From policy to practice

A review of the Canterbury Cervical Screening Programme

Valerie Norton
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A report for the National Cervical Screening Programme and the Canterbury Cervical Screening programme
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EXECUTIVE SUMMARY

1. INTRODUCTION

The National Cervical Screening Programme was set up to co-ordinate and initiate screening strategies through Area Health Boards with the aim of reducing the incidence of cervical cancer among New Zealand women, and its consequent morbidity and mortality. The programme represents a managed approach to the integration of all elements from recruitment to treatment. This, it is believed, will minimise the deficiencies associated with a predominantly opportunistic approach. The National Cytology Register provides the management system for the programme, linking women, smear takers, laboratories and treatment services.

2. EVALUATION RESEARCH AND THE CANTERBURY CERVICAL SCREENING PROGRAMME

There is a strong tradition of evaluation research in health and social services. Evaluation is seen as integral to service policy and implementation, and helps fulfil the accountability requirements of management in the public sector.

Funding for the evaluation of the Canterbury Cervical Screening Programme was made available by the Department of Health. The Canterbury Area Health Board contributed additional funds to specific projects.

Priorities for evaluation were based on an understanding of the key clients of the Canterbury Cervical Screening Programme, and their interrelationships, and the limited resources available for evaluation.

Five separate research projects were developed, each selected for its potential to contribute to the overall evaluation: The Historical Background and Context (Chapter 3), Implementation of the Canterbury Cervical Screening Programme (Chapter 4), Women's Perspectives on Cervical Screening (Chapter 5), General Practitioners' Perspectives (Chapter 6), Maori Women's Experiences of Cervical Screening (Chapter 7).

The rationale for selection of these project areas was that they would allow a detailed understanding of the relationships within the Programme and between various participants. It was an important task of the evaluation to gain an understanding of both how the programme works (process) and how it affects both women and screening service providers (outputs).

3. THE NATIONAL CONTEXT FOR CERVICAL SCREENING IN NEW ZEALAND

In 1955 senior staff at National Women's Hospital were in agreement that the taking of cervical smears was the only means of diagnosing pre-invasive cervical cancer. Interested general practitioners were also offering the test to women, and in the early 1960's the Royal New Zealand College of General Practitioners established a short-lived population based screening programme which included a national cytology and histology register.

Through the 1970's there was considerable debate about the effectiveness of cervical screening. By 1985 a medical consensus had largely been achieved on this, and at
the same time, other organisations such as the Society of Cytologists, the Department of Health, the Cancer Society of New Zealand and the Ministry of Women's Affairs were all exploring ways of promoting cervical screening among women.


In late 1988, the then Minister of Health, Hon David Caygill, announced the implementation of a national cervical screening programme, to be in place by November 1989. In retrospect this was an unrealistic goal. A number of important initiatives were nevertheless undertaken to assist the development of the Programme, including a National Hui on cervical screening, the setting up of the National Screening Implementation Unit, and four community pilot projects focusing on the needs of Maori and low-income women.

Regional cytology registers were piloted and working groups set up to develop guidelines for managing abnormal smears and for smear-taker training. A Ministerial Review Committee recommended the appointment of an Expert Group and a National Co-ordinator.

By the time a National Co-ordinator was appointed in June 1990, considerable progress had been made with computer software for the register. Arrangements were directed towards an "opt on" enrolment process, that is, women choosing to be on the register would sign a consent form to become registered. Implementation of the programme was to be through area health boards.

4 IMPLEMENTATION OF CANTERBURY CERVICAL SCREENING PROGRAMME

The goal of the Canterbury Cervical Screening Programme is:

To increase the number of women (aged between 20 and 70 years) who have a current smear history and are enrolled on the Cytology Register within the Canterbury Area Health Board Area.

To achieve this goal the Manager has brought a number of strategies into play:

Community involvement

A number of groups have been set up to advise the Manager, including a Community Committee and committees to address special topics such as publicity and education, evaluation and monitoring, service development and smear taker training, and the needs of the South Canterbury area. Liaison with the community was given effect through the appointment of a Community Education/Liaison Team. This team comprises two Maori women, four women representing Samoan, Cook Island, Tongan and Niuean women, and a Pakeha woman with a focus for women aged 35 years and over.
The National Cytology Register

A pamphlet explaining the National Cytology Register has been developed and distributed widely in Canterbury. The Register was also a focus for the regional publicity campaign, in contrast to the national campaign which excluded comment about the Register.

The Cytology Register in Canterbury became operational in February 1991; within three months 1791 women had been enrolled on the Register. By May 1992 17,396 women were enrolled, 13% of the total eligible population of women aged between 20 and 70 years.

Community Initiatives

The Canterbury Cervical Screening Programme has supported several general health programmes which include cervical screening as part of the overall health programme. These include: Whanau Whakatipu, a training course in sexual health and general well-being for Maori women (a joint venture between Te Roopu Tautoko Trust and the Family Planning Association, with financial support from the Canterbury Cervical Screening Programme), South Canterbury Women's Wellness Centre Rural Clinic (sponsored to provide subsidised cervical smear tests especially for women aged over 35 years.), Arowhenua Marae Health Clinic (a clinic within Arowhenua Marae, Temuka.)

Special relationships

The Programme has sought to maintain effective contact with key groups such as general practitioners, laboratory services, other regional managers and the Family Planning Association.

5 Perspectives on Cervical Screening among Canterbury Women

This study aimed to establish levels of screening within the regional population of women 20-69 years old, and to ascertain women's screening practices and preferences, and their knowledge of cervical screening and the National Register.

From a stratified random sample of women drawn from the rolls of 12 Mid- and North-Canterbury electorates 524 were interviewed. The age and ethnic distribution of the sample was similar to that of the regional population from which it was drawn.

Screening Coverage and Frequency

Younger women have higher screening rates than older women, with 89.3% of the 25-34 year age group screened within the last three years. The proportion of women adequately screened in the 35-44 (85.3%) and 20-24 (82.4%) groups was also high. Lower rates were found in the older age groups, 55-64 (34.4%) and 65-69 (38.2%). Overall in the sample 74.8% of women had an up-to-date screening history (73.8% when weighted to reflect the age distribution of the population).

Of 328 women who had routine smears, 51.8% reported annual smears, with a further 33.2% indicating two-yearly smears. More frequent screening was more
likely among younger age groups, with 93.5% of women between 20 and 34 having annual smears. Overall, 85% of women presenting for routine screening has smears more frequently than the recommended three year interval.

**Knowledge about Screening**

Women tended to identify correctly the circumstances in which cervical smears are recommended. They knew that any woman who has ever had sexual intercourse needs a smear (91.3%); that being childless is not relevant to the need for a smear (92.7%); that women still need smears after menopause (79.2%) and that older women (over 60) need a cervical smear (76.0%). Most uncertainty was reported on the question of whether women who had had a hysterectomy needed a smear. Overall, women with an up-to-date smear history have a better knowledge of when a smear is needed than those without a recent smear.

Women reported that they gained their information from a variety of sources, particularly their own reading of books, magazines and newspapers (67%), from their doctors (60%), from friends and family (33%) and TV/radio (33%).

**Use of Services**

The main reasons for not maintaining an up-to-date smear were hysterectomy (38%), 'didn’t think it was necessary' (20.7%), 'too embarrassed or shy' (17.2%), 'not sick' (12.6%), 'the doctor didn’t suggest it' (9.2%). Women who had never been screened responded in a similar way.

Smear taking was initiated by the doctor or nurse more frequently than by women. Most women received their smear from a general practitioner, with smaller numbers using practice nurses (4.1%), Family Planning Association staff (7.8%) or other services (1.5%). When women indicated future preferences for a smear taker, general practitioners were slightly less popular (77.5%), as were Family Planning personnel (6.5%), with an increasing preference expressed for practice nurses (8%) and 'other' practitioners (8%).

Among women screened by general practitioners, 80% indicated a general practitioner as their preferred smear taker in future. Women who expressed a preference for another general practitioner nearly always indicated a preference for a woman practitioner in the future. For nearly two thirds of women who had never had a smear (60.5%), having a woman smear taker was important if they were to have a cervical smear in the future.

**Screening Register**

The majority of women (68.5%) had never heard of the Register. Of those who had, a considerable proportion were uncertain about it, or did not know its purpose. Only 16% knew that enrolment is voluntary, 39% thought women would be enrolled automatically. Thirty of the women interviewed (5.5%) said that they were already enrolled on the register. When the register was explained to respondents, 39.5% said they would be willing to enrol and a further 23.5% indicated a willingness to do so, but said that they would need more information.
Discussion

This research confirms the importance of educating women in the community about the circumstances in which a cervical smear is necessary and of supporting screening within general practice, including the encouragement of practice nurses as smear takers. Some of the reasons why women say that they do not have smears can be addressed through these strategies and through additional training for health professionals.

There is, also, a small group of women for whom alternative services are appealing. Such services will be particularly important for recruiting women who have never previously had a cervical smear. This group is also less likely to have good knowledge of the need for screening and priority will need to be given to reaching these women and ensuring that a responsive service is available to them.

6 GENERAL PRACTITIONERS' PERSPECTIVES

The objectives of this project were: to ascertain the cervical screening and recall procedures and information systems in Canterbury general practices, and to determine from general practitioners their views on the Cervical Screening Programme and the National Cytology Register.

Two methods were used: a telephone survey of all general practices in north and mid Canterbury (94% response) and in-depth interviews with a selected sample of 34 general practitioners.

Screening Practices and Procedures

Computerisation and Recall in General Practice

The telephone survey indicated that 62.5% of practitioners were already working in computerised practices; 46% practices were using the computer to generate a recall list of women while 52.5% were using a manual system. Two (2%) practices had no recall procedure. Evidence from this and other local studies indicates that over the last three years there has been a steady increase in the use of computer systems for recalling for cervical smears. Practice nurses are important administering recall systems whether or not practices were participating in the screening programme.

Enrolment of women on the National Cytology Register

The telephone survey showed that 72% of practices (76.5% of all practitioners) are enrolling women on the Register. Of the thirty-four doctors interviewed, only five were consistently and actively enrolling women. Fourteen indicated that they enrolling only intermittently, and a further fifteen either enrolled women initially and have now stopped or have never participated in the programme.

All doctors interviewed commented on the forms and the extra paper work involved and cited this as one reason for not enrolling. Most general practitioners regarded the main benefit of the register as being a source of epidemiological information and not as a benefit to themselves or their patients.
Screening Frequency and Age Recommendations

Many practitioners had adopted the three yearly recall of women with a normal smear result, but most felt that the programme was not be as flexible as they needed. Many also felt that the three year time gap was too long.

Several doctors were not convinced that three yearly was safe. Most also found the lower age limit of 20 years inappropriate and in practice were beginning to take smears when women became sexually active.

Issues for Smear Taking in General Practice

"More than a Smear"

Many practitioners were concerned about the narrow focus of the Cervical Screening Programme on just the smear test. The notion that there is more to a smear than simply taking a smear was the reason some practitioners were concerned about practice nurses, and lay smear takers in particular, taking cervical smears.

There was a wide range of opinion amongst general practitioners with regard to lay smear takers. While many accepted there was a place for alternative services, some practitioners were not enthusiastic about lay smear takers.

In eleven practices the nurses were also involved in taking cervical smears. The primary reason for this was to give women another option, particularly where there were only male practitioners, or to provide a less costly service. There were often times, however, when the doctor was called in to examine the woman.

In the thirteen practices where nurses were not taking cervical smears a variety of reasons for this were discussed: it was policy established by the doctors; the practice nurses did not want the responsibility; it wasn’t necessary in some practices where there were women doctors; there were not the facilities; it would be too much competition.

"Shopping List"

Whether women responded to being recalled for a cervical smear appeared to depend on economic circumstances. All the doctors talked about the issue of "shopping list" where a consultation includes several clinical problems. This is an important issue as appointments are arranged at 10-15 minute intervals with a cervical smear requiring the full appointment time.

Family Planning Association

New Zealand Family Planning Association has contributed to the Cervical Screening Programme in a number of important ways: providing a smear taking service; training general practitioners, nurses and lay smear takers, and participating in an advisory capacity on various committees.

General practitioners, while they accepted Family Planning as an option for women, generally were concerned about what they regarded as fragmentation of services. Most of the practice nurses who were taking smears had been trained through Family Planning.
Issues for the Future

The possibility of an "opt off" register was discussed in the interviews. There was a complete spectrum of views. Some doctors were totally opposed, others welcomed the possibility while others expressed mild concerns.

Many of the general practitioners felt that the Cervical Screening Programme was a political imposition. Several doctors said they felt that the programme had not involved general practitioners and that it was trying to by-pass them.

The notion of the programme as a third party in the relationship between general practitioners and their patients was discussed several times. General practitioners were also concerned about accountability and the possibility of women being over investigated.

Many of the general practitioners were concerned about the sustainability of the programme. Their view was that just as it was politically introduced, with the stroke of a pen it could also be taken away. This possibility meant that their priority was for their own recall systems.

7 CERVICAL SCREENING SERVICES FOR MAORI WOMEN

There are three studies in the Maori Evaluation of the Canterbury Cervical Screening Programme.

A. Whanau Whakatipu

This report provides an overview of Whanau Whakatipu, a course for Maori women in the area of sexual health and total wellbeing. Whanau Whakatipu is joint venture between Te Roopu Tautoko Trust and the Family Planning Association. Fourteen women completed the course and five are currently being trained as lay smear takers.

B. Maori Community Study

Sixteen Maori women participated in tape recorded indepth interviews with a Maori researcher. The group includes a cross section of Maori women, with a range of ages from 17 years to 60 years as well as a variety of circumstances and experiences.

Most of the women described healthy active childhoods. For whanau was the basis of family life, and for some of the women the marae had been an important focus. Several women, particularly the older ones talked about the wisdom of the Kaumatua and the handing on of knowledge. For other women life was different. Trying to live in the pakeha world was often a struggle.
Te Hauora ki te Maori

Maori View of Health

The women described that health is more than physical and emotional. It encompasses one's total environment. Most pakeha services did not identify with this concept, making a shared understanding of health difficult.

Te Whakamatautau o te Waha Whare Tangata

Cervical Smear test

Twelve of the sixteen women had had a cervical smear test at some time. Five of these women continued to have the test on a regular basis. Three women had never had a smear taken, while one woman did not know whether she had had one or not.

Cervical Screening Cytology Register

Only one of the women was enrolled on the cytology register. She was aged over 40 years and had a cervical smear taken regularly at a Family Planning clinic. Another five women were aware of the register. Concern was expressed that young women under 20 years were excluded from the register and about the use of statistical information.

Nga He e pa ana ki te Roopu Hauora

Factors affecting access to health services

The women commented on the factors that made it difficult to have a smear taken.

Te Wahi Tapu o te Wahine

Cultural values

Te Whare Tangata is very sacred. The women said it was very important that this was understood.

Nga Ahuatanga

Previous Experiences

Several of the women said they had previously had bad experiences when being examined by doctors or when they were having their baby. The process was so clinical and there was no awareness of them as Maori women. This made it more difficult for them to use the established health services.

Te Ututanga

Cost

Cost was seen as one of the barriers for Maori women using health services but it was not considered to be a primary factor. Because of the cost many of the women only went to the doctor when the problem was really serious. Children’s health often takes priority over the women’s health. The additional cost of hospitalisation if further treatment is required also an issue.
The women also discussed changes in the organisation of health services which would make their access to and therefore their use of health services more appropriate. Many of the women had a strong preference for a Maori woman to be their smear taker. For many of the women the marae was the place where they felt they would be most supported.

The women identified two important issues to be addressed if services are to meet the needs of Maori:

- Mana Paerangatiratanga Raueni
  Autonomy over Resources
- Nga Kai Mahi Maori
  Maori Health Workers

C Ama’s Story

The case study of a Maori woman having gynaecological investigations. Information was gathered in a tape recorded indepth interview.

While the Area Health Board Policy Statement makes a commitment to the principles of the Treaty of Waitangi; to respect the dignity of the individual and to be responsive to consumer need and choice, this was not always borne out in practice. The Area Health Board Policy Statements are therefore often experienced by Maori people as meaningless and empty. This woman’s experience demonstrates that there was little awareness, appreciation or respect for her needs as a Maori woman.

This has specific implications for the Cervical Screening Programme. What are the consequences of implementing the Cervical Screening Programme if the follow up and treatment services do not address the cultural needs of Maori women, one of the Programme’s priority groups.

8 CONCLUSION

The Cervical Screening Programme involves a complex set of interrelationships between various groups: those developing and implementing the Cervical Screening Programme; those providing the cervical smear testing services; those advocating for women as well as women from a wide spectrum of circumstances, experiences, and understandings.
On one hand, there is unanimous agreement about the need for all women to have regular cervical smears to prevent cervical cancer and widespread recognition of the importance of organised cervical screening. On the other hand, there is considerable tension and conflict between these groups making difficult to communicate clearly.

However, the sustainability of the Cervical Screening programme is dependent on the co-operation negotiated between these groups involved in providing cervical screening services.
1 INTRODUCTION

The National Cervical Screening Programme was set up to co-ordinate and initiate screening strategies through Area Health Boards with the aim of reducing the incidence of cervical cancer among New Zealand women, and its consequent morbidity and mortality. The programme is not a single entity, but represents a managed approach to the integration of all elements from recruitment to treatment. A managed approach is believed to minimise the deficiencies associated with a predominantly opportunistic approach. The national cytology register provides the management system for the programme, linking women, smear takers, laboratories and treatment services.

Although the programme has been set up nationally, it is managed at regional (Area Health Board) level. The Canterbury Programme was set up on a "fast-track", with the intention of providing experience which can be shared with other parts of the country. Resources for evaluation have been made available by the National Co-ordinator for a comprehensive, independent evaluation in Canterbury. These resources have been supplemented by funds from the Canterbury Cervical Screening Programme.

It is important that this evaluation is located in the context of the development of cervical smear testing services and cervical screening programmes generally. The social and political environment has had important consequences for the Canterbury Cervical Screening Programme and the relationships between different groups involved in the Canterbury Cervical Screening Programme and the smear testing services can best be understood within the context of their histories in regard to cervical screening.

The aim of the evaluation is to not only provide information about "what" is happening but also to understand "why". Chapter 2 will address the methodological issues inherent in the study and provide an overview of the evaluation and research process. A detailed historical review will provide the background understanding for the study in Chapter 3. The implementation of the Canterbury Cervical Screening Programme will be discussed in Chapter 4. Women are central to the programme so it was important to find out from women themselves what they knew about cervical cancer and smear tests and what they did about having cervical smears taken. Chapter 5 provides an overview of the community survey which addressed screening coverage and women's views on cervical screening in Canterbury. As general practitioners are the major providers of cervical screening services an evaluation of their practices, experiences and views is integral to understanding the Cervical Screening Programme. Chapter 6 reviews primary medical practices in regard to cervical smear testing and the Canterbury Cervical Screening Programme. Maori women are one of the priority groups for the Cervical screening programme. Chapter 7 provides an account of the experiences and understandings of Maori women. Through out the evaluation recurring themes have emerged from the experiences of people involved in the Cervical Screening Programme, people providing health services and women in the Community. Chapter 8 addresses these themes and discusses the issues arising from the overall evaluation.
2 EVALUATION RESEARCH AND THE CANTERBURY CERVICAL SCREENING PROGRAMME

2.1 The evolution of evaluation research

There is a strong tradition of evaluation research in health and social services (Weiss 1972, Patton 1980, Rossi and Freeman 1989, Guba and Lincoln 1989). This tradition dates back to the 1960's and the 'War on Poverty' in the United States when an infusion of funds into social programmes was accompanied by a requirement for evaluation. Evaluation is now seen as integral to service policy and implementation, and is relevant to fulfilling the accountability requirements of management in the public sector.

While there has been development of evaluation concepts over the years there have been constant notions that remain at the heart of any evaluation. These include the relationship between inputs, processes and results:

\[
\text{Input} \rightarrow \text{Processes} \rightarrow \text{Outputs} \rightarrow \text{Outcomes}
\]

\[
\begin{array}{c|c|c}
\text{(Why?)} & \text{(What?)} & \text{(What?)} \\
\text{(Immediate)} & \text{(Long Term)} & \\
\end{array}
\]

This framework implies that actions have consequences (both intended and unintended), but it is also important to recognise that no activity is in one direction, but is itself subject to influences and feedback.

The way in which evaluation addresses these issues has varied over time, originally focusing on 'measurement', through a 'descriptive phase' and then a 'judgement' phase where the evaluator assumed the role of 'judge'. These three phases, 'measurement', 'description' and 'judgement' have been described by Guba and Lincoln (1989) as the first three 'generations' of evaluation.

Guba and Lincoln now recognise a new form of evaluation referred to as 'Fourth Generation Evaluation', the key dynamic of which is negotiation. This approach is particularly relevant to evaluation of complex health programmes and can be reviewed briefly (Guba and Lincoln 1989:7-8):

- Evaluation research cannot be regarded as a neutral scientific process. To do this they caution, is to miss completely the fundamental social, political, and value-orientated character of evaluation.

- Evaluation outcomes represent meaningful constructions that individual actors or groups of actors form to 'make sense' of the situations in which they find themselves.

- Evaluation findings are not 'facts' in some ultimate sense, rather they are created through an interaction process that includes the evaluator.

- The constructions are shaped by the values of the people involved in making sense of their situations. These constructions are inextricably linked to the particular physical, social and cultural contexts in which they are formed and to which they refer.
The nature of New Zealand’s health services with its complex set of relationships, the continuing restructuring, and the uncertain economic, social and political environment creates problems for an evaluation.

At one level evaluation has been a routinised and institutionalised administrative activity within health services, for example via financial audits and performance indicators. At another level evaluation is a way of coping with political pressures or particular problems. The Cartwright Inquiry was, in a sense, a response to the failure of a form of evaluation known as peer review, resulting in a public hearing and widespread debate.

Somewhere between these routinised superficial methods and the detailed analysis of an expert enquiry are evaluation approaches which can be designed to suit the circumstances of specific programmes. Evaluations use a variety of methods, both quantitative and qualitative, which allows for a more comprehensive assessment of service dimensions. These methods arise out of the context of each specific evaluation and are not prescribed by any ‘model’ of evaluation.

2.2 The framework for evaluation of Canterbury Cervical Screening Programme

The terms of the independent evaluation of the Canterbury Area health Board Cervical Screening Programme, established the boundaries and links between the independent researchers, the Canterbury Manager and the National Co-ordinator.

The National Co-ordinator:
- makes a research budget available for developing evaluation strategies and implementing evaluation projects, and identifies national research priorities.

The Canterbury Manager:
- informs the researchers of the implementation strategy of the Canterbury Area Health Board Cervical Screening Programme and local evaluation priorities.

The researchers:
- design and implement a comprehensive evaluation of the Canterbury Cervical Screening Programme.
- implement selected evaluation projects. Selection is determined by budget constraints and situation opportunities and takes account of local and national priorities.
- report to the Manager, Canterbury Cervical Screening Programme on the evaluation methods and advise her of the evaluation results.
- provide the National Co-ordinator with details and examples of methodology, sample results and information which can be used to advise other area health boards.

Funds for the overall evaluation were provided by the Department of Health. The Canterbury Area Health Board contributed additional funds to specific projects.

Key features of the evaluation are:
• independence: with research decisions made by the research team
• collaboration: working with the Regional Manager and Evaluation Working Party.
• concern for both the results of the programme and an understanding of the reasons for such results.
• transparency: with the evaluation methods fully documented.
• ethics: conforming to the requirements of the Canterbury Area Health Board Ethics Committee and the ethical standards of social research.

2.3 Evaluation design for the Canterbury Cervical Screening Programme

Time and resources necessary for a comprehensive evaluation were unlikely to be available, so the scope of the project necessarily became limited. Priorities for evaluation were based on an understanding of the key clients of the Canterbury Cervical Screening Programme, and their interrelationships (Fig 2.1).

Five separate research projects were developed, each selected for its potential contribution to the overall evaluation. Two of these projects involved the organisational context, with three projects relating to participants.

The two contextual areas for study were:

The Historical Background and Context (Chapter 3)

The Cervical Screening Programme can only be fully understood when evaluated within the context of New Zealand’s health system and the social and political environment.

Implementation of Canterbury Cervical Screening Programme (Chapter 4)

A descriptive study of the overall implementation of the Canterbury Cervical Screening Programme.

The three studies related to clients were:

Women’s Perspectives on Cervical Screening (Chapter 5)

A survey of women in the community was necessary to provide information about women's experiences and knowledge of both the cervical smear test and the Cervical Screening Programme.

Figure 2.1 Generalised evaluation model for the Cervical Screening Programme
INPUTS

<table>
<thead>
<tr>
<th>Cervical Screening Programme</th>
<th>Women in the Community</th>
<th>Health Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educ. &amp; publicity, Cytology Register, Training, Co-ordination Monitoring</td>
<td>Knowledge, understanding, preferences participation</td>
<td>Screening Services</td>
</tr>
</tbody>
</table>

PROCESS

The functioning of the individual components, of the inputs, their interaction with each other and the economic and social environment, provision of additional resources.

OUTPUTS

Understanding of cervical screening Population coverage Coverage of unscreened groups Earlier detection & intervention Quality smear taking Satisfied clients Cytology Register enrolment Effective management of the abnormal smear

OUTCOMES

Reduced incidence Reduced mortality & morbidity

In the case of the Cervical Screening Programme OUTPUTS will only become apparent over time, and will not fall within the scope of this evaluation project.

OUTPUTS, which are known contributors to eventual OUTCOMES, should become apparent within the life of this project (12-18 months).

The PROCESSES of the Programme, which are expected to contribute to effective OUTPUTS and OUTCOMES should become evident early. INPUTS are largely known.
General Practitioners' Perspectives (Chapter 6)

General practitioners, as the primary providers of cervical screening services, have a key role in implementing the Area Health Board programme. At the same time general practitioners are being affected by the programme itself. Research to gain an understanding of their practices and their perspectives on the Screening Programme was essential.

Maori Women's Experiences of Cervical Screening (Chapter 7)

Maori women are one of the Cervical Screening Programme's priority groups. Maori women also have expressed specific concerns about the Cytology register. A study focusing on the experiences of Maori women was of major importance.

