DRAFT

REPORT OF THE
NATIONAL
CERVICAL SCREENING WORKSHOP
6-8 DECEMBER 1988
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INTRODUCTION

In June 1987, “Metro” magazine published an article by Sandra Coney and Phillida Bunkle, which made allegations about the treatment of cervical cancer at National Women’s Hospital. As a result of this article, a one person Committee of Inquiry was set up to investigate the issues raised.

Judge Sylvia Cartwright was charged with conducting the inquiry. In August 1988 the results of her inquiry, “The Report of the Cervical Cancer Inquiry”, were published.

Following the recommendations of the Cartwright Inquiry, the Minister of Health made a commitment to establish a national cervical screening programme as soon as possible. The Department of Health initiated a project to develop a nationwide population based cervical screening programme.

Planning for the national cervical screening programme is a complex process requiring consultation with a wide range of groups and individuals, particularly women as consumers and providers of health services.

In order to make effective use of the consultative process the national cervical screening workshop was proposed. Not only would participants be encouraged to make recommendations, but through their interaction during the three day workshops, their recommendations should reflect a common ground between a diverse range of participants.

The National Cervical Screening Workshop was held in Porirua from 6 to 8 December 1988. Approximately 100 people, broadly representative of the groups and organisations concerned with the provision of an appropriate cervical screening service, participated in the workshop. The full list of participants is included in Appendix 1.

The Hon David Caygill gave the opening address at the workshop. He stressed the common purpose of the participants – to save women’s lives. He indicated that the role of the participants at the workshop was to:

- recommend how we should structure a national programme;
- identify resource needs;
- determine what the training needs are, and are likely to be.

“What we need to know, in essence, is: What do we need to do to get a national screening programme up and running as soon as possible?” said the Hon David Caygill.
OBJECTIVES OF THE WORKSHOP

The objectives of the workshop were as follows:

1. To provide the fullest possible information relating to the current rationale of the National Cervical Screening Programme, such that the participants will be aware of present policy.

2. To provide details on the current stage of development of the National Cervical Screening Programme to inform participants of the steps taken to date in the establishment of the National Cervical Screening Programme.

3. To identify those values and principles upon which to base the next steps in this development.

4. To seek agreement in priorities for the next steps to be taken, including identification of specific needs in terms of personnel, resources and a timetable.

5. To seek specific recommendations to go forward from the workshop.

6. To seek agreement on the procedure for setting up a Steering Committee.

FORMAT OF THE WORKSHOP

At various times during the workshop, participants had the opportunity to join three types of small groups. The different types of small groups were:

1. Based around the representatives at the workshop, whether consumer or provider.
   These groups were asked to indicate what would be one sign for them that progress is being made towards the implementation of the national cervical screening programme.

2. Self-selected according to what individuals perceived to be their principle affiliation.
   These groups were asked to define issues that would need to be addressed as an integral part of the development of the national cervical screening programme. The qualities of the programme were, therefore, under consideration.

3. Focussed on specific issues related to the establishment of a national cervical screening programme. The identified issues were as follows:
   - Register and recall system
   - Uniformity of laboratory Reporting
   - Voice and choice
   - Consensus on a protocol for the management of women's abnormal cervical smears
   - Training and quality control of smear taking
   - Resource implications
   - Education, promotion and publicity
   - Evaluation and quality control

   Each group was asked to consider their “issue” in the framework of:
   - What needs to Happen?
   - To what Standard?
   - By When?
   - Who should be Responsible?
   - Resources needed?
   - Estimated Cost?
On the last morning of the workshop, a spokesperson from each group reported back to the assemblage. The final plenary session was intended to present the representative of the Minister (Dr Karen Poutasi, Chief Health Officer) with the outcomes of the workshop. The plenary session began with the presentation of papers by Maori women, Pacific Island women and women with disabilities. The full texts of these presentations are included in the appendices.

Full and frank discussions ensured that while many issues were raised, only some could be resolved in that particular forum at that particular time.

Time was a limiting factor, as was the diversity of views, but in the end six recommendations were sent to the Minister.

**FORMAT OF THE REPORT**

The report presents the outcomes of the small groups discussions in the order listed above, that is, the representative groups, the self-selected groups, and the issue based groups. In the case of the issue based groups, the report follows the format taken by each group. In some cases the format deviated from that recommended. The morning and afternoon workshop provided a combined report in some instances. The comments on the reports from the issue based groups to the full assemblage is included after each group report. The report concludes with the recommendations from the plenary session.
REPORT FROM THE WORKSHOP

1. Themes

Common themes emerged from the workshop reports, and these were consistent with the outcomes of discussion in the plenary discussion. The themes identified some of the principles upon which the programme should be based.

It was reiterated that the principles of the Treaty of Waitangi be recognised and implemented to indicate a true partnership.

Cultural sensitivity in all aspects of the planning, development, administration and provisions of cervical screening services was seen as crucial to the success of a national population based cervical screening programme.

One of the aims strongly expressed was the empowerment of individual women through the provision of information so that each woman could make informed decisions.

2. Reports from the representative groups

The representative groups included:

- Maori women
- Pacific Island women
- Women with disabilities
- Health educators
- Nurses
- Specialists in obstetrics and gynaecology
- General practitioners
- Laboratory staff
- Consumer advocates
- Area health board representatives

Each of the above groups were asked to indicate what would be one sign for them that progress is being made towards the implementation of the national cervical screening programme. The responses were as follows:

2.1 Maori women

That adequate resources for Maori management of screening for cervical cancer are given to Maori women to enable us to be in control of our own programmes and their delivery.

This includes resources for:
- decision making processes, both nationally and tribally
- design, implementation and evaluation of programmes
- training and workforce development
- co-ordination and management nationally and tribally.

2.2 Pacific Island Women

An increased number of Pacific Island women being screened for cervical cancer and a decrease in the number of Pacific Island women dying of cervical cancer.

2.3 Health educators

A media statement to the public that a budget has been approved by the Minister.

Appointment of a national co-ordinator and formation of a working party to initiate training procedures.
2.4 Nurses

Total allocation of necessary funds for an effective national cervical screening programme that is monitored by an expert group.

That the “expert group” is established, as recommended by Judge Cartwright. The expert groups should direct, monitor, implement and evaluate.

That staffing are identified and provided for the whole programme.

That a massive preventative health care campaign is mounted.

2.5 Specialists in obstetrics and gynaecology

That adequate funding is provided specifically for the cervical screening programme, allocated by government over and above Vote Health.

A practical manifestation will be the establishment of national and area health board registers for the purpose of cervical screening.

2.6 General practitioners

That a specific amount of money is committed to implement the programme.

2.7 Laboratory staff

That a suitably graded tutor specialist in cytology is appointed at a tertiary institute. This should be an appropriately funded position with realistic support funding.

2.8 Consumer advocates

That the implementation of the national and regional structures, as recommended by this workshop, are managed and controlled by women consumers and funded separately from the existing health vote.

2.9 Area health board representatives

That extra funding is provided in Vote Health which will be sufficient for an effective national cervical screening programme and will be targetted specifically for that programme.

3. Reports from the self-selected groups

The self-selected groups identified the qualities of a national, population based, cervical screening programme.

Each group was asked to define issues that would need to be addressed as an integral part of the development of the national cervical screening programme.

The list below is a summation of the issues raised by the differing interest groups.

3.1 Principles

3.1.1 The programme should recognise that women need to be empowered to be responsible for their own health.*

3.1.2 The programme should ensure that women’s dignity, respect, and needs are primary.

3.1.3 The service should be effective in reducing the chance of women developing and dying from cervical cancer.

3.1.4 The programme should be controlled and overviewed by women.*

3.1.5 The recall system should be confidential.

3.1.6 All women should be directly involved, through representatives, in ongoing structures.
3.1.7 The programme should recognise that women are owners of their information.
3.1.8 The programme should overcome sectional interests and be based on co-operation.
3.1.9 The programme should be committed to the Maori perspective.

3.2 Funding
3.2.1 It is essential that funding is provided to ensure success of the programme.
3.2.2 Women should be made aware that the practice nurse is subsidised.
3.2.3 There should be funding for women's health centres.
3.2.4 There should be separate funding to area health boards for the cervical screening programme.
3.2.5 The flow on implications of the screening programme will also need adequate funding.
3.2.6 There is a need for management decisions from the providers of funding.
3.2.7 The existing providers of the service need to have their funding reviewed to improve accessibility.
3.2.8 The options which are available if funding is not forthcoming, or is insufficient, need to be explored.

3.3 Planning
3.3.1 All women should be involved in hui and forums before the programme begins.

3.4 Education, promotion and publicity
3.4.1 Public information should be provided so that women are aware of the choices which are available to them.

