtained from public and private hospital discharge information and from death certificates.
Ethnic-specific data

The standard ethnicity question for the New Zealand health and disability sector is the Statistics New Zealand 2001 census ethnicity question. Accordingly, the NZHIS reports that the NCR uses the same definition in registering incident cancer cases. In New Zealand ethnicity is regarded as a social construct of group affiliation and identity. Ethnicity is self-defined and individuals may choose as many ethnic groups to which they feel they belong. Recording systems are required to be capable of storing three ethnicities for an individual, and where an individual identifies more than three ethnicities these should be prioritised according to standard protocols. Whilst the Cancer Registry Regulations 1994 stipulate that the report to the NCR should contain the person’s ethnicity where available, in practice laboratory reports forwarded to the NCR do not contain ethnic-specific information. Registry staff rely on routine information sources to assign ethnicity, in particular the National Health Index (NHI) database and the National Mortality Collection. NHI ethnicity data are derived from individual encounters with the health service (both at District Health Board (DHB) facilities and primary health organisations (PHOs) and it is expected that when these encounters occur individuals will be asked to update their ethnicity information. In reality, inconsistent collection and recording practices exist throughout the sector and this is an ongoing problem. Where the NCR is unable to assign an ethnicity to a registered case, these individuals are excluded from Māori/non-Māori comparisons. The NZHIS advises caution when reviewing such comparisons as the numbers and rates will be understated.

Stage data

In general the NCR obtains staging information directly from the hospitals and clinics where women have been diagnosed and treated.

Reporting

The NZHIS provides incidence and mortality data for cervical cancer per 100,000 female population, age-standardised to Segi’s world population, and publishes annual statistics as part of its monitoring processes. Incidence data are currently available up to and including the 1999 calendar year, and some provisional data are available for 2000–2002. Mortality data are available up to and including the year 2000.

* The 2001 census ethnicity question is essentially the same as that used in the 1991 census. The ethnicity question used in the 1996 census had a somewhat different format from the 1991 and 2001 censuses, and subsequent research suggests that this lead to changes in response attributable more to the format of the question as opposed to changes in the population (http://www.stats.govt.nz, accessed on 15/10/04).
† The Audit has been informed that the Ministry of Health plans to implement a training programme for ethnicity collectors within DHBs and PHOs (Personal communication Tracey Vandenberg, NZHIS: October 2004).
2.4.4 National Mortality Collection

The National Mortality Collection is also sited within the NZHIS.

Until 1 January 2000, the National Mortality Collection used the Ninth Revision of the International Classification of Diseases, 2nd edition, Australian Modification, to classify deaths. From 1 January 2000, causes of death have been coded to the Tenth Revision of the International Classification of Diseases, 2nd edition, Australian Modification.20

The National Mortality Collection uses three main information sources: death certificates from doctors or coroners, post-mortem reports from private pathologists and hospitals, and death registration forms.20 The death registration forms used by the National Mortality Collection continue to use the 1996 census ethnicity question for the classification of ethnicity.20 The Audit is unable to determine what impact, if any, this will have had on the ethnicity data on the NCR (as death registration data are sometimes used to inform NCR ethnicity assignation) or on the comparability of mortality rates for cervical cancer with incidence data when statistics beyond 2001 are reported.

2.4.5 New Zealand goals and targets

The New Zealand NCSP has a number of targets, including for incidence and stage of disease at diagnosis.25, 26 Whilst these have recently been updated, the targets below are those that were current during the period relevant to this Audit. The targets are as follows:

**Incidence**

To reduce the age-standardised incidence rate of cervical cancer in women from 12.0 per 100,000 women in the 1989–93 time period to below 8.6 per 100,000 by the year 2005.

**Māori incidence**

To reduce the age-standardised incidence rate of cervical cancer in Māori women from 29.8 per 100,000 Māori women in the 1989–93 time period to below 11.0 per 100,000 by the year 2005.

**Early detection**

To ensure that no more than 30% of invasive cervical cancers are beyond stage 1 at diagnosis by the year 2000.
2.4.6 The New Zealand National Cervical Screening Programme (NCSP)

The NCSP in New Zealand is an organised national programme aimed at women aged 20–69 years (inclusive). An outline of the history of the NCSP in New Zealand is given in Appendix 4.

The central office for the NCSP is sited within the National Screening Unit (NSU) of the Ministry of Health. This office is responsible for all national operations for the programme, including planning, co-ordination, data management, funding, recruitment strategies, workforce development, quality standards, monitoring and other quality assurance activities.

The NCSP recommends women commence screening at 20 years and, following two normal smears at a 12-month interval, continue with three-yearly smears until their 70th birthday. Women with abnormal screening histories are recalled for screening at more frequent intervals.

There is no complete register of women eligible for screening in New Zealand available to the NCSP for the purposes of identifying and inviting women to be screened. Therefore the NCSP relies predominantly on smear-takers to inform women about the NCSP and invite them for screening. In addition to this, health education material is available and there are health promotion workers who inform women about the NCSP and recommend them to be screened.

There are 13 NCSP regional co-ordination offices responsible for local programme co-ordination, provision of tracking and monitoring reports to providers, local health promotion activities and free smears to priority groups.

Over 400,000 cervical smears are taken and read annually in New Zealand. Smear-taking occurs predominantly in the community and is undertaken by primary care doctors and nurses, and private gynaecologists. A small number of smears are taken in hospital-based gynaecology clinics. In general women pay a regular primary care visit fee for their smear to be taken, although they do not pay for their smear to be read.

The NCSP currently contracts with 10 laboratories* to read cervical smears, and smear results are sent back to the smear-taker and to the NCSP-R. Smear results are coded using a modified version of the 1998 Bethesda coding system. Public hospital gynaecology services at each of the 21 DHBs provide colposcopy and treatment services according to the programme policies and standards for women requiring follow-up as a result of an abnormal smear result. Women may also choose to attend a private practitioner for these services.

* The number of laboratories that read cervical smears has been reducing, particularly since 2000.
Recall for screening in the first instance is a smear-taker’s responsibility. Where there is a normal screening history and a current smear result is also normal, the smear-taker is responsible for informing the woman of her result, noting when the next smear is due and recalling her at the next appropriate interval. When a smear result is abnormal and recall at a shorter interval or referral to a specialist is required, the NCSP-R will also inform the woman of her result. As discussed in more detail below, the NCSP-R provides a back-up service for women who are overdue for screening by a certain defined interval. The NCSP does not have a direct relationship with smear-takers and does not audit their systems, thus there is no NCSP mechanism for ensuring nationally consistent recall systems are operating.

Various guidelines, policies and health education material support those working in the NCSP, including high-level policy documents; operational policies, quality standards and monitoring indicators; guidelines for screening frequency and for the follow-up of women with abnormal smears; a range of health education material prepared on a national basis; and quarterly and annual quantitative monitoring reports.

The NCSP–Register (NCSP-R)

The NCSP-R is a national register of women’s cervical smear and cervical histology results. It is both a clinical management tool for the programme and the vehicle that facilitates ongoing monitoring. Whilst the NCSP does not have a defined enrolment process, enrolment in the programme is effected by having an initial smear or biopsy result entered on the NCSP-R.

During the period relevant to the Audit, the operation of the NCSP-R was governed by Section 74A of the Health Act 1956. This section of the Act was passed in 1993 and stipulates that all cervical smear results (including cervical histology results) must be entered onto the NCSP-R unless a woman indicated that she does not want this to occur for a specific result or results, known as ‘opting off’ the result.

Until recently all the regional NCSP offices had NCSP-R responsibilities, but currently six of these regional offices have accountabilities for entering smear and biopsy results onto the NCSP-R. They receive cervical smear and histology results from laboratories for entry and, once matched to the appropriate woman, these results form part of the national database. The information held on the NCSP-R forms the basis for routine quantitative monitoring of the NCSP.

The NCSP-R fulfils its clinical management function through the provision of women’s screening histories on request and by provision of a ‘back-up’ function for women who are overdue for a smear. It provides women’s screening histories to laboratories and smear-takers as requested and sends a range of letters and reports to women and health professionals to support women receiving regular screening and appropriate referral and follow-up. Although the NCSP-R is pre-programmed according to the Bethesda
coding system to set appropriate recall intervals for women based on their previous screening history, it
does not proactively provide this information to smear-takers who hold the primary responsibility for
recalling women for repeat smears.

Quality standards

Mandatory quality standards and operational policies were introduced for most aspects of the NCSP in
2000/2001.26 These standards and policies are binding on all NCSP contracted providers but not on the
majority of smear-takers or private gynaecologists as these groups do not contract with the programme.

Monitoring

An independent monitoring group (NCSP IMG) was established in 2000 to provide regular programme
monitoring against a range of standards and monitoring indicators. The arrangement between the NCSP
and the University of Otago for independent monitoring services expired and was not renewed at the end
of 2003. The NCSP plans to establish a new external monitoring group, and meanwhile has implemented
interim monitoring arrangements. Quarterly reports are available for the period 1 October 2000–30 June
2003, and there is one annual monitoring report for the year 2001. Not all indicators are reported against
in the quarterly reports, but a majority are included in the 2001 annual monitoring report.

Monitoring indicators

Whilst NCSP targets for incidence, mortality, stage and coverage were in existence in the 1990s other
indicators and targets were introduced in 2001. For a number of these indicators, historical data are
available that enable trends to be observed.30, 31 Such indicators include ‘coverage’ and a number of
laboratory reporting measures. Table 3 provides the definitions of the indicators and how they are
calculated.
Table 3  Selected NCSP indicators and targets

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Definition</th>
<th>Target</th>
</tr>
</thead>
</table>
| Coverage                         | The proportion of all 20–69 year old women who have had a cervical smear recorded on the NCSP-R in the previous 36 months  
Hysterectomy adjusted coverage rates are calculated by adjusting the denominator for the age-specific proportions of women estimated to have had a hysterectomy | 80% unadjusted  
85% hysterectomy adjusted |
| Laboratory reporting             | The number of satisfactory and satisfactory but limited cervical smears in the specified broad cytological categories reported to the NCSP-R as a proportion of the total number of satisfactory and satisfactory but limited cervical smears reported in the specified period | HSIL – not less than 0.6%  
ASCUS-H – no target  
LSIL – no target |
| Accuracy of cytology reports predicting HSIL (PPV) | The number of women with a cytological report of HSIL/invasive carcinoma who are confirmed as having high-grade or more serious disease on histology within six months as a proportion of all women with a cytology report of HSIL/invasive carcinoma within the same period | Not less than 65% and not greater than 85% |

Table 4 and Table 5 show coverage rates for the period 1998–2004 and selected laboratory data for the period 1996-2003. As described in Table 3, coverage is defined as the proportion of the eligible population that has had a smear reported to the NCSP-R in the previous three years. Census data are used to estimate the eligible population, and these data are adjusted for the proportion of women in different age groups who have had a hysterectomy. Prior to 2004, the method for estimating the adjustment proportions did not take into account hysterectomy rates in different ethnic groups. As this is likely to reduce the accuracy of the adjustment for these groups, the table reports coverage as unadjusted only. The NCSP has recently updated the methodology and currency of the hysterectomy adjustment proportions and so the 2004 adjusted figure may not be exactly comparable with previous ones.

Table 4 shows that little change in programme coverage has occurred since 1998, either at a population level or for Māori or Pacific women.
### Table 4  Selected NCSP coverage data 1998–2004

<table>
<thead>
<tr>
<th>Year</th>
<th>Coverage adjusted %</th>
<th>Coverage unadjusted %</th>
<th>Māori unadjusted %</th>
<th>Pacific unadjusted %</th>
<th>Other unadjusted %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>73</td>
<td>65</td>
<td>43</td>
<td>44</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>70</td>
<td>63</td>
<td>49</td>
<td>50</td>
<td>66</td>
</tr>
<tr>
<td>2001</td>
<td>72.7</td>
<td>63.9</td>
<td>46.3</td>
<td>45.0</td>
<td>67.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>20–24</td>
<td>62.4</td>
</tr>
<tr>
<td>25–29</td>
<td>71.3</td>
</tr>
<tr>
<td>30–34</td>
<td>74.7</td>
</tr>
<tr>
<td>35–39</td>
<td>72.9</td>
</tr>
<tr>
<td>40–44</td>
<td>68.6</td>
</tr>
<tr>
<td>45–49</td>
<td>62.8</td>
</tr>
<tr>
<td>50–54</td>
<td>56.9</td>
</tr>
<tr>
<td>55–59</td>
<td>52.0</td>
</tr>
<tr>
<td>60–64</td>
<td>47.9</td>
</tr>
<tr>
<td>65–69</td>
<td>38.3</td>
</tr>
</tbody>
</table>

2004*: 73

---

### Table 5  Selected NCSP cytology indicators 1996–June 2003

<table>
<thead>
<tr>
<th>Year</th>
<th>HSIL %</th>
<th>ASCUS-H %</th>
<th>ASCUS (excluding ASCUS-H) %</th>
<th>LSIL %</th>
<th>PPV %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996</td>
<td>0.86</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>0.92</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>0.84</td>
<td>68†</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>1.09</td>
<td>0.25</td>
<td>3.98</td>
<td>2.86</td>
<td>74.5‡</td>
</tr>
</tbody>
</table>

2002

<table>
<thead>
<tr>
<th>Month</th>
<th>LSIL %</th>
<th>PPV %</th>
</tr>
</thead>
<tbody>
<tr>
<td>January–March</td>
<td>1.0</td>
<td>2.93</td>
</tr>
<tr>
<td>April–June</td>
<td>1.06</td>
<td>2.73</td>
</tr>
<tr>
<td>July–September</td>
<td>1.13</td>
<td>3.1</td>
</tr>
<tr>
<td>October–December</td>
<td>1.10</td>
<td>2.9</td>
</tr>
</tbody>
</table>

2003

<table>
<thead>
<tr>
<th>Month</th>
<th>LSIL %</th>
<th>PPV %</th>
</tr>
</thead>
<tbody>
<tr>
<td>January–March</td>
<td>1.05</td>
<td>3.2</td>
</tr>
<tr>
<td>April–June</td>
<td>1.1</td>
<td>72.5†</td>
</tr>
</tbody>
</table>

* Personal communication Dr Hazel Lewis, Clinical Leader, NCSP, October 2004.
† This proportion measured the correlation of the first smear result with a recommendation for immediate referral reported in 1996 with the subsequent histology up until and including December 1998 for women aged 20–69 years.
‡ For smears reported as HSIL or more serious abnormalities 1/7/2000–30/06/2001.
§ For smears reported as HSIL or more serious abnormalities 1/6/2001–31/12/2001.
** For smears reported as HSIL or more serious abnormalities 1/7/2000–30/6/2001.
†† For smears reported as HSIL or more serious abnormalities taken 1/7/2002–31/12/2002.
2.4.7 Recent developments

The Audit team is aware of a range of developments in the NCSP and wider Ministry that have occurred subsequent to the timeframe of the Audit. These include:

- Revised colposcopy standards\textsuperscript{39} and standards for NCSP-R regional offices\textsuperscript{40} have been developed and introduced in 2003. (From the perspective of this Audit the relevant standards are those contained in the October 2000 document.)

- New targets for cervical cancer incidence and mortality and cervical screening coverage are in development.

- A recent amendment to the Health Act 1956 was passed in March 2004. The Health (National Cervical Screening Programme) Amendment Act 2004 will come into force in March 2005. This amendment provides for a number of changes to the operation of the NCSP that clarify the NCSP enrolment processes, make provision for collection of colposcopy information and facilitate programme evaluation. In particular, women will no longer be able to “opt off” individual specimen results but will either be enrolled in the NCSP and have all their results recorded on the NCSP-R, or will cancel their enrolment. Initial enrolment, however, will continue to be on the basis of a specimen having been taken and the result sent to the NCSP-R.

- A work programme to implement the revised legislation has been established, and this includes development of an NCSP colposcopy dataset. In conjunction with this the NCSP is making improvements to the NCSP-R that will enable it to collect up to three ethnicity codes and is revising the NCSP guidelines for the management of women with abnormal smears. The latter review will include consideration of appropriate screening intervals and adjunctive testing options.*

- An NZHIS plan has been developed to implement training in ethnicity data collection processes with DHBs and PHOs.

\* Personal communication Dr Hazel Lewis, Clinical Leader, NCSP, October 2004.
2.5 Audit

ōtitanga

In screening programmes audit is a central component of the ongoing quality assurance activities. It is an activity that can lead to overall improvements in the programme and thus benefits for the population.

Audit is a process whereby a service is examined against a set of pre-defined standards established in accordance with expectations of high quality. Some audits will be confined to a particular component of the service (e.g., cytology or smear-taking services). Other audits, such as this one, examine the screening pathway from the perspective of the whole population or groups of individuals who have developed the relevant condition.

2.5.1 Audits of women with invasive cervical cancer

There are a number of published audits of women with invasive cervical cancer. These audits are of variable size and may or may not include a smear re-read, and many have been undertaken outside the context of an organised cervical screening programme. Some audits are restricted to women who have died of invasive cervical cancer and others to incident cases within a certain time period. Some involve interviews with women, but others are entirely records-based.

A review of a number of previous published audits of women with invasive cervical cancer was undertaken. In general the review was restricted to those audits in the English language peer-reviewed literature published during the past 15 years or those deemed to have particular relevance to the current Audit.

2.5.2 New Zealand audits

Two previous audits of women with invasive cervical cancer have been carried out in New Zealand.

MacLean et al reviewed the screening histories of 18 women diagnosed as having invasive squamous cell carcinoma at Christchurch Women’s Hospital over four years from October 1980 to October 1984. Only 16% (3/18) had been regularly screened, and 44% (8/18) had never had a smear.

Ratima et al reviewed the screening histories for 15 years pre-diagnosis of all women recorded as Māori who had presented with invasive cervical cancer at any of the six New Zealand oncology treatment centres during the 12-month period 1 May 1989 – 30 April 1990. Information was gathered from interviews with women as well as hospital, laboratory and general practice records. The most significant finding from this audit was the high proportion of women who had either never been screened (54%) or had been screened infrequently (22%).
2.5.3 International audits

A predominant finding of international audits of the screening histories of women with invasive cervical cancer is the high proportion of women with absent or ‘inadequate’ screening histories.\textsuperscript{43-46} Although definitions of ‘inadequate’ screening vary between studies, proportions of women with absent or inadequate screening histories have been found to range between 45\% and 74\%.\textsuperscript{43,46}

Some studies have attempted to quantify both the proportion of false negative smears and the proportion of women with invasive cervical cancer for whom this was a feature of their screening history. Where smear re-reads have been carried out there is great variation in the time period over which smears are collected for re-read and in the actual re-read methodologies employed, including the severity of abnormality defining an upgrade, which makes valid comparisons difficult. In general, some kind of expert review is used. Expert review usually involves a panel of cytotechnologists and cytopathologists reviewing the smears from women with invasive cervical cancer. In the one study reporting a smear re-read in the relevant time period, when prior negative smears from women with invasive cervical cancer are used as the denominator, 22\% of smears were upgraded to high-grade or worse.\textsuperscript{43}

In a review of the records of women who were members of a large prepaid health plan in the USA, Sung et al\textsuperscript{45} found that of women with invasive cervical cancer who had a cervical smear in the six to 36 months prior to diagnosis, 59\% had had a cervical smear read as normal in the three years prior to diagnosis. This study did not include a smear re-read so it is not possible to quantify the proportion of these women who had a laboratory false negative in their history.

Inadequate or delayed management of women with abnormal smears is also a feature of the screening histories of some women with invasive cervical cancer. However, the proportion of women for whom this is a feature is relatively minor compared with the proportions either not, or inadequately, screened. Published proportions range from 4\% to 10\%.\textsuperscript{43-45}

2.5.4 Purpose of this Audit

The purpose of this Audit was to provide information to the screening programme regarding potential systemic issues that, if addressed, would improve its quality and thus further reduce the number of women developing and dying from invasive cervical cancer. The Audit was a systems audit. The Audit was not designed to investigate individual practitioners or to determine the cause of an individual woman’s cancer.
Since Māori women develop and die from invasive cervical cancer at a greater rate than non-Māori women, the Audit needed to examine potential reasons for this inequality. Thus it was important for sufficient numbers of Māori women to be included in the Audit. This was achieved by planning the period for which data collection occurred so that approximately 100 Māori women could be identified as potential participants.

Routine data suggested this time period for data collection would also enable 20–30 Pacific women to be included. Unfortunately this was not achieved as insufficient numbers of Pacific women met the Audit’s eligibility criteria.

2.5.5 Timeline/history of the Audit

An audit of women with invasive cervical cancer was first planned as part of an evaluation of the New Zealand NCSP in the late 1990s. In 2000, the Report of the Ministerial Inquiry into the Under-Reporting of Cervical Smear Abnormalities in the Gisborne Region,² stated in its first recommendation that an Audit of this kind must be undertaken.* The inquiry committee clearly envisaged the Audit could be conducted in a much shorter timeframe than has been possible. The Audit has thus been undertaken in the context of the preceding inquiry and the recognised requirement to carry out evaluations that can provide information to both strengthen the quality and effectiveness of the NCSP and provide direction for ongoing NCSP development.

This Audit project commenced in January 2001. The period January 2001–May 2002 was used to undertake necessary preparation, including understanding and making provision for the legal and ethical context in which the Audit was occurring, securing the necessary expertise and equipment, developing policies and procedures, engaging epidemiologists to the project, developing the methodology, preparing an ethics application and obtaining ethical approval to proceed. Data collection – including interviewing women, locating and obtaining the necessary information from their medical records and collecting and re-reading cervical smears – occurred over the 18-month period from June 2002 until December 2003. Between February and October 2004 data analysis, interpretation and report writing occurred.

* In 1999, the then Government established a ministerial inquiry to investigate whether unacceptable under-reporting had occurred at Gisborne Pathology Laboratories during the period 1990–1996. The inquiry committee consisted of a Queen’s Counsel, cytopathologist and consumer representative. The committee sat during 2000 and reported to the Government in 2001. The committee concluded that unacceptable under-reporting had occurred and this was partly due to systemic issues in the NCSP. The committee made 46 recommendations all of which were accepted by the Government. Conducting an audit of women with invasive cervical cancer was the first recommendation.
2.5.6 Ethical, legal and data protection issues

Ethics

The Cervical Screening Inquiry Committee expressed the view that it should not be necessary to obtain ethical approval for audit of a public health programme such as the NCSP as audit is a fundamental aspect of a well-run programme. However, for various reasons a decision was made to obtain ethical approval. First, the success of this Audit was dependent on the goodwill of women and health professionals and the Audit team considered that their co-operation would be more likely if they knew that ethical approval had been obtained. In addition, as there is no widely agreed differentiation between ‘audit’ and ‘research’, and as this Audit required the collection of primary data, the Audit team considered a case for ethical approval could be made. Thus ethical approval was obtained in May 2002.

As a result of the passage of the Health (National Cervical Screening Programme) Amendment Act 2004, future audits should be able to rely on routine and NCSP data sets for most of the information required and women enrolled in the programme will have been informed that the NCSP now routinely audits the programme. Thus ethical approval may not be required in future.

Legal

The conduct of the Audit is governed by the provisions of the Privacy Act 1993 and Health Information Privacy Code 1994, the Cancer Registry Act 1993, Section 74A of the Health Act 1956, and the Official Information Act 1982. In particular, the provisions of the Privacy Act prevent the identification of any individuals in the Audit report.

Data protection

The Health Act 1956 contains regulations the Health (Cervical Screening (Kaitiaki) Regulations 1995) that require a ministerially appointed Kaitiaki Group to approve applications for the analysis and release of aggregate Māori women’s data contained on the NCSP-R. One purpose of the regulations is to ensure Māori women’s data are used in a way that is likely to benefit Māori women. Accordingly, the Audit team applied to the Kaitiaki Group in April 2002 and received correspondence approving the application in May 2002.
2.5.7 What can this Audit demonstrate?

This Audit was designed to provide information on the following among women with invasive cervical cancer:

- the characteristics of women developing invasive cervical cancer in New Zealand
- the completeness and accuracy of these women’s data on the NCR and NCSP-R
- refined incidence data for the timeframe in which the Audit was conducted as well as ethnic-specific rates
- NCSP progress towards meeting incidence targets for 2005, and achieving stage targets for 2000
- whether or not women with invasive cervical cancer were screened in the six months to seven years prior to their diagnosis with invasive cervical cancer, and the proportion having at least three-yearly smears in accordance with NCSP policies
- the adequacy and timeliness of the follow-up process for women with abnormal cytology and abnormal bleeding
- the proportion of smears that were upgraded to high-grade or more serious by the smear re-read
- the proportion of women with invasive cervical cancer who had at least one smear upgraded
- whether the experience of Māori women differed from that of non-Māori women.

2.5.8 Goals, aims and objectives of this Audit

**Goal 1:** To provide information to support improvements to the NCSP and thus contribute to the ongoing reduction in the incidence of and mortality from invasive cervical cancer in New Zealand women.

**Goal 2:** To provide information to support eliminating disparities between Māori and non-Māori women in the incidence of and mortality from invasive cervical cancer.

**Aim 1:** To determine areas where the NCSP could operate more effectively, including identifying possible systemic failures.

**Aim 2:** To contribute information to assist in informing women of the quality of service provided by the NSCP.

**Aim 3:** To inform NCSP providers of potential problems that may lead to screening failure, in order to inform practice improvement.
Aim 4: To inform the development of a process for any ongoing audit of women with invasive cervical cancer.

Aim 5: To design and implement an audit process that will separately address the above issues for Māori women.

Aim 6: To determine whether the experiences of Māori women with invasive cervical cancer in relation to the NCSP differ from those of non-Māori women.

Objective 1: To identify potential screening-related contributory factors to the development of invasive cervical cancer.

Objective 2: To accurately measure the stage distribution of squamous carcinoma and adenocarcinoma of the cervix.

Objective 3: To assess the accuracy and completeness of information on the NCSP-R and the NCR relating to women developing invasive cervical cancer.

Objective 4: To independently review, mimicking a screening environment, smears taken up to four years prior to the diagnosis of invasive cervical cancer and to compare review reports with original reports.

Objective 5: To undertake a separate Māori analysis for each of the objectives listed above.
3 Methods: Identification of Women with Invasive Cervical Cancer and Data Collection

Āhuatanga mahi: whakäturanga o ngā wahine e mau ana ite mate pukupuku taiawa urutomo me te kohikohinga raraunga

This section provides an overview of the methods used in the Audit to identify women with invasive cervical cancer and to collect data about their screening history from questionnaire and medical records and from re-reading their recent cervical smears.

3.1 Overview

Tiro whänui

The Audit sought to review the screening histories of women who were diagnosed with histologically proven invasive cervical cancer during the time period 1 January 2000 to 30 September 2002, who had been living in New Zealand for at least four consecutive years of the seven years prior to their diagnosis, whether or not they had smears recorded on the NCSP-R.

Cancer registration details were obtained from the NCR. Data on screening history and the path to diagnosis were gathered from the NCSP-R, structured interviews with women and/or next of kin, primary care and hospital gynaecological records, and a cervical cytology smear re-read. Screening history data were collected relating to the seven years prior to diagnosis. However, the smear re-read was restricted to prior negative, low-grade and unsatisfactory smears taken within four years of the diagnosis of cancer.

3.2 Sample

Tauira

3.2.1 Inclusion criteria

The women whose screening histories were analysed as part of the Audit were women who definitely had primary invasive cervical cancer, who were diagnosed in New Zealand, who had lived in New Zealand for a period during which it would be reasonable to expect that the NCSP could have had an impact on preventing their cervical cancer, and who were aged under 80 years at the time of diagnosis. Women whose diagnosis had not been definitively confirmed by histology were excluded, as were women whose cancer was diagnosed outside New Zealand and those who had not been living here for at least four years during the period for which data were collected. Four years was chosen as the cut-off as it comprises one
screening cycle (three years) plus six months at each end of the three years, since the NCSP-R does not send a woman a reminder until she is six months overdue for a smear (where her screening history is normal).

Women diagnosed over a 33-month period were potentially eligible for inclusion in the Audit. This length of time was chosen in order to try to include approximately 100 Māori women, so that separate analyses of Māori women’s data could be undertaken.

The Audit sample therefore comprised women meeting the following criteria:

- histologically confirmed primary invasive (including microinvasive) carcinoma of the cervix diagnosed between 1 January 2000 and 30 September 2002, whether alive or dead at the time of Audit
- diagnosed within New Zealand
- living in New Zealand for at least four consecutive years of the seven years prior to diagnosis
- aged < 80 years at the time of diagnosis.

These criteria were chosen because the Auditors wanted to be sure that the cases included in the Audit were directly relevant to the NCSP.

### 3.2.2 Process followed to define the sample

The NZHIS provided information from the NCR on all women registered with invasive cervical cancer with recorded dates of diagnosis between 1 January 2000 and 30 September 2002. The information was initially supplied in a series of data extracts grouped according to the women’s date of diagnosis. The NZHIS also provided regular updates of data about women whose date of diagnosis was within this time period. These data were supplied up to the end of September 2003, to ensure that any notifications to the NCR up until that time would be included.

The NZHIS does not necessarily use the date of histological confirmation of cancer as the date of diagnosis on the NCR but in some cases uses the date of a prior high-grade smear or suspicious histology as the recorded date of diagnosis. Therefore records from women with dates of diagnosis on the NCR from 1 October 1999 were also checked for cases where a confirmatory histology fell within the Audit’s timeframe.

Registration on the NCR is based on different criteria from inclusion in the Audit (in particular, histological confirmation is not an absolute requirement), so further input was required to determine whether women fitted the Audit eligibility criteria.
Where the NCR did not hold information that included histological confirmation of invasive cervical cancer, further information was sought from the gynaecologist recorded by either the NCR or the NCSP-R as the woman’s medical specialist. Copies of histology results were requested where they existed.

Hard copy histology results were reviewed by a pathologist and gynaecological oncologist to confirm the diagnosis of invasive primary cervical carcinoma. If the only histology result showed ‘probable’ invasive carcinoma, the specialist was asked to confirm the clinical diagnosis. Women whose clinicians confirmed that the clinical diagnosis made was invasive (including microinvasive) carcinoma, and who therefore received treatment for that diagnosis, were included in the Audit sample.

Women for whom no histological confirmation of invasive cervical cancer was available, or whose histology did not confirm that there was a primary cervical cancer, were excluded from the Audit sample.

### 3.3 The consent process

**Te raupapa mahi whakaae**

Consent was obtained in two stages: initial consent for interview and subsequent consent to access medical records and cervical smears. If women declined to be interviewed, the interviewer asked if they were willing to give consent to relevant information being collected from their medical records and to the re-reading of their cervical smears.

### 3.4 Approaching women

**Te tono atu ki ngā wāhine**

#### 3.4.1 Further checking prior to approaching women

Prior to commencing contact with individual women, the Audit checked whether any women had had smears re-read as part of the Gisborne smear re-read. In addition, the Audit was aware of other related studies that were being conducted simultaneously. The Audit team ensured that contact with women involved in these studies was appropriately sensitive.

* For example, ‘suspicious of invasion’, ‘probable early invasion’, ‘cannot exclude invasion’.
3.4.2 Contacting health care providers prior to contacting women

Prior to contacting women, health care providers (the treating specialist and the main primary care provider) were contacted by letter, in order to inform them that one of their patients was to be included in the Audit, and to ask them to confirm the following:

- that the woman was aware of her cancer diagnosis
- the woman’s most recent contact details
- the woman’s preferred language
- that the woman was still under their care
- the woman’s most recent other medical providers
- any relevant information about the woman’s current health status that would have an impact on the appropriateness of contacting her regarding the Audit (eg, if she were terminally ill, it may not be appropriate to approach her).

Health care providers who did not post back the response form accompanying the letter were followed up by telephone. Whilst the Audit attempted to obtain confirmatory details from both the primary care provider and treating specialist, in many cases only one of them provided information.

Following the responses of health care providers to the initial letters, and prior to contacting women (with whom it was appropriate to make contact), the specialist or general practitioner (GP) was asked to contact the woman and inform her that the Audit was taking place and that she could expect to be approached by the Audit team. A pro-forma letter was provided to health care providers that could be sent to the woman, but they were free to choose the method of contact.

Some women were excluded at this stage as the Audit found their histology had been reviewed and determined to be non-invasive.

3.4.3 Contacting women

Once women had heard about the Audit from their health care provider, a letter, consent form for interview and information sheet were sent to the most recent known address. The letter informed them that a named interviewer would contact them. Once the consent process form for interview was returned, or it was confirmed by telephone that the woman was agreeable to being interviewed, a date and time for this was organised.
Consent for access to relevant medical records was sought subsequently at the time of interview, where this was face-to-face. Where the interview occurred by telephone or the woman consented to access to relevant records and cervical smears but declined to be interviewed, the consent form was mailed to the woman with a stamped return envelope enclosed.

Where possible, the Audit team endeavoured to have the same interviewer approach and interview women and complete any follow-up contacts.

Women were advised that they could change their mind about participation at any time during the data collection phase.

For women who declined to participate in any aspect of the Audit, only anonymised information from the NCR and NCSP-R was included in analyses.

Again, some women were found to be ineligible for the Audit prior to, or at, the interview because they did not meet the Audit’s residency criteria.

### 3.4.4 Approaching Māori women

In general, the process for approaching Māori women was the same as that described above. However, every effort was made to have a Māori interviewer contact and interview women of known Māori ethnicity. If a non-Māori interviewer approached a woman who was Māori (this could occur because women’s ethnicity indicators on the various information sources were not always accurate or consistent), an offer was made to replace the non-Māori interviewer with a Māori interviewer. A small number of Māori women were interviewed in te reo Māori.

### 3.4.5 Approaching non-English-speaking women

Interpreters were available for interviews with non-English-speaking women. A small number of Asian women required this service.

### 3.4.6 Women who could not be contacted

A range of techniques was used to attempt to locate women who were not easily contacted, including visiting them and leaving written messages in their letter boxes. These methods were of particular relevance where women were without a telephone. After five separate attempts at contact, they were classified as ‘uncontactable’. Only information about these women obtained from the NCR and NCSP-R could be included in analyses.
3.4.7 Deceased women

Every effort was made to establish and include the screening histories of deceased women. However, contact with next of kin or others was not attempted until at least six months after the woman had died. At that time, the woman’s personal representative or administrator* was contacted.

Personal representative or administrator and next of kin

The personal representative (or administrator) was contacted to obtain consent for access to relevant medical records and cervical smears. Contact with next of kin was sought to determine the names of relevant medical practitioners, from whom their deceased relative may have sought treatment in the seven years prior to their diagnosis with cancer, to assist with accessing the relevant information. In many instances the next of kin was also the women’s personal representative. Where consent was declined, only information from the NCR and NCSP-R was included in the Audit.

3.5 Data collection

Kohikohinga raraunga

Data on eligible women were available from the NCR, NHI, and NCSP-R. Data from interviews with women or next of kin; primary care, specialist and hospital medical notes; and smear re-read were collected subject to the women’s consent. The aim of data collection was to describe each woman’s screening history as completely as possible for the seven years prior to her diagnosis with invasive cervical cancer, and to establish the stage and histological type at diagnosis.

3.5.1 ‘Routine’ data sources

The NZHIS supplied data from the NCR and from the NHI database, and the NCSP supplied data held on the NCSP-R, for all women fulfilling the Audit inclusion criteria. Table 6 shows the data supplied from these three ‘routinely collected’ sources.

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* A woman’s personal representative in the legal sense is that person appointed under the deceased woman’s will to administer her estate and execute her will. An administrator is the person appointed by the High Court to undertake that function where the woman has died intestate and where for some reason no executor has been, or is able to be, appointed.
Table 6  Various information supplied from routine data sources

<table>
<thead>
<tr>
<th>Information supplied</th>
<th>NCR</th>
<th>NHI database</th>
<th>NCSP-R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying information (name, address, date of birth, NHI number)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Date of death, where relevant</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Histological specimen results</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Other information about cancer diagnosis (date of diagnosis, stage, histological type)</td>
<td>✔</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Names of health professionals who had taken smears or histological specimens, or had treated the woman</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>Smear results</td>
<td></td>
<td></td>
<td>✔</td>
</tr>
</tbody>
</table>

Regular updates of the NHI and NCSP-R data were supplied, to enable a check for name changes and up-to-date addresses before contacting the women, and so appropriate processes would be used to contact next of kin should any women have died prior to being contacted.

