

**UNDER THE HEALTH AND DISABILITY
SERVICES ACT 1993**

**IN THE MATTER OF THE MINISTERIAL
INQUIRY INTO THE UNDER-REPORTING OF
CERVICAL SMEAR ABNORMALITIES**

EVIDENCE OF RIA EARP

MINISTRY OF HEALTH

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I, **RIA EARP**, of Wellington, say:

Introduction

1. My full name is Lorraine Ria Earp but I am known as Ria Earp. I hold the position of Deputy Director-General Māori Health, for the Ministry of Health. I started in this position in October 1996 following ten years experience in the Public Service. My work has ranged across programme and policy management, with a particular focus on Māori social policy. I am a graduate of Victoria University where I gained a Bachelor of Arts, Master of Arts (Applied in Social Work), and a Master of Business Administration. I am of Te Arawa descent, Ngāti Pīkiao and Ngāti Whakaue.
2. I am authorised to give evidence on behalf of the Ministry on Māori women and cervical screening. This evidence is an overview of Māori women's involvement in the National Cervical Screening Programme (NSCP) as smear takers, health promotion educators, co-ordinators and most importantly as participants. It is set in the context of the then Government's strategic direction for Māori health (*Whāia te ora mō te iwi*)¹ and its response to enhancing Māori women's involvement in the Programme. I produce a copy of that document as **LRE/MOH/0001**. As much of the information I provide is sourced from Ministry of Health files and publications, I have referenced my evidence to documents using endnotes.

The role of Māori women in their communities

3. In 1997 the Ministry published a document called *A Brief Narrative on Māori Women in the National Cervical Screening Programme*. A copy is produced as **LRE/MOH/0002**. Much of what follows is emphasised in that publication.

4. It is important to examine the role of Māori women in their whānau, hapū, iwi and wider communities to gain a better understanding of the incentives that might encourage them to participate in the programme as well as provide the necessary information to design a programme that meets their needs.
5. Māori women are an integral part of the Māori community. The health and well being of Māori women ensures the continued health and well being of Māori people. Māori women therefore play a pivotal role in ensuring the health and wellbeing of their whānau is sustained.² In this context it is important to recognise that for many Māori women the health and wellbeing of the whole whānau often takes precedence to her own health needs.
6. Māori women are considered as *te whare tangata*, which translates as ‘the house of procreation’ and includes the womb or uterus.³ The cervix is considered the gateway to *te whare tangata*.⁴ The spiritual link between land and the health and well being of Māori women is reflected in the language used to describe the functional anatomy of *te whare tangata*. The relationship between women and land acknowledges that they carry the same role of providing nourishment to future generations.⁵
7. Māori women have had a long history in trying to bring about changes in the way that health services are provided to Māori.⁶ This is evident in the way that Māori women have shown their commitment and energy regarding cervical screening.

Māori Concepts of Health

8. The role of Māori women also has to be set in the context of Māori concepts of health which are holistic and comprise the physical, mental, spiritual and whānau wellbeing dimensions, as espoused by Durie’s *Te Whare Tapa Whā* model. Other models include *Te Ao Turoa* (physical

environment), taonga tuku iho (cultural heritage) and tūrangawaewae (land base).⁷ All of these dimensions are embraced by te reo and tikanga which are crucial factors in determining Māori health and wellbeing.⁸ Māori consider these dimensions to be interrelated and do not view them separately.

9. The concepts are referred to in a 1997 Ministry publication *Rangatahi Sexual Wellbeing and Reproductive Health: The public health issues*, a copy of which is attached as **LRE/MOH/0003**.