3.5 Training
3.5.1 Additional training should be established for laboratory staff.
3.5.2 Nurses and midwives need access to training programmes.
3.5.3 There should be re-education of general practitioners, undertaken by the Royal New Zealand College of General Practitioners, to ensure that general practitioners respond to the needs of consumers.

3.6 Management
3.6.1 There is a need for centralised management of the cervical screening programme.
3.6.2 Area Health Boards need to be provided with clear national directives concerning the development and implementation of the national cervical screening programme.
3.6.3 One person should be identified as being accountable for the implementation of the national cervical screening programme.*
3.6.4 The programme needs to be well co-ordinated.
3.6.5 There must be effective communication throughout the structure of the programme.
3.6.6 The national register must be developed and managed.
3.6.7 There must be clarification of national and area health board responsibilities concerning the implementation of the national cervical screening programme.

3.7 Access
3.7.1 The national cervical screening programme must be developed in a way which maximises choice. This will include the option of attending a lay smear taker.
3.7.2 Information concerning the programme should be available in a woman's first language.
3.7.3 The provision of the service must recognise where women are in terms of work, location and timing. This may require a mobile service, especially for rural areas.

3.7.4 Colposcopy services should be provided in rural areas.

3.8 Participation in Client Responsiveness

3.8.1 Acceptable support systems, including chaperones, should be provided for women participating in the programme.

3.8.2 Appropriate counselling services must be available to women and their partners.

3.8.3 Women must be empowered to participate as equals in their health management.

3.8.4 Women should receive a copy of their cervical smear results.

3.8.5 Women should have the option of holding their own patient records.

3.8.6 Never-screened women must be identified and motivated to participate in the national cervical screening programme.

3.8.7 Planning for the national cervical screening programme must involve the community, in particular, women, Maori women, and young women.

3.9 Diagnosis and treatment

3.9.1 Women who have an abnormal cervical smear are entitled to be referred to an efficient, effective and appropriate service for definitive diagnosis and treatment of their condition.

3.9.2 The service must have the capacity to respond to other indications identified through screening.

3.9.3 Smears must be taken skillfully.

3.10 Primary Health Care

3.10.1 The national cervical screening programme must be flexible so that it can be integrated with other screening programmes.

3.10.2 Other sexually transmitted diseases should be screened for and breast examination should be undertaken.

3.10.3 The national cervical screening programme should also be used for preventative health education.

3.10.4 The national cervical screening programme should incorporate a holistic approach to women's health.

3.10.5 The national cervical screening programme should explore the feasibility of monitoring men for human papilloma virus.

3.11 Evaluation and Quality Control

3.11.1 There must be ongoing research into the effectiveness of the programme.

3.11.2 There must be accountability in respect of programme.

3.11.3 There must be appropriate safeguards throughout the system.

3.11.4 Clear guidelines for accountability must be developed.

* indicates that the point was controversial
4. Reports from the issue based workshops

4.1 Register and recall system

Workshop 1

What needs to happen

The following matters were identified:

Smear takers should encourage women to have cervical smears using age/sex registers and personal invitation. Smear takers should particularly encourage women to enrol in the regional register.

Regional registers should be established in area health boards with the aim of:

- improving call/recall and acting as a back up for smear takers
- ensuring appropriate follow up of abnormal smears
- evaluating the programme by
  - the number of smears (normal and abnormal)
  - the number of women receiving smears
  - the quality of cytology
- providing the capacity to notify the cervical smear result directly to the woman concerned, if requested.

Cervical Screening must have political commitment, resources, and a high priority at area health board level.

Specific points in relation to the register were identified as follows:

- Registration should be voluntary but strongly encouraged.
- Registration should be based on the cytology result forms.
- The register should include integration of cytology and histology reports and should link up with the National Cancer Registry.
- The register must record final results of the treatment of abnormal smears and validate that treatment has occurred.
- A target should be set for reaching 80% of 18-65 year old women in 3 years (by 1991).
- Confidentiality must be ensured.
- The register should record ONLY gender, name, address, date of birth and a unique national number.
- The register should be a total population register.
- There is a need for a public education campaign to convince people of the need for a national health register and to actively encourage registration, aiming for comprehensive coverage by the next census.
- The register must allow evaluation of programmes on a national basis and improve accuracy of regional records by covering the mobile population.

Estimated cost

The estimated cost to establish national and regional registers is $2.5m in the first year (for 17 area health boards), according to a background paper prepared for the workshop by Frances Sutton, Economics Unit, Department of Health.
Workshop 2

What needs to happen

The following matters were identified:

A national health register should be established by October 1989. This should be the responsibility of the Ministry of Health. This Register should not be just for cervical screening. It should only contain non-clinical information and should cover the entire population (male and female). The minimum information should include:

- name
- date of birth
- gender
- address
- identification number (unique to the individual).

A regional cervical screening register should be established forthwith. This should be the responsibility of the area health board or health development unit. The purpose of this register is to ensure that every eligible woman on the national register is invited to have a smear within a three year interval.

This regional register should contain clinical information relevant to cervical screening.

The development of the software required for the regional registers is a matter of urgency.

Recall should be generated by the smear taker, with the register acting as a safety net to try to ensure that women are screened within the recommended screening interval.

The register information required on request forms should be clearly understood by smear takers and women clients.

There should be legal protection for the laboratory when transferring confidential information to the regional register.

Estimated cost

The estimated cost of these registers is $50,000-$80,000.

To what standard?

Confidentiality must be ensured. Concerns of the group included:

- Accessibility to the regional register by the smear taker.
- The definition and registration of "smear taker".
- Quality checks of information on regional register and the processing of this information.
- The question of whether Maori women wish to have a separate register.

It was also noted that area health board cervical screening co-ordinators needed training. The group considered that this should be the responsibility of the Ministry of Health.

Comments made at the report back session

The following comments were made at the report back session:

- The register should record follow-up of abnormal cervical smears.
- It would be helpful to include information on employment categories to assist in the development of health education programmes.
- Registration should be available to women who are younger than 18 years.
- Access to the register must be controlled.
There should be a compulsory health register, only including name, age, address etc.

Pilot schemes should be established for the local registers.

Letters of invitation to enrol in the national cervical screening programme should offer a choice of provider/smear taker.

There is a need for further discussion on the frequency of cervical smears.

The regional register should act as a safety net.

4.2 Uniformity of laboratory reporting

The following recommendations concerning laboratory reporting were made:

Descriptive reports should be universal.

It is important that recommendations on abnormal reports go to the smear taker.

A statement as to why a smear is unsatisfactory, that is, blood, contaminated material etc., must go with the report.

Endocervical cells should be reported as an indication that the transformation zone has been sampled (the percentage of smears containing endocervical cells is one parameter which may be used to assess the skill of the smear taker).

Severe inflammation should be reported. A cervical smear should be taken and evidence of pathogens responsible for the inflammation should be reported.

This group sees as a problem that nurses and lay smear takers have not the specific access to the schedule for funding to take swabs as a necessary adjunct to taking smears.

The term atypical metaplasia should not be used as it is confusing in regard to follow up action.

Dysplasia must be indicated and may be qualified as mild, moderate or severe.

It is understood that women in future will get their report after a delay of about 3 days following the smear taker receiving the report. This report will be sent out by the area health board registry to the smear taker, who will then notify the woman.

Liason should be established between the Society of Pathologists, the Society of Cytologists, the College of Pathologists and the New Zealand Institute of Medical Technologists to continue discussion regarding a common terminology for reporting cervical cytological diagnoses.

The following recommendations concerning training of laboratory staff were made:

**Cytologists – qualified Technical Assistant standard**

This should involve an extensive training with a minimum of three months total in a training school.

Training is also needed in an accredited laboratory.

The examination should involve a clinical (practical) component and should be recognised by the Department of Health.

There is a need for about 20 technical assistants to qualify each year.

A block course should be offered to:

Those already trained but coming back to the workforce.

Those being updated from small laboratories.

New trainees – at a suitable technical institute, for example, ATI and CIT.

The examination would be sponsored by the New Zealand Society of Cytology and should receive resources from the Minister of Health.
Technologists


Cytopathologists

There is a shortage of cytopathologists but there is not enough funding from the hospital boards or from the cytology fee in private laboratories to cover these salaries.

The following recommendation in relation to workloads required to maintain competence was made:

Where there is training in the laboratory, there should be a substantial number of cervical smears screened per annum [International Academy of Cytology recommendations are 25,000 cervical smears screened per annum] and/or there should be special expertise in teaching available in the area. Non training laboratories should do 1000 cervical smears per annum. Below 1000 cervical smears per annum work should go elsewhere or a special case should be made to justify this small load.

There is some quality control envisaged in the co-relation of colposcopy, biopsy and cytology.

No comments were made at the report back session.

4.3 Voice and choice

The combined report of the two workshops is presented here.