3.5.2 The questionnaire

The questionnaire used in the interview with women was developed from the questionnaire used in an earlier study of Māori women with cervical cancer.\(^{42}\) It was pre-tested on a number of women who had been diagnosed with invasive cervical cancer earlier than the Audit sample period.

The questionnaire obtained information mainly relating to the seven years prior to diagnosis. Structured questions covered eligibility for inclusion in the Audit, ethnicity and language, address at and one year prior to diagnosis, use of GPs, gynaecological symptoms and signs, episodes of health care when a smear might have been taken, cervical smears, investigation and treatment, education and income.

3.5.3 Medical records

Where consent was given, relevant medical information was sought from primary care, specialist gynaecologist and hospital records for up to seven years prior to diagnosis. Information obtained at the interview and from the NCSP-R and NCR was used to identify the relevant health care providers.

Information was abstracted from records of consultations where there was a history of abnormal vaginal bleeding, consultations where a smear was taken, or where a reminder of or invitation for a smear was given, and consultations with specialists relating to the cervix, including investigation, treatment and follow-up. The information abstracted included the reason for consultation, whether a smear was taken and if so the result, procedures undertaken by specialists, the results of any biopsy, plans for action.
following the results of smears and biopsies, dates of referral decisions (where noted) and letters, and dates of reminders or invitations for subsequent smears.

### 3.5.4 Smear re-read

A smear re-read methodology was chosen that replicated as far as possible a usual screening environment. The reason for this was that a method that involves blinded review by usual screening personnel was considered a fair standard against which to assess screening laboratories and therefore was likely to provide useful information to the screening programme.

#### Smears included in the re-read

Smears taken from participants and originally read as negative, low-grade or unsatisfactory, and with a date of reporting within four calendar years prior to the date of diagnosis of invasive cervical cancer were identified and included in a smear re-read. These were known as ‘index’ smears. Smears taken within six weeks of diagnosis were excluded from re-read as it was considered that they were unlikely to provide useful information regarding clinically significant false negatives having been taken so close to the woman’s diagnosis. In addition, smears taken and reported outside New Zealand, or smears that were irretrievably damaged, were not re-read. These ‘index’ smears were included in sets of fifty smears that also included control and reference smears (see ‘re-read process’ below).

Four years encompasses one normal screening cycle plus a period of six months on either side to allow for the fact that the NCSP-R does not recall women until six months after their smear is overdue. Therefore any woman who was having regular smears according to the NCSP guidelines would have had at least one smear during this period. Cytology practice is evolving and the Audit team considered that going back further than four years would involve reviewing cytology results that reflected obsolete practice and thus would dilute the usefulness of the Audit results to the programme.

Given that women included in the Audit were diagnosed in the period 1 January 2000–30 September 2002, smears that met the Audit re-read criteria needed to have been reported by the originating laboratory during the period 1 January 1996 and 19 August 2002 (excludes six weeks prior to diagnosis).

#### Re-read process

Smears were grouped together in sets of approximately 50, this equating to a day’s work for a primary screener. Sets were assembled as follows: up to five index smears were seeded within sets of 50 specimens, including a variable mix of reference smears (confirmed high, low, or unsatisfactory smears) and control smears (cervical smears reported as negative from women who were not part of the Audit sample, but were enrolled in the NCSP) that had been taken at a similar time to the index smears.
In any re-read, even one specifically designed to mimic screening, there is a risk of false positives. To minimise false positives, the Audit built a number of criteria into the re-read methodology including the following:

- Control and reference smears were selected from the same laboratory, and were taken and stained within the same era as the index smears for that set.
- The re-read was conducted in a high-quality Australian laboratory that was commercially independent and geographically removed from New Zealand.
- The smears were read using normal laboratory processes, by three discrete teams, in normal working hours.
- The re-read teams were not permitted to know the purpose of the re-read or the origin of the smears.
- Each smear was read by each of the three teams, who were not permitted to know the results of each other’s read before or after their own read.
- No re-staining or re-overslipping of any smears was permitted and slides were cleaned between re-reads.

Importantly, an ‘upgrade’ was defined as a re-read diagnosis by all three teams that would be accompanied by a recommendation for more urgent management than the original diagnosis.

In contrast to unblinded ‘expert review’ the methodology used in this Audit means that some laboratory false negatives will not have been detected.

The reference smears were included as a quality control measure. They had been previously selected as good examples of their type by the Audit pathology review team (PRT).* It was expected that each of the three teams would correctly identify over 90% of the high-grade reference smears, and this was monitored at regular intervals during the course of the re-read. All teams met the criteria.

The Australian re-reading laboratory was required to report the smears in the same manner and using the same protocols it would for routine reporting and to continue with its routine quality assurance practices. The Australian re-reading laboratory used a different system to that used by the New Zealand NCSP, and with the assistance of the PRT, New Zealand codes were mapped to the re-reading laboratory’s reporting system.

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* The Audit PRT consisted of a New Zealand co-ordinating pathologist, an Australian pathologist and a New Zealand medical laboratory scientist. This team was integral to the design and conduct of the smear re-read.
When the smears were returned, the PRT reviewed the index smears up-graded to high-grade to assess possible reasons why they had not initially been recognised as abnormal.

In total 87 sets were re-read, including 336 index, 3,785 control and 216 reference smears. The Audit team had identified seven smears (six women) that could not be located for re-reading.

Following the re-read, control and reference specimens were returned to laboratories. Index specimens and their re-read results were returned at the conclusion of the Audit.

A priori thresholds

Prior to analysing the smear re-read data, the Audit undertook a systematic literature review and modelling exercise to establish a priori thresholds to be used in the smear re-read analysis. The thresholds were to be used to determine whether or not the smear re-read results indicated that an unacceptably high proportion of negative index and control smears had been upgraded to high-grade or more serious. The threshold development work was externally peer reviewed by experts in the fields of epidemiology and cytopathology. After considering the peer reviewers feedback and its own work on the issue, the Audit decided to use the NCSP Monitoring Indicator B6 target\textsuperscript{26} as the basis for a threshold for negative index smears upgraded to high-grade for women with invasive squamous cell carcinoma. The target is: ‘Not more than 20%’.

No attempt was made to establish a threshold for index smears re-read from women with adenocarcinoma.

The Audit decided that, based on the comments of expert peer reviewers, there was insufficient basis for establishing a threshold for the upgrade of control smears.

Upgraded control smears

As would be expected, some control smears were upgraded by some or all re-reading teams. Where it was available from the NCSP-R, relevant screening history information was provided to laboratories with the returned smear. The Audit team and the NCSP national office provided advice to laboratories regarding the management of these situations, and the NCSP followed up with individual laboratories to confirm that appropriate actions had been taken.
3.6 Data management

*Whakahaere raraunga*

A separate, secure Audit office was established within the Auckland office of the Ministry of Health for the duration of the Audit.

Completed records of screening history, interview and smear re-read were coded and checked by Audit staff prior to data entry. Data were double-entered into an *Epi Info* dataset. Relevant data from the operational management databases and data received from the NZHIS and NCSP-R were de-identified and supplied to the epidemiologists, along with the *Epi Info* data as *SAS* data sets.

Details of analytical methods are provided with the results tables (chapter 9).

3.7 Provision of information back to participants

*Te tuku pārongo atu ki ngā kaiwhakauru*

All women participating in the Audit, including deceased women’s personal representatives, were offered the option of receiving a summary of the final report. This will be mailed to women when this report is released. At this time, women will also be offered a copy of the information the Audit included about them in the Audit analysis. The Audit office will follow up with women after the information has been sent to them to determine what further assistance they may require to understand the nature of the Audit and the information that they have received.

3.8 Methodological limitations

*Ngā āhuatanga mahi whakawhātitanga*

The aim of the Audit was to establish whether the New Zealand NCSP is performing to an acceptably high standard. It was not designed to investigate whether cervical screening prevents cervical cancer, or the optimal interval between smears, or to identify risk factors for cervical cancer. As with any project, aspects of the methodology limit the scope of the conclusions that can be drawn from its results.
3.8.1 Retrospective data

The Audit assessed the performance of the screening programme over a period prior to the participants’ diagnosis of invasive cervical cancer. Therefore, information regarding any part of the screening programme, from smear-takers to laboratories to the NCSP-R, will relate to past rather than current practices. This is inevitable in an audit of screening histories but does not preclude useful conclusions and recommendations for the improvement of practice as it is highly unlikely that all issues identified by an audit would have been adequately dealt with before the audit is complete.

The screening histories identified by the Audit include a period prior to the introduction of minimum volumes for laboratories (2001), routine quantitative monitoring of the programme (2001) and the NCSP Interim Operational Policy and Quality Standards (implemented November 2000 to July 2001). Where relevant, reference to appropriate standards and indictors is included in the Audit results chapters.

3.8.2 Focus on women with invasive cervical cancer

The Audit collected data only on women who had been diagnosed with invasive cervical cancer. Since the aim of cervical screening is to prevent invasive cervical cancer by detecting and treating pre-cancer, it is likely that any problems with the screening programme would be particularly apparent in women whose invasive cervical cancer was not prevented. However, although the Audit may indicate possible areas of systemic inadequacy, in some cases additional investigation may be required to provide conclusive evidence.

It is known that a high proportion of women with invasive cervical cancer are likely to be under-screened. However, to press women who have already developed cancer on why they had had insufficient smears was felt to be insensitive, therefore the Audit did not systematically collect data on this issue.

3.8.3 Identification of systemic under-reporting of high-grade smears

Recommendation One from the Cervical Screening Inquiry implied that the Audit should closely examine whether or not previous systemic high-grade under-reporting had occurred in the NCSP. The committee appeared to place importance on determining the issue of systemic under-reporting because of the information this could provide regarding the ‘safety’ of the programme (ie, the committee was concerned that systemic issues existed for the NCSP between 1990 and 1996 and that these extended to cytology laboratories).
Although the Audit has developed a smear re-read methodology for review of prior negative smears that could be used in other re-reads, the Audit cannot completely resolve this issue. There are a number of reasons for this, including that:

- The index smears are from women with invasive cervical cancer, and they are not representative of all women having smears taken.

- The most useful information to determine this issue would have come from the control smear re-read. However, a threshold for what would be an acceptable upgrade proportion for re-read control smears could not be set.
4 Results: Descriptive Analysis of Audit Population

Ngā Hua: Whakāturanga tātaritanga a ngā ōtita taupori

4.1 Key findings

Ngā kitenga nui

Overall
- Of women whose medical records were obtained by the Audit, 287 (77%) had squamous cell carcinoma, 57 (15%) had adenocarcinoma, 22 (6%) had adenosquamous and the five remaining (1%) had other histological types of cancer.
- The proportion of women with medical record data who were diagnosed with stage 1 cancer was 75% for all women, 74% for women diagnosed with squamous cell carcinoma, and 86% for women diagnosed with adenocarcinoma.
- Almost all women had a regular GP during the seven years the Audit reviewed.

Māori
- Māori women were younger at diagnosis of cancer than non-Māori.
- Sixty-nine percent of Māori women were diagnosed with stage 1 cancer compared with 79% of non-Māori, although this difference was not statistically significant.
- Twenty-two percent of Māori women aged under 45 at diagnosis had stage 2 disease and above, compared with 9% of non-Māori women of that age (a statistically significant difference).

4.2 Introduction

Timatanga

This chapter describes the process of identifying the women who were eligible to take part in the Audit, contacting them, and asking for their consent to collect further data about their screening histories. Characteristics of included and excluded women are described using the information available from routine sources. The proportions of eligible women who consented to collection of data about their screening history from interview, primary care and hospital records, and smear re-read, are tabulated and the characteristics of consenting and non-consenting women are described. Demographic data and data on the histological type and stage at diagnosis for participating women are tabulated. The following Audit objectives are addressed in this chapter:
Objective 2: To accurately measure the stage distribution of squamous carcinoma and adenocarcinoma of the cervix.

Objective 5: To undertake a separate Māori analysis.

4.3 Sample identification

Whakāturanga tauira

4.3.1 Potentially eligible women

Source of information

The NZHIS supplied information as extracts from the NCR database for 549 women who were registered on the NCR with a diagnosis of invasive cervical cancer between 1 January 2000 and 30 September 2002. Information on an additional 13 women was supplied through other sources. Three of these women had a date of diagnosis on the NCR before 1 January 2000, but on review by Audit pathology advisors the date of their first histological diagnosis of invasive cervical cancer was found to be within the Audit sample timeframe. Other women’s information appeared in NCR ‘update’ files supplied to the Audit, and in one case through a hand search of a treatment centre’s records of women diagnosed with cervical cancer during the relevant time period (her data were then obtained from the NCR).

As well as the 562 women whose information was supplied during the course of data collection by the Audit, death certificates of two further women who were recorded as dying of cervical cancer in 2002 were sent by the NZHIS to the Audit team in April 2004. Although one of the women’s death certificates stated that she had been diagnosed with cervical cancer one year before she died, and the basis for the diagnosis in the other case appeared to be a post-mortem examination, neither of these women had been registered on the NCR prior to 2004. No data from these two women could be included in the Audit analysis because the notification arrived too late.

Ethnicity

The three health routine data sources (NCR, NCSP-R and NHI) each identified 17% of the 562 women as Māori, but while 103 women were identified as Māori by at least one of these sources, only 82 were identified as Māori by all of them. In addition, 13 other women were identified as Māori by either the Electoral Roll or death certificate. Using an ‘any routine source’ definition of ethnicity, 438 (78%) women were identified as ‘European’, 116 (21%) as Māori, 23 (4%) as Pacific, 28 (5%) as Asian, and 29 (5%) as another ethnicity (Table 9).
4.3.2 Confirmation of eligibility for the Audit

Confirmation of eligibility was not possible on the basis of the information provided by the NCR for 12% of women. In a few cases further information from the NCR enabled a decision about the woman’s eligibility to be made, but for 10% of women more information was requested from the specialist, GP or laboratory involved in her care, to confirm whether or not the woman had been diagnosed with primary invasive cervical cancer. This was extremely time-consuming but was designed to ensure that no woman who had not been diagnosed with cervical cancer was inadvertently approached by the Audit.

Of the 562 women whose information was supplied to the Audit, a histological diagnosis of invasive cervical cancer, made in New Zealand within the Audit timeframe, could not be confirmed for 61 women. Further data collection was not carried out for an additional 18 women who were over 80 years at the time of diagnosis and 38 who did not meet the Audit residency criteria (ie, had not been resident in New Zealand for at least four consecutive years of the seven years prior to diagnosis) (Table 10). Women over 80 at diagnosis were excluded because the NCSP recommends screening to the age of 70, and so women over 80 were unlikely to have a history of screening within seven years of diagnosis. Similarly, women were included only if they had been resident in New Zealand for four or more consecutive years and so would be expected to have completed at least one screening round. A total of 445 women were eligible for further data collection for the Audit.

A higher proportion of Māori women whose information was supplied to the Audit were eligible for the Audit (85%) than of non-Māori women (78%). This is largely because there were no Māori women aged over 80 at the time of diagnosis and few Māori did not fit the residency criteria. Most other reasons for non-eligibility were similar in frequency for Māori and non-Māori, except that Māori were significantly more likely than non-Māori to have had no histological specimens taken (4% vs 1%). These women without histological confirmation were most often older, had advanced disease and died soon after clinical diagnosis.

4.4 Eligible women

Ngā wāhine arotau

4.4.1 Description

Analyses of eligible women use a definition of ‘Māori’ based on interview, when available, and on routine data sources (‘Māori on at least one routine source’) where no interview took place. This definition maximises the number of Māori women who are correctly identified, while misidentifying a small number of non-Māori women (see Table 11).
The 445 women who were eligible for the Audit ranged in age from 21 to 79, with a mean age of 47 years. Sixty-two (14%) had died before the Audit began data collection for them (18% of Māori women and 13% of non-Māori women). The 95 Māori women were younger at diagnosis (mean age 43) than the 350 non-Māori women (mean age 48). By December 2003, when the last data update was received by the Audit, the NCR had a stage recorded for 329 (74%) of these women, of whom 214 (63%) were recorded as stage 1. The NCSP-R had records of smears taken during the period between seven years and six months prior to diagnosis for 255 (57%) of the eligible women.

4.4.2 Consent to interview and medical record data collection

Consent to at least one of the forms of further data collection – interview, access to primary care records, access to hospital/specialist records or to smear re-read – was given for 376 (85%) of the 445 women who were eligible for inclusion in the Audit. Consent for collection of each individual type of data was over 80%, and 349 (78%) consented to all. Details of consent to different aspects of the Audit are given in Table 12.

Consent rates for Māori women for all types of data collection were not significantly different from those for non-Māori women. For both Māori and non-Māori women, next of kin and legal representatives were significantly less likely than the women themselves to give consent for interview (66% vs 83%) or access to medical records (69% vs 86%).

4.5 Audit participants

Ngā kaiwhakauru ōtīta

4.5.1 Completeness of data collection

Interviews were performed with all of the 318 women and 41 next of kin who gave consent for interview. Interviews were conducted either by telephone or face-to-face according to the interviewee’s preference.

During the interview, women or next of kin were asked for names and addresses of health care providers they had attended to seek care for cervix-related symptoms or signs, or who may have taken a smear at a consultation. Health care providers consulted over the seven years prior to diagnosis were sought. At least some medical record information was collected for all women who gave consent for its collection. However, for a number of women not all of their medical records could be obtained for abstraction of data. If a woman had consulted more than one primary care provider over the seven years, the Audit was less likely to be able to locate all her primary care records. Reasons for non-availability of complete medical records included:
• Four women consented to access to either hospital/specialist or GP records but not both.
• Some providers named by women or relatives were unable to be found.
• Some providers had retired or ceased business, and their medical records had been destroyed or not stored in a retrievable way.
• In some instances notes from a former GP were said to have been sent on to the woman’s subsequent GP, but that GP had no record of receiving them.
• Some providers named by women or relatives had no record of seeing the women.
• Some women had seen the named providers only once or twice, and records for ‘casual’ patients were not archived.
• In some instances providers or women made partial clinical notes available to the Audit for data abstraction.

Table 13 shows the completeness of data collection for primary care and hospital/specialists.

The most important reason for obtaining primary care records was to ensure that the smear histories of Audit women were as complete as possible. All known relevant primary care records were obtained for 71% of Māori women and 84% of non-Māori women (a significant difference, mainly accounted for by the fact that a higher proportion of Māori women had more than one GP during the period). However, information on smears recorded on the NCSP-R was available and shown to be nearly complete (see section 7.4.2).

Eight women reported that they had had smears that neither appeared on the register nor were recorded in any of their available primary care records. All primary care records were obtained for five of these women and partial records for three of them. The electronic records of the laboratories most likely to have processed the reported smears were checked and no records of them found. The smear data collected by the Audit were therefore effectively complete.

All known relevant hospital and specialist records were obtained for 95% of Māori and 92% of non-Māori. Therefore data on colposcopy and diagnosis were also close to complete.

4.5.2 Demographic information

Participating women were aged from 21 to 79 years at diagnosis (mean age 47), with Māori women being on average younger (mean age 42) than non-Māori women (mean age 48).
At interview, women or next of kin were asked to identify all ethnic groups that the woman belonged to (Table 14). Ethnicity identified at interview included Māori for 75 (21%), with 282 (79%) identifying as New Zealand European, eight (2%) as Chinese, six (2%) as Pacific, two (1%) as Indian, and 21 (6%) as from other ethnic groups (including ‘other European’). A high proportion (38%) of women had no secondary school qualification, compared with the expected proportion for New Zealand women of this age (23%) calculated from 2001 census data.49 Twenty percent of interviewed women came from households with an income of less than $20,000 per year, the same proportion as in the population as a whole.49 NZDep2001 scores* were able to be assigned for most women’s addresses at diagnosis. Scores denoting higher levels of deprivation were slightly over-represented, with 23% of women in deciles nine and ten and 18% in deciles one and two (each decile includes approximately 10% of the whole New Zealand population).

Māori women were significantly more likely to have had fewer years of secondary school education, to have no secondary school qualification, to live in larger households, and to have lower levels of household income than non-Māori women (Table 14). About half of Māori women (54% (95% CI 42% to 65%)) lived at addresses in the two highest deprivation deciles, in comparison with 15% of non-Māori women. This is similar to the population figures of 43% Māori and 17% non-Māori who live in these deciles.

### 4.5.3 Self-reported use of health services

Some information about use of health services was available for the 359 women who had been interviewed or whose next of kin were interviewed (Tables 14 and 15). Some questions were not asked of next of kin, so some of this information is available only on the 318 women who were interviewed themselves.

All except four women (three Māori) were reported to have had a regular GP in the seven years prior to their diagnosis of cervical cancer. More non-Māori women (60%) than Māori women (47%) had only one GP during that time, although the difference was not statistically significant.

Twenty-six (8%) of the interviewed women reported that they could not remember ever having a smear before their diagnosis of cervical cancer. More Māori (15%) than non-Māori (6%) did not remember ever having a smear before diagnosis (Risk Difference 9% (95% CI: 2% to 18%)).

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* NZDep2001 is a New Zealand area-based measure of socioeconomic status. See section 9.4.7 for further description.
4.5.4 Disease information

Self-reported information

Just over half of the interviewed women (both Māori and non-Māori) reported that a ‘routine smear’ (a smear in the absence of symptoms) had led to their diagnosis (Table 15). However, for a number of these women the smear was their first for a number of years (ie, they were not smears taken as part of a routine screening schedule). For some of these women their visit to the smear-taker may have been prompted by symptoms that they do not remember or do not consider to be related to their cervical disease, and for others their diagnosis was the result of opportunistic smear-taking.

Information from medical records

Of women whose medical records were obtained by the Audit, 287 (77%) had squamous cell carcinoma, 57 (15%) had adenocarcinoma, 22 (6%) had adenosquamous and the five remaining (1%) had other histological types.

The Audit was able to ascertain the stage at diagnosis for 349 (94%) of the 371 women for whom medical records were available (Tables 16 and 17). For the women where a stage could be ascertained, the proportion diagnosed at stage 1 was 75% for all women, 74% for women diagnosed with squamous cell carcinoma, 86% for women diagnosed with adenocarcinoma, and 77% for non-Māori women. For Māori women, the proportion diagnosed at stage 1 was 69%, with a 95% confidence interval from 58% to 79%.

When women of all ages and with all histological types of cancer are considered together, there are no statistically significant differences between Māori and non-Māori in the stage distribution, although amongst women with squamous cell carcinoma there is a suggestion that a higher proportion of Māori women have later stage (2+) disease (32% vs 24%). The proportion of women with later-stage disease is strongly related to age (Table 17), so the younger Māori population would be expected to have fewer rather than more cases of later-stage disease. However, when women are divided into those over 45 and those under 45 at diagnosis, the proportion of younger Māori women with later-stage disease is significantly higher than that for non-Māori (22% vs 9%).
4.5.5 Comparison with non-participants

For both Māori and non-Māori, women for whom consent to access medical records was obtained had more smears on the NCSP-R and fewer had late-stage disease (where the NCR had a stage recorded) than those where records were not accessed. However, the high consent rates mean that the smear numbers and stage of consenting women were representative of the eligible women as a whole (Table 18). The Audit data on participating women are likely to be sufficiently complete to draw robust conclusions on the screening histories of these women, including Māori women.

4.6 Pacific and Asian women

Ngā wāhine o te moana nui a Kiwa me Āhia

Using a definition of ethnicity based on interview, when available, and on routine data sources where no interview took place, 13 Pacific women and 16 Asian women were eligible for further data collection for the Audit. Only half of Pacific women for whom a stage was available on the NCR had stage 1 disease, but Asian women were similar to other non-Māori women in their stage distribution. No Pacific or Asian women were aged over 70 at the time of diagnosis. Pacific women had similar numbers of smears on the NCSP-R to other women, but half the Asian women had no smears on the NCSP-R. Consent for further data collection was obtained for fewer Pacific women than for Māori or all non-Māori women but for high proportions of Asian women.
5 Results: Pathways to Diagnosis in Audit Participants

Ngā hua: Huarahi tätari i ngā kaiwhakauru ďtīta

5.1 Key findings

Ngā kitenga nui

- Women with cervical cancer were under-screened by all definitions used. Only half of women of screening age had a smear in the six to 42 months before diagnosis.

- Māori women were more poorly screened than non-Māori women.

- Women with high deprivation indices, low income and lower education were less well screened.

- The definition ‘coverage’ does not capture the extent to which New Zealand women with cervical cancer are under-screened.

- Women with lower-stage disease were more likely to have been screened. This supports the evidence that screening is beneficial in down-staging cervical cancer.

- Women with adenocarcinoma were more likely to have been screened.

- Māori women experienced longer times to follow-up of abnormal smears.

- Eight percent of women with cervical cancer had a history of prior treatment for cervical dysplasia.

- Documentation of colposcopy during the period of this Audit would not have met current NCSP targets.

5.2 Introduction

Timatanga

This chapter describes the pathways of women with invasive cervical cancer, from smear history and/or symptoms through colposcopy to diagnosis. Not all women had screening, symptoms, high-grade smears or colposcopy prior to diagnosis, but the majority of women experienced at least one of these. The analyses are discussed in terms of this pathway to diagnosis, and where relevant and available the Audit results are compared with programme standards and programme data.
Many factors may contribute to the development of cancer in an individual woman. The usual natural history of cervical cancer is progression, over a long period, from HPV infection to dysplasia and then (in some women) to cancer. The aim of cervical screening is to detect precancerous changes and treat them before cancer arises, and regular cervical smears have been shown to reduce the incidence of and mortality from cervical cancer in populations with high coverage. At an individual level even regular smears, all taken by expert smear-takers and read by high-quality laboratories, will not prevent every case of cervical cancer. In addition, infrequent smears, and variability in the quality of smear-taking, smear-reading and the management of abnormal smears, may all have an impact on an individual’s risk of developing cervical cancer. Therefore, the analyses have not attempted to determine which was the ‘key’ factor for each of the women included in the Audit but instead show for each factor the proportion of women for whom it occurred.

The following Audit objectives are addressed in this chapter:

**Objective 1:** To identify potential screening-related contributory factors to the development of invasive cervical cancer.

**Objective 5:** To undertake a separate Māori analysis.

**NCSP national indicators and targets and standards**

The women with cancer who are described in this report are a subgroup of women eligible for the NCSP. The NCSP has defined a number of indicators, targets and standards intended to describe aspects of a high-quality service.\(^26\) Some of these have been used in this report, either to report against (where appropriate) or to describe aspects of the experience of participating women.

Some targets are designed to measure NCSP performance among the women represented in this Audit, and so can appropriately be applied to the Audit population. However, other NCSP national indicators and targets are for monitoring the NCSP as a whole and are not directly applicable to a subset of women with cervical cancer. Therefore, while the NCSP indicators have been calculated for Audit women, caution is required when interpreting the Audit results against NCSP standards.

Women with cancer may fall outside the thresholds dictated by the standards and targets. This implies that those indicators are associated with cervical cancer but does not necessarily mean that they cause or increase the risk of developing cancer. There may be other factors that confound the association with cervical cancer. Similarly, if the Audit results fall within the programme standards and targets, this suggests – but does not prove – that the indicators are not factors in the development of cancer.
If Audit results fall outside targets or standards that are intended for the programme as a whole, this does not necessarily mean that the programme is under-performing.

It is possible that ethnic differences in standards or targets may be masked in the Audit data, as the women included in this Audit all have cancer and so all are perhaps more likely to have ‘failed’ the NCSP standards. Conversely, if ethnic differences are evident within this group of women, it is almost certain that these exist to an even greater extent for women in the NCSP as a whole, and therefore the need for these disparities to be addressed is even greater.

The national indicators and targets and standards relevant to this Audit are documented in full in Appendix 3.

5.2.1 Definitions and analyses

Women included in analyses

Most of the analyses were performed by histological type and by ethnicity (Māori and non-Māori), and for squamous cell carcinoma, by stage groupings. Because data abstracted from medical records had the most complete stage and smear information, most analyses were performed on data from the 371 women whose medical records were abstracted or, for analyses of income and education, the subset (N = 354) where medical records were abstracted and the woman or her next of kin was interviewed. Analyses of screening history include only women aged up to 69 years, the age at which the NCSP-R ceases to recommend routine screening.

Histological type and stage

Screening is known to reduce the incidence of invasive squamous cell carcinoma, but its effectiveness in preventing adenocarcinoma and other types of cancer has not been quantified. Therefore the focus of the analyses is squamous cell carcinoma. Analyses were performed by stage for squamous cell carcinoma because stage is strongly associated with outcome and also with screening. Most of the analyses presented in this report categorise stage as 1A, 1B, and 2+ for squamous cell carcinoma. These stage groupings were chosen because the groups have significant differences in prognosis and the number of women with late stage disease was insufficient to allow further breakdown of the 2+ group. Data for women with adenocarcinoma were not split by stage as the majority (42/49 with adenocarcinoma and known stage) were stage 1. The remainder were stage 2+ (seven women) or the stage was unknown (eight women).
Age standardisation

The proportion ‘screened’ (by any of several definitions) is strongly related to age (Table 21), and the Māori and non-Māori women in the analyses have different age distributions (there is a higher proportion of young and a lower proportion of older women in the Māori group (Table 17)). Therefore, screening history analyses show the proportion of Māori and non-Māori screened and also the percentage of non-Māori screened, age-standardised to the age distribution of Māori women. This age-standardised percentage is the proportion of non-Māori who would be found to be screened if they had the same age distribution as the Māori women whose data are shown.

Definition of ‘screening smears’

The focus of this Audit of women with cervical cancer is to identify systemic problems in the screening programme, and so it was necessary to define what might constitute a screening smear. It seems likely that smears taken close to diagnosis were being taken as part of the diagnostic process rather than as part of routine screening, although some smears taken in this period, especially for women with stage 1A cancer, will have been routine screening smears that triggered the work-up to diagnosis. It was not possible to definitely identify from medical records which smears were taken with the intention of routine screening and which were taken as part of the investigation of symptoms or signs of malignancy. Therefore, on the advice of the Audit clinical advisors and consistent with some published studies, the Audit made an assumption that smears taken during the six months prior to diagnosis were likely to be part of the diagnostic process. The Audit has therefore defined screening smears to be those taken before the six months immediately prior to diagnosis.

It is of note that of the 285 women within the sample of 371 who had a high-grade smear in the three and a half years immediately prior to diagnosis, only 29 were taken in the six to 42 month time interval and 256 were within six months of diagnosis. This demonstrates the importance of definitions when undertaking an audit of this kind or comparing Audit data with other studies.

Screening history

Analyses of screening history include only those smears that are assumed to be ‘screening smears’, therefore exclude the six months prior to diagnosis. Three definitions of ‘screening history’ are used in this document. The definitions used are approximations of women’s histories because they can be very complex.
Smear in six to 84 months prior to diagnosis

The loosest definition of screening is ‘at least one smear in six to 84 months’ (the six and a half years before the six months immediately prior to diagnosis). This period should encompass at least two screening cycles, if smears were being taken according to the NCSP recommendations. This definition is similar to the definition of ‘participation’ used by the NCSP, which calculates the proportion of women who have a smear recorded on the NCSP in a six-year period.

Smears in six to 42 months prior to diagnosis

The second definition is ‘at least one smear in six to 42 months’ (the three-year period before the six months immediately prior to diagnosis), which uses the same time period as the definition of ‘coverage’ used by the NCSP. This period will include a previous smear from any woman who had a screen-detected cancer, where her smear leading to investigation and diagnosis was taken in the six months prior to diagnosis and so is excluded from the definition of ‘screening smear’.

Adequate frequency of screening

The third definition is intended to reflect the fact that regular smears are necessary to achieve the potential reductions in cervical cancer incidence and mortality from cervical screening. The NCSP in New Zealand recommends that the maximum interval between smears should be three years. Therefore this definition – termed ‘adequately screened’ – is the proportion of women who had no between-smear interval of more than three years in the period from six to 84 months prior to diagnosis. To fulfil this criterion a woman would have to have had at least two smears in this six and a half year period, no more than three years apart. Even this definition will overestimate the proportion of adequately screened women, since women who have any smear abnormality reported during or prior to this period should be receiving more frequent screening but would be called ‘adequate’ by this definition if they were having smears three-yearly. The complexity of the New Zealand guidelines for follow-up of abnormal smears, limitations in the completeness of the data obtained by the Audit, and inadequate data on women’s screening history prior to seven years before diagnosis prevented a determination of whether each individual woman who participated in the Audit had been screened exactly according to the guidelines.
5.3 Limitations

Whakawhäititanga

5.3.1 Causation

The key limitation of the analyses presented in this chapter is that because the data arise only from cases of cervical cancer, they do not enable the screening programme as a whole to be evaluated. This is not a limitation with respect to the purpose of this specific Audit, which aimed to identify possible weaknesses in the diagnostic pathway for women with invasive cervical cancer. Various aspects of screening and diagnosis are described in order to demonstrate the ‘pathway to diagnosis’ followed by this group of women and, where programme standards exist, to see whether the care of these women met those standards. However, the existence of any factor in this group of women does not allow the conclusion that the factor ‘caused’ cervical cancer in those for whom it occurred. Determination of the impact of any factor on progression to cancer would require comparison with an appropriately selected control group.

5.3.2 Data completeness

It was not always possible to collect all records for the seven years prior to diagnosis (see chapter 4, section 4.5.1), and some women had periods of time when they were living or travelling outside New Zealand, during which time they may have had relevant care or treatment. Records from other countries were not requested or included in the dataset for this Audit. The data are as complete and correct as possible, but some inaccuracies will exist.

5.3.3 Symptoms

Some analyses of the pathway to diagnosis of women with bleeding symptoms are included in this chapter. There are many symptoms associated with cervical cancer that are not specific to cervical cancer. The only symptoms that were considered to be sufficiently specific to cervical cancer to include in the ‘pathway to diagnosis’ were postmenopausal vaginal bleeding and postcoital vaginal bleeding. Even using this very limited definition of cervical cancer-related symptoms, it was difficult to be certain about the completeness and accuracy of these data based on the retrospective collection of information from medical records. A conservative definition was used, with bleeding identified as current at a consultation only if it was specifically noted at that consultation. If at some later consultation it was noted that there had been ‘bleeding for the last three months’, data from previous consultations during that three months were not amended to show that bleeding was occurring as it could not be determined whether the earlier health care professionals were aware of the bleeding at those consultations. In
addition, postmenopausal bleeding and postcoital bleeding were only defined as related to cervical cancer if they persisted into the six months leading up to diagnosis (although if they did persist the duration of bleeding was measured from the consultation when it was first recorded).

5.4 Results in Audit participants

Ngā hua a ngā kaiwhakauru ētīta

5.4.1 Screening coverage in Audit participants

Screening histories

As expected, women with a diagnosis of cervical cancer were poorly screened on average (Table 19). Two-thirds had had a smear in the six to 84 months prior to diagnosis, and only half had had a smear in the six to 42 months prior to diagnosis. Using the stricter definition of an adequate screening history (no between-smear interval of more than three years in the time from six to 84 months prior to diagnosis), only one-fifth of all women were adequately screened. If this strict definition is extended out to no between-smear interval of more than 39 months, thus allowing women to be three months late for a repeat smear, a third of women were adequately screened.

The definition of screened as the proportion of women who had had a smear in the six to 42 months prior to diagnosis is equivalent to the NCSP indicator ‘coverage’. Since data are available for comparison from the NCSP monitoring reports, this measure is mostly used in the description below. However, it would be preferable to be able to compare the proportions adequately screened as it would better reflect regular cervical screening.

Screening in women with different histological types and stages of disease

For all measures of screening the proportion screened was substantially higher for women with adenocarcinoma (74% screened in the six to 42 months prior to diagnosis) than for women with squamous cell carcinoma (43% screened in the six to 42 months prior to diagnosis) (Table 19). This is consistent with screening not being as effective at preventing adenocarcinoma as squamous cell carcinoma over the period prior to the presentation of cases included in this Audit.