The rationale for selection of these project areas was that they would allow a detailed understanding of the relationships within the Programme and between various participants. An important task of the evaluation was to gain an understanding of both how the programme works (process) and how it affects both women and screening service providers (outputs).

2.4 Evaluation process

All the research projects in this evaluation relied on direct contributions of time and information by participants.

It is important to note that the evaluation process neither supported nor challenged any of the participants on the nature of their involvement in the Programme. The evaluation did not make judgements about participants' practices. Rather the purpose of the process was to receive their comments and compile an accurate and comprehensive view of their experiences. Then the questions 'What is happening?' and 'What sense do people make of their situation and the circumstances?' could be reflected upon.

The integrity of the evaluation is dependent upon establishing and sustaining relationships with those involved so that it is 'safe' for people to speak freely. There were a number of reasons why this relationship might be difficult to secure:

- For women:
  - cervical screening is a very personal issue, and yet it has a highly public, controversial aspect.
  - the sample of women interviewed covered a wide age range (20-70) from a variety of socio-economic circumstances.
  - cervical cancer is an issue that raises fear and anxiety.

- For screening providers and programme personnel:
  - the evaluation explored issues that were politically sensitive and had important professional implications

Securing individual participation in the evaluation required people to have enough information about the various studies. For the survey of women in the
community, for example, an introductory letter was important in ensuring a high response rate as well as allowing women to consider their decision to be involved and make an informed decision whether or not to participate.

In the indepth interviews the notion of 'making it safe' to talk was important. The process of indepth interviews requires the interviewer to be involved in a face to face discussion that is only loosely directed by the interviewer. The dialogue generates further questions which become part of the research. As a method it involves uncertainties, ambiguities, ambivalence and a diversity of views. It is a process that involves 'total communication', in other words, it is not just the words spoken that are the basis of the research data but also the tone of voice and the accompanying facial expressions and body language. The process often appears very 'easy', 'just having a chat' and may be regarded by some as not being particularly scientific or rigourous. This is not the case; it demands very exacting skills.

2.5 Ethical Issues

Ethical approval was granted by Canterbury Area Health Board Ethics Committee for three of the studies: the telephone survey with women, the study involving general practitioners and the study involving Maori women.

Three important ethical issues for the evaluation were:

- informed consent
- confidentiality of participants' identity
- feedback to participants

All people who contributed to the evaluation received an introductory letter or were spoken to personally prior to participating in an interview. This provided people with background information about the overall evaluation and the study with which they were specifically involved. People were informed that their identity would be confidential and statements of agreement to participate in the interview was gained. Where appropriate this was a signed statement.

All people who participated in the various research projects subsequently received a letter which included a summary of the findings of that particular study.
3 THE NATIONAL CONTEXT FOR CERVICAL SCREENING IN NEW ZEALAND

3.1 Introduction

One of the consequences of the Cartwright Inquiry has been the overshadowing of previous initiatives and practices in relation to cervical smear tests and the developments of population based screening services.

The cervical smear test, also referred to as the 'Pap' smear in recognition of Dr Papanicolaou who developed it, had been available for several decades. In 1928 Dr Papanicolaou demonstrated that cancer cells could be detected by a vaginal smear examination. By 1943 he was able to show that the cancer could be detected in women who had no symptoms of disease.

Cervical smear testing has a long history and it is important that the complex set of relationships between the different groups involved in the Canterbury Cervical Screening Programme and the cervical screening services are understood. This chapter therefore outlines the background to cervical screening in New Zealand and the main participants in its development. (A chronology of events is set out in Appendix 1.)

3.2 Contextual study

The contextual study provides an overview of the national social and political environment in which Canterbury Cervical Screening Programme has been implemented. The complex relationships between the different groups involved in the Canterbury Cervical Screening Programme and the cervical smear testing services can best be understood within the context of their histories in regard to cervical screening.

3.2.1 Objectives

- To provide an overview of the national context for cervical screening in New Zealand.

- To demonstrate the complex set of relationships involved in the development of the Cervical Screening Programme.

3.2.2 Methodology

- Indepth interviews with key people involved in the development of the National Cervical Screening Programme

- Review of national and international literature.

There were several occasions during the indepth interviews when the informant asked not to be identified or when detailed discussion of a sensitive nature occurred after the tape recorder had been turned off. There was a common theme to comments made in this context; they were usually to do with either the relationship between the various groups involved in the Cervical Screening Programme and the politics of the programme, or decisions being made to meet...
a political agenda. This information has been incorporated into the content of this chapter. Direct quotes have been used without identifying the specific source of the comments.

3.3 Smear testing in the 1950's and 1960's: the beginnings of a screening approach.

The need for a nationally organised cervical screening programme has been considered by groups of health professionals over the last thirty years. In 1955 senior staff at National Women's Hospital were in agreement that the taking of cervical smears was the only means of diagnosing pre-invasive cervical cancer. They established policy that all women over 35 years of age attending the outpatients department or admitted to the gynaecological wards were to have cervical smears taken (Cartwright 1988:25).

Interested general practitioners were also offering the test to women. A separate initiative during the early 1960's undertaken by the Royal New Zealand College of General Practitioners attempted to establish a population based screening programme, including a national cytology and histology register. In September 1962 the College notified medical practitioners through the New Zealand Medical Journal that they wished to promote cervical cytology examination throughout New Zealand. The aim of the campaign was to reduce the number of deaths from cancer of the cervix and to conduct long-term research into the results of this campaign and to publish these results (Marshall 1962).

These aims changed slightly. A report of the promotion in October 1964 (Marshall 1964) states that the aims now were to "promote routine cervical cytology for early detection of cervical carcinoma, and to study the incidence of cervical carcinoma in New Zealand." It also notes that seventeen thousand women were screened in the first year resulting in seventy positive smears being identified. A wider publicity campaign was advocated. In 1964 an update of the survey reported over nineteen thousand women had had smears taken (Marshall 1966).

As part of the campaign supported by the Auckland Division of The British Empire Cancer Campaign Society (from 1963 the Cancer Society Of New Zealand) clinics were set up in the provinces, including Thames (McIndoe 1964), a mainly rural area, and in urban Wanganui (Bayertz 1965). Both clinics were supported by some general practitioners, although others were very suspicious and remained uninvolved. It was also reported that a number of the doctors had been doing routine cervical smear examinations prior to this. Publicity included posting brochures to homes in the area. The studies demonstrated the divergence of experience and views in the debate about cervical screening. However, the need to follow up all women with cervical smears was strongly emphasised in both studies.

At the time 337 doctors (mainly GP's) participated in registering women in the campaign. The campaign register was administered by a medical records clerk in Wellington.

The register ceased to operate in 1965 as enthusiasm and co-operation for a nationwide screening project waned. The impetus for the programme lapsed when one of the main proponents shifted to Australia and the secretary responsible for keeping the medical records died. At the same time, there was increasing concern that women were being subjected to hysterectomy when less radical treatment would suffice. A view was developing among practitioners that population based screening could lead to over treatment.
Over the years many general practitioners have continued to take cervical smears, some setting up sophisticated manual and later computerised recall systems. However without an organised process providing a national overview the concept of screening for cervical cancer as a public health measure is not applicable. Comprehensive population screening for cervical cancer can only occur at a centrally organised level, not at the level of an individual practice. (Cox 1992)

3.4 The 1970's and 1980's: The emerging consensus

In the 1970's considerable scepticism regarding the effectiveness of cervical screening was expressed through the Auckland Medical School's Post Graduate School of Obstetrics and Gynaecology:

New Zealand age standardised mortality rates for cervical cancer in women 20-34, 35-64 and 65 years and older show that mortality has been falling steadily for women 35 years and older ever since 1941, 14 years before cytology screening was introduced. Mortality has risen significantly since about 1959 in women 20-34 years old. These findings cast doubt on the value of screening (Green 1978).

The Auckland Medical School, through its undergraduate and postgraduate programme had an important impact on the thinking and practices of many general practitioners in relation to cervical screening and women's health services in general.

However, there was considerable debate over these views nationally (Duncan 1981; Skegg et al 1985) and internationally (IARC 1986). In 1985 the paper Cervical Screening: Recommendations for Routine Cervical Screening (Skegg et al 1985) was published in the New Zealand Medical Journal. The recommendations were endorsed in the New Zealand Family Physician:

Those of us who still doubted the efficacy of the regular asymptomatic cervical smear in preventing cancer deaths will have great difficulty in arguing their case against the advice in this report. The doctor who advises a woman that cervical smears are not useful can no longer be regarded as harmlessly wayward: he could well be seen as dangerous (St George 1985).

Between 1986-88 there were a number of papers published in the New Zealand Family Physician dealing with issues of women's access and knowledge (Reid 1986; Kingston 1987; Chang 1987) and providing education for general practitioners about technical aspects of smear taking (Chang 1986, 1987 Fitzgerald 1988).

At the same time some general practitioners were also exploring the way in which they communicated with women. Botting (1987) acknowledged the emotions of embarrassment, nervousness and vulnerability usually associated with a vaginal examination. Importantly he also recognised that these emotions were experienced not only by women but also by doctors.

The New Zealand Society of Cytology

The New Zealand Society of Cytology had been concerned about the standard of smear taking and reporting. There were small laboratories reading fewer than 50 smears a year but no standards existed either for training smear readers or for
conditions of their work, such as length of viewing sessions. In 1985 a working party developed and published *Recommendations for Cytology: Minimum Requirements for Cytology Laboratories* (New Zealand Society of Cytology. 1985).

Cytologists wanted a national cytology register. They required ready access to information about previous smears so that more informed decisions could be made about the current smear being assessed and more specific information provided for general practitioners making clinical decisions. It was emphasised that this should be a national registry (personal communication Roger Davis Cytology Technologist Medlab South).

**Screening for cervical cancer in New Zealand: The Department of Health and The Cancer Society of New Zealand November 1985.**

A meeting was called by the Department of Health and the Cancer Society of New Zealand on 5 November 1985. Twenty three people involved in the development of cervical screening services attended. Their brief was to:

> consider the present state and future needs of screening for cervical cancer as recommended by the Skegg Report - "Recommendations for Cervical Screening" New Zealand Medical Journal 1985;98:636-39


**Cervical Screening : Towards a woman-orientated programme. Ministry of Women's Affairs April 1987**

Considerable work on cervical screening had been undertaken by the Ministry of Women's Affairs. A staff member had visited England to review the organisation of the more co-ordinated programme being put in place at that time. A report by the Ministry briefly reviewed international cervical screening research and practices and advised that the establishment of a successful screening programme in New Zealand would require many features: effective procedures for follow-up of abnormal smears; adequate resource allocation to meet the increase in treatment created by a national programme; education programmes for medical students and doctors (communication and technical skills); culturally appropriate education programmes for women; co-ordinated computerised recall systems; and monitoring for accountability. The most important issue for a programme, the Ministry stated, was its ability to reach women most at risk. Cultural appropriateness and easy accessibility should be the principles underpinning any New Zealand programme. The report emphasised that there was wide spread support for alternative services (Cervical Screening : Towards A Woman-Orientated Programme. Ministry of Women's Affairs April 1987).
3.5 An "Unfortunate Experiment" at National Women's and The Cartwright Inquiry.

In June 1987 Metro magazine published an article 'An "Unfortunate Experiment" At National Women's' (Coney and Bunkle 1987), reviewing practices at the National Women's Hospital Auckland.

Immediately on 10 June 1987 the Minister of Health, Hon. Michael Bassett, instituted an investigation and appointed Judge Sylvia Cartwright to pursue the inquiry. The enquiry which followed took 14 months. The reporting time, originally 3 months was extended three times because of the complexity and the extensive implications of the evidence (Cartwright 1988).

Judge Cartwright's Recommendations

On 5 August 1988 the "Cartwright Report" was released, submitting a number of recommendations to government including the development of treatment protocols, the appointment of a Health Commissioner and associated patient advocates and interpreters. Patient rights and issues of informed consent were addressed as were ethical standards, research training and medical disciplinary procedures. Specifically, Judge Cartwright stated:

A nationally planned population based [cervical] screening programme should be implemented immediately (Cartwright 1988:216).

3.6 The Cartwright Inquiry: response of the medical profession.

The deliberations of the Cartwright Inquiry were reported widely in the media. On an almost daily basis the "scandal" of research practices at National Women's Hospital was thrust in to the homes of many New Zealanders on the evening news. For the first time in New Zealand's history, practices of the medical profession were publicly scrutinised and found to be wanting. Many practitioners could privately acknowledge the issues, but many appeared to feel personally attacked.

In response to the inquiry the New Zealand Medical Journal published papers and regularly printed letters to the editor.

'Life After Cartwright' was the leading article in February 1989. Hopkins (1989) referred to the maelstrom of emotions ranging from guilt, sympathy, uncertainty, and indifference. He regarded the report as an excellent starting point from which to review the profession's position on ethics. The scientific approach had been developed, Hopkins suggested, without being aware to the degree that medicine had been dehumanised:

We have captured the science and now we must relearn the art (Hopkins 1989).

Letters to the editors of this journal between 1989 and 1991 are witness to the hurt and indignation that some practitioners experienced, including reference to "a predetermined witch hunt" "militant feminists protesting at the fall out from the Cartwright Report, setting medical research back by decades, screening programmes costing millions and of doubtful value" and referring to Judge Cartwright "like Moses descending from Mount Sinai".
Other letters advocated the necessity for public debate while recognising the prospect of unhealed wounds and irreparable damage to the relationship between the medical profession and the public (NZMJ 1989-91).

In October 1990 The Medical Council found Professor Bonham guilty of disgraceful conduct as a consequence of the Cartwright Inquiry. The censure included a statement that the Council was saddened to have to make the verdict, given the major contribution Professor Bonham had made to the practice of obstetrics and maternal health since his arrival in New Zealand in 1963. This recognition was reinforced in several letters to the editor which, while conceding to the verdict of the Council, acclaimed the benefits for New Zealand women and children of his overall contribution to medical practices.

This ongoing correspondence is evidence of the intense response to the enquiry and the diverse range of positions held by practitioners within the medical profession.

One response has been to address the issues of the relationship between women and their general practitioners, focusing on women's experience of having a cervical smear taken. Marwick (1989) wrote *Women and Doctors Talking* with the intention of using women's comments to help doctors explore their practices, beliefs and attitudes and so make changes in the way they examined women.

### 3.7 Implementation of the National Cervical Screening Programme.

It was against this background that in late 1988 the then Minister of Health, Hon David Caygill, adopted the recommendation to implement a national cervical screening programme. A deadline of November 1989 was set for the launching of the programme. This posed an extremely tight time frame on the development of the programme. In retrospect it became clear that this was an impossibly unrealistic goal. Straton stated:

> There seems to have been an underestimation of the complexity of the task of establishing an operational and effective register in one Area Health Board, let alone the whole country. To set a deadline for establishing of the Register nationwide only two or three months after the beginning of the pilot registers was quite unrealistic and led to hasty decisions in a number of areas (Straton 1990:27).

This is confirmed through interviews with several people involved in this process (specific sources confidential).

> There was a feeling that the Department was not that interested in implementing the intent of the programme. ....

I think the Department totally under-estimated the complexity of implementing the programme. I mean, the complexity is, we have got a highly sophisticated computerised register. We have got all sorts of issues about screening interval, management protocols for abnormal cervical smears. We have got the question of health promotion, public information, public awareness. We have got the whole issue of private laboratories who do most of screens, and the competency of some of the smaller laboratories...
that were providing this service and you have the issue of waiting lists for colposcopy etc, etc, so the whole cervical thing is enormously complex. There are interest groups out there, there is women's groups, the concerns for the Maori community about Maori women being on the register, and who would have access to that information. General practitioners who saw the programme as additional work, the general practitioners who have got well-organised recall systems, see that they didn't actually need the programme.

3.7.1 National hui on cervical screening : December 1988

A three day workshop was held at Porirua Police College in December 1988. Approximately 100 people were invited to participate, representing a wide range of backgrounds including Maori and Pacific Island women, consumer groups, low income women's groups, New Zealand Family Planning Association, Cancer Society of New Zealand, medical and nursing personnel, cytologists, and health researchers.

3.7.2 National Cervical Screening Implementation Unit

A National Cervical Screening Implementation Unit was established within the Department of Health in April 1989. Prior to this, though, Health Department staff had already been working on cervical screening in response to the report from the Ministry Of Women's Affairs in 1987.

People involved in the initial implementation of the programme after the Cartwright Inquiry indicated that while the Inquiry had formalised the Cervical Screening Programme the fundamental process already in place did not change. What changed was the pace of the implementation. This was seen to be a result of the political imperatives arising from the high public interest following the Cartwright Inquiry. The register appeared to be central because it was more tangible than other ongoing processes such as education and consultation.

3.7.3 Pilot projects

Four community projects were piloted in 1988-89 by the National Cervical Screening Programme with the objectives of reaching the groups of women regarded as being 'high risk' and of training women without health professional qualifications to take cervical smears. The projects established in Kaikohe and Wanganui had a specific focus for Maori women. The Nelson project largely used existing resources to meet the needs of low income women (Lynch and Kainuku 1990), while Kawerau's focus on low income women also addressed the needs of a mixed population of Maori and Pakeha women.

Pilot programmes for the establishment of cytology registers were undertaken in Marlborough (Dowland 1990) and Wanganui Area Health Boards.

The pilot projects tested the documentation required to support the programme. They also tested the capacity of the software and associated problems. A smear taking benefit was provided for women who were enroled in the programme by general practitioners.
3.7.4 Treatment protocol for management of abnormal, inadequate and inconclusive cervical smears

A small working group, consisting of gynaecologists, primary medical practitioners, and a pathologist met in 1988 to prepare a preliminary draft of a protocol for the management of abnormal cervical smears. Prior to its approval in September 1989, comment was sought from the appropriate specialist vocational colleges and societies as well as consumer and provider groups. Provision was made for the protocol to be reviewed within three years. It included discussion of 'contentious issues'.

3.7.5 Competency and training

A critical aspect of the Cervical Screening Programme is the quality of the actual cervical smear slide itself. In 1989 a working party representing specific interest groups was established by the Department of Health to prepare standards of competency for smear taking. A sub committee was formed of three people representing the Family Planning Association, The Health Alternatives for Women and New Zealand Nurses Association. Seven standards were agreed covering: technical competency; respect and dignity for women according to culture; assessment; effective interpersonal skills; privacy and safety; explanation to build women's understanding and knowledge base; accuracy of records. Guidelines to evaluate standards of competency were also established (Standards of Competency for Smear Takers 1991).

This sub committee was also responsible for developing guidelines for the training of nurse, midwife and lay smear takers which included: criteria for selection; the theoretical and practical training programme; assessment for certification and approval by the medical officer of health; on-going competency; complaints; supervision and evaluation of the training programme and liaison with interested groups (Guidelines for the Training of Nurse, Midwife and Lay Smear Takers 1991).

3.7.6 Ministerial Review Committee

A Ministerial Review Committee reported on The Implementation of a National Cervical Screening Programme in November 1989. This committee had been convened by Hon Helen Clark, (who had taken up the position of Minister of Health in December 1988), in response to expressions of concern that there was a lack of consultation, that an expert committee had not been established, nor had a co-ordinator at a national level been appointed. There was also concern that the programme had appeared to be spending most of the $14 million dollars allocated to it on computer based registers rather than free, accessible and culturally appropriate services (Adams 1991:14). The committee made a number of recommendations including the establishment of an expert committee and the appointment of a national co-ordinator.

3.7.7 The Expert Group: review and policy development

The Expert Group was set up in December 1989. Organisations were invited to nominate representatives. The Minister of Health, Hon Helen Clark made appointments from these nominations to the committee which included five women representing Maori, Pakeha and Pacific Island consumer groups and the community (the Maori Women's Welfare League, the Maori women's screening pilot schemes, Pacifica, Fertility Action, The Health Alternatives for Women), as well as
representatives from the Cancer Society, the Ministry of Women's Affairs, the Department of Health, Family Planning Association, the Royal College of General Practitioners, the Royal College of Obstetricians and Gynaecologists, New Zealand Nurses Association, as well as an epidemiologist and a pathologist. It's brief was to oversee the implementation of the programme and advise the Minister of Health on national policy, resource allocation and on modifications to the programme. The task was made difficult:

by the non-existence of a written policy on the National Cervical Cancer Screening Programme. This situation has been compounded by the fact that some aspects of the programme have already been implemented, while other are still undecided (Koopman Boyden 1990).

The major goals of the programme were taken directly from the New Zealand Health Goals and Targets, which identified cervical cancer as one of the ten priority areas.

The Expert Group's Policy Statement for the National Cervical Screening Programme was released in August 1990. It documented existing policy for the programme, commented on the appropriateness of that policy, set out recommendations for future policy directions, and integrated the various elements of the programme into a unified policy package. It also outlined the rationale for cervical cancer screening and for a nationally co-ordinated programme. The Expert group was stated:

... only with a nationally co-ordinated screening programme will cervical cancer be significantly reduced in New Zealand (Koopman Boyden 1990).

The Expert Committee initiated a review of the Programme undertaken by Dr Judith Straton, an Australian public health expert. This was carried out in July 1990 but the report was not available until November 1990 three months after the Expert Groups Policy Statement was released.

Straton identified tensions between the Expert Committee and the Department of Health and suggested that problems had arisen because of lack of clear definition of the role of the group and communication difficulties. Rather than being supportive of each other the different groups of people involved worked independently. Straton commented:

There is no doubt that there is considerable suspicion on both sides, which is inimical to the establishment of a successful screening programme (Straton 1990:59).

3.7.8 National Co-ordinator Cervical Screening Programme

At the end of 1989 The Department of Health was reorganised. It was to this new organisation that the National Co-ordinator was appointed and took up her position on 5th June 1990. Considerable progress had been made with the computer software for the register. While no specific decision was made about the logistics of the register, events were already leading towards an "opt on" enrolment process, that is, women choosing to be on the register would sign a consent form to become
Legislative changes would have been required to authorise the laboratories to release information to the registers to allow for an "opt off" process. In this case all women would have been automatically enrolled on the register. To exercise their choice women would have had to sign a form indicating their wish to be removed from the record. It would appear that the legislative process would have taken longer than the original launching date of November 1989 so this option was not fully considered at that time.

The Expert Group was disbanded in February 1991. Their task of developing policy had been completed. The focus for the programme was now to implement the policy and evaluate the progress.

Not everyone was in agreement with disbanding the Expert Group. In March 1991 an article in Broadsheet referred to the 'dumping' of the Expert Group (Rosier 1991). Sandra Coney who had been a member of the Expert Group expressed concern in the article that New Zealand lacked experience in implementing screening programmes and argued that a strong management system was needed to make the programme work. Rosier concluded:

The expert group developed policy that would work. It seems like rank incompetence or ignorance (or maybe fear of losing control?) that the group was not left intact to see it into full operation (Rosier 1991).

3.7.9 The Advisory Committee

An advisory group with expertise in the technical aspects of monitoring and evaluation was now seen to be warranted. The Advisory Committee appointed to monitor the evaluation and implementation of the Cervical Screening Programme first met in May 1991 and continues to meet on a regular basis. Membership includes a health economist, an epidemiologist, a biostatistician, a pathologist, and a Maori woman. The chairperson is from the Cancer Society. The national Co-ordinator and her advisory officer also attend these meetings.

3.8 Social and political issues in health

During the time of the evaluation there was ongoing debate in New Zealand about important health and social reforms including ACC payments, introduction of the Community Services Card and the associated medical and hospital fees. With regard to service delivery the debate continued over the status of publicly funded health services. Regional Health Authorities were about to be set up with significant implications for general practitioners in terms of contracting for services and whether cervical screening would be one of the core health services.

With unemployment rates remaining at a level of about 10% the question of access to health services for those women identified as the target groups for the cervical screening programme is a recurring issue.

3.9 Discussion

The concept of screening to prevent cervical cancer has been acknowledged for the last four decades and efforts to establish screening in New Zealand have previously been attempted in New Zealand over the last two decades. Over this time period major advances have been made in all areas associated with screening including understanding the pathology of the disease; improving the cytological technology for assessing the smear test slides; and developing the computer information
technology in regard to establishing registers. Changes have also occurred in clinical practice in relation to the technical procedure of taking cervical smears and in the area of interpersonal relationships particularly with respect to ethical concerns and informed consent. Over this time there has been considerable development of smear taking services by nurses and alternative non-health professional smear takers. Of particular importance, many women have sought and gained more access to information, consequently some women are better able to negotiate the service they require from service providers.

Within all these developments, not surprisingly, there are various and often divergent opinions and attitudes towards these developments. Compounding this is the fact that these developments are ongoing and always debatable, and the established recommendations change as more information is accumulated, for example, in 1992 the recommended age to begin screening was changed from the age of becoming sexually active to 20 years of age. The debate often occurs between the more vocal proponents of the various positions. This tends to result in the arguments becoming entrenched in more polarised opposing positions as the proponents seek to influence the policy and practice decisions. Judgements are sometimes made about previous practices based on 1992 knowledge and experience. It is suggested here, however, after having discussions with many people involved in the arena of cervical screening, that most people are open to more constructive dialogue and are willing to explore the various possibilities.

This chapter has attempted to place the Cervical Screening Programme in the context of these developments. One of the aims of this evaluation has been to provide a comprehensive overview so that the historical context of the Cervical Screening Programme and the practices of both women and smear takers in relation to cervical smear tests and participation in the Cervical Screening Programme can be clearly understood and appreciated. Only when there is a willingness to understand and appreciate the experiences of other groups will it be possible to engage interactive discussion necessary for the development of cervical screening services.
4 IMPLEMENTATION OF THE CANTERBURY CERVICAL SCREENING PROGRAMME

4.1 Introduction

The Manager of the Canterbury Area Health Board Cervical Screening Programme took up her appointment in July 1990. The main strategies of the Canterbury Cervical Screening Programme are community education, particularly directed to groups of women with low screening rates (Maori and Pacific Island women; older women) and the development of effective liaison with general practitioners. Important priorities for this region are support for screening in general practice and enrolment of women on the National Cytology Register. The Canterbury Programme has chosen not to provide screening services itself, but provides resources to support screening initiatives in the community.