What needs to happen

The following matters were identified:

National policy needs to be developed to reduce the incidence and mortality from cervical cancer by 80 per cent. This policy development should be undertaken immediately by the Minister/Department of Health.

Specific funding should be allocated from Vote: Health for the establishment of:

- adequate screening, diagnostic and treatment facilities
- education programmes at a national level for all existing providers (general practitioners) and other providers (nurses, lay health workers)
- a recall system at both national and local levels
- screening sites at the local level to meet the specific needs to particularly at-risk groups, such as, low paid women, Maori and Pacific Island women.

Some of this funding will be required at a national level and some should be specifically tagged for cervical screening services to be funded by area health boards. This funding policy should be established by the Minister of Health.

There should be immediate implementation of Judge Cartwright’s recommendation (page 209 para 7 in the Report of the Cervical Cancer Inquiry 1988) that:

“The Minister of Health should establish a group representative of a wide range of women health consumers and appropriate health professionals, including representatives of cytology, pathology, colposcopy and nursing personnel. . . . The objectives of the group should be to evaluate procedures, advise on resource allocations and implement within “a reasonable period” a population based cervical screening programme for New Zealand women.”

Women in both workshops put forward the Ministry of Women’s Affairs national structure which they see as ensuring that implementation is effective and that it involves all groups concerned (Appendix 5). This national programme must achieve its aims.

Consumer representatives on the above expert group should include Maori and Pacific Island women. To be eligible these women must have proven records of work with women’s health at the community level.
They should be selected by the Minister of Health on the advice of an advisory group of four women to be named at this workshop.

The appointment of the national co-ordinator should be postponed. The national co-ordinator should be appointed by the expert group. There should be two positions, one at least to be filled by a Maori woman. The review of the vacancy of national co-ordinator should be undertaken immediately by the Minister of Health or Chief Health Officer.

While women's issues must continue to be identified and addressed as part of the above implementation process, the voice and choice workshops made a start with the following recommendations for specific groups of women.

Low Income women:

Health and Safety officers should be in all workplaces.

The development of a Code of Practice on Health and Safety should be mandatory.

Legislation should entitle workers to take preventative health care leave (2 extra days to be in 2 hour blocks).

Maori women:

Funding should be given to Maori women in the community to set up their appropriate screening and other services.

Once referred for diagnosis and treatment, the woman and her whanau should have the right to negotiate treatment etc.

Non-Maori women:

Funding should be provided for the development of initiatives for screening and prevention by all area health boards (for example, women’s health centres, Trade Union Medical Centres etc).

Other matters identified were as follows:

The national programme should monitor the implementation of the Cartwright recommendations on cervical cancer and medical education.

Women’s health groups and patient surrogates should be paid as resources.

In conjunction with the smear being taken, women should be asked if they want tests for other sexually transmitted diseases. They should be advised of the benefits of these tests in protecting their health and fertility. Priority should be given to tests for chlamydia.

Lay smear takers: once they have been trained according to national standards they should be approved by the Medical Officer of Health. The criteria for approval must be the satisfactory completion of training, not whether the Medical Officer of Health thinks that lay workers should take cervical smears or not.

A national cervical screening awareness programme should be developed. Funding for this must be directly channelled to initiatives, such as those run by Waireti Walters for Maori women. Pamphlets and videos are not suitable means of developing awareness of health issues for many Maori and Pacific Island women. One-to-one contact is needed. This should be funded through area health boards from the budget for the national cervical screening programme.

There must be a national education programme for existing and future providers of cervical screening services. Providers must opt into the national programme once they provide evidence they are taking quality smears, have effective recall and follow up, and provide the service in a way that is appropriate: for example, by providers who are women, and who demonstrate cultural, and other sensitivity.

The national protocol on follow up and treatment should include women’s perspectives.

There must be acknowledgement that preventative measures are the best use of resources. and so free cervical smear tests should be available to all women. Early follow up, diagnosis, and treatment should be provided at no cost to women in a publicly funded, publicly provided health system.

A national mammography workshop should be held once the national cervical screening programme is up and running.
THESE AND OTHER ISSUES OF CONCERN TO WOMEN CAN ONLY BE ADDRESSED IF WOMEN ARE INVOLVED AT EVERY LEVEL IN THE IMPLEMENTATION OF THE NATIONAL CERVICAL SCREENING PROGRAMME. THIS IS AN AGREED PRINCIPLE.

Comments made at the report back session

A number of points were raised and questions formulated. These included:

Who is going to make up the expert groups?
Do the expert groups select the sub groups?
The groups should number at least 10.
The sub-groups should be matched to each “interest group”.
The detail of the national cervical screening programme should be developed at the sub group level.
The expert group must be adequately serviced and supported.
Who will advertise/establish the expert group? This will presumably be undertaken by the Minister of Health.
Funding for the national cervical screening programme must be over and above Vote: Health.

4.4 Consensus on a treatment protocol for the management of women’s abnormal cervical smears

The combined report of the two workshops is presented here. The workshops identified a number of additional points which should be included in the protocol. These were:

Effective management of women’s abnormal cervical smear is dependent on women’s full, informed consent (there should be protocols for giving informed consent).

For women in the reproductive age group, who have not had previous cervical abnormalities, one sample, taken with a modified Ayre’s spatula, is generally adequate.

In certain specified conditions, for example, women on Depo Provera, preganacy, breastfeeding women, post-menopausal women, distortion of the cervix after surgery, endocervical cells are frequently not found. For these women (excluding pregnant women) two samples should be taken, one with a modified Ayre’s spatula and one with a cytobrush. Both specimens can go on one slide. Each half can be fixed independently.

In relation to colposcopy appointments: general practitioners should also receive information concerning the appointment and the health information that the woman has received.

In relation to New Zealand research needs: The development of new cost-effective means of sampling the cervix and endocervical canal must be explored.

Some modifications to the protocol were recommended. These modifications included:

For repeats of cervical smears, the terms “within” a certain interval should be used throughout the protocol.

The protocol should be divided into:

Normal
Inadequate, for example, no endocervical cells, neutrophils, too much blood
Abnormal
Inconclusive cervical smear result, in women who are post-menopausal, post-irradiation, post-cone biopsy. The smear should be repeated in three months. If this repeat smear is still abnormal then the woman should be referred for an urgent colposcopy. If the smear is normal, then the smear should be repeated in six months in the first instance, then 12 monthly for life.
A number of clear messages emerged in relation to cervical smears. These were:

*IF THE CERVIX APPEARS TO BE CLINICALLY ABNORMAL, IGNORE THE CERVICAL SMEAR.*

*IF THERE ARE ANY SYMPTOMS AND SIGNS, TREAT THESE FIRST AND THEN TURN ATTENTION TO SMEAR.*

*ALL WOMEN WHO HAVE HAD A HYSTERECTOMY SHOULD HAVE A VAGINAL EXAMINATION TO CHECK THAT THIS HAS BEEN A TOTAL HYSTERECTOMY.*

*CYTOLOGY NEVER EXCLUDES INVASIVE CARCINOMA.*

In relation to marked inflammatory changes, it was recommended that if any atypia are noted on the cervical smear at 6 or 12 months, then the woman should be referred for colposcopy.

It was also considered that tirage for colposcopy should be undertaken on the referral letter.

The management of women whose cervical smear showed *human papilloma* virus should be different from the management of women whose cervical smear showed mild dysplasia. In relation to human papilloma virus, the smear should be repeated with a cytobrush within 6/12 months or earlier if there are no endocervical cells. If two cervical smears are abnormal, then the woman should be referred for non-urgent colposcopy. Non-urgent colposcopy should be undertaken within 3-6 months. By contrast, all women who have *mild dysplasia* should have non-urgent colposcopy.

The addition of a *glossary* was recommended. The glossary should include terms such as:

- Colposcopy
- Urgent colposcopy
- Non-urgent colposcopy
- CIN

*In relation to referral for CIN 3,* ensuring an urgent appointment by urgent referral letter or telephone, which ever is appropriate, was considered important.

Comments were made on the treatment section. These included both changes and improved specification, such as:

- Change to “Refer to gynaecological oncology centre where a multidisciplinary decision can be made with each individual woman”; and

Specify types of treatment. For example, for local destruction these would be laser, cryotherapy (CIN 1 only), cold coagulation, cautery, and diathermy. For excision biopsy, LLETZ, large loop excision of the transformation zone, would be included. Radiation and chemotherapy would be options for treatment of carcinoma.

Action which should be taken should not just be action on diagnosis and treatment. Information and support action was also required. This included:

- Information with the appointment.
- The opportunity to attend a group education session with support person.
- The provision of appropriate counselling services.

**Comments made at the report back session**

A number of points were raised in relation to the protocol. These were as follows:

- The system must allow for whanau advocates for Maori women needing treatment.
- There is a need for patient advocates and counselling at every stage.
- A process for informed consent at each level is needed.
Treatment protocols need developing with a women's perspective as part of an ongoing process. The language on "forms" should be understood by all women.