Amongst women with squamous cell carcinoma, the proportion screened was greatest in women with stage 1A disease (54% screened in the six to 42 months prior to diagnosis), less in women with stage 1B disease (45% screened in the six to 42 months prior to diagnosis), and lowest in women with stage 2+ disease and above (25% screened in the six to 42 months prior to diagnosis). This result is as expected. Women who are being screened are more likely to have their disease detected while it is still at an early stage.
Screening in Māori and non-Māori women

The overall proportion of Māori women who were screened by any definition was similar to the overall proportion of non-Māori women screened (59% and 69% respectively) (Table 20). However, because screening coverage is higher in younger women, and the Māori women were younger, a screening programme that was equally effective in ensuring screening in both ethnic groups would result in a higher overall proportion of Māori screened. Therefore the proportion of Māori screened should be compared with the age-standardised non-Māori proportion rather than the overall non-Māori proportion. Using this comparison, the differences between the proportions of Māori and non-Māori women who were screened in the six to 84 months and in the six to 42 months prior to diagnosis is greater (59% in Māori and 74% in non-Māori in the six to 84 months, and 42% in Māori and 54% in non-Māori in the six to 42 months prior to diagnosis).

When screening in different age groups is examined (Table 21, which uses NCSP-R data for all eligible women), Māori and non-Māori patterns appear different. Amongst non-Māori women, screening coverage was best in the youngest women (20–29-year-olds) and decreased with increasing age. Amongst Māori women, those aged 20–29 and 30–39 years were similarly screened and the proportion then decreased with increasing age. At most ages Māori women were more poorly screened than non-Māori, and the disparity was greatest in the 20–29 years age group. Although numbers are small, these data suggest that Māori women with cancer, as well as being more poorly screened overall, are entering the screening programme later. This is of importance given that a single smear has low sensitivity and the incidence rate of high-grade dysplastic disease is highest in the 20–30 years age group.28

Screening and other characteristics

Women with lower income, fewer years of education and higher deprivation scores were less well screened (Table 22).

Screening in women with cancer in comparison with the general population

The NCSP reports show that coverage (the proportion of women aged 20–69 years screened in the previous 36 months) for all women, adjusted for hysterectomy, has been about 73% in recent years. The proportion of women with squamous cell carcinoma of all stages who had a smear in the six to 42 months prior to diagnosis was considerably lower than this. This observation is expected because screening is known to prevent squamous cell carcinoma.
The proportion of women with adenocarcinoma who had a smear in the six to 42 months prior to diagnosis was very similar to population coverage, consistent with the lower efficacy of cervical screening for detecting glandular abnormalities in New Zealand during the years that these women were being screened.

Because the NCSP-R ethnicity variable significantly under-identifies Māori women (see Table 11), it is not possible to compare Audit ethnic-specific proportions of women screened with NCSP IMG data.

5.4.2 Smear results in Audit participants

Original results of smears

Results of screening smears during the six to 42 months prior to diagnosis were analysed (Table 23). There are, as expected, women who have cancer despite having had smears. Sixty-one percent of women with cancer who had smears had only negative smears in this screening period (103 women), of whom 23 (22%) had more than one negative smear. Some of these women have had less than adequate screening histories, which reduces the efficacy of screening. However, some of these women will have been screened adequately and still have had only negative screening smears. Although a rapid-onset cancer of the cervix may occasionally occur, in most instances an abnormality will have existed at the time these smears were taken and so these are ‘false negative’ smears. For these women, only improvements in smear-taking or smear-reading could have increased their chance of avoiding invasive cancer, although, even so, not all would be prevented.

Women with adenocarcinoma were more likely to have had only normal smears than women with squamous cell carcinoma, consistent with the known lower sensitivity of cervical screening for glandular abnormalities.

One high-grade or two low-grade smears should have led to referral for colposcopy, followed by biopsy and treatment within six months. However, 17% of women who had smears in the six to 42 months prior to diagnosis had a high-grade smear and a further 4% had at least two low-grade smears. These women represent delays in the management of abnormal smears. Māori women were significantly more likely to have had a high-grade smear in this period than non-Māori (Risk Difference 21% (95% CI: 5% to 40%)), suggesting that inadequate follow-up of abnormal smears, in addition to inadequate screening, is a more common issue for Māori women (Table 24).
Women's smear re-read results

Smears from 178 women, originally taken between four years and six weeks prior to diagnosis, were re-read for the Audit (see chapter 6 for smear-based results). The majority of these women (160/178, 90%) had at least one smear with an original negative result included (Table 25). There are a number of points worth noting:

- One-third of women whose smears were re-read had at least one smear upgraded to high-grade.
- A quarter of those who had negative smears re-read had at least one upgraded to high-grade. These women therefore had smears that had abnormal cells present that were not detected by the laboratory that first read them.
- About half of the women who had low-grade smears re-read had at least one upgraded to high-grade. These are smears where abnormal cells were detected but under-reported on initial reading.
- The proportion of women who had smears re-read with upgraded smears was the same for women with squamous cell carcinoma and with adenocarcinoma. This suggests that, in the current environment, glandular abnormalities can be identified on smears and so adenocarcinoma potentially prevented or downstaged.
- Very few women had unsatisfactory smears re-read, and very few women had smears re-read as unsatisfactory.
- Women who had prior treatment for cervical dysplasia had smears upgraded as often as women who had no history of cervical disease.

5.4.3 Investigation and diagnosis in Audit participants

The most common ‘pathway to diagnosis’ for women in the Audit included a high-grade smear followed by colposcopy and histological diagnosis (218/371, 59%). One hundred and twenty-two women (33%) had either postmenopausal or postcoital bleeding prior to diagnosis, of whom 48 (13%) experienced these types of bleeding in the absence of a high-grade smear. In total, 274 women (74%) had a colposcopy at some time in the diagnostic work-up.

Follow-up of high-grade smears

Of women who had a high-grade smear prior to their first colposcopy in the seven-year period, 94% had this colposcopy within 12 weeks of the high-grade smear (Table 26). Women with later-stage disease were more likely to have a colposcopy within 12 weeks than women with microinvasive disease – presumably because in women with later-stage disease the high-grade smear was accompanied by
symptoms or signs that led to more urgent action. Similarly, 90% of women had a histology within 12 weeks of their first high-grade smear.

A similarly high proportion (87%) of all women who had a high-grade smear prior to diagnosis (whether or not they had a colposcopy) were diagnosed within six months of their first high-grade smear (Table 28).

Māori women were significantly more likely than non-Māori women to have their colposcopy more than 12 weeks after their high-grade smear, and to have a longer time from their high-grade smear to diagnosis (Tables 27 and 29). They were also more likely to have their first subsequent histology more than 12 weeks after their high-grade smear, although this difference did not reach statistical significance.

**Follow-up of abnormal bleeding**

A third (122) of the women whose medical records were available to the Audit had symptoms of postcoital or postmenopausal bleeding in the seven years before diagnosis, most of whom had abnormal bleeding that persisted into the six months prior to diagnosis (Table 30). The majority of these women also had a high-grade smear and so are represented in the data among all women with a high-grade smear.

About a third of women (48) with abnormal bleeding did not have a high-grade smear before diagnosis, and of these, 35% were undiagnosed at two months after their first reported episode of bleeding, with no difference between Māori and non-Māori (Table 31). Of the nine women (none Māori) undiagnosed by a year, four were diagnosed with adenocarcinoma.

Of the 17 women with bleeding undiagnosed at two months after first report, 13 had isolated postmenopausal bleeding and four isolated postcoital bleeding. These women all had at least stage 1B disease.

**Follow-up of histological abnormalities**

Amongst women with high-grade disease on the histology of a colposcopic biopsy, three-quarters were diagnosed with cancer within two months, with 7% remaining undiagnosed at six months (Tables 32 and 33). The two-month time category was used for this analysis because it is consistent with the NCSP standard for colposcopically directed treatment (and for the Audit women, the majority would have been diagnosed at the ‘treatment’ biopsy). However, two months may not represent a clinically significant delay in diagnosis, although a six-month delay almost certainly represents a clinically significant deviation. It is not clear from this Audit why there have been delays in follow-up in individual cases, which may represent patient and/or service/provider factors. The NCSP has not publicly reported against this standard, so a comparison with Audit data cannot be made.
In contrast to women with high-grade biopsies, two-thirds of women with less than high-grade disease (includes normal tissue, CIN1, HPV, inflammation and endometrial diagnoses) on the histology of colposcopic biopsy did not have a diagnosis of cancer within two months. This result demonstrates that high-grade histology facilitates expeditious diagnosis.

**Colposcopy standards**

The *Interim Operational Policy and Quality Standards*, published in October 2000, included a standard for accurate documentation of initial colposcopic findings. The standard states that documentation of colposcopic findings must include:

- visibility of the squamo-columnar junction
- presence or absence of a visible lesion
- visibility of the limits of the lesion
- colposcopic opinion regarding the abnormality and recommendation for treatment
- site of biopsy.

The NCSP has not reported against these standards for colposcopy documentation.

An analysis was undertaken of the first colposcopy performed within one year of diagnosis of cancer, if one occurred in this time period (January 1999–September 2001). Of the colposcopies where clinical notes taken at the time could be found, no statement as to the completeness of colposcopy was made in 39%. The implications of poor-quality documentation have not been analysed or reported here. However, documentation is a quality-of-care issue and should be addressed.

A colposcopic diagnosis (based on colposcopic impression alone, exclusive of biopsy results) of high-grade dysplasia (CIN2+) or cancer was made at 62% of the first colposcopies within 12 months of diagnosis (excluding colposcopies noted to be incomplete). No diagnosis was recorded in 18% of cases. A diagnosis of high-grade dysplasia was recorded more often in women with squamous cell carcinoma (67%) than in women with adenocarcinoma (35%), consistent with the known difficulty of colposcopic diagnosis of glandular lesions. This supports the NCSP recommendation that women with cytological abnormalities suggesting a high-grade glandular lesion be examined by ‘an experienced colposcopist’.  

High-grade dysplasia or cancer was diagnosed less often in microinvasive squamous cell carcinoma (65%) than for later-stage squamous cell carcinoma (70%). This is consistent with the findings of a 1998 systematic review of the quality of colposcopic impression. If biopsy results are added to colposcopic impression, including either an impression of at least high-grade disease* or a biopsy of at least high-

* High-grade disease or cancer
grade disease, then the ability of colpo-biopsy to identify high-grade disease in the presence of cancer for Audit women (sensitivity) was 88% (or 91% for women with a high-grade smear).

5.4.4 Summary of screening pathway factors

The single most important issue in women’s pathways to diagnosis is inadequate screening. One-third of women aged 20–69 had no screening smears in the six to 84 months prior to diagnosis, half had none in the six to 42 months prior to diagnosis and nearly 80% had periods of more than three years with no smear in the six to 84 months prior to diagnosis. Even this definition of ‘adequate screening’ is a conservative estimate, which probably underestimates the proportion of women who have not been screened according to NCSP recommendations. Inadequate screening was more evident amongst Māori women and women with late-stage disease.

Tables 34 and 35 summarise the factors discussed in this chapter, as a proportion of all 371 women with medical records available to the Audit. This denominator demonstrates the absolute impact of each factor on the population of women with cancer. In contrast, the denominators used previously in this chapter, and in the tables, were the number of women who were at risk of the particular factor.

Sixteen percent of women had a negative, low-grade or unsatisfactory smear upgraded by re-read to high-grade (and 11% of women had a prior negative smear upgraded to high-grade). These proportions are small in comparison to the likely effect of inadequate frequencies of or no screening of women in this Audit.

Diagnosis of cancer occurred more than six months following a high-grade smear for 9% of women in the Audit. Diagnosis more than two months following abnormal bleeding in the absence of a high-grade smear occurred for 5% of women overall. It is not clear to what extent these delays were clinically relevant and contributed to the diagnosis or stage at diagnosis for these women. However, delays following a high-grade smear occurred more frequently for Māori women than non-Māori women, suggesting that there are issues to be addressed in follow-up for Māori women.

Eight percent of women overall had a history of previous treatment for cervical dysplasia, and this was more common among Māori than non-Māori women (12% and 7%), though this difference was not statistically significant. Women with previous dysplasia are known to remain at increased risk of cervical cancer, both in the early years when persistent disease may be an issue and later when new lesions may arise. It is imperative that these women have increased surveillance, as recommended by the programme. Previous IMG reports have stated that there is a problem in achieving regular smears among these women, especially Māori and Pacific women.37
6 Results: Smear re-read

Ngā hua: Ūkuikui pānui ano

6.1 Key findings

Ngā kitenga nui

- The upgrade proportion for prior negative smears from women with cervical squamous cell carcinoma did not exceed the NCSP standard.
- ‘Missed’ unsatisfactory smears and satisfactory but limited smears (Bethesda code A2) were not associated with cancer.
- There is potential for improved detection of glandular abnormalities.

6.2 Introduction

Timatanga

This chapter reports the analysis of the re-read of 4,121 smears: 336 ‘index’ smears (smears negative for dysplasia and malignancy, low-grade smears, and unsatisfactory smears from women with cancer) and 3,785 ‘control’ smears (smears negative for dysplasia and malignancy from women without cancer).

The following Audit objective is addressed in this chapter:

Objective 4: To independently review, mimicking a screening environment, smears taken up to four years prior to the diagnosis of invasive cervical cancer and to compare review reports with original reports.

6.2.1 False negative smears

As noted previously, smears taken in women with cervical disease are not all read as abnormal. Those that are not are termed “false negatives”. False negative smears may have no abnormal cells, either because the lesion was not sampled or because no abnormal cells were present on the surface of the cervix when the smear was taken. These are ‘sampling false negatives’. The other group of false negative smears are those where abnormal cells were present on the smear but the laboratory either did not detect them or misinterpreted them as a variant of normal or a lower grade of abnormality than was actually indicated. These are ‘laboratory false negatives’.
In order to accurately identify which false negative smears were laboratory false negatives, the usual procedure is an ‘expert review’. This is a retrospective review undertaken without time constraint by one or more cytopathologists and/or cytotechnologists, in full knowledge that the smear belonged to a woman with cancer, and thus with the expectation that there should be abnormal cells. Since there is a significant subjective element in cytological prediction, this type of review is known to be more sensitive than usual screening of smears predominantly from healthy women, when there is both a time constraint and the expectation that most of the smears will be negative.

All smears taken within four years of a diagnosis of cancer and not read as high-grade are probably false negatives, since it is almost certain that a high-grade or cancerous lesion was present on the woman’s cervix during the four years prior to diagnosis. Re-reading such smears can determine the ratio of laboratory to sampling false negatives. ‘Expert review’ would be expected to identify all smears with abnormal cells present.

New Zealand cytology laboratories undertake a review of all negative smears reported in the 42 months prior to a squamous high-grade or cancer histology. This indicator for accuracy of negative cytology reports is:

‘For women with a histological diagnosis of CIN2, CIN3 (high-grade) or invasive squamous cell carcinoma, the proportion of slides originally reported within the preceding 42 months as negative which on review of slides are consistent with HSIL or ASCUS possible high-grade.’

The target for this indicator is not more than 20%. This indicator has been reported only once, and all laboratories reported that they met the target. The actual data, either by laboratory or overall, were not reported.

6.2.2 Audit re-read

Even in a high-quality screening laboratory, not all the false negative smears identified as laboratory false negatives on expert review would be read as abnormal in a usual screening situation. The Audit smear re-read was designed to assess the proportion of the false negative smears from women with cancer that could be picked up on re-read in a screening environment. This was considered to be a reasonable standard against which to assess the laboratories that originally read the smears.

In a re-read there is always a risk of false positives, where the re-read team over-interprets possibly abnormal cells on a smear. To minimise this, the re-read teams were blinded to the identity of index smears and three independent teams re-read the smears. A smear was considered ‘upgraded’ only if all teams independently reported an upgrade. Therefore the proportion upgraded by the Audit re-read would
likely be lower than the proportion upgraded by an expert review and will be lower than a re-read by only one team.

There was a difference between the smear-reporting systems in use in New Zealand and the Australian re-read laboratory with regard to the use of the term ‘satisfactory but limited’ (Bethesda A2 adequacy code). During the period that the smears were originally read, New Zealand laboratories reported a range of reasons for a smear being ‘limited’, including the presence of blood on the smear, a lack of endocervical cells, etc. A2 smears, if reported negative for dysplasia, should attract a recommendation for a repeat smear within a shorter interval than the usual screening interval for that woman. In the next version of the Bethesda coding system, due to be implemented in New Zealand in 2005, A2 will be removed from the list of adequacy codes reported by laboratories, although the limitations may still be noted as a text comment.

The Australian re-read laboratory does not use A2 codes – smears are classified as either ‘unsatisfactory’ and require an immediate repeat, or they are ‘satisfactory’ and a result is reported. The re-read enabled an assessment of whether the use of A2 codes in New Zealand was leading to women with disease being given a smear result rather than a recommendation for immediate repeat. A repeat smear would have been a potential opportunity for earlier diagnosis.

### 6.3 Index smear findings

*Ngā whakataunga ūkuikui taupū*

In total 336 index smears (smears from women with invasive cervical cancer) from 178 women were re-read; 70% of smears were not upgraded, 21% were upgraded to high-grade, and the remainder were upgraded to other results or a mixture of results. Only one index smear was upgraded to low-grade – reflecting the known greater inter-observer variation for this category, and therefore a lower probability of agreement on low-grade by all three teams. No index smears were ‘unreadable’.

Among prior negative smears from women with squamous cell carcinoma, 18% (95% CI: 12% to 24%) were upgraded to high-grade (Table 36). A similar proportion of negative smears from women with adenocarcinoma were upgraded to high-grade (22%). This shows that at least some glandular abnormalities can now be detected.

Smears originally read as low-grade were, as expected, more likely to be upgraded to high-grade than those originally read as negative (33% for squamous cell carcinoma and 46% for adenocarcinoma). These were smears where abnormal cells had been detected by the original laboratory, but their significance was under-called.
Another group of smears that may represent laboratory false negatives due to misinterpretation of abnormal cells are those negative smears reported as ‘benign cellular changes’. These comprised 10% of negative index smears, significantly more than controls (5%). As expected, a higher proportion were upgraded to high-grade than those originally read as completely ‘normal’ (35% vs 15% for index smears) (Table 37). These findings confirm that dysplastic cells are at times undercalled as ‘benign cellular changes’.

Published studies\(^{53, 54}\) have suggested that features of false negative smears prior to a diagnosis of CIN3 explain why some of these smears were not initially recognised as abnormal. In addition these features are such that these cells are likely to be repeatedly missed even with tighter laboratory quality assurance. These features include the number of abnormal cells and the proportion of abnormal to normal cells, the small size of individual abnormal cells, and the nuclear chromatin pattern. The 72 index smears upgraded to high-grade by the re-read were reviewed by the Pathology Review Team, consisting of a cytotechnologist and two pathologists – one Australian and one from New Zealand. They noted that among upgraded index smears from women with squamous cell carcinoma, fewer than 50 high-grade cells were present in 50%, bland chromatin was a feature in 22%, small cell size in 8%, and the presence of single cells in 33%. Small numbers of high-grade cells, single cells, and bland chromatin were not features of upgraded index smears among women with adenocarcinoma. Small cell size was a feature in 2/20 (10%) of cases.

### 6.4 Control smear findings

**Ngā kitenga o ngā whāū ōkuikui**

A total of 3,785 control smears (negative smears\(^*\) from women without cancer) were included in the re-read. Thirty-two smears were unreadable and thus excluded from the re-read analysis. Results from 3,753 smears were analysed, of which 96% were not upgraded, 0.3% were upgraded to high-grade, 0.2% were upgraded to low-grade, and 2.7% were regraded to unsatisfactory (Table 38). Fewer control smears were upgraded to low than to high-grade, as with index smears.

\(^*\) Negative for dysplasia or malignancy.
The proportion of control smears upgraded to high-grade is much lower than that found in previous re-reads of negative smears; for example, that undertaken in Inverclyde (2.2%) and Gisborne (2.7%). However, these re-reads were performed in very different conditions from the current re-read. Specifically, they were unblinded re-reads, undertaken as a result of established concerns about laboratory performance and women’s clinical safety. Therefore high upgrade rates might be expected because of both poor-quality original reporting and a potential tendency for the re-reading laboratories to ‘overcall’ abnormalities to ensure that women with possible disease were followed-up.

### 6.5 Regraded to ‘unsatisfactory’ and A2 smear findings

Māhititanga ki te kaore e pai me ngā kitenga ūkuikui a te A2

The proportions of negative index, low-grade index and control smears that were regraded to unsatisfactory did not differ significantly (Table 39). The proportions of negative index and control smears that had originally been read as ‘satisfactory but limited’ (A2) were not significantly different, and the proportions of index and control A2 smears regraded to ‘unsatisfactory’ were almost the same. ‘Missed’ unsatisfactory smears and A2 smears are not associated with cancer in these data.

In both index and control smears, similar proportions of A1 and A2 negative smears were upgraded to high-grade or low-grade, which does not support the idea that the use of the A2 code masks abnormalities that would otherwise lead to earlier investigation and diagnosis.

These findings suggest that the removal of the A2 code from the New Zealand reporting system is unlikely to lead to better detection of cervical dysplasia, while increasing the proportion of smears reported as ‘unsatisfactory’, with the recommendation for an immediate repeat smear. In both index and control smears, the proportion of A2 smears regraded to ‘unsatisfactory’ was about 4% higher than the proportion of A1 smears. This may give some indication of the proportion of A2 smears that would be read as unsatisfactory if the A2 code were unavailable.

The most recent IMG report shows that 17,912 smears were reported as A2 in New Zealand from January to March 2003, and 851 were reported as ‘unsatisfactory’. If the A2 code were removed from the codes available to New Zealand cytology laboratories and 4% of A2 smears were instead called ‘unsatisfactory’, this would mean that in the whole of New Zealand only about 720 extra women in this quarter would have been recalled for an immediate repeat smear.
7 Results: Accuracy of Routine Data Sources

Ngā hua: Te tika o ngā raraunga mai i ngā tikanga mahi mātāpuna

7.1 Key findings

Ngā kitenga nui

Overall

- The NCR reports accurate total figures for incident cases of invasive cervical cancer. It is therefore an accurate method of monitoring incidence and mortality from cervical cancer in New Zealand.

- Information on change in diagnosis arising from multidisciplinary meetings or histology review does not routinely reach the NCR.

- Definitions for registration of cervical cancer and date of diagnosis are not consistently applied.

- The most recent available confirmed, ethnic-specific incidence data are for 1999.

- Approximately one-quarter of women had no stage recorded on the NCR. Half of women with stage 1A disease had no stage recorded on the NCR. Therefore the NCR is currently not an adequate source of data to monitor the proportion of women with cervical cancer presenting with stage 1 disease.

- The NCSP-R is an accurate source of women’s screening histories for the monitoring of programme coverage within New Zealand.

Māori

- NCR and NCSP-R data misclassified about 20% of Māori women with cervical cancer as non-Māori. This resulted in an underestimation of the Māori incidence rate of cervical cancer.

- Using ‘any routine source’ (NCR, NCSP-R, and NHI) as the definition of ethnicity maximises the number of Māori women who are correctly identified, while misidentifying a small number of non-Māori women.

7.2 Introduction

Timatanga

In this chapter data held in routine sources on ethnicity and disease type and stage are compared with those collected by the Audit. This addresses the following Audit objectives:
Objective 3: To assess the accuracy and completeness of information on the NCSP-R and the NCR relating to women developing invasive cervical cancer.

Objective 5: To undertake a separate Māori analysis.

Data collected by the Audit were more complete and accurate than those held by the NCR and NCSP-R because the Audit contacted women, obtained medical records, and confirmed information with medical carers where appropriate. Therefore the Audit data can be used to assess the accuracy of some of the data held by these ‘routine’ sources. Data on ethnicity, incident cases of cancer, stage and histological type on the NCR and data on ethnicity and smear history on the NCSP-R were assessed.

7.3 National Cancer Registry

Rēhita Mate Pukupuku o te Motu

7.3.1 Ethnicity on the NCR

NCR documentation states that its ethnicity data are derived from information in which ‘individuals select up to three ethnic groups that they feel they belong to’. These data are then prioritised so that any person who selects Māori as one of their three ethnicities will be recorded as Māori ethnicity. However, people diagnosed with cancer are not specifically asked about their ethnicity by the NCR; the NCR is reliant on ethnicity codes recorded on the NHI database. These should have been ascertained by the health care providers who provide the information in the way described by the NCR documentation but may not have been. In addition, for women whose cancer is registered following their death, the ethnicity may have been collected differently (see section 2.4.4 National Mortality Collection).

There were insufficient women of Pacific and Asian ethnicity interviewed to enable assessment of the accuracy of those ethnicities on the routine data sources. However, Table 11 shows that 81% of women who were identified at interview as Māori were identified as Māori by the NCR, and the same proportion were identified as Māori by the NHI. The NCR data were not identical to the NHI data: of the 98 women identified as Māori by at least one of these two sources, four were identified as Māori only by the NHI and five only by the NCR. This may be partly because NHI ethnicity data can be changed at subsequent encounters with the health system and this would not alter the NCR registration information.

7.3.2 Incidence data

The NCR states that it registers cases that have been diagnosed in New Zealand, in the year of their first known diagnosis.
Registration and diagnosis of cancer

International standards for cancer registration\(^57\) state that the ‘incidence date’ (effectively the date of diagnosis) is determined by, if possible, the date of first consultation at a hospital, clinic, or institution for the cancer in question, and if that is not available then by the date of first diagnosis of the cancer by a physician or the date of the first pathology report. Because cervical cancer has a long precancerous stage, consultations and pathology reports prior to the cancer’s diagnosis are likely to exist. However, cytology is not diagnostic of cervical cancer, and smears showing changes consistent with cancer can occur in women who do not have cancer. Registration on the basis of a cervical smear consistent with cancer or of a non-definitive histology, in the absence of a clinical diagnosis of cancer, is inappropriate, as is the use of these to determine the date of diagnosis.

As noted in Table 10, some women whose information was provided to the Audit were registered as having invasive cervical cancer despite having never had an histological specimen that demonstrated invasion; for example, they may have had a smear showing changes ‘consistent with’ cancer but subsequent histology had not confirmed invasion. Others had an initial histological diagnosis of invasive cancer, but this had been downgraded on review by a pathologist expert in gynaecological cancer or a ‘tumour panel’ that included a gynaecological pathologist. There is no apparent current protocol for the feedback of the decision of a multidisciplinary group to the NCR.

Clinicians of some women whose only histology result was reported as ‘suspicious’ of cancer (or similar) confirmed that the women had not gone on to be diagnosed with cancer. The NCR registers women on the basis of some ‘inconclusive diagnoses’ in accordance with the Surveillance Epidemiology and End Results Program recommendations\(^58\). However, these recommendations also state that ‘it is the practice to accept the thinking and information about the case based on the latest or most complete information’. It seems appropriate, therefore, that women whose latest information is that they do not have cancer should not continue to be recorded on the Registry. Again, there is apparently no system in place to send this information routinely to the NCR.

Definition of appropriate registration on the NCR

In order to assess the accuracy of the number of women registered with invasive cervical cancer on the NCR, a definition of ‘appropriately registered on the NCR’ was used. All women with histologically proven invasive cervical cancer were considered to be appropriately registered irrespective of age or residence in New Zealand over the previous seven years. In addition, women with no histological information, for whom the primary site of their cancer was unclear, or whose only cervical histology did not demonstrate invasion but where the clinical information available to the Audit suggested that their clinical diagnosis was probably cervical cancer, were also considered appropriately registered. Women
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were not considered appropriate for registration if there was no indication that a clinical or histological diagnosis of primary invasive cervical cancer had been made, or if their histology was initially reported as invasive but on review was downgraded to non-invasive.

Assessing the accuracy of reported incidence rates

On 5 August 2004 the NZHIS website reported that 208 women were registered with cervical cancer in 2000 and 191 in 2001: age-standardised incidence rates of 8.7 and 8.2 per 100,000. For comparison with these figures, incidence rates were calculated from Audit data, using only women who were appropriately registered (ie, who by definition had primary invasive cervical cancer) (Table 40). These calculations were made firstly for all women using the NCR date of diagnosis to assess the effect of the inclusion in reported figures of women who were not appropriately registered with primary cervical cancer, then using the date of histological diagnosis where available. Next, incidence rates for Māori and non-Māori were calculated keeping the NCR date of diagnosis but using the Audit’s self-identified ethnicity where available, to assess the effect of the NCR’s undercounting of Māori women. Finally incidence rates were calculated using both the Audit date of diagnosis and Audit self-identified ethnicity, for the best estimates of ethnic specific incidence in 2000 and 2001.

Incidence using only women appropriately registered on the NCR

Using the NCR date of diagnosis, and including only women who were appropriately registered, the Audit identified that 200 women should have been registered in 2000 and 189 in 2001: age-standardised incidence rates of 8.4 and 8.0 per 100,000. The figures reported by the NCR thus represent an overcount by eight women (5%) in 2000 and by two (1%) in 2001, and a slight overestimate of the incidence rate.

Date of diagnosis

For most women in New Zealand, registration is made on the basis of laboratory specimen results rather than a clinician filling in a form and stating the date of clinical diagnosis. Therefore the date of a pathology specimen usually determines the date of diagnosis that is recorded on the NCR. Where inappropriate laboratory specimens (see above) are used to determine registration of women who do have cancer, the date of diagnosis recorded will be incorrect.

In the women included in the Audit, although for the majority of women the date of diagnosis recorded by the NCR was within a week of that determined by the Audit, for a number of women the NCR had used a range of dates, including in some cases the date of a high-grade or cancer smear, or an earlier non-invasive or ‘suspicious’ histology, as the date of diagnosis.
Using the date of the first invasive histology, where present, and the date reported on the NCR where no histology was available, the Audit identified 196 women who were appropriate for registration in 2000 and 192 in 2001, giving age-standardised rates of 8.2 per 100,000 and 8.1 per 100,000.

**Ethnic specific incidence rates**

It was not possible to directly compare the ethnic-specific registration data reported by the NCR with that ascertained by the Audit, as the most recent published data are from 1999. However, the numbers of cases of Māori and non-Māori women who were appropriately registered on the NCR (as defined above) were calculated, using self-identification of ethnicity where available, and ‘Māori on at least one routine source’ if not, and compared with the figures obtained using the NCR ethnicity variable (Table 40).

These data show that, while slightly overestimating the overall incidence as shown above, the NCR data underestimate the number of Māori cases. Including only women appropriately registered, over the years 2000 to 2001 the impact of the inaccuracy of the NCR ethnicity data is to undercount Māori cases by 13% (10 cases), and underestimate the age-standardised incidence rate by 1.8 per 100,000 in each year.

Using the Audit ethnicity and the Audit date of diagnosis, where available, the age-standardised incidence for Māori women was 14.9 per 100,000 and that for non-Māori women 7.2 per 100,000 in 2000. In 2001 the rates were 13.6 per 100,000 and 7.5 per 100,000, respectively. For Māori incidence to fall from the average of the 2000 and 2001 rates (14.3) to the 2005 target (11.0) would require a 22% reduction over four years.

**7.3.3 Stage on NCR**

When women’s data were first supplied to the Audit, which was always at least six months after diagnosis, 42% of NCR records had missing data on the stage. By the date that the last data update from the NCR was received (December 2003), this had reduced to 26% for both Māori and non-Māori women. Accuracy of stage for the stage groups 1A, 1B, and 2+ is shown in Table 41. The majority of women (72%) were in the same stage group using stage recorded on the NCR as they were using stage ascertained by the Audit, including 15 women who were unstaged by both the NCR and the Audit. Where both sources had a stage recorded, the group was the same for 94% of women.

For women with stage 1B and 2+ disease, the NCR stage group agreed with that ascertained by the Audit in over 80% of cases. Where it did not agree, this was due to missing stage data on the NCR in about 10% of cases. Women with stage 1A disease were able to be completely ascertained by the Audit because this diagnosis is made on histology, and therefore all women included in the Audit with 1A disease had histological specimen results. However, only 49% of the women with confirmed stage 1A disease had any stage recorded on the NCR.
7.3.4 Histological type on NCR

The histological type recorded by the NCR agreed with that ascertained by the Audit for 97% of women (Table 42). Most of the disagreements occurred where one source had recorded “adenosquamous” and the other had either adenocarcinoma or squamous cell carcinoma only. One reason for these disagreements may be that in some cases an initial report was issued, but on review by a multidisciplinary meeting or an expert gynaecological pathologist the histological type was changed. This information was sometimes, but not always, conveyed to the NCR (the hard copies of histological results held by the NCR were forwarded to the Audit, and these did not always include revised reports where a change had been made).

7.4 National Cervical Screening Programme Register

Hōtaka Taiawa Arai o te Motu

7.4.1 Ethnicity on the NCSP-R

Seventeen percent of women who identified as Māori at interview were not identified as Māori by the NCSP (Table 11). If this also occurs for women on the NCSP-R who do not have cancer, then Māori coverage is actually better than that reported in the NCSP monitoring reports.

It is also of note that the NCSP-R records only one ethnic group. This is inconsistent with other official datasets such as the NHI and with current protocols for the collection of ethnic data.1*

7.4.2 Smear history from the NCSP-R

The NCSP-R had fewer smears than were able to be found from medical records for 26 women, including nine who had no smears on the NCSP-R but between one and five in their records (Table 43). It was not possible to determine from the medical records of these women whether their smears had been formally ‘opted off’ the NCSP-R (ie, not sent to the NCSP-R at the woman’s request). Ninety-three percent of women had the same number of smears on the NCSP-R as in their records, and this did not significantly differ between Māori and non-Māori.

* These protocols were not operational at the time the data analysed in this Audit were collected.
In the analyses of women’s screening histories in this report (chapter 5), several ways of defining the extent of screening are used. These definitions exclude smears in the six months prior to a diagnosis of cancer, which have been assumed to be smears taken in the work up to cancer rather than screening smears. The definitions of screening are:

- any smears in the six to 84 months prior to diagnosis (a six and a half year period)
- any smears in the six to 42 months prior to diagnosis (a three year period)
- no between-smear interval of more than three years in the time from six to 84 months prior to diagnosis.

Each of these definitions was calculated using only the data available on the NCSP-R and then using all the data available to the Audit (from medical records and the NCSP-R). The proportion of women ‘screened’ by any of these definitions was only slightly higher when NCSP-R data were augmented by data available from medical records (Table 44).
8 Discussion of Audit Findings and Recommendations

Kōrero e pā ana ki ngā kitenga mai i te ôtita me ngā tūtohutanga

In this chapter the key findings of the Audit and their implications are discussed and Audit recommendations given. As noted in the background to this report, some NCSP system changes have been made or planned since September 2002 when the last of the Audit participant’s cancer was diagnosed. The recommendations below, however, are based on the Audit findings. Some of the system changes, when fully implemented, may go some way to addressing some of the Audit recommendations. Monitoring of their impact will demonstrate their effectiveness.

8.1 Overview

Tiro whānui

The New Zealand Cervical Cancer Audit compiled and analysed the screening histories of 371 women diagnosed with invasive cervical cancer between 1 January 2000 and 30 September 2002 and re-read over 4000 cervical smears, both from women with cancer and from women who do not have cancer.

The Audit found that the NCSP met the 2005 cervical cancer incidence target in 2000 and that more than 70% of women who consented to participate in the Audit were stage 1 at diagnosis, an internationally accepted measure of a good quality screening programme. Evidence of systemic under-reporting of high-grade cervical smears from women with invasive squamous cervical cancer was not found. The Audit also found that the majority of women, once they had an abnormal smear or symptoms relating to cervical cancer, were investigated and diagnosed within acceptable timeframes. Data from the NCSP-R provided accurate estimates of the proportion of these women who had been screened prior to their diagnosis, and the incidence rates for cervical cancer reported by the NCR for all women in 2000 and 2001 were substantially accurate.