4.2 Implementation study

The implementation study provides an overview of the processes involved in implementing the Canterbury Cervical Screening Programme and the various community/professional interfaces involved in managing the programme.

4.2.1 Objectives of the study

The objectives of the study included:

- To provide an overview of Canterbury Cervical Screening Programme
- To identify factors which have enhanced or constrained the implementation process.

4.2.2 Methodology

A variety of research methods were used to obtain the information required for this study:

- Participant Observation (including participation in formal and informal meetings, attending public events and associating with staff as they undertook tasks).
- Review of administrative and management documents such as minutes of meetings, planning documents and files.
- Indepth interviews with key people including the Manager, Primary Health Division, the Manager, Canterbury Cervical Screening Programme, Cytology Technologist, Medlab South, and others.
- Analysis of the Cytology Register enrolment statistics.

4.3 Overview of Canterbury Cervical Screening Programme
The Canterbury Cervical Screening Programme Business Plan to June 1991 declares the Statement of Purpose underpinning the implementation of the Programme:

*In consultation with the women of Canterbury, to develop and implement an effective and culturally appropriate Cervical Screening Programme that is:*

- Ethical
- Equitable
- Accessible
- Affordable
- Sustainable

*and thereby promote their total health*

The specific goal of Canterbury Cervical Screening Programme is:

*To increase the number of eligible women (aged between 20-70 years) who have a current smear history and who are enrolled on the Cytology Register within the Canterbury area health Board area.*

The main responsibilities of the Programme include:

- To ensure the delivery of cervical screening services
- To liaise with general practitioners and other health providers
- To implement a cervical screening programme consistent with the National Cervical Screening Programme's policy
- To ensure focus of services reflects those groups of women most at risk
- To ensure that the standards of competency for certified smear takers are met
- To ensure that there are adequate diagnostic and treatment services in the region to meet the needs of the National Cervical Screening Programme
- To monitor and evaluate the programme within Canterbury Area Health Board
- To maintain the Cytology Register
- To provide data to the National Cervical Screening Programme for national evaluation

4.4 *Area Health Board - Department of Health Relationship*

The Cervical Screening Programme is organised nationally but managed regionally. This means that the regional Manager while appointed to the Canterbury Area Health Board and responsible to the Manager of Primary Health Services, also has accountabilities to the National Co-ordinator, Department of Health (Refer to Fig 4.1). This dual responsibility and accountability means responding to two sets of requirements, a substantially increased workload. While the requirements of each authority were not in conflict they may frequently be different, so that in many instances two sets of information are required.
The National Cervical Screening Programme has had an important impact on the Regional Programme in relation to policy. It was not until late September 1990 that the Policy Statement providing guidelines for the implementation of the Cervical Screening Programme was available. Regional Managers therefore were without guidelines on which to base their proposals for implementing the Programme until only shortly before these proposals were due to be completed.

4.5 Programme relationships

A primary directive of the policy statement for the implementation of the Cervical Screening Programme requires the service to be women-orientated. That is the services initiated by providers of cervical smear tests must be organised to take account of the needs of women (Koopman Boyden 190:21).

Canterbury Cervical Screening Programme has endeavoured throughout the process of implementing the Programme to involve women in all stages of discussion and implementation. This has involved two strategies: the establishment of a number of advisory committees; and the establishment of paid positions within the Programme which have specific responsibilities for women whom the Programme has identified as having special needs including Maori and Pacific Island women, older women and women with low incomes (Refer to Fig 4.1).

4.5.1 The Community Committee

Pending the appointment of a manager of the Cervical Screening Programme, a Coordinator of Cervical Screening had been involved in preparatory work. The establishment of a Community Committee laid the foundation for consultation with the community. This committee meeting has continued in the form of a three monthly public meeting. This is advertised in the local newspapers and on community radio as well as postal invitations to individual women and groups.

The terms of Reference for this committee are:

- To provide a forum for community discussion and feedback on the implementation and monitoring of the Cervical Screening Programme within the Canterbury Area Health Board region.
- To provide a forum to raise, debate and clarify issues of concern regarding the Cervical Screening Programme within the Canterbury Area Health Board region.
- To provide an opportunity for co-ordination of resources, skills and knowledge to assist in the implementation and monitoring of the Cervical Screening Programme within the Canterbury Area Health Board region.
- That this committee make recommendations to the Manager, Cervical Screening Programme on implementation and monitoring.

Figure 4.1 Organisational structure of Canterbury Cervical Screening Programme
National Co-ordinator
Department of Health
Wellington

CANTERBURY CERVICAL SCREENING PROGRAMME

Manager 1 x 1
Personal Assistant 1 x 1
Senior Typist 1 x 1
Systems Administrator 1 x 1
Data Operator 1 x 1
Co-ordinator/Educator 1 x .5
Mid/south Canterbury

Community Health/Liaison Officers:
Maori 2 x .5
Samoan 1 x .5
Cook Island 1 x .25
Tongan 1 x .25
Niuean 1 x .25
Over 35 years 1 x .5

Advisory Committees:
Community
Publicity and Education
Evaluation and Monitoring
Service Delivery Gaps and Provision of Alternative Services
Smear Taking Training
Ensuring that all women's groups, especially 'at risk' groups, were represented at Community Committee Meetings, was an important consideration. An extended mailing list was used to ensure that people were informed of proceedings even if they were unable to be represented at meetings.

The meeting is a process by which the Manager is able to bring women from the community up to date with the activities of the Programme. It also provides women with an opportunity to discuss any aspect of cervical screening.

Attendance at the meetings has varied considerably over the last eighteen months. Many of those people who have attended the meetings are involved in health services in some way. While the organisation of these meetings is time consuming and the benefits are sometimes not readily tangible, the Manager feels the existence of the opportunity to have discussions in this way is very important.

4.5.2 Special interest committees

The Manager of the Canterbury Cervical Screening Programme established four committees in Christchurch to ensure she was advised by people with a broad range of perspectives on cervical screening, including representation from consumers, service providers and community groups. This also ensured input into the Programme from all sectors of the community. The committees addressed issues concerned with publicity and education; evaluation and monitoring; service development and smear taking training. In South Canterbury a Core Group was set up to advise on all these areas. While the committees each dealt with specific areas each committee had input into other committees, for example, the evaluation and monitoring committee provided the publicity committee with detailed information for developing information pamphlets.

It is important to note that a member of THAW (The Health Alternatives for Women) provides consumer and community representation on all the Special Interest Committees.

Publicity and education

This committee was concerned with selecting the design of the regional logo and developing the regional pamphlets:

'An Invitation for Life' outlines the advantages for women of joining the National Cervical Screening Programme and issues an invitation to women to have a smear test taken. 'Myths and Fallacies' comments on common thoughts women have about cervical cancer and cervical smears that may result in them not having a smear test. The function and advantages of the Cytology Register are explained in another pamphlet, 'National Cytology Register'.

A major initiative of this committee was the regional media publicity campaign held in October 1991. Two important messages were the focus of the campaign: one was concerned with the need for a smear and the other emphasised the importance of the National Cytology Register. The aim was to reach all women, but particularly those aged over 35 years and Maori and Pacific Island women. A public relations company, Clarity Communications (Christchurch) Ltd, was contracted to implement the promotional work for the Programme. The publicity campaign was launched with public meeting in Christchurch Town Hall. A post graduate education seminar was arranged for general practitioners and practice nurses. Advertising included most local radio stations and the regional television
Print advertisements were published in the major regional newspapers and the three community newspapers. Two key messages were promoted: the importance of having a cervical smear taken every three years; and that if a woman felt embarrassed to ask her doctor there were other people who could take smears such as a practice nurses.

The regional campaign followed the national campaign so it is not possible to separate out the effects of each. There was a substantial increase in the number of women presenting for cervical smears following the publicity campaign. Many general practitioners commented on the effectiveness of the publicity. There is evidence from Medlab South Christchurch, that the quality of cervical smears has improved significantly (personal communication with Roger Davis, cytology technologist, 19.2.91).

Table 4.1 Smear taking and quality of smears in Canterbury. June 1991- Jan 1992

<table>
<thead>
<tr>
<th></th>
<th>June '91</th>
<th>%</th>
<th>Jan '92</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of smears</td>
<td>5,117</td>
<td></td>
<td>6001</td>
<td></td>
</tr>
<tr>
<td>Adequate smears</td>
<td>4,040</td>
<td>79</td>
<td>5316</td>
<td>88.5</td>
</tr>
<tr>
<td>Less than adequate smears</td>
<td>1,050</td>
<td>20.5</td>
<td>651</td>
<td>11.0</td>
</tr>
<tr>
<td>Totally inadequate smears</td>
<td>27</td>
<td>0.5</td>
<td>34</td>
<td>0.5</td>
</tr>
</tbody>
</table>

(Medlab South)

(Less than adequate = no endocervical cells or scant epithelial cells. Totally inadequate = insufficient cells on the slide.)

In January 1992 the proportion of adequate smears had increased by 9.5% (88.5%) in comparison with the adequate smears in June 1991 (79%). The proportion of less than adequate smears in January 1992 this was 11%, again an improvement of 9.5% over June 1991. The proportion of totally inadequate smears stayed more or less the same.

The cytology technologist suggested that the publicity campaign had been one of the factors in increasing smear takers awareness of the need to take good quality smears.

Whether the publicity campaign has been effective in increasing women's awareness of the National Cytology Register is not yet able to be established. According to comments from general practitioners, very few women are asking about enrolment on the Register, which could suggest that the publicity has not been effective in informing women about the National Cytology Register.

The next publicity campaign, in March 1992, was more focused on the priority groups. The advertisements were spoken or printed in six languages: English, Maori, Tongan, Samoan, Cook Island and Niuean. Another publicity campaign
is organised for October 1992. The primary focus of this effort will be directed at increasing general practitioners advocacy for the Programme as well as maintaining the profile of the Programme among women.

**Evaluation and monitoring committee**

This committee includes community and consumer representatives as well as people with clinical and technical expertise to review the internal monitoring and evaluation of the Programme. It is concerned with issues of quality assurance and quality control. While this committee has not met on a regular basis, it has always met with a purpose. It has been a forum for generating discussion about the quality of the services as well as the quality of the Programme. For the Manager, this committee provides an overview for the Programme and is a very important source of advice.

**Committee on service delivery gaps and provision of alternative services**

While the Canterbury Cervical Screening Programme is not involved in providing specific cervical smear testing services itself, it has a strong commitment to supporting initiatives in the community concerned with alternative services. This committee was responsible for developing the criteria for distributing funds allocated from the Programme's Community Initiatives budget.

In November 1991 applications were invited from community organisations and iwi to apply for funding especially aimed at encouraging older women, Maori and Pacific Island women to have a smear and be enrolled on the Register.

Some members of the Service Delivery committee were also involved in reviewing the applications, interviewing applicants and making the funding allocation decisions. An allocation of $32,000.00 was divided between various community groups and organisations, including initiatives for increasing screening coverage amongst groups of women currently under screened.

**Committee on smear taking training**

This committee included a representative from the Family Planning Association who was involved in smear taking training and a representative from THAW who had been on the national sub committee which developed the national Standards of Competency for Smear Takers. It focused on the training of nurse smear takers and 'lay' smear takers. The Family Planning Association had an established programme for training nurses and continues to do so. This committee was concerned that the training programme for 'lay' smear takers should lead to a high level of competence. On the recommendations of this committee the Canterbury Cervical Screening Programme has contracted the Family Planning Association to provide a bridging course for lay smear takers which would prepare them to take the same smear taking training programme as nurses. The legal implications for 'lay' smear takers and their protection is an important issue being addressed by this committee. While they have not yet arrived at a definitive position, the Medical Officer of Health has a statutory responsibility for the certification of smear takers.
**4.6 Community liaison strategies**

**Community Liaison Officers**

In October 1990 Canterbury Cervical Screening Programme appointed a Pacific Island woman and a Maori woman six weeks later to liaise with these Maori and Pacific Island Communities.

**Maori Proposal**

The Maori Community Liaison Officer developed a Maori Proposal outlining the needs of Maori women, offering strategies to aid in the development of Cervical Screening Services and providing a forum for identifying the issues Maori indicated were relevant (Mills 1991).

This proposal reported:

> ... that health services as they exist are still not meeting the needs of Maori (Mills 1991).

It included recommendations:

- Employ and train Maori health educators
- Establish Marae based services
- Plan and develop the implementation of a Maori mobile unit.

The Canterbury Cervical Screening Programme has addressed the first two of these recommendations.

**Pacific Island Report**

The main issues raised for Pacific Island women were that the information about Canterbury Cervical Screening Programme and cervical smear tests be available in the various languages including Cook Island, Niuean, Samoan and Tongan. It was stressed that access to these communities was through the churches and established community organisations.

**Education Liaison Officers**

The Canterbury Cervical Screening Programme's commitment to providing a of culturally appropriate affordable, ethical, accessible and sustainable service is reflected in the appointment of seven women in the positions of Community Education/Liaison Officers in December 1991. Two Maori women each work 20 hours a week, one covering the mid and south Canterbury region and the other covering Christchurch and the northern region of Canterbury. Four women representing Samoan, Cook Island, Tongan and Niuean women are also employed for a combined total of 40 hours per week. A Pakeha woman with a focus for women aged 35 years and over is also part of this team of enthusiastic women dedicated to improving the health status of women in their communities and empowering women to make their own choices.

These women work in a variety of ways and in a wide range of places. In describing how they reach their communities in a presentation at Public Health Association Conference 1992 they identified two main barriers to informing
women about the importance of having a regular cervical smear test and enrolling on the Cytology Register. These barriers are:

- fear of the unknown
- that part of the body is tapu or sacred and is not openly discussed.

One of the women told how she contacts her community.

*I meet them at home, in community group meetings, in the shopping mall, at celebrations, sports, picnics, and at parties.*

*It is important that I first meet with women as individuals. Why? To break down the barrier of shyness and win their hearts. And when we talk we don't use medical language. We talk about things that we understand. We use things that are real and natural to relate the message. For example beautiful flowers. They are well looked after and nurtured. So it is with our lives we look after them and they will be beautiful and healthy.*

She concluded:

*When I establish a heart connection with my women, they willingly accept a smear. It is very important work and it takes a lot of time.*

The Community Education/Liaison Officers were aware of the ongoing work to be done and asked themselves "What about the women who don't come to church, to the marae, to group meetings? What about the 'invisible woman'?"

The Manager of the Programme reported that there was evidence that the work of the Community Education/Liaison Officers was being effective. There had been a small increase in the numbers of women enrolling on the Cytology Register. However the effects of their work is more far reaching than this. While enrolment on the Register is a tangible measurement of their effectiveness it is does not reflect the extensive impact of their work in relation to the health of their communities.

### 4.7 The National Cytology Register

The Policy Statement of The National Cervical Screening Programme states that the National Cytology Register is the key tool in providing a management system for the Cervical Screening Programme. The primary functions of the Register are to ensure the systematic recall of women, to maintain a high technical quality of smears and to ensure that appropriate action is taken where abnormal smears are detected. It would also be the means to continuing evaluation and monitoring (Koopman Boyden 1990:2).

Implementation strategies were developed by the Expert Committee to provide guidelines for the regional managers. (Koopman Boyden 1990:43-47). However, in her review of the National Cervical Screening Programme Dr Judith Straton considered the enrolment procedures for the Register to be 'excessively complicated'. She suggested there was a likelihood of this being a deterrent to general practitioners enrolling women on the Register (Straton 1990:6-7).

Canterbury Area Health Board was selected to 'fast track' the implementation of the Cervical Screening Programme's Cytology Register. The Manager of the Canterbury Cervical Screening Programme places equal priority on increasing the
coverage of women having cervical smears taken and the number of women being
enrolled on the register.

Canterbury Cervical Screening Programme has concentrated on providing
information about the Cytology Register. A pamphlet explaining the National
Cytology Register has been developed and distributed widely. The Cytology
Register was also a central focus for the regional publicity campaign, in contrast to
the national campaign which provided no information about the Register.

The Cytology Register for Canterbury Cervical Screening Programme became
operational on 18 February 1991. By the end of three months 1791 women had
been enrolled on the Register. At the end of June 1991 this had increased to 3,000.
In May 1992 the total number of women enrolled on Canterbury Cervical Screening
Cytology Register was 17,396, 13% of the total eligible population of 132,000
women aged between 20 and 70 years in Canterbury. On average 1656 new
enrolments per month were processed by the Register between October 1991 and

Unfortunately it is not possible to identify the proportion of women who have
smears who also enrol on the Register. The laboratory is able to report only the
total smear test numbers (not total client numbers) and is not able to report repeat
smears and smears where two slides are used. The number of reported smears is
therefore far in excess of the actual number of women receiving smears.
Consequently it is misleading to compare the number of smears processed with the
number of Register enrolments. However the data available can be used to indicate
the proportion of enrolments on the Register over time. Between October 1991 and
May 1992 the percentage of smears processed at Medlab South which resulted in
women being enrolled on the Cytology Register ranged between 22% and 36% with
an average of 29%.

Table 4.2 The percentage of cervical smears processed at Medlab South
which are enrolled on the Cytology Register October 1991 - May 1992

<table>
<thead>
<tr>
<th>MONTH</th>
<th>NUMBER OF ENROLMENTS</th>
<th>NUMBER OF SMEARS PROCESSED AT MEDLAB SOUTH</th>
<th>% ENROLED ON CYTOLOGY REGISTER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct</td>
<td>2290</td>
<td>6838</td>
<td>33</td>
</tr>
<tr>
<td>Nov</td>
<td>2219</td>
<td>6155</td>
<td>36</td>
</tr>
<tr>
<td>Dec</td>
<td>1485</td>
<td>5329</td>
<td>28</td>
</tr>
<tr>
<td>Jan</td>
<td>1334</td>
<td>5467</td>
<td>24</td>
</tr>
<tr>
<td>Feb</td>
<td>1407</td>
<td>4746</td>
<td>30</td>
</tr>
<tr>
<td>Mar</td>
<td>1818</td>
<td>5545</td>
<td>33</td>
</tr>
<tr>
<td>Apr</td>
<td>1165</td>
<td>5352</td>
<td>22</td>
</tr>
<tr>
<td>May</td>
<td>1533</td>
<td>5930</td>
<td>28</td>
</tr>
</tbody>
</table>

In April and May 1992 information was available to allow a direct comparison
between the total number of smears processed through the Cytology Register and
those processed through Med Lab South (including all repeat smears). In April
1992, 1747 smears were processed through the Cytology Register, 32.5% of the
5352 processed through Medlab South. In May 1992, 2334 or 42% of the 5530
smears processed through Medlab South were processed through the Cytology
Register.
Table 4.3 Comparison of the number * of smears processed through Medlab South with the number processed through the Cytology Register

<table>
<thead>
<tr>
<th></th>
<th>MEDLAB SOUTH</th>
<th>CYTOLOGY REGISTER</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>April '92</td>
<td>5352</td>
<td>1747</td>
<td>32.5</td>
</tr>
<tr>
<td>May '92</td>
<td>5530</td>
<td>2334</td>
<td>42.0</td>
</tr>
</tbody>
</table>
(* includes repeat and follow up smears)

Figure 4.2 compares the number of smears processed with the number of enrolments. As stated above it is misleading to compare these figures. The figure is included to show visually the pattern of enrolments over time.

4.8 Community Initiatives

The Canterbury Cervical Screening Programme has supported several health programmes which included a cervical screening component, for example:

Whanau Whakatipu

Whanau Whakatipu is a joint venture between Te Roopu Tautoko Trust and the Family Planning Association. It was a course of training for Maori women in the area of sexual health and total well-being. (See Chapter 8. Cervical Screening for Maori Women) Canterbury Cervical Screening Programme contributed $10,000.00 in support of the programme, as well as making a contribution to the teaching sessions.
South Canterbury Women’s Wellness Centre Rural Clinic

South Canterbury Women’s Wellness Centre were funded with a grant of $5,755.00 to provide subsidised cervical smear tests especially for women aged over 35 years. No charge was made. Women were asked to make a donation. A mobile rural clinic meant that this initiative was readily accessible.

Arowhenua Marae Health Clinic

Canterbury Cervical Screening Programme contributed $2,000.00 to the completion of the building of the Health Clinic based within Arowhenua Marae, Temuka. The Programme has also participated in a health hui specifically for cervical screening at this clinic.

4.9 Promotion Of Canterbury Cervical Screening Programme

Promoting the Canterbury Cervical Screening Programme is integral to the day to day work of the Manager and her staff. They are constantly providing information about the Programme, encouraging both women and smear takers to participate in the Programme and especially to promote enrolment on the Register. Specifically this has involved promotional talks with a wide variety of groups and organisations such as Maori Women’s Welfare League, Country Women’s Institute, Royal New Zealand College of General Practitioners.

General Practitioners

General Practitioners are the primary providers of services for cervical smear tests and so have a key role to play in the cervical screening services, particularly in enrolling women on the Cytology Register. An important aspect of the Manager’s implementation of the Programme has been to visit personally many practices within the region to inform them of the Programme’s policy and practice and discuss issues of concern. Recognising the service provided by general practitioners, the Canterbury Cervical Screening Programme specifically did not embark on developing as smear taking service within the regional Programme, as has happened in all other Area Health Boards.

On a one to one basis the Manager has generally found these meetings positive and constructive. However it is of concern to her that there continues to be considerable caution and resistance from some general practitioners to promote enrolment on the Cytology Register. She feels that she made every effort to engage in constructive discussion with general practitioners and deal with their issues of concern.
4.10 Special Relationships

Other Regional Managers

The fourteen Regional Managers and the National Co-ordinator meet four times a year. In addition to this Managers from the South Island meet on another three occasions. These meetings report on the progress of the Programme, regionally and nationally and issues of concern are discussed. While there are many aspects of the Programme common on a national basis there are specific regional issues. This networking with regional Managers has been very supportive and productive.

Laboratory Services

The majority (approximately 95-98%) of cervical smears taken in the primary health services are currently processed through a private laboratory, Medlab South. A small proportion are processed through Canterbury Area Health Board. Canterbury Cervical Screening Programme has established strong and supportive links with Medlab South personnel who are represented on the Evaluation and Monitoring Committee. One of the cytology technologists is also an important resource person, providing advice and information on technical issues as well as speaking at various forums organised by Canterbury Cervical Screening Programme.

Medlab South is accredited by TELARC, a national laboratory accreditation organisation responsible for quality control of laboratories. In regard to cervical screening the criteria for quality assurance includes:

- screening of a minimum number of smears per year
- the employment of a certain proportion of qualified staff at each level
- the maximum workload for each screener
- participation in internal and external quality control procedures

Family Planning Association

The Family Planning Association has made an important contribution to Canterbury Cervical Screening Programme. As well as rigorously promoting the programme and ensuring that all women attending the clinics are informed of the option of enrolling on the National Cytology Register, Family Planning has been involved in other ways, particularly in regard to training smear-takers.

Family Planning Association provides cervical smear training courses based on the guidelines developed by the Cervical Screening Programme for the training of nurse, midwife and lay smear-takers. The two day workshop includes theoretical and practical aspects, cultural and social discussions, normal and abnormal clinical conditions and an understanding of cytological results. Smear takers are required to take thirty smears before they can be certificated. Direct supervision is required for the first fifteen smears and is usually done at Family Planning. Smear taking is then supervised by medical practitioner who continues to provide ongoing support. Canterbury Cervical Screening Programme has funded 15 practice nurses for this training at a cost of $497.00 each, a total of $7,455.00.
Lay smear takers are required to complete a bridging course before they take the smear training course. This is a thirty-five hour course held one day per week over seven weeks. Again, Canterbury Cervical Screening Programme had contributed funds for this course.

4.11 Staffing of Canterbury Cervical Screening Programme

For the first six months of her appointment, during the crucial development phase of the implementation, the Manager had no secretarial support. This put additional pressure on her position. It was not until March 1991 that funds were made available for the appointment of a secretary.

The Data Entry Operator was appointed in January 1992 the same day the Cytology Register became operational.

Two Community Liaison Officers had short term appointments between January and March 1991 to consult with Maori and Pacific Island communities. Nine months later in December 1991 seven women were appointed as Community Education/Liaison Officers.

Because education is an important focus for Canterbury Cervical Screening Programme a Supervising Educator was appointed to a middle management position in August 1991. This position was restructured in April 1992 to allow for the position of Education Officer for South and Mid Canterbury. A position for a General Practitioner Liaison Officer has also been developed. This position, to increase general practitioner advocacy of the Canterbury Cervical Screening Programme, is to be advertised in July 1992.

The increase in staffing numbers and the restructuring of the Programme meant that the Manager’s administrative role also increased. A Personal Assistant took up her position in April 1992 to relieve the Manager from some of these organisational aspects of the Programme.

4.12 Discussion

The National Cervical Screening Programme has, from its inception, been highly political and controversial. The Programme has been set up nationally, but is managed at regional (Area Health Board) level. Canterbury Cervical Screening Programme therefore has a particular management organisation and structure with dual responsibility and accountability to both Canterbury Area Health Board and the National Co-ordinator, Department of Health Wellington.

The fact that Canterbury was selected to fast track the implementation of the Cytology Register and that this process be documented in evaluation has made another claim on the Manager. This has tended to place an emphasis on the numbers of women enrolling on the Register as the tangible measure of the Programme’s success. The impact of Canterbury Cervical Screening Programme has had more far reaching consequences than this. For example, there is evidence from the laboratories that the publicity campaign has resulted in a marked increase in the number of smears taken. The tangible consequences of the work of the Community Education Liaison Officers resulting in women enrolling on the Cytology Register may not be obvious for some time, yet the work they do is very important and very effective.
Canterbury Cervical Screening Programme also has primary relationships with various professional groups and community organisations including general practitioners, practice nurses and Family Planning Association and THAW. These groups while being in agreement about the importance of cervical screening services often have disparate views on how this should be managed so Canterbury Cervical Screening is often involved in maintaining a balance between professional and community groups. In particular there has been cautious acceptance of the Programme by some professional groups, while community groups have watched the implementation of the Programme with a critical eye.

