
A Brief Narrative on
Māori Women and the
National Cervical Screening
Programme

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Foreword

Hūtia te rito

Hūtia te rito o te harakeke

He aha te mea nui?

He aha te mea nui o te ao?

Māku e kī atu

He tangata, he tangata, he tangata.

This publication records and acknowledges Māori women's contribution to and achievements in the National Cervical Screening Programme (NCSP). Since the NCSP was established in 1990, Māori women have played a major role in many aspects of the programme. Despite some of the barriers that Māori women have faced, such as cultural appropriateness, cost and geographical access, Māori women have made a significant and largely unrecognised contribution to the NCSP.

It is important to note that this is not a definitive record of Māori women's involvement in the programme. For a more complete picture, individual Māori women themselves need to tell their own story. There are other oral and written sources which record Māori women's encounters and achievements in the NCSP. I hope that by recording the development of the NCSP and involvement of Māori women, this publication continues to uplift the profile of Māori women within our society. Finally I would like to personally thank those individuals who have contributed to this publication.



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Director of Public Health, and
General Manager, Public Health Group

Introduction

What would you change in the programme for the betterment of Māori women and their whānau?

Have cultures working side by side, acknowledging the different ways of giving and learning from one another.

More empowerment of Māori.

(Source: Responses to a questionnaire by kaimahi Māori, March–May 1997.)

This publication is a brief chronological record that acknowledges and describes the journey of Māori women and the National Cervical Screening Programme (NCSP). It looks at Māori beliefs about te wharetangata, and the origins of, and Māori involvement in, the NCSP.

Māori women are at the centre of their whānau, hapū and iwi, and fulfil an important role in sustaining them. They are te wharetangata, the house of the people. The spiritual link between land and the health and wellbeing of Māori women is reflected in the language used to describe the functional anatomy of te wharetangata. The cervix is the doorway to te wharetangata (Te Korimako Committee 1990). The relationship between women and land acknowledges that they carry the same role in terms of providing nourishment: without them humanity is lost (Department of Health 1989).

Background

The Cartwright Inquiry and Report

In June 1987 the *Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women’s Hospital and into Other Related Matters* commenced. It ended in August 1988 with the release of Judge Silvia Cartwright’s report on her findings and recommendations

of the inquiry. The inquiry gave many women the opportunity to tell of their experiences at National Women's Hospital in Auckland during their time as patients of Dr Herbert Green. It also offered Māori women an opportunity to express their deeply felt cultural beliefs relating to the sanctity of te wharetangata and the practices that legitimise those beliefs, and ensured that the voice of Māori women would be heard.

Essentially there are two issues to be considered. The first is the sacredness of the area of the genital tract both to Māori and, to a lesser degree, to Pākehā women.

(Cartwright 1988: 115)

The Cartwright Inquiry, as it was to become more commonly known, recommended the urgent establishment of a national population-based cervical screening programme. The NCSP was launched nationally in 1990 and is the first national population-based cancer screening programme in New Zealand. The NCSP is delivered by a range of providers including general practitioners, nurse and lay smeatakers, health educators and laboratories. Local co-ordination of the NCSP is provided from 14 sites around the country, based on the old area health board boundaries (Ministry of Health 1996).

As a medium for the voice of women, the Cartwright Report captured women's attitudes and beliefs about cancer of the cervix and internal examinations.

The implications of the genital area for Māori women cannot be underestimated. They will have repercussions not only for population-based cervical screening but also for the treatment and monitoring of CIS as well as invasive cancer. There seems to have been little cultural understanding of these mores on the part of the profession.

(Cartwright 1988: 116)

Mana Wahine

What would you change in the programme for the betterment of Māori women and their whānau?

That all the whānau take responsibility and be part of the whole process. Encourage women to use services available to them.

What are your highlights (positive or negative) of the National Cervical Screening Programme?

Recognition that Māori women are a high priority group but then [there is] no commitment to ensure that adequate resource people are available to deal with the problem. Achievements of the programme have been largely reliant on voluntary input from Māori involved in the community, marae and Māori community based services.