However, as with audits conducted in other jurisdictions, the overriding finding from this Audit is that, by any definition used, women with invasive cervical cancer were either not screened at all or screened with inadequate frequency. For example, whilst two-thirds of women had had a smear in the six to 84 months prior to their diagnosis, only 50% had had a smear in the preceding six to 42 months. When the Audit definition of ‘adequately screened’ was used, only one-fifth of women met this criterion. Māori women, older women and women on lower incomes, living in more socioeconomically deprived
areas, and with fewer years of education, were less well screened in the years prior to diagnosis with invasive cervical cancer.

These findings are important because although cervical screening prevents cervical cancer, to be able to fully benefit from cervical screening women require regular smear tests. Being under-screened potentially denied many women with invasive cervical cancer the opportunity to have their cervical abnormalities diagnosed before they became cancerous, or before cancer was at an advanced stage.

The Audit also found that the NCR held incomplete stage information. Whilst the Audit was able to ascertain whether the NCSP stage target was met for women with invasive cervical cancer participating in the Audit, it could not determine this for those women with invasive cervical cancer who were ineligible or did not consent to participate in the Audit. For women with invasive cervical cancer, a significant level of misclassification of ethnicity was found on both the NCR and the NCSP-R. The Audit cannot determine whether this misclassification is more generalised on both registers, but there is a high probability that it is.

8.2 Māori women

Wāhine Māori

The Audit has documented differences in the experience of Māori and non-Māori women across a range of aspects of the NCSP. These differences were consistently in the direction of poorer care for Māori women, with lower proportions screened and longer intervals from high-grade smear to colposcopy and diagnosis. As noted previously, differences in care between ethnic groups may be masked by studying only women with cancer, all of whom are more likely than women without cancer to have experiences such as poor screening or management delays. Therefore, differences between Māori and non-Māori women found by the Audit suggest that even greater differences may exist for women in the NCSP as a whole.

The rates of screening of Māori women found in this Audit were higher than those reported in a 1993 study of 46 Māori women with cervical cancer, of whom only 22 (46%) had ever been screened and 11 (24%) had been screened in the three years prior to diagnosis. In comparison 42% of Māori women in the Audit had a screening smear in the three years from six to 42 months prior to diagnosis, indicating that there has been improvement in the screening rates in Māori women over the last 10 years. Nonetheless, the single most important factor noted in the Audit for Māori women is the failure of the NCSP to reach a high proportion of Māori women and effectively engage them with the programme so that they are adequately screened. Also, differences in Māori and non-Māori screening by age group
have implications for strategies to improve screening, which needs to be appropriate for young Māori women.

Māori women were more likely to experience longer waits for management along the screening pathway. The clinical implications of these are not clear, but the consistent delay for Māori women compared to non-Māori is of concern in an area where the consequence may be a higher stage at diagnosis, which has an impact on the effectiveness of treatment. Māori women were more often outside NCSP targets for follow-up for time between first high-grade smear and colposcopy, first high-grade smear and diagnosis, and between high-grade biopsy and diagnosis. This Audit is unable to identify why delays occurred. For example, delays between first high-grade smear and colposcopy may occur because of delayed referral by smear-taker to colposcopy provider, delayed response by provider, or patient-related factors.

The disparities identified by the Audit probably contribute to the slightly higher proportion of Māori women who have later stage disease at diagnosis and to the continuing disparities between Māori and non-Māori in both the incidence of and mortality from cervical cancer. However, the differences in stage do not explain why the disparity in mortality (Māori mortality is four times that of non-Māori) is so much greater than the disparity in incidence (Māori incidence is twice that of non-Māori). This is consistent with the findings of a study being carried out by the Centre for Public Health of Massey University, which has found that most of the difference between Māori and non-Māori in cervical cancer mortality is not accounted for by stage at diagnosis and is therefore likely to be due to post diagnosis factors such as differences in treatment or differences in the rate of progression of disease.*

The results of this Audit support other work demonstrating that Māori experience of the health system differs from that of non-Māori. For example it has been demonstrated that Māori are significantly less likely to receive interventions for ischaemic heart disease than non-Māori despite the excess burden of mortality and morbidity experienced by Māori.59

Pathways of care are complex, and problems along pathways may occur at a number of different points or sites, and/or during a range of processes. Further investigation of the extent of the problem at different points along the pathway of care for cervical cancer prevention and management is required. However, in the area of ensuring regular screening, opportunities already exist for the NCSP to implement change and improve responsiveness to, and outcomes for, Māori women. Although evaluation of health services and programmes is limited, it is clear that ensuring programmes and services are appropriate and acceptable for Māori is associated with better outcomes. For example, Te Whānau o Waipareira was able to significantly improve preschool routine immunisation coverage by instituting a service that met these criteria.60

* Personal communication M. Jeffreys, October 2004.
During planning for programme changes and future research to reduce disparities between Māori and non-Māori, the temptation to locate the cause of Māori women’s differing experience solely within the behaviour and attitudes of the women themselves must be resisted. While new approaches to improving screening must be designed in collaboration with Māori women and giving consideration to their attitudes and other cultural determinants of behaviour, identifying and remediying deficits within services is likely to be more effective in reducing disparities than solely attempting to change women’s attitudes.61

It is imperative that future changes do not increase disparities. Interventions aimed at improving the health of the whole population can, at least initially, increase disparities.62, 63 In contrast, achievement of NCSP incidence and mortality targets, while not eliminating the difference between Māori and non-Māori rates, would reduce the disparity.*

8.3 Levels of regular screening

Ngā taumata o te ārai rite tonu

8.3.1 Women with cancer

The most important issue in women’s pathways to diagnosis identified by this Audit was under-screening, and Māori women, older women, women with low income, women living in high deprivation areas and women with fewer years of education were particularly poorly screened.

The New Zealand NCSP recommends three-yearly smears for women with no prior history of abnormal smears. However, only half the women with cancer in the Audit had a screening smear in the six to 42 months prior to diagnosis. This is in contrast with the 73% of all New Zealand women (hysterectomy adjusted) reported by the NCSP-R to have had a smear in the three years before 2001 and with the NCSP target of 85% (hysterectomy adjusted). In addition, only a fifth of women with cancer had no between-smear interval of more than three years in their screening history.

The observation that women on the NCSP-R are better screened than women with cancer is expected because screening is known to prevent cancer.

8.3.2 Women with smears recorded on the NCSP-R

Despite having an organised screening programme in New Zealand for over a decade, during which time reductions in incidence and mortality have occurred, the proportion of women having a smear in three years has never met the programme’s targets, and disparities between Māori and non-Māori women exist in incidence, mortality and screening.

In early quarterly reports of the NCSP IMG and in the Annual Monitoring Report 2001, the IMG recommended that the NCSP should be improving coverage and participation, especially in Māori, Pacific, and older women. The Audit results, demonstrating low overall rates of screening of women with cancer, and squamous cancer in particular, emphasise that lack of screening is an important factor in the incidence of squamous cervical cancer and provide further support for the IMG recommendations.

The proportion of women having a smear in three years has not been reported publicly for any years since 2001, but the Audit team has been advised that in September 2004 the figure for the proportion of all women who had a smear in the previous three years was 73%* (hysterectomy adjusted) – the same proportion as in 2001. Improvement in the effectiveness of the NCSP in achieving high levels of regular screening – and thus in incidence, mortality and disparities – will require some changes in the way the NCSP operates.

8.3.3 Achieving high levels of regular screening

The organisational design of a screening programme is considered a major determinant of its effectiveness. It is difficult to be sure which aspects of the NCSP have been most effective in achieving the reductions in incidence and mortality that have occurred and which most require improvement.

Enrolment on the NCSP currently occurs when a woman has her first smear or other cervical pathology specimen and the result is entered on the NCSP-R. The responsibility for inviting a woman for her first smear rests with her primary care provider, if she has one, and there is no process for ensuring that women who have not had a smear by a certain age are invited to have one. Recall for subsequent smears is initially the smear-taker’s responsibility, and the NCSP-R provides a back-up system of reminders if a woman does not have a smear reported within six months of the date it was due. For these women the NCSP is therefore effectively providing at best a system of smears every three and a half years.

* Personal communication H. Lewis, October 2004.
Although infrequent smears offer women some protection from cervical cancer, the full benefit of cervical screening only accrues to women who have smears regularly. To ensure that a high proportion of eligible women have regular smears, a cervical screening programme must both recruit women to the programme and then ensure that they are recalled for smears at appropriate intervals. Low levels of screening in women with cancer and sub-optimal levels of screening in New Zealand women in general are likely to reflect inadequacies in both these steps to regular screening.

At the system level, better approaches are required to ensure that all eligible women are invited to have their first smear and are then recalled at the appropriate interval. These should be nationally consistent, so that women receive the same standards of invitation and recall irrespective of where they live and what kind of primary health care services, if any, they usually attend. Recall should be proactive to ensure that smears are taken at the appropriate interval. Since this interval depends on past smear results and treatment, the organisation performing the recall must have access to records of these and must use the national guidelines for follow-up of abnormal smears to determine the appropriate interval.

One approach to ensuring national consistency that has achieved high levels of screening in organised programmes internationally is a population based, centralised invitation and recall system. This approach uses a register of all eligible women in the population to invite women for screening and to ensure they are recalled at the appropriate time for their next smear. The establishment of a population-based system for inviting and recalling women for screening in New Zealand has been recommended by a number of authorities over the past two decades. The findings of this Audit give further support to these recommendations.

A national population register is likely to be the most effective basis for ensuring that each woman is invited for her first smear when she reaches the eligible age (currently 20 years) and for inviting women of other ages who are currently unscreened. A population based register also enables identification of the characteristics of unscreened women so that strategies to improve screening can be appropriately targeted. Once women have had a smear, and if they do not decide to cancel their enrolment on the NCSP, then the NCSP-R could form the basis for ensuring proactive recall, whether that recall was actually undertaken by smear-takers or by the NCSP-R itself. The complexity of the algorithm for integrating the multipart Bethesda smear reporting system with the woman’s past smear history and to determine the appropriate interval for the next smear is a good reason for using the NCSP-R to perform this task. The NCSP should consider assisting smear-takers whose patients cancel their enrolment in the NCSP to determine the recall interval by producing a simplified explanation for their use.
In addition, there are a number of individual level strategies to improve recruitment to cervical screening and the proportion of women having regular smears, such as reminder letters and telephone calls. Some of these are already used by some smear-takers and the NCSP but could be used more widely. Innovative projects to improve screening uptake, such as providing free smear-taking or smear-taking in places or at times preferred by women should be evaluated and, if found to be effective, extended.

8.4 Recommendations for achieving high levels of regular screening

E taea ai ngā taumata tiketike o te ārairite tonu

The Audit recommends that the NCSP develops and implements strategies to increase the proportion of women who are regularly screened, and that these strategies should:

- include systems to identify and invite unscreened women for screening
- include systems to ensure that women are recalled proactively so that most women have their smears at the recommended interval
- prioritise Māori women
- not increase disparities between Māori and non-Māori women
- prioritise other groups of women at risk of not being screened
- be evidence-based and consider measures to improve individual access to screening, such as the removal of financial and practical barriers.

8.4.1 Identification and invitation

The Audit recommends that:

1. the NCSP utilises a national, population-based database along with the NCSP-R for identifying unscreened and under-screened women aged 20–69 years and inviting them to have a smear. Along with the introduction of the new legislation, a staged process of identifying and inviting all women who have not had a smear for more than three years would help to give every New Zealand woman the opportunity to be enrolled in the NCSP. In addition, as women reach the eligible age for screening, this population-based system should be used to invite them for their first smear. It could also be used to identify unscreened or under-screened groups to inform the design of interventions to improve screening in those groups.
The process for establishing this system should take into account other potential successful models, utilise a database that most women nationally are listed on, and be acceptable, effective and appropriate for Māori women and other women who are currently less screened. The NHI is likely to be the most appropriate population database, and impediments to its utilisation need to be resolved as soon as possible.

8.4.2 Recall

The Audit recommends that:

2. the NCSP 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 NCSP/NCSP-R and smear-takers
   • clearly identify the organisation responsible for determining the recall interval for women. (For women who are enrolled in the NCSP, the NCSP-R 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 NCSP, 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 NCSP screening interval (in addition the NCSP-R may still provide a fail-safe mechanism for women who do not respond to the proactive system).

3. the NCSP explores how linkages between the NCSP-R, NHI, and primary health organisation registers can be made to ensure that those responsible for recalling women have their most up-to-date contact details.

4. the NCSP ensures that women who cancel their enrolment in the NCSP 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.
8.4.3 Reducing barriers to screening

The Audit recommends that:

5. the NCSP 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.

8.4.4 Reducing disparities

The Audit recommends that:

6. the NCSP 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.

8.5 Smear reading

Pānui i ngā ūkūkū

8.5.1 Under-reporting by original laboratories

The Audit devised a smear re-read methodology that would determine whether or not prior negative smears from women with invasive cancer would be read differently under normal screening conditions in a high-quality laboratory. It was considered that this would provide more useful information to the NCSP regarding the overall quality of smear reading in New Zealand than using expert review to determine the laboratory false negative rate in women with invasive cervical cancer.

In a re-read, even where the reading teams are blinded as to the identity of the smears, there is always concern that the teams may have an increased sensitivity to abnormalities and therefore ‘over-call’ them, resulting in some of the upgraded smears being positives – ie, smears called abnormal that under normal circumstances would not have been called abnormal. The requirement for three teams to independently upgrade a smear in order for it to be called ‘upgraded’ by the Audit minimised the probability of over-calling. This also means that the upgrade proportion reported is lower than the proportion that would have been obtained if only one team had been used for the re-read.

The proportion of index smears upgraded to high-grade by the re-read did not breach the threshold of 20%. The Audit did not identify systemic under-reporting of high-grade abnormalities amongst women with invasive squamous cell carcinoma diagnosed between 1 January 2000 and 30 September 2002. The number of smears re-read was such that systemic under-reporting cannot be completely ruled out.
However, the upper limit of the confidence interval (24%) suggests that if a problem had existed, it would not have been of a serious magnitude.

A small proportion (0.3%) of control smears (negative smears from women not known to have cancer) was upgraded to high-grade by the re-read. It was expected that some control smears would be upgraded, but the Audit was unable to determine the level of control smear upgrading that would indicate unacceptable under-reporting by the original laboratories. However, the Audit considers that the proportion upgraded is not clear evidence of systemic under-reporting during the time these smears were originally read.

As noted in chapter 3 section 3.8 of this report, this Audit could not definitively determine whether systemic under-reporting of high-grade smears had occurred in New Zealand. However, the results of the smear re-read do not support the hypothesis that serious systemic under-reporting of high-grade abnormalities occurred in the New Zealand NCSP between 1996 and 2002. In addition it should be noted that the proportion of smears reported as high-grade (excluding ASCUS-H) increased from 0.86% in 1996 to 1.07% in 2002/2003 without any reduction in the positive predictive value (the proportion of women with high-grade smears who had high-grade disease confirmed on histology). This suggests that laboratories have become more sensitive to high-grade abnormalities since 1996. The Audit was unable to identify, from the data available, whether problems existed in any individual laboratory.

### 8.5.2 Contribution of false negative smears to the incidence of cervical cancer

False negative smears are not uncommon prior to the diagnosis of cervical cancer because of the fairly low sensitivity of a single smear. Of women in the Audit who had had a screening smear in the six to 42 months prior to diagnosis, 61% had only negative smears, consistent with the 59% of women with only normal smears in the six to 36 months prior to diagnosis reported in a study from the USA.45

Missed high-grade smears (ie, false negatives) are currently a minor contributor to the incidence of cervical cancer in New Zealand, compared with the levels of inadequate screening. Although a third of women with smears re-read had a smear upgraded to high-grade, the proportion of all women with cervical cancer who had a smear upgraded to high-grade on re-read was much lower, at 16%. Continued attention to laboratory quality assurance, and improvements in smear-taking, may reduce the proportion of women experiencing false negative smears, but some high-grade disease will not be detected even with the highest quality smear-taking and reading, and not all cancers can be prevented. For individual

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* If levels of regular screening increase in the eligible population, then false negatives contribute to a greater proportion of cases of cervical cancer.
women though, the most effective way of mitigating the consequences of false negative smears and reducing their risk of cervical cancer is to have regular smears at the recommended interval.

Consistent with the reduced ability of smears to detect pre-invasive glandular disease, more women with adenocarcinoma had been screened and had only normal smears than women with squamous cell carcinoma. The proportion of smears from women with adenocarcinoma that were upgraded on re-read was the same as for those from women with squamous cell carcinoma. However, the greater proportion of women with adenocarcinoma who had been screened meant that overall prior negative smears (both sampling and laboratory ‘false negatives’) were a more frequent factor in the pathway to diagnosis for women with adenocarcinoma than for women with squamous cell carcinoma. The NCSP was designed to prevent squamous cell cancer, but recent reports suggest that with current knowledge it may be possible to improve detection of pre-invasive glandular lesions of the cervix. Educational initiatives to train New Zealand screening staff to recognise more recently described glandular precursor lesions should have the potential to reduce the incidence of and mortality from adenocarcinoma.

8.5.3 Current laboratory quality assurance processes

The overall proportion of Audit index smears re-read as high-grade was under, but close to, the threshold. Individual laboratory results always vary around an average, but when laboratories reported their results for the prior negative review indicator for 2001, all laboratories reported individually meeting the target of fewer than 20% negative smears upgraded to high-grade. The Audit cannot determine whether the laboratory prior negative review results are appropriate for a number of reasons. These include the fact that no methodology is specified for the laboratory prior negative review (although it is highly unlikely that any laboratory uses the conservative methodology used by the Audit) and the Audit included only women with cancer whereas laboratories review prior negative smears from women with high-grade pre cancer as well as cancer.

Prior negative review provides a good opportunity for laboratories to review their previous work and learn from any missed abnormalities. The results of such review are also a very important aspect of monitoring laboratory quality. However, the best value from such an exercise, for both purposes, is likely to be gained if there is some external input into the review. If staff in a laboratory missed or misinterpreted abnormal cells when a smear was first read, they are presumably more likely to miss or misinterpret them when they examine the smear a second time. In addition, if reviews are being performed in different laboratories using different methodologies, then their utility for monitoring laboratory quality is limited.
The NCSP should specify educational and productive approaches to the review of prior negative smears, with the following characteristics:

- A standard review methodology for use by laboratories
- Collaborative review with input from recognised ‘experts’ or staff from other laboratories in order to enhance learning opportunities (rather than a laboratory performing the entire review itself)
- Review results to be submitted by the laboratory to the NCSP for programme monitoring purposes

If any concerns about laboratory quality then still exist, the prior negative smears reviewed by the original reading laboratory could be reviewed again by laboratory accreditation assessors, or alternatively by an external laboratory using an agreed standard methodology and a process for constructive discussion with cytology staff about identified laboratory false negatives.

8.6 Recommendations for smear reading

Ngā tūtohutanga pānui i ngā ākuikui

8.6.1 Laboratory quality assurance

The Audit recommends that:

7. the NCSP continues to ensure laboratory operational policies and quality standards are current and regular provider audits occur, and to support cytology workforce development initiatives.

8. the NCSP and laboratories collaborate to review the approach to the review of negative smears taken within the previous 42 months from 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.

9. the NCSP reviews the upper limit for the prior negative review target, in the 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.

10. while acknowledging that the NCSP was established to detect the precursors of squamous cell carcinoma, the NCSP and laboratories continue educational activities to improve the detection of glandular abnormalities in cervical smears within New Zealand laboratories.
8.6.2 **Information for women**

The Audit recommends that:

11. 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.

8.7 **Investigation of abnormal smears and bleeding**

*Ngā tūtoruanga mo ngā āta titiro i ngā ōkuikei me ngā toto rereke*

8.7.1 **Investigation and diagnosis**

The Audit has attempted to identify systemic issues in the follow-up of women with a high-grade smear and abnormal bleeding. However, clear conclusions with regard to women’s follow-up were difficult to draw for a number of reasons. These include a lack of data on the details of referral, appointments and attendance at follow-up (in part due to the retrospective nature of this Audit), incomplete clinical documentation and the need to examine systemic issues rather than do individual case reviews. Rather than attempting to characterise the complete pathway of investigation for each woman, analyses were undertaken that represent segments of the investigative pathway – the time intervals from high-grade smear to colposcopy, biopsy and diagnosis of cancer; from biopsy to diagnosis; and from first report of bleeding to diagnosis of cancer.

Overall, almost all women (over 90%) in the Audit who had a high-grade smear were investigated promptly, and a high proportion (87%) of them were diagnosed with cancer within six months of the high-grade smear. However, Māori women experienced longer intervals to investigation and diagnosis. Services need to review their provision of care to Māori women.

A third of women had some abnormal bleeding prior to diagnosis, most of whom (61%) also had a high-grade smear prior to diagnosis. However, 17 (35%) women with abnormal vaginal bleeding (13 with postmenopausal bleeding and four with postcoital bleeding) and no high-grade smear had not been diagnosed by two months after the first episode of bleeding. These women all had frankly invasive disease at diagnosis and so their cancers may have been detectable on examination. Cervical cancer is an infrequent diagnosis in women with postmenopausal bleeding, but it should be considered early in investigation.
Over the time that the IMG published monitoring reports, the proportion of women on the NCSP-R who have histology reported within 12 weeks of a high-grade smear has remained constant at about 77%, well below the target. The NCSP IMG has been recommending since their second report, published in October 2001,74 that the NCSP investigate the reasons for the failure to meet this target, noting that this is especially a problem for Māori and Pacific women. The Annual Monitoring Report 200128 reports the findings of a review of women with no histology report on the NCSP within a year of a high-grade smear. This found that all women had been followed up but that there had been delays in obtaining colposcopy, deferrals due to medical reasons, delays in forwarding of histology results by laboratories, and in some cases no histology had been taken. No specific findings were presented for Māori and Pacific women. It is encouraging to see that a greater proportion of women who have cancer have timely follow-up of a high-grade smear than the population in general. However, the NCSP has some way to go in ensuring timely follow-up for all women with high-grade smears, and the monitoring data as well as the Audit data show that there remains a need to determine why follow-up times differ for Māori and Pacific women.

8.7.2 Colposcopy

The Health (National Cervical Screening Programme) Amendment Act 2004 confers on the NCSP the power to collect information about colposcopy performance and results, and the NCSP is currently planning the data that will be collected.* Completeness of colposcopy was not recorded in 39%, and diagnosis in 18%, of colposcopies on Audit women within one year of diagnosis. These findings suggest that the NCSP will need to work with colposcopists to ensure that documentation improves sufficiently to enable collection of good quality monitoring data.

Even within a year prior to the diagnosis of cancer, colposcopy and biopsy does not identify high-grade disease in all women (88% of colposcopies within a year of cancer diagnosis identified high-grade disease or cancer). Guidelines for management of abnormal cytology need to take into account that colposcopy and biopsy can not definitively rule out high-grade disease.

* Personal communication Dr Hazel Lewis, Clinical Leader, NCSP, October 2004.
8.8 Recommendations for investigation of abnormal smears and bleeding

Ngā tūtohutanga mo ngā āta titiro i ngā ūkukuii me ngā toto rereke

The Audit recommends that:

12. when defining the colposcopy data elements that the NCSP 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 the colposcopy, the colposcopic impression and biopsy result and plans for follow-up.

13. the NCSP 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.

14. where significant ethnic disparities in times to investigation or diagnosis are found, either between or within clinics, the NCSP works with clinic staff to establish reasons for the disparities and strategies for addressing them.

8.9 Routine data quality

Raraunga pai mai i ngā tikanga mahi

8.9.1 Accuracy and completeness of information on the NCR relating to women developing invasive cervical cancer

The NCR reports accurate total figures for incident cases of invasive cervical cancer. However, some women with records on the NCR should not be registered as having primary cervical cancer, either because it was not confirmed on histology, was subsequently downstaged at a multidisciplinary meeting, or the primary was not cervical. In addition some of the details of registered cases are incomplete or inaccurate. The impact of this is most profound on stage information and on ethnic-specific rates, although dates of diagnosis are also in some cases inaccurate.

The process for determining eligibility for the Audit from the information provided by the NCR was time-consuming and required contact with women’s clinicians in 10% of cases. While the NCR does have its own checking processes, which continued after data were initially supplied to the Audit, some of
this checking should have been performed soon after the registration was received. In particular, scrutiny of histological results by a pathologist and follow-up of ‘suspicious’ results with clinicians would prevent a number of inappropriate registrations. There is currently no process in place whereby changes in diagnosis are communicated with the NCR, and this would also assist with preventing inappropriate registrations.

Staging information is absent for such a high proportion of women registered with invasive cervical cancer on the NCR that the stage distribution cannot be monitored using NCR data. This does not seem to have altered significantly since the 1996 NCSP policy document was published, in which it notes on page seven that in 1993 31% of cervical cancer registrations were unstaged on the NCR. The stage distribution is an important indicator of programme effectiveness and therefore stage needs to be better ascertained by the NCR. In addition, lack of improvement in this area will affect the efficiency with which future audits can be carried out, despite the provisions of the recent Health (National Cervical Screening Programme) Amendment Act 2004, because reference to clinical notes will be necessary to ascertain stage for a significant proportion of women (where stage was present on the NCR, it was sufficiently accurate that it would need to be sought only for women where it is absent on the NCR).

The staging information collected by the Audit was available in the clinical notes and should be able to be ascertained by the NCR under its statutory power to obtain all the information necessary to complete registrations. Stage 1A, which is the most incompletely recorded on the NCR, is determined from histology. Although a clinical examination at diagnosis that indicated a higher stage would override the histology result, scrutiny of histological results by a pathologist would identify cases likely to be stage 1A and the NCR could confirm this with the clinician.

Ethnicity data must be accurate in order to monitor the health and access to health services of different ethnic groups, and processes for collecting ethnicity data should be consistent with the Ministry of Health recommendations across the whole health sector. Māori women were significantly under-identified in both NHI and NCR data on women with cancer, and strategies to improve this situation are required. The NZHIS is implementing a training programme for ethnicity collectors in DHBs and PHOs, that should improve the ethnic coding of all health data, in particular the NHI database. The Audit endorses this initiative. Since the NHI is widely used in the health sector, it is appropriate that the NZHIS focuses its efforts on its accuracy. However, it will be necessary to evaluate the impact of the project on the accuracy of ethnic-specific NCR data for cervical cancer, where Māori incidence and mortality are of concern and specific Māori targets have been set.
8.9.2 **Accuracy and completeness of information on the NCSP-R relating to women developing invasive cervical cancer**

Extra smears were found by searching medical records for only seven percent of those women whose medical records were available to the Audit, and the proportion of women screened (by any of the definitions used) was almost the same when calculated from the NCSP-R as when all smears, including those found only in medical notes, were included. The NCSP-R is therefore an accurate source of women’s screening histories, at least among women with cervical cancer. Women who participated in the Audit are a small proportion of the women on the NCSP-R, but there is no reason to believe that the NCSP-R would be any less accurate for women in general than for women with cancer.

A significant proportion (19%) of Māori women had misclassified ethnicity; therefore the accuracy of ethnicity indicators on the NCSP-R for women with invasive cervical cancer is inadequate. The NCSP-R is a large operational data set used for both clinical management and programme monitoring purposes. It relies on correct completion of the ethnicity field on the NCSP cytology request form or on information contained on the NHI. If the misclassification of ethnicity that the Audit has found amongst women with invasive cervical cancer is also present amongst women enrolled on the NCSP-R who do not have cervical cancer (and it is likely that it is), then this will have an impact on monitoring information (e.g., coverage amongst Māori women will be underestimated) and operational planning. To improve the accuracy of the request for ethnic information, smear-takers need to be familiar with recommended best practice for collecting ethnicity data.¹

The most accurate way of identifying all Māori women from routine data sources was to define ‘Māori’ as ‘Māori on at least one routine data source’. This enabled 97% of those women identifying as Māori at interview to be correctly identified using routine information sources and misclassified only two percent of non-Māori women as Māori. Until ethnicity data collection from cytology request forms is complete and accurate the NCSP-R could improve its own data by comparing it with those held by the NCR and the NHI databases (electoral roll data are not available to the NCSP-R) and use the definition of ‘Māori on any source’. This would give more accurate ethnicity data in the interim.
8.10  Recommendations for routine data quality

Ngā tūtohutanga mo Raraunga pai mai i ngā tikanga mahi

8.10.1 Ethnicity information

The Audit recommends that:

15. the NZHIS 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*,¹ published by the Ministry of Health in 2004.

16. 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 NCR and NCSP-R.

17. if evaluation shows that Māori cervical cancer incidence and mortality remain underestimated by the NCR data, the NCR should consider other avenues than the NHI 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 NCR).

18. the NCSP reviews its processes for obtaining ethnicity data (if the NCSP cytology request form requires smear-takers to collect this information from women, then the NCSP needs to liaise with the NZHIS 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 NCSP 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.

8.10.2 Cancer registration

The Audit recommends that the NCR:

19. 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 reconsideration of her case, this information is routinely provided to the NCR.
20. 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.

21. ensures that it consistently adheres to international standards for assigning date of diagnosis and for determining eligibility for registration.

8.11 Monitoring the NCSP

Rarangi me te tātari o te NCSP

The NCSP target that at least 70% of women with cervical cancer should be stage 1 at diagnosis was met in Audit women. Other NCSP indicators and targets relating to this group of women are shown in Appendix 3.

In women who participated in the Audit, fewer than half of those with a smear in the six to 42 months prior to diagnosis had an adequate frequency of screening over the six month to seven years prior to diagnosis. While this proportion can not be extrapolated to the general population, it seems highly likely that the ‘coverage’ measure currently used does not reflect the prevalence of regular screening in the population, which is likely to be much lower than the 73% coverage reported for 2001. A stricter definition of the adequacy of screening history could be used in monitoring the NCSP and might highlight more clearly the limitations and needs of the programme in this area.

When the Health (National Cervical Screening Programme) Amendment Act 2004 comes into force in March 2005, the NCSP will know how many women have opted off and how many are on the NCSP-R, and these can then be monitored.
8.12 Recommendations for monitoring the NCSP

\textit{Ngā tūtohutanga mo te arotutuki o te NCSP}

8.12.1 NCSP

The Audit recommends that:

22. the NCSP 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.

23. the NCSP 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.

24. screening indicators, such as coverage and ‘adequate frequency of screening’, reported for different ethnic groups are age-standardised.

25. the NCSP continues to report both hysterectomy adjusted and unadjusted screening indicators

26. 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 and also reports screening indicators both as numbers and proportions of enrolled women and of all eligible women.

27. the NCSP considers ways of ensuring that annual monitoring data, including screening indicators can be available in a timely way.

8.12.2 NCR

The Audit recommends that:

28. the NZHIS 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 NZHIS website should include ethnic-specific rates.
8.13 Future audits

Ngā ātā a mua

8.13.1 Participation of women with cancer

The new legislation governing the operation of the NCSP ensures that the complete smear histories of enrolled women will be on the NCSP-R and allows access by auditors to medical notes without the consent of women with cancer. However, an approach to women who have cancelled their enrolment or who have never been enrolled in the NCSP is likely to be necessary to identify the health care providers who have records of their smears and cervix-related consultations. Therefore consent to participate by those women will need to be gained in order to perform audits similar to this one in the future.

In this Audit, overall consent to all aspects of the process was obtained for 78% of women who were eligible for data collection, and consent to some data collection (although not necessarily all aspects) was obtained from 85% of eligible women. These consent rates include consent by next of kin for data collection on the women who were deceased at the time of the Audit.

The value of some previous evaluations has been hampered by low consent rates, particularly amongst Māori women. The Audit team put significant effort into ensuring that consent rates were as high as possible for all women. These efforts included going to great efforts to locate eligible women, informing women about the Audit through a trusted health professional, being prepared to undertake face-to-face interviews, and ensuring consistency of Audit data collection personnel through the data collection phase. The appropriate level of effort put into engaging Māori women and their whānau with the Audit resulted in consent rates that were as high for Māori as for non-Māori, and thus Audit results that are as valid for Māori as for non-Māori women. Whilst it is not possible to specifically attribute the consent rates to any of these factors, they make up a package that overall was successful and should be used as the basis for gaining consent to participate in future audits for women who are not enrolled in the NCSP. However, data collection could in future be performed prospectively as women are diagnosed with cervical cancer, rather than as a retrospective project.

Future audits of screening histories of women with invasive cervical cancer should not occur until recent changes and those following this Audit have been in place for sufficient time to have an impact. However, other audits may be performed under the new legislation, and these could include audits designed to investigate the ethnic disparities in mortality following diagnosis.
A robust system of review of prior negative smears, as part of a laboratory quality assurance programme that includes laboratory accreditation and audits and workforce development, should ensure that large-scale smear re-reads need not necessarily be performed as part of future audits, unless a specific indication arises.

### 8.14 Recommendations for future audits

**Nga tūtohutanga mo ngā ātita ā mua**

The Audit recommends that:

29. prior to further audits of women with invasive cervical cancer, priority be given to implementation of the other Audit recommendations described above.

30. following the implementation of changes in the NCSP, 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. 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.

31. 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.
9 Tables

Papatau

9.1 Presentation of tables

Whakaturanga o ngā papatau

The table section is organised so there are tables on one page and accompanying notes on the facing page. The accompanying notes describe the purpose of the specific analysis, the data included in the table(s), data sets from which the analyses arise, any relevant methodology, and the findings. For further interpretation and implications of the findings, the reader should refer to the relevant section of chapters 4, 5, 6 and 7.

9.2 Definitions

Whakamāramatanga

9.2.1 Date of diagnosis

This is defined as the date that definitive histology was taken for women whose medical records were available, or the earliest date on the histological result form for women whose medical records were not available.

9.2.2 Histological type

Information from medical records was used to categorise the final histological diagnosis of women’s tumours into the categories squamous, adenocarcinoma, adenosquamous carcinoma, and other. In most cases the histological type obtained from medical records was as recorded on the diagnostic histology result form, but in some cases the type was amended at a multidisciplinary review/tumour panel meeting. These data were abstracted as part of the medical records abstraction process, with advice from the Audit pathology advisors given in any cases where the diagnosis was not clear.

In analyses where squamous, adenocarcinoma and ‘other’ histological types are shown, the categories ‘adenosquamous’, and ‘other’ were combined as ‘other’. In analyses where only squamous, adenocarcinoma, and ‘all histological types’ groups are shown, the other categories are included in ‘All’. 
9.2.3 Staging

The Audit procedure for ascertaining stage was as follows.

FIGO clinical staging was abstracted from the clinical notes (except FIGO stage 1A, which was determined by the Audit pathology advisors from the histology result). The following were sought in order of priority:
1. report from a tumour panel, multidisciplinary meeting or clinico-pathological conference
2. staging data from a gynaecological oncologist’s letter/notes
3. staging data from an operation note of an examination under anaesthesia (EUA) (if an EUA was performed at a peripheral hospital and then repeated at an oncology centre, then the EUA findings at the oncology centre took preference)
4. if none of the above were available, the woman was coded as ‘stage unknown’.

Squamous carcinomas were subdivided into 4 stage categories (1A, 1B, 2+, and unstaged) as many of the issues related to screening analysed here are associated with stage. These stage groupings were chosen because the groups have significant differences in prognosis and the number of women with late stage disease was insufficient to allow further breakdown of the 2+ group. Only squamous tumours were subdivided because of small numbers of other histological types.

9.2.4 Ethnicity

Ethnicity identified at interview, where available, is used to define women as Māori or non-Māori. Where neither the woman nor her next of kin was interviewed, Māori ethnicity is defined from routine sources as ‘Māori on any routine source’.

9.2.5 Age at diagnosis

Age at diagnosis was calculated as date of diagnosis (date of histological sample was taken from medical records where available or histology result where not) minus date of birth (from questionnaire where the woman herself was interviewed or from the NHI where not).

9.2.6 Screening smears

The focus of this Audit of women with cervical cancer was to identify systemic problems in the NCSP, and so it was necessary to define what constituted a screening smear. It seems likely that smears taken close to diagnosis were being taken as part of the diagnostic process rather than as part of routine
screening. It was not possible to identify from medical records which smears were taken with the intention of routine screening and which were taken as part of the investigation of symptoms or signs of malignancy. Therefore, in consultation with the Audit clinical advisors, an assumption was made that smears taken during the six months prior to diagnosis were likely to be part of the diagnostic process. Screening smears have been defined to be those taken more than six months prior to diagnosis.