Incidence and mortality for Māori women

10. Many Māori women have helped to forge and shape the management of cervical screening in New Zealand. However 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.
11. The first statistical report about Māori women on the Register was published by the Ministry in 1999. A copy is produced as **LRE/MOH/0004**. The report gives a description of the trends in this data up to 31 December 1995.⁹ Data shows that:
 - a) there has been a decline in the incidence and mortality rates of cervical cancer for Māori women since 1991;
 - b) 76,130 Māori women were enrolled on the Register;
 - c) 92 percent of the Māori women enrolled were aged 20-69 years;
 - d) a total of 132,413 smears from Māori women had been recorded on the Register;
 - e) 71 percent of Māori women mainly attended medical practitioners to have their smears taken.¹⁰

12. While the incidence for Māori women is dropping, it is still higher than for all women. It is particularly important for Māori women aged between 20 and 70 years to be regularly screened.¹¹
13. The significance of Māori women's data, and protection for, is referred to later in my evidence.

Treaty of Waitangi

14. The Government recognised the Treaty of Waitangi as the founding document of New Zealand and that any discussion of Māori Health should begin by an acknowledgement of the special relationship between Māori and the Crown under the Treaty. The Treaty relationship between the Crown and Māori as tangata whenua is an enduring relationship characterised by utmost good faith and reasonable co-operation.¹²
15. The Government acknowledged the need to achieve equity in health status for Māori and established a Crown objective for Māori health - that improvements are achieved in Māori health status so Māori will have the opportunity to enjoy the same level of health as non-Māori.¹³

Māori Health Policy context

16. In 1993 the Government released its policy statement *Whāia te ora mō te iwi*¹⁴ which outlined the policy directions for Māori health (already referred to, see **LRE/MOH/0001**). Those directions (which have been retained through to the present day) included:
 - a) greater Māori participation at all levels of the health sector
 - b) resource allocation priorities which would take into account Māori health needs

- c) the development of culturally appropriate practices and procedures in the purchase and provision of services for Māori.

The National Cervical Screening Programme and Māori Women

17. Cervical screening for Māori recognised the important role in addressing the disparities in cervical health outcomes for Māori women through the provision of ‘by Māori for Māori’ services. This is particularly important as Māori continue to experience higher incidence of morbidity and mortality from cervical cancer than non-Māori women.

18. The Ministry recognised that in order for cervical screening to be successful for Māori women, the NCSP must:
 - a) incorporate community development strategies to best meet the need for a holistic approach to Māori women’s health
 - b) offer screening in ways that they felt were acceptable, accessible, affordable and culturally appropriate
 - c) achieve equity of outcome through appropriate allocation of resources
 - d) appropriate promotion of the benefits of screening for Māori women and provide a service or range of services that meets their needs.¹⁵

This is set out in the 1996 National Cervical Screening Policy **(GRB/MOH/0001)**

17. The Ministry also recognised that to bring about willing participation of Māori women involved a process that encompassed every aspect of the NCSP. It has attempted to respond to repeated requests over the years from Māori women to have a more integral role in the delivery of this programme at various levels.¹⁶ These responses are outlined below.

The National Cervical Screening Register

21. The Register is the key management tool for the National Cervical Screening Programme and has two functions:
- a) it is a personal health management tool
 - b) it provides summary information for monitoring and evaluation.
22. Māori women were apprehensive about enrolling on the Register because of their main concerns about the protection of Māori data as their belief in the sanctity of te whare tangata meant that information about it needs to be afforded special protection.
23. There is also an element of whakamā (humility or embarrassment) associated with cervical screening and has been explained as a cultural inhibition or modesty about the inappropriate exposure of the pubic area.¹⁷ Every woman's information on the Register is highly confidential and can only be obtained by special application to the National Kaitiaki Group who approve access to Māori women's summary data on the register.¹⁸

National Māori Cervical Screening Co-ordinator (Kaihautū Māori, Te Whare Tangata)

24. In addition to the Ministry of Health appointing a kuia (elderly woman) for the NCSP in 1993, the Ministry also established a National Māori Cervical Screening Co-ordinator position in 1994. This position was later extended to also include sexual and reproductive health and was renamed Kaihautū Māori, Te Whare Tangata, National Co-ordinator, Māori.
25. The Kaihautū Māori worked in partnership with the National Cervical Screening Co-ordinator to jointly provide leadership and co-ordination

and liaison of the NCSP.¹⁹ In April 1998 the Ministry transferred the resources for management of the Register and national co-ordination of the programme to the Health Funding Authority. Both the Kaihautu Māori, Te Whare Tangata and National Cervical Screening positions reside within the Health Funding Authority.