Over the last eighteen months since the Cytology Register became operational the number of women who are enrolled on the Register has gradually increased. However, a significant proportion of women having cervical smears are not being enrolled on the register. There are various factors contributing to this. These are discussed in Chapters 5, 6, and 7.

Being a test case for the Cervical Screening Programme as well as for other screening programmes within health services has meant that Canterbury Cervical Screening Programme has been subject to rather more extensive scrutiny by these different groups. While the Manager has made it possible for these groups to have input into the Programme, working within these often strained interfaces has placed considerable demand on the manager and her staff. Canterbury Cervical Screening Programme has addressed the responsibilities set and continues to meet the ongoing challenges of implementing Canterbury Area Health Boards Cervical Screening Programme.
5 PERSPECTIVES ON CERVICAL SCREENING AMONG CANTERBURY WOMEN

VALERIE NORTON, Contract researcher
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PENNY BRANDER, Researcher

5.1 Introduction

An early task of the evaluation was to acquire base-line information on screening within the regional population, and on women's views about services.

This survey was initiated because it was important to establish the level of screening coverage within the community. The monitoring of screening rates in the population has been based on regional cytology reports (Jones et al. 1988; McCafferty et al. 1989) except for questions incorporated in a national random population study of women's contraceptive practices in 1987 (Paul et al. 1988) and a 1990 national study specifically of cervical screening (Bonita and Paul 1991). No regional study was available.

A further reason for the survey lay in the identified strategy of the Canterbury Cervical Screening Programme, which had determined that its approach would be both to support existing screening services and identify opportunities to make screening more accessible to women. It was considered important, therefore, to ascertain women's screening practices and preferences, and any barriers to screening that they could identify.

The importance of registration in monitoring the impact of cancer screening is well established (Skegg 1989; Cooke et al. 1988; Bonita and Paul 1991) and information was required on women's knowledge and perception of the National Cytology Register.

This chapter reports the first results of a random survey of women aged between 20 and 69 years of age from the Canterbury Area Health Board (excluding South Canterbury and Chatham Islands). The survey took place in June-July 1991 before the launching of national and regional publicity campaigns to promote cervical screening.

5.2 Methods

5.2.1 The questionnaire

The questionnaire was developed in collaboration with personnel of the Canterbury Cervical Screening Programme and was approved by the Canterbury Area Health Board Ethics Committee and the Survey Control Section of the Department of Statistics. It covered two broad areas: (1) screening history, practices and preferences and (2) women's knowledge of cervical screening and the National Cervical Screening Register. The questionnaire provided for mainly closed
responses, but for those questions where opinions and preferences were sought there was an opportunity to record additional comments.

5.2.2 Sample selection

A stratified random sample of women was drawn from the rolls of the twelve Canterbury electorates between the Clarence and Rangitata rivers: eight electorates within metropolitan Christchurch (Avon, Christchurch Central, Christchurch North, Lyttelton (excluding the Chatham Islands) St. Albans, Sydenham, Yaldhurst), three rural electorates (Ashburton, Rangiora, Selwyn) and the Southern Maori roll (including only those women within the boundaries of the other eleven mid and north Canterbury electorates). The electoral roll provides good coverage of women, with overall registration estimated to be 91%, varying from 81.5% for women aged 20-24 to 97.5% for women aged 65 and over (Department of Statistics 1991).

A single stage sampling procedure from each electorate was used with supplementary sampling from the Southern Maori roll. For the initial sample between 60 and 64 names were selected from each of 11 electorates (depending on the exact size of the roll) and 28 names were selected from the Southern Maori roll, making a total of 703. In order to analyse Maori women's responses as a group a much larger sample would be needed, but this was beyond the brief of this project.

Women aged under 20 and 70 years and over were excluded from the study. A randomly selected replacement sample was drawn from each electorate so that if women were found, on contact, to be outside the 20-69 aged range they could be excluded from the study and replaced from this additional sample. Women who could not be contacted either by telephone or letter were replaced in the same way up to a maximum of 20 replacements from each electorate.

5.2.3 Contact with the sample

Considerable efforts were made to ensure a high response rate from the sample. An introductory letter was sent to all women selected from the electoral roll. The letter was important in preparing the way for the study by providing women with information about the research. This allowed women to consider their decision to be involved and ensured informed consent to their participation. Women were contacted by telephone where possible, but otherwise by a further letter. Most of the interviews took about 20 minutes to complete and were conducted by telephone, with five women requesting the option of a face to face interview.

The final sample comprised 683 women, approximately 1:176 women aged 20-69 in Canterbury. Of these women, 524 (77%) completed interviews, 72 (10%) refused to participate and a further 87 (13%) were unable to be contacted. This provides a sampling error of 3.7% at 95% confidence level when estimating proportions. Data from the survey was analysed using the SAS statistical package.
Table 5.1 Population distribution, women aged 20 - 69, from sample and regional population

<table>
<thead>
<tr>
<th>Age group</th>
<th>Sample</th>
<th>Canterbury electorates 1991 Census</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
<td>%</td>
</tr>
<tr>
<td>20-24</td>
<td>34</td>
<td>6.5</td>
</tr>
<tr>
<td>25-35</td>
<td>131</td>
<td>25.0</td>
</tr>
<tr>
<td>35-44</td>
<td>151</td>
<td>28.8</td>
</tr>
<tr>
<td>45-54</td>
<td>97</td>
<td>18.5</td>
</tr>
<tr>
<td>55-64</td>
<td>74</td>
<td>14.1</td>
</tr>
<tr>
<td>65-69</td>
<td>37</td>
<td>7.1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>524</td>
<td>100.00</td>
</tr>
</tbody>
</table>

5.3 Results

According to the 1991 provisional census results (Department of Statistics 1991) the age profile of the sample closely resembles that of the regional population from which it was drawn (Table 5.1).

The youngest age group was underrepresented as a proportion of all women aged 20-69. This was expected as this age group is least likely to be registered on the electoral roll and more likely to be residentially mobile and more difficult to contact. The proportion of Maori in the sample (5.5%) closely approximates the regional proportion (4.5%) for females all ages in 1986 (Department of Statistics 1987).

5.3.1 Screening coverage

Women were asked whether they had had a cervical smear test in the last three years. Women who had had a smear test in the last three years were considered to be adequately screened. Women who could not remember when their last smear was taken were not considered to have adequate screening protection. For the purpose of this study women who had had a hysterectomy were not considered to require a regular smear, although there are circumstances when this may not be the case.

Table 5.2 indicates, by age group, the proportion of women with up-to-date or inadequate screening history. As expected from other research (Bonita and Paul 1991) a higher proportion of younger women are adequately screened, compared with older women. The highest screening rate is for women 25-34 (89.3%), followed by the 35-44 year age group (85.3%) and those 20-24 (82.4%). The screening rate drops for older women, to 75.6% for women 45-64 and below 40%
for women 55 and over. The sample profile was weighted to match the age profile of the actual population, allowing an estimate of a screening rate for the population overall. The survey estimates that nearly 75% of women between ages 20-69 who require screening are adequately screened i.e. reported a cervical smear within the last three years. Twenty-five per cent of women were estimated to be inadequately screened, i.e. they had never been screened, had not been screened within the last three years, and had not had a hysterectomy.

**5.3.2 Screening frequency**

Women were asked if they had a smear taken regularly, and at what interval. Of 338 women who indicated that they had regular smears, 10 reported time intervals between 3 and 5 years. Of the 328 women who indicated that they had a smear taken at least once every three years, 170 (51.9%) reported annual smears, with a further 109 (33.2%) indicating two-yearly smears (Table 5.3). Overall, 85% of women presenting for routine screening had smears more frequently than the recommended three yearly intervals. More frequent screening was more likely among younger age groups, with 93.5% of women between 20 and 34 having smears.

**Table 5.2 Women in selected age groups, without hysterectomy, screened within the last three years**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>N (1) (485)</th>
<th>Screened within the last three years (2)</th>
<th>Not screened within the last three years (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>34</td>
<td>28 (82.4)</td>
<td>6 (17.6)</td>
</tr>
<tr>
<td>25-34</td>
<td>131</td>
<td>117 (89.3)</td>
<td>14 (10.7)</td>
</tr>
<tr>
<td>35-44</td>
<td>143</td>
<td>122 (85.3)</td>
<td>21 (14.7)</td>
</tr>
<tr>
<td>45-54</td>
<td>82</td>
<td>62 (75.6)</td>
<td>20 (24.4)</td>
</tr>
<tr>
<td>55-64</td>
<td>61</td>
<td>21 (34.4)</td>
<td>40 (65.6)</td>
</tr>
<tr>
<td>65-69</td>
<td>34</td>
<td>13 (38.2)</td>
<td>21 (61.8)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>485</td>
<td>363 (74.8)</td>
<td>122 (25.2)</td>
</tr>
</tbody>
</table>

(1) Excludes women reporting hysterectomy

(2) Women without hysterectomy and screened within the last three years

(3) Women without hysterectomy and never screened, screened more than three years ago or unable to recall when last screened
more often than three-yearly. Among routinely screened women 35 years of age and over this frequent screening declined to 78.9%. Annual screening was also more frequent among the young (67.3% of 20-34 year olds), but still quite high (40.5%) among women 35 and over.

Table 5.3 Frequency of smears for women with an up-to-date screening history* and reporting regular screening (N = 328)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>N</th>
<th>Every Year</th>
<th>Two Yearly</th>
<th>Three Yearly</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>20-24</td>
<td>26</td>
<td>24 (92.3)</td>
<td>2 (7.7)</td>
<td>-</td>
</tr>
<tr>
<td>25-34</td>
<td>112</td>
<td>69 (61.6)</td>
<td>34 (30.4)</td>
<td>9 (8.0)</td>
</tr>
<tr>
<td>35-44</td>
<td>103</td>
<td>39 (37.9)</td>
<td>44 (42.7)</td>
<td>20 (19.4)</td>
</tr>
<tr>
<td>45-54</td>
<td>60</td>
<td>26 (43.3)</td>
<td>21 (35.0)</td>
<td>13 (21.7)</td>
</tr>
<tr>
<td>55-64</td>
<td>18</td>
<td>7 (38.9)</td>
<td>5 (27.8)</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>65-69</td>
<td>9</td>
<td>5 (55.5)</td>
<td>3 (33.3)</td>
<td>1 (11.1)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>328</td>
<td>170 (51.8)</td>
<td>109 (33.2)</td>
<td>49 (15.0)</td>
</tr>
</tbody>
</table>

* Without hysterectomy and screened within last three years

5.3.3 Knowledge about screening

There are a number of possible influences on the decision to maintain an adequate screening history, including the level of women's knowledge of the need for regular screening. Women were read a series of statements and asked whether these were definitely or probably true, definitely or probably untrue, or whether they were uncertain or did not know. Responses are summarised in Table 5.4.

Overall women tended to identify correctly the circumstances in which cervical smears are recommended. Most uncertainty was reported on the question of hysterectomy.

With respect to frequency of smears, women were uncertain about the recommended time between smears and indicated that they were quite often receiving conflicting information saying for example:

- There's a lot of different information. One person says one thing, another tells you something else.

The questions on this topic were structured not to force a choice between time intervals within any one question, and a high level of uncertainty was evident. In
response to the statement: `women who need cervical smears should have one about every three years', 43.4% of respondents expressed agreement, with 24% uncertain and 30.5% indicating the statement was untrue. When the same statement was made about a one year time interval, 67.5% agreed that a smear should be taken annually, with 16% uncertain and 16% indicating that the statement was untrue.

Table 5.4 Women's knowledge of circumstances when regular cervical smears are recommended

<table>
<thead>
<tr>
<th>Statement</th>
<th>Identified Correctly</th>
<th>Identified Incorrectly</th>
<th>Uncertain/Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older women, say over 60, do not need a cervical smear (N = 522)</td>
<td>396 (76.0%)</td>
<td>63 (12%)</td>
<td>63 (12%)</td>
</tr>
<tr>
<td>Women who have not had children do not need a cervical smear (N = 520)</td>
<td>482 (92.7%)</td>
<td>21 (4%)</td>
<td>17 (3.3%)</td>
</tr>
<tr>
<td>Any women who has ever had sexual intercourse needs a cervical smear (N = 520)</td>
<td>475 (91.3%)</td>
<td>29 (5.6%)</td>
<td>16 (3.1%)</td>
</tr>
<tr>
<td>Women who have had a hysterectomy do not need a cervical smear* (N = 522)</td>
<td>269 (51.5%)</td>
<td>64 (12.3%)</td>
<td>189 (36.2%)</td>
</tr>
<tr>
<td>Women do not need a cervical smear after menopause/change of life (N = 520)</td>
<td>412 (79.2%)</td>
<td>49 (9.4%)</td>
<td>59 (11.4%)</td>
</tr>
</tbody>
</table>

NB Not all women responded to every statement

It is important to establish whether there is any difference in knowledge between women who had up to date smears and those who did not. The sample of women was divided according to whether they had an up-to-date smear history or not, and their responses to the statements tested for differences, using a Chi square test (Table 5.5). There is a significant relationship between women's smear status and their knowledge with respect to childbearing and the need for a cervical smear (Chi square = 6.4; p < 0.05 with Yates' correction), i.e. women with an adequate screening history identified the correctness of the statement significantly more often than women who did not have an up-to-date screening history. Furthermore a significant difference was found between the two groups in relation to knowledge of the need for cervical screening for any woman who has ever had sexual intercourse (Chi square = 7.12; p < .01 with Yates' correction) and the need for screening of women after menopause (Chi sq=8.44; p < .001 with Yates' correction).
Among women 55 years and older there was no significant difference between those with and without up-to-date smears and their knowledge of the need for cervical screening in women over 60 years old.

**Table 5.5 Difference in knowledge of the need for screening according to women's screening history**

A. Statement: *Women who have not had children do not need a cervical smear* *(N=491)*

<table>
<thead>
<tr>
<th></th>
<th>Adequately Screened</th>
<th>Not Adequately Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correct response</td>
<td>No %</td>
<td>No %</td>
</tr>
<tr>
<td></td>
<td>366 (94.3)</td>
<td>89 (86.4)</td>
</tr>
<tr>
<td>Incorrect/uncertain/ don't know</td>
<td>22 (5.7)</td>
<td>14 (13.6)</td>
</tr>
<tr>
<td></td>
<td>388 (100)</td>
<td>103 (100)</td>
</tr>
</tbody>
</table>

Chi sq (1 df) = 6.4 P < .05 with Yates’ correction

B. Statement: *Any woman who has ever had sexual intercourse should have a cervical smear* *(N=491)*

<table>
<thead>
<tr>
<th></th>
<th>Adequately Screened</th>
<th>Not Adequately Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correct response</td>
<td>No %</td>
<td>No %</td>
</tr>
<tr>
<td></td>
<td>359 (92.8)</td>
<td>87 (83.7)</td>
</tr>
<tr>
<td>Incorrect/uncertain/ don't know</td>
<td>28 (7.2)</td>
<td>17 (16.3)</td>
</tr>
<tr>
<td></td>
<td>387 (100)</td>
<td>104 (100)</td>
</tr>
</tbody>
</table>

Chi sq (1 df) = 7.12 (P < .01) with Yates correction

Table 5 (Contd.)
C. Statement: **Women do not need a cervical smear after menopause/change of life (N = 482)**

<table>
<thead>
<tr>
<th>Adequately Screened</th>
<th>Not Adequately Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correct response</td>
<td>No % 293 (86.9)</td>
</tr>
<tr>
<td>Incorrect/uncertain/ don't know</td>
<td>No % 90 (75)</td>
</tr>
<tr>
<td></td>
<td>Incorrect/uncertain/ don't know</td>
</tr>
<tr>
<td></td>
<td>Adequately Screened</td>
</tr>
<tr>
<td></td>
<td>337 (100)</td>
</tr>
</tbody>
</table>

Chi sq (1 df) + 8.44 (P < .01) with Yates' correction

D. Statement: **Older women, say over 60, do not need a cervical smear test (N = 96); women 55 years and older**

<table>
<thead>
<tr>
<th>Adequately Screened</th>
<th>Not Adequately Screened</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correct response</td>
<td>No % 33 (82.5)</td>
</tr>
<tr>
<td>Incorrect/uncertain/ don't know</td>
<td>No % 40 (71.4)</td>
</tr>
<tr>
<td></td>
<td>Adequately Screened</td>
</tr>
<tr>
<td></td>
<td>40 (100)</td>
</tr>
</tbody>
</table>

Chi sq (1 df) = 1.02 (not significant with Yates' correction)

N = number of women responding to the questions, excluding women who have had a hysterectomy.

Women, therefore, appear to be informed about the need for cervical smears among particular groups of women, but are less informed of the recommended screening interval. Women reported that they gained their information from a variety of sources, particularly their own reading of books, magazines and newspapers (67%), from their doctors (60%), from friends and family (33%) and TV/radio (33%). When invited to comment on sources of information, several women spontaneously mentioned the importance of the Cartwright Inquiry (Cartwright 1988) in stimulating their interest: "it made me read every article I saw...the controversy in Auckland certainly increased my awareness".
5.3.4 Use of services

Despite their high levels of knowledge, some women do not always maintain an up-to-date screening history. All women (including those reporting having a hysterectomy) without an up-to-date smear (102) and those who had never been screened (33) were given a list of reasons women sometimes give for not having a smear, and were asked which applied to them. Their responses are listed in Table 5.6.

Of the 102 women with an outdated smear history, 87 responded to this question. Of these, 33 (38%) gave hysterectomy as the main reason for not having a cervical smear. For 29 women this was the only reason offered. Other reasons given by women for not keeping their screening history up-to-date included: 'didn't think it was necessary' (20.7%), 'too embarrassed or shy' (17.2%), 'not sick' (12.6%), 'the doctor didn't suggest it' (9.2%). Women who had never been screened responded in a similar way (Table 5.6).

Many women made additional comments:

- Basically I only go to the doctor when I'm ill or when I'm pregnant. If I got a memo I would go.
- I just didn't get round to it. I often need prompting.
- I'm too busy and not sick. Have been a bit lax about it
- My doctor was a bit off hand and a bit rushed. He doesn't suggest it, he's got too much to do, and you forget yourself.

Overall, the smear taking was initiated by the doctor or nurse more frequently than by the women. Doctors or nurses initiated smears for 70.5% of the women compared to the 29.5% initiated by women. However only 15% of the women who had had a cervical smear had received a letter or a telephone call reminding them to have a smear test taken.

Women were asked who had taken their last smear and invited to select, from a list of eight possible options, which person they would most like to take their smear in the future (Table 5.7). Of the 412 women who reported receiving smears in a primary health care setting (i.e. not a hospital clinic or specialist's rooms), in nearly 87% of cases a general practitioner had taken the smear, with much smaller numbers using practice nurses (4.1%), Family Planning Association personnel (7.8%) or other services (1.5%). When women indicated their future preferences for a smear taker, general practitioners were slightly less popular (77.5%), as were Family Planning Association personnel (6.5%), with an
Table 5.6 Reasons given by women for not having a cervical smear

<table>
<thead>
<tr>
<th>Reason</th>
<th>Frequency of Response</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Outdated</td>
<td>Never</td>
<td>Total</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Smear</td>
<td>Screened</td>
<td>(N=118)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>History</td>
<td>(N=87)</td>
<td></td>
</tr>
<tr>
<td>Hysterectomy</td>
<td>%*</td>
<td>33 (38)</td>
<td>4 (12.9)</td>
<td>37 (31.3)</td>
</tr>
<tr>
<td>Didn't think it was necessary</td>
<td>18 (20.7)</td>
<td>9 (29)</td>
<td>27 (22.9)</td>
<td></td>
</tr>
<tr>
<td>Too embarrassed/shy</td>
<td>15 (17.2)</td>
<td>5 (16.1)</td>
<td>20 (16.9)</td>
<td></td>
</tr>
<tr>
<td>Not sick</td>
<td>11 (12.6)</td>
<td>6 (19.4)</td>
<td>17 (14.4)</td>
<td></td>
</tr>
<tr>
<td>Doctor didn't suggest it</td>
<td>8 (9.2)</td>
<td>6 (19.4)</td>
<td>14 (11.9)</td>
<td></td>
</tr>
<tr>
<td>Too busy</td>
<td>5 (5.7)</td>
<td>6 (19.4)</td>
<td>11 (9.3)</td>
<td></td>
</tr>
<tr>
<td>Forgot</td>
<td>2 (2.3)</td>
<td>5 (16.1)</td>
<td>7 (5.9)</td>
<td></td>
</tr>
<tr>
<td>Costs too much</td>
<td>4 (4.6)</td>
<td>2 (6.5)</td>
<td>2 (1.7)</td>
<td></td>
</tr>
<tr>
<td>May hurt</td>
<td>4 (4.6)</td>
<td>2 (6.5)</td>
<td>6 (5.1)</td>
<td></td>
</tr>
<tr>
<td>Afraid of the result</td>
<td>4 (4.6)</td>
<td>2 (6.5)</td>
<td>6 (5.1)</td>
<td></td>
</tr>
<tr>
<td>Didn't want a man to do it</td>
<td>2 (2.3)</td>
<td>3 (9.7)</td>
<td>5 (4.2)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>14 (16.1)</td>
<td>11 (35.5)</td>
<td>25 (21.2)</td>
<td></td>
</tr>
</tbody>
</table>

*Percentages represent proportion of women in each group reporting each reason for not having a cervical smear.

increasing proportion of preferences expressed for practice nurses (8%) and 'other' practitioners (8%). This latter group included specially trained Maori and Pacific Island smear takers as well as 'women from a community health clinic...trained to take cervical smears.' Chi square testing of the raw scores indicates a significant difference between the pattern of current use of primary screening service providers and future preferences (Chi sq = 25.9; p < .001).

Among women screened by general practitioners, 80% indicated a general practitioner as their preferred smear taker in future. A further 4.5% would prefer a practice nurse to take the smear and 8.1% indicated another smear taker would be
preferred. More detailed examination of the data indicates that similar percentages of women would return to the same male general practitioner (71%) as would return to the same female practitioner. However, women who expressed a preference for another general practitioner nearly always indicated a preference for a woman practitioner in the future. Women who have never had a smear (N=33) were also asked about their smear taker preferences should they be screened in future. Of these 33 women, 36.5% indicated that they would go to their own general practitioner, a further 27.5% would go to another general practitioner who is a woman, and 15% would prefer a trained woman smear taker at a community health clinic. For nearly two thirds of women who had never had a smear (60.5%), having a woman smear taker was important if they were to have a cervical smear in the future.

When women were asked why they preferred the person they chose to take their smear there were a range of comments.

(see insert pages)

Table 5.7 Women's use of and preference for screening service providers in primary health care settings

<table>
<thead>
<tr>
<th>Person taking most recent smear (N=412)</th>
<th>Own or another GP</th>
<th>Practice Nurse</th>
<th>FPA Staff</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>G.P.</td>
<td>357 (86.7)</td>
<td>286</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>Practice Nurse</td>
<td>17 (4.1)</td>
<td>5</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>Family Plan. Assoc Staff</td>
<td>32 (7.8)</td>
<td>6</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>6 (1.5)</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Overall preference for future smear taker</td>
<td>31(8%)</td>
<td>301(77.5%)</td>
<td>31(8%)</td>
<td>25(6.5%)</td>
</tr>
</tbody>
</table>

Twenty four people (5.8%) did not respond to this question, 20 of whom had had their previous smear with a general practitioner, 2 with a practice nurse and 2 with a person at Family Planning Association.
**Cost**

The women were asked if cost of going to the doctor had ever put them off having a cervical smear test. For 5 (16%) of those women who had never had a smear cost had been a significant issue. It is also important to note, that of the 33 women who had never had a smear, 14 (43%) had a household income of less than $20,000.00.

While the majority of women (79%) responded "No" to the question: *Has the cost of going to the doctor ever put you off having a cervical smear?*, most women made additional comments which indicate that cost is an important factor in the present circumstances.

(See insert pages)

**5.3.5 The Cytology Register**

An important feature of the National Cervical Screening Programme is the establishment of a series of regional registers, set up and maintained within individual area health boards. The majority of women interviewed (358, 68.5%) had never heard of the register. Of the 139 (26.5%) who had, a considerable proportion were uncertain about it, or did not know its purpose. Only 22 of these women (16%) knew that enrolment is voluntary, 53 (39%) thought women would be enrolled automatically. Thirty of the women interviewed (5.5%) said that they were already enrolled on the register. When the register was explained briefly to respondents who were not already enrolled, 39.5% said they would be willing to enrol and a further 23.5% indicated a willingness to do so, but said that they would need more information. They commented:

- *It's a good idea. Getting information is very important.*
- *It should be compulsory.*
- *I like the idea of an organised register.*
- *I already look after this for myself but if it would benefit other women I would.*

Several women referred specifically to the benefit of getting a reminder letter from the register.

- *I've never had a letter to remind me. I would like that.*
- *It would be good to get a letter to remind me.*

Most of those who said they did not wish to be enrolled on the registered said that they felt that there was no need for this as they were too old. Others said that they were happy with the service provided by their own GP.

A few women said they would like to be enrolled, but only if their doctor approved.


**Choice of Smear Taker**

Women who said they preferred their own GP most often stated that this was because they knew the doctor or because their doctor knew their history. Other comments included:

- *I go there for everything else.*
- *He's our family doctor.*
- *I've known him for years. He's a kind and gentle person.*
- *He's been there to deliver my kids. He's seen it all before.*
- *I like him. He knows me and he makes me feel comfortable and relaxed. He reminds me of the time to have a smear.*
- *The less people that look at my body the better.*

Many made comments which included references to trust, and confidence:

- *He knows all my other history. It gets very bitsy otherwise. You put your trust in him. That's very important.*
- *I know her. You need to have confidence in the person. It's important to know the person.*
- *Trust is all important.*

Many women preferred another woman to be their smear taker, either a woman general practitioner, a practice nurse, Family Planning Clinic or a trained woman in the community. There were also indications that women were making changes in order to receive the quality of service they required.

Female general practitioner:

- *She does a really good job and I feel at ease with her. I changed from a male GP about a year ago.*
- *My old GP never asked me if I wanted a smear so I changed to a woman GP.*
- *I like to have continuation of care. I have changed doctors after a traumatic time.*
Trained woman from Community:

- Women at THAW are concerned for women as a whole rather than as a medical problem. They empathise with women.