9.2.7 Screening history

Analyses of screening history include only those smears that have been assumed to be screening smears, and therefore exclude smears taken in the six months prior to diagnosis.

Three definitions of ‘screening history’ are used in this document. These definitions are approximations of women’s histories because women’s histories can be very complex.

Smear in 6–84 months prior to diagnosis

The loosest definition of screening is ‘at least one smear in 6½ years’ (the 6–84 months prior to diagnosis). This period should encompass at least two screening cycles, if smears were being taken according to the New Zealand guidelines. This definition is similar to the definition of ‘participation’ used by the NCSP, which calculates the proportion of women who have a smear recorded on the NCSP-R in a six-year period.

Smear 6–42 months prior to diagnosis

The second definition is ‘at least one smear in three years’ (the 6–42 months prior to diagnosis), which uses the same time period as the definition of ‘coverage’ used by the NCSP.

Adequately screened

The third definition is intended to reflect that regular smears are necessary to achieve the potential reductions in cervical cancer incidence and mortality from cervical screening. The NCSP in New Zealand recommends the maximum interval between smears should be three years. Therefore this definition – termed ‘adequately screened’ – is the proportion of women who had no between-smear intervals of more than three years in the 6–84 months prior to diagnosis. To fulfil this criterion, a woman would have to have had at least two smears in this 6½ year period, no more than three years apart. Even this definition will overestimate the proportion of adequately screened women, since women who have any smear abnormality reported during or prior to this period should be receiving more frequent screening but would be called ‘adequate’ by this definition if they were having smears three-yearly. The complexity of the New Zealand guidelines for follow-up of abnormal smears, limitations on the
completeness of the data obtained for the Audit period, and inadequate data on women’s screening history prior to seven years before diagnosis prevented a determination of whether each individual woman who participated in the Audit had been screened exactly according to the guidelines.

**Smears**

If there was more than one smear result from a single date this was counted as one smear. For analyses relating to smear results, if there was more than one smear, or more than one result for a single smear, the more serious of the recorded results was included in the analysis.

**9.2.8 Smear categories**

Smear results were categorised into four groups: unsatisfactory, negative, low-grade and high-grade, reflecting different levels of recommendation with regard to urgency and type of follow-up. Table 7 shows the mapping of Bethesda codes to these groups, reflecting use of Bethesda coding in practice in New Zealand.

**Table 7 Smear categories for analyses and the smear re-read**

<table>
<thead>
<tr>
<th>Category</th>
<th>Usual management</th>
<th>Specimen adequacy</th>
<th>Assessment</th>
<th>Bethesda A (adequacy) codes included</th>
<th>Bethesda C (diagnosis) codes included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsatisfactory</td>
<td>Immediate repeat</td>
<td>Unsatisfactory for assessment</td>
<td>This smear has no diagnosis code</td>
<td>A3</td>
<td>None</td>
</tr>
<tr>
<td>Negative</td>
<td>Repeat in 1–3 years</td>
<td>Satisfactory for assessment or satisfactory but limited by ...</td>
<td>No epithelial cell abnormality, including ‘benign cellular changes’</td>
<td>A1, A2</td>
<td>None C1A1–C1E2 C2A1–C2A4 C2B1A–C2B4B C3B1, C5B1, C7 Normal</td>
</tr>
<tr>
<td>High-grade</td>
<td>Immediate referral for assessment</td>
<td>Satisfactory for assessment or satisfactory but limited by ...</td>
<td>ASCUS favour high-grade Dysplastic cells cannot grade as either high/low HSIL Adenocarcinoma in situ, malignant</td>
<td>A1, A2</td>
<td>C3A1E C3A2B–C3A2B7 C3A3, C3B2A1 C3B2B2, C3B2D C3B3–C3B3F C3C, C4</td>
</tr>
</tbody>
</table>
Smear re-read results

The re-read laboratory reported that smears were either unsatisfactory (U), negative (N), low-grade (L), high-grade (H), or inconclusive (I). The ‘I’ report is similar to ASCUS favour high-grade, and is grouped with the H reports as ‘high-grade’ for analyses.

The reports of the three re-read teams were combined into categories, as shown in Table 8.

Table 8 Smear re-read result categories

<table>
<thead>
<tr>
<th>Original</th>
<th>Re-read</th>
<th>Audit categorisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsatisfactory</td>
<td>All H and/or I</td>
<td>Upgraded to high-grade</td>
</tr>
<tr>
<td></td>
<td>All U</td>
<td>Unsatisfactory as reported</td>
</tr>
<tr>
<td></td>
<td>Any other</td>
<td>Not upgraded</td>
</tr>
<tr>
<td>Negative</td>
<td>All U</td>
<td>Regraded as unsatisfactory</td>
</tr>
<tr>
<td></td>
<td>All L</td>
<td>Upgraded to low-grade</td>
</tr>
<tr>
<td></td>
<td>All H and/or I</td>
<td>Upgraded to high-grade</td>
</tr>
<tr>
<td></td>
<td>Mixture U, L, H and I</td>
<td>Upgraded (mixed)</td>
</tr>
<tr>
<td></td>
<td>Any other</td>
<td>Not upgraded</td>
</tr>
<tr>
<td>Low-grade</td>
<td>All U</td>
<td>Regraded as unsatisfactory</td>
</tr>
<tr>
<td></td>
<td>All H and/or I</td>
<td>Upgraded to high-grade</td>
</tr>
<tr>
<td></td>
<td>Mixture U and H</td>
<td>Upgraded (mixed)</td>
</tr>
<tr>
<td></td>
<td>Any other</td>
<td>Not upgraded</td>
</tr>
</tbody>
</table>

9.2.9 Timing of events

Fixing a date to events retrospectively can be difficult. The Audit has tried to represent the ‘actual’ course of events as closely as possible, though at times this has involved approximations or the exclusion of data with missing dates. Where approximations have been used, this is described in the text in relation to the tables.

9.2.10 Smears re-read as part of other studies

The results of prior smear re-reads have been excluded from the analyses. The original smears have been included if they were taken within the appropriate time interval along with the original reported results. Investigations, such as colposcopy, which may have occurred following receipt of results of a re-read, have been included in the analyses.
9.3 Statistics

*Tatauranga*

Data were analysed using both *SAS* v8.2 and *SAS* v6.12. Where appropriate, Chi squared and Fisher’s Exact tests were used to compare frequency data. In most cases, differences are only given where they are statistically significant. Statistical significance was defined as $p < 0.05$.

Most differences between groups have been presented as risk difference with 95% confidence intervals, calculated using the Wilson method and the confidence interval calculator CIA. A risk difference confidence interval that does not include zero indicates statistical significance at $p<0.05$.

9.4 Layout and abbreviations

*Whakatākotoranga me ngā whakarāpopototanga*

In all tables, percentages have been rounded to the nearest whole number, so totals may not add up to 100%.

In most tables, numbers are presented as $N (%)$, where the denominator is shown at the top of the column in that section of the table.

**List of abbreviations in tables**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adeno</td>
<td>Adenocarcinoma</td>
</tr>
<tr>
<td>AGUS</td>
<td>Atypical glandular cells of undetermined significance</td>
</tr>
<tr>
<td>AIS</td>
<td>Adenocarcinoma in situ</td>
</tr>
<tr>
<td>ASCUS</td>
<td>Atypical squamous cells of undetermined significance</td>
</tr>
<tr>
<td>ASCUS+</td>
<td>Smear result of ASCUS or more serious</td>
</tr>
<tr>
<td>ASCUS-H</td>
<td>ASCUS, possible high-grade (follow-up as for high-grade smear)</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>CIN</td>
<td>Cervical intraepithelial neoplasia (grades from CIN1 to CIN3)</td>
</tr>
<tr>
<td>Dep score</td>
<td>Deprivation index score</td>
</tr>
<tr>
<td>EUA</td>
<td>Examination under anaesthetic</td>
</tr>
<tr>
<td>FIGO</td>
<td>International Federation of Gynaecology and Obstetrics</td>
</tr>
<tr>
<td>HG</td>
<td>High-grade</td>
</tr>
<tr>
<td>HSIL</td>
<td>High-grade squamous intraepithelial lesion</td>
</tr>
<tr>
<td>LG</td>
<td>Low-grade</td>
</tr>
<tr>
<td>N/A</td>
<td>Not applicable</td>
</tr>
<tr>
<td>PCB</td>
<td>Postcoital bleeding</td>
</tr>
<tr>
<td>PMB</td>
<td>Postmenopausal bleeding</td>
</tr>
<tr>
<td>RD</td>
<td>Risk difference</td>
</tr>
<tr>
<td>SCC</td>
<td>Squamous cell carcinoma</td>
</tr>
<tr>
<td>vs</td>
<td>Versus</td>
</tr>
<tr>
<td>yr</td>
<td>Year</td>
</tr>
</tbody>
</table>
9.4.1 Ethnic groups identified by routine data sources

Purpose

Ethnic-specific health statistics are an important part of identifying and monitoring differences in disease incidence and need for services in different population groups. In order to document the proportion of women eligible for the Audit and who consented to further data collection, ethnicity from routine data had to be used. Table 9 shows the ethnic groups identified by the different routine data sources.

Data in this table

Denominator: all 562 women whose data were supplied to the Audit by the NCR as having been registered on the NCR with a diagnosis of invasive cervical cancer between 1 January 2000 and 30 September 2002.

Data: ethnicity data from the NCR, NCSP-R and NHI databases, the electoral roll, and the death certificate where appropriate.

Methods

The electoral roll records only whether a person is registered as being of Māori descent or not. The NCSP-R records only one ethnic group and only one was available from the death certificate data. The NHI database records up to three and the NCR up to two ethnic groups.

Asian ethnicity includes Chinese, South-East Asian and West Asian women. Pacific includes women from all Pacific Island nations.

For each source, Table 9 shows all the ethnic groups identified for each woman, so for the NCR and NHI the number of women of each ethnic group does not add up to 562. In addition, the NCSP-R column adds up to 548, because two women were identified by the NCSP as ‘Fijian Indian’, and they have been included in both ‘Pacific’ and ‘Asian’ groups.

Findings

The NCSP-R had no data on 16 of the women with data on the NCR. The three health routine data sources – the NCR, NCSP-R and NHI – each identified a similar proportion (about 17%) of women as Māori. However, this consistency masks some differences at the level of individual women. There were only 82 women who were identified as Māori by all three of these data sources, although 103 women were called Māori by at least one of them. A further 13 women were called Māori on either the electoral roll or death certificate only, giving a total of 116 women who were identified as Māori on at least one
routine data source. Asian was the next most common ethnic group, with about 5% of women identified as Asian by at least one routine source. The Pacific group had slightly fewer women but a similar proportion to Asian.

The NHI database had no ethnicity specified for 22 (4%) women.

**Table 9  Ethnic groups identified by routine data sources**

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>NCR N = 562</th>
<th>NCSP-R N = 546</th>
<th>NHI N = 562</th>
<th>Electoral roll N = 393</th>
<th>Death certificate* N = 64</th>
<th>Any N = 562</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>94 (17)</td>
<td>92 (17)</td>
<td>93 (17)</td>
<td>72 (18)</td>
<td>15 (24)</td>
<td>116 (21)</td>
</tr>
<tr>
<td>Pacific</td>
<td>21 (4)</td>
<td>19 (4)</td>
<td>20 (4)</td>
<td>N/A</td>
<td>2 (3)</td>
<td>23 (4)</td>
</tr>
<tr>
<td>‘European’</td>
<td>426 (76)</td>
<td>391 (72)</td>
<td>404 (72)</td>
<td>N/A</td>
<td>44 (69)</td>
<td>438 (78)</td>
</tr>
<tr>
<td>Asian</td>
<td>26 (5)</td>
<td>21 (4)</td>
<td>25 (4)</td>
<td>N/A</td>
<td>2 (3)</td>
<td>28 (5)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (0)</td>
<td>19 (4)</td>
<td>11 (2)</td>
<td>N/A</td>
<td>0 (0)</td>
<td>29 (5)</td>
</tr>
<tr>
<td>Not specified</td>
<td>1 (0)</td>
<td>6 (1)</td>
<td>22 (4)</td>
<td>N/A</td>
<td>1 (2)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

* For women who had died before the beginning of the Audit data collection.
9.4.2 Confirmation of eligibility for the Audit

Purpose

Table 10 shows the proportion of women whose data were supplied by the NCR who were eligible for inclusion in the Audit, and, for those ineligible, the reasons for ineligibility.

Data in this table

Denominator: all 562 women for whom data were supplied to the Audit.

Data: eligibility for the Audit and reasons for ineligibility from the Audit database.

Methods

In this table, Māori ethnicity is defined as ‘Māori on at least one routine source’.

Findings

Histological diagnosis of invasive cervical cancer, made in New Zealand within the Audit timeframe, could not be confirmed for 61 women. For seven of these women the NCR had recorded a date of diagnosis within the Audit timeframe, but histological confirmation of invasive cancer occurred outside the timeframe – in six cases after 30 September 2002, and one woman had originally been diagnosed in 1994. No cervical histological samples had been taken from nine women, either because the women declined further investigation following a smear suggestive of cancer or because the woman presented with advanced disease, which was managed without histological confirmation. Staging information was not available on the NCR for six of these women; the other three were stage 3B or higher.

Histological confirmation of invasive disease was available for 14 women in whom the primary tumour could not be confirmed as cervical carcinoma from the records available.

In a further 18 cases, women were registered on the NCR where histological specimens had been taken but invasive cancer not definitively reported. Where the histology showed no evidence of invasion or was not confirmatory (eg, the only specimen available showed ‘suspicious of invasion’), the clinicians identified by the NCR were contacted and confirmed that 12 of these women had not been considered clinically to have invasive cancer. Four had a subsequent histology clear of cancer, and two were excluded without further confirmation.

The histological specimen, originally reported as cancer, had been reviewed and determined to not show invasion for six women (‘downgraded’).
Of women with histologically confirmed primary cervical invasive carcinoma, 18 were over 80 years old at the time of diagnosis and so were not eligible for inclusion in the Audit. The stage recorded on the NCR for these women was 2A or above for 11 (61%) and missing for the seven others. The NCSP-R had a record of one smear in the period from seven years to six months prior to diagnosis for one of these older women. None of these women were Māori.

An additional 38 women were not resident in New Zealand for at least four consecutive years of the seven years prior to diagnosis and were therefore not eligible for inclusion in the Audit. These women were aged between 26 and 73, with a mean age of 39. Stage was recorded on the NCR for 29 (82%) of them, of whom 10 had stage 1A disease, 14 had stage 1B and 7 had stage 2 and above. The NCSP-R had between one and eight smears recorded in the period from seven years to six months prior to diagnosis for 14 (37%) of these women.

A higher proportion of Māori women whose information was supplied by the NCR were eligible for the Audit (85%) than of non-Māori women (78%). This is largely because there were no Māori women aged over 80 at the time of diagnosis and few Māori did not fit the residency criteria. Most other reasons for non-eligibility were similar in frequency for Māori and non-Māori, except that Māori were significantly more likely than non-Māori to have had no histological specimens taken.

Thirteen of 22 (59%) Pacific women and 16 of 31 (52%) Asian women were eligible for the Audit, with the majority of the ineligible women being diagnosed overseas or not resident in New Zealand for at least four consecutive years of the seven years prior to diagnosis.

### Table 10  Confirmation of eligibility for the Audit

<table>
<thead>
<tr>
<th>Information supplied to the Audit</th>
<th>Māori N = 116</th>
<th>Non-Māori N = 446</th>
<th>Total N = 562</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total ineligible</td>
<td>17 (15)</td>
<td>100 (23)</td>
<td>117 (21)</td>
</tr>
<tr>
<td>Histological date of diagnosis outside date range</td>
<td>1 (1)</td>
<td>6 (1)</td>
<td>7 (1)</td>
</tr>
<tr>
<td>No cervical histology available</td>
<td>5 (4)</td>
<td>4 (1)</td>
<td>9 (2)</td>
</tr>
<tr>
<td>Histological confirmation of cancer, but primary not confirmed as cervical carcinoma</td>
<td>2 (2)</td>
<td>12 (3)</td>
<td>14 (2)</td>
</tr>
<tr>
<td>Histology does not confirm invasion</td>
<td>4 (3)</td>
<td>14 (3)</td>
<td>18 (3)</td>
</tr>
<tr>
<td>Histological diagnosis subsequently downgraded to non-invasive</td>
<td>2 (2)</td>
<td>4 (1)</td>
<td>6 (1)</td>
</tr>
<tr>
<td>Diagnosed overseas</td>
<td>0</td>
<td>7 (2)</td>
<td>7 (1)</td>
</tr>
<tr>
<td>Over 80 at time of diagnosis</td>
<td>0</td>
<td>18 (4)</td>
<td>18 (3)</td>
</tr>
<tr>
<td>Not fulfilling residency criteria</td>
<td>3 (3)</td>
<td>35 (8)</td>
<td>38 (7)</td>
</tr>
<tr>
<td>Eligible for further Audit data collection</td>
<td>99 (85)</td>
<td>346 (78)</td>
<td>445 (79)</td>
</tr>
</tbody>
</table>
9.4.3 Definition of ethnicity

Purpose

Objective 3 of the Audit is ‘to assess the accuracy and completeness of information on the NCSP-R and the NCR relating to women developing invasive cervical cancer’. Table 11 assesses the accuracy of the ethnicity recorded on the NCSP-R and NCR.

The ‘gold standard’ for defining ethnic group is self-report. For women where an ethnicity was reported at interview by either the woman or her next of kin, this ethnicity is compared with that recorded on the NCR and NCSP-R and other routine sources.

Also, in order to compare the characteristics of eligible and ineligible women, and women who consented to data collection with those who did not, a definition using only routine data sources was needed (since self-reported ethnic group was available only for those women who were interviewed). The ethnicity at interview is used to determine the most complete definition of ethnicity using a combination of routine sources.

Data in this table

Denominator: the 359 women where an interview was carried out, including women who were personally interviewed and those whose relatives were interviewed and reported the woman’s ethnicity where the woman had died (nine Māori, 32 non-Māori). The denominator for each comparison with a routine source includes women with an interview ethnicity who had any data on that source.

Data: ethnicity at interview and as recorded on the NCR, NCSP-R, NHI, death certificate and electoral roll.

Methods

The proportions of women identified at interview as Māori and non-Māori, who were identified as Māori on the different routine sources, were calculated. The proportions identified as Māori on at least one source, and at least two sources, were also calculated to determine the most complete definition of ethnicity using routine sources. At interview, six women were identified as Pacific and 14 women as Asian. A detailed analysis of these ethnicities was not performed because of these small numbers.

Findings

Each of the health routine sources correctly identified about 80% of women identified at interview as Māori and misidentified a small number of non-Māori women as Māori. Ethnicity was correctly shown on the electoral roll for 93% of the Māori women who were enrolled, but 21 of the 75 Māori women
could not be found on the electoral roll. The most complete ascertainment (97%) of Māori was obtained using a definition of ‘Māori on any routine data source’, although 2% of non-Māori women were defined as Māori using this definition. A definition requiring women to be identified as Māori on two routine sources reduced the proportion of Māori women who were correctly identified to 88% and the proportion of non-Māori women misidentified to 1%.

The two Māori women who were not identified as Māori on any routine source were identified as ‘other’ or ‘other European’ on the available sources. Of the seven Māori women who were identified as Māori on only one routine source, six were shown as Māori on the electoral roll and one on the NCR. The two non-Māori women who were identified as Māori on at least two routine sources were both identified as Māori on the NCR. In addition one was identified as Māori on the NCSP and one on the NHI. Of the four non-Māori women who were identified as Māori on only one routine source, two were shown as Māori on the electoral roll, one was identified as Māori on her death certificate and one on the NCSP-R.

The proportions of women whose ethnicity was correctly identified by the different routine data sources were almost the same when the analysis was restricted to women who had been personally interviewed (data not shown).

One woman who was not identified as Pacific at interview was identified as Pacific by at least one routine data source, but all women identified as Pacific at interview were also identified as Pacific by at least one routine source. No non-Asian women were identified as Asian by routine sources, but three women identified as Asian at interview were not so identified by routine sources.

### Table 11 Definition of ethnicity

<table>
<thead>
<tr>
<th>Definition of Māori from routine source</th>
<th>Women identified at interview* as Māori, defined as Māori by routine source N (%)</th>
<th>Women identified at interview* as non-Māori, defined as Māori by routine source N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCSP-R ethnicity</td>
<td>62/75 (83)</td>
<td>2/284 (1)</td>
</tr>
<tr>
<td>NCR ethnicity</td>
<td>61/75 (81)</td>
<td>2/284 (1)</td>
</tr>
<tr>
<td>NHI ethnicity</td>
<td>61/75 (81)</td>
<td>1/284 (0)</td>
</tr>
<tr>
<td>On Māori electoral roll</td>
<td>50/54 (93)</td>
<td>2/227 (1)</td>
</tr>
<tr>
<td>Death certificate (for women who had died before the collection of their Audit data)</td>
<td>7/9 (78)</td>
<td>1/31 (3)</td>
</tr>
<tr>
<td>At least one routine source</td>
<td>73/75 (97)</td>
<td>6/284 (2)</td>
</tr>
<tr>
<td>At least two routine sources</td>
<td>66/75 (88)</td>
<td>2/284 (1)</td>
</tr>
</tbody>
</table>

* Identified by questionnaire respondent – either the woman herself or her next of kin.
9.4.4  Consent to data collection in the Audit

Purpose
Great effort was made to contact eligible women and request their consent to further data collection. (Table 12 shows the proportion of women who gave consent to further data collection). Of the 445 eligible women, 62 had died by the beginning of the process of Audit data collection. For these women, their next of kin were approached for interview and their legal representative (often but not always the same person) for permission to collect further data from medical records and for smear re-read. Similar proportions of Māori (18%) and non-Māori (13%) women had died.

Data in this table
Denominator: the 445 women eligible to be included in the Audit.

Data: consent by the woman or her next of kin for interview and by the woman or her legal representative for collection of data from medical records and for smear re-read.

Findings
The first part of Table 12 shows the proportion of women for whom consent was obtained for different aspects of further data collection, including women who gave consent themselves and women where consent was gained from next of kin and legal representatives. The second part of the table shows consent given by women themselves, and by next of kin and legal representatives, separately.

There were 14 women (3%) for whom further data were not collected, either because they could not be found or because the women’s or next of kin’s medical carers advised it would be inappropriate to contact them.

Overall, consent rates for Māori women for all types of data collection were not significantly different from those for non-Māori women.

Next of kin/legal representatives were less likely than the women themselves to give consent for interview (66% vs 83%; Risk Difference -17% (-30% to 5%)) or for access to medical records (69% vs 86%; Risk Difference -17% (-29% to -4%)). Although the proportion of Māori relatives who gave consent for further data collection was lower than the proportion of non-Māori relatives who gave consent, this difference was not statistically significant (consent for any further data collection 59% vs 73%, Risk Difference -15% (-42% to +14%)).
Pacific women were less likely to give consent for interview (6/13; 46%) or records (7/13; 54%) than Māori or other non-Māori women, whereas Asian women had high levels of consent to both interview (14/16; 88%) and record collection (13/16; 81%).

Table 12  Consent to data collection in the Audit

<table>
<thead>
<tr>
<th>Total number</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number</td>
<td>N = 95</td>
<td>N = 350</td>
<td>N = 445</td>
</tr>
<tr>
<td>Unable to be contacted for consent</td>
<td>3 (3)</td>
<td>11 (3)</td>
<td>14 (3)</td>
</tr>
<tr>
<td>Consented to any further data collection</td>
<td>77 (81)</td>
<td>293 (84)</td>
<td>370 (83)</td>
</tr>
<tr>
<td>Consented to interview</td>
<td>75 (79)</td>
<td>284 (81)</td>
<td>359 (81)</td>
</tr>
<tr>
<td>Consented to GP records</td>
<td>77 (79)</td>
<td>293 (84)</td>
<td>368 (83)</td>
</tr>
<tr>
<td>Consented to hospital/specialist records</td>
<td>75 (79)</td>
<td>293 (84)</td>
<td>371 (83)</td>
</tr>
<tr>
<td>Consented to have smears re-read</td>
<td>75 (79)</td>
<td>293 (84)</td>
<td>368 (83)</td>
</tr>
<tr>
<td>Consented to at least one medical record source</td>
<td>72 (76)</td>
<td>277 (79)</td>
<td>349 (78)</td>
</tr>
<tr>
<td>Consented to all</td>
<td>72 (76)</td>
<td>277 (79)</td>
<td>349 (78)</td>
</tr>
<tr>
<td>Consented to records only (no interview)</td>
<td>3 (3)</td>
<td>14 (4)</td>
<td>17 (4)</td>
</tr>
<tr>
<td>Consented to interview only (no medical record collection)</td>
<td>1 (1)</td>
<td>4 (1)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Refused all</td>
<td>14 (15)</td>
<td>41 (12)</td>
<td>55 (12)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent by women themselves</th>
<th>N = 78</th>
<th>N = 304</th>
<th>N = 382</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consented to interview</td>
<td>66 (85)</td>
<td>252 (83)</td>
<td>318 (83)</td>
</tr>
<tr>
<td>Consented to at least one medical record source</td>
<td>67 (86)</td>
<td>261 (86)</td>
<td>328 (86)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consent by next of kin/legal representative</th>
<th>N = 17</th>
<th>N = 45</th>
<th>N = 62</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consented to interview</td>
<td>9 (53)</td>
<td>32 (71)</td>
<td>41 (66)</td>
</tr>
<tr>
<td>Consented to at least one medical record source</td>
<td>10 (59)</td>
<td>33 (73)</td>
<td>43 (69)</td>
</tr>
</tbody>
</table>
9.4.5 Data collection

Purpose

Interviews were performed with all of the 318 women and 41 next of kin who gave consent for interview. Interviews were conducted either by telephone or face-to-face according to the interviewee’s preference. During the interview, women or next of kin were asked for names and addresses of health care providers they had attended to seek care for cervix-related symptoms or signs, or who may have taken a smear at a consultation. Health care providers consulted over the seven years prior to diagnosis were sought.

Consent for collection of data from primary care and hospital/specialist records, and for re-reading smears, was sought at the interview or at the time when women declined to be interviewed. Five women were interviewed but did not consent to the Audit collecting information from medical records, and 17 were willing for the Audit to collect medical record information but did not want to be interviewed. For the latter, information on the NCSP-R and NCR and in the health care records obtained was used to identify the health care providers who may have had relevant records.

Data in this table

Denominator: for each data type, the number of women who gave consent for collection of that data (see Table 12).

Data: Completeness of record data collection. Where records covering all identified consultations during which a smear might have been taken were obtained, data collection was considered to be complete. Where some but not all possibly relevant records were obtained, data collection was considered ‘partial’. Because the NCSP-R data were available to the Audit and most smears are on the NCSP-R, these women’s smear histories are probably complete, but it is possible that smears not on the NCSP-R were recorded in the unobtained records.

Findings

All known relevant primary care records were significantly less likely to be obtained for Māori women (Risk Difference -12% (-23% to -1%)), but all known relevant hospital and specialist records were obtained for over 90% of all women: 96% of Māori and 92% of non-Māori.
Table 13  Data collection

<table>
<thead>
<tr>
<th>Data source/completeness</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All known potentially relevant primary care records obtained</td>
<td>55/77 (71)</td>
<td>245/292 (84)</td>
<td>300/370 (81)</td>
</tr>
<tr>
<td>All known relevant hospital and specialist records obtained</td>
<td>71/75 (95)</td>
<td>270/293 (92)</td>
<td>341/368 (93)</td>
</tr>
</tbody>
</table>
9.4.6 Interviewed women – ethnicity, education, number in household

Purpose

The interview consisted of a structured questionnaire in which most questions were designed to elicit information about health care providers who might have taken smears in the seven years prior to diagnosis. Some demographic questions were also included.

There were five women who gave interviews but did not give consent for any medical record collection. Their data are shown here for completeness but do not appear in later tables where demographic variables are cross tabulated with disease data.

Data in this table

Denominator: the 359 women where consent to interview was obtained either from the woman or her next of kin. Some questions were not asked of next of kin, so for them the denominator is the 318 women where the woman herself was interviewed.

Data: answers to questions at interview.

Methods

Ethnicity – women were asked whether they identified with any of a number of different ethnic groups, and all that were identified are shown here.

Differences between Māori and non-Māori women (not including women who declined to answer the question) were tested using the $\chi^2$ test, accepting as statistically significant those where $p < 0.05$.

Findings

Fifty-seven women (16%) were not born in New Zealand but had lived here for a minimum of six and a maximum of 75 years. There were 22 women who had not been living here for the whole of the seven years prior to diagnosis, (but had been living here for at least a four-year period within that time).

Māori women were statistically significantly more likely to have spent fewer years at secondary school, to have no secondary school qualification, and to live in larger households than non-Māori women.
Table 14  Interviewed women – ethnicity, education, number in household

<table>
<thead>
<tr>
<th>Ethnic group (any identified)</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All N = 359</th>
</tr>
</thead>
<tbody>
<tr>
<td>Māori</td>
<td>/ /</td>
<td>/ /</td>
<td>75 (21)</td>
</tr>
<tr>
<td>NZ European</td>
<td>/ /</td>
<td>/ /</td>
<td>282 (79)</td>
</tr>
<tr>
<td>Chinese</td>
<td>/ /</td>
<td>/ /</td>
<td>8 (2)</td>
</tr>
<tr>
<td>Any Pacific</td>
<td>/ /</td>
<td>/ /</td>
<td>6 (2)</td>
</tr>
<tr>
<td>Samoan</td>
<td>/ /</td>
<td>/ /</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Tongan</td>
<td>/ /</td>
<td>/ /</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Cook Islander</td>
<td>/ /</td>
<td>/ /</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Indian</td>
<td>/ /</td>
<td>/ /</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Other (includes ‘other European’)</td>
<td>/ /</td>
<td>/ /</td>
<td>21 (6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Years of secondary education</th>
<th>N = 66</th>
<th>N = 252</th>
<th>N = 318</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>10 (15)</td>
<td>10 (4)</td>
<td>20 (6)</td>
</tr>
<tr>
<td>1–3</td>
<td>34 (52)</td>
<td>106 (42)</td>
<td>140 (44)</td>
</tr>
<tr>
<td>4+</td>
<td>17 (26)</td>
<td>132 (52)</td>
<td>149 (47)</td>
</tr>
<tr>
<td>Unknown/declined</td>
<td>5 (8)</td>
<td>4 (2)</td>
<td>9 (3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest secondary qualification</th>
<th>N = 66</th>
<th>N = 252</th>
<th>N = 318</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>36 (55)</td>
<td>85 (34)</td>
<td>121 (38)</td>
</tr>
<tr>
<td>School Certificate</td>
<td>9 (14)</td>
<td>44 (17)</td>
<td>53 (17)</td>
</tr>
<tr>
<td>University Entrance qualification</td>
<td>11 (17)</td>
<td>88 (35)</td>
<td>99 (31)</td>
</tr>
<tr>
<td>Other secondary school qualification (mostly overseas)</td>
<td>0</td>
<td>28 (11)</td>
<td>28 (9)</td>
</tr>
<tr>
<td>Unknown/declined/not applicable</td>
<td>10 (15)</td>
<td>7 (3)</td>
<td>17 (5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number in household in year prior to diagnosis</th>
<th>N = 66</th>
<th>N = 252</th>
<th>N = 318</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5 (8)</td>
<td>34 (13)</td>
<td>39 (12)</td>
</tr>
<tr>
<td>2</td>
<td>14 (21)</td>
<td>76 (30)</td>
<td>90 (28)</td>
</tr>
<tr>
<td>3–5</td>
<td>32 (48)</td>
<td>127 (50)</td>
<td>159 (50)</td>
</tr>
<tr>
<td>6+</td>
<td>11 (17)</td>
<td>12 (5)</td>
<td>23 (7)</td>
</tr>
<tr>
<td>Unknown/declined/not applicable</td>
<td>4 (6)</td>
<td>3 (1)</td>
<td>7 (2)</td>
</tr>
</tbody>
</table>
9.4.7 Interviewed women – deprivation index, income, regular GP, reported reason for consultation that led to diagnosis

**Purpose**

The interview consisted of a structured questionnaire in which most questions were designed to elicit information about health care providers who might have taken smears in the seven years prior to diagnosis. Some demographic questions, questions about the woman’s use of GPs, and a question about the consultation that led to diagnosis of cervical cancer were also included.

There were five women who gave interviews but did not give consent for any medical record collection. Their data are shown here for completeness but do not appear in later tables where demographic variables are cross tabulated with disease data.

**Data in this table**

**Denominator:** the 359 women where consent to interview was obtained either from the woman or her next of kin. Some questions were not asked of next of kin, so for them the denominator is the 318 women where the woman herself was interviewed.

**Data:** answers to questions at interview.

**Methods**

Socioeconomic status was measured by the New Zealand Deprivation Index 2001 (NZDep 2001),\(^7\) which is an area-based score from 1 to 10, incorporating eight dimensions measuring deprivation from the New Zealand 2001 census. The scores represent deciles of the total New Zealand population. A score of 10 describes the most deprived areas. It was assigned according to the census meshblock where the woman lived at the time of diagnosis. Addresses for 16 women were unable to be matched by this process. Differences between Māori and non-Māori women in the distribution of NZDep2001 scores were tested using the \(\chi^2\) test.

**Findings**

The distribution of NZDep2001 scores was significantly different between Māori and non-Māori. Māori women lived in more ‘deprived’ areas, with 54% (95% CI: 42% to 65%) of the Māori women whose address could be assigned a deprivation score being in deciles 9 and 10 – the poorest two deciles. In contrast, 15% (95% CI:12% to 20%) of non-Māori women lived in decile 9 and 10 areas.

Among women who answered the question on household income, Māori women were statistically significantly more likely to have a lower household income in the year prior to diagnosis.
All except four women (three Māori) reported that they had a regular GP to whom they or their family went if they were ill during the seven years prior to their diagnosis of cervical cancer. Sixty percent of non-Māori women and 47% of Māori women had only one GP during that period (Risk Difference 12% (-1% to 25%)).

Just over half of the interviewed women reported that a routine smear (a smear in the absence of symptoms) had led to their diagnosis (eight of these had a routine smear that was subsequently re-read as part of the re-read of Gisborne smears). Twenty-six women (8%), 10 (15%) Māori and 16 (6%) non-Māori, could not remember ever having a smear prior to their diagnosis of cervical cancer (Risk Difference 9% (2 % to 18%).

Table 15 Interviewed women – deprivation index, income, regular GP, reported reason for consultation that led to diagnosis

<table>
<thead>
<tr>
<th>Deprivation index at diagnosis</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 69</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–2</td>
<td>2</td>
<td>(3)</td>
<td>60</td>
</tr>
<tr>
<td>3–4</td>
<td>4</td>
<td>(6)</td>
<td>57</td>
</tr>
<tr>
<td>5–6</td>
<td>9</td>
<td>(13)</td>
<td>67</td>
</tr>
<tr>
<td>7–8</td>
<td>17</td>
<td>(25)</td>
<td>80</td>
</tr>
<tr>
<td>9–10</td>
<td>37</td>
<td>(54)</td>
<td>79</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Total household income in year prior to diagnosis</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>19</td>
<td>(29)</td>
<td>63</td>
</tr>
<tr>
<td>Between $20,000 and $30,000</td>
<td>15</td>
<td>(23)</td>
<td>50</td>
</tr>
<tr>
<td>Between $30,000 and $50,000</td>
<td>17</td>
<td>(26)</td>
<td>72</td>
</tr>
<tr>
<td>Between $50,000 and $70,000</td>
<td>4</td>
<td>(6)</td>
<td>50</td>
</tr>
<tr>
<td>Over $70,000</td>
<td>4</td>
<td>(6)</td>
<td>53</td>
</tr>
<tr>
<td>Unknown/declined</td>
<td>7</td>
<td>(11)</td>
<td>31</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>General practice</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 75</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had a GP for care of self and family in the seven years prior to diagnosis</td>
<td>72</td>
<td>(96)</td>
<td>355</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Consistency of care for women with at least 1 GP</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One GP only in the seven years prior to diagnosis</td>
<td>34</td>
<td>(47)</td>
<td>202</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reason for consultation</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 66</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Routine smear</td>
<td>36</td>
<td>(55)</td>
<td>172</td>
</tr>
<tr>
<td>Postmenopausal or postcoital bleeding</td>
<td>13</td>
<td>(20)</td>
<td>63</td>
</tr>
<tr>
<td>Any other abnormal vaginal bleeding</td>
<td>8</td>
<td>(12)</td>
<td>50</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>(14)</td>
<td>33</td>
</tr>
</tbody>
</table>
9.4.8 Histological types and FIGO stage from medical records

Purpose

Cervical screening is known to be effective in the early detection of squamous cell abnormalities, and therefore in reducing the incidence of squamous cell carcinoma. In many of the analyses of screening history, women are separated into those with squamous cell carcinoma, those with adenocarcinoma and those with other types of cervical cancer. Table 16 shows the distribution of histological types diagnosed in the women who gave consent for access to their medical records.