A personal approach to women is important.

4.5 Training and quality control of smear taking

Workshop 1

What needs to happen

The following matters were identified:

- Training is needed for lay people, nurses and doctors.
- National Guidelines and standards for training should be developed.
- Training would need to be overseen by a national body.
- Trainers and trained people would require appropriate recognition.

To what standard

Participants at the workshop considered that there were certain basic requirements of knowledge, attitudes and skills required by all smear takers. More advanced knowledge and skills may be required by some smear takers.

i) Basic requirements

Knowledge (needed for all smear takers)

- Anatomy and physiology
- Process and requirements for good smear takers.
- Cervical cancer
- Cervical screening
- Informed consent
- Treaty of Waitangi/cultural issues.

Skills

- How to explain, listen, take a history, inform, educate, examine, demonstrate, take a good smear
- How to organise place, time & equipment, record, referrals, co-ordination
- Sensitivity, action of empowering women

Attitudes

- Partnership with women
- Commitment to empower women
- Sensitivity to other women's needs
- Working with other health workers

ii) Advanced requirements

Further skills and knowledge are required by some and the acquisition of these additional skills and knowledge would be optional for others.
When

Now

Whose responsibility

Responsibility for ensuring that adequate training of smear takers occurs will vary depending on the category of smear taker under consideration. Variations will also result depending on whether existing smear takers' knowledge and skills are to be updated or new smear takers are being trained. Organisations responsible for training therefore include:

- Lay smear takers – area health boards according to national directives
- Doctors: new established – medical schools established – The Medical Council of New Zealand
- Nurses: new established – Polytechnics established – The Nursing Council

Resources

The following matters were identified:

- Lay trainers and trainees should receive funding.
- Initiatives using surrogate patients should be explored.
- Surrogate patients will also need funding.
- Both equipment and training resources will be needed.
- The training resources should be available in appropriate languages as a national resource.
- A body, which will oversee training of smear taking, should be established with local subgroups.

Workshop 2

What needs to happen

The following matters were identified:

- Training, to ensure the development of appropriate knowledge, attitudes and skills, is required for doctors, medical students, nurses, lay smear takers and trainers.

**GUIDELINES OF UNIFORMITY OF TRAINING NEED TO BE SET AT THE NATIONAL LEVEL.**

The training process must be ongoing and include re-evaluation. Supervision and experience in undertaking a set number of smears should be required as part of the training process. Trainees will need support during training. Some form of recognition (not necessarily a certificate) is important on the completion of training.

- When women who have an abnormal smear result, cooperation between the smear taker and supervisor will be required to follow up the client.

- For Pacific Islander women, trained nurses would be appropriate smear takers.

By when

March 1989

Whose responsibility

The following matters were identified:

- The expert group of consumers and medical professionals should be responsible for ensuring that training to an agreed standard is provided.
A national supervisor of trainees should be appointed.

Issues related to legal liability will need to be investigated.

**Resources needed**

The training resources required will include sites/facilities such as family planning clinics, wellness clinics and polytechnics.

**Comments made at the report back session**

A number of issues were raised in the report back session in relation to training. These were as follows:

- Women should nominate the person they wish to undertake follow-up of their smear result, rather than the smear taker and supervisor.

- In the selection of trainees for smear taking, the following matters should be considered:
  - There should be no educational prerequisite.
  - Trainees should come from the community (interest group).
  - A self selection process should be considered with the process of training deciding whether people should continue.

- Trainees/ers can learn on each other.

- Medical students need to be competent before graduation.

- Feedback from women is an important aspect of training.

- The existing quality and standard of training varies.

- Trainers must be trained.

- Who decides the number of trainers?

- Nurses want to be trained using family planning clinics or polytechnics, not general practitioner's clinics.

- Good models exist for the training of Maori women and these models should be followed.

**4.6 Resource implications**

**Workshop 1**

In this workshop, participants identified the standard, time frame, accountability and resources required for a number of issues as follows:

**1) What needs to happen**

National funding must be provided. The funding should be controlled by a monitoring group in conjunction with the national co-ordinator.

Funding for the provision of services through area health boards is essential with clear guidelines for minimum standards.

**To what standard**

Clear guidelines must be established on access, quality control, training and the register (national and area health board's).

**By when**

By 1 April 1989.
Whose responsibility

The monitoring group appointed by the Minister with appropriate Maori and other cultural representation in the spirit of the Treaty of Waitangi.

Resources

The following resources were identified as being necessary:

- Administration
- National co-ordinators (at least one of whom should be Maori)
- Area monitoring groups

ii) What needs to happen

The real costs of processing cervical smears and the flow on effects of colposcopy and pathology, when done in the public and private systems should be compared.

To what standard

This should be undertaken to the required standard of training and to a standard acceptable to quality control.

Whose responsibility

The monitoring group and the Ministry of Health.

iii) What needs to happen

Women who are not being screened, for example, women of low socio-economic status, migrant women etc. need to be identified.

Whose responsibility

This may be undertaken by:

- The local monitoring group with appropriate Maori and cultural representation.
- Area health boards.
- Other community groups.

iv) What needs to happen

There should be more colposcopists and colposcopes and reduced waiting time for colposcopy (with more space and support staff). Information is required on the appropriate numbers of colposcopists. There is also a requirement for more laboratory/pathology staff.

To what standard

The standard should be monitored by quality control and evaluation procedures.

Training and retraining of non-obstetric and gynaecological specialist colposcopists should be considered.

Whose responsibility

The following groups are responsible:

- Area health boards
- Local monitoring group
- National co-ordinators
Resources

The resources required will include colposcopists, colposcopes, nurses, secretaries, space and furniture, laboratory and pathology staff and counsellors.

v) What needs to happen

Information needs to be shared with clients to empower them.

To what standard

The following matters were identified:

- Information should be in the client's first language.
- It should be responsive to the needs of the client/patient.
- Information concerning strategies for action and recall should be included.
- Patients should receive their own results if they wish.

Whose responsibility

The information should be generated by the register/recall, which is the responsibility of the national and local co-ordinators. Smear takers (who will also get the results) will have an important responsibility in ensuring that women receive the information.

Resources

Paid translators will be essential to ensure that all women receive this information.

vi) What needs to happen

Free smears should be available on the issuing of a reminder letter from the register. This would be done by an approved smear taker (for example, general practitioner, iwi authority, and other groups) as for the maternity benefit. The subsidy must be sufficient to cover costs but smear takers may charge on top of this. If the service is provided by a public hospital, the subsidy would be payable to the institution.

Registration as a matter of choice may need to be reviewed.

To what standard

The quality control of smear taking, clinics, or centres should be ensured.

The recommended frequency of smear taking should be according to the national guidelines.

Whose responsibility

National co-ordinators and the monitoring group working through area co-ordinators and the local monitoring groups.

Resources

The following resources have been identified:

- Computer personnel
- Clerical staff
- Smear takers
- Treatment services

vii) What needs to happen

The costs and benefits of additional screening, for example, chlamydia, should be investigated by the national co-ordinators and the monitoring group.
Workshop 2

What needs to happen

The following matters were identified:

There must be acknowledgement by government that it has a responsibility to fund a public health system. The specific funding for the screening programme should be an addition to Vote: Health and the funding must be ongoing.

The Vote: Health budget must be increased.

The Vote: Education budget should be accessed for education of health workers.

Funds for programmes allocated through area health boards must be available, but subject to directives from the national committee.

The services which should be free include taking and reading the first smear, referral, and treatment. These services should be freely available and provide choice in terms of time, location and provider. The payment for the first smear should take the form of a uniform subsidy specifically for smears to smear takers.

An effective cervical screening programme will have positive spin offs in other areas of women's health. It will increase the sensitivity of providers to women's health issues and will enhance women's interest in their own health. The long term resource implications are that there will be less long-term cancer care and less expensive treatments.

Comments from the report back session

A number of points were raised at the report back session in relation to resource implications. These are as follows:

Good health is a right.

There is an immediate need to have information when a cervical smear is reported as abnormal. The basic information should be in the woman's own language and should include a recommendation for action.

Smear takers should not get paid for inadequate smears.

4.7 Education, Promotion, Publicity

Workshop 1

What needs to happen

The following matters were identified:

Clients, the community and providers need education concerning their knowledge, attitudes and behaviour.

A sexual education programme should be established.

Key educators and a local co-ordinator should be identified.

Local educators and networks should be identified.

Ongoing evaluation of all components must be established.

To what standard

To reach everybody over the age of 9 years.

To be culturally and socially appropriate.

To be responsive to the changing needs of consumers.

By when

Immediately
Whose responsibility

The following groups are responsible:

- The national co-ordinator and national advisory group will be responsible for the education of clients, the community and providers, using key educators, local educators and networks.

