

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

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

SUPPLEMENTARY EVIDENCE OF JULIA MARY PETERS

HEALTH FUNDING AUTHORITY

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PART 1 - INTRODUCTION

1. This evidence relates to events and work undertaken by the Public Health Change Management Team (which has also been known as the National Prevention Team and will be known as the National Screening Team within the new Ministry of Health) during the period 13 March 2000 to 16 June 2000. Since my initial brief was written further progress has been made with key projects and the purpose of this brief is to provide an up-date on the main items of work-in-progress.

PART 2 - FUNDING AGREEMENT JULY – DECEMBER 2000

2. The Funding Agreement with the Ministry of Health for the period 1 July 2000 to 31 December 2000 has been finalised. A special measure for the National Cervical Screening Programme (NCSP) has been established. This relates to: access to the Programme, provision of a quality service, implementation of the interim operational policies and quality standards, and implementation of monitoring processes. The Public Health Operating Group will lead the process of ensuring these measures are met, however meeting the proposed requirements will be a joint public health and personal health cross-operating group undertaking, given personal health's responsibility for funding laboratory, colposcopy and smear-taking services. A copy of the funding agreement measure is provided as exhibit **JMP/HFA/0039**.

PART 3 - NCSP PROJECT

3. In my earlier brief at paragraph 122, I explained some of the project work being undertaken to establish quality assurance processes within the National Cervical Screening Programme. I stated that a Project Team had been established to undertake this developmental work and that the Project had a specific timeframe, budget and dedicated workforce. In the subsequent paragraphs I will up-date the Inquiry on the main items of work-in-progress.

A - Policy and Quality Sub-project

4. The Policy and Quality Standards sub-project, referred to in paragraphs 125-133 of my first brief, has progressed. Since completion of the previous brief, the initial consultation round has been completed and the document has been re-drafted taking into account the large amount of feedback received from organisations, professional groups, consumer groups and Maori and Pacific groups. I produce a copy of the second draft and accompanying covering letter as exhibit **JMP/HFA/0040**.

5. Prior to external distribution, the document was circulated to senior managers and other key staff within the Health Funding Authority (HFA) for comment. Subsequent to that, it was printed and sent to 467 external stakeholders and 28 internal stakeholders on 9 June 2000 for written consultation. Four weeks will be provided for this process. In addition, key groups and organisations are being contacted by telephone and face-to-face meetings are being arranged to further consult on the draft document.

6. When the consultation process is complete and any further changes agreed and made, the document will be printed and distributed as the Interim Operational Policy and Quality Standards for the National Cervical Screening Programme. A review of the document will be initiated in approximately 12 months. The reason for this is that once the policies and standards have been in operation for some months providers will be able to give feedback relating to their practical application. Some standards may require strengthening or other modification. A similar process has been under-taken with the Interim Standards for the Breast Screening Programme and I understand that recommendations to strengthen a number of the standards will be made through this process. The twelve-month period enables providers to familiarise themselves with the standards and the review enables them to be refined and up-dated after a period of practical application.

7. The second draft contains six chapters entitled:

1. National Cervical Screening Overview
2. General Policy Requirements
3. Providing a Health Promotion Service
4. Smear-taking and the NCSP
5. Providing a Laboratory Service
6. Providing a Colposcopy Service

8. The first two chapters provide general information about the NCSP and specify policy requirements relevant to all providers. Chapter three outlines the operational and policy requirements for NCSP Health Promotion providers. The revised draft public health plan referred to later in this brief details the provision of health promotion services within the Programme. Chapters four, five and six contain the proposed interim operational policies and standards for smear-takers,

laboratory services and colposcopy services. Appendix one provides a glossary of important definitions and other appendices referred to will be included in the final interim document.

9. More specifically, chapter five, which covers laboratory services, contains 21 proposed standards covering a range of issues including but not limited to:

- The minimum volumes of smears which need to be read at a laboratory site per annum
- Minimum volumes for primary screeners and pathologists per annum
- Minimum training requirements for primary screeners
- Quality control measures to be employed such as rapid re-screening of negative smears
- Expected correlation rates between primary and secondary screening
- Criteria for full rescreening of certain slides
- The required reporting codes and timeframes for reporting cytology and histology results to smear-takers and the NCSR.