Data in this table

Denominator: the 371 women who gave consent for access to medical records.

Data: histological type and stage ascertained from medical records, ethnicity from questionnaire and routine sources.

Methods

Stage is grouped into 1A (microinvasive), 1B and 2+ for squamous cell carcinoma and into 1 and 2+ for adenocarcinoma and for all histological types when considered together.

Findings

Three-quarters of invasive cervical cancers were squamous cell carcinoma. The proportion of women with squamous cell carcinoma was not statistically significantly different between Māori and non-Māori (Risk Difference 6% (-4% to 16%).

Stage could be determined using the Audit procedures for 349 (94%) women. Of all women with a stage ascertained, 75% (263/349) were diagnosed at stage 1. For squamous cell carcinomas this proportion was 74% (204/277) and for adenocarcinomas it was 86% (42/49). 69% (50/72) of Māori women were stage 1 at diagnosis (95% CI: 58% to 79%) and the figure for non-Māori was 77% (213/277). The differences between histological types and ethnic groups in the proportion diagnosed at stage 1 are not statistically significant.

There are no statistically significant differences between Māori and non-Māori in the stage distribution, although amongst women with squamous cell carcinoma there is a suggestion that a higher proportion of Māori women have later stage (2+) disease (32% vs 24%). The relationship between ethnicity and stage at diagnosis is explored in more detail by including consideration of age in Table 17.
Table 16  Histological types and FIGO stage from medical records

<table>
<thead>
<tr>
<th>Histological type</th>
<th>Māori N = 77</th>
<th>Non-Māori N = 294</th>
<th>All N = 371</th>
</tr>
</thead>
<tbody>
<tr>
<td>Squamous cell carcinoma</td>
<td>63 (82)</td>
<td>224 (76)</td>
<td>287 (77)</td>
</tr>
<tr>
<td>Adenocarcinoma</td>
<td>8 (10)</td>
<td>49 (17)</td>
<td>57 (15)</td>
</tr>
<tr>
<td>Adenosquamous</td>
<td>5 (6)</td>
<td>17 (6)</td>
<td>22 (6)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1)</td>
<td>4 (1)</td>
<td>5 (1)</td>
</tr>
</tbody>
</table>

| Stage – all histological types         | N = 63       | N = 224           | N = 287     |
| 1                                      | 50 (65)      | 213 (72)          | 263 (71)    |
| 2+                                     | 22 (29)      | 64 (22)           | 86 (23)     |
| Unknown                                | 5 (6)        | 17 (6)            | 22 (6)      |

| Stage – squamous cell carcinoma only   | N = 63       | N = 224           | N = 287     |
| 1A                                     | 26 (41)      | 79 (35)           | 105 (37)    |
| 1B                                     | 15 (24)      | 84 (38)           | 99 (34)     |
| 2+                                     | 20 (32)      | 53 (24)           | 73 (25)     |
| Unknown                                | 2 (3)        | 8 (4)             | 10 (3)      |

| Stage – adenocarcinoma only            | N = 8        | N = 49            | N = 57      |
| 1                                      | 7 (88)       | 35 (71)           | 42 (74)     |
| 2+                                     | 1 (13)       | 6 (12)            | 7 (12)      |
| Unknown                                | 0            | 8 (16)            | 8 (14)      |
9.4.9 Women with medical record data – age, stage and ethnicity

Purpose

The incidence of cervical cancer in Māori women is approximately double that in non-Māori women, and death rates are around four times as high. Possible reasons for the bigger disparity in death rates than in incidence rates include presentation at later stage, more aggressive or hard-to-treat disease, or poorer treatment. In view of the higher mortality rates, the results shown in the previous table – no significant differences between Māori and non-Māori in stage at presentation – are surprising. However, age is a possible confounding factor.

Table 17 shows the relationship between stage, ethnicity and age for women for whom reliable stage data were available.

Data in this table

Denominator: the 349 women for whom a stage could be ascertained from medical records.

Data: from questionnaire (date of birth), NHI (date of birth where woman was not interviewed), medical records (date histological specimen taken, stage).

Methods

Stage is grouped into 1A (microinvasive), 1B and 2+ for squamous cell carcinoma, and into 1 and 2+ for adenocarcinoma, and for all histological types when considered together.

Findings

The proportion of women with late-stage disease is strongly related to age, with 51% of 70 to 79-year-old women having stage 2+ squamous disease compared with 6% of 20 to 29-year-olds. Given this, the younger Māori population would be expected to have fewer rather than more cases of late-stage disease. However, when women are divided into those over 45 and those under 45 at diagnosis, the proportion of younger Māori women with later-stage disease is higher than that for non-Māori, although this difference is not statistically significant (22% vs 9%, Risk Difference 13% (-1% to 28%)).
Table 17  Women with medical record data – age, stage and ethnicity

<table>
<thead>
<tr>
<th>Age</th>
<th>20–29</th>
<th>30–39</th>
<th>40–49</th>
<th>50–69</th>
<th>70–79</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>N = 12</td>
<td>N = 26</td>
<td>N = 19</td>
<td>N = 15</td>
<td>N = 3</td>
</tr>
<tr>
<td>SCC 1B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 2+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adeno</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>8 (67)</td>
<td>10 (38)</td>
<td>4 (21)</td>
<td>4 (27)</td>
<td>0</td>
</tr>
<tr>
<td>SCC 1B</td>
<td>1 (8)</td>
<td>10 (38)</td>
<td>1 (5)</td>
<td>2 (13)</td>
<td>1 (33)</td>
</tr>
<tr>
<td>SCC 2+</td>
<td>2 (17)</td>
<td>1 (4)</td>
<td>11 (58)</td>
<td>6 (40)</td>
<td>0</td>
</tr>
<tr>
<td>Adeno</td>
<td>1 (8)</td>
<td>3 (12)</td>
<td>3 (16)</td>
<td>1 (7)</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>2 (8)</td>
<td>0</td>
<td>2 (13)</td>
<td>2 (67)</td>
</tr>
</tbody>
</table>

Non-Māori women

<table>
<thead>
<tr>
<th>Age</th>
<th>20–29</th>
<th>30–39</th>
<th>40–49</th>
<th>50–69</th>
<th>70–79</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>N = 24</td>
<td>N = 82</td>
<td>N = 61</td>
<td>N = 89</td>
<td>N = 30</td>
</tr>
<tr>
<td>SCC 1B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 2+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adeno</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>14 (58)</td>
<td>32 (39)</td>
<td>14 (23)</td>
<td>18 (20)</td>
<td>1 (3)</td>
</tr>
<tr>
<td>SCC 1B</td>
<td>4 (17)</td>
<td>29 (35)</td>
<td>20 (33)</td>
<td>27 (29)</td>
<td>4 (13)</td>
</tr>
<tr>
<td>SCC 2+</td>
<td>0</td>
<td>5 (6)</td>
<td>12 (20)</td>
<td>18 (20)</td>
<td>18 (56)</td>
</tr>
<tr>
<td>Adeno</td>
<td>6 (25)</td>
<td>11 (13)</td>
<td>11 (18)</td>
<td>17 (19)</td>
<td>4 (13)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>5 (6)</td>
<td>4 (7)</td>
<td>9 (10)</td>
<td>3 (10)</td>
</tr>
</tbody>
</table>

All women

<table>
<thead>
<tr>
<th>Age</th>
<th>20–29</th>
<th>30–39</th>
<th>40–49</th>
<th>50–69</th>
<th>70–79</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>N = 36</td>
<td>N = 108</td>
<td>N = 80</td>
<td>N = 104</td>
<td>N = 33</td>
</tr>
<tr>
<td>SCC 1B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 2+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adeno</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCC 1A</td>
<td>22 (61)</td>
<td>42 (39)</td>
<td>18 (23)</td>
<td>22 (22)</td>
<td>1 (3)</td>
</tr>
<tr>
<td>SCC 1B</td>
<td>5 (14)</td>
<td>39 (35)</td>
<td>21 (27)</td>
<td>29 (27)</td>
<td>5 (14)</td>
</tr>
<tr>
<td>SCC 2+</td>
<td>2 (6)</td>
<td>6 (5)</td>
<td>23 (29)</td>
<td>24 (22)</td>
<td>18 (51)</td>
</tr>
<tr>
<td>Adeno</td>
<td>7 (19)</td>
<td>14 (13)</td>
<td>14 (18)</td>
<td>18 (17)</td>
<td>4 (12)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>7 (7)</td>
<td>4 (5)</td>
<td>11 (11)</td>
<td>5 (15)</td>
</tr>
</tbody>
</table>

Age < 45

<table>
<thead>
<tr>
<th>Stage</th>
<th>Māori N = 41</th>
<th>Non-Māori N = 108</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCC 1A</td>
<td>21 (51)</td>
<td>54 (50)</td>
</tr>
<tr>
<td>SCC 1B</td>
<td>11 (27)</td>
<td>44 (41)</td>
</tr>
<tr>
<td>SCC 2+</td>
<td>9 (22)</td>
<td>10 (9)</td>
</tr>
</tbody>
</table>

Age 45+

<table>
<thead>
<tr>
<th>Stage</th>
<th>Māori N = 20</th>
<th>Non-Māori N = 108</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCC 1A</td>
<td>5 (25)</td>
<td>25 (23)</td>
</tr>
<tr>
<td>SCC 1B</td>
<td>4 (20)</td>
<td>40 (37)</td>
</tr>
<tr>
<td>SCC 2+</td>
<td>11 (55)</td>
<td>43 (40)</td>
</tr>
</tbody>
</table>
9.4.10 Comparison of women with consent for collection of medical record data with all eligible women

Purpose

The majority of the analyses in this report were performed using data from the 371 women for whom information from medical records was collected. Therefore Table 18 compares these women with all eligible women to assess the generalisability of the sample for whom medical record data were available.

Data in this table

**Denominator:** the 445 women eligible for further Audit data collection.

**Data:** from NCR (stage), questionnaire (date of birth), NHI (date of birth where woman not interviewed), medical records (date histological specimen taken), histology result (date, where no medical record collection), and NCSP-R (smears).

Methods

The table shows data that compare the distribution of stage and age at diagnosis, and the number of smears, among women whose medical records were available with the whole group of eligible women. Some direct comparisons between those with and without consent for records are reported below.

Findings

Age at diagnosis was similarly distributed in women with and without consent to medical records, and the mean age was 47 in both groups.

Stage at diagnosis was missing on NCR data for 26% of women. Among women for whom a stage was available, women with consent to medical record collection were less likely to have stage 2 disease or greater (86/275 vs 28/54; Risk Difference -21% (-32% to -9%)). They were also more likely to have had smears in the 6–84 months prior to diagnosis (226/371 vs 29/74; Risk Difference 22% (11% to 31%)), and more likely to have had three or more smears during that period (96/371 vs 10/74; Risk Difference 12% (4% to 19%)). The high proportion with consent for records meant that despite the differences between those with and without consent, those who gave consent were representative of the eligible women overall in their age, stage and smear history.

Stage was available on the NCR for eight (62%) Pacific women, of whom half had stage 1 disease. Five Pacific women were aged over 50, but none were over 70 years old. Pacific women had similar numbers of smears on the NCSP-R to other women.
A stage was available for 11 (69%) Asian women, and nine of them had stage 1 disease. Half the Asian women were over 50 but none were over 70 years old. Half the Asian women had no smears recorded on the NCSP-R.

The small numbers of Pacific and Asian women preclude meaningful conclusions about the representativeness of those who gave consent for medical records collection.

Table 18  Comparison of women with consent for collection of medical record data with all eligible women

<table>
<thead>
<tr>
<th>Stage*</th>
<th>Māori Consent N = 77</th>
<th>All eligible N = 95</th>
<th>Non-Māori Consent N = 294</th>
<th>All eligible N = 350</th>
<th>Total Consent N = 371</th>
<th>All eligible N = 445</th>
</tr>
</thead>
<tbody>
<tr>
<td>1A</td>
<td>15 (19)</td>
<td>17 (18)</td>
<td>43 (15)</td>
<td>50 (14)</td>
<td>58 (16)</td>
<td>67 (15)</td>
</tr>
<tr>
<td>1B</td>
<td>18 (23)</td>
<td>21 (22)</td>
<td>113 (38)</td>
<td>127 (36)</td>
<td>131 (35)</td>
<td>148 (33)</td>
</tr>
<tr>
<td>2 and higher</td>
<td>22 (29)</td>
<td>32 (34)</td>
<td>64 (22)</td>
<td>82 (23)</td>
<td>86 (23)</td>
<td>114 (26)</td>
</tr>
<tr>
<td>Unknown</td>
<td>22 (29)</td>
<td>25 (26)</td>
<td>74 (25)</td>
<td>91 (26)</td>
<td>96 (26)</td>
<td>116 (26)</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20−29</td>
<td>12 (16)</td>
<td>13 (14)</td>
<td>24 (8)</td>
<td>30 (9)</td>
<td>36 (10)</td>
<td>43 (10)</td>
</tr>
<tr>
<td>30−39</td>
<td>27 (35)</td>
<td>32 (34)</td>
<td>83 (28)</td>
<td>98 (28)</td>
<td>110 (30)</td>
<td>130 (29)</td>
</tr>
<tr>
<td>40−49</td>
<td>20 (26)</td>
<td>26 (27)</td>
<td>63 (21)</td>
<td>78 (22)</td>
<td>83 (22)</td>
<td>104 (33)</td>
</tr>
<tr>
<td>50−69</td>
<td>15 (19)</td>
<td>19 (20)</td>
<td>92 (31)</td>
<td>106 (30)</td>
<td>107 (29)</td>
<td>125 (28)</td>
</tr>
<tr>
<td>70−79</td>
<td>3 (4)</td>
<td>5 (5)</td>
<td>32 (11)</td>
<td>38 (11)</td>
<td>35 (9)</td>
<td>43 (10)</td>
</tr>
<tr>
<td>Smears on NCSP-R†</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>32 (42)</td>
<td>43 (45)</td>
<td>113 (38)</td>
<td>147 (42)</td>
<td>145 (39)</td>
<td>190 (43)</td>
</tr>
<tr>
<td>1−2</td>
<td>24 (31)</td>
<td>28 (29)</td>
<td>106 (36)</td>
<td>121 (35)</td>
<td>130 (35)</td>
<td>149 (33)</td>
</tr>
<tr>
<td>3+</td>
<td>21 (27)</td>
<td>24 (25)</td>
<td>75 (26)</td>
<td>82 (23)</td>
<td>96 (26)</td>
<td>106 (24)</td>
</tr>
</tbody>
</table>

* Stage as recorded on the NCR.
† Smears recorded on the NCSP-R in the 6−84 months prior to diagnosis of cancer.
9.4.11 Screening history for women with medical record data

Purpose

Tables 19 and 20 describe adequacy of screening for women with cancer of screening age, using a number of definitions, and according to histological type, stage, and ethnicity.

Data in these tables

Denominator: women aged 20–69 years at diagnosis who consented to medical record collection.

Data: medical records.

Definitions

Analyses of screening history include only those smears that were assumed to be screening smears, therefore exclude any smears taken in the six months prior to diagnosis. The following specific definitions have been used:

- **At least one smear in 6–84 months prior to diagnosis**: this means at least one smear in the 6½ years leading up to the six months immediately prior to diagnosis.

- **At least one smear in 6–42 months prior to diagnosis**: this means at least one smear in the three-year period leading up to the six months immediately prior to diagnosis.

- **Adequate screening**: this means no between-smear interval of more than three years in 6–84 months prior to diagnosis. To fulfil this criterion, a woman would have to have had at least two smears in this 6½-year period, no more than three years apart.

Screening rates for non-Māori were age-standardised to the Māori population to adjust for the younger age structure of the Māori population and the differing screening rates at different ages.

Findings

Sixty-seven percent of women aged between 20 and 69 years (226) had at least one smear within the 6½-year screening period, and only 51% in three years. By the stricter definition, only 21% were adequately screened. If the stricter definition is extended out to 39 months between smears, 30% are adequately screened. Women with adenocarcinoma were more likely to have been screened than women with squamous cancers.
Women with microinvasive (1A) squamous cancer are more likely to have been adequately screened by all definitions than women with higher-stage disease. The Audit was unable to explore the impact of screening on the stage at diagnosis of adenocarcinoma as only seven women had adenocarcinoma beyond stage 1.

Māori women were less likely than non-Māori, after age-standardising, to have been screened within 6–84 months or 6–42 months prior to diagnosis.

Table 19  Women with medical record data (20–69 years) – screening by histological type and stage

<table>
<thead>
<tr>
<th></th>
<th>SCC 1A N = 104</th>
<th>SCC 1B N = 94</th>
<th>SCC 2+ N = 55</th>
<th>ALL SCC N = 261</th>
<th>Adeno N = 53</th>
<th>Total N = 336</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one smear in 6–84 months prior to diagnosis</td>
<td>84 (81)</td>
<td>58 (62)</td>
<td>19 (35)</td>
<td>164 (63)</td>
<td>47 (89)</td>
<td>226 (67)</td>
</tr>
<tr>
<td>At least one smear in 6–42 months prior to diagnosis</td>
<td>56 (54)</td>
<td>42 (45)</td>
<td>14 (25)</td>
<td>113 (43)</td>
<td>39 (74)</td>
<td>165 (49)</td>
</tr>
<tr>
<td>Adequate screening</td>
<td>23 (22)</td>
<td>15 (16)</td>
<td>6 (11)</td>
<td>45 (17)</td>
<td>17 (32)</td>
<td>71 (21)</td>
</tr>
</tbody>
</table>

Table 20  Women with medical record data (20–69 years) – screening by ethnicity

<table>
<thead>
<tr>
<th></th>
<th>All women aged 20–69 years (n = 336)</th>
<th>Non-Māori age-standardised proportion (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Māori N = 74</td>
<td>Non-Māori N = 262</td>
</tr>
<tr>
<td>At least one smear in 6–84 months prior to diagnosis</td>
<td>44 (59)</td>
<td>182 (69)</td>
</tr>
<tr>
<td>At least one smear in 6–42 months prior to diagnosis</td>
<td>31 (42)</td>
<td>134 (51)</td>
</tr>
<tr>
<td>Adequate screening</td>
<td>15 (20)</td>
<td>56 (21)</td>
</tr>
</tbody>
</table>

*  Risk Difference 15% (95% CI: 4%–26%).
†  Risk Difference 12% (95% CI: 0%–25%).
9.4.12 All eligible women – age and screening

Purpose

Table 21 shows the prevalence of screening in all women eligible for the Audit, in different age groups, for Māori and non-Māori, using the three definitions of screening used by the Audit.

Data in this table

**Denominator:** all 445 women eligible to participate in the Audit.

**Data:** from NCSP-R (smears), questionnaire (ethnicity, date of birth), NHI (date of birth where woman were not interviewed), medical records (date histological specimen taken), histology result (date where no medical record collection existed), and all routine sources (ethnicity where no interview took place).

Methods

Smears on the NCSP-R were used to determine women’s screening histories.

Findings

The proportion of Māori women screened was lower than that for non-Māori women in all age groups except 30- to 39-year-olds, where they were similar. The only statistically significant differences between Māori and non-Māori was in 20- to 29-year-olds for at least one smear in 6–42 months prior to diagnosis, and in 40- to 49 and 50- to 69-year-olds for at least one smear in 6–84 months prior to diagnosis. Screening should begin at age 20, so although women aged less than 24 have not had time to accumulate an ‘adequate screening history’ by the Audit definition, the majority should have had a single smear in the previous three years. Although numbers are small, these data suggest that Māori women with cancer, as well as being more poorly screened overall, are entering the programme later.

The proportion of 70- to 79-year-olds who were screened by any definition was low since they were outside the age group for whom regular smears are recommended for at least some of the last seven years. The proportion with a smear in 6–84 months prior to diagnosis was 23%, while the proportion with a smear in 6–42 months prior to diagnosis was 14%, and the proportion adequately screened was 2%.
### Table 21  All eligible women – age and screening

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total N</th>
<th>At least one smear in 6–84 months prior to diagnosis</th>
<th>At least one smear in 6–42 months prior to diagnosis</th>
<th>Adequately screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>20–29</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>13</td>
<td>10 (77)</td>
<td>5 (38)</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Non-Māori</td>
<td>30</td>
<td>28 (93)</td>
<td>* 22 (73)</td>
<td>9 (30)</td>
</tr>
<tr>
<td>All</td>
<td>43</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–39</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>32</td>
<td>25 (78)</td>
<td>19 (59)</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Non-Māori</td>
<td>98</td>
<td>72 (73)</td>
<td>53 (54)</td>
<td>22 (22)</td>
</tr>
<tr>
<td>All</td>
<td>130</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40–49</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>26</td>
<td>10 (38)</td>
<td>7 (27)</td>
<td>4 (15)</td>
</tr>
<tr>
<td>Non-Māori</td>
<td>78</td>
<td>* 50 (64)</td>
<td>34 (44)</td>
<td>16 (21)</td>
</tr>
<tr>
<td>All</td>
<td>104</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50–69</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Māori</td>
<td>19</td>
<td>3 (16)</td>
<td>3 (16)</td>
<td>0</td>
</tr>
<tr>
<td>Non-Māori</td>
<td>106</td>
<td>* 47 (44)</td>
<td>37 (35)</td>
<td>13 (12)</td>
</tr>
<tr>
<td>All</td>
<td>125</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* * p < 0.05 for comparison of % Māori vs % non-Māori.
9.4.13 Participating women (20–69 years) – socioeconomic characteristics by screening

Purpose

Table 22 explores demographic associations with participation in screening.

Data in this table

**Denominator:** women with cervical cancer aged between 20 and 69 at date of diagnosis who consented to medical record collection and were interviewed and responded to questions about their income and education.

**Data:** medical records, questionnaire for income, education, and address at diagnosis.

Methods

Income has been split into two categories: < $20,000 and ≥ $20,000 total gross household income in the year prior to diagnosis. The categories beyond $20,000 were collapsed into one because of a lack of association with screening. Education has also been grouped so that the data presented demonstrate the associations seen.

Socioeconomic status was measured by NZDep2001, which is an area-based score from 1–10 incorporating eight dimensions measuring deprivation from the New Zealand 2001 census. It was assigned according to the census meshblock where the woman lived at the time of diagnosis. Some addresses were unable to be matched by this process. A score of 10 describes individuals living in the most deprived areas. The deprivation indices were then categorised into 1–7 and 8–10 for the analyses. These groups were chosen in an attempt to spread the distribution of both ethnic groups evenly across the categories.

Findings

There were missing data for all of these demographic variables. Data on education were available for 228/262 (87%) non-Māori aged 20–69, and 58/74 (78%) of Māori. Data on income were available for 81% of non-Māori and 76% of Māori. Deprivation indices were available for 65/74 (88%) of Māori and 240/262 (92%) of non-Māori.

High deprivation index and low income are associated with lower levels of screening overall.
Deprivation index was not significantly associated with screening among non-Māori. However, among Māori, women with higher deprivation indices were significantly less well screened in the 6–42 months prior to diagnosis. This finding was consistent across other measures of screening although the differences did not reach statistical significance. Māori and non-Māori with low deprivation indices (less deprived) were similarly screened. Women with missing deprivation indices were similarly screened overall to women in the high deprivation score category of 8–10.

Increasing years of secondary school education (as categorised here) were associated with higher levels of screening among Māori and non-Māori. This was not evident for the third definition of adequate screening, although there were low numbers for comparison.

Non-Māori women were more likely to have been screened if they were in the higher income bracket (≥ $20,000 total annual household income) than those in the lower income bracket. No trend was evident among this group of Māori women. However, there were significant numbers of women who did not provide these data. Women who did not answer the income question were more poorly screened overall than women in the lowest income category.

Table 22 Participating women (20–69 years) – socioeconomic characteristics by screening

<table>
<thead>
<tr>
<th></th>
<th>Non-Māori</th>
<th>Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total N</td>
<td>One smear in 6–84 months prior to diagnosis</td>
</tr>
<tr>
<td></td>
<td>One smear in 6–42 months prior to diagnosis</td>
<td>One smear in 6–84 months prior to diagnosis</td>
</tr>
<tr>
<td>Deprivation index</td>
<td>240</td>
<td>65</td>
</tr>
<tr>
<td>1–7</td>
<td>178 (72)</td>
<td>98 (55)</td>
</tr>
<tr>
<td>8–10</td>
<td>62 (65)</td>
<td>28 (45)</td>
</tr>
<tr>
<td>Education (years at secondary school) (20–69 years)</td>
<td>228</td>
<td>58</td>
</tr>
<tr>
<td>0</td>
<td>7 (43)</td>
<td>2 (29)</td>
</tr>
<tr>
<td>1–3</td>
<td>98 (69)</td>
<td>47 (48)</td>
</tr>
<tr>
<td>4+</td>
<td>123 (79)</td>
<td>74 (60)</td>
</tr>
<tr>
<td>Income (20–69 years)</td>
<td>213</td>
<td>56</td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>36 (56)</td>
<td>12 (33)</td>
</tr>
<tr>
<td>≥ $20,000</td>
<td>177 (80)</td>
<td>106 (60)</td>
</tr>
</tbody>
</table>

* Risk Difference 30% (95% CI: 5%–51%).
† Chi squared test for trend p < 0.05.
‡ Risk Difference 24% (95% CI: 8%–41%).
§ Risk Difference 27% (95% CI: 9%–41%).
9.4.14 Original reporting of smears in women participating in screening

Purpose

Tables 23 and 24 look at potential missed opportunities for prevention of cancer among women who had at least one ‘screening smear’.

Data in these tables

Denominator: those women (20–79 years) who had at least one smear in the three years from 6–42 months prior to diagnosis.

Data: medical records (371 women).

Methods

This table reports the results of screening smears in the 6–42 months prior to diagnosis in women with cervical cancer. As this table is attempting to report screening smear results, only smears more than six months prior to diagnosis are included. Numbers of women who had at least one high-grade, at least two low-grade (without a high-grade), only one low-grade (without a high-grade), or only negative screening smear results in the period from 6–42 months prior to diagnosis are included. This does not attempt to describe all women’s screening histories as some will have been more complicated than these options. These categories may have significance because of NCSP standards or other policy implications.

Findings

170 women had at least one smear in the 6–42 months prior to a diagnosis of cancer.

Of these women, 17% overall had at least one high-grade ‘screening’ smear with no significant difference by histological type. 20/29 of these were within one year before diagnosis. Māori (30%) were more likely than non-Māori (14%) to have had a high-grade screening smear (Risk Difference 16% (95% CI: 2% to 34%). Many women had a high-grade smear prior to diagnosis of their cancer, but seldom more than six months prior to diagnosis as the majority have already been diagnosed.

Twenty-eight women overall had one low-grade smear in this period without a high-grade, and seven had at least two low-grade screening smears during this interval. When a woman has two low-grade reports, a recommendation for referral for colposcopy and biopsy is usual within the New Zealand NCSP.

Sixty-one percent of the women who had a screening smear had only negative smears. This proportion differed significantly by histological type (Risk Difference 25 (95% CI:10%-36%)).
Table 23  Women with medical record data – original smear results by histological type and stage

<table>
<thead>
<tr>
<th>Smear history (results)</th>
<th>SCC 1A N = 56</th>
<th>SCC 1B+ N = 58</th>
<th>SCC N = 115</th>
<th>Adeno N = 40</th>
<th>Total N = 170</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one HG smear in the 6–42 months prior to diagnosis</td>
<td>13 (23)</td>
<td>9 (16)</td>
<td>22 (19)</td>
<td>5 (13)</td>
<td>29 (17)</td>
</tr>
<tr>
<td>At least two LG smears (but no HG) in the 6–42 months prior to diagnosis</td>
<td>1 (2)</td>
<td>4 (7)</td>
<td>5 (4)</td>
<td>2 (5)</td>
<td>7 (4)</td>
</tr>
<tr>
<td>One LG smear (but no HG) in the 6–42 months prior to diagnosis</td>
<td>17 (30)</td>
<td>7 (12)</td>
<td>24 (21)</td>
<td>2 (5)</td>
<td>28 (16)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – one negative smear</td>
<td>20 (36)</td>
<td>28 (48)</td>
<td>48 (42)</td>
<td>24 (60)</td>
<td>80 (47)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – more than one negative smear</td>
<td>5 (9)</td>
<td>8 (14)</td>
<td>13 (11)</td>
<td>7 (18)</td>
<td>23 (14)</td>
</tr>
</tbody>
</table>

Table 24  Women with medical record data – original smear results by ethnicity

<table>
<thead>
<tr>
<th>Smear history (results)</th>
<th>Māori N = 33</th>
<th>Non-Māori N = 137</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one HG smear in the 6–42 months prior to diagnosis</td>
<td>10 (30)*</td>
<td>19 (14)</td>
</tr>
<tr>
<td>At least two LG smears (but no HG) in the 6–42 months prior to diagnosis</td>
<td>1 (3)</td>
<td>6 (4)</td>
</tr>
<tr>
<td>One LG smear (but no HG) in the 6–42 months prior to diagnosis</td>
<td>5 (15)</td>
<td>23 (17)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – one negative smear</td>
<td>12 (36)</td>
<td>68 (50)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – more than one negative smear</td>
<td>4 (12)</td>
<td>19 (14)</td>
</tr>
</tbody>
</table>

* Risk Difference 16% (95% CI: 2%–34%)
9.4.15 Re-read findings

Purpose

Table 25 represents the findings of the re-read by woman rather than by smear.

Data in this table

**Denominator:** the first section of the table includes all women (20–79 years) with any smears reviewed in the Audit. The remainder of the table sections have denominators describing the number of women with smears according to original cytology reporting.

**Data:** re-read results expressed in terms of women.

Methods

Within each original cytology report category (unsatisfactory, low-grade or negative), the highest upgrade for a woman for any smears within that category re-read are represented. This means that if a woman had smears originally reported as negative re-read, with re-read diagnoses of high-grade and unsatisfactory, this woman is included as a highest upgrade of a negative specimen to high-grade. The original and re-read diagnoses were prioritised in terms of the recommendations associated with each diagnosis; ie, (1) high-grade, (2) unsatisfactory, (3) mixed high, low, unsatisfactory, (4) low-grade.

Findings

Women in the Audit with adenocarcinoma were more likely to have had smears re-read (43/57 = 74%) than women with squamous cell carcinoma (120/287 = 42%). This is consistent with the known lower efficacy of cervical screening in adenocarcinoma.

The majority of re-read smears were originally read as negative.

Overall, 33% of the women who had any smear re-read had at least one smear upgraded to high-grade. There was no difference in this upgrade rate between women with squamous carcinoma and adenocarcinoma. As more women with adenocarcinoma had smears in the re-read, screening error was a more important contributor in the pathway to cancer than among women with squamous cell carcinoma (26% of all women with adenocarcinoma compared with 15% of all women with squamous carcinoma (p = 0.03)).

Twenty-two women with a history of prior cervical treatment had smears re-read. Of these women, 32% had a smear upgraded to high-grade.
Findings of re-read of prior negative smears of women with squamous carcinoma by stage

Of the 49 women with microinvasive (1A) squamous carcinoma who had negative smears re-read, 29% had an upgrade to high-grade compared with 20% of the 55 women with stage 1B−4B squamous carcinoma, who had negative smears re-read (p = 0.3). Rates for highest upgrade to unsatisfactory were also similar at 6% and 4%. These results do not suggest a differential in the findings of re-reading microinvasive versus frankly invasive cervical squamous carcinoma.

<table>
<thead>
<tr>
<th>Table 25 Women with medical record data – re-read findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women with smears included in re-read</strong></td>
</tr>
<tr>
<td>At least one smear with original read negative</td>
</tr>
<tr>
<td>At least one smear with original read LG</td>
</tr>
<tr>
<td>At least one smear with original read unsatisfactory</td>
</tr>
<tr>
<td>At least one re-read smear upgraded to HG</td>
</tr>
</tbody>
</table>

**Findings of re-read of prior negative smears**

<table>
<thead>
<tr>
<th>Number of women with negative smears re-read</th>
<th>SCC</th>
<th>Adenocarcinoma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one negative smear upgraded by re-read</td>
<td>44 (42)</td>
<td>16 (40)</td>
<td>61 (38)</td>
</tr>
<tr>
<td>Highest upgrade to HG</td>
<td>27 (25)</td>
<td>11 (28)</td>
<td>39 (24)</td>
</tr>
<tr>
<td>Highest upgrade to unsatisfactory</td>
<td>5 (5)</td>
<td>2 (5)</td>
<td>7 (4)</td>
</tr>
<tr>
<td>Highest upgrade to mixed high, low and unsatisfactory</td>
<td>11 (10)</td>
<td>3 (8)</td>
<td>14 (9)</td>
</tr>
<tr>
<td>Highest upgrade to LG</td>
<td>1 (1)</td>
<td>0</td>
<td>1 (1)</td>
</tr>
</tbody>
</table>

**Findings of re-read of prior LG smears**

<table>
<thead>
<tr>
<th>Number of women with LG smears re-read</th>
<th>SCC</th>
<th>Adenocarcinoma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one LG smear upgraded by re-read</td>
<td>18 (46)</td>
<td>5 (50)</td>
<td>25 (47)</td>
</tr>
<tr>
<td>Highest upgrade to HG</td>
<td>17 (44)</td>
<td>5 (50)</td>
<td>24 (45)</td>
</tr>
<tr>
<td>Highest upgrade to unsatisfactory</td>
<td>1 (3)</td>
<td>0</td>
<td>1 (2)</td>
</tr>
</tbody>
</table>

**Findings of re-read of prior unsatisfactory smears**

<table>
<thead>
<tr>
<th>Number of women with unsatisfactory smears re-read</th>
<th>SCC</th>
<th>Adenocarcinoma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one unsatisfactory smear upgraded by re-read</td>
<td>1 (17)</td>
<td>0</td>
<td>1 (13)</td>
</tr>
</tbody>
</table>
9.4.16 Timeliness of follow-up of high-grade smears

Purpose

The pathway to diagnosis of cervical cancer for many women includes a high-grade smear followed by colposcopy or biopsy. Delay in the step following a high-grade smear may impact upon the diagnosis of cancer and stage at diagnosis.

Data in these tables

Denominator: women aged between 20 and 79 who had a high-grade smear prior to diagnosis. The first analysis includes women who had a colposcopy following a high-grade smear. The second analysis includes all women who had a high-grade smear prior to subsequent histology (which may or may not have diagnosed the woman’s cancer).

Data: medical records.

Methods

The experience of all women within the full seven-year review period has been considered here. Retrospectively, it is sometimes difficult to be certain about the timing of some events for some women. These data represent the Audit’s best effort at defining ‘the truth’ but may contain some inaccuracies.

Time from high-grade smear to colposcopy or subsequent histology has been calculated as the difference between the date the smear was taken and the date the colposcopy was performed or biopsy taken.

Twelve and 52 weeks have been used as categories in this analysis based on the NCSP standard for subsequent histology after high-grade cytology. The target for the proportion of women who have a subsequent histology report within 12 weeks of the date the smear was taken is 90% and at 52 weeks 99%.26

Findings

218 women (59% of the 371 women for whom medical record data were available) had a high-grade smear followed by colposcopy. Of these women, 94% overall had a colposcopy within 12 weeks of their first high-grade smear.