- The Education Department (health syllabus) should be used for the sexuality programme, with the national co-ordinator and the national advisory group (sub-committee on education) having responsibility and employing key educators and local educators and networks.

- Local Community groups and Area Health Boards should be responsible for identifying key educators and a local co-ordinator.

- The key educators and the local co-ordinator should be responsible for the local educators and networks. The national co-ordinator and the national advisory groups should be responsible for the ongoing evaluation via the key educators, local educators and networks, consumers and the local co-ordinators.

Resources

- National publicity campaign: 1 million
- Local initiatives funding (population based):
  - Area health boards' co-ordinators under contract: 3 million
  - Programmes – including salaries
  - Special needs – to train and update groups: 2 million
- Ongoing evaluation: 0.6 million

Workshop 2

In this workshop, participants identified what needs to happen, the standard, timeframe, accountability and resources for a number of issues as follows:

i) What needs to happen

Education, promotion and publicity is required for:

- The public, smear takers, low paid women, consumers, low socio-economic group women, men, sexually active women, community outreach workers, decision makers, (BOS, DOH, TREASURY), planners, medical students, medical practitioners, health workers, school children, Maori women (consumers, smear takers), Pacifica, fundamentalists, elderly women, the never-smearred.

What is to be learned

The following learning needs were identified:

- Life is valuable
- Women have the power to decide about themselves
- Consumer rights
- Women are equal in the partnership with providers
- Women's voice must be heard
- Representative input for all groups of women
- Wart Virus, HPV
- Smoking
- Limited partners
- Barrier protection
- Joint responsibility
- Basic reproductive facts
- Cervical screening saves women's lives
- Cervical screening is a normal healthy behaviour
- Informed consent and requests
- Smear taking skills (quality, sensitivity, consensus, appropriateness, cultural and social)
- What smear results mean
Treatment options
Other services, alternatives health practices
Follow up skills

ii) What needs to happen

The following matters were identified:

- Resources should be provided, both nationally and regionally.
- A structure must be set up to ensure that the funding gets to where it is needed.
- Government funding for publicity should be targeted to meet local/national needs.
- The message must be culturally appropriate.
- A national publicity campaign, accountable to women, must be evaluated against standards which include research, funding and quality.
- Confidence in the programme must be generated.
- It is essential to capitalise on the present momentum, enthusiasm and commitment. This will reduce the fear of a backlash.
- Health professionals must demonstrate role model behaviour.
- All curricula must include cervical screening information.

How

Through lay educators and providers, using the structure set in place which must provide variety and flexibility in the system. There is also a need for:

- Education for providers and providers in training.
- Mass media – at the national and local level using multi media techniques over time and targeted at the general public and “at risk” groups.

The expert women’s groups should oversee these programmes. There should be two sub-committees for education and the publicity campaign, linked to the local co-ordinators and their support groups. Separate Maori representation is essential.

iii) What needs to happen

Two national sub-committees linked to a local co-ordinator and her support group should be established. These committees are for the national/local multi media campaign and the education for providers and providers in training.

To what standard

The following standards were identified:

- There should be separate Maori representation.
- National guidelines must be established by the expert group.
- Health education, promotion and publicity must be culturally and socially appropriate.
- Standards of excellence for all screening providers must be developed which are flexible to local and changing needs.
- Lay people and professionals must be included in the structure.

By when

The sub-committees need to be established immediately and should be ongoing.
Whose responsibility
Ministry of Health

EXPERT GROUP

Sub Comm 1 Sub Comm 2

Local cervical screening programme through local co-ordinator

Resources

Resources will be required for the multi media campaign, salaries for the local co-ordinator, administrative support, fees and allowances, equipment, training and transport will be required. A contribution from Vote: Education should be sought.

Estimated costs

$1m every year for 3 years and review
$1m depending on workforce size, related to numbers of women to be screened.

Comments from the report back session

The only comment made in the report back session was that it will be important to set up funding for a pre-programme launch campaign.

4.8 Evaluation and Quality Control

Workshop 1

What needs to happen

The flow diagram (Appendix 6) shows the points at which quality control and evaluation need to happen (registers are important for evaluation). The specific issues which need to be considered are as follows:

Education of Women

The following aspects should be evaluated:

- Baseline evaluation of current education levels including:
  - knowledge of cervical cancer
  - knowledge of the cervical screening services available
  - attitudes/beliefs/values/practices.
  
  It is essential to involve women working in the community.
  
  Performance measures will require repeat surveys of education levels.

Contact with Services

The following aspects should be evaluated:

- The provision of choice of a woman smear taker in each area.

- Women's satisfaction with services available.

- Ongoing quality control.

- Feed back from women about the service.
Smear taking

The following aspects should be evaluated:

- Percentage of women in each age group having a smear in the last 3 years.
- Monitoring of proportions of unsatisfactory smears, by smear taker (indicate name, category of smear taker on the form).

Training of smear takers is part of quality control, but is being considered by another workshop.

Smear Reading

Evaluation of this aspect will require laboratory internal control as follows:

- A laboratory standard should be introduced to reach the optimal standard suggested by the Cytology Society, through compulsory TELARC registration.
- Cytology results should be linked with histology reports and the cancer register to evaluate the sensitivity and specificity of laboratory reporting.

Smear Reporting

The following aspects should be evaluated:

- The proportion of women who know the results of their last smear.
- The proportion of women with abnormal smears lost to follow up before treatment has occurred.

Investigation and treatment

The following aspects should be evaluated:

- The length of wait for colposcopy and biopsy following an abnormal smear. Delays should be monitored in different areas, especially rural areas.
- The evaluation of the acceptibility of colposcopy etc to women on a local basis.

Recall

The following aspects should be evaluated:

- The proportion of women invited for screening, who have a smear within 3 months.
- The reasons for non response.
- The proportion of women with normal smears having a repeat smear in less than 3 years.

Invasive Cancer

The following aspects should be evaluated:

- The screening history of women with invasive cancer.
- The trends in age specific rates of invasive cervical cancer.

There is a need for timely statistics. Cancer registration needs adequate funding.

The Director-General of Health should examine legal and ethical issues of confidentiality.

Deaths

The following aspects should be evaluated:

- The trends in age specific mortality rates of cervical cancer.
Whose responsibility

The following groups are responsible:

- An independent monitoring group should be set up to oversee the evaluation of the ongoing programme. This should include consumers and providers.

- A resource group should be available for area health boards which do not have sufficient expertise.

- Working groups should develop details of quality control and evaluation in special areas such as laboratory quality control and colposcopy.

Workshop 2

What needs to happen

A national monitoring group should be set up, that will oversee quality control and evaluation.

The national monitoring group will be public, independent and ongoing.

The following aspects need evaluation:

Access

- Options
- Education including school programmes
- Information

Smear taking by smear takers, patient and regional co-ordinator.

Smear reading

Smear reporting needs standardisation.

Follow up and recall by the last smear taker and patient. There should be random checks on non attenders.

Patient satisfaction

- services available
- services at risk
- options/choices
- treatment and services
- the non attending of population at risk.

Evaluation and quality control of investigation and treatment

- access
- treatment protocol
- the balance between public and private services.

Whose responsibility

Regional co-ordinators and the national co-ordinator will be responsible for access, smear taking, smear reading, smear reporting and follow-up and recall. They will also be responsible for retraining or replacing smear takers.

The national monitoring group and the regional and national co-ordinators will be responsible for the indicators of patient satisfaction and the evaluation and quality control of investigation and treatment.

To what standard

National guidelines for urgent and non-urgent colposcopy and treatment waiting times must be developed. The national and regional co-ordinators and monitoring group will be responsible for developing these guidelines.
5. Recommendations sent to the Minister of Health

The following recommendations were sent to the Minister of Health:

1. That an executive group, with decision-making power, be formed to control the national cervical screening programme and to allocate funding for the programme to the area health boards.

2. That the national co-ordinator of the national cervical screening programme be accountable to the executive group.

3. That there be two national co-ordinators, both women, at least one of whom is a Maori woman.

4. That the workshop strongly supports specific and separate funding for the national cervical screening programme, over and above that presently allocated to the Vote: Health.