The concept of mana wahine describes the status, power and authority of Māori women. The Royal Commission on Social Policy outlined that in the context of Māori culture, mana wahine is a reminder of Māori women's matrilineal descent from Papatuanuku (Royal Commission on Social Policy 1988). The notion of mana wahine has embedded within it a philosophy concerning the sphere of influence, a code of behaviour and knowledge built up over generations. It is the intellectual property that belongs to all Māori women (PHC 1995b).

In terms of promoting mana wahine, the Public Health Commission (1995b) cites Kupenga (1988) and considers that this paper identifies the positive gains to society once identity is restored to a person or

to a people, and negative conditions are arrested. Health, self-esteem and the quality of life are restored.

In reclaiming Māori women's autonomy we seek to reunite with Papatuanuku and her resources. To assist this process, we claim, in economic terms, fiscal protection to quantify the quality of life for whānau, thereby ensuring te mana me te tapu o te wahine.

(Kupenga 1988: 9)

Māori women have a long history of trying to bring about changes in the provision of health services to Māori people (Royal Commission on Social Policy 1988). Services run by Māori for Māori are more acceptable and appropriate for many Māori women. It is therefore essential to provide Māori women with the resources to develop health promotion resources and deliver programmes which raise the awareness of cervical screening services among their own people (PHC 1994).

Māori Health

Any discussion of Māori health must begin with reference to the Treaty of Waitangi. The Treaty is recognised as the founding document of New Zealand. The Treaty is a living document which recognises the special tangata whenua status of Māori and establishes an ongoing relationship between Māori and the Crown (Ministry of Health 1997). The Treaty sets parameters for the relationship between Māori, as tangata whenua, and the Crown.

Māori concepts of health are holistic. They span the dimensions of physical, mental and spiritual wellbeing and family, language, land and culture. These various dimensions are interrelated and cannot be viewed separately. Many Māori regard health as a “taonga” with

the same rights of protection afforded under the Treaty of Waitangi to lands, fisheries, language and other taonga of Aotearoa (Te Korimako Committee 1990). The commitment and energy of Māori women resulted in the emergence of the kaimahi Māori network which recognised Māori women's rights under the Treaty of Waitangi.

Whāia te Ora mō te Iwi

In *Whāia te Ora mō te Iwi* (Department of Health 1992), the Government reaffirmed its objective to improve Māori health status so that in the future Māori will have the opportunity to enjoy the same level of health as non-Māori. The Government acknowledged it must meet the health needs of Māori and help improve Māori health status in order to achieve its objectives for Māori health. *Whāia te Ora mō te Iwi* proposed three Māori policy directions:

- greater participation of Māori at all levels of the health sector
- resource allocation priorities which take account of Māori needs and perspectives
- the development of culturally appropriate practices and procedures as integral requirements in the purchase and provision of health services.

An important function of the NCSP is to address the disparities in health outcomes for Māori women through the provision of services by, for and with Māori.

Diverse Māori Realities

Māori are not a homogeneous population group. A range of public health policies, programmes and service delivery methods needs to be developed, monitored and evaluated to provide for different age groups, men and women, and for the various rural, urban and socioeconomic groups. Also, hapū, iwi and Māori community-based groups need to be acknowledged as structures whose ability and capacity to respond to, and participate in, the provision of services will be various and diverse (Minister of Health 1995).

Cervical Cancer

What are some of your regional experiences?

Encouraging Māori women to have cervical smears is/ has been very difficult. Always trying to think of new strategies.

Experience difficulty encouraging older Māori women to be screened.

Invasive cervical cancer is a disease which is substantially preventable by using cervical smears to detect pre-cancerous changes of the cervix and early non-invasive cervical cancer, and by appropriately managing the abnormalities detected. Despite this, cervical cancer remains a significant cause of mortality amongst women in New Zealand. Each year about 100 women in New Zealand die from invasive cancer of the cervix and 250 cases are diagnosed. The rate of cervical cancer for Māori women is still nearly three times that of non-Māori (PHC 1995a).

The National Cervical Screening Programme (NCSP) was established as a means of dealing with the high mortality rate of a disease that can be successfully treated if identified early.

The Government continues to reiterate its commitment to reducing the morbidity and mortality of cervical cancer in Māori women. A Government target for the NCSP policy (Ministry of Health 1996) states:

Māori Mortality:

To reduce the age-standardised death rate from cervical cancer from 10.6 per 100,000 Māori women in the 1989–93 time period to 7.5 per 100,000 Māori women by the year 2000; and to 5.3 per 100,000 or less by 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.