271 women had a high-grade smear in the seven years prior to diagnosis. Eleven of these women had a histology on the same day as their first high-grade smear and so are excluded from this analysis. Of the remaining 260, 90% had their first subsequent histology taken within 12 weeks of the date their first high-grade smear was taken.
Table 26  Women with medical record data – time from high-grade smear to colposcopy and histology, by histological type and stage

<table>
<thead>
<tr>
<th></th>
<th>SCC 1A</th>
<th>SCC 1B</th>
<th>SCC 2+</th>
<th>SCC total</th>
<th>Adeno</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time from first HG smear to first colposcopy</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 weeks</td>
<td>88</td>
<td>68</td>
<td>14</td>
<td>175</td>
<td>33</td>
<td>218</td>
</tr>
<tr>
<td>&gt; 12 weeks – 1 year</td>
<td>79 (90)</td>
<td>66 (97)</td>
<td>14 (100)</td>
<td>164 (94)</td>
<td>31 (94)</td>
<td>204 (94)</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>8 (9)</td>
<td>2 (3)</td>
<td>0</td>
<td>10 (6)</td>
<td>2 (6)</td>
<td>13 (6)</td>
</tr>
<tr>
<td><strong>Time from first HG smear to first subsequent histology</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 weeks</td>
<td>95</td>
<td>74</td>
<td>29</td>
<td>205</td>
<td>40</td>
<td>260</td>
</tr>
<tr>
<td>&gt; 12 weeks – 1 year</td>
<td>81 (85)</td>
<td>69 (93)</td>
<td>27 (93)</td>
<td>184 (90)</td>
<td>37 (93)</td>
<td>235 (90)</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>1 (1)</td>
<td>0</td>
<td>1</td>
<td>1 (3)</td>
<td>2 (1)</td>
<td>4 (2)</td>
</tr>
</tbody>
</table>

Table 27  Women with medical record data – time from high-grade smear to colposcopy and histology, by ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Time from first HG smear to first colposcopy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 weeks</td>
<td>47</td>
<td>171</td>
</tr>
<tr>
<td>&gt; 12 weeks – 1 year</td>
<td>41 (87)*</td>
<td>163 (95)</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>6 (13)</td>
<td>7 (4)</td>
</tr>
<tr>
<td><strong>Time from first HG smear to first subsequent histology</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 weeks</td>
<td>54</td>
<td>206</td>
</tr>
<tr>
<td>&gt; 12 weeks – 1 year</td>
<td>47 (87)†</td>
<td>188 (91)</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>6 (11)</td>
<td>15 (7)</td>
</tr>
</tbody>
</table>

* Risk Difference 8% (95% CI: 0.1% to 21%).
† Risk Difference 4% (−4% to 16%).
9.4.17 High-grade smear to diagnosis

Purpose

A high-grade smear is part of the pathway to diagnosis of cervical cancer for the majority of women in this Audit (271/371 = 73%). Analysing the interval from the first high-grade smear to diagnosis demonstrates the extent to which a delay in follow-up may have contributed to the diagnosis of cancer for these women.

Data in these tables

Denominator: women who had a high-grade smear that was taken before a biopsy confirming the diagnosis of cancer.

Data: medical records.

Methods

Six months was used as a threshold in this analysis as it was thought to represent a clinically significant delay.

Findings

Eighty-seven percent of women were diagnosed within six months of the date their first high-grade smear was taken. The numbers are small for comparisons by stage and histological type.

Māori women were more likely to experience a delay of longer than six months (21%) than non-Māori (10%).
Table 28 Women with medical record data – time from high-grade smear to diagnosis, by histological type and stage

<table>
<thead>
<tr>
<th>Time from first HG smear to diagnosis of cancer</th>
<th>SCC 1A</th>
<th>SCC 1B</th>
<th>SCC 2+</th>
<th>SCC total</th>
<th>Adeno</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 6 months</td>
<td>100</td>
<td>76</td>
<td>31</td>
<td>214</td>
<td>41</td>
<td>271</td>
</tr>
<tr>
<td></td>
<td>84 (84)</td>
<td>69 (91)</td>
<td>28 (90)</td>
<td>188 (88)</td>
<td>35 (85)</td>
<td>237 (87)</td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>16 (16)</td>
<td>7 (9)</td>
<td>3 (10)</td>
<td>26 (12)</td>
<td>6 (15)</td>
<td>34 (13)</td>
</tr>
</tbody>
</table>

Table 29 Women with medical record data – time from high-grade smear to diagnosis, by ethnicity

<table>
<thead>
<tr>
<th>Time from first HG smear to diagnosis of cancer</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 6 months</td>
<td>57</td>
<td>214</td>
</tr>
<tr>
<td></td>
<td>45 (79)*</td>
<td>192 (90)</td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>12 (21)</td>
<td>22 (10)</td>
</tr>
</tbody>
</table>

* Risk Difference 11% (95% CI: 1% to 24%).
9.4.18 Management of abnormal bleeding

Purpose
Postcoital and postmenopausal bleeding are symptoms of cervical cancer, but are not specific for this diagnosis. Bleeding does not generally occur until cervical cancer is advanced. For this reason, disease is generally evident at presentation. When there is also an abnormal cervical smear this assists clinicians to consider the diagnosis. The women presented here experienced bleeding but had not had a high-grade smear. The analysis looks at the time interval between the first report of symptoms to diagnosis of cancer among women of all ages.

Data in these tables

Denominator: women with persistent abnormal bleeding (bleeding reported during the six months leading up to diagnosis but prior to the date the diagnostic biopsy was taken) who did not have a high-grade smear at any time prior to the date of diagnosis. Women of all ages are included.

Data: medical records.

Methods
Abnormal bleeding has been defined for this purpose as either postcoital or postmenopausal bleeding because of their recognised association with cervical cancer. Persistent postcoital bleeding or postmenopausal bleeding were defined as postcoital bleeding or postmenopausal bleeding that was reported on at least one occasion in the six months leading up to diagnosis, but the date of onset was taken as the first time that the symptom was recorded. If bleeding was not reported in the six months immediately prior to diagnosis of cancer, it was assumed that the bleeding was due to another cause.

Findings
Postcoital or postmenopausal bleeding persisting into the six months prior to diagnosis was abstracted from the clinical records of 122 (33%) women. There were no differences in the rate of bleeding symptoms by histological type or ethnicity. Of the women with squamous cell carcinoma, abnormal bleeding was more common in women of higher stage (43% of women 1B+ compared to 10% of 1A).

Sixteen women had postcoital or postmenopausal bleeding recorded during the seven years pre-diagnosis but not recorded within the six months before diagnosis and so are not included by this definition.
The tables describe the 48 women with abnormal bleeding who did not also have a high-grade smear at some time in their work-up. No women with stage 1A squamous cell carcinoma are represented within this group. Thirty-five percent were undiagnosed within two months of the first report of their bleeding.

**Table 30  Women with medical record data – time to diagnosis in persistent abnormal bleeding and no high-grade smear, by histological type and stage**

<table>
<thead>
<tr>
<th>Time from first clinical record of PCB or PMB to diagnosis</th>
<th>SCC 1A</th>
<th>SCC 1B</th>
<th>SCC 2+</th>
<th>SCC</th>
<th>Adeno</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 2 months</td>
<td>0</td>
<td>11</td>
<td>21</td>
<td>33</td>
<td>9</td>
<td>48</td>
</tr>
<tr>
<td>2−12 months</td>
<td>4 (36)</td>
<td>2 (10)</td>
<td>6 (18)</td>
<td>0</td>
<td>8 (17)</td>
<td></td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>5 (24)</td>
<td>5 (15)</td>
<td>4 (44)</td>
<td>9</td>
<td>19</td>
<td></td>
</tr>
</tbody>
</table>

**Table 31  Women with medical record data – time to diagnosis in persistent abnormal bleeding and no high-grade smear, by ethnicity**

<table>
<thead>
<tr>
<th>Time from first clinical record of PCB or PMB to diagnosis</th>
<th>Māori</th>
<th>Non-Māori</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 2 months</td>
<td>6 (67)</td>
<td>25 (64)</td>
</tr>
<tr>
<td>2−12 months</td>
<td>3 (33)</td>
<td>5 (13)</td>
</tr>
<tr>
<td>&gt; 1 year</td>
<td>0</td>
<td>9 (23)</td>
</tr>
</tbody>
</table>
9.4.19 Time from colposcopy to diagnosis among women with high-grade histology

Purpose

To investigate the timeliness of diagnosis among women with high-grade histology.

Data in these tables

**Denominator:** all women who had a colposcopy, irrespective of whether this was indicated for a high-grade smear or symptoms, did not have a cancerous biopsy at their first colposcopy, but who had CIN2+ or AIS on biopsy at colposcopy.

**Data:** medical records.

Methods

Two months was used as a threshold in this analysis in line with the NCSP standard for colposcopically directed treatment following high-grade histology. This assumes that a diagnostic biopsy following a high-grade histology is equivalent to treatment and that the biopsy at which the diagnosis of cancer was taken was the subsequent biopsy for these women. A six-month interval was also given as it may have more clinical significance for these women.

Findings

274 women had a colposcopy during the seven years prior to diagnosis of cancer.

Sixty-five women had their diagnostic biopsy for cancer at their first colposcopy. Of the remaining 209 women, 45 had no biopsy, 30 had diagnoses less severe than high-grade (one missing result), and 134 had a biopsy showing CIN2+ or AIS.

Overall, 26% of women with an HSIL/AIS biopsy were undiagnosed within two months of their high-grade biopsy.

Thirty-nine percent of Māori women were undiagnosed at two months following HSIL/AIS biopsy compared to 23% of non-Māori (Risk Differences 17% (95% CI: -1% to 35%).

Of the 30 women with a biopsy result less severe than high-grade, 20 (67%) were undiagnosed within two months of this biopsy.
Table 32  Women with medical record data – time from colposcopy to diagnosis among women with CIN2+/AIS at colposcopic biopsy, by histological type and stage

<table>
<thead>
<tr>
<th>Time from first colposcopy to diagnosis</th>
<th>SCC 1A N = 68</th>
<th>SCC 1B N = 40</th>
<th>SCC 2+ N = 7</th>
<th>SCC N = 116</th>
<th>Adeno N = 13</th>
<th>Total N = 134</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 2 months</td>
<td>50 (74)</td>
<td>29 (73)</td>
<td>6 (86)</td>
<td>85 (73)</td>
<td>10 (77)</td>
<td>98 (73)</td>
</tr>
<tr>
<td>2–6 months</td>
<td>12 (18)</td>
<td>9 (23)</td>
<td>0</td>
<td>22 (19)</td>
<td>3 (23)</td>
<td>26 (19)</td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>6 (9)</td>
<td>2 (5)</td>
<td>1 (14)</td>
<td>9 (8)</td>
<td>0</td>
<td>10 (7)</td>
</tr>
</tbody>
</table>

Table 33  Women with medical record data – time from colposcopy to diagnosis among women with CIN2+/AIS at colposcopic biopsy, by ethnicity

<table>
<thead>
<tr>
<th>Time from first colposcopy to diagnosis</th>
<th>Māori N = 33</th>
<th>Non-Māori N = 101</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 2 months</td>
<td>20 (61)*</td>
<td>78 (77)</td>
</tr>
<tr>
<td>2–6 months</td>
<td>9 (27)</td>
<td>17 (17)</td>
</tr>
<tr>
<td>&gt; 6 months</td>
<td>4 (12)</td>
<td>6 (6)</td>
</tr>
</tbody>
</table>

*  Risk Difference 17% (-1% to 35%).
9.4.20 Screening pathway factors summary

Purpose of these tables
The following two tables are a summary of the key analyses relating to chapter 5: Results: Pathways to Diagnosis in Audit Participants. Further detail of these analyses, and the complexities related to these, are given in the associated tables. The relevant table is noted in the summary table for easy reference.

Data in these tables
Denominator: these tables include all 371 women who gave consent for collection of medical records. Screening history variables are examined only among the 336 women who were aged 20–69 years.

Data: medical records (371).

Methods
Screening data for non-Māori have been age-standardised to the Māori Audit sample population because of the age structure of the Māori population and the association between screening and age.

For further methodological details and definitions, see related tables.

Findings
The factors presented in these tables are not mutually exclusive. They represent factors that may have had an impact on either diagnosis or stage at diagnosis of cervical cancer, although the design of this study means that it cannot be said for certain that these factors caused cancer in any of these women. These findings may help to direct the priorities of the NCSP.

Seventy-nine percent of the women in the Audit aged 20–69 were under-screened. Māori women were significantly more likely to have had low rates of screening in 6–42 and 6–84 months prior to diagnosis. Women with adenocarcinoma had higher screening rates than women with squamous cell carcinoma.

Twenty-eight percent of women overall had only negative smears in the 6–42 months prior to diagnosis of cancer. More (54%) of women with adenocarcinoma had only negative smears in the 6–42 months prior to cancer compared to 21% of women with squamous carcinoma.

Sixteen percent of women overall had at least one smear upgraded to high-grade. Women with adenocarcinoma had at least one smear upgraded to high-grade compared to 15% of women with squamous cell carcinoma. Smears from women with adenocarcinoma were upgraded to high-grade at the same rate as smears from women with squamous cell carcinoma. However, because women with adenocarcinoma had been screened more often than women with squamous carcinoma, both screening...
false negatives and true false negative smears (smears not upgraded at re-read) constituted a greater percentage of all women with adenocarcinoma.

Nine percent of women overall were undiagnosed at six months from their first high-grade smear and 5% of women with postmenopausal or postcoital bleeding, without a high-grade smear, were undiagnosed at two months. A longer internal to diagnosis following a high-grade smear was more common among Māori women.

Eight percent of women overall had a past history of treatment for cervical dysplasia. There were no statistical differences between subgroups.

Table 34  Women with medical record data – screening pathway factors summary, by histological type and stage

<table>
<thead>
<tr>
<th></th>
<th>SCC stage 1A</th>
<th>SCC stage 1B+</th>
<th>All SCC</th>
<th>Adeno</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women, age 20–69 years only</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening history (see Table 19)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never screened in the 6–84 months prior to diagnosis</td>
<td>20 (19)</td>
<td>77 (52)</td>
<td>97 (37)</td>
<td>6 (11)</td>
<td>110 (33)</td>
</tr>
<tr>
<td>No smear in the 6–42 months prior to diagnosis</td>
<td>48 (46)</td>
<td>93 (62)</td>
<td>148 (57)</td>
<td>14 (26)</td>
<td>171 (51)</td>
</tr>
<tr>
<td>Inadequately screened</td>
<td>81 (78)</td>
<td>128 (86)</td>
<td>216 (83)</td>
<td>36 (68)</td>
<td>265 (79)</td>
</tr>
<tr>
<td><strong>Total women, age 20–79 years</strong></td>
<td>105</td>
<td>172</td>
<td>287</td>
<td>57</td>
<td>371</td>
</tr>
<tr>
<td>At least one HG smear reported in the 6–42 months prior to diagnosis</td>
<td>13 (12)</td>
<td>9 (5)</td>
<td>22 (8)</td>
<td>5 (9)</td>
<td>29 (8)</td>
</tr>
<tr>
<td>At least two LG smears (but no HG) reported in the 6–42 months prior to diagnosis</td>
<td>1 (1)</td>
<td>4 (2)</td>
<td>5 (2)</td>
<td>2 (4)</td>
<td>7 (2)</td>
</tr>
<tr>
<td>One LG smear (but no HG) reported in the 6–42 months prior to diagnosis</td>
<td>17 (16)</td>
<td>7 (4)</td>
<td>24 (8)</td>
<td>2 (4)</td>
<td>28 (8)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – one negative smear</td>
<td>20 (19)</td>
<td>28 (16)</td>
<td>48 (17)</td>
<td>24 (42)</td>
<td>80 (22)</td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – more than one negative smear</td>
<td>5 (5)</td>
<td>8 (5)</td>
<td>13 (5)</td>
<td>7 (12)</td>
<td>23 (6)</td>
</tr>
<tr>
<td><strong>Findings of re-read (see Table 25)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any smear (prior negative, LG, unsatisfactory) upgraded to HG</td>
<td>22 (21)</td>
<td>18 (10)</td>
<td>42 (15)</td>
<td>14 (25)</td>
<td>59 (16)</td>
</tr>
<tr>
<td>Any prior negative smear upgraded to HG</td>
<td>14 (14)</td>
<td>11 (6)</td>
<td>27 (9)</td>
<td>11 (19)</td>
<td>39 (11)</td>
</tr>
<tr>
<td><strong>Time to diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time from first HG smear to diagnosis &gt; 6 months (see Table 28)</td>
<td>16 (15)</td>
<td>10 (6)</td>
<td>26 (9)</td>
<td>6 (11)</td>
<td>34 (9)</td>
</tr>
<tr>
<td>Time from first clinical record of PCB or PMB to diagnosis &gt; 2 months (in women with no HG smear) (see Table 30)</td>
<td>11 (6)</td>
<td>11 (4)</td>
<td>4 (7)</td>
<td>17 (5)</td>
<td></td>
</tr>
<tr>
<td><strong>Past history of cervical treatment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In 1–7 years prior to diagnosis</td>
<td>7 (7)</td>
<td>17 (10)</td>
<td>24 (8)</td>
<td>5 (9)</td>
<td>30 (8)</td>
</tr>
<tr>
<td>&gt; 7 years prior to diagnosis</td>
<td>3 (3)</td>
<td>15 (9)</td>
<td>18 (6)</td>
<td>4 (7)</td>
<td>22 (6)</td>
</tr>
<tr>
<td>Women, age 20–69 years only</td>
<td>Māori (N = 74)</td>
<td>Non-Māori (N = 262)</td>
<td>Non-Māori Age-standardised proportion (%)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------</td>
<td>----------------</td>
<td>---------------------</td>
<td>------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Screening history (see Table 20)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never screened in the 6–84 months prior to diagnosis</td>
<td>30 (41)†</td>
<td>80 (31)</td>
<td>(26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No smear in the 6–42 months prior to diagnosis</td>
<td>43 (58)‡</td>
<td>128 (49)</td>
<td>(46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequately screened</td>
<td>59 (80)</td>
<td>206 (79)</td>
<td>(77)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total women, age 20–79 years</strong></td>
<td>77</td>
<td>294</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least one HG smear reported in the 6–42 months prior to diagnosis</td>
<td>10 (13)</td>
<td>19 (6)</td>
<td>(6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least two LG smears (but no HG) reported in the 6–42 months prior to diagnosis</td>
<td>1 (1)</td>
<td>6 (2)</td>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One LG smear (but no HG) reported in the 6–42 months prior to diagnosis</td>
<td>5 (6)</td>
<td>23 (8)</td>
<td>(8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – one negative smear</td>
<td>12 (16)</td>
<td>68 (23)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only negative smears in the 6–42 months prior to diagnosis – more than one negative smear</td>
<td>4 (5)</td>
<td>19 (6)</td>
<td>(6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Time to diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time from first HG smear to diagnosis &gt; 6 months (see Table 29)</td>
<td>12 (16)§</td>
<td>22 (7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time from first clinical record of PCB or PMB to diagnosis &gt; 2 months (in women with no HG smear) (see Table 31)</td>
<td>3 (4)</td>
<td>14 (5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Past history of cervical treatment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In 1–7 years prior to diagnosis</td>
<td>9 (12)</td>
<td>21 (7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 7 years prior to diagnosis</td>
<td>4 (5)</td>
<td>6 (2)</td>
<td>(2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 7 years prior to diagnosis</td>
<td>6 (8)</td>
<td>16 (5)</td>
<td>(5)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Standardised to Audit Māori population.
† Risk Difference compared with non-Māori age-standardised proportion 15% (95% CI: 4% to 26%).
‡ Risk Difference compared with non-Māori age-standardised proportion 12% (95% CI: 0% to 25%).
§ Risk Difference 8% (95% CI: 1% to 18%).
9.4.21 Results of index smear re-read from women with cervical carcinoma

Purpose

Table 36 includes the findings of the re-read of smears from women with cancer (‘index smears’) where the unit of analysis is ‘smear’ rather than ‘woman’. This analysis identifies the proportion of false negative smears, taken in the four years prior to a diagnosis of cancer (excluding smears in the six weeks immediately prior to diagnosis) that were laboratory false negatives.

Data in this table

Denominator: prior negative and low-grade index smears.
Data: smear re-read results.

Methods

This table includes the composite results from the re-read teams. The results are presented separately for squamous cell carcinoma and adenocarcinoma because cervical screening was introduced to detect squamous cell precursors and because New Zealand laboratories might have been less successful at detecting adenocarcinoma precursors (especially during the period these smears were originally read) than the re-reading Australian laboratory is currently. The results are also presented for all smears, including re-read smears of women with ‘other’ histological types.

The smear re-read protocol, developed in collaboration with the Australian and New Zealand pathology advisors to the Audit, determined that the Australian categories of ‘high-grade’ and ‘inconclusive’ should be grouped together as ‘high-grade’. The category ‘inconclusive’ is approximately equivalent to the New Zealand/Bethesda category ‘ASCUS possibly high-grade’. However, the Audit appreciates that ‘ASCUS possibly high-grade’ is a relatively new code (introduced in 1997/98 in New Zealand) and that the differential diagnosis for such a smear during the time period when the earlier index smears were originally read included ‘high-grade’ and ‘benign cellular changes’. Thus, it may not be reasonable to infer that an upgrade to ‘inconclusive’ was a sign of poor-quality cytology. For this reason, the combined results are presented in this table, along with the upgrades of smears to ‘inconclusive’ by all three teams.

Findings

336 index smears were re-read. The Audit team identified seven smears that could not be located for re-reading.
There were only eight originally unsatisfactory (group 1) index smears re-read. One of these was upgraded to high-grade, and the remainder were not upgraded.

The re-read of 160 prior negative smears from women with squamous cell carcinoma revealed an upgrade proportion to high-grade of 18% (95% CI: 12% to 24%). Very few smears were upgraded unanimously to ‘inconclusive’. Four percent were ‘re-graded’ to unsatisfactory, 1% to low-grade, and 8% to a mix of these upgrade types. The remaining 70% of smears were not upgraded. The re-read diagnoses of the 65 prior negative smears from women with adenocarcinoma were upgraded in similar proportions and so the overall re-read results were similar to those reported for smears of women with squamous cell cancers.

Of the 78 low-grade smears re-read, 36% (95% CI: 26% to 47%) overall were upgraded to high-grade, 33% (95% CI: 22% to 45%) from women with squamous cancer and 46% (95% CI: 23% to 71%) from women with adenocarcinoma.

Table 36  Re-read results – index smears

<table>
<thead>
<tr>
<th>Results of re-read of negative smears</th>
<th>Squamous histology</th>
<th>Adenocarcinoma histology</th>
<th>All histological types</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 160</td>
<td>N = 65</td>
<td>N = 250</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>P(95%CI)</td>
<td>N</td>
</tr>
<tr>
<td>Upgraded to HG</td>
<td>28</td>
<td>18 (12–24)</td>
<td>14</td>
</tr>
<tr>
<td>Upgraded to inconclusive</td>
<td>3</td>
<td>2 (1–5)</td>
<td>0</td>
</tr>
<tr>
<td>Regraded to unsatisfactory</td>
<td>6</td>
<td>4 (2–8)</td>
<td>2</td>
</tr>
<tr>
<td>Upgraded to LG</td>
<td>1</td>
<td>1 (0.1–4)</td>
<td>0</td>
</tr>
<tr>
<td>upgraded mixed</td>
<td>13</td>
<td>8 (5–13)</td>
<td>3</td>
</tr>
<tr>
<td>Not upgraded</td>
<td>112</td>
<td>70 (63–77)</td>
<td>46</td>
</tr>
</tbody>
</table>

| Results of re-read of LG smears      | N = 61             | N = 13                    | N = 78                  |
|                                      | N                  | P(95%CI)                  | N                      | P(95%CI)                | N                      | P(95%CI)                |
| Upgraded to HG                       | 20                 | 33 (22–45)               | 6                      | 46 (23–71)              | 28                     | 36 (26–47)              |
| Upgraded to inconclusive             | 0                  | 0 (0–6)                  | 0                      | 0 (0–23)                | 0                      | 0 (0–5)                 |
| Regraded to unsatisfactory           | 2                  | 3 (1–11)                 | 0                      | 0 (0–23)                | 2                      | 3 (1–9)                 |
| upgraded mixed                       | 1                  | 2 (0.3–9)                | 0                      | 0 (0–23)                | 1                      | 1 (0.2–7)               |
| Not upgraded                         | 38                 | 62 (50–73)               | 7                      | 54 (29–77)              | 47                     | 60 (49–70)              |
9.4.22 Smear re-read results of negative index smears, subgrouped as normal and benign cellular changes at original report

Purpose

Table 37 is an expansion of Table 36. It subgroups the prior negative smears into those with an original report of ‘normal’ or those with an original report of ‘benign cellular changes consistent with reaction and repair’ or ‘inflammation and repair’. Upgrades of smears originally read as benign cellular changes may represent laboratory false negatives due to misinterpretation of abnormal cells because of the marked similarity between the appearance of damaged or reactive cells and some malignant cells, whereas upgrades of smears originally read as normal are more likely to be laboratory false negatives due to a lack of detection of abnormal cells.

Data in this table

Denominator: smears originally read as negative, subgrouped as originally read as ‘benign cellular changes’ and ‘normal’.

Data: re-read results.

Methods

Results are presented separately for women with adenocarcinoma and squamous cell carcinoma. Results for all upgrades to high-grade are presented along with unanimous upgrades to ‘inconclusive’.

Findings

Negative smears originally reported as ‘benign cellular changes’ constituted 12% of re-read smears from women with squamous cell cancer, 11% from women with adenocarcinoma, and 10% overall. Thus, the numbers were small for comparison with the remainder of negative smears.

There was a higher rate of upgrades to high-grade among negative smears previously read as ‘benign cellular changes’ than those previously read as normal, although this is only statistically significant when all histological types are pooled (p = 0.01).
Table 37  Re-read results – negative index smears, subgrouped as normal and benign cellular changes at original report

<table>
<thead>
<tr>
<th>Results of re-read of smears originally reported as normal (excludes benign cellular changes)</th>
<th>Squamous histology</th>
<th>Adenocarcinoma histology</th>
<th>All histological types</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 141</td>
<td>N = 58</td>
<td>N = 224</td>
</tr>
<tr>
<td><strong>N</strong></td>
<td><strong>P(95%CI)</strong></td>
<td><strong>N</strong></td>
<td><strong>P(95%CI)</strong></td>
</tr>
<tr>
<td>Upgraded to HG</td>
<td>22</td>
<td>16 (11–23)</td>
<td>11</td>
</tr>
<tr>
<td>Upgraded to inconclusive</td>
<td>2</td>
<td>1 (0.4–5)</td>
<td>0</td>
</tr>
<tr>
<td>Regraded to unsatisfactory</td>
<td>6</td>
<td>4 (2–9)</td>
<td>2</td>
</tr>
<tr>
<td>Upgraded to LG</td>
<td>1</td>
<td>1 (0.2–4)</td>
<td>0</td>
</tr>
<tr>
<td>Upgraded mixed</td>
<td>12</td>
<td>9 (5–14)</td>
<td>2</td>
</tr>
<tr>
<td>Not upgraded</td>
<td>100</td>
<td>71 (63–78)</td>
<td>43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Results of re-read of smears originally reported as benign cellular changes</th>
<th>N = 19</th>
<th>N = 7</th>
<th>N = 26</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td><strong>P(95%CI)</strong></td>
<td><strong>N</strong></td>
<td><strong>P(95%CI)</strong></td>
</tr>
<tr>
<td>Upgraded to HG</td>
<td>6</td>
<td>32 (15–54)</td>
<td>3</td>
</tr>
<tr>
<td>Upgraded to inconclusive</td>
<td>1</td>
<td>5 (1–25)</td>
<td>0</td>
</tr>
<tr>
<td>Regraded to unsatisfactory</td>
<td>0</td>
<td>0 (0–17)</td>
<td>0</td>
</tr>
<tr>
<td>Upgraded to LG</td>
<td>0</td>
<td>0 (0–17)</td>
<td>0</td>
</tr>
<tr>
<td>Upgraded mixed</td>
<td>1</td>
<td>5 (1–25)</td>
<td>1</td>
</tr>
<tr>
<td>Not upgraded</td>
<td>12</td>
<td>63 (41–81)</td>
<td>3</td>
</tr>
</tbody>
</table>
9.4.23 Results of re-read of control smears

Purpose

The control smears were originally reported as ‘negative’ (no abnormalities or only benign cellular changes present) and ‘satisfactory’ (Bethesda A1 code) or ‘satisfactory but limited’ (Bethesda A2 codes) and from women who are not known to have since developed cancer. They were included in the re-read primarily to blind the reviewers to the identity of the index smears. They are not a random sample of all smears taken in the period and may constitute a sample with greater chance of upgrading than a pure random sample as they were originally read at around the same time and in the same laboratories as the index smears. However, their re-read results are presented here as they represent a sample of smears taken and originally read in New Zealand over the years 1996–2002.

Data in this table

Denominator: all control smears re-read by the Audit, excluding unreadable smears.

Data: re-read results.

Methods

The definition for an upgraded smear is as for the index smears (described in chapter 3 section 3.5.4). Glandular and squamous cell cytological abnormalities were defined by combining Laverty Laboratory ‘result code’ data. In the one case where there was disagreement between teams on whether abnormalities were glandular or squamous, the majority view was taken. However, in the table the squamous and glandular cytological diagnoses have been included together because there were only two glandular diagnoses.

The data presented below represent the findings of the re-read alone. No investigation was undertaken by the Audit team into any histological findings that might have ensued from the upgrades identified within this Audit. The clinical care of the women whose smears were re-read was handed on to the original reading laboratories and to the NCSP.

Findings

3785 control smears were re-read. These smears were uplifted from 24 laboratories who reported cervical cytology smears over the period 1996–2002, with a range of 42–828 smears being lifted from anyone laboratory. 3357 smears were collected from the years 1996–2000 and 428 smears from January 2001–August 2002 (the NCSP published standards during 2000). Thirty-two smears were found to be unreadable and so were excluded from the analysis. The amended denominator is 3753.
0.3% of control smears were upgraded to high-grade (95% CI: 0.2% to 0.6%). 202 (5%) of the control smears had originally been reported as ‘benign cellular changes’. Of these, two of the 200 readable smears (1%) were upgraded to high-grade. Of the 3553 prior normal (excluding benign cellular changes) smears, 11 (0.3%) were upgraded to high-grade. These percentages did not differ significantly (p = 0.15 FE).

Table 38  Re-read results – control smears

<table>
<thead>
<tr>
<th>Category</th>
<th>N</th>
<th>Proportion (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsatisfactory (cat 1)</td>
<td>103</td>
<td>2.7 (2.3–3.3)</td>
</tr>
<tr>
<td>LG (cat 3)</td>
<td>9</td>
<td>0.2 (0.1–0.5)</td>
</tr>
<tr>
<td>HG (cat 4)</td>
<td>13*</td>
<td>0.3 (0.2–0.6)</td>
</tr>
<tr>
<td>* Inconclusive only</td>
<td>4</td>
<td>0.1 (0.0–0.3)</td>
</tr>
<tr>
<td>Upgraded mixed</td>
<td>26*</td>
<td>0.7 (0.5–1.0)</td>
</tr>
<tr>
<td>Not upgraded</td>
<td>3602</td>
<td>96.0 (95.3–96.6)</td>
</tr>
</tbody>
</table>

* Includes one glandular cytological diagnosis.
9.4.24 Re-read upgrade rates by original reporting of adequacy for smears originally reported as negative

Purpose

To explore the hypothesis that New Zealand laboratories may be over-using Bethesda A2 (‘satisfactory but limited …’) codes in cases where cervical disease is present but good assessment is prevented by the smear’s limitations. In these cases, calling the smear A3 (‘unsatisfactory’) rather than A2 would have meant that the woman would have had an immediate repeat smear, with the consequent opportunity for earlier diagnosis. This hypothesis would be supported if A2 smears were more common among women with cancer than women without cancer, or if A2 smears were more often upgraded to high-grade than A1 (satisfactory) smears.

Data in this table

Denominator: all prior negative index smears and control smears, excluding unreadable smears.

Data: re-read results.

Methods

All Bethesda A2 codes have been combined. Upgrades of smears originally read as A1 are compared with those for smears originally read as A2.

Findings

A2 smears constituted 19% of control smears and 23% of index smears. That these two proportions are not significantly different (Risk Difference 3.5% (95% CI: 1.9% to 8.8%)) suggests that A2 codes are not being over used by New Zealand laboratories in cases where there is a high risk of malignancy.

Not surprisingly, in both index and control smears, those with Bethesda A2 codes were more likely to be regraded to unsatisfactory by the re-read than A1 (‘satisfactory’) (p < 0.0001 for control smears). The proportion regraded to unsatisfactory is similar in index (7%) and control (6%) smears. Anecdotally, Australian laboratories have a different threshold for calling a smear ‘unsatisfactory’ and do not use an equivalent to A2, so some degree of upgrading to unsatisfactory was expected. However, the absolute difference between the proportions of A1 smears and A2 smears upgraded to unsatisfactory is about 4% in both index and control smears. This suggests that, if New Zealand stopped using the A2 codes, about 4% of the smears currently called A2 would be called unsatisfactory.
Within both index and control smears, the proportion upgraded to high-grade was not statistically significantly different in A1 and A2 smears. This suggests that the limitations of A2 smears are not leading to their being more likely to be laboratory false negatives.

**Table 39  Re-read upgrade rates by original reporting of adequacy for smears originally reported as negative**

<table>
<thead>
<tr>
<th>Bethesda adequacy code</th>
<th>Smear type</th>
<th>N</th>
<th>N (%)</th>
<th>N (%)</th>
<th>N (%)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 (satisfactory)</td>
<td>Index</td>
<td>193</td>
<td>6 (3)</td>
<td>1 (1)</td>
<td>35 (18)</td>
<td>10 (5)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>3027</td>
<td>57 (2)</td>
<td>8 (0)</td>
<td>12 (0)</td>
<td>13 (0)</td>
</tr>
<tr>
<td>A2 (satisfactory but limited)</td>
<td>Index</td>
<td>57</td>
<td>4 (7)</td>
<td>0</td>
<td>8 (14)</td>
<td>6 (11)</td>
</tr>
<tr>
<td></td>
<td>Control</td>
<td>726</td>
<td>46 (6)</td>
<td>1 (0)</td>
<td>1 (0)</td>
<td>13 (2)</td>
</tr>
</tbody>
</table>
9.4.25 Comparison of NCR incidence data with Audit incidence data

Purpose
The data sent to the Audit included information on women who should not have been registered on the NCR as having invasive cervical cancer (see Table 10). The NCR registers women on the basis of some ‘inconclusive diagnoses’ in accordance with the Surveillance Epidemiology and End Results (SEER) Program recommendations. However, these recommendations also state that ‘it is the practice to accept the thinking and information about the case based on the latest or most complete information’. It seems appropriate, therefore, that women whose latest information is that they do not have cancer should not continue to be recorded on the NCR. In addition, the NCR does not necessarily define the date of diagnosis as the date of first invasive histology, even where such histology exists. Finally, the NCR ethnicity data underestimate the number of Māori women diagnosed with invasive cervical cancer (Table 11). Table 40 compares the number of cases and the incidence rate (overall and for Māori and non-Māori) reported by the NZHIS with those confirmed by the Audit.

Data in this table
Data: from NCR (ethnicity, date of diagnosis), the Audit database and information obtained in the process of determining eligibility (appropriateness of registration), medical records (date diagnostic histological specimen taken), interview (ethnicity), all available routine sources (ethnicity where no interview).