Family Planning Clinic:

- She gives a good explanation and is really thorough. It's cheaper than the GP too.
- They are very skilled and gentle. They consider your feelings and need for privacy and modesty.

Practice nurse:

- She talks to me about it and makes me feel really relaxed. She seems to know what it's like and how I feel. She is trained specifically. She seems confident and knows what she is doing.
- I got used to being examined when I was having children but now I want a woman to do it.

Nearly two thirds of the 33 women who had never had a cervical smear expressed a future preference for a woman smear taker.

Many women said they wanted their smear taker to be properly trained and skilled at taking smears.

General practitioner:

- He's the natural person to do it. It's what doctors do and I feel confident. As long as it's a doctor who is properly trained.

Family Planning Clinic:

- I know they do it properly and have the most current technique and knowledge. It's their area of expertise. Being women they have more awareness.

Practice nurse:

- As long as the person has the skill and the expertise. I would prefer a female and the practice nurse has all these qualities.

Not surprisingly, women's comments about satisfaction with the way the test was done range from positive to negative. Most comments however referred to the process of communication rather than the technical procedure.
Cost

A small number of women said cost wasn't an issue because they had medical insurance or student health cover.

- *My medical insurance is paid by my work otherwise it would be a problem.*
- *Not a problem. I've got medical insurance*

A few women said cost was a concern, however having a smear taken was important.

- *I have second thoughts, but it never stops me.*
- *My health comes first.*
- *I think carefully about it.*
- *I would worry too much if I didn't go.*
- *It wouldn't stop me but it certainly is a consideration.*
- *I feel it is a necessity*
- *It could be soon but my health comes first.*
- *I have to have it done. $30.00 a month goes towards having smears*
- *It makes me organise my finances. It's too important to put off. Medical Insurance has played a big role.*

The majority of women said they don't go to the doctor just for a smear.

- *I wouldn't go only for a smear now. I take a `shopping list with me.*
- *The costs are exorbitant. I take a list.*
- *I wait until I have to go for something else*
- *Not just for that. It's too expensive.*
- *Not yet. I take a list and combine it with other things.*
- *I think twice and wait until there are other things.*
Some said yes, cost had put them off.

- It should be a reasonable price. You can't expect people to pay for that if they haven't got enough food - and there's plenty of people like that just now.

- It cost me $32.00 last time. I've got to be dying now before I go to the doctor.

- I only go if I'm really ill. I wait until I have to go with something else so I can kill two birds with one stone.

- I would need to be very ill to go to the doctor now.

- Cost is a problem. I sometimes have to get them to send a bill

Other women mentioned that they saved up or put it off until they could afford it.

- I have to think about it and I save up to go to the doctor.

- I've put it off till another month. But it has never really stopped me.

- It will be a problem in the future. I tend to save up.

Several women commented on other options open to them.

- It was a problem until I discovered the practice nurse does it for a lesser cost.

- It cost me $33.00 at the local GP and $12.00 at the Women's Wellness Centre.

- I'm checking out for cheaper places.

Two women talked in detail about their experience:

- I'm on a widows benefit and I had to make a special appointment. He wouldn't do it when I was there. It cost me $28.00 just for that. It's not on.

- I got charged for a repeat smear when the first one was faulty. His procedure had been incorrect. I won't be going back there again.

Other women mentioned the good will of their doctor:

- Yes it is a problem but our GP is good to us and only charges low fees.

- It never costs me. Even if it did it wouldn't put me off.
5.4 Discussion

Based on the weighted sample it is estimated that 74% of Canterbury women aged 20-69 years who need cervical smears have an up-to-date screening history (i.e. have been screened within the last three years). This is slightly lower than the national screening rate reported by Bonita and Paul (1991).

Younger women in the Canterbury sample, as for New Zealand as a whole and elsewhere (Bonita and Paul 1991; Mitchell 1991) have a higher rate of screening than older women. Younger women in Canterbury are also screened more frequently, reflecting the hitherto usual practice of annual screening. Overall, women sampled were found to be uncertain about the recommended screening interval, and frequency of screening might be expected to decline once the impact of most recent guidelines recommending three-yearly routine smear-taking (Skegg et al 1985) become established in medical training and practice and part of women's expectations.

This research has indicated that women are well informed of the need for cervical screening. They are able to identify correctly the circumstances in which screening is necessary, such as for women who have experienced sexual intercourse whether or not they have had children, and for post-menopausal women. There was some uncertainty concerning the need for a smear post-hysterectomy, reflecting the range of clinical circumstances in which hysterectomy may occur. Research in the mid- and late 1980's (Brebner et al 1985; Chang 1987; Grace 1985) indicated a much lower level of knowledge of screening among women than was found in this Canterbury sample. This can be attributed partly to the debate surrounding the Cartwright Inquiry (Cartwright 1988) which enhanced awareness of the issues, but perhaps more specifically to more recent publicity surrounding the setting up of the National Cervical Screening Programme. This research preceded the formal publicity launching the national education and recruitment campaign (October 1991), but the considerable media attention given to cervical screening and the funding of pilot projects and national and regional initiatives increased awareness among women of screening and related issues.

Levels of knowledge are not uniformly distributed among women. In the Canterbury sample there were significant differences in knowledge of the circumstances in which screening is required between women who have an up-to-date screening history and those who do not. While knowledge alone is not sufficient to ensure a current screening history, there is an important association between the two.

So why are some women not being screened? Canterbury women sampled gave a variety of reasons, the most frequent being that they did not think it was necessary, they felt embarrassed or shy, were not sick, or their doctor did not suggest it. These findings are consistent with other New Zealand and international research, as reviewed by Adams (1991), which suggests that a combination of both practical and attitudinal barriers come into play. When seeking critical factors which actively encourage participation (rather than merely removing barriers), the role of the doctor and other health workers is important. There is good evidence from New Zealand (Grace 1985; Ballie and Petrie 1990) and elsewhere (Pierce et al 1989; Wilson and Leeming 1987) that a personal invitation to women to have a cervical smear is the most effective mechanism to increase participation, even among groups with traditionally low screening rates (Cockburn et al 1990; Macavoy and Raza 1991). This is significant in view of the finding from this research that most women express a preference for smear taking within traditional primary health care settings, i.e. the smear being taken by their own or another general practitioner or a practice nurse. This will be particularly important for the 'never screened' group of women who expressed a clear preference for women smear-takers and who may
find fewer barriers to screening as more women enter general practice and more practice nurses become involved in taking smears.

Women also indicated in their comments that cost of going to the doctor is one of the important factors limiting their opportunity to have a smear taken. There is an increasing tendency, especially for those women in the priority groups, to consult a general practitioner only when there are several items to discuss. Women referred to this as taking a 'shopping list' (general practitioners also commented on this tendency. See Chapter 6). Frequently the reason for an appointment to be made is a child needing urgent attention. In these circumstances having a cervical smear taken is not a priority for the woman nor the doctor.

This research has direct relevance to future strategies for the Canterbury Cervical Screening Programme. It confirms the importance of educating women in the community about the circumstances in which a cervical smear is necessary and of supporting screening within general practice, including the encouragement of practice nurses as smear takers. Some of the reasons why women say that they do not have smears can be addressed through these strategies and through additional training for health professionals.

There is, also, a small group of women for whom alternative services are appealing. Such services will be particularly important for recruiting women who have never previously had a cervical smear. This group is also less likely to have good knowledge of the need for screening and priority will need to be given to reaching these women and ensuring that a responsive service is available to them. The Canterbury Cervical Screening Programme is already providing resources, for example, for Maori women to train as smear takers and for specific community initiatives among Pacific Island women. While the numerically small sample in this study precluded investigation of the perspectives of these groups of women, it is also likely that a survey of this type may not necessarily the best way for their needs to be established and views sought. It is probable that more specific qualitative research, integrated into existing community networks and closely linked to decision-making, can provide more relevant information. Studies of this type are now taking place (see Chapter 7).

While it will never be possible to achieve complete screening coverage there are indications from this research that there are specific strategies which will encourage women to be screened. These include the continuation and more systematic application of current approaches which emphasise community education, existing screening services and a wider range of smear takers. In addition, it will be necessary to widen the range of research approaches and responses in order to acquire and act on the detailed information necessary to meet the needs of special groups of women in the community. With an appropriate balance between alternative approaches to both research and resource allocation, in time it should be possible to increase the numbers of women receiving regular screening.
6 GENERAL PRACTITIONERS' PERSPECTIVES

6.1 Introduction

Viewed from a central policy perspective, the Cervical Screening Programme is a rational tool for identifying women 'at risk', encouraging smear taking among groups currently underscreened, improving the quality and standardising the frequency of smears. The central policy was to be implemented through regional programmes. To secure the policy objectives the appointment of regional cervical screening managers was accompanied by the provision of performance targets related to enrolment of women on the register.

The means by which women can be enrolled is through their smear taker, acting as an agent of the Register. As the majority of smears in Canterbury are taken in general practice (87% on women use their general practitioner and 4% the practice nurse), and for most women (73%) their general practitioner is their preferred smear taker (Norton et al 1992), then the role of general practitioners is crucial to the success of the Register.

It is the purpose of this chapter to examine the relationship between the Cervical Screening Programme in Canterbury and its main 'opt-on' agents - the general practitioners.

6.2 The national and regional context

Since her appointment in July 1990, the Canterbury Manager has personally visited many practices within the region to inform general practitioners of the Programme's policy and practice and discuss issues of concern.

Recognising the service provided by general practitioners, the Canterbury Cervical Screening Programme chose not to develop smear taking services within the regional programme, as has happened in all other Area Health Boards. The Canterbury programme has, to date, granted funds for a nurse from each of 15 general practices to be trained as smear takers through the Family Planning Association at a cost of $497.00 each ($7,455.00). Currently the Programme is piloting a $15.00 subsidy per cervical smear in one general practice in the Canterbury Area Health Board area, extending practice nurse hours to promote cervical smear testing and enrolment on the cytology register. There is provision for four such pilot projects.

At the time the Regional Manager was attempting to build relationships with general practitioners, other factors intervened which undermined these efforts. For example, nationally the then Minister of Health attempted to introduce contracts for general practitioners. The New Zealand Medical Association National Assembly strongly recommended to all general practitioners that no legal contract with health authorities be entered into that had not been negotiated with and approved by the General Practitioners Association (NZMJ 103/895 August 1990).

When the Canterbury Area Health Board indicated that it would begin providing service similar to the After Hours Surgery, there was a reaction from some general practitioners involved in the After Hours Surgery against the Area Health Board, which resulted in some general practitioners withdrawing from active involvement in enrolling women onto the Cytology Register.
Events such as these made building relationships between the Programme and general practice difficult.

6.3 Objectives of the study

The objectives of this project with general practitioners were:

1. To ascertain the cervical screening and recall procedures and information systems in Canterbury general practices.

2. To determine from general practitioners their views on the Cervical Screening Programme and the National Cytology Register.

3. To highlight the interrelationships between individuals and groups involved in cervical screening in Canterbury.

6.4 Methods

Two methods were used: a telephone survey of all general practices in north and mid-Canterbury and indepth interviews with a sample of general practitioners.

Telephone survey

A short telephone survey was conducted involving all general practices in mid and north Canterbury, as far south as Ashburton.

At the time of the study there were 129 practices involving 296 general practitioners. One hundred and eight practices (84% of all practices) involving 279 (94%) general practitioners participated. Another 6 (4.5%) practices involving 8 (3%) general practitioners declined to participate, while 15 (11.5%) practices involving 24 (8%) general practitioners were unable to be contacted after at least four telephone calls at various times.

Of the six practices which declined to participate four were solo practices and two were dual partnerships. All were located within metropolitan Christchurch. Nine of the fifteen practices which were unable to be contacted were solo practices with three being located in each of the metropolitan, urban and rural areas. Four practices involved two general practitioners and two involved 3-4 general practitioners, all of whom were located within metropolitan Christchurch. Generally the practice nurse or the receptionist answered the questions, however on eight occasions a general practitioner was the respondent.

The questionnaire sought the following information: size of practice, gender of practitioners, whether the practice was computerised, whether the computer was being used to recall for cervical screening, and whether the general practitioner(s) were enrolling women on the cervical screening register.

Indepth interviews

Indepth interviews provided a selection of general practitioners with an opportunity to review their experiences and comment on all aspects of cervical screening services. The indepth interview method was selected because the views of practitioners on such complex issues could not be ascertained through brief interviews or mail questionnaires.
Thirty four general practitioners were selected though a process of purposeful sampling (Paton 1980:100) or non probability judgement sampling (Burgess 1984:55), to include a cross section of general practitioners covering a wide range of practices ie. metropolitan, urban and rural practices; group, dual and solo practices; male and female practitioners and a range of practitioner ages. Five of the practitioners were selected for more specific reasons eg. membership of Canterbury Cervical Screening Programme committees, development of computer programmes for recall, support for Maori lay smear taking training.

General practitioners were invited by letter to participate in an interview, then were contacted by telephone to confirm and arrange a time to talk. Thirty four interviews were completed. Twenty four practices were involved in the study. Seventeen interviews were with individual general practitioners and on six occasions a practice nurse also participated. On two occasions the interviews included a group of three and four doctors from the practice and on five occasions two general practitioners from a practice were interviewed. Fourteen of the doctors interviewed were women and twenty were men.

Five general practitioners declined to participate. All five were male. Three of these practitioners were in solo practice and two were in dual partnerships.

The indepth interviews involved an open ended discussion about cervical screening and the Cervical Screening Programme. The format and content of each interview varied, with each interview providing a basis for subsequent interviews. All interviews except one involved both researchers. Two doctors asked that the interview not be tape recorded.

**Characteristics of participants**

The participants in the indepth interviews were similar to those participating in the telephone survey in terms of location of practice, ie metropolitan, urban or rural, and in terms of size of practice, ie whether they were in solo practice, in a dual partnership or in a practice involving 3-4 practitioners or 5-8 practitioners. Slightly more female general practitioners participated in the indepth interviews than the proportion involved in the telephone survey (41% compared to 32.5%).

### 6.5 Results

#### 6.5.1 Computerisation and recall in general practice

**Practice computerisation**

Of the 108 practices which participated in the telephone survey 56 (52%) were computerised and 41 (38%) were not. Another 11 (10%) practices said they were intending to computerise within the next year, 3 practices already had the equipment ordered. When computerisation was related to the actual number of general practitioners (as opposed to the number of practices) 174 (62.5%) were working in computerised practices while 105 (37.5%) were not. Twenty four doctors (8.5%) had an intention to computerise.

In the indepth interviews with 34 general practitioners 25 (73.5%) worked in practices with computers systems. All these practices used the computer for screening recall, particularly cervical screening recall. These doctors also said that
having the ability to recall for cervical screening had been important in initiating the decision to install a computer system.

- *The screening side of it, the recall, certainly swayed the decision to get a computer.*

Generally, a practice management and accounting programme and a recall programme were the first computer programmes installed on the practice computer systems.

**Recall for cervical screening**

Recalling women for regular smears is an important aspect of cervical screening. Respondents in the telephone survey were asked whether the practice was recalling women and whether this was a computerised or manual process.

Forty nine (46%) practices were using the computer to generate a recall list of women while 56 (52.5%) were using a manual system. Two practices had no recall procedure. Overall 153 (55%) doctors were working in practices with a computerised recall system while 122 (44%) were not. One respondent made no comment about this.

There have been two other studies reporting proportion of general practitioners using a computer recall systems for cervical screening in Canterbury. In June 1989 results of a study involving 244 general practitioners in 119 practices show that 61.5% regularly recalled women for cervical smears and that 31.5% used a computerised age-sex register to facilitate this (Holmes 1989). Harper, Botting and Robinson (1991) reported a 1991 study on recall for cancer screening. Of the 210 responses (79% response rate), 97% of general practitioners were offering cervical screening recall and 47% used a computerised age-sex register. Table 6.1 sets out the findings from all three recent studies, indicating that in the last 3 years there has been a steady increase in the use of computer systems for recalling women for cervical smears.

**Table 6.1 Percentage of general practitioners using a computerised age-sex register for recalling women for cervical smears (1989-1992)**

<table>
<thead>
<tr>
<th></th>
<th>1989 n = 244</th>
<th>1991 = 210</th>
<th>1992 = 279</th>
</tr>
</thead>
<tbody>
<tr>
<td>recall</td>
<td>31.5</td>
<td>47</td>
<td>55</td>
</tr>
</tbody>
</table>

The indepth interviews with thirty four general practitioners indicate that most of them have a recall system of some kind for cervical screening. Most practitioners (25 or 73.5%) had a computer system installed and were using this for recalling women for a cervical smear. In most cases we were shown the detail of their recall system and the computer print outs. Having a computer had made a big difference:

- *It makes it possible to virtually instantly call up any group of patients we want to.*
I know now that is not a haphazard sort of a recall system. Before it was like a black cloud because I didn't quite know how big it was. I know now people are being recalled. I know that if someone is overdue for a smear I know I've contacted them and they have been recalled and it didn't get forgotten because I was too busy last week or anything. I know it has been followed through.

Seven doctors who did not have a computerised system continued to use a manual recall process. Only two doctors said they offered women cervical smears only on an opportunistic basis. (See Table 6.2). As most of the general practitioners had their own recall systems their reliance on a national register for recall was limited. Many felt that the national register was a duplication of services and money that could be more effectively spent elsewhere. In relation to this many general practitioners made reference to breast cancer.

Some doctors have had detailed manual recall systems in place for up to 15 years, and many for at least five years. Practice nurses had a central role in most practices in the administration of cervical screening recall whether practices were participating in the screening programme or whether they were running their own recall systems.

Oh yes, absolutely. The practice nurse is quite crucial.

One of the nurses manages the recall. It's quite a big job.

A quarter of doctors installed computerised systems between five and seven years ago, though most of them have computerised during the last two years.

### Table 6.2 General practice recall systems

<table>
<thead>
<tr>
<th>Type</th>
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<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>computer recall</td>
<td>25</td>
<td>73.5</td>
</tr>
<tr>
<td>manual recall</td>
<td>7</td>
<td>20.5</td>
</tr>
<tr>
<td>opportunistic only</td>
<td>2</td>
<td>6.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>34</td>
<td>100.00</td>
</tr>
</tbody>
</table>

#### 6.5.2 Enrolment of women on the National Cytology Register

Respondents to the telephone survey were asked whether women attending the practice were being enroled on the National Cytology Register. Overall the results show that 72% of practices involving 76.5% of all general practitioners are enroling women on the register while 27.5% practices (23.5% of general practitioners) are not.

While these results are similar to the numbers of general practitioners listed as enroling women each month on the Cytology Register, this is not consistent with the numbers of women actually being enroled. In other words there is a discrepancy between the number of general practitioners enroling women, the number of smears being processed by the laboratory and the number of women being enroled on the cytology register.

Information from the inddepth interviews provided an understanding of this discrepancy. Of the thirty four doctors interviewed only five were consistently and
actively enrolling women on the National Cytology Register. Fourteen said they were enrolling women but that this practice was not consistent. When asked in more detail about this the proportion of women being enroled ranged between less than 5% of women having smears, up to perhaps 50%. Another fifteen either enroled women initially and have now stopped or have never participated in the programme (See Table 6.3).

### Table 6.3 General practitioner enrolment on the Cytology Register

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>enrolling</td>
<td>5</td>
<td>15.0</td>
</tr>
<tr>
<td>inconsistently</td>
<td>14</td>
<td>41.0</td>
</tr>
<tr>
<td>not enrolling</td>
<td>15</td>
<td>44.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>34</td>
<td>100.0</td>
</tr>
</tbody>
</table>

See insert pages for comments

Practice nurses had a strong influence on whether the practice participated in the programme and enroled women on the National Cytology Register. In some practices the nurses promoted the programme, in others they opposed it.

- I said to the nurses, well what do you want to do about it, and they said, well, we have too much to do filling out forms as it is, we are just setting up our own screening thing, we can't be bothered. I didn't feel strongly about it one way or the other, I just thought that it was quite important that we have a screening programme in place, but I thought that we were about to start doing our own recalls and all the rest of it, that it probably wasn't vital. So I went along with what they said and that's where it has got to.

- It was going to put a lot more work for my nurses. I would rather they were doing other things. Interestingly they are absolutely dead against it. Quite independently our nurses have been critical for much the same reason as me. 'Who needs Big Brother?' has really been their attitude.

### Enrolment Forms

The paper work in general practice appears to be increasing with the changes to ACC and the introduction of the Community Services Card.

All the doctors interviewed commented on the forms and the extra paper work involved and cited this as one of the reasons they were not enrolling women on the Cytology Register. Forms are an immediate and visible symbol of the Register, and protesting about the forms is a visible form of resistance by practitioners to perceived inappropriateness and lack of flexibility.

### Enrolment of Women on the National Cytology Register

Those doctors who are enroling women commented:
At the moment the only advantage to us so far has been it gives us a feedback of how women have enrolled. It tells me my efficiency and it means that it's a back-up. There was one situation where it was of great help when it demonstrated that having a back-up system was good. That was when they rang us from the register and said, what are you doing about these two women, they are due for recall smears and you haven't done them. I looked up their files and we hadn't got a result. The lab hadn't sent us a result .... There weren't terrible things but of course they could always be and that's probably a good indication of the use of the register. It is really a back-up to a doctor's own register. I think that's the real problem. Doctors have registers but they have got to be convinced that the register can be helpful.

It is very easy, you say, do you want to put your name on the national cervical register, all you have to do is sign the form.

It actually takes a little while to enrol people. I am actually in favour of the reasonably new idea that is being wafted around about pre-enrolment. It means that people are coming in and they are already enrolled, and all you have to do is the clinical and medical stuff and that is a reasonable amount to get through anyway.

For those doctors who are enrolling inconsistently the detailed discussion reveals that generally this process tends towards them of enrolling fewer and fewer women. Many were ambivalent about the benefits of the programme. Time was also an important factor.

I think I was probably doing at least every second smear, if not more in fact to begin with but I have had a couple of weeks off in November and then I had 3 weeks between then and Christmas and I've probably got out of the pattern of things. I have been enrolling people to some degree and the main thing that stops me enrolling people is if I'm getting behind and it's an extra form to fill in. I mean, because I am quite keen about it in principle although it doesn't make any difference to the patients here because we already have a recall system and so it's not going to make any difference to them but most people in fact are happy to be involved. It's just signing the form and they understand it's just to collect information.

I have to say I have flurries of enthusiasm.

Only if they ask for it. I am not actively not putting people on. I am doing 8 or 9 in a full day. I mean I don't get time to go chasing up a form every time.

We've offered to our patients in a very random the way the opportunity of going off our recall system and going onto the national recall system. .... 5% or less [have gone onto the national register].

I am trying to enrol as many as I can but if time runs out I forget about it so if it gets late at night, and I am tired, the chances of them being on the register is less likely or if they are in the 60 plus age group, I might be less likely because I know them well and I figure that I'm going to keep pretty close control on them. .... My feeling is I tried harder initially and I'm
getting less and less enthusiastic about it. I try not to, I think that defeats
the purpose of it.

Those not enrolling women at all commented:

- Well I guess the first point is that I have not signed any women up on the
National Scheme, and I can't see any good reason to do so, and the reason
why I say this is, that although I think it's very important that women who
have cervical smears are recalled, and that women are encouraged to have
cervical smears, I think the system that I have is a superior one.

- Three years is not an appropriate thing. We didn't feel it was appropriate
because that wasn't what we were using our smear programme for. We
were using it as more of a complete check. It seems to me a crazy thing to
come and pay $36.00 for a smear or whatever. .... I guess there is some
resentment that our programme wasn't recognised, the effort we had been
putting in for 15 years wasn't acknowledged. I guess we all felt a bit tarred
with whatever brush they were tarring or whoever they were going for. I
guess we felt that some of it was anti-doctor driven.

- It's really cumbersome. I don't know what the national programme is going
to do. I would rather keep my own thing, I would rather stick to this
programme because I know what I'm doing. I know I am in control. I
know when people are coming here. I can read it straight away. If it's a
national programme, I don't know anything.

- I was encouraging them to enrol until we had a problem about three weeks
ago where a lady had two smears done, one with the brush and one with the
spatula and she enroled and the two copies were sent off and one of them
came back with no endocervical cells and the other came back with normal,
okay the brush was normal with endocervical cells so it was a normal smear
so her doctor who works here interpreted it as normal and she rang up and
was given that information by him and then she received a letter from the
register saying that she was to repeat her smear in three months and was
most upset. For a start had her doctor lied to her, had he got it wrong, had
he looked at it wrong, so immediately the trust that he's had with her for
years is out the window and naturally that makes us very wary because the
computer stuffed up. The computer can't analyse two results like we did.
Until that kind of thing gets sorted out, I am very wary now of enroling
people. I let them know it's there but I tell them my misgivings about it.
Forms

Several referred to their receiving a wad of forms in the mail.

- It's yet more paper work. Paper work in general practices is increasing; every week some person thinks up some new forms to fill out, and my initiation to this was simply that a large wad of forms arrived in the mail for me, and it doesn't actually make you feel overly inclined to get involved in the project, if you see yet another mountain of paper that you are supposed to do something with.

Others commented on effects of the accumulation of time taken to fill in forms.

- The main one is just having to fill out an extra form because it takes time and we're in a tight time schedule, you know. Each piece is just one piece of paper but if you are seeing somebody and you have got to fill in one form of their swabs and one form for that and then, you know, you have got another referral to do and it mounts up and that ends up making you get well behind. You can say that doing the form here is no big deal but it is in fact and it is the fact that stops more people being enrolled here.

- I mean, it doesn't sound like much time, 2 minutes, but if you multiply it by 12,000 patients in the practice, then it's hundreds and thousands of dollars per year. Who do you think should pay for this? Do you think we should pay for it?

One doctor commented that at the end of the day he often had another 2 hours of paper work to deal with:

- I am going to write down one day all the paper work that I have to fill in. You would be stunned, you know. People would be stunned. To fill in the forms relating to the new health charges, there is a 39 page booklet you have to look up to find out what you are supposed to be doing.