5. That cervical screening services be provided free of charge to all women.

6. That the executive group should consist of representatives of the following women’s consumer groups – lower paid women, rural women, Maori women (two), and “a survivor of the National Women’s Hospital experiment”, as well as health professionals as recommended in the Cartwright Report (page 209) and according to criteria established by the Minister of Health and Women’s Affairs.
Appendix 1

List of Participants
PARTICIPANTS

Ms Phillida Bunkle, Wellington
Ms Gemma Callaghan, Takaka
Ms Caroline Cartwright, Christchurch
Ms Jenny Chilcott, Auckland
Dr Gabrielle Collison, Auckland
Dr Diana Edwards, Blenheim
Ms Ellen Gordon, Auckland
Ms Victoria Grace, Christchurch
Ms Tennah Handiside, Nelson
Ms Celia Lampe, Wellington
Ms Ramari Maipi, Huntly
Ms Colleen Manhera, Tauranga
Dr John Marwick, Wellington
Ms Anne McSherry, Palmerston North
Dr Gail Meekin, Porirua
Ms Gillian Moir, Tauranga
Dr Peter Moodie, Wellington
Ms Trish Mullins, Wellington
Ms Sue Neal, Auckland
Ms Ruth Norman, Auckland
Dr Charlotte Paul, Dunedin
Ms Alison Quigg, Lower Hutt
Dr Paparangi Reed, Wellington
Ms Heather Thompson, Auckland
Ms Waireti Walters-Ratima, Auckland
Ms Mavis Watson, Christchurch
Ms Lynda Williams, Auckland

REPRESENTATIVES

Ms Chalfidd, Auckland Women’s Health Council, Auckland
Mrs Beryl Allison, Taranaki Women’s Wellness Network, New Plymouth
Dr Glenys Arthur, NZ Medical Association, Wellington
Ms Barbara Bagley, Women’s Division Federated Farmers, Central Otago
Ms Joy Bickley, NZ Nurses Association, Wellington
Ms Steph Breen, Nurses Union, Wellington
Ms Helen Chambers, The Health Alternatives for Women, Christchurch
Mr Michael Churchouse, Institute of Laboratory Technologists, Auckland
Dr Brian Cox, University of Otago Medical School, Dunedin
Ms Linda Erihe, National Council of Maori Nurses, Marton
Ms Catherine Evans, Pacifica, Auckland
Ms Jocelyn Fish, National Council of Women, Hamilton
Dr Norman Fitzgerald, Royal College of Pathologists of Australasia, Dunedin
Ms Margaret France, Natural Family Planning Association, Auckland
Dr Alan Gray, Cancer Society of New Zealand, Wellington
Ms Karen Guililand, Midwives Section of NZ Nurses Association, Christchurch
Ms Eleanor Horton, Waikato Women’s Health Action Centre, Hamilton
Dr Patrick Kelleher, NZ Society of Pathologists, Christchurch
Dr David Kitchen, Royal NZ College of Obstetricians and Gynaecologists, Hamilton
Ms Allison Lagaluga, Pacific Island Women’s Health Project, Auckland
Dr Margaret Maxwell, NZ Medical Women’s Association, Auckland
Ms Liz McPherson, WIN Cervical Screening Pilot Project, Nelson
Ms Jan Morrison, South Canterbury Women’s Wellness Centre, Timaru
Ms Vai Naisere, Samoan Nurses Association, Auckland
Ms Annie Newe, Combined Health Employees’ Committee, Wellington
Dr Johanna Nixon, Auckland University Medical School, Auckland
Ms Stephanie Orchard, Wellington Polytechnic School of Nursing, Wellington
Ms Regina Peretina, Ministry of Women’s Affairs, Wellington
Ms Mereana Potaka, Maori Women’s Welfare League, Porirua
Dr Helen Roberts, NZ Family Planning Association, Auckland
Dr Warren Robertson, NZ Obstetric & Gynaecological Society, Ngaruawahia
Ms Kathleen Rourangi, Te Korimoko Maori Cervical Screening Pilot Project, Wanganui
Ms S Rowland, Niue Island Nurses Association, Levin
Dr Janet Say, NZ Venerological Society, Auckland
Dr Ann Smith, Royal NZ College of General Practitioners, Te Horo
Dr Lorraine Smith, General Practitioners Society, Wellington
Dr Clinton Teague, NZ Society of Cytologists, Wellington
Ms Heather Yamamoto, Kawerau Cervical Screening Project, Kawerau
Ms Colleen Yeoman, Country Women’s Institutes, Onga Onga, Te Kakano o te Whanau
LOCAL CO-ORDINATORS

Dr Geoff Allwood, Co-ordinator for Bay of Plenty Hospital Board
Ms Phillipa Andrews, Co-ordinator for Thames Hospital Board
Ms Merle Bradshaw, Co-ordinator for Wanganui Area Health Board
Dr Elizabeth Chapman, Co-ordinator for Waikato Hospital Board
Mr Howard Clentworth, Co-ordinator Wellington Area Health Board
Dr Laraine Dickson, Co-ordinator for Palmerston North Hospital Board
Dr Roger Foote, Co-ordinator for Wairarapa Hospital Board
Dr J.N. Herrild, Co-ordinator for Wairarapa Hospital Board
Dr Anna Holmes, Co-ordinator for Canterbury Hospital Board
Dr Jonathan Jarman, Co-ordinator for Southland Area Health Board
Ms Elizabeth Lee, Co-ordinator for Northland Area Health Board
Dr Maree Leonard, Co-ordinator for Marlborough Area Health Board
Mr Paul Malpass, Co-ordinator for Taumarunui Hospital Board
Ms Harriet Fitzpatrick, Co-ordinator for Central Hawkes Bay Hospital Board
Ms Margaret Moeran, Co-ordinator for Taranaki Area Health Board
Ms Sharon Rayner, Co-ordinator for Dannervirke Hospital Board
Dr Christine Robertson, Co-ordinator for West Coast Area Health Board
Professor Richard Seddon, Co-ordinator for Otago Area Health Board
Dr Anne Simpson, Co-ordinator for Auckland Hospital Board
Dr Jane Smith, Co-ordinator for Tairawhiti Area Health Board
Ms Patricia Stent, Co-ordinator for Nelson Area Health Board
Dr Maria Stoker, Co-ordinator for Ashburton Hospital Board
Dr John Weir, Co-ordinator for South Canterbury Hospital Board
Dr Angela Wijetunga, Co-ordinator for South Otago Hospital Board
Ms Phillipa Wilson, Co-ordinator for Tauranga Hospital Board
Appendix 2
Report from the Maori Women's workshop
The proverb which says:

“He wahine he whenua ka ngaro te tanagata”

is often interpreted as meaning

“By women and land men are lost”

But it can also mean that women and land both carry the same role in terms of providing nourishment and without them humanity is lost.

“Maori women describe mana wahine (female status and power) as linked in a vital and integral way to the spiritual wellbeing of the land and the environment. The sense of self worth through knowing one’s status as a Maori woman; one’s whakapapa to Papatuanuku and one’s place in the whanau structure, is encompassed by the physical – social – and spiritual dimensions. When these links are broken, dysfunction occurs (“Maori Women and Social Policy” p.11).

Our world functions through complex interactive dynamics. It is a world that is often denigrated by Pakeha culture.

Te Tiriti o Waitangi

The Royal Commission on Social Policy’s booklet on the Treaty of Waitangi states. “In essence the Treaty was a partnership between the Maori inhabitants of New Zealand and the British government. While it has potential for a fair and even arrangement, inequalities between the partners quickly developed. Control, power, and decision making passed from one partner to the other and even by 1852, with the passing of the Constitution Act, the effective administration of New Zealand had become the province of the European settlers. The Anglo-Saxon traditions of individual effort and industry and the promise of full citizenship to male settlers, left little room for those whose traditions and values had other origins.” (p.2)

As Maori women we are forced to exist in a reality that has been created for us by Tauwi and this is expressed in our paper. This reality has perpetuated the dishonouring of te Tiriti o Waitangi signed in good faith by our people 149 years ago, a reality that has seen the negative statistical data for Maori rise continually, to the point that we are now third world citizens in our own country. This is reinforced by the report of the World Health Organisation.

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

Cervical Screening Management

Principles

Actioning of the principles of te Tiriti would be an integral part of the process which follows. However, we stress that the Area Health Board model is not one which we support. We propose that funding for cervical cancer screening go directly to Iwi authorities.

Interim model

<table>
<thead>
<tr>
<th>Tauwi system</th>
<th>Iwi system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area Health Boards</td>
<td>Whanau</td>
</tr>
<tr>
<td>Promotion/education</td>
<td>Training</td>
</tr>
<tr>
<td>Smear taking</td>
<td>Smear taking</td>
</tr>
<tr>
<td>counselling</td>
<td>recall</td>
</tr>
<tr>
<td>register</td>
<td>register</td>
</tr>
</tbody>
</table>
Treatment of abnormal smear

Colposcopy

Explanation of the process

Inherent in the above process are five issues that are fundamental to its smooth operation.

