

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

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

**CLOSING SUBMISSIONS OF PRUE KAPUA - COUNSEL FOR
MAORI WOMEN AFFECTED**

INTRODUCTION

1. At the time of presenting evidence to this Inquiry introductory submissions were made and it is not proposed to repeat those but merely to adopt those submissions as part of this closing submission.
2. The submissions made by both Mr Grieve QC and Mr Corkill are supported and it is not proposed to repeat the detail of those submissions.

TERM OF REFERENCE ONE

3. The first term of reference required the Inquiry to determine whether there has been an unacceptable level of under-reporting in the Gisborne region. That term of reference clearly requires a determination of what is or is not acceptable but it is submitted that the submissions of Mr Corkill, particularly in reference to the women who have given evidence before this Inquiry is particularly relevant. The fact of there being an unacceptable level of under-reporting is confirmed by medical witnesses who have raised concerns about how women are presenting currently, essentially as Dr Wain remarks, as “typical of an unscreened population”.

TERM OF REFERENCE TWO

4. The major term of reference for all people of the Gisborne region and particularly the many women who have had to face the implications of this under-reporting is the Term of Reference Two which is the identification of the factors that are likely to have led to that under-reporting. It would seem that those factors fall into a number of broad categories some of which are interrelated:

- (a) Lack of monitoring and evaluation;
 - (b) Lack of central responsibility;
 - (c) Lack of resources;
 - (d) Lack of commitment to establish a Programme in line with expert recommendations; and
 - (e) Lack of involvement of people and organisations that would assist in implementation and delivery of the Programme.
5. At the outset it must be stated that there is a general acceptance that a screening Programme is an effective preventative strategy for cervical cancer. The issue of causes of cervical cancer has rather strangely arisen in the context of this Inquiry and while it is not properly a matter for this Inquiry to deal with in the course of its investigation, I support Mr Corkill's submissions (paragraphs 46-51) that any suggestion relating to the incidence of cervical cancer being linked to sexual behaviour ignores the evidence and the reality of a number of risk factors. This is particularly important in relation to women who are suffering from various degrees of this disease and for the well- being of the future of a National Screening Programme.
6. The issue is, having accepted the importance of a Programme, for there to be an assurance that the Programme can, as a minimum, fulfil its preventative role. There is no question that once a Programme is established reliance is placed upon what occurs as part of that Programme. That reliance, it would appear from the evidence, is placed both by general practitioners and by the women participating. Every woman who participates in the Programme believes that she is taking action which is protecting herself and she is entitled to have faith in the system established as part of that Programme. In reality, the example in Gisborne has shown that without the proper system that faith is misplaced.

7. There has been much during the course of this Inquiry about monitoring and evaluation and it is dealt with in detail in other submissions. A large part of those submissions deal with the quality control issues in respect of laboratories but it also involves the reporting requirements in respect of the Programme. Those were the requirements of the Ministry of Health and it is submitted that the information that was required from those operating the Register and was in fact kept on the Register showed little concern for those women who put their faith and participated in the Programme. What is the use of enrolling as many women as possible, and particularly Maori women who had not been so keen to be registered, if once they are on the Register there is nothing that occurs to ensure the quality of what follows. What does it matter what time is taken to read smears when there is no information as to the quality of the reading of those smears. As the evidence has shown, what occurred in the implementation of the Programme was a grave and tragic departure from the recommendations of those with knowledge and experience of such Programmes. For Maori women this was an even greater abrogation of responsibility because this Programme was part of an overall health strategy aimed at bettering the position of Maori women in the context of health outcomes.
8. It is in this context that the rather vexed issue of the National Kaitiaki Group arose and the role that it may have played in restricting access to information. In my submission the National Kaitiaki Group has been wrongly accused of restricting access to information on Maori women that may have assisted to identify issues earlier on. In my submission this would not have occurred. It has only been in the context of this inquiry that information regarding the position of Maori women has been obtained and as seen in the evidence presented by the HFA (particularly by Tracey Mellor) the figures show that in the Tairāwhiti region there had been an enormous turnaround in respect of incidence of cervical cancer in the years from 1990-1996. But it must be remembered that this information was not available, was not requested, or required for the purposes of monitoring the Cervical Screening

Programme. The fourth statistical report (LRE/MOH/4) does not provide that detail. It is important to recall that the National Kaitiaki Group has by regulation to approve the disclosure of only “protected information” which is information that “is on or from the Register”. To that end, suggestions of the National Kaitiaki Group having an impact on the ability to compare mortality and incidence rates between Maori and non-Maori is not an issue, as that information is on the Cancer Register which is not covered by the Kaitiaki Regulations. The data that is available is data relating to screening that is held on the Register.