- It really irritates me to death to have to fill out two forms and if I am doing swabs with them then I can't be bothered enrolling them and I am sure most other general practitioners would say the same. It's just too much damned paper work. There is quite enough of it without running up unnecessary paper work. Unnecessary I mean, given that we recall our patients. You know, most of us have been deluged with extra paper work for ACC and God knows what else and community service cards and numbers, expiry dates. The last thing I want to do is start doing anything that is going to give me more work and it does give you more work. Definitely.

Even those who are committed to the programme and who are enrolling most women on the programme found difficulty with the paper work. These people also commented on the complexity of the forms dealing with abnormal smears and change of status:

- I am actually more pro than other people. But it's all this paper work. I mean everyone is complaining about the form, and even me and I am very very pro.
One of these doctors had specifically tried to find out about the forms:

- I found it very frustrating having to try and get the information. One of the reasons why these are confusing because they are so similar.

Another was concerned about the information being collected on the form. This person felt that some very important data was missed:

- My concern about it, too, is that we had forms that have been formulated somewhere and to me, we actually missed the main boat on that form completely. We have got a lot of data that we already know but the data that we don’t know, is things like the smoking, the age of first intercourse with history of sexual diseases - that’s not put on that and my understanding of that is that in fact that has a tremendous bearing or may have a tremendous bearing on the persons that are more likely to be at risk from cervical cancer and if that’s what our aim is to try and educate, then we need to actually have facts behind us so that we can educate and the whole aim of this programme, as I understood it, was not just to increase the rate of smear taking but was to educate.
Dr Judith Straton reported similar experience in her review of The National Cervical Screening Programme in July 1990:

- It is quite likely that the complexity of the form is a deterrent to general practitioners in inviting women to be on the register. (Straton 1990:7)

See insert pages for comments

**Screening frequency and age recommendations**

While many of the general practitioners had adopted the three yearly recall of women with a normal smear result, most of them felt that the programme could not be as flexible as they needed. Many also felt that the three year time gap was too long.

- We would prefer a more flexible recall and I would be happier with two rather than a three year recall. It's just going to take me while to get used to.

- The criteria has changed as the Cervical Screening Programme has promoted three years and I have followed, I can't talk for the others but I think they all have followed the suggestions. There are some misgivings about three years. I think three years sounds wonderful when you are a statistician and you are looking at figures but if it happens to be one of your patients, three years is a long time.

- Well it used to be two yearly up to 35 and then five yearly after that. We've changed to fit in with the recommendations so I am now doing people three yearly up to 65.

The introduction of the recommendations has meant that general practitioners have to re-educate women. This also takes time.

- We used to do two to three about a year apart, then we'd do it two yearly so we've had to re-educate women. The women say, "oh but isn't that too long?" So, we have had to re-talk to them about that.

- There is a huge sort of changeover going on. The advice has been given from the committee that it should be every three years and annually for the first two so we are now lining up as people come through. But we have to de-programme all these people who are convinced that they have to have it every year.

While they were aware of the costs involved the doctors were concerned for their patients.

- I am very conscious and I have heard Skeggs talk about epidemiology of smears. .... I say to women sometimes, if we smear you every year from 15 to 40, that's 45 smears. Whereas if we do it every three years, it is 15. I mean, that is a lot of difference in terms of cost. I am aware of that which is why I have changed but I am not willing, just on an economic basis, to change all of it.
Several however were not convinced that three yearly was safe.

- It's two years. It has always been 2 years.
- The standard thing is every two years.
- I am not convinced that the three years that has been recommended is in fact correct. If I was a woman myself I would want more than three yearly smears, though I have seen Health Department figures suggesting there is only a 2% reduction in mortality by increasing the period. I'm sure the figures are correct but that is a community base view. I have a personal view for my patients.
- I think the problems with most general practitioners is that we see the exceptions rather than the statistics and maybe we are biased because of that but we believe that human beings cannot be just categorised into groups.

Most of the doctors also found the lower age limit of 20 years inappropriate and in practice were beginning to take smears when women became sexually active.

**National Cytology Register as a back-up**

The National Cytology Register is promoted as a back-up to general practitioners own recall systems. However most general practitioners regarded the main benefit of the register to be a source of epidemiological data and not as a benefit to themselves or the women.

- Basically I am not relying on the programme for my recalls. I have got a good system here.
- It's a back up. Some might need the back up but we don't.

One practitioner saw the practice register as a back up to the programme register. The doctor had notified the programme that a young woman had died, then received information six months later indicating that the person was still on the register. This could then be rectified.

- My records are a back-up for when they do something wrong so there's a cross-check.

**6.5.3 Issues for smear taking in general practice**

**More than a smear**

Many general practitioners were concerned about the narrow focus of the Cervical Screening Programme on just the smear test. The notion that there is more to a smear than simply taking a smear was the reason some general practitioners were concerned about practice nurses, and lay smear takers in particular, taking cervical smears.
There is more to a cervical smear than simply doing the smear. I think that
women should have a bi-manual examination done. From time to time you
detect things from bi-manual examinations like ovarian cysts which you
would never detect on a cervical smear.

Doing a smear is more than just a mechanical thing. You talk about lots of
other things and at the same time I talk about contraception and STDs. If
you start handing things out to your practice nurses to do, especially when
you’ve got time to do them yourself, you lose that patient contact.

You can take smears as much as you like but you have to look at the cervix,
you have to feel the cervix. It’s a clinical examination that gives you more
information. The cases that I remember of cancer of the cervix in young
women, they were negative smears but you looked at that, and you say,
there’s something wrong here so it’s the clinical examination that gave me
more information than the smear.

I think the longer I’m in medicine the less reliant I am on tests because I
know of the false negatives and the false positives and they really throw you
when you realise later, gee, that was a negative. So you become very
suspicious of your tests and you rely more and more on your clinical
information and knowledge.

**Lay smear takers**

There was a wide range of opinion amongst general practitioners with regard to lay
smear takers. While many accepted there was a place for alternative services,
some general practitioners were not in favour of this practice.

I think it would depend entirely on how well they can do them. I think that
it’s just a simple little job that anyone can learn to do as long as people
learn to do them.

If they want to go to a lay smear taker, that’s fine. That’s choice again and
people have to have that choice. I appreciate that there are times when a
cervix seems healthy but there is something to be said for the trained eye
looking

If it gets people to have smears then I don’t really mind as long as they are
properly trained. I think that’s fine as long as there is good liaison with
people. Ultimately there has to be a doctor who sees the result and deals
with it and that’s the only problem with having lots of people.

The thing about other smear takers is that there’s more to taking a smear
than taking a smear. We are taught to check it out for yourself and not just
take someone else’s word for it. From what I can see in the training
programmes, that point is being missed. It takes months to recognise
abnormalities.

Well, I’ll give you the practical answer. I don’t think it is really necessary.
I’ve got no philosophical objection, I just find it hard to believe that in New
Zealand there is a big role. There may be a role in perhaps an isolated
Maori community where for reasons of culture the local doctor, the local
nurse, are unacceptable. I guess in that situation there may be a
geographical call for it. But in a city like Christchurch it would be a
terrible waste of money because there is a huge range of choices. From
male doctors, female doctors, female nurses.
In cultural circumstances, yes, [there maybe is a place for some lay smear takers] but I'm still uneasy about them. It's a compromise.

**Practice nurse smear takers**

In eleven of the 24 practices practice nurses were also involved in taking cervical smears. The primary reason for this was to give women another option, either of having a woman where there were only male practitioners, or to provide a less costly service. There were often times, however, when the doctor was called to examine the woman.

> The problem is when they have to do a clinical examination, they have no medical training so they don't really know what to look for and they can’t interpret what they see. ... So I would say about 40 or 50 per cent of the examinations they do they have to call us in anyway to have a look. This happens a lot, it happens repeatedly.

In the thirteen practices where nurses were not taking cervical smears a variety of reasons for this were discussed: it was policy established by the doctors; the practice nurses did not want the responsibility; it wasn’t necessary in some practices where there were women doctors; there were not the facilities; it would be too much competition.

**"Shopping list"**

Whether women responded to being recalled for a cervical smear appeared to depend on economic circumstances. All the doctors talked about the issue of "shopping list" where a consultation includes several clinical problems. Given that appointments are arranged between 10 and 15 minutes and that a cervical smear takes a full appointment, this is an important issue.

> As the financial environment has changed people will come with a list of things ... Occasionally I get someone back but I am a bit of a softie really, just doing everything at once. Because frequently the reason why there are five different items is that they can’t afford to come back to the doctor in the next week and pay another $33 or whatever it is. So I understand that and that’s part of the way that general practitioners traditionally subsidise care for those that need it.

> Sometimes I have to ask people to come back. It depends how I’m going time-wise. If I’m up with myself or there is a spare appointment next, I am happy to do things but often I ask them to come back.

> Very very few come in for a smear alone. We do it. Very rarely do we turn them down.

> I don’t treat the smear as being a big deal thing. If they come with five other problems, I will always do it. It only takes a moment and it’s no big deal. I don’t ever, unless I’m running late, turn down a smear opportunity.

The practice of waiting until there was another reason for going to the doctor to have a smear taken often affected the way women responded to their receiving a recall letter.
It was interesting that we sent letters of recall in March last year .... and then you know, they still are responding. There are still people over a year later coming saying I got a letter.

We call them in every two years because that would give us a frequency maybe overall of two to three years. If you call them every three years you might get a frequency of 5 years.

6.5.4 New Zealand Family Planning Association

New Zealand Family Planning Association has contributed to the Cervical Screening Programme in a number of very important ways: providing a smear taking service; training for general practitioners, nurses and lay smear takers, and participating in an advisory capacity on the various committees.

General practitioners, while they accepted Family Planning as an option for women, generally were concerned at what they regarded as fragmentation of services. For some this raised ethical questions of responsibility:

- It's a bit of a bone of contention really because ethically when a patient goes to a doctor who is other than their normal doctor, normally the other doctor writes back or communicates and says, this happened. Now, the communication from Family Planning is frequently non-existent. .... The problem for me, sometimes I get a cervical smear which says - moderate dysplasia, suggest colposcopy - and it's quite clear that the smear has been taken at Family Planning and a copy sent to me and I ring up the medical director of Family Planning and say, who do you feel is responsible for the care of this patient because there is a bit of fragmentation of care here, and I mean, clearly something should be done about this.

While that situation is easily sorted out this doctor raised the question of what happens when there is different clinical problem.

- When they do a blood test because they are feeling a bit tired on the pill and it turns out to be something totally unrelated to gynaecology or family planning, then there is a bit more of a problem, you know, whose problem is this? .... The left hand frequently doesn't know what the right hand is doing and frequently mistakes are made and it's a bit of a shambles. Like sometimes the responsibility for things are a bit fuzzy, you know, and each person thinks the other person is responsible and nobody is responsible and that's how sometimes mistakes are made.

Other general practitioners found it frustrating.

- It's slightly sort of, well, what do I say, it seems slightly illogical to me that they go there for one thing and come here for another. If that's the only thing they do and they don't come here then that's fine. It seems slightly frustrating that they have their smear there and then they come in here every other day with something else. On the other hand if they are working in town, I can quite understand that. There's not many that work here that do that.
Yes some women do go to Family Planning. Years ago I may have given you a more assertive answer on that one really but I have mellowed. I just take the view that people make their own minds up. Having said that I do think that we offer a fairly comprehensive service, most of the ones that go to Family Planning I say to them that there is a nurse here who will do their smears for them.

Many of the doctors had specifically spent time working at the Family Planning to get experience in women's health.

- Family Planning was the one that I chose to do because I wanted to learn more about women's health and contraception.
- It provided me with the contraception and the standard gynaecology background that I need.

Most of the practice nurses who were taking smears had been trained through courses at Family Planning Association.

- I have had two nurses now who have been through the programme for the Family Planning and I think they do a very thorough training there, excellent training.

6.5.5 Issues for the future

Opt on - opt off register

The possibility of an 'opt off' register was discussed in the interviews. Again there was a complete spectrum of views. Some doctors were totally opposed, others welcomed the possibility while others expressed mild concerns.

- That would be more useful. They can opt off and that would pick up more that we're not smearing. I thought that was the object of the exercise. Some of those women, it would be more hassle for some of them to opt off than to come in and have it done. So, I think it's an effective tool that would be better.

- Personally I wouldn't be that upset about it, I mean I guess that by the time the government fought their way through civil liberties and everybody else, the head of steam would be well and truly stemmed. Providing that somebody else was doing all the paper work it might make my job a little bit easier. In fact it may be a preferable system to what we have now. What I'm trying to say is I haven't got any really strong objections to the Cervical Screening Programme. Philosophically it is good to encourage women to have smears.

- Well I would be very unhappy about it indeed.

The ethics of an opt off register was a recurring question.

- I just thought people had to sign their consent for that information to be used. Is it ethical to use their information without their signed consent.
My misgivings really stem from the giving information, the information issue is really a hot one. There are ethical implications, there are legal implications about giving information without the patient's permission.

It's a civil liberties thing. When you are talking about a cervical screening computer, you are talking about Big Sister and no-one wants to talk about Big Sister.

Women's right to choose was another important factor for some general practitioners caution about an opt off register.

Because we live in a democracy where people have freedoms and people have the choice. You know, I occasionally see people who elect not to have treatment and that is their absolute right of choice.

You can't legislate for health. I mean the naivety of the whole thing is really staggering. Any doctor can tell you that they have had people who have refused help and died and they have had it clearly explained and they have opted to die. Medically I respect that, I mean if people don't want to be screened then that's fine. I mean that's their decision, they should be educated about it but it's naive to expect the whole of New Zealand to line up in a row and be screened for anything. People just aren't like that.

One thing that really makes me cross is saying, everyone should have a smear and I don't think that's true. I think that everyone should be offered a smear. Whether she chooses to have one is her right.

The politics of the Cytology Register

Many of the general practitioners felt that the Cervical Screening Programme was a political imposition.

You see, we have got this highly emotionally charged, emotional thing, cancer of the cervix, ... but this is a political reaction to National Women's.

But again it has been imposed by politics if you like. Not a medical decision but a political decision. I guess that made a few people angry.

I'm certainly tired of being politically interfered with. I think it's blown out of proportion by this business at National Women's.

You play along with the political game that is involved at this particular moment and next year it will be something else - in grown toe-nails probably and we'll play along with that.

Several doctors said they felt that the programme had not involved general practitioners and that it was trying to by-pass them.

I think many doctors perceive it as another slap in the face. "You guys can't get yourself organised so we're going to bloody do it for you", and with that sort of approach, you're sure as hell not going to get doctors' assistance. You see they were basically saying, look, we don't need you. We'll get the suitcase nurses and the other bits and pieces and we're going to do it anyway. It is all confrontational, putting down stuff.
General practitioners have been slayed as being useless .... We are proud of what we have achieved and we are proud of the service we offer our patients.

I think we were excluded because people thought we had done a bad job up until now, quite clearly. This has come through again and again. That came through the Sylvia Cartwright report, that doctors are not to be trusted, that doctors are covered up in Auckland. I accept that there must have been mistakes and stupidity but I don't think they did it through maliciousness which is what really seemed to come through. We are not infallible. We are fallible and it's important.

The notion of the programme posing as third party interference in the relationship between general practitioners and their patients was discussed several times.

I'm just philosophically reluctant to be told that you will smear women three yearly and if you smear them more often than that you will pay for it. Now I will also accept that there has to be cost containment and that people having smears unnecessarily puts a strain on resources etc, and I know there is a balance there. I reckon I can make that judgement. I am reluctant to have that forced upon me. I also think that I can decide who needs to be smeared at what intervals better in my practice than anybody else. Because I know the people I am dealing with.

General practitioners were also concerned about accountability.

We fear that the more people you put in between the GP and the patient, the less accountable the GP has to be. Filling in forms is very easy. Signing a thing saying you are seeing X number of people is very easy but actually responding to someone's eyeball contact, yeouch. The more space you put in between it is easier to dodge it.

The possibility of women being over investigated was a concern for one doctor after he had looked at his records.

I am a bit concerned about this over-investigation of cervical smears because I am pretty certain, I looked at it last year and I can think of 6 women who had unnecessary operations as a result of the cervical smear programme. They were totally normal and I think just a clinical examination would have proven that there was nothing abnormal but because of the anxiety in society about the progressive therapies introduced throughout. .... There is so much pressure on us to do something when you have a CIN2 or 3, people start having sleepless nights. There is a lot of anxiety generated by this campaign which still has to be treated, rightly or wrongly.

Sustainability of the National Cervical Screening Programme

Many of the general practitioners were concerned about the sustainability of the programme. Their view was that just as it was politically introduced, with the stroke of a pen it could also be taken away. This possibility meant that their priority was for their own recall systems.

Is the cervical screening programme feasible in the future? It depends on the available funding arrangements. My gut feeling is that the cervical screening programme is all going down the tubes, actually. It is very difficult to be enthusiastic about something, you know most other people
aren't doing. Because to have it succeed in any sort of way, everybody has got to be doing it.

- I think 1993 is going to be a testing year when the funds start coming from the RHA. And if it weathers that, maybe it'll weather longer but I would think it might fall for cost-cutting and political reasons. Who is going to pay for it.

- The area health boards have been yet again demolished and I was told that they were starting to work quite well and then they get chopped. That's why, I mean, most of these programmes don't last forever so we really not that fussed about the national programme. I don't trust it really because we've seen so many systems sort of instituted which when a Government changes they change the whole thing.

- We are independent of whatever Government is in, whatever the foibles of the Minister of Health, we are actually able to continue saying, hey, look, don't worry. We'll just box on doing what we're doing.

- We'd have to say that listening to reality it's got less prominence in the present National regime than it had in the Labour regime. And it's the sort of process that unless you are constantly working at it and putting money into it it's going to dwindle away. So you'd have to say that its already less secure than it was 3 years ago.

6.6 Discussion

This chapter has focused on the attempt by the National Cervical Screening Programme to engage general practitioners as agents for an opt-on register, and practitioners' response to that in Canterbury. There is evidence that relatively few practitioners are systematically enrolling women on the Register, and the interviews detailed above explored the reasons for this gap between the requirements of national policy and its implementation at the local level.

This gap is not unexpected given the lack of any real authority on the part of central policy makers over the other main decision-making participants - general practitioners with their established ethical and work practices, and women, who exercise choice and consent. Given the autonomy and expectations of both these groups it is difficult to see how the successful implementation of the Register could be expected to be a routine technical matter, and in practice any progress has been based on a complex social process.

On the one hand general practitioners see the National Cervical Screening Programme as a managerial initiative from the Department of Health, with themselves as the main agents to carry it out. On the other hand they see no incentives for them in the Programme: most already had recall systems (many computerised), enrolment meant additional paperwork, and the contact between the Register and patients was seen to duplicate existing information flows. The additional time required to secure consent to enrolment was not recompensed in any way.

At the same time general practitioners are concerned about loss of autonomy in clinical management, particularly the frequency with which smears are taken. Practitioners have a long history in defending this autonomy from external management control. This autonomy is rooted in claims of clinical freedom and the privacy of the consultation relationship. If the requirements of the National
Cervical Screening Programme are seen to challenge these then they will be resisted. An opt-off register is clearly a contentious issue.

Doctors indicated strong support for cervical screening and effective recall. The existence of the National Cervical Screening Programme has clearly led to a renewed interest on their part in their own recall procedures. Developing these systems to a greater level of sophistication has enhanced doctors' capacity to manage their own practices. It has also generally upgraded the role of the practice nurse who is often responsible for the recall system, and particularly in those practices where the nurse also offers smear taking. This involves not only wider choice (at less cost) for women but reflects the increased professionalism of both clinical and information services in those practices.

In other quality areas the National Cervical Screening Programme has had an impact on general practice. Clearly there has been an important improvement in the quality of smears (Chapter 4). In addition it has called into sharp focus existing concerns about fragmentation of primary health care services as other smear takers become involved in cervical screening.

In terms of the future of the Cervical Screening Programme, many general practitioners doubted that it could be sustained in a changing political environment and within a reformed health service. In general few appeared concerned about a possible demise, while at the same time they subscribed to the service aims of the Programme, i.e to offer smears to all women in the appropriate age ranges, to recall at the necessary interval and to follow up to ensure effective management of abnormal smears.
7 CERVICAL SCREENING: A MAORI PERSPECTIVE

Permission to use information

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7.1 Introduction

Maori women are identified as a priority group in the National Cervical Screening Programme:

- The women most likely to develop invasive cancer of the cervix are the women who are least likely to have had a cervical smear taken.
- Maori women are less likely to have had a cervical smear taken or to have been offered a cervical smear test (Grace 1985, Cox 1989).
- Maori women as a group have a rate for carcinoma of the cervix 2.5 times that of European women (Duncan 1981).

The Programme's Policy Statement specifically refers to "encouraging participation, giving the full protection of the programme to Maori women by providing choice, and ensuring equity." The Policy Statement charges Area Health Boards with the responsibility for making sure that culturally appropriate cervical screening services are available in their areas, including screening, colposcopy and treatment services (Policy Statement of The National Cervical Screening Programme 1990).

7.2 Canterbury Area Health Board's commitment to the Treaty of Waitangi


A high quality service is an important focus for the Board. The Board has identified several principles that underlie this focus. The first principle makes a commitment to the Treaty of Waitangi and the consequent strategy:
Implementation of programmes to examine bicultural issues and the implications of the Treaty of Waitangi.
This strategy endorses cultural appropriateness as particularly crucial in health promotion and community based services.

Respect for the dignity of the individual is the principle of the second strategy. Another seven strategic principles which have important implications for Maori include issues of: community involvement; equity of access; disease prevention and health promotion; efficient use of resources; consumer choice; continuity of care and co-ordination among agencies; equal employment opportunities; and continued professional development.

7.3 Canterbury Cervical Screening Programme and Maori women

The Business Plan for Canterbury Cervical Screening Programme July 1991- June 1992 reports it's Statement of Purpose:

In consultation with the women of Canterbury, to develop and implement an effective and culturally appropriate cervical screening programme that is:

Ethical
Equitable
Accessible
Affordable
Sustainable

and therefore promotes their total Health.

The inequities of health status for Maori women and their increased risk of having cancer of the cervix stressed the need for a holistic approach in encouraging ownership of the programme by Maori women (The Business Plan for Canterbury Cervical Screening Programme July 1991- June 1992).

Initiatives implemented by the Canterbury Cervical Screening Programme to actively involve Maori women include:

Initially employing a Maori Liaison Officer part time over a period of three months to identify the needs of Maori women and to assist developing the services appropriately (See Chapter 4.6 Community liaison strategies).

In December 1991 two Maori women were appointed as part time Community Education Liaison Officers to the Canterbury Cervical Screening Programme.

The Canterbury Cervical Screening Programme contributed funding to Whanau Whakatipu, a joint venture of Te Roopu Tautoko Trust and the Family Planning
The Trust provides a course on sexual health for Maori women working in the community.

In South Canterbury the programme has contributed funds towards the Arowhenua Marae Health Clinic which opened on 30 November 1991. Several cervical screening clinics have been held on the Marae.

Within the Canterbury region Health Hui providing cervical screening services have been held at various locations, including Rehua Marae.

### 7.4 Te Kohi Toi: Maori health research

Sam Rolleston (1989) described how 'health' looks different and has different meanings depending on the position a person is in from which it is viewed. While 'health' in itself does not change, 'Maori' health has most often been viewed from a Pakeha window. His study He Kohikohinga: A Maori Health Knowledge Base questioned the overwhelming emphasis on the negative aspects and asked:

"Why don't you listen to what we have to say about our own well being? Listen to some of the good things that there are about being Maori, instead of just recording all that is bad."

Maori people reflected on Maori involvement in health research saying:

"You must get us involved in research. There are appropriate processes for finding out, collating and distributing information."

Rolleston also raised the issue that while researchers may be sensitive and respectful of Maori concerns this may not be extended once the research information leaves the researchers arena and enters 'departmental' territory.

### 7.5 Developing the evaluation process with Maori women

There were three aspects to developing the evaluation process:

- To be advised by Maori women about the process and content of the evaluation
- To support Maori women in developing and undertaking the evaluation.
- To explore funding options to facilitate the future training of Maori researchers.

In this evaluation Maori women were involved in making the decisions about what the evaluation of Maori women in regard to the Cervical Screening Programme would involve and the way it was undertaken.
7.5.1 Maori women's reservations about research

The evaluation of all aspects of cervical screening as it is experienced by Maori women is very important. Their reservations about the nature of research on Maori people and the use made of the data collected are endorsed in a report from Maori Women's Cervical Screening Hui held at Wanganui in 1988. Maori women stated:

> Our people have suffered the indignity of being the most researched race in the world. Little of this research has benefited us and almost none of it has remained within our control or within our cultural framework. Research results however have been used to sensationalise our people's plight in the media. ...

> We acknowledge the importance of a national data base and the need for valid statistics to inform us of changing trends of both health status and service delivery. But let us be cognizant of the fact that the current negative statistics represent a dysfunctional system not a dysfunctional people (Maori Women's Cervical Screening Hui 1988).

7.5.2 Distribution of Evaluation Information

The distribution of the evaluation information documented about Maori is an issue that was negotiated between the researcher and the National Co-ordinator Cervical Screening Programme and between the researcher and the Maori women involved in the studies:

- What data should be collected?
- What data should be avoided?
- To whom should the data be made available?
- Under what conditions should the data be distributed?

A recent experience in Christchurch when Te Kohanga Reo first learned the statistics relating to the testing of their children's hearing on national radio and from newspapers has highlighted the consequences of inadvertent and indiscriminate use of documented information.

7.6 Maori studies

There are three studies in the Maori Evaluation of Canterbury Cervical Screening Programme.

A. 'Whanau Whakatipu' is a course of training for Maori women in the area of sexual health and total well-being in a joint venture between Te Roopu Tautoko Trust and the Family Planning Association involving the researcher in a participant observation study.
B. A study involving taped recorded indepth interviews with 16 Maori women contacted through the office of the Aranui-Wainoni Community Coordinator.

C. The case study of a Maori woman having gynaecological investigations. Information was gathered in a tape recorded indepth interview.