10. A minimum volume of 12,000 cytology smears read at each laboratory site is proposed in the document and a discussion paper regarding this issue is being prepared to further inform the debate on this issue. The latest draft of this paper is included as exhibit **JMP/HFA/0041**. Although this paper is not yet finalised, I am producing it because it explores a number of issues associated with establishing and enforcing minimum volumes for cytology laboratories in New Zealand.

11. While the final consultation is being carried out, an internal Health Funding Authority (HFA) process is underway to plan for the

implementation of the interim operational policy and quality standards. A joint Public Health/Personal Health project team has been formed to agree and action an implementation plan with agreed milestones. Progress with implementation will be closely monitored.

B - Monitoring and Evaluation Sub-project

12. In my previous brief at paragraphs 134 - 144, I explained that a draft monitoring plan and set of national monitoring indicators had been developed and consulted on. The summary of the issues raised by the consultation process is provided as exhibit **JMP/HFA/0042**. This document contains general feedback regarding the proposed indicators, suggestions for additional indicators, feedback about issues not necessarily relating to the proposed indicators, a summary of the data sources for the currently proposed indicators, and version 4.0 of the proposed indicators with a summary of significant comments included. The set of indicators requires finalisation, however an earlier attempt to convene an expert working party to do this was unsuccessful due to the unavailability of key participants. The currently proposed process for finalisation will be described below.

13. In my previous brief I also stated that a Registration of Interest (ROI) process had been initiated to seek expressions of interest for the establishment of an independent monitoring group to monitor and evaluate the NCSP.

14. There are a large number of activities involved in establishing monitoring, audit and evaluation for a national cervical screening programme. These include:

- (a) Development of a monitoring framework and processes for continuous quality improvement
- (b) Establishment of comprehensive quantitative monitoring processes
- (c) Development of a minimum data-set for colposcopy and implementation of data collection processes (to enhance b)
- (d) Establishment of provider audit processes
- (e) Establishment of processes to audit individual cases of cervical cancer
- (f) Periodic Programme evaluations

15. In considering these, my team and I have reconsidered our approach to the establishment of comprehensive monitoring and audit processes and determined that more developmental work is required to ensure all components can be carried out to a high standard. We also want to be sure that the processes are in place to respond to the outcomes of the various monitoring processes. For this reason, we have decided not to progress the original ROI process and now propose to take a staged approach to the establishment of Programme monitoring and audit.

16. Feedback from the initial consultation process favoured establishment of an independent monitoring process. I do not see anything that the HFA is doing currently will preclude that development. However, it is essential to ensure that all processes are commenced on a firm footing with buy-in from key stakeholders regarding the methods to be employed.

17. The first stage of the process will be to commence quantitative Programme monitoring during the fourth quarter of this calendar year based on consideration of the feedback to date and finalisation of an indicator set referred to above as exhibit **JMP/HFA/0042**. During the next three months a multi-disciplinary working party will be convened to

consider the feedback and proposed indicator set. Negotiations with a preferred provider of this monitoring service are underway and the provider will be closely involved in finalisation of the indicators.

18. The proposed monitoring process will provide regular, overall programme information, for example, enrolment and coverage rates, and detection rates of various cytological abnormalities per 1000 women screened by region, age and ethnicity. However, it will also be possible, using information currently collected by the NCSR, to monitor certain aspects of provider quality. For example, it will be possible to correlate individual laboratory reporting patterns against the demographics and coverage of the populations they serve. Using the date of receipt of histology information on the NCSR and correlating this with the date of receipt of the index abnormal smear report will enable some information to be generated regarding timeliness of colposcopy and completeness of follow-up. The monitoring reports which will be generated as a result of this process will provide vital information by which to assess the quality of the Programme and early indications of possible lapses in quality which require further exploration.

19. The second stage of this work will involve establishing a framework and processes by which all the other aspects of comprehensive monitoring, audit and evaluation can be developed in a robust and systematic way. This will include all providers involved in the Programme. Monitoring compliance with many of the proposed Quality Standards will only be possible through an audit process. Planning for this developmental work has commenced.