National Kaimahi Māori Hui

26. Kaimahi Māori (Māori cervical screening co-ordinators, educators and smeeartakers) working in the NCSP met at least annually to consider policy and operational issues to improve the effectiveness of the NCSP for Māori women. At these hui, kaimahi Māori had the opportunity to make recommendations to the NCSP on how to best meet the needs of Māori and enhance Māori wellbeing. The health education resources for Māori was one example.²⁰

The National Kaitiaki Group

27. The National Kaitiaki Group was set up under the Health (Cervical Screening (Kaitiaki)) Regulations 1995, to provide appropriate protection for Māori women's summary data on the Register.²¹ It helped to reassure Māori women of the continuing safety of their information on the Register. The promulgation of the 1995 Health (Cervical Screening (Kaitiaki)) Regulations was a landmark for Māori who were concerned about the level of protection when providing their personal data.
28. The process of establishing formal protection specifically for Māori women's cervical screening data was raised at the National Cervical Screening Workshop convened by the then Department of Health in 1988. This workshop is referred to in Dr Boyd's evidence (and see **GRB/MOH/0013** for the draft report).
29. Participants strongly expressed the need to develop procedures to protect the use of and access to Māori women's health data.²² A National hui for

Māori women was held in December 1991 to discuss the NCSP and a National Register. This resulted in the establishment of the Māori Women's Cytology Working Group in 1991.

30. Over the next year twelve more consultation hui were held around the country. The Working Group recommended that the Health Research Council's Māori Committee be nominated as the Interim National Kaitiaki Group, until the formation of a National Kaitiaki Group, to act as guardian of Māori women's data. In November 1992 the interim Kaitiaki Group was established and operated from April 1993 until 1 April 1995.
31. The National Kaitiaki Group is a group of between 3 and 6 members who are appointed by the Minister of Health after consultation with the Ministers of Māori Affairs and Women's Affairs. Its function is to oversee the protection of Māori women's summary data on the Register. It considers and monitors all applications to access aggregated Māori women's health information. It meets up to 4 times a year.
32. It has the challenging role of balancing the tension between access to Māori women's health information (on cervical screening) to enable research which contributes to informed programme and service decision-making, and protecting the personal information and intellectual property rights of Māori women in the Register.
33. In order to use Māori women's summary data, an application has to be lodged with the National Kaitiaki Group. Approval is given by the Group for release of data in an aggregated, unidentifiable form, subject to the applicant demonstrating that:
 - a) the information is being used for the benefit of Māori women;

- b) the principle of the sanctity of ‘ te whare tangata’ is addressed; and
- c) the information released is protected in a culturally appropriate way.²³

34. The National Kaitiaki Group is still serviced by the Ministry.

Developing Māori resources

35. Māori health education resources for cervical screening were a major feature in raising Māori women’s awareness of the importance of cervical screening and to encourage them to enrol on the Register.
36. The Government recognised the personal commitment of Māori health educators and promoters of cervical screening in providing and delivering the message about cervical screening to Māori. It also recognised the importance of Māori aspirations to take responsibility for their own health.²⁴
37. In 1995, a resource package called “*Atawhaitia Te Wharetangata*” was launched. In keeping with the philosophy of providing health education resources appropriate to the intended audience, *Atawhaitia Te Wharetangata* was designed by Māori, for Māori, to be delivered by Māori.
38. The assessment of educators and smear takers was an important issue for the Kaimahi Māori network working in the NCSP. They recommended in February 1995, that standards and competencies for Māori educators and promoters of cervical screening be developed, by Māori.²⁵ The Standards were developed by the Kaihautu Māori, Te Whare Tangata before the NCSP was transferred to the Health Funding Authority for implementation in 1998.