7A WHANAU WHAKATIPIU
Blossoming Families

For each ecstatic instance there is an equal anguished pain. For every step forward it often feels like you have to climb a mountain to make that step connect and flow to a walk.

Te Roopu Tautoko Trust, Otautahi and New Zealand Family Planning Association in 1991, coordinated a 250 hour pilot Maori Health Training Programme. This pilot programme was designed to include as its primary technique for learning - tutoring from skilled Maori, proficient in traditional and contemporary approaches to health and wellbeing.

Resourcing from New Zealand Family Planning Association Christchurch, and the Canterbury Area Health Board Cervical Screening Programme enabled Maori to benefit from the medical instruction and facilitation of information about approaches to improve health and treat disease.

Operation of the pilot was undertaken by a komiti of representatives from Te Roopu Tautoko Trust, Otautahi, Christchurch, New Zealand Family Planning Association, Canterbury Area Health Board Health Promotion Service, and volunteers from various Maori community groups in Christchurch. Trainees were accepted upon written nomination from their whanau, employer and support group. Selection was made at a hui, of which collective agreement, by those present, confirmed committment by nominees and their supporters. Late nominations were accepted, after consultation with the Komiti, Tutors and Coordinator. Trainees travelled from Seddon in North Canterbury, and Temuka and Timaru in South Canterbury.

Certification was granted on the basis of formal and informal assessment by the two main Tutors and their Advisers. These were made after agreement with the Komiti and Trainees that written assignments, open book testing, oral presentations and minimum hours of attendance would be adhered to. A special ceremony, to celebrate, was held and whanau, employers, supporters, media, community groups and community leaders were invited to attend.

Evaluation involved Tutors, trainees, supporters and representatives of the Komiti. At each training session, all present were encouraged to express criticisms and articulate viewpoints. Evaluation then became a time for sharing - making challenges, acknowledging differences and accepting that individuals, within a group, have a right to self expression and maintain their right to be individual. Christchurch Health Research Services contributed with advice on planning and evaluation, and donations to complete the process for a formally written evaluation.
Outcomes
Whanau Whakatipu Trainees have blossomed. Fourteen women completed the course. Five trainees, three from Christchurch and two from Timaru are currently training as lay smear takers.

ACKNOWLEDGEMENTS

Te Roopu Tautoko Trust Otautahi volunteers and New Zealand Family Planning Association Christchurch contributed the inestimable resource of time, energy and space for sharing.

Funding was awarded after successful application - from the Canterbury Area Health Board Cervical Screening Programme and N.Z. Family Planning Association.

Whanau Whakatipu Komiti, Taua, Poua, Kaumatua, Kuia, Tutors, Trainees and whanau supporters all contributed skills, knowledge, advice and perspectives on:

- tikanga Maori, whanaungatanga, mana, ihi, wehi, wairua, tapu, aroha, fitness, nutrition, diet, catering, Te Tiriti o Waitangi, Tohungatanga, Rongoa healing, HIV/AIDS, STD's, aerobics, parenting and Tipu Ora, Sexual Abuse, Midwifery, Breastfeeding, Trailblazing, Sexuality, Maori Women's Refuge, the Immune System, Cervical Cancer, Cervical Screening Register, Cancer, Te Whare Tangata, Maori Fertility Management, safe sex, colposcopies, smear taking, accounting, photocopying, taking messages, stress management, communication, native plants, waiata, karakia...... to name but a few.

Te Tiriti o Waitangi as the guiding document for partnership by Tangata Whenua, the Crown and Tau Iwi.

Graphics and Layout of Te Roopu Tautoko Trust kowhaiwhai for Whanau Whakatipu letterheads, certificates and banner to Jude Eldridge & Co. The Director of Te Roopu Tautoko Trust for Caligraphics.

"All who contributed became a part of the natural growth of Whanau Whakatipu of Families Blossoming"
Tena Tatou Katoa

E hiahia ana matou ki te mihi ki a koutou te iwi Maori o Aotearoa me Te Wai Pounamu.

Ka mihi tautou ki te Atua nana i hangai nga mea katoa.

Ka mihi atu ki nga Tangata Whenua o tenei rohe nga iwi o Kai Tahu raua ko Kati Mamoe.

He mihi nunui ki nga Kaumatua e awhi ana i a matou.

Ki nga wahine i korero mo nga mea e pa ana ki o ratou Whare Tangata i tenei kohikohinga. Ka nui te mihi ki a koutou.

He whakawhetai ki nga tangata, nga hoa me nga whanau e manaaki, e awhi, e tiaki hoki i a matou. Ka nui te mihi ka nui te aroha mo o tautoko ki te hapai i te kaupapa kia whai huarahi nga taonga o nga Matua Tupuna.

No reira e te iwi kia kaha, kia maia, kia manawanui.

TENA KOUTOU TENA KOUTOU TENA TATOU KATOA.

Te Roopu Whakahaere
Acknowledgements

Ehara ta te tangata kai he kai titongi kau, engari mahi ai ia ki te whenua tino kai tino makona. Food provided by someone else is only food nibbled. Food produced by one's own labour on the land is good satisfying food.

A special tribute to the women who shared their memories, their struggles and their hopes for the future. Thank you for the privilege of being one of many who will benefit from your valuable contribution to the study.

Many thanks to those who have advised and nurtured the growth of this study by the sharing of their knowledge and wisdom throughout the journey of this taonga. Rangi Mullany, Terehia Kipa, Kiwa Hutchen, Te Hei Pirika, Riria Pirika, Heeni Phillips, Maurice Gray and Shona Hickey.

My deepest gratitude to you who joined hands and committed your time, skills and energies to the kaupapa. To those who sifted the chaff from the wheat, who left no stone unturned in the completion of this mahi. Many thanks. Your invaluable input has been as precious as having the opportunity of working together. Karen Mills, Shane Dick, Maire Kipa, Herena Stone, Joy Minhinnick and Charles Tohu.

A special acknowledgement to Valerie Norton, Contract Researcher, Health Research Services, Christchurch. Many thanks Val for working through the process and making the bends.

I Whaia te iti kahurangi Ka tuohu koe Mehe Maunga teitei
Seek that which is precious and if you must bend Let it be to the lofty mountain

Fondest regards to Pauline Barnett, Health Research Services Christchurch. Many thanks Pauline for your support, encouragement and much needed assistance with resources.

Mihi Ki Te Whanau Ko te tuatahi ko tuku mihi aroha ki tuku hoa tane ko Charles Tohu raua ko tuku whaea, ko Mirianata Ripeka Witoko hoki, mo o raua tautoko ki au i nga tau o mua, a nga tau e heke iho mai nei.

Community Co-ordinators Trust I would like to acknowledge the support of my management Committee.

Faith Tohu
Te Roopu Whakahaere


The study was supervised and supported by Te Roopu Whakahaere. This group took responsibility for:

- networking, identifying the study objectives, editing, layout and writing the discussion for the report. They also held hui to explain the research. The interviewing was confidential to the Maori researcher.

7B.1 Te Korero Whakataki

Introduction

While the idea of this study was thought through at the beginning of the overall evaluation in February 1991, its actual development happened after a meeting between Faith Tohu, the Aranui Wainoni Community Co-ordinator and Valerie Norton, contract researcher from Health Research Services in December 1991. Faith, in her position as the Community Co-ordinator is involved in a wide Community network. Faith wanted to discuss the possibility of a research project looking at health services in the Aranui Wainoni community. The meeting was to discuss research methods and the possibility of research being undertaken from the Community Co-ordinator's office. From that meeting the possibility of this study developed.

7B.2 Te Whainga Rangahau

Objectives of the study

Maori research objectives

- To provide background information that identifies the basis from which Maori viewpoints are formed with respect to Health Services
- To create supportive environments for Maori choosing to participate in research studies. Whether their role is as researcher, interviewer, interviewee, supervisor or supporter of a health research study.
To demonstrate commitment by Maori to the articles of the Treaty of Waitangi:

Article 1. Upon agreement by Maori, to provide information that will assist providers and decision makers to develop appropriate and acceptable ways in which Maori can participate in decision and policy making.

Article 2. Co-ordination and cooperation by Maori to Health Research studies.

Article 3. Active protection of information shared by Maori to health research studies thus ensuring the maintenance of good health.

Agreement with Health Research Services, Christchurch

Objective: To identify for Health Research Services, Christchurch, the extent of cervical screening services accessible and available to Maori women, contacted through the networks of Aranui-Wainoni Community Co-ordinator.

Research Objectives

- To establish the extent to which a cervical screening service is accessible and available to women in Aranui

- To understand the circumstances which foster the opportunities for Maori women to have regular cervical smears taken

- To document how different women experience the cervical screening services.

- To establish what circumstances and facilities might improve women's experiences.

7B.3 Te Ahuatanga

Methodology

Sixteen Maori women participated in tape recorded indepth interviews with a Maori researcher. The interviews provided the Maori women with an opportunity to tell their story and identify the basis from which their viewpoint was formed and to identify and comment on all aspects of cervical screening. The indepth interview method was selected because it was in the process of 'telling their story' that the detail of the Maori women's experiences and views could best be expressed.

The group includes a cross section of Maori women, having a range of ages from 17 years to 60 years as well as a variety of circumstances and experiences. The background and the purpose of the study was discussed so that women could make an informed decision whether to participate or not. They were also informed that while their identity was confidential that the interviews would be transcribed. None of the women declined to participate.
Te Roopu Whakahaere identified two important issues in regard to the research process:

- Transcription of the taped interviews.

For future Maori research having a Maori transcriber was considered to be crucial.

- Time frame for Maori research.

There was conflict between the time required to fulfil the networking process inherent in Maori research, the number of hours budgeted and the deadline to complete the study. This means that a considerable amount of extra time was put into the study on a voluntary basis.

Intrinsic to Maori research methods is resourcing of active support: Maori researcher(s), Maori supervisors, Maori interviewer(s) and interviewees, Maori transcriber, hui costs, travel allowance and training costs.

**Ethical Approval**

The study was approved by the Canterbury Area Health Board Ethics Committee.

**7B.4 Results**

NB Italic denotes direct quotes from interview transcripts.

**7B.4.1 Te Whakatipuranga**

**Background**

The women came from a variety of backgrounds and circumstances. Six of the women, including all the older women had been brought up in rural communities. Seven of the women, all aged under 40, had grown up in an urban environment while three women had shifted from the country to the city during their childhood.

Most of the women described healthy active childhoods.

- *We never got sick. We were very healthy children. No, I think [it was] very rare in our family that any of us became physically unwell.*

Only one woman said she had been a sickly child:

- *I was very sickly as a child. Believe it or not, I was bronchial.*

She described what happened:

- *When I wasn't well, because we lived in the bush, my grandfather used to go and get Maori medicine. ... I would go into the bush and my grandfather would show me different trees that were the rongoa for myself*
I would have to have things like ti kauka. I had to drink the rongoa to clear the mare away. And then in the summer we were all encouraged to go and gather the berries and eat as many berries as we could off the tree, the totara tree. There were berries on the totara tree. You know, I mean, we didn't need encouragement because they were lovely.

For most of the women whanau was the basis of family life:

- The meal part of the day I would say probably the major event if you like. Because that was the time that we all had to be here no matter what, and if we had outside interests like we were in sports we always had to get home for tea.

Most women had memories of fresh home grown vegetables:

- Well, it's just like that from quite young, mum and dad always had a thing about us eating our vegetables and lots of fruit.

- The big thing for mum and dad was that the vegetable garden and the trees were looked after. Anything that grew off them, they never wasted, they picked everything up, we had to pick everything up. And I mean, mum would make jam and pickles and dad would make wine. ...

Yea, he just made use of everything. Also dad would go down to, because they were labourers or working class families, dad used to go up to the bread factory on the corner and wait for bread, so we could have fresh and hot bread every morning.

For some of the women the marae had been an important focus for their lives:

- We were dairy farmers. The whole community was. A lot of the area was still Maori land, all Maori owned and run and marae based. Everyone had the marae operating to the fullest, you know, like having all functions and stuff so that they didn't need to book halls or anything. Everything was done on the marae.

This brought back really good memories:

Oh really good memories, very protected. Safe, always felt safe. A good, healthy life. ...

We used to have a big garden that everyone used to come and work in down at the bottom of our place and everyone used to help themselves. ...

Mum used to preserve all her fruit and that because we had an orchard as well and everything she did herself, our clothes, knitted, she crocheted, she did everything. We didn't have much money being a dairy farm at that time but we never went without. I mean we never sort of, we didn't have a car. We had a sledge with a draft horse that pulled us down the tracks because we didn't have a road at that time.

- Well, you know, we had no money so we had to enjoy our environment, we went swimming in our lake, we went fishing for eels. When we went swimming we would look around for kai to take home.
Several women, particularly the older women talked about the wisdom of the Kaumatua and the handing on of the knowledge:

- My upbringing was mainly to do with Te taha tinana, Te taha wairua, Te taha hinengaro, conservation and of course we lived in the bush. I was quite happy you know, as a child growing up talking to trees and getting food from the trees, a lovely, peaceful upbringing I think. ...

  I was brought up, I was a whangai, because my mum and dad split up when I was two, so my grandparents brought me up. So I guess the values of old from his karani was handed down to me. Values of the land, values in our self-esteem, values in our personal being was handed down from him to me

This wisdom continues to be handed on:

- I feel it is my role as a Maori woman is to pass on some of those values to our own people and that their personal wellbeing is part of, it is not just one on its own, their health involved the whole of their bodies. I relate my health to the land and to the environment.

- The thing is that our old people, our Kaumatua had been taught from mai ranoa which has been handed down from generation to generation, that there were trees, there were herbs that could fix your problems right there within your community because the doctors were only in the urban towns.

- Our nearest doctor was 65 miles away so if we got ill we used all the herbal medicine that grandma taught us. ...

  Mum was very fussy about what she fed us and I suppose that came down to me I suppose because they grew a big garden. They had everything like kumara and pumpkin, silver-beet and carrots and one of the things that she always used to have was a huge pot on the oven with all the vegetables mixed up. We used to do a lot of bottling. We bottled everything but everything had to come out of the garden for the kids.

- It was those things that passed, like even with me when I had my children, I was doing the same things that Mum taught me. One of the things that she used to teach me to do was, every day, whenever you change your baby or bath your baby, she used to massage the baby and we used to do a lot of that, olive oil and massage all the joints of the baby, the toes, she would pull all the toes out, even the ears.

Sometimes there were accidents:

- Back then in the country you couldn't afford to get sick but I must admit, though, if you broke a leg or you broke an arm, the old people had a way of setting it themselves. ...

  They would set your arm with certain bark off the bush, off the trees. They would scrape this to put across your arm and then they would do their own sling and tie it up with flax. Flax was grown in every home because flax was also a medicine. Any stomach troubles, cuts, if you had sores. If you cut a flax, you will see that it has got a really gluey juice that runs out of it. You put it in between your toes, you know how some people get tinia, put it
through your toes. If you have got infections, you put that stuff on it and it's good for healing so we used all that stuff from the bush.

Other trees were important too:

- That round, heart-shaped bush, calco I suppose it's called, that was boiled and drank. That cleared your liver and cleared the stomach and got rid of all that stuff. There was a use for everything and it was always got from the bush. Like if we had a bee sting, we had this white, milky stuff that grows by the side of the road. I don't know what it's called but anyway the old lady used to always go and get it and she squeezed it out because it's white, comes out white and you put it over the sting, you know. All those things, if you got cut, they had all the different kinds of trees that they would use to boil up and you know, pack you, if you had boils they used the dock leaves, you know, put it on to draw all the muck out...

As was the sea:

But the sea was the other great healer. If you got hakihaki or any of those things, straight into the sea. They believed in the sea water.

For other women life was different. One woman described the consequences of moving to the city:

- And my father was a the sort of man that hunted and fished so we lived a sort of natural... He was a man that took pride in the fact that he could feed us and did really well.

And then when we came into the city he changed and he worked at the freezing works.

And he was a really sad person. He couldn't communicate with the people around, with the pakeha people in the cities.

But he was a beautiful musician, and he played the piano and that was his only form of communication with pakeha people. So I remember, I think if I remember him, I remember the night that I heard through the wall- him playing on the piano. The piano was crying. He did it alone.

Trying to live in the pakeha world was often a struggle:

- I was brought up in a very Maori surroundings but it was not tikanga Maori it was more alcohol and that kind of upbringing and I was sent to very pakeha schools and so through my years of growing, being the only Maori in a class or the only person with colour or a bit different. I've learnt about systems and structures and how they can come down on our people if we don't, you know, pull ourselves out.
7B.4.2 Te Hauora ki te Maori

Maori View of Health

The women described health as more than physical and emotional. It encompasses one’s total environment.

- It involves the Wairua and the whole feeling good about yourself and your family, whanau; how we all work in together; being Maori; Aroha; taking care of myself by eating the right foods, exercise, all those things.

- Hinengaro, taha wairua and taha tinana which is your body, your heart or your soul or that inner thing and your spirit and your mind because if you’re mind is not happy with what you are feeling or you’re feeling something that your mind can’t fathom out, you know, then you can force your body to show really bad signs too. So it’s all connected.

Most pakeha services did not identify with this concept, making a shared understanding of health difficult.

- Pakehas, they forget about the bit in between [spiritual] which is really the most important thing, aye. If you see someone who is really really poor and hasn’t got a coat, it’s the difference between saying from your mind, “oh I know a place where you can get a really cheap coat” but if it was from your heart, you would take your coat off and say, here, have this.” We tend to go from the heart. ... I mean, we might not have any money but who cares, you know. We’ve all got each other and we’ve got good friends. Our bodies for us have never been a real high priority with Muori people, aye.

7B.4.3 Te Whakamatautau o te Waha Whare Tangata

Cervical Smear test

Twelve of the sixteen women had had a cervical smear test at some time. Five of these women continued to have the test on a regular basis. Three women had never had a smear taken, while one woman did not know whether she had had one or not.

The women who had a cervical smear taken regularly commented:

- I decided to have cervical smears when I, just after I had my first child which would have been 14 years ago and I have had regular check-ups ever since. I think it’s because of my own upbringing and the value that was placed on me as a person to make sure that I look after myself.

- When I went to Family Planning over 20 years ago. It was for contraceptives really and then they found out how many children I had and asked if I had a cancer smear and I asked them what it was, and they explained, they were really good, they explained fully to me and showed me the diagram of the uterus and what could happen if it goes unchecked. So I agreed for them to do my smear and I was quite happy once I knew, you know, the value of having one. So I’ve kept it up really and I’ve had one this year, right up to this year

However having a smear taken was a necessity rather than a choice for most of the women.
I didn't like having any sort of examination or internal or any sort of physical check-up but after the operation, because I realised what could happen if you left it too long. Once upon a time there was no way - you couldn't get me in there unless you knocked me out first.

I don't like them looking at me down there. I know it's necessary and I know it's got to be done but because cancer runs in my family. So for me, I want to have that smear because I know I have to. And I hope that my girls will do the same but it's something that I don't like. You know, if I had a choice I wouldn't do it but I know it is necessary for me.

I went to get an IUD fitted. One of the conditions was that you had a smear before you get one in. So, yes, I didn't have a choice. But if I had a choice I probably wouldn't have wanted one. I guess for me it was just having someone else poking around down there you know because that part for me is really, it's really sacred to me.

Four of the women had had their last smear taken when their last child was born over five years previously (over 30 years for one of them).

Not since my son was born 5 years ago. And that's mainly through the cost, they're too dear. Well, I don't mind going, it's not a worry, I have a fantastic doctor.

This women said she knew it was important and would have a smear taken soon:

Mainly because thinking of my kids. I want to be around for my kids. I want to see them walk down the aisle. I want to see them happy. So it's not for myself, it's for them.

Another woman had previously had a bad experience with her doctor when she went for a smear:

He said "Oh no." He couldn't do it that day, because something to do with me being too big, overweight. So that's why I never went back.

She also feels anxious about getting the results:

I still get fearful about it. I think to myself I don't want to hear him say, my fear is to hear a person say "yes, you have got cervical cancer".

Another woman felt that if you go looking for something then you will find it:

As soon as they go for a test, something happens to them. If they are left alone, they are all right. No, I'll just back off a while so far as the cervical smear is concerned.

Three of the women had never had a smear taken.

One of the main reasons why I've never had one is because I don't like them down there. It's a total invasion of privacy and [there] doesn't seem to be much sympathy or empathy.
One of these women encourages the young women she works with to have cervical smears taken but has not had a smear test herself. Her previous childbirth experiences had not been good for her.

- No, never had one. I just thought it never existed but when I started to become aware and I was hearing of lots of women who had actually died from cancer that could have been prevented. Then I took an interest and I always encourage young women to go in and have one done although I wouldn't have one done myself. But I see it's importance. There's a lot of reasons why I haven't had it done because I think I have to be really comfortable about it in myself. I haven't settled it in myself. I think it's that whole thing about going up inside there, you know.

For another woman there were lots of other things happening in her life so having a smear taken was not a priority.

- No I haven't. I suppose if I really wanted to I would go all out and do it. But a lot of factors come into it; busy with the job, my personal life, and like my house; not going and getting a doctor and seeing a doctor often. Perhaps if I really wanted to I'd go out there and do it but I've found, like there's more important things than my health and me, you know.

In addition, this woman was fearful of the smear result:

Plus the fear of having some disease. That can get in the way. But, I mean, why take the risk I think. Why take the risk. Why worry about something you might not even have. I mean, you should just get off your backside and just go and find out whether you're OK or not. I mean, it's less worry and less pressure.

One of the women had never had a smear taken until she was admitted to hospital.

- I was never sick. I don't think in the sixties and seventies, perhaps there was, perhaps they did advertise having a smear but, yes, I think they were advocating, you know, after you went over the age of 40, to have a smear but it never entered my head to have one because I was fit and healthy and it never never entered my head at all. There were campaigns about having a cervical smear after the age of 40 but when you are well and healthy, that is the last thing you think about, that you would get cancer.

Once in hospital she had tests:

They started doing the tests and that's what they found. I had cancer of the cervix.

Within 24 hours she had had a hysterectomy.

One minute I was all right, the next minute I was sick and I was in hospital and I was in that hospital for six months treatment on and off. It was only by pure luck that my cancer got caught in time. Otherwise I would have been six feet under.
Now she says:

*If I had a chance to talk to every Maori woman there was, I would say, go. I would say, go.*

**7B.4.4 Cervical Screening Cytology Register**

Only one of the women was enroled on the cytology register. She was aged over 40 years and had a cervical smear taken regularly at a Family Planning clinic. Another five women were aware of the register. One of the younger women was concerned about the age limit:

- *I think that age should go down a bit into the younger teenagers, especially - sort of starting off 13 year olds, or even 12 year olds that they have the knowledge of how important this is.*

  *I mean, they are learning sex education in schools and they learnt about all the precautions and that and I think this is a good precaution to know so get a cervical smear. I mean I think that's really important that they learn about it. It's their life, they've got to know.*

  *I mean, it's not going to hurt if they know. It's going to hurt if they don't know.*

Others expressed their concern about the use of statistical information.

- *Well, the register, from the beginning has been has just been crazy in our community. You know, we've been trying to work out what it actually means, and then looking at what it will do for our people.*

  *We’ve had to learn a lot and I think because we’ve become such know it all now, it’s getting too hard for them. They want to put it away in the hard box because Maori people, Maori women want their own register because we see it as ours. Any information that is put on that register belongs to us. It does not belong to an area health board or whatever. Because from that register they can determine our destinies. We want to determine our own destinies. We feel that we should be giving them the information to enable the funding, to ensure that we have more people in our community working with our people.*

**7B.4.5 Nga He e pa ana ki te Roopu Hauora**

**Factors affecting access to health services**

The women all talked more about cervical smear tests and the factors that made it difficult to have a smear taken.
Te Wahi Tapu o te Wahine

Cultural values

Te Whare Tangata is very sacred. The women said it was very important that this was understood.

- The tapu of the body, the tapu of our body. And I've never, ever met a Maori person who hasn't got those values.

- In Maoridom all that woman stuff is considered really tapu anyway. Aye. Like it was in the old days, you know.

- That part for me is really, it's really quite, it's sacred to me.

- I think this area is tapu. It's been like that for years though, hasn't it. A person gets really whakama about it. That is private.

One woman explained:

- The reason why I say very much about their fears is that, to a Maori woman, the bottom of a Maori woman's body is a very holy and tapu place as far as women are concerned. That is their birth place. The only man that ever touches the womb of a woman is their husband.

For another male to come along and touch that part, that tapu part, it's against the upbringing of some of the Maori, particularly with the Maori women. They can't help it. It's the teachings of their Kaumatua from generation to generation to generation. The wahi tamaraki is tapu of the women.

When you want a woman to go a long for a cancer smear and especially if she's been brought up within that scope of the old teachings, no way will you get them to go unless it's a Maori present, a Maori doctor, but it's got to be Maori and it's got to be a woman. Sometimes Maori women will let a woman doctor be present but they still like the whanau there.

She advised:

So I think a doctor needs to be really sensitive to Maori women, how they feel about, you know, being looked at or touched down there in their private parts. Because in Maori, in our own culture, it is a very sacred part of the woman and nobody should touch that part at all unless it was her husband.

Te Whakahonoretanga Nga Ngawetanga

Respect of feelings

- I never liked anybody looking at me privately down there, whether it be a doctor, I still found it really embarrassing and you know, and if they were insensitive to how you were feeling while they are examining you, it puts you off for life.
My first experience was with a doctor and when I went into his rooms he said, come up on the bed, take your pants down and I was already embarrassed then even though I was married because I didn’t know what he was going to do to me. Then you know, legs apart and he was looking and it was a horrible experience anyhow. One that I don’t want to go through again and that still stays with me even now.

So I’ve never, ever been to a male doctor for a smear. I’ve never. If and when I do go to a doctor it’s for something it’s not anything down below my waist, between my waist and my knees. A male doctor doesn’t go to that area. I think it’s just me, personal.

**Nga Ahuatanga o mua**

**Previous Experiences**

Several of the women said they had previously had bad experiences when being examined by doctors or when they were having their baby. The process was so clinical and there was no awareness for them as Maori women. This has made it more difficult for them to use the established health services.