C - Information Management Sub-project

20. At paragraphs 159-163 of my previous brief I described the purpose of the IM sub-project. Progress with this sub-project has been made although it cannot be completed until the data items for quantitative monitoring have been finalised. These will be finalised within the next three months.

21. A component of this sub-project has been to undertake a review of the operation of NCSP - Register at Regional Sites. Findings from the review indicate that there are a number of inconsistencies in the processes and practices employed at register sites. This situation is likely to arise as a result of inadequate specificity regarding nationally consistent practice and the minimum requirements for achieving this. The findings of the review will be used by the HFA national team as it endeavours to develop greater national consistency within the NCSP.

22. A NCSP Monitoring Data Manual is currently being prepared and, when completed, will specify the data requirements and processes for the initial quantitative monitoring of the NCSP. This document is based on the draft monitoring indicators specified by the Cervical Screening Project 1999-2000 and will be finalised when the monitoring indicators are finalised and quantitative Programme monitoring commences.

D - Public Health Sub-Project

23. All the public health review documents, referred to at paragraph 152 of my previous brief, have been finalised. These are the reviews undertaken by Robyn Whittaker, Women's Health Action Trust, Holibar-Fidler Research Associates and Helen Wihongi. In my previous evidence I produced the final version of Robyn Whittaker's review as exhibit

JMP/HFA/0026 and a draft of the report from Women's Health Action Trust as exhibit **JMP/HFA/0025**. The final report from Women's Health Action Trust is now available and is produced as exhibit **JMP/HFA/0043**. It contains a review of current knowledge of and developments in health education resources in cervical screening and provides recommendations as to how the HFA should proceed with the development of new resources. Holibar-Fidler and Helen Wihongi conducted in-depth qualitative interviews with health promotion workers and key stakeholders. Their reports summarise their findings and make recommendations for enhancement of existing strategies. These are substantial reports which need to be considered in conjunction with each other. Although not directly relevant to the terms of reference of the Inquiry, they can be made available if required.

24. The first draft of a revised national public health plan for the NCSP is provided as exhibit **JMP/HFA/0044**. The plan is based on the public health review reports referred to above as well as consultation with women's groups and other key stakeholders. The plan emphasises the need to enhance public health activities among Maori and Pacific women and other under-screened groups using culturally appropriate methods. It also emphasises the importance of providing accurate information for women in an appropriate form and in their own language where possible. Further work will be under-taken to ascertain the most effective strategies and resources for Maori and Pacific women. To respond to the request from providers that they be more involved in the planning of strategies, an inclusive process for this will be developed over the coming year.

25. As a first step in this process of providing nationally consistent information for women, a new colposcopy brochure is nearing completion. This will be printed using the new, finalised visual identity

for the Programme. Production of a detailed brochure for women and a new general information pamphlet will be a priority during the next six months.

26. A national training event for health promotion workers in both the NCSP and BreastScreen Aotearoa (the National Breast Screening Programme) was held in Napier from the 20-23 June 2000. The purpose of the workshop was to provide a national training opportunity for Health Promotion workers to ensure they have the knowledge and skills required to educate women about screening programmes in general and specifically about the NCSP and BSA. Such Health Promotion training opportunities need to become a regular feature of both programmes.

27. In addition, the HFA is launching a national 0800 number for the NCSP and a website dedicated to both screening programmes. The 0800 number will be launched on 1 July 2000 and will enable women to access their local co-ordination site and also to anonymously receive answers to frequently asked questions about cervical screening. The web-site called "Healthy Women", will be launched in September 2000 and provide up-to-date information for women and providers on both the NCSP and BSA.

PART 4 - HEALTH SECTOR RESTRUCTURING

28. In my previous brief, at paragraph 170, I noted the policy of the Labour-led government to abolish the Health Funding Authority (HFA) and to devolve its functions into a new Ministry of Health and 22 District Health Boards (DHBs). Abolition of the HFA and the formation of DHBs requires legislation to be passed which will replace the current Health and Disability Services Act 1993. This legislation is currently being drafted and policy work being under-taken to define the roles and responsibilities of organisations within the new sector arrangements. It is likely that legislation will be passed by the end of this calendar year abolishing the Health Funding Authority, enabling the new Ministry structure to take effect, and DHB formation to proceed.