39. Regional Health Authorities and their successors have purchased locally co-ordinated health education, promotion and smearing services for Māori women and their whānau in a way which acknowledges holistic Māori concepts of health.²⁶ (refer 1996 National Policy **GRB/MOH/0001** p14).

Monitoring and Evaluation of Services

40. One of the principles of the NCSP included the way in which RHAs [and now the Health Funding Authority (HFA)] made purchasing decisions for health and disability services. These decisions were, themselves, based upon a set of principles, one of which referred to the acceptability of the services. The Ministry, expected, through funding agreements with the RHAs, that they would consult with, involve and be responsive to the diverse needs of all women and particularly recognise Māori aspirations for self-management and preferences for services to be provided by Māori.²⁷
41. The Service Obligations in the Funding Agreements between the Minister and funders stipulated that cervical screening services should be purchased by including local co-ordination, health education, participation strategies and smearing services for women and their whānau.
42. These expectations still hold currency in the Funding Agreement with the HFA, which is the tool by which the Ministry monitors the HFA.

Māori Representation

43. Māori representation in structures of the Programme was an issue raised by Māori women. Where possible, the Ministry and Kaimahi Māori looked at how they could increase Māori representation on various advisory committees regarding cervical screening. As a result, Māori representation was either included or increased on bodies such as the :

- a) Cervical Screening Advisory Committee
- b) Cancer Society and the Ministry of Health joint working party to review the recommendations for routine cervical screening.²⁸

44. Therefore there have been a number of appointments of Māori women to advise the Programme on its work.

Māori regional co-ordination

45. The growing network of Māori cervical screening co-ordinators strengthened the provision of appropriate services being delivered to Māori by Māori. A desired outcome was for an increase in the numbers of Māori women being screened and enrolled to benefit from the Programme. The ultimate goal was to reduce the incidence and deaths from cervical cancer in Māori women.²⁹

46. During 1994-5, there were some very good Māori models of co-ordination of the Programme for Māori. In the Auckland region the delivery of services for Māori was provided by the Waipareira Trust. There were co-ordinators positions for some time in the Waikato, Hawkes Bay, Wellington and Otago regions. Services for Māori were being provided by Māori in other regions in a variety of different contractual ways.³⁰

Tairāwhiti

47. A focus of this Inquiry is the Tairāwhiti region in which there is a high Māori population (44.9%)³¹, and participation in the Programme was highest among Māori women (64%) according to data trends as at 31 December 1995.³² (LRE/MOH/0004, p.xi).

48. Educating women to have their smears and offering support for colposcopy women were important developments within the Programme in the region.³³
49. In 1995, Tairāwhiti Healthcare had all Māori staff in their cervical screening programme which was beneficial for the high population of Māori in that area.³⁴
50. Tairāwhiti's Māori co-ordinator reported that the Programme's September promotion in 1997, resulted in positive comments from women about services provided, screening venues, smearthakers, educators and health promoters. It was also noted that the new national form has improved the numbers filling out the ethnicity question.³⁵
51. Sponsorship in the region created an awareness of the importance of cervical screening.³⁶ As such the region has been seen as a model in achieving high rates of participation by Māori women in the Programme.