(Ministry of Health 1996: 1)

The Voice of Māori Women

Other general comments

They put me into a room, left the door open and carried a steel speculum in a tray, in front of the waiting room public. Although they smeared me with the doors closed, I felt that the people in the waiting room knew what had happened. I was totally embarrassed.

In the Cartwright Inquiry, Government agencies such as Te Ohu Whakatupu (Māori Policy Unit of the Ministry of Women's Affairs) were able to articulate and provide valuable information on Māori attitudes to health issues.

Our cultural mores of modesty are not understood by, or even recognised by most health professionals and especially doctors. . . . The cultural inhibitions on modesty and what is or isn't proper exposure is ingrained into most Māori girls at an early age. Exposure of the pubic area is forbidden and proper behaviour and practice during menstruation especially is taught at the onset of menses.

(Cartwright 1988: 115)

This statement helps to explain the reluctance of Māori women to be screened and why they are less likely than non-Māori women to be screened. The reasons for the differences in screening between Māori and non-Māori women are varied but one of the main barriers to screening for Māori women appears to be whakamaa (PHC 1994). This may be due to the strong Māori belief in the sacredness of the genital area, and also perhaps to a perceived insensitivity and inappropriateness of smertakers.

Māori Cervical Screening Pilot Projects

The success rate of adequate treatment has made it crucial for health providers to provide services that are effective and acceptable to Māori women. In many areas Māori women have been employed to take smears and provide education. These women have been integral in encouraging other Māori women who have been unable to actively participate in screening to do so.

Māori women have been involved in planning and providing screening services particularly where screening is offered by marae-based clinics. Māori smeartakers are not available in all areas, although Māori community health initiatives are offered in most areas.

The issue of choice of service provider is important to Māori women. All areas should be encouraged to provide and promote Māori women smeartakers.

(PHC 1994: 22)

As the Cartwright Inquiry proceeded, Māori women from Te Ohu Whakatupu and the Department of Health's Māori Health Project Group set up a Cervical Screening Working Group.

From this Working Group came the initiative, leadership and energy to establish cervical screening pilot projects around the country. The Department of Health provided funding for four pilot projects in Kaikohe, Whanganui, Kawerau and Nelson. The focal groups were Māori and low income women (Peretini 1992).

Each of these pilot projects was unique as local women were empowered to operate them. In Whanganui, Te Korimako Committee (established 1987) and its health workers provided a base for the Whanganui Cervical Screening Pilot Project. This programme was a

combination of education and screening services designed to promote the whole issue of cervical screening amongst Māori women in the Whanganui region.

These pilot programmes paved the way for cervical screening programmes in other areas and the establishment of a national register.

Māori involved in the pilot projects felt that they could not express cultural values in all their totality. A service based on wellness of the whole being and not just te wharetangata encompassed the Māori holistic approach to health. Waireti Walters, who has been involved in this issue since its inception, expressed this idea succinctly with the following comment:

Know my face before you know my cervix.

The main idea underlying these words is that women are more than a cervix and should be treated and respected as total beings.

National Cervical Screening Register

One of the tools for monitoring and achieving the NCSP targets for reducing Māori mortality and incidence is the National Cervical Screening Register (NCSR). All women between the ages of 20 and 69 are encouraged to enrol on the Register. The NCSR's main function is to provide a backup to the recall system that smarttakers already have in place for their clients. The NCSR also provides information for quality assurance and evaluation.

One of the features of the NCSR is the opt-off system. The opt-off system means a woman can choose whether or not her smear information is loaded on to the Register. Unless a woman chooses

not to have her smear information on the Register, her results are automatically sent to the NCSR for enrolment.

There was some apprehension amongst Māori women about the opt-off system. The biggest fear arose because Māori women often had great difficulty expressing their anxieties to their general practitioners, and were concerned that it would be difficult to say they wanted to opt off the Register.

The Department of Health convened a National Cervical Screening Workshop in 1988. Women at the hui acknowledged the importance of a national database and the need for valid statistics to monitor changing trends in both health status and service delivery. They identified, however, the need to be aware that.