Methods
In order to assess the accuracy of the number of women registered with invasive cervical cancer on the NCR, women considered to be appropriately registered included:
- women eligible for the Audit
- women with histologically proven invasive cervical cancer excluded because of age or residency
- women with no histological information, who had a clinical diagnosis of cervical cancer
- women for whom the primary site of their cancer was unclear but clinically was probably the cervix
- women whose only cervical histology was not invasive but who clinically had cervical cancer
- women whose only cervical histology was ‘suspicious of invasion’ or similar, and the Audit had no confirmation of clinical diagnosis,

Women considered inappropriately registered included:
- women whose primary site was unclear, but there was no indication that a clinical diagnosis of cervical cancer had been made
- women who had no histology demonstrating invasion and no clinical diagnosis of cervical cancer
- women whose initial histology report was invasive, but on review it was downgraded to non-invasive
- women whose initial histology report was ‘suspicious of invasion’ or similar, and the specialist confirmed that on further investigation the woman had been clinically considered not to have cancer
- women whose initial histology report was ‘suspicious of invasion’ or similar and the Audit had no confirmation of clinical diagnosis, but a follow-up histology was clear of cancer.

Variable definitions:
- ‘NCR date of diagnosis and ethnicity’ are as recorded in the NCR data supplied to the Audit
- Audit date of diagnosis is the date of histological diagnosis where a histology was taken, otherwise the date reported by the NCR
- Audit Māori ethnicity is identified as Māori at interview where an interview took place and otherwise Māori on any routine data source
- age-standardised incidence rates are standardised to Segi’s world population.
Findings

The 562 women who were possibly eligible for the Audit had dates of diagnosis recorded on the NCR between 1999 and 2002. The data from 1999 and 2002 were not from the full years and so the appropriateness of registrations in 2000 and 2001 was assessed. The NCR had, at the request of the Audit, not excluded women diagnosed overseas from the information sent to the Audit for checking, but the seven women who were diagnosed overseas were presumably not included in the official statistics reported by the NCR.

The NCR date of diagnosis for women diagnosed in New Zealand was during 2000 for 206 of the 555 women on whom the Audit had information and during 2001 for 200 women. The NZHIS reported 208 registered cases in 2000 and 191 in 2001. Therefore there are seven women from these two years whose data were supplied to the Audit but who do not appear in the official statistics. Presumably after their data were supplied to the Audit, NCR checking determined that they should not be registered.

The number of incident cases and the age-standardised incidence rates reported by the NZHIS for 2000 and 2001 are shown in the first part of the table. The second part shows the figures obtained by continuing to use the NCR date of diagnosis and ethnicity but restricting the calculations to women who were appropriately registered (ie, those who by the definition above had invasive cervical cancer). The case numbers are 200 in 2000 and 189 in 2001, which means that NCR-reported figures overcounted by eight women (5%) in 2000 and by 2 (1%) in 2001, and slightly overestimated the overall age-standardised incidence rate. The third part of the table continues to use the NCR ethnicity variable but shows that using the Audit date of diagnosis changes the numbers only slightly. The fourth part shows the numbers and rates that the NCR would have reported (ie, using their date of diagnosis) if they had only registered appropriate women but had access to the Audit definition of ethnicity. This shows that the NCR data underestimated the number of Māori cases by 13% over the two years, with 67 women identified as Māori by the NCR over that time but 77 by the Audit. Māori incidence rates were underestimated by 1.8 per 100,000 in each year. Finally, the bottom section of the table shows what the Audit considers to be the correct Māori, non-Māori and overall number of cases and age-standardised incidence for 2000 and 2001.

<table>
<thead>
<tr>
<th>NZHIS reported cases and incidence rates</th>
<th>Māori</th>
<th>Non-Māori</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000 – NZHIS website</td>
<td>Not given</td>
<td>Not given</td>
<td>208 (8.7)</td>
</tr>
<tr>
<td>2001 – NZHIS website</td>
<td>Not given</td>
<td>Not given</td>
<td>191 (8.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confirmed cases* and incidence rates using NCR ethnicity and NCR date of diagnosis</th>
<th>Number (age-standardised rate per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>38 (13.7) 162 (7.6) 200 (8.4)</td>
</tr>
<tr>
<td>2001</td>
<td>29 (11.3) 160 (7.6) 189 (8.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confirmed cases* and incidence rates using NCR ethnicity and Audit date of diagnosis†</th>
<th>Number (age-standardised rate per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>36 160 196 (8.2)</td>
</tr>
<tr>
<td>2001</td>
<td>30 162 192 (8.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confirmed cases* and incidence rates using Audit ethnicity‡ and NCR date of diagnosis</th>
<th>Number (age-standardised rate per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>44 (15.5) 156 (7.3) 200 (8.3)</td>
</tr>
<tr>
<td>2001</td>
<td>33 (13.1) 156 (7.4) 189 (8.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confirmed cases* and incidence rates using Audit ethnicity and Audit date of diagnosis</th>
<th>Number (age-standardised rate per 100,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>43 (14.9) 153 (7.2) 196 (8.2)</td>
</tr>
<tr>
<td>2001</td>
<td>34 (13.6) 158 (7.5) 192 (8.1)</td>
</tr>
</tbody>
</table>

* Cases considered appropriately registered on the NCR given Audit data.
† Date of histological diagnosis where histology available; otherwise date of diagnosis recorded on the NCR.
‡ Ethnicity defined at interview where available; otherwise Māori if Māori by any routine data source.
9.4.26 Stage data on NCR and from medical records

Purpose

The NCSP indicator ‘A11. Stage of invasive cancer’ sets a target that the proportion of women beyond stage 1 at diagnosis will be 30% or less. In order to monitor this aspect of the performance of the NCSP, the NCR must accurately record stage data. The Auditors understand that the NCR undertakes some checking with gynaecological oncology units to ascertain stage, but their stage data remain so incomplete that they are not reported in the official cancer statistics.16

When women’s data were first supplied to the Audit, which was always at least six months after diagnosis, 42% of NCR records had missing data on stage. By the date that the last data update from the NCR was received (December 2003), this had reduced to 26% with missing stage data on the NCR. Table 41 compares that updated stage information with the stage information ascertained from medical records.

Data in this table

Denominator: the 371 women who gave consent for Audit access to medical records.

Data: NCR (stage), medical records (stage), and interview and all routine sources (ethnicity).

Methods

For each stage ascertained from medical records, the proportion of women with that and other stages recorded on the NCR was calculated. Stage has been categorised as 1A, 1B, and 2+.

Findings

For the majority of women (72%), the stage recorded on the NCR was in the same category as that ascertained from medical records, including 15 women who were unstaged by both. Where the two sources did not agree, this was often due to missing stage data on the NCR. When both sources had a stage recorded, there was agreement for 95% of women. Agreement within the stage 2+ category does not imply that women had exactly the same stage on both sources.

For women with stage 1B and 2+, the NCR stage group agreed with that ascertained by the Audit in over 80% of cases. However, only 49% of the women with confirmed stage 1A disease had any stage recorded on the NCR. Women with stage 1A disease were able to be completely ascertained by the Audit because this diagnosis is made on histology, and by definition all women included in the Audit had histological specimen results.
When stages over 1B were grouped as 2, 3 and 4, there were 25 women (7% of the total) who had a stage available from both sources, but they disagreed. Of these, nine women had a lower stage on the NCR than the Audit ascertained, and 16 had a higher stage on the NCR. In some of these cases, the NCR had initially recorded a lower stage, or the stage had been missing, and then a higher stage had been supplied in a data update.

**Table 41 Stage data on NCR and from medical records**

<table>
<thead>
<tr>
<th>Stage on NCR</th>
<th>Māori women</th>
<th>Stage ascertained from medical records</th>
<th>Non-Māori women</th>
<th>Stage ascertained from medical records</th>
<th>All women</th>
<th>Stage ascertained from medical records</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1A</td>
<td>1B</td>
<td>2+</td>
<td>Unknown</td>
<td>1A</td>
<td>1B</td>
</tr>
<tr>
<td>Stage on NCR</td>
<td>N = 29</td>
<td>N = 21</td>
<td>N = 22</td>
<td>N = 5</td>
<td>N = 84</td>
<td>N = 129</td>
</tr>
<tr>
<td>1A</td>
<td>14 (48)</td>
<td>1 (5)</td>
<td></td>
<td></td>
<td>41 (49)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>1B</td>
<td>18 (86)</td>
<td></td>
<td></td>
<td></td>
<td>5 (6)</td>
<td>103 (80)</td>
</tr>
<tr>
<td>2+</td>
<td>1 (5)</td>
<td>20 (91)</td>
<td>1 (20)</td>
<td></td>
<td>5 (4)</td>
<td>56 (88)</td>
</tr>
<tr>
<td>Unknown</td>
<td>15 (52)</td>
<td>1 (5)</td>
<td>2 (9)</td>
<td>4 (80)</td>
<td>38 (45)</td>
<td>19 (14)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9.4.27 Histological type ascertained from medical records and recorded on NCR

Purpose

In order to assist the NCSP in monitoring trends in incidence of and mortality from cervical cancer, the NCR needs to keep accurate data on the histological type of registered cancers. The NCR includes two fields that record this information – an ICD-oncology code\textsuperscript{78} and a free text description. Table 42 compares those data with pathology abstracted from medical records.

Data in this table

Denominator: the 371 women who gave consent for Audit access to medical records.

Data: NCR (ICD-O code, histology free text information), medical record abstraction (histological type).

Methods

Audit pathology advisors classified each of the free text descriptions of tumour type recorded on the NCR into the same categories as the Audit histological type categories – squamous, adenocarcinoma, adenosquamous and other.

ICD-O codes were grouped as in the ICD-O manual.

Findings

Using the free text descriptions categorised by Audit pathology advisors, 364 (98\%) of NCR records agreed with the histological type ascertained from medical records. The ICD-O code\textsuperscript{78} recorded on the NCR was almost as accurate, with 361 (97\%) agreeing.
### Table 42  Histological type ascertained from medical records and recorded on NCR

<table>
<thead>
<tr>
<th>Histological type recorded on NCR</th>
<th>Histological type ascertained from medical records</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Squamous cell carcinoma</td>
</tr>
<tr>
<td>Free text description</td>
<td>N = 287</td>
</tr>
<tr>
<td>Squamous cell carcinoma</td>
<td>286 (100)</td>
</tr>
<tr>
<td>Adenocarcinoma</td>
<td>0</td>
</tr>
<tr>
<td>Adenosquamous carcinoma</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1 (0)</td>
</tr>
<tr>
<td>ICD-O code</td>
<td></td>
</tr>
<tr>
<td>805–808 (squamous cell neoplasms)</td>
<td>286 (100)</td>
</tr>
<tr>
<td>809–811 (basal cell neoplasms)</td>
<td>0</td>
</tr>
<tr>
<td>812–813 (transitional cell papillomas and carcinomas)</td>
<td>1 (0)</td>
</tr>
<tr>
<td>814–838 (adenomas and adenocarcinomas)</td>
<td>0</td>
</tr>
<tr>
<td>844–849 (cystic, mucinous and serous neoplasms)</td>
<td>0</td>
</tr>
<tr>
<td>856–857 (complex epithelial neoplasms)</td>
<td>0</td>
</tr>
</tbody>
</table>
9.4.28 Accuracy of women’s smear data on NCSP-R

Purpose

The main reason for interviewing women in the Audit was that the NCSP-R was known to be incomplete, and therefore it was necessary to get women’s consent to access their medical records in order to completely ascertain their screening history. Table 43 compares, for each woman, the number of smears recorded on the NCSP-R with the total number following medical record checking.

Data in this table

Denominator: the 371 women who gave consent for Audit access to medical records.
Data: NCSP-R (smears and ‘screening history’ variable), medical records (smears), and interview and all routine sources (ethnicity).

Methods

For each woman, the number of smears recorded on the NCSP-R was compared with the number ascertained by augmenting the NCSP-R data with information from medical records.

Findings

The NCSP-R had recorded 600 of the 645 total smears identified for the period from 6–84 months prior to diagnosis. Twenty-six women had more smears in their records than on the NCSP-R, including nine who had no smears on the NCSP but 1–5 in their medical records. However, 93% of women, whether Māori or non-Māori, had the same number of smears on the NCSP as was found by searching medical records, including 136 with no smears found in either source.
Table 43  Accuracy of women’s smear data on NCSP-R

<table>
<thead>
<tr>
<th>Number of smears per woman*</th>
<th>Māori N = 77</th>
<th>Non-Māori N = 294</th>
<th>Total N = 371</th>
</tr>
</thead>
<tbody>
<tr>
<td>None on NCSP-R, 1 or more in records†</td>
<td>2 (3)</td>
<td>7 (2)</td>
<td>9 (2)</td>
</tr>
<tr>
<td>Same number in records and on NCSP-R‡</td>
<td>72 (94)</td>
<td>273 (93)</td>
<td>345 (93)</td>
</tr>
<tr>
<td>1 more in records than on NCSP-R§</td>
<td>2 (3)</td>
<td>4 (1)</td>
<td>6 (2)</td>
</tr>
<tr>
<td>2 more in records than on NCSP-R</td>
<td>6 (2)</td>
<td>6 (2)</td>
<td>12 (2)</td>
</tr>
<tr>
<td>3+ more in records than on NCSP-R</td>
<td>1 (1)</td>
<td>4 (1)</td>
<td>5 (1)</td>
</tr>
</tbody>
</table>

* In the period from 6–84 months prior to diagnosis.
† NCSP-R data augmented by medical record data.
‡ Including 136 women with no smears recorded on the NCSP-R or in medical records.
§ Excluding those with no smears on the NCSP-R.
9.4.29 Smear histories on NCSP-R compared with medical records

Purpose

The main reason for interviewing women in the Audit was that the NCSP-R was known to be incomplete, and therefore it was necessary to get women’s consent to access their medical records in order to completely ascertain their screening history. An important component of monitoring the NCSP through the register is identifying the proportion of women in the population who are adequately screened (‘coverage’), so that efforts to recruit and recall women can be prioritised and potentially directed at specific geographic, age or ethnic groups. By using complete screening histories, with smear records from the register augmented with records of smears obtained from medical records, it is possible to assess the accuracy of estimates of coverage derived from NCSP-R data among women with cancer.

Table 44 shows the proportion of women ‘screened’, using the three definitions of smear in 6–84 months prior to diagnosis, smear in 6–42 months prior to diagnosis, and ‘adequate screening history’, calculated from NCSP-R data and from all the data obtained by the Audit (NCSP-R and medical records), to assess the suitability of the NCSP-R for monitoring coverage among women with cancer.

Data in this table

Denominator: the 371 women who gave consent for Audit access to medical records.
Data: NCSP-R (smears), medical records (smears), and interview and all routine sources (ethnicity).

Methods

Numbers of smears within specified timeframes and ‘adequate smear history’ were calculated using only data held on the NCSP-R and also using all Audit data, including NCSP-R and medical record data.

Findings

The proportion of women with smears in the 6–84 months prior to diagnosis, in the 6–42 months prior to diagnosis and with an adequate screening history was very similar whether the NCSP-R was used alone or augmented with information from medical records, for Māori, non-Māori and all women. The proportion of these women with an adequate screening history is much lower than the proportion of women screened in the 6–42 months prior to diagnosis (19% compared with 46%).

If the NCSP ethnicity variable is used to define women as Māori or non-Māori, the number of women defined as Māori drops to 66. However, the proportions of Māori and non-Māori women screened using any of the Audit definitions were unchanged (data not shown).
Table 44 Smear histories on NCSP-R compared with medical records

<table>
<thead>
<tr>
<th></th>
<th>Māori N = 77</th>
<th>Non-Māori N = 294</th>
<th>Total N = 371</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recorded on NCSP-R</td>
<td>Ascertained from medical records</td>
<td>Recorded on NCSP-R</td>
</tr>
<tr>
<td>No smears in the 6–84 months prior to diagnosis</td>
<td>32 (42)</td>
<td>30 (39)</td>
<td>113 (38)</td>
</tr>
<tr>
<td>Any smears in the 6–84 months prior to diagnosis</td>
<td>45 (58)</td>
<td>47 (61)</td>
<td>181 (62)</td>
</tr>
<tr>
<td>Any smears in the 6–42 months prior to diagnosis</td>
<td>32 (42)</td>
<td>33 (43)</td>
<td>134 (46)</td>
</tr>
<tr>
<td>Adequate screening history</td>
<td>14 (18)</td>
<td>15 (19)</td>
<td>54 (18)</td>
</tr>
</tbody>
</table>
References

Kōrero whakatara


### Appendix 1: Glossary of Abbreviations

**Papakupu o ngā Whakarāpopototanga**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGUS</td>
<td>Atypical glandular cells of undetermined significance</td>
</tr>
<tr>
<td>AIS</td>
<td>Adenocarcinoma in situ</td>
</tr>
<tr>
<td>ASCUS</td>
<td>Atypical squamous cells of undetermined significance</td>
</tr>
<tr>
<td>CIN</td>
<td>Cervical intraepithelial neoplasia (grades from CIN1 to CIN3)</td>
</tr>
<tr>
<td>DHB</td>
<td>District Health Board</td>
</tr>
<tr>
<td>EUA</td>
<td>Examination under anaesthetic</td>
</tr>
<tr>
<td>FIGO</td>
<td>International Federation of Gynaecology and Obstetrics</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HPV</td>
<td>Human papilloma virus</td>
</tr>
<tr>
<td>HSIL</td>
<td>High-grade squamous intraepithelial lesion</td>
</tr>
<tr>
<td>LSIL</td>
<td>Low-grade squamous intraepithelial lesion</td>
</tr>
<tr>
<td>NCSP IMG</td>
<td>National Cervical Screening Programme Independent Monitoring Group for the National Cervical Screening Programme</td>
</tr>
<tr>
<td>NCSP</td>
<td>National Cervical Screening Programme</td>
</tr>
<tr>
<td>NCSP-R</td>
<td>National Cervical Screening Programme Register</td>
</tr>
<tr>
<td>NCR</td>
<td>National Cancer Registry</td>
</tr>
<tr>
<td>NHI</td>
<td>National Health Index</td>
</tr>
<tr>
<td>NSU</td>
<td>National Screening Unit</td>
</tr>
<tr>
<td>NZHIS</td>
<td>New Zealand Health Information Service</td>
</tr>
<tr>
<td>PCB</td>
<td>Postcoital bleeding</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary health organisation</td>
</tr>
<tr>
<td>PMB</td>
<td>Postmenopausal bleeding</td>
</tr>
<tr>
<td>PPV</td>
<td>Positive predictive value; the proportion of abnormal smears where investigation confirms a cervical histological lesion</td>
</tr>
<tr>
<td>PRT</td>
<td>Pathology review team</td>
</tr>
<tr>
<td>SCC</td>
<td>Squamous cell carcinoma</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Appendix 2: Glossary of Terms

**Papakupu o ngā kupu**

- **Ablative therapy**: Treatment to the cervix to destroy dysplastic tissue (e.g., by laser, cryotherapy, diathermy)
- **Abnormal smears**: All smears showing epithelial cell abnormalities, including atypical squamous cells of undetermined significance (ASCUS) and atypical glandular cells of undetermined significance (AGUS) but not including benign cellular changes (i.e., infection and reaction epithelial cell changes)
- **Adenocarcinoma**: A cancer involving the columnar cells rather than the squamous cells
- **Adenocarcinoma in situ**: High-grade changes to glandular cells of the cervix
- **Adenosquamous carcinomas**: The epithelial cells of the cervix have the ability to mature towards glandular type. While most carcinomas of the cervix show either pure squamous or glandular features, a number show mixed features in varying proportions and these are termed ‘adenosquamous’ carcinomas
- **Age-standardised rate**: A derived rate where age-specific rates from one population are applied to the age structure of a different population in order to allow comparisons adjusted for age
- **Bethesda coding system**: A systematic method of reporting cervical smear results
- **Biopsy**: The removal of a small piece of body tissue for testing in the laboratory to assist in diagnosis of cell changes or disease
- **Carcinoma**: Cancer that begins in the lining or covering of a tissue
- **Carcinoma in situ**: Cancer cells that are restricted to a very local area. The abnormal cells are evident throughout each of the layers of the epithelium, but they have not extended into other tissue or surrounding areas. Equivalent to CIN3
- **Cervical smear test**: A screening test where a sample of the surface cells, of the cervix or vaginal vault is taken, preserved immediately and sent to the laboratory for examination
- **Colposcopy**: Examination of the cervix and vagina to check for abnormal cells using a magnifying instrument called a colposcope
- **Control smears**: Negative smears from women enrolled on the NCSP-R who have not been diagnosed with cancer
- **Downgraded histology**: Following a review, the original histology result is altered to a lesser classification; for instance, changed from invasive to non-invasive
- **Dysplasia**: Abnormal cell growth
- **Electoral roll**: A government list of name and contact details of New Zealand voters
- **Endocervix**: Internal aspect of the cervix
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>False negative smear</td>
<td>A smear from a woman who has disease that is reported as not indicating a cervical abnormality</td>
</tr>
<tr>
<td>False positive</td>
<td>A smear from a woman who does not have disease that is reported as indicating a cervical abnormality</td>
</tr>
<tr>
<td>Glandular cells of the cervix</td>
<td>Cells lining the inner canal of the cervix. Also called columnar or endocervical cells</td>
</tr>
<tr>
<td>High-grade</td>
<td>Encompasses cervical cytological abnormalities (CIN2, CIN3, CIS (carcinoma in situ), AIS, suspicious of cancer, cancerous changes) that are associated in New Zealand with a recommendation for immediate referral</td>
</tr>
<tr>
<td>Histological date of diagnosis/histological confirmation</td>
<td>The date the biopsy that determined the woman had cervical cancer was taken</td>
</tr>
<tr>
<td>Human Papilloma Virus (HPV)</td>
<td>A group of viruses that can cause infection in the skin surface of different areas of the body, including the genital area. The virus can cause visible warts or may only cause microscopic changes in the cells.</td>
</tr>
<tr>
<td>Index specimens</td>
<td>Prior negative, low-grade and unsatisfactory smears from women with cancer</td>
</tr>
<tr>
<td>Low-grade</td>
<td>Encompasses cervical cytological abnormalities (condylomatous change, HPV, CIN1, dysplasia (unstated severity)), which are associated in New Zealand with a recommendation for repeat smear in six months. If similar or more serious cytological abnormalities are detected on the repeat smear, referral for colposcopy is indicated.</td>
</tr>
<tr>
<td>Microinvasive cervical carcinoma</td>
<td>An early stage of invasive cervical cancer that is not visible macroscopically, with virtually no risk of lymph node metastases; carcinoma that has invaded no more than 5 mm in depth through the basement membrane and no more than 7 mm in horizontal extension</td>
</tr>
<tr>
<td>Misread</td>
<td>A false negative smear that was read as normal either because the abnormal cells present were not detected by the laboratory staff or because abnormal cells were identified but their significance was misinterpreted as benign rather than dysplastic or malignant. Encompasses the terms ‘detection error’, ‘screening error’, ‘interpretation error’, commonly used in the published literature</td>
</tr>
<tr>
<td>Multidisciplinary meeting</td>
<td>A meeting of pathologists, clinicians, including gynaecological oncologists, at which cytological and histological specimens and management are reviewed. Also known as a ‘tumour panel’ or ‘clinico-pathological conference’</td>
</tr>
<tr>
<td>Negative smear</td>
<td>Smear with result showing no suspicious or dysplastic cell abnormalities (but may include benign cellular changes)</td>
</tr>
<tr>
<td>Next of kin</td>
<td>The deceased woman’s personal representative who is the executor or administrator of the woman’s estate and who can give consent for GPs, specialists or laboratories to disclose health information (including smears)</td>
</tr>
<tr>
<td>Normal smear</td>
<td>Smear with result showing no epithelial cell abnormalities</td>
</tr>
<tr>
<td>Opportunistic smear-taking</td>
<td>Taking cervical smears when a woman visits her GP for another reason</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Opt off</td>
<td>A woman choosing not to have a result sent to the NCSP-R</td>
</tr>
<tr>
<td>Pap test</td>
<td>Cervical smear test. This term is not used very often in New Zealand.</td>
</tr>
<tr>
<td>Pathology review team</td>
<td>The Audit team of three pathology experts: Drs Gabriele Medley, Peter Bethwaite and Harold Neal</td>
</tr>
<tr>
<td>Postcoital bleeding</td>
<td>Vaginal bleeding after sex</td>
</tr>
<tr>
<td>Postmenopausal bleeding</td>
<td>Vaginal bleeding after the menopause</td>
</tr>
<tr>
<td>Precancerous phase</td>
<td>A condition that, if left untreated, may go on to become cancerous</td>
</tr>
<tr>
<td>Reference specimens</td>
<td>Representative unsatisfactory, biopsy-proven high-grade and low-grade smears, collected from laboratories providing index specimens and inserted randomly into re-read sets of approximately 50 specimens</td>
</tr>
<tr>
<td>Regular screening</td>
<td>In New Zealand, a smear every three years for a woman who has a normal screening history</td>
</tr>
<tr>
<td>Routine data source</td>
<td>A data set, such as the NHI and NCR, that collects identifiable data on a population or subset of the population</td>
</tr>
<tr>
<td>Sampling miss</td>
<td>A false negative smear that was read as normal because abnormal cells from the histological lesion were not transferred to the slide. Referred to as ‘sampling error’ in some of the published literature</td>
</tr>
<tr>
<td>Satisfactory but limited</td>
<td>Bethesda A2 code for adequacy of a smear, which is associated with a recommendation in New Zealand for a repeat smear in six months to three years</td>
</tr>
<tr>
<td>Screening</td>
<td>When a test is done on people at risk of developing a certain disease, even if they have no symptoms. Screening tests can predict the likelihood of someone having or developing a particular disease.</td>
</tr>
<tr>
<td>Segi’s world population</td>
<td>A hypothetical population used for age standardisation that allows populations with different age structures to be compared</td>
</tr>
<tr>
<td>Sensitivity of smears</td>
<td>The proportion of smears from women with histological disease that are read as positive</td>
</tr>
<tr>
<td>Smear</td>
<td>Cervical cytology specimen</td>
</tr>
<tr>
<td>Smear-taker</td>
<td>Individual trained to take cervical smears</td>
</tr>
<tr>
<td>Suspicious histology</td>
<td>Terminology that is ambiguous in regard to whether the specimen is cancerous or not</td>
</tr>
<tr>
<td>Transformation zone</td>
<td>Area on the uterine cervix where squamous epithelium transitions to glandular epithelium, from which dysplasia arises</td>
</tr>
<tr>
<td>Unsatisfactory result</td>
<td>The smear could not be read at the laboratory. Either there were too few cells on the slide, or many were damaged or hidden (eg, by blood or mucous); associated in New Zealand with a recommendation for a repeat smear in three months.</td>
</tr>
</tbody>
</table>
Appendix 3: National Cervical Screening Programme Indicators and Targets

Tāpiritanga 3 Taiawa Arai o te Motu Tohu me ngā pārure

The NCSP has set a number of National Indicators and Targets. Audit data could be used to report against some of these, for women with cancer. Others are used in this report for determining categories for analysis. The two sets of indicators are shown below, with results for women with cancer calculated where appropriate.

Some of the indicators and targets described below are being updated by the NCSP, but the ones shown are those that were current at various stages of the Audit period.

Indicators and targets with results for women with cancer

A9. Incidence: Target: age-standardised incidence of 8.6 or less per 100,000 for all women, by 2005.

Result: the age-standardised incidence for all women, using Audit definitions of appropriateness for registration and date of diagnosis, was 8.2 in 2000 and 7.9 in 2001.

Conclusion: the target for all women has been met.

A9. Incidence in Māori women: Target: age-standardised incidence of 11.0 or less per 100,000, by 2005.

Result: the age-standardised incidence for Māori women, using Audit definitions of appropriateness for registration, date of diagnosis and ethnicity, was 14.9 in 2000 and 13.3 in 2001.

Conclusion: despite the exclusion of women who should not have been registered, the Audit Māori incidence figures are likely to be higher than those reported by the NCR because of the NCR’s undercounting of Māori women. Māori incidence figures are based on small numbers and so vary from year to year by more than the overall incidence rates (see chapter 2). The apparent downward trend during these two years should not be extrapolated to assume that the target will be met in 2005.
A11. **Stage of invasive cancer:** Target: the proportion of women beyond stage 1 at diagnosis will be 30% or less.

**Result:** for eligible women whose medical records were available and for whom a stage could be ascertained, the proportion diagnosed at stage 1 was 75% for all women, 74% for women diagnosed with squamous cell carcinoma, 86% for women diagnosed with adenocarcinoma, and 77% for non-Māori women. For Māori women, the proportion diagnosed at stage 1 was 69%, with a 95% confidence interval from 59% to 80%.

**Conclusion:** the stage distribution target for 2000 has been met for women with invasive cervical cancer participating in the Audit. It is not possible to answer this for all women eligible for the Audit or all women who are appropriately registered on the NCR due to approximately 25% having missing stage information on the NCR.

A14. **Interval cancer:** the measure is the number of women with invasive cervical cancer who have had a screening smear in the 36 months prior to diagnosis with a result negative for dysplasia or malignancy. No target.

**Result:** including only women who were appropriate for registration on the NCR, 152 had a negative smear on the NCSP-R in the 36 months prior to diagnosis. This is 29% of all women appropriate for registration and 37% of those who had any smears in the 36 months prior to diagnosis. For women with squamous cell carcinoma, these figures were 25% and 30% respectively.

A15. **Programme sensitivity:** the number of women with invasive cancer detected by screening divided by that number plus the number of interval cancers in a defined period. An estimate can be calculated as the number of women with at least one high-grade smear in the year prior to diagnosis, divided by the number of women with any smears in the year prior to diagnosis. The target for squamous cell cancer is greater than 85% at one year.

**Result:** including only women who were appropriate for registration on the NCR, the NCSP sensitivity at one year was 352/402 = 88%. For women with squamous cell carcinoma, the NCSP sensitivity was 288/321 = 90%.

**Conclusion:** the target has been met.
B6. **Accuracy of negative cytology reports:** for women with a histological diagnosis of CIN2, CIN3 (high-grade) or invasive squamous cell carcinoma, the proportion of smears originally reported within the preceding 42 months as negative, which on review of smears are consistent with HSIL or ASCUS possible high-grade: Target – not more than 20%.

**Result:** the Audit calculated this target for women with squamous cell carcinoma only. 18% (95% CI: 12% to 24%) of normal smears from women with squamous cell carcinoma were re-read as high-grade.

**Conclusion:** the target is not exceeded.

**Indicators and standards used to determine categories for analysis**

A1. **Participation of women:** the proportion of women with a cervix (ie, who have not had a hysterectomy) in the 20–69 years age group who have had a smear recorded on the NCSP-R in the previous six years. Target: at least 90%.

A2. **Coverage of women:** the proportion of 20 to 69-year-old women with a cervix who have had a cervical smear recorded on the NCSP-R in the previous 36 months. Target: at least 85%.

A8. **Follow-up of women with HSIL cytology:** the proportion of women who have had a cervical smear showing a high-grade cytology result for whom a histological report has been received. The targets are that 90% of women will have a histological specimen taken within 12 weeks of the date the high-grade squamous intraepithelial lesion (HSIL) smear was taken and 99% of women within 52 weeks.

**Standard 608. Colposcopically directed treatment:** at least 95% of women with HSIL should be treated within two months of histological confirmation.
Appendix 4: Brief History of the National Cervical Screening Programme

Tāpiritanga 4 Te hitori o te Taiawa Arai o te Motu

This appendix gives some more detail about the history of cervical screening in New Zealand.

Background

Prior to the establishment of an organised screening programme in New Zealand in the 1990s a number of academics, women’s groups and non-governmental organisations such as the Cancer Society advocated for the establishment of organised screening. 80 In 1985 in the absence of such a programme, the Cancer Society and Department of Health jointly convened a working party chaired by Professor David Skegg to review the evidence for cervical screening and to make recommendations for screening in New Zealand. 81 However, the main impetus for establishing an organised programme came from the Cartwright Report. 6 The Committee of Inquiry had been established to inquire into research practices at National Women’s Hospital following an article in the June 1987 edition of Metro Magazine that alleged that women who had attended that hospital with cervical abnormalities had, without their consent, been part of a research programme into the progression of Carcinoma in Situ. As part of her report, Judge Cartwright recommended that a population-based cervical screening programme be established in New Zealand as well as making some recommendations as to how she considered this should occur. The Government of the day accepted her recommendation and implementation of a NCSP commenced forthwith.


On the basis of a review of the 1985 Skegg recommendations, the programme was directed at women from the onset of sexual activity up to 69 years inclusive. Women commencing screening were encouraged to have two smears 12 months apart and from then on, provided their screening history was normal, to have three-yearly smears. Women with abnormal screening histories were advised to have more frequent screening.

A devolved configuration was adopted. This involved the establishment of 14 regional offices. The responsibilities of these offices were to provide local programme co-ordination and management of the local, stand-alone cytology register. Smear-taking was provided by general practitioners, some practice nurses, gynaecologists and a small number of trained lay smear-takers. A majority of laboratories provided smear-reading services to the programme, whilst diagnostic services were funded through the public hospital system (although women could opt for private assessment). The cytology register acted
as a back-up for smear-takers and gynaecologists, sending reminders primarily when women were overdue for their next smear test. The Ministry of Health provided national policy, co-ordination, and cytology register help-desk functions. It also convened technical and cytology advisory groups. Funding for the programme was administered by the various funding agencies that existed at the time. A 1993 amendment to the Health Act 1956 enshrined the cytology register (known at that time as the National Cervical Screening Register (NCS-R)) in law and changed its modus operandi from “opt-on” to “opt-off”. This change meant that women had to actively “opt off” if they did not want their smear results included on the NCSR and lead to a rapid increase in enrolments. It also made it possible to provide more accurate measures of programme coverage as well as other statistical reporting.

Kaitiaki Regulations were passed in 1995 (the Health (Cervical Screening (Kaitiaki)) Regulations 1995). These provide for a ministerially appointed panel to protect Māori women’s information held on the NCSP-R. The panel receives and approves applications for the analysis and reporting of Māori women’s data.

In 1996 the Ministry of Health embarked on a process in which all the local stand-alone cytology registers were re-configured into one national database, still with local data entry.

1998 onwards

In 1997 the Health Funding Authority was formed as a national operational policy and funding agency. A decision was made to transfer Ministry of Health responsibilities for the NCSP to the Health Funding Authority, and with co-location of national policy, register, planning and funding activities, it was theoretically possible to influence the operation and delivery of the programme at all levels. Soon after the transfer, a woman who had developed invasive cervical cancer as a result of cervical smears allegedly having been misread came to the attention of the Health Funding Authority. This occurred as a result of the actions of her solicitor and media attention following her taking legal action against the pathologist concerned. Concerns arising from this case (ie, that other women might also have suffered as a result of misread smears) lead to the Health Funding Authority seeking expert external advice and subsequently carrying out a mass re-reading of approximately 23,000 smears reported by Gisborne Pathology Laboratories during the period 1990–1996.

Initial results from the re-reading exercise suggested that there might have been significant under-reporting at the laboratory concerned. This prompted the Government of the day to announce a Ministerial Inquiry to determine whether or not unacceptable under-reporting had occurred in the Gisborne region and if so, what factors may have lead to it. The Inquiry Committee sat from April to September 2000 and reported to the Government in April 2001. It concluded that unacceptable under-reporting had occurred and that this was as a result both of inadequate practice at the laboratory
concerned and systematic problems with the design, configuration and operation of the NCSP during the period 1990–1996. The Inquiry made 46 recommendations, all of which were accepted by the Government. As a result of the Inquiry and increased recognition of the necessary components of a high-quality screening programme, many changes have been made to the structure and operation of the NCSP. These changes relate primarily to:

- the establishment of a National Screening Unit (NSU), within which sits the national office of the NCSP, and thus a national workforce dedicated to the NCSP and the planning thereof
- alignment of accountability for policy development, funding, planning and national quality assurance activities for both the NCSP and Breast Screening Aotearoa (BSA) all within one entity, the NSU
- the ongoing establishment of comprehensive quality assurance processes including mandatory quality standards and until recently ongoing quantitative monitoring
- legislative changes to clarify the programme’s informed consent and enrolment process, improve the completeness of women’s information on the programme register and facilitate evaluation of the programme
- revision of NCSP health education material
- the establishment of a screening workforce development project
- the establishment of a complaints process within the NSU
- an audit of screening histories of women with invasive cervical cancer.