29. The structure for the new Ministry of Health was announced on the 29 May 2000. There will be eight directorates namely:

- Personal and Family Services
- Mental Health
- Public Health
- Sector Funding and Performance
- Sector Policy
- Disability Issues
- Maori Health
- Corporate and Information

30. The Deputy Director-General of Public Health will be Dr Don Matheson. The team presently known as the Public Health Change Management Team or National Prevention Team will be known as the National Screening Team and will be situated in the Public Health Directorate.

The team will be located in Auckland and the manager of the team will report directly to the Deputy Director-General of Public Health.

31. As a result of the new sector arrangements and policy decisions taken earlier this year to align all the national functions relating to the NCSP under one national team, the roles and responsibilities of the National Screening Team will increase. Responsibility for funding both the breast and cervical screening (excluding smear-taking) programmes will rest with the national screening team. It is yet to be determined whether funds, once identified, will flow through the funding directorate within the new Ministry or whether the National Screening Team will retain a direct role in funding providers. The National Team also envisages increased activity in terms of strategic and structural planning, monitoring, audit, continuous quality improvement, provider co-ordination and data management for both Programmes. To ensure that the National Screening Team can successfully meet these demand additional staff will be required and I am currently progressing this issue within the HFA.

32. Until legislation is passed disestablishing the Health Funding Authority, the National Change Management Team/National Prevention Team will remain part of the Public Health Operating Group of the Health Funding Authority. I, as manager, will continue to report to Dr Don Matheson as the General Manager Public Health and through him to Peter Hughes the Interim Chief Executive Officer and the Board of the HFA. The same accountability arrangements with the Ministry of Health will prevail until the legislation is passed and takes effect.

33. The HFA Screening Advisory Group has continued to meet during this transition period holding meetings on 3 March and 6 June 2000. Confirmed minutes from the 3 March meeting and recent

correspondence between the group and my general manager are provided as exhibits **JMP/HFA/0045** and **JMP/HFA0046**. My understanding is that the Advisory Group will continue in its role when the new Ministry of Health is formed.

PART 5 - UP-DATE ON SIGNIFICANT OPERATIONAL TASKS

A - Statistical report 1996-98

34. My previous brief described, in paragraphs 189-196, the process for compiling the Statistical Report for the years 1996-98. A first draft of the report has been completed and is currently being reviewed and revised accordingly. Most of this work involves editing the text and working on the data interpretations. To ensure that the Inquiry has some recent statistical information available to it, I am presenting the tables from the report, working notes on some data limitations and the appendices from the report as exhibit **JMP/HFA/0047**. When the report is complete, we will review and revise our approach as necessary prior to commencing the data extract for the 1999 Statistical Report.

35. The tables provided contain enrolment and coverage data, cytology and histology reporting patterns data, cancer incidence and mortality data to 1995, and some information regarding quality aspects of the Programme.

36. Some of the key results are as follows:

(a) At 31 December 1998, the proportion of all women, currently actively enrolled on the NCSP - Register was 82.9% (n=884,001). The denominator has been adjusted for hysterectomy (*refer table 3*).

(b) At 31 December 1998, the number of all Maori women actively enrolled on the NCSP - Register was 94,899 or 62.6% of the Maori population aged 20-69, and the corresponding proportion for "other women" (non-Maori, non-Pacific) was 76.5% (*refer table 29*). The

corresponding proportion for Pacific women was 65.2% (n=34,931). These data are not adjusted for hysterectomy (*refer table 56*).