The gross mismanagement of health service delivery to Māori people has resulted in the appalling current health statistics. This is exacerbated by other government departments' fragmented responses to our people's needs. The resolution of this mismanagement lies within the Māori arena.

(Department of Health 1989: 36).

There was also a strong call at the hui for procedures to protect Māori women's data so they could not be accessed or used without their approval.

In 1991 thirteen consultative hui on the Register were held, where Māori women said that if the opt-off system was initiated it would not be supported by Māori women. The opt-off system was seen as a further mechanism that would disempower Māori women and take away what little sense of control they had.

However a National Māori Register under an opt-off option would return a sense of power and control to Māori. Therefore, the key to an effective opt-off system not being

boycotted by Māori is through the control and management of a Māori register by Māori guardians for the betterment of Māori health.

(Peretini 1992: 6)

The opt-off opportunity was seen as a positive contribution to the debate and to the need to ensure that Māori women would receive all the advantages of a Māori register which acknowledged their particular cultural mores of guardianship.

Māori Women's Cytology Working Group

The 1991 consultative hui recommended that a Māori Women's Cytology Working Group be established and resourced to investigate further options for cervical screening for Māori women.

The nine Māori women chosen for the Working Group were Sharon Challis, Nellie Curtis, Connie Hassan, Lorraine Knutsen, Ramari Maipi, Karen Parata, Regina Peretini, Dr Paparangi Reid and Waireti Walters.

The Working Group recommended that.

Māori women have remained consistent in what they wanted in a cervical screening programme. While the way of describing what is needed has varied slightly, the essential elements to a successful programme, as perceived by Māori, has not. They are the appointment of a National Māori Co-ordinator, regional Māori Co-ordinators, Māori smear takers and the establishment of a separate Māori register.

(Peretini 1992: 3)

A further recommendation was the installation of a lock-out system to protect all ethnicity data, and the formation of a National Kaitiaki Group to act as guardian of the data. The lock-out system for Māori women's data was subsequently approved by Government and meant that individual Māori data could not be accessed at local register sites. Aggregated non-identifiable Māori data could only be accessed with the permission of the National Kaitiaki Group.

The system of guardianship is an extremely old and cherished concept in Te Ao Māori, with many of the roles of guardians being to act as caretakers, mentors, teachers, protectors.

(Peretini 1992: 12)

National Kaitiaki Group

At each of the Māori Women's Cytology Working Group hui in 1991, Māori women supported a recommendation that the Health Research Council's Māori Committee be nominated as the Interim National Kaitiaki Group until a nationally selected, mainly Māori female kaitiaki group was established (Peretini 1992).

The Interim National Kaitiaki Group representatives were Dr Erihapeti Rehu Murchie, Irihapeti Ramsden and Lorna Dyall, selected from the Health Research Council's Māori Committee. Ramari Maipi and Keri Wikitera also became members of the Interim Group.

Kaitiaki Regulations

Before the Kaitiaki Group could legally operate to provide guardianship for Māori women's personal data on the NCSR, new legislation for the Health (Cervical Screening (Kaitiaki)) Regulations 1995 had to be introduced to Parliament. This also required an amendment to Section

74 of the Health Act 1956. These changes prohibited the disclosure, use or publication of information from the NCSR without the approval of the National Kaitiaki Group. The Kaitiaki Regulations were a landmark and laid the foundation for other kaitiaki groups to be established to protect other classes of women's health information.

The Interim Kaitiaki Group operated from April 1993 until 1 April 1995 when the Regulations came into force. The National Kaitiaki Group was then appointed. Current members of the National Kaitiaki Group are Raeleen de Joux, Lorna Dyall (Convenor), Ramari Maipi, Puti Puti O'Brien, Keri Wikitera and, until recently, Dr Paparangi Reid.

The National Kaitiaki Group meets up to four times a year to consider applications for Māori women's data. The main criterion for releasing data is whether the information will be used for the benefit of Māori. Other criteria include the principle of the sanctity of te whare tangata and the need for culturally appropriate protection of the taonga of information.

National Māori Co-ordinator

What are some of your regional experiences?

A Māori Manager Co-ordinator for the area or service provider ensures a better attitude to partnership and future progress of programme for Māori.