Whanau Hapu Iwi support
Control of all phases by Te Iwi
Data collection and retention
Liaison
Actioning principles of the Treaty

The Management Process

NEGOTIATED FUNDING AND RESOURCING

PROMOTION

TRAINING

SMEAR TAKING – COUNSELLING

DIAGNOSTIC WORK → MAORI HEALTH WORKFORCE

- Laboratory Technicians
- Counselling
- Recall
- Register

ABNORMAL SMEARS → MAORI WORKFORCE

- Colposcopy
- Medical Consultancy

- Medical
- Technical – Colposcopy

POSITIONS

Commissioner
Advocates
National Co-ordinator
Local Co-ordinators

WHANAU SUPPORT – DATA COLLECTION – LIAISON – TREATY OPERATIONAL

Throughout the process above these are continually operational.
A Philosophy of Health is an attempt to provide a cultural framework and guideline on which the concept of Health from a Maori perspective can be more easily understood.

Good health is one of the foundations on which the future development of a group of people depends. This aspect is also closely related to their historical, social, cultural, political and environmental circumstances.

It is these and related issues that the Maori perspective of health is all about.

Notion of Health

1. A Maori view of health is broad in that it incorporates a spiritual component holistic philosophy, thus forming a definition of:

   “a state of complete spiritual, mental, family and physical unity, harmony and well-being”.

   Maori people believe these various dimensions are inter-related and can not be viewed separately.

   Definitions of Health

   The foundations of the Maori view point of health rests in Te Ao Tawhito (the Old World).

   During this time spiritual, social, cultural and economic circumstances of the Maori was governed by the or of Tapu.

   Tapu means more than sacred or religious, it is a means of social and behavioural control which maintains harmony and balance.

2. This “system” ensured an inter-relation and continuity with the past and future through a system of tikanga (customs and values), ture (love), ritanga (customary practices), kawa (rituals), karakia.

3. This indirectly fostered an integrated set of values, beliefs and attitudes.
Te Whenua: The Land

5. According to Maori tradition, land, health and well-being are closely related. Land provides resources for man’s growth and development.

6. Essentially, the land gives the Maori people a sense of belonging, an identity and positive sense of tribal, whanau and individual well-being. It is a place where one has Turangawaewae (a place to stand), the place of one’s roots and where one has a sense of belonging.

7. The land provides a vital link with one’s tipua (Gods) and tupuna (ancestors).

Te Whanau: The Family

8. The Whanau or family is the main social, living and learning unit within Te Ao Maori (the world of the Maori).

9. This concept of family, however, did not merely involve the immediate family but also to an extended family system based on geneological ties or whakapapa.

10. The whakapapa is that which linked man with the past and present. Individuals had certain functions and roles to fulfill during different stages of the life cycle.

- elders (kaumatua) are respected because of their special knowledge, wisdom, life experience and links with the past.
- mokopuna (grandchildren) and tamariki (children) were also cherished because they represented continuity with the future and needed protection and guidance.

11. Parental roles extended across the entirety of the whanau with decisions concerning the health and well-being of a person involving the advice, support and counsel of the extended family group.

Te Marae: The Marae

12. The marae was and still is a very important facet of Maori life. It provides a link between human and spiritual dimensions.

13. The Marae is now physically represented by a building complex which personifies an area in which a person has Turangawaewae.

14. It is the focus point at which an individual has a sense of identity and where the Maori language, values and philosophies are reaffirmed.

15. This in turn strengthened self-respect, family relationships, pride and social control.

Nga Tikanga Maori: Maori Values

16. The Maori value and belief system centred on maintaining balance and harmony between man and his natural, physical and spiritual world.

17. The elders, tohunga and wananga (centres of learning) are given responsibility of teaching and maintaining tribal customs, protocol and values.

18. Maori values were perceived as taonga tikanga (precious gifts) imparted to man from ancestors.

Aroha – Conveys the notion of love, concern, compassion and hospitality in its widest sense.

Manaakitanga – Means caring, sharing, respect and hospitality.

Awhinatanga – Incorporates the concept of assistance, to help to relieve to embrace.

Whanaungatanga – Element which provides the strength, warmth, support and understanding in family and kinship relationships.

Tiaki – Means to take care of, cherish, nurture and to be a guardian.
Concept of Life

19. Life is considered a gift given to man from his parents, the wairua (spirit) of his tupuna and Tane Mahuta. It incorporates virtues which personify the tapu, the mana, the ihi (power) and the wehi (fear) nature of life.

20. Te Hauora and Te Waiora are concepts that convey wellness and well-being in a broad physical and spiritual sense.

21. Oranga (health and well-being) are outcomes to which an infant is expected to grow while developing the knowledge, wisdom and skills necessary to maintain good health, confidence, dignity and pride.

Conclusion

Maori people see themselves as part of the whole universe and always living in harmony and balance with their spiritual, physical and natural world. The Maori philosophy of health has its roots in Te Ao Maori, the Maori Universe and embodies unity of the mind, body, soul and family.

Te Taha Wairua: Spiritual Well-being

22. Te Taha Wairua is the immaterial, spiritual soul of a person. It is perceived as being present everywhere and at all times.

23. Te Taha Wairua determines who one is, where one has come from and where one is going. It provides a link to ones tupuna and serves to strengthen values within the cultural system.

Te Taha Hinengaro: Mental Well-being

24. Te Taha Hinengaro is the mental and emotional aspect of a person. Central to the concept of Hinengaro is the principle of Mauri, the vitality spark and life essence of a person.

25. It is an aspect primarily concerned with how one feels about themselves – confidence and self-esteem.

Te Taha Whanau: Family Well-being

26. Te Taha Whanau is the principal social, living and learning unit in Maori society. In the respect of following the Maori definition of health the Whanau (or family) play an important support system.

Te Taha Tinana: Physical Well-being

27. Te Taha Tinana is the aspect which western medicine focuses upon and can not be dealt with separately from the family, spiritual, mental and environmental world of the Maori.

Relevance to the Present and Future

28. It is obvious that many factors influence health. Many of which can be categorised as being outside the health system. Such factors include unemployment, housing, socio-economic status, educational attainment and exposure to modern lifestyles diseases.

29. Cultural interpretation of modern health care methods also play a role. Therefore the Maori point of view must be dealt with from a holistic perspective.

Finally

"To achieve and maintain good health requires a sense of spiritual, mental and physical well-being which depends on the security of one’s self in relation to one’s family and community, as well as knowledge and comfort from one’s roots and cultural background."
In asserting people’s rights to equity in health, we assert also their rights to freedom from discrimination. These rights include their access to:

- Adequate income, in or out of employment.
- Safe, warm, sound, affordable housing.
- Healthy, cheap, accessible food.
- Worthwhile, safe, property rewarded work.
- Cheap, ecologically sound public and private transport.
- Freedom from sexual or racial harassment.
- Equal respect regardless of personal circumstances.
- Safe, planned, health enhancing environments.
- Leisure facilities and social support networks.
- Comprehensive, properly resourced public services.

William Morris, 1884
TAHA MAORI

TAHA MAORI

TAHA PAKEHA
TAHA PAKEHA
WHANAU

NEEDS

C/S  P.P.  S.T.D.  SEXUAL ABUSE

DESIGN PROGRAMME WITH \textbf{WHANAU}

SHARE INFORMATION EXPERIENCE

\textbf{KAUPAPA} – PASS COMPREHENSIVE INFORMATION TO EMPOWER \textbf{WHANAU} AND INDIVIDUALS ON CHOICES AVAILABLE.

\textbf{SCREEN}

\textbf{POSITIVE}  \textbf{NEGATIVE}

\textbf{SUPPORT} \textbf{RECALL}

\textbf{WHANAU ARBEDDY}
Appendix 3

Addressing the needs of Pacific Island women
The needs of Pacific Island women

Facts

1. Research confirms that Pacific Island women figure in the high risk groups.
2. Pacific Island women are not presenting for smears.
3. The present medical systems do not attract Pacific Island women to present for smears.
4. Basic education about cervical cancer is not reaching Pacific Island women, for example Health Department pamphlets.
5. There are people in the Pacific Island community who are able to begin to address the needs of Pacific Island women, with adequate funding.

How can we begin to address the issue?

By

1. Disseminating information about cervical cancer.
2. Taking smears.

Who can be employed to do this?

1. Pacific Island trained nurses.
2. PACIFICA Inc.
3. Pacific Island Women's Health Project.
6. Cook Island, Tongan, Fijian, Tokelau, community groups.
7. Pacific Island Affairs Unit, Wellington.

The only factors that will prevent Pacific Island women from being screened effectively are the health professionals and the Health Department not allowing Pacific Island women access to appropriate education and smear taking by:

a) insisting that Pacific Island women use present services.

b) not providing funding and personnel to train for smear taking to disseminate information about cervical cancer.

The national cervical screening programme must include the needs of Pacific Island women as separate from other medical services but within the umbrella of the Health Department and area health boards. Recognition of these separate services will be seen in the provision of funding and resources for dissemination of information about cervical cancer and for smear taking to Pacific Island women for Pacific Island women.