- (c) At 31 December 1998, 70.5% of all women actively enrolled on the NCSP - Register and aged 20-69 years had had a smear reported to the NCSP - Register within the past three years, adjusted for hysterectomy (*figure 5*).
- (d) The proportion of Maori women aged 20-69 years actively enrolled on the NCSP – Register and who had had a smear reported to the NCSP - Register in the past three years at 31 December 1998, was 50% (*figures 11 & 12*). The coverage rate at 31 December 1998 for Pacific women was also 50% (*figure 19*). The 3-year coverage figure for other women (that is, non-Maori, non-Pacific women) was approximately 67%. These data are not adjusted for hysterectomy.
- (e) Age-standardised reporting rates per 1000 smears taken for all women aged 20-69 years over the period 1996-98 are found in tables 16-18.
- (f) Similar tables have been produced for Maori, Pacific women and other women (non-Maori, non-Pacific women). These indicate that between 1996-98 Maori women appear to have had lower, age-standardised rates of normal smear diagnoses and higher rates of ASCUS, low-grade and total high-grade abnormalities per 1000 smears taken than did other women (that is, non-Maori, non-Pacific women)(*refer tables 39-45*). Pacific women appear to have the lowest rates of smears reported as normal but the highest rates of smears reported as showing infection and inflammation (*tables 66-72*). These data are limited by the fact that women may have more than one smear reported to the NCSP - Register covering a

particular episode of care (for example, women are likely to have a repeat smear taken at colposcopy clinic prior to biopsy).

- (g) The incidence of cervical cancer for all women appears to have declined from an age-standardised rate of 13/100,000 in 1980 to approximately 10.5/100,000 in 1995.
- (h) The incidence of cervical cancer among Maori women appears to have declined between 1981-1994, from 32.5/100,000 to 22.4/100,000. However, the rates remain more than twice those of non-Maori women (11.6/100,000 in 1981 and 9.5/100,000 in 1994).
- (i) Mortality from cervical cancer for all women has declined with age-standardised mortality rates over the period 1981-1995 declining from 5.5/100,000 to 3.5/100,000.
- (j) Mortality rates for Maori women have also declined between 1981 and 1993 from 17.8/100,000 to 8.4/100,000. However, the rate remains over 2.5 times that of non-Maori (4.7/100,000 in 1981 to 3.2/100,000 in 1993).
- (k) Tables 21-23 provide information about sample adequacy rates for various smear-taker categories. Overall adequacy rates are around 80% with rates of "satisfactory but limited" smears of 18-19% and less than 1% of smears categorised as unsatisfactory. Tables 49-51 provides the same information for smears taken on Maori women compared with those taken on "other" women (that is, non-Maori, non-Pacific women). These tables indicate that a lower proportion of smears taken from Maori women are completely satisfactory for examination as compared with "other" women and

table 52 provides some possible explanations for this. Similar data are provided for Pacific women in tables 75-78.

- (l) Table 25 provides data for 1996-98 demonstrating the range and median percentage of cytological categories of smears reported to the NCSP - Register for laboratories.

B - Laboratories

- 37. Following on from the October 1999 letter to all laboratories referred to in my previous brief at paragraphs 199-204 and provided as exhibit **JMP/HFA/0037**, a follow-up letter was sent to 9 laboratories in April 2000. A copy of the letter is provided as exhibit **JMP/HFA/0048**. The purpose of the follow-up letter was to raise the specific issue of transfer of histology results in electronic format to the National Cervical Screening Programme - Register (NCSP - Register). All but one laboratory has responded to this letter. Some of the laboratories written to have resolved their interface problem, while others have undertaken to develop their IM interface with the NCSP - Register. The National Team continues to have on-going communications with laboratories to discuss issues that arise.

SUPPLEMENTARY EXHIBITS PRODUCED BY JULIA MARY PETERS

Exhibit No.	Document Description	Document Location
JMP/HFA/0039	Funding agreement	Tab 39
JMP/HFA/0040	Policy & Quality Standards Draft 2 and Covering letter	Tab 40
JMP/HFA/0041	Cytology Volumes Working Paper	Tab 41
JMP/HFA/0042	Monitoring & Evaluation Feedback Document	Tab 42
JMP/HFA/0043	Women's Health Action Report	Tab 43
JMP/HFA/0044	Draft Health Promotion Plan	Tab 44
JMP/HFA/0045	Confirmed Minutes Screening Advisory Group Meeting, dated 3 March 2000	Tab 45
JMP/HFA/0046	Correspondence between the Screening Advisory Group & Don Matheson	Tab 46
JMP/HFA/0047	Statistical Report 1996-1998 – Working Draft	Tab 47
JMP/HFA/0048	Laboratory Letter dated 17 April 2000	Tab 58