9. The National Kaitiaki Group was established in response to a request for a separate Maori Register. It was something a little less than those involved in the Porirua workshop were asking for in 1988. However, it reflected a real concern expressed by Maori in relation to the release of data. In my submission there would not have been information that was forthcoming in respect of the Fourth Statistical Report that would have assisted to identify the problems that we now know occurred in Gisborne. There is also no justification for removing one of the only requests by Maori that was met by the Government in implementing this Programme. This despite the priority given to Maori women in respect of the National Cervical Screening Programme.
10. The next factor involved the lack of central responsibility which is a significant theme running throughout the evidence that has been presented to this Inquiry. It was clearly anticipated that there would be some central organisational body running the Programme and clearly the Ministry’s own evidence showed the complete inability to identify any person with particular power and authority in respect of overseeing the Programme as a whole. This is a fundamental need for any National Screening Programme to meet its most basic objectives. Related to this matter as well is the issue of an overseeing body or group that is involved with the Programme. It is noted that Mr Corkill’s submissions deal with the appointment of consumer

representatives and while that submission is supported it is important to also remember that with Maori as a priority group the involvement of Maori in that central body is fundamental and must be provided for. It is the delivery to Maori that is a priority and it is important that in the context of the National Kaitiaki Group and in the context of the need for a central body or organisation that that reality is not lost in the call for technical medical expertise. That is certainly required as is the statistical expertise but the expertise in relation to delivery of services to Maori is found in a small number of organisations and people and it is important that those with knowledge of the Maori community and a connection to it are called upon for their expertise (see evidence of Tracey Tangihaere 3/7/200 page 22 lines 17-23).

11. Lack of resources is a matter that has already been dealt with in introductory submissions but clearly both Ms Glackin's evidence and Ms Reid's evidence indicate clearly that Tairawhiti suffered from a lack of resources - a position that defies commonsense when you consider the large number of Maori in the area, the priority given to Maori women and the fact that prior to the implementation of the Programme Tairawhiti had the highest number of deaths from cervical cancer in the country. There is no question that the future of the National Cervical Screening Programme requires appropriate resources to be placed into regions to meet the needs of that region. It would seem that from its own priorities set out in its policy the National Cervical Screening Programme would be able to determine those regions requiring possibly greater resources. Clearly Tairawhiti was one and clearly that did not happen. Lack of resources, though, is a matter that is fundamental to all factors leading to the under-reporting because one can only assume that the deficit in monitoring and evaluation occurred because of a desire to not commit the resources necessary to run the Programme properly.
12. The lack of commitment to establishing the Programme in accordance with the advice given and the recommendations made is again more likely to be related to the

lack of resources and the need to trim costs from the implementation. That was clearly a Government decision and the responsibility rests there.

13. Involved also in the resources question is the lack of involvement of appropriate people and organisations in implementation of the Programme. This is particularly relevant to Maori and perhaps relates more to the decisions being made at a local level by Tairāwhiti Healthcare Limited in particular in respect of the needs in relation to delivery and implementation of the Programme. The lack of involvement of Maori healthcare providers in the system is particularly damning in an area of such a high Maori population.

TERM OF REFERENCE THREE

14. In terms of the question of whether Gisborne is an isolated case or that it is evidence of a systematic issue for the National Cervical Screening Programme, it is submitted that there are issues that relate to the geographic isolation of Gisborne and the limited availability of services in the area that raise the hope that this can be considered an isolated case. However, the factors that gave rise to the under-reporting are not limited to Gisborne. The Programme Manager's minutes show clearly a concern about a lack of resources being common in all areas. The monitoring and reporting requirements in respect of the Register were the same throughout the country and therefore the quality of the service delivered once a woman was registered was not properly monitored. The Health Funding Authority contracts do little to appease concerns as there is no requirement to undertake the kind of monitoring that would identify problems at an early stage. The lack of central leadership and authority is an issue for all areas and it is clear that when warnings have been issued there has not been a person responsible for taking appropriate and proper action in respect of those warnings.

15. Clearly, with the same circumstances and the situation of a person in the chain who is not performing or not trained to perform, this situation could occur anywhere throughout New Zealand. It is hoped that the recommendations from this Inquiry will be put in place to ensure that this will never happen again and that women can again have confidence in the Screening Programme as an effective preventative strategy for cervical cancer.

TERM OF REFERENCE SIX

16. Counsel representing women affected have made recommendations that are supported and are either emphasised or supplemented in the following way:
- (i) That the National Cervical Screening Programme is the responsibility of a central organisation that has authority and accountability in respect of running the Programme throughout the country.
 - (ii) That the Programme is properly resourced. Anything short of appropriate resourcing to enable proper monitoring and evaluation to be undertaken should mean that the Cervical Screening Programme should cease. It is inherently wrong to set up a Programme, expect people to have confidence in it and then restrict the resources to enable it to operate properly.
 - (iii) That the recommendations of the Advisory Group as to the establishment of the Programme be implemented and followed through except in those areas where this Inquiry considers there should be amendment. The involvement of an independent person such as Professor Skegg is applauded.