Conclusion

52. The Ministry recognises the special contribution of Māori women to the NCSP. Māori women have been at the forefront of initiatives for Māori development and this commitment continues within the Programme.
53. The Ministry acknowledges that cervical screening is a culturally important health issue for Māori. As a commitment to lowering the incidence and mortality rates from cervical cancer for Māori women, the Ministry has sought to ensure that the NCSP is responsive and appropriate to their needs by:
- a) establishing a National Māori Cervical Screening Co-ordinator position, which later became the Kaihautu Māori, Te Whare Tangata position, to provide leadership on Māori aspects of the NCSP;

- b) holding annual hui of the kaimahi Māori network to consider policy and operational issues to improve the effectiveness of NCSP for Māori women and make recommendations;
- c) establishing the National Kaitaiki Group to provide appropriate protection for Māori women’s personal data on the register;
- d) developing Māori specific health education resources to raise awareness of and encourage participation in the NCSP;
- e) developing standards for assessment of Māori educators and promoters of cervical screening.

54. This Inquiry is a sad reminder that we cannot be complacent about our achievements and our need to recognise that there is much more to be done to ensure that the NCSP continues to enhance the health and wellbeing of Māori women.

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Ria Earp

Date:.....

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4. Ministry of Health. 1999. *Māori Women in the National Cervical Screening Programme: Analysis of Māori women's data to 31 December 1995.* Wellington. (LRE/MOH/0004)

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- ³ *ibid.* p25
- ⁴ Ministry of Health. 1996. *National Cervical Screening Programme: Policy*. p44
- ⁵ Ministry of Health. 1997. *A Brief Narrative on Māori Women and the National Cervical Screening Programme*. p7
- ⁶ *ibid.* p10
- ⁷ Ministry of Health. 1997. *Rangatahi Sexual Wellbeing and Reproductive Health: the public health issues*. p5.
- ⁸ Ministry of Health. 1996. *National Cervical Screening Programme: Policy*. p8.
- ⁹ Ministry of Health. 1999. *Māori Women in the National Cervical Screening Programme. Analysis of Māori women's data to 31 December 1995*.
- ¹⁰ *ibid.* pxi.
- ¹¹ Minister of Health. 1998 Media Release.
- ¹² Department of Health. 1993. *Whāia te ora mō te iwi*.
- ¹³ *ibid.* p13.
- ¹⁴ Department of Health. 1993. *Whāia te ora mō te iwi*.
- ¹⁵ Ministry of Health. 1996. *The National Cervical Screening Programme: Policy*. p 13
- ¹⁶ *ibid.* p13.
- ¹⁷ Ministry of Health. 1997. *A Brief Narrative on Māori Women and the National Cervical Screening Programme*. p14.
- ¹⁸ Newsletter of the NCSP, May 1995.
- ¹⁹ Ministry of Health. 1997. *A Brief Narrative on Māori Women and the National Cervical Screening Programme*. p3.
- ²⁰ *ibid.* p21.
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- ²² Ministry of Health. 1999. *Māori Women in the National Cervical Screening Programme. Analysis of Māori women's data to 31 December 1995*. p3.
- ²³ *ibid.* pp3-4.
- ²⁴ Associate Minister of Health. 1995. Speech notes: *Attendance at the National Māori Hui and Launch of the New Māori Health Education Resources for Cervical Screening*.

²⁵ *ibid.*

²⁶ Ministry of Health. 1996. *The National Cervical Screening Programme: Policy.* p14.

²⁷ Ministry of Health. 1996. *The National Cervical Screening Programme: Policy.* p9.

²⁸ Associate Minister of Health. 1995. Speech notes: *Attendance at the National Māori Hui and Launch of the New Māori Health Education Resources for Cervical Screening.*

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³¹ Statistics New Zealand. 1998. *New Zealand Now: Māori.* p24.

³² Ministry of Health. 1999. *Māori Women in the National Cervical Screening Programme. Analysis of Māori women's data to 31 December 1995.* pxi.

³³ Māori Co-ordinators National Hui Nov 1992.

³⁴ Ministry of Health. 1995. *Correspondence to Southern Regional Health Authority.*

³⁵ NCSP Tairāwhiti Report to Programme Managers Meeting, Dec 1997.

³⁶ Tairāwhiti Healthcare Report to National Māori Hui for NCSP, Nov 1997.