We recommend this workshop endorse this paper on behalf of Pacific Island women in Aotearoa, for presentation as part of the national cervical screening programme recommendations.
Appendix 4

The Disabled Women's Workshop
The Disabled Women’s Workshop

We recommend that:

The Department of Health incorporate into its policy that a physically disabled woman representative be invited on a consultative basis to any workshops, hui, conferences or seminars at which matters of health are being debated or proposals made.

Disabled people have special needs often not covered in a health model/practice.

Most disabled people have a physical difference rather than an illness, this must be recognised.

Disabled women, in particular, are interested in a health rather than an illness model, but are subjected to exclusion from consultation procedures through a lack of awareness by organisers of such seminars/workshops. This prevents disabled women from making their special needs met. Disabled women used as consultants should have recognised networking skills within the disabled community.

DISABILITY IS LACK OF ACCESS
Appendix 5

Ministry of Women's Affairs information package on cervical screening
Cervical screening has been a major area of the Ministry's work since prior to its formal establishment in 1986. The aims have been to achieve:

1. Identification of the needs of women, particularly low paid women and Maori women.
2. Establishment of pilot schemes for low paid women and Maori women.
3. Establishment of a national screening programme which is culturally appropriate, affordable and accessible to all women.

All aspects of the cervical screening programme should be provided according to local needs but centrally co-ordinated and monitored — evaluated against the overall aim of reducing mortality and morbidity.

Specific policy aims to ensure that the prerequisites to successful mass screening of women are put in place are now required. For example we know that access by women to affordable, accessible, culturally appropriate facilities will do much to increase the numbers of at-risk women having smears and therefore have a direct effect on mortality. Very specific aims for this and other aspects of the programme are required:

1. Prerequisites for screening of women
   - provision of facilities by Area Health Boards so that all women have access to affordable, culturally appropriate, accessible screening (for example work-based clinics, community based care for Maori women, women's health centres);
   - the choice of a woman and culturally appropriate provider: doctor, nurse, lay health worker;
   - an education programme for women designed with their involvement;
   - an education programme for providers: refresher courses and written material; training of nurses and lay health workers to take smears; medical education on screening;
   - establishment of a national register through consultation with women as consumers.

2. Prerequisites for diagnosis facilities
   - cytology: details aims to ensure an effective backup to the screening programme;
   - colposcopy: stated aims to achieve the required number of colposcopists by Board area to cope with the demand generated by the programme (one estimate done prior to agreement to set up the national programme appears in the Service Planning Guidelines for Cancer Treatment Services, 1988); training requirements etc.

3. Prerequisites for treatment
   - aims here could include development of the treatment protocol and its adoption by all Boards.

The Ministry has set out the above as a framework because it is clear that without the necessary screening, diagnosis and treatment facilities we will fail to achieve a significant reduction in morbidity and mortality from cervical cancer. A more detailed framework for implementing the national programme is attached. It is based on the establishment of a small group of women as consumers and medical professionals, as recommended by Judge Cartwright. A series of sub-groups are proposed to address the need for the different services to be adequately equipped to cope with the demand generated by the national programme: screening sites; cytology, colposcopy, and treatment services and education programmes for providers and consumers.

December 1988

Extracts from the Ministry's submission to the Inquiry into the Treatment of Cervical Cancer at National Women's Hospital are enclosed.
CERVICAL SCREENING: FRAMEWORK FOR A NATIONAL SCREENING PROGRAMME

1. The expert group recommended by Judge Cartwright should be set up without delay. It must be high status, report directly to the Ministry of Health on progress, comprise the director of the national screening programme, women as providers and consumers and other experts as appropriate.

The Ministry of Women's Affairs should be involved in nominations to this group, particularly over representation of low paid women and Maori women.

2. Further planning of the screening programme must await the setting up of this group. Its task must be to plan and implement a national screening programme aimed specifically at reducing mortality and morbidity from cervical cancer. It should evaluate progress and monitor the success of the screening programme.

3. A national screening programme will require:
   a. funding allocation (refer Health Department cervical screening paper);
   b. national policy with the aim of reducing mortality and morbidity;
   c. adequate colposcopy facilities nationwide; contracting of overseas colposcopists may be required in the short term; information on actual requirements was provided by Mr Graeme Duncan, President NZ Society for Colposcopy and Cervical Pathology to a meeting on 'Screening for Cervical Cancer' in NZ, April 1986:

<table>
<thead>
<tr>
<th>Place</th>
<th>Suggested Number</th>
<th>Actual Number of Colposcopists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whangarei</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Auckland</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Hamilton</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Tauranga</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Rotorua</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>New Plymouth</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Wanganui</td>
<td>?1</td>
<td>0</td>
</tr>
<tr>
<td>Palmerston North</td>
<td>1</td>
<td>?1</td>
</tr>
<tr>
<td>Napier/Hastings</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Gisborne</td>
<td>?1</td>
<td>0</td>
</tr>
<tr>
<td>Wellington/Hutt</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Nelson/Blenheim</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Christchurch</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Timaru</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Dunedin</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Invercargill</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>West Coast</td>
<td>?1</td>
<td>0</td>
</tr>
</tbody>
</table>

Therefore, there is a need for 10 or 12 more gynaecologists in New Zealand trained in the skills of colposcopy, and it should be our aim to have one reasonably trained gynaecologist in the above cities as a minimum. (page 39)

d. adequate cytology facilities and standards nationwide; likewise expert personnel may need to be contracted in the short term;

e. adequate treatment facilities and a treatment protocol to be adopted nationwide;

f. a national register of all women at risk of cervical cancer (the object being not to increase the number of smears being taken, but rather, the number of women having smears, especially those most at risk of the disease);
EXPERT GROUP OF WOMEN AS CONSUMERS AND MEDICAL EXPERTS

- reporting to Minister of Health

- Function to set in place National policy directives and funding for national screening programme

  - sub-group to devise and implement colposcopy programme with Hospital/Area Health Boards; to contract sufficient colposcopists from overseas in short-term.

  - sub-group to implement cytology programme (adequate facilities, contracting of overseas cytotechnologists if insufficient in number, devising of standardised cytology guidelines/standards).

  - sub-group to devise treatment protocols for adoption by all hospitals treating cervical cancer.

  - sub-group to set up national register of women and co-ordinate access by women to a range of screening sites at the local level.

  - sub-group to devise and implement mass education of women.

  - sub-group to implement education programme for doctors and other providers (techniques and follow-up) and oversee changes to medical education.
g. Facilities where smear tests can be taken reaching women most at risk. Hospital/Area Health Boards to allocate funding and ensure that women in their area have access to work-based 'suitcase' clinics, women's health centres, clinics for Maori women with services provided by those women, Family Planning as well as general practice. Considerable work on services and sites for smear tests which are accessible, affordable and culturally appropriate has been done by the Ministry of Women's Affairs. The screening programme must offer women these choices even if incentives make smear tests more affordable in general practice. Boards should consult widely with women in their communities over preferred sites for screening.

h. Smear tests to be provided by nurses and trained lay health workers. All women must have access to a woman provider.

i. An education for providers. Specific funding to be available. More than written material circulated to doctors will be required: for example, a travelling education unit consisting of a doctor, nurse and women as consumer, to visit all general practices and other sites and demonstrate techniques. Standardised guidelines on follow-up must be adopted by all providers, and also given to women.

j. Changes to medical education in cervical cancer as per the Report of the Inquiry at National Women's Hospital. Women as consumers must be involved and different cultural perspectives incorporated into all education programmes on the disease.

k. A mass education programme of women once adequate diagnosis and treatment facilities are in place, an education programme of doctors and other providers is underway, and a national register of women has been set up.
Appendix 6

Flow diagram showing the points at which quality control and evaluation needs to happen
Education of women about cervical cancer and cervical smears

† Contact with services
† Smear taking
† Smear reading
† Smear reporting

‡ Normal

‡ Abnormal

† Investigation and treatment

‡ Follow up after treatment

Total Women 15 +

Invasive cancer → Death from Ca Cervix
(age-specific rates)
NATIONAL CERVICAL SCREENING WORKSHOP: RECOMMENDATIONS

1. That an executive group, with decision-making power, be formed to control the national cervical screening programme and to allocate funding for the programme to area health boards.

2. That the National Co-ordinator of the national cervical screening programme be accountable to the executive group.

3. That there be two National Co-ordinators, both women, at least one of whom is a Maori woman.

4. That the workshop strongly support specific and separate funding for the national cervical screening programme, over and above that presently allocated to Vote: Health.

5. That cervical screening services be provided free of charge to all women.

6. That the executive group should consist of representatives of the following women's consumer groups – lower paid women, rural women, Maori women, (two), Pacific Island women, women with disabilities, homemakers and “a survivor of the National Women’s Hospital experiment”, as well as health professionals, as recommended in the Cartwright Report (page 209) and according to criteria established by the Ministers of Health and Women’s Affairs.