There are now more Māori smeartakers in our region and our women are becoming less "whakamā" to have their smears done.

In August 1993, the Public Health Commission recommended that the position of National Māori Co-ordinator be established. This was supported by the Ministry of Health, subject to additional resources

being made available for the establishment of the position.

In early 1994, Te Kete Hauora (Māori Health Group) was set up in the Ministry of Health. Discussions between Ministry officials were held to ascertain whether Māori support for the National Cervical Screening Programme could best be provided by Te Kete Hauora or by a designated Māori Co-ordinator within the National Cervical Screening Programme.

Later in the year approval was granted for the Māori Co-ordinator position within the Ministry of Health. The position was widely advertised and in November 1994 Maria Rangiawha (Waikato/Ngāti Raukawa) was appointed. Maria held the position until December 1995.

At the second national kaimahi Māori hui in Whangarei in 1995, support was given to expanding the role of the National Māori Co-ordinator to address a holistic sexual reproductive focus.

Further, it was recommended that the position be transferred to He Kākanō Oranga (Māori Public Health Policy Section) within the Ministry. The position was subsequently retitled Kaihautu Māori, Te Wharetangata (National Māori Co-ordinator, Cervical Screening and Sexual and Reproductive Health).

This role is currently held by Raina Meha (Ngāti Pikiao/Ngāti Kahungunu) and gives leadership to Māori aspects of the NCSP. Raina works in partnership with the current NCSP National Co-ordinator, Di Best, to jointly provide leadership, co-ordination and liaison of the NCSP.

An annual national hui of kaimahi Māori working in the NCSP considers policy and operational issues to improve the effectiveness of the NCSP for Māori women. Kaimahi Māori have the opportunity to make recommendations to the NCSP on how best to meet Māori needs and enhance Māori wellbeing, for example, on the development of national health education resources for Māori.

Conclusion

In the last decade many Māori women have helped to forge and shape the management of cervical screening in New Zealand. Emphasis is now largely focused on a holistic approach which acknowledges a woman's multiple role as whānau member, wife/partner, mother, carer and worker.

Although much has been achieved for cervical screening in New Zealand, the statistics show that there is still much to do to hasten the decline in the number of Māori women still affected by cervical cancer.

The establishment and operation of the National Kaitiaki Group, coupled with a small but effective group of Māori smeatakers and educators, are heartening achievements towards the reduction of cervical cancer among Māori women.

In preparing this brief narrative, we are proud to record the achievements of those who argued for and achieved gains for the health of Māori women. Significant achievements include the establishment of a lock-out of Māori information, establishment of the National Kaitiaki Group as guardians of that information, the appointment of a National Māori Co-ordinator, and national recognition of the rights of Māori to express and stay true to their beliefs of the sacredness of te wharetangata. All of these achievements have set the foundations, directions and boundaries for future national registers.

We acknowledge the achievements of those who pursued, and continue to pursue, with such passion, the goal of wellness for all Māori. We recognise the struggle, courage and dignity Māori women have displayed since the inception of the National Cervical Screening Programme.

Me aro koe ki te hā o Hine-ahu-one

Pay heed to the dignity of women

Glossary

Cytology	The study of cells using a microscope. Used in cervical screening to detect cancer or cell changes which may be precursors of cancer.
Hāpu	Sub-tribe
Hinengaro	Mental wellbeing
Iwi	Tribal group, people
Kaimahi Māori	Māori smeaftakers and educators in the NCSP
Kaitiaki	Guardian, caregiver
Mana	Authority, control, influence, prestige, power
Mana wahine	Dignity and power of women
Māori	Person of the native race, New Zealander Māori
NCSP	National Cervical Screening Programme
NCSR	National Cervical Screening Register
Pākehā	A person of predominantly European descent

Papatuanuku	Mother earth
PHC	Public Health Commission
Reo	Language, voice
Tangata whenua	Indigenous people of a region, land, country
Taonga	Anything highly prized or valued
Tapu	Sacredness
Te wharetangata	The house of procreation including the womb and uterus
Tikanga	Cultural values
Tinana	Physical wellbeing
Wairua	Spiritual wellbeing
Whakamaa/whakamā	Humility, embarrassment
Whānau	Family
Whenua	Placenta, land

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