I was 16 and I thought at the time I had better go and do something about myself. So I decided to go and make an appointment with my doctor, family doctor. I was very very tense and I was quite terrified of what was going to happen because they actually had to do a - They never explained to me what they were doing. They just told me to undress and then the doctor just -, I just remember what I felt, quite dirty. He never explained anything to me. I just remember crying after it. I just felt dirty.

Some doctors are a bit funny, you know. Sometimes they just talk away as though you are not even there. Talk about all these different things, to nurses or other doctors around as if you are not even there. Just talking about parts of you.

The first internal that I ever had was when I was pregnant with my oldest daughter. It was the way he examined me. Oh, there was this whole thing you know, like I wanted to go in with my mother and he wouldn’t let my mother come in. And then he agreed, you know, agreed that she could come in but completely ignored her and directed the questions at me. The reasons that I wanted my mother in there in the first place was that I wanted her to ask the questions and to get the answers really. I wasn’t confident enough to sort of do that. But in the end he had his own way - when I was having an internal he asked her to go out and she did. And when he was examining me he made a crack about how big I was, so I made a decision then that they would just have to drag me in before I was ever going to go again.

When I was pregnant. Oh, I hated going. The first time I went to get an internal it was really horrible. It was really horrible because I had a man doctor, and he was just really cold: “Come in and take your knickers off and lie on the table”, you know, no talking and I just did what I was told. You know, it was so cold and really impersonal because then I struggled to open my legs.
And the worst thing, the worst thing for me having my baby was that I was in a room giving birth with all these strangers. They were students, medical students and I didn’t even know they were there and this was when I was having baby. You know, I sort sat up and there were all these white faces around just watching me and they were talking about me. All these students, fifteen of them in the room standing around my bed.

Te Ututanga

Cost

The women were asked a direct question about cost so all the women commented about this aspect. However for many women cost was not a primary factor in their decision to have a cervical smear.

- Well, I think that for Maori women today, it’s really hard because you know, we have got so much unemployment.
- Often mothers that are sick themselves are stressed, or don’t have enough money to help them to even feed their children. How can they on the budgets they’ve got. How can mothers be expected to feed a family on what little money they’ve got and keep themselves healthy, you know.
- When it comes to money, the bottom line is our families will not use the health system no matter who they put there because the money will be spent on just daily living like keeping your families alive.

Because of the cost many of the women only went to the doctor when the problem was really serious:

- You know, a lot of times we haven’t gone. You wait until you get really sick and then go because you get a feeling oh, I don’t want to waste it [money].
- Usually I can’t afford it so I find some way of getting out of paying for it. …. I don’t bother going if it’s not really that serious or if I think it will go away soon.
- I was unemployed for two years and I would get sick very often, I wouldn’t go to the doctor because I couldn’t fit it into my budget. I had this thing about me, no way will I get debts and I thought no way will I go to the doctor’s, it’s just like a debt.
- Well, it causes me not to go because of the cost. I’d go if I feel it’s an emergency. Otherwise I won’t bother. Like I wouldn’t go and have a general checkup because I think it’s a waste of time, unless I’m feeling sick. They say you should go and have a check up every now and again but I don’t bother until I’m sick. That’s when I go.

Family support was important:

- I couldn’t afford to always go. That’s probably where the support of my family would come in and they would maybe give me the money to go.
Having a cervical smear test was not a priority when money was short:

- Cost always affects you. Of course it does. If I had a choice of spending 30 bucks on myself or go and have a cervical smear, I’d go and spend 30 bucks on myself. Get a lot more pleasure out of it!

Children’s health often takes priority over the women’s health:

- Now I’m overdue [for a smear test], I can’t afford it. If I have a choice I prefer to spend the money on the kids.

Another woman, on the other hand, was concerned about the cost to her family if she became ill:

- Well, cost always affects us when we haven’t got the money but then I felt, you know, that if I don’t have that check then my cost to my family would be, the cost to my family would greater.

One of the women discussed the arrangements she made with her doctor:

- I have a fantastic doctor. Since we’re broke and I’ve explained to him that we are broke now I just ring him up and he passes it [the cost] through.....

Sometimes I pray that my daughter will have a cold so it looks like I’m a worrying mother. I go and then I’ll ask him to write me out a prescription. The appointment is under her name, not mine. But he knows that’s the honest truth, that we are broke.

It is not just the cost of having an appointment to have a smear taken that is an issue but the additional cost of hospitalisation if further treatment is required:

- Although it is said within the hospital system that nobody will be turned away, that’s all right saying that but you still have to pay the bill at the end and by fair means or foul, they will get that money off you. So I’m fearful now of going to the hospital.

The problems associated with cost happened because often the people making the decisions had no appreciation of poverty:

- The approach sometimes coming from the Hospital Boards that have never known poverty, they have never known to be without because they have always worked.

7B.4.6 Nga Tipuranga o te Ratonga Hauora Maori

Organisation of Health Services

The women also discussed how changes in the organisation of health services would make their access to and therefore their use of health services more comfortable. Even if there was no cost involved many women would still not go for a smear test until there was a person each woman identifies as appropriate to take her smear and a place in which she felt comfortable to have it taken.
Preferences and Options

When women are asked what their preference is in terms of who their choice of smear taker might be and their choice of place, they can only choose from what they know and have experienced. In the interviews the women were given a range of possibilities to consider.

While most of the women commented that they had never actually had the option of a Maori doctor, several women had had their smear taken by a Maori nurse working in the community. Many of the women had a strong preference for a Maori woman to be their smear taker:

- Maori people or even a Maori physician or doctor or whatever, I would feel more comfortable with, and being a woman I think a woman doctor would be a bonus.

- I would go to a Maori doctor. I feel more comfortable talking to a Maori. I've never, ever had a Maori doctor, but I feel more comfortable talking to a Maori woman.

- Well, apart from having my sisters or my mother do it, or someone from my own whanau, then it would have to be another Maori. A Maori woman. You know, it doesn't have to be a health professional, just someone who knows you. At home or of course a marae.

For many of the women the marae was the place where they felt they would be most supported.

- Just Maori women, oh, I'd go there [to the marae]. You'd feel at home. I mean they've probably already got the jug on. The thought of having a smear on a marae - I mean, but if they had a - and it was going to be done then I would go there because they would make you feel really good.

- I have gone to health hui on marae. I've found them so neat, you know, like just being amongst the people and all of us in the same boat kind of thing. And just the surroundings and the open talking and things like that. So I would like a place where it's, where all our people can go and including pakeha. They'd probably love to come to our services.

- I would like it to be a clinic where it is based on a marae and where it is run by Maori people. And I also like it to go with groups of people because I find it, you learn so much together.

- Yes, somebody, not explaining it, but being able to talk about it. I suppose calming me down and not getting myself all worried about it.

- If there was a Maori woman down here who was older, who I didn’t know well, then I would probably get one done but I would have to get it on the marae too. I would want one on the marae because that's home. That's a home and that's safety, you know.
One of the women explained:

- You find some Maoris will accept the concept of a health system by the European standards and you will find that there are some who won’t for that simple reason. Not because they don’t want to go. Some are reluctant to go, some are very shy about their bodies but if you take it to a marae, where a group of them can go, yes, you’ll get them participating within that system. They are more comfortable on the marae because of the shy nature of Maoris in general. There is confidence in numbers.

The women also talked about the established pakeha health services. They expressed a need to talk; to establish trust and respect.

- The most comfortable way for me is to have been through that whole process of talking about it openly.

Being greeted in a friendly way was important:

- Just a warm place to go where it is warm and friendly and somebody Maori attending to me. I’d just feel more comfortable that way. That whanau feeling.

When I come in that door and there’s a Maori standing there saying “Kia ora! Come on darling!”

- I think that’s some of the sensitivity that doctors have to learn, that you feel it like, if you’re approached by a doctor who makes you feel good, talks to you, you know, they talk to you and say even “Kia ora!” Some of them can’t. I know that is not part of their learning but even learning the language for Maori they could say “Kia ora!” and you feel good towards them straight away!

One woman explained:

- There is a group of Kaumatua that I have met and I have talked to. Now, they don’t mind going to a doctor providing there is a Maori present, a Maori woman present. They seem to gain confidence from their own and the doctor that they go to see. The Maori woman who arranges it must also have confidence in that doctor and his attitude to them must be to allay their fears that not in any circumstances will they ever be taken advantage of. That if there is any treatment that need, he will discuss it with them.

Because I have dealt with the Pakeha system in my illness I had confidence in a doctor. Now, it’s only through my experience why I had confidence in a doctor but for a Kaumatua or Maori who has never ever been in that situation of having to go to a doctor before, you have to build the confidence in them first before they accept the health system.

If you respect Maori, Maori will always respect you.

Two women said that they didn’t mind who took their cervical smear as long as the person knew what they were doing:

- It doesn’t really worry me where it is or whose doing it you know; just as long as it’s done, ’cause I’d really like to know.
I don't really care about whether the doctors are Maori or Pakeha, actually. Just so long as they know what they are doing.

One woman said she would prefer to go to a clinic at Family Planning:

- I just straight away think of Family Planning because they deal with that sort of thing, that part of your body. Plus they are all females.

It was important for some of the women to have the opportunity to check the person out then make their decision:

- So being a Maori and being brought up round Maori, that's the first one I would go to. If I was sick then I keep my illness to myself until I had just had a good natter.
- I observe first their attitude towards me and once I get to know their attitude I might take my choice.

7B.4.7 Nga Tipuranga o te Ratonga Hauora Maori

Development of Health Service For Maori

The women identified two important issues to be addressed if services are to meet the needs of Maori:

- Mana Pae Rangatiratanga Rauemi
  Autonomy over Resources
- Nga Kai Mahi Maori
  Maori Health Workers

Mana Pae Rangatiratanga Rauemi

Autonomy over Resources

Some of the women referred to the Treaty of Waitangi and the concept of biculturalism when they reflected on access to resources:

- We try all to be equal in this country but firstly, I believe that Maori have a right over all other cultures in this country to maintain their status as Tangata Whenua, as indigenous people. Because of the Treaty our rights as indigenous people needs to be honoured, and I don't think that's pushed enough.
- By right we should have everything available for us as Maori. As of right, to make us well.
However the women experienced partnership as an empty idea:

- If we talk about the Treaty of Waitangi then we talk about the partnership. Maori have always been the forgotten. And the services of the Health Board has never worked for us.

- Being a minority group, an ethnic minority group, we just never, ever had the chance, we never had the chance that are available to pakeha people.

The women made strong recommendations for access to the resources:

- We cannot be measured by numbers and neither can our diseases. They can't be put down to statistics. They must be, the people, our status must be maintained as the Tangata Whenua, whether there is one of us or 200,000.

With the health services, or any government service, Maori people can't be put down to a percentage of the population. They are entitled of right to 50% resources.

I don't believe health services will ever be fully accessible or appropriate to Maori until we have control over our own health services and it doesn't matter how culturally safe an environment is, if it is not controlled by Maori, then it will never be safe.

- The resources and the decisions should be shared. The resources should be fairly distributed to the users of that system. Maori people should be given the resources to look after their own. And not have to constantly battle. Not battle, but negotiate to get their resources.

**Nga Kai Mahi  Maori**

Maori Health Workers

Within health services the women acknowledged that there were Maori people working within the services. However the numbers were minimal and the women felt that this was only a gesture towards a commitment to biculturalism:

- Bicultural to me is, it means two cultures working side by side. Two cultures understanding one another, understanding each other's culture, being able to share in conversation.

It's just so bad. It's a partnership thing that we've never ever had in New Zealand. I have never, ever seen it work. It doesn't.

I mean, they employ, one Maori Health Worker, and they say that's a bicultural component that they've put into that job description. Or the Area Health Board has adopted a bicultural policy. It's a joke. They've only employed one Maori, one Maori Health Worker for the whole of the geographical area of Christchurch. Or two Plunket women under the Treaty of Waitangi. Well that's their commitment to biculturalism for a year, for a couple of days a week. To me it's a joke. That's just a cheek putting those people there, as a face to promote their pakeha service: to us.
There was a need for alternatives for Maori:

- We have asked for funding for a marae based medical centre. We have asked for a choice in our health system that there be alternatives and be something that's more suited to our people.

But there was always a battle to be heard:

- They also are not too forthcoming in giving us the funding and anything that we do is a battle. Everything we do, not only are we battling with our own people with consultation, we are also battling with them in meeting after meeting after meeting.

And nothing had changed:

- People are still being treated like, like cards or numbers and I just don't think that if we had our own services, I reckon that we would never have that kind of thing happen.

It is no wonder Maori people don't use the health services:

- You can see that Maori women don't go to the doctor, or don't go and get check ups. You know for me, it really identifies those reasons why we don't go. It goes against our values, our way of thinking and our knowledge about how things are for us and what's best for us.

- There has to be an alternative for us. There's got to be an alternative. These things are going to have to be provided for us in the Maori way. We never, ever have had choice. They're just put there and you know, it's expected that we use them.

Health services must be provided for Maori by Maori:

- Looking at the health system and how the whole health system has been structured to cater for Maoris within that system. The lack of Maori workers within that system, right from the top levels down to the grass-roots services.

- I just think that we are the ones who know what is best for each other because we've been through things and we have an understanding about things like you know, shyness and just having that thing about bodies. I mean, for me, it doesn't matter how much a Pakeha doctor talks to me about it, it doesn't make any difference because he is not a Maori so how the hell does he know, you know. I mean, the service might be all right in that, you know, the test gets done and the results come through but all the other things like, how I feel inside and how it feels in my head, they haven't been met so it hasn't been a total thing for me. For me, I like to talk it through. I mean, that's pretty, that's really too impersonal. What we need for women - Manawahine!

- You know, those are all pressures and you never forget them and they hurt, so you go through your life getting hurt all the time, being hurt by people who should know better. ...

I mean we've been around here for yonks, you know. If they don't know us now they never will and so if they're never going to know us, why not just give us our own things and our own resources. And our own health centres.
7B.5 Nga Whakawatanga

Discussion

This research questions the accessibility of cervical screening services to Maori women interviewed in this study.

The results show clearly that ignoring cultural values and Maori women's past bad experiences are factors in their decision to:

- consult health services
- have a smear test
- return for further consultations

Maori language, values and concepts appear not to have been taken into account in the planning, implementation and delivery of health services.

Recommendations:

- Maori workers be trained, resourced and employed in the established health services. This must be monitored and evaluated by Maori.
- Resource the establishment of Marae based clinics.
- Requests for Maori support to be present at consultation, examination be respected and adhered to.
- Maori control of Maori data stored on the Cytology Register.
- Established health services staff to undertake interpersonal skills training to enhance staff's ability to communicate with Maori.
- Include Maori in policy and decision making processes for service delivery.

Summary

The resources and decisions must be shared so that partnership is not an empty experience.

Improving Maori health status will assist the preservation of Maori society, its people, values and traditions.
7C AMA'S STORY

The Policy Statements of both the Cervical Screening Programme and Canterbury Area Health Board honour the principle and the intent of the Treaty of Waitangi, however in practice the Treaty of Waitangi is not generally being addressed.

The experience of one Maori women demonstrates this. This is her story. It is told to bring to notice her experiences. There are indications that it is possible that Ama's experience could be common for other Maori women.

The names of the women involved have been changed to maintain the privacy of their identity. The content of the 'story' is how it was told in two tape recorded conversations with the researcher, one before her admission to hospital and the other after it.

Ama recently had a cervical smear taken because she was bleeding. She had never had a smear taken prior to this. She rarely went to the doctor. At that time while she was embarrassed about the procedure of having a smear, she appreciated the need for herself and other women to have one. So she wanted to encourage her friends and other women to have a cervical smear taken. This was followed up with an admission to hospital for an examination under anaesthetic. Now she worries that if she did encourage and support them, they, like her, might need to go to hospital. She is concerned that other women might have to go through an experience similar to hers.

An important person in Ama's story is her niece Cilla - a registered nurse and midwife.

Ama's story

Since the birth of her son 23 years ago Ama had not had a period at all. Then at the age of 53 years she started bleeding. At the time cervical cancer had been the focus for publicity campaigns.

I got the fright of my life when I started hearing about this cancer thing.

She wasn't feeling sick - just very tired. It was difficult to talk about and at first she didn't tell anyone. Then it was easier to make light hearted comments to her friends about getting her period again at her age.

Her family were worried because she was very tired and the year previously she had had a slight stroke. Another one of her nieces asked Cilla if she would call to see Ama without mentioning the bleeding.

Cilla took Ama's blood pressure and they talked for a long time. Eventually Ama admitted to Cilla that she was bleeding. They talked some more. Then a couple of days later Cilla brought a doctor to see Ama. It was clear that it was not a good time to suggest a smear test.

For Ama having a vaginal examination was very private. While she had, from an early age, been present when her younger brothers and sisters were born and many
births since as well as having her own babies, this was something different.

You know I was only tiny, when my brothers and sisters, well most of them after me were born at home, and I used to be the only one allowed in there and it didn't worry me because I had seen it happen so many times.....

.... but when it came to, I think just getting up on a table and opening your legs and getting someone to look at you is a different thing altogether. Even if it is for our own good, I just can't...

The doctor and Cilla tried to arrange for Ama to go directly to see a woman doctor at the hospital, without the necessity of seeing and being examined by yet another person. Cilla knew there were ways of arranging direct appointments. But she was told Ama would have to have a smear taken first by a general practitioner. Cilla found a Maori doctor in general practice. She talked to the doctor:

I explained about Ama, that it was really important that she was coming to see a Maori doctor and that she was a woman too.

A week later Ama had an appointment with the doctor. Cilla went with her.

She talked to me about it. If she had never come I would never to this day have had it. I would never have gone to have it done, ever, even if they had told me about (the doctor), I still wouldn't have gone to her on my own. There is no way I would have gone on my own.

Ama was still hoping she would not need to be examined nor have a smear taken.

Oh no, I didn't think that I was going to have anything like that at all. I thought that she was just going to talk to me and try and convince me that I should go to hospital.

She didn't want the doctor to have to examine her at that time especially as she had started bleeding again. Her concern was for the doctor - it was an awful thing to have to do.

Ama was also frightened.

Well I knew that I shouldn't have been bleeding and I was frightened because in the meantime all this thing about cancer in the womb had been on TV and was highlighted. And I was just, I was just frightened that if it was true that I had it, I didn't want to be cut up. That's what frightened me.

Her fear was that once she started having investigations maybe things would happen that she didn't have any control over.

That's what I was frightened of and that's why - I didn't want to be cut up there and then. You know, if they did find anything wrong, I would have just had to talk about it, there's no way that I would have wanted to be taken back into the theatre again to be cut up straight away.

These things were going through my mind. I was just afraid that they would find something and yet I felt well.
Having Cilia's support was really important.

*Just being there, talking to me, getting me to go and see [the doctor]*

There were times, however when Ama wished that she would just go away and not come back.

*A-ha. Often, I'd think "Oh God! here she goes again" and I thought "Why?" Because I didn't feel sick ... All I knew was that I had to open up my legs and that was what I was against to start with. When she started to tell me what happens when you have a smear I thought "Oh God! fancy getting those sort of things done to you". I still thought I didn't have to have it.*

Having the smear taken didn't actually take long, but Ama was relieved when it was over. The main thing about actually having the smear taken was the embarrassment.

*It didn't take long at all, but I still couldn't wait to get off that table and get out of it. Because knowing that I had been bleeding and having a person looking there, Oh! But the embarrassment of knowing I was bleeding while someone was looking at me. I mean that part of our lives as far as my people are concerned is very sacred and you know, you don't let people look at you while you're - while you've got that. I mean you don't. We don't go into our gardens when we've got that, so you know how sacred that is. So I think a lot of that etched in my mind about not letting people look at you at that time. I couldn't wait to get out of there.*

Cilia understood how Ama was feeling:

*Like I can understand Ama's feelings about that. It was a dilemma for me as a Maori because I understood how she felt but I also knew that it was important for her to have a smear taken. And to have to sort of try and push her along into something that she believes is wrong was really hard.*

They appreciated that the doctor talked really directly about it. She was understanding but firm.

*She was really straight up first thing. I mean she said straight away that this could be cancer. Several times Ama would say "Oh, it's nothing, it's normal." and she would say "It's not normal, it's abnormal, it could be cancer". She was very firm.*

*And not saying "What the hell are you worried about because you've got your period, it's nothing to us". She didn't say that, she just said very firmly "look it has to be done and whether you are bleeding or not, we will do it now".*

An appointment was made to see a hospital surgeon at a clinic a week later.

The smear result was normal. However the bleeding still needed to be investigated. Arrangements were made for Ama to be admitted to hospital to be examined under an anaesthetic. The surgeon wanted to examine Ama at the clinic but respected her decision and agreed to leave it until she was asleep under the anaesthetic. Ama was able to discuss her needs with the surgeon: that her niece accompany and remain with her during the examination; that this doctor be the only person who examined her; that there would be no one else observing and that she had given consent only to have an examination biopsy performed.
Ama commented on the surgeons cultural sensitivity and her willingness to comply with her requests. Ama felt this helped allay some of her nervousness and apprehension about her forthcoming hospitalisation.

The doctor wanted Ama to be in hospital the night before the examination, so on Tuesday afternoon Ama was admitted to hospital. The nurse assigned to Ama introduced herself and said she would be with her all the way through the operation. The nurse also said Ama wouldn’t need Cilia there because she would be there. Ama didn’t take too much notice because Cilia had been in to say everything was arranged. When Cilia explained to the nurse that she was a registered nurse who had worked for the hospital board and that the arrangements had been made with the doctor, the nurse seemed rather put out and replied "Oh no, you won't be allowed. You can come to the anaesthetic room but you won't be allowed into theatre."

At 11 am the next morning Ama was getting ready to go to the operating theatre. Cilia was there so Ama was feeling reasonably OK about it. Then unexpectedly a nurse administrator arrived at her bedside and said she needed to talk to Ama. There had been a misunderstanding. Only Area Health Board employees could go into theatre. As well, she said, one of the consultant surgeons had said he knew nothing of the arrangements.

Ama was stunned.

And then I don't know, I was just stunned, when she said Cilla couldn't come in - well that was just it. I just - well, I wasn't staying. I just wasn't staying. So all I said was "I don't want the operation then. I'm going home". But it was her manner as well. You know, it was like you're just a patient, - who in the hell do you think you are. Oh, I just didn't like her attitude. I really didn't. So I just said to Cilla “Come on, Let's go home." I was going home because I certainly wasn't going to theatre without her. I said to Cilla “Come here and take me home.”

Cilia informed this nurse that she was a contracted employee of the board and questioned this decision. She asked to see the hospital manager but she was not available. Cilia also attempted to contact the Maori adviser to the Commissioner without success. She felt utterly frustrated that there were no Maori liaison staff employed to who she could take this concern at this time.

Having taken care in making these arrangements to ensure everything would go smoothly, it seemed like everything was suddenly in chaos.

I mean how dare they do this. I think I said to her "Do you realise just how much it has taken us to get here? And you come here just before she is due to go into theatre and say that."

Ama dressed herself and was ready to leave. The nurses on the ward were understanding and helped her sign the forms. The operating surgeon was informed and came up immediately. She was distressed at what had happened
and persuaded Ama to stay and have the examination. It was arranged that Cilia was
able to stay with her in the anaesthetic room and wait there throughout.

_She explained to me that I should have it done now that we were here. Well I
don’t know which is which but I all I knew was at least Cilia would be close by
and anybody that was going to come in would have had to come past her._

For Cilia it was important that Ama have the examination.

_I knew that it was paramount that she have this examination. But it was at the
expense of our cultural needs. Our mana had been trampled on and our
agreed wishes disregarded. Sadly this is a reality for us as a people. It
happens far too often!_

At the same time she was really worried about what had happened:

_I was crying and upset and I just kept thinking that something was going to go
wrong. It was awful._

Ama thought about this too:

_She [the doctor] had been upset and that scared me. You see it on the movies,
if doctors get upset it means they don’t do things properly. She was upset, I
was scared and when they said that Cilia wasn’t allowed to go anywhere near
the theatre. Then they relented and said that she could come to the anaesthetic
room._

She also appreciated the support she had been given by Cilia and the doctor.

_She [the doctor] had tried so hard with me and I just kept thinking of all the
hard work that Cilla had done for me, not because it was her job but because
she loved me. I didn’t want any more trouble for her. They would just never
know how hard it was for me to say yes. It was only because she had done so
much for me that I thought that I might as well to save her worry. That’s why
I went through with it knowing that she wasn’t coming into the theatre with me
and not having anybody there. It’s just hard. I mean it could be the last
time I ever saw anybody._

When Ama woke from the anaesthetic all she could see was a person in blue. She
described how it felt:

_It's lonely and it's horrible. You wake up and you don't know a soul. And I
just felt - well I said "Where's Cilla? where's Cilla?" till they wheeled me out.
It was horrible. It was lonely. It was horrible._

_I was just waking up - and I wasn't sure if I was alive or dead anyway. I think
we need somebody we love and trust to be there for us._

Soon Cilla was with her and they went back to the ward. Ama went home in the
evening, feeling very disillusioned and angry that this could have happened.

She never wants to go through anything like that again. And certainly she wouldn’t
want that to happen to anyone else.
Discussion

While the Area Health Board Policy Statement makes a commitment to:

- the principles of the Treaty of Waitangi
- to respect the dignity of the individual
- to be responsive to consumer need and choice

this was not borne out in practice.

The Area Health Board Policy Statements are therefore experienced by Maori people as meaningless and empty. This woman's experience demonstrate that there was little awareness, appreciation or respect for her needs as a Maori woman.

This has specific implications for the Cervical Screening Programme. What are the consequences of implementing the Cervical Screening Programme if the follow up and treatment services do not address the cultural needs of Maori women, one of the Programmes priority groups?

It has broader implications for all health services.

Questions must be asked about the way in which the Area Health Board's Policy Statement is implemented in practice throughout all services?
CONCLUSION

The Canterbury Cervical Screening Programme, an integral part of the National Cervical Screening Programme, includes a highly complex set of interrelationships existing in a political, social, economic and cultural environment. These relationships include various groups of people, those developing and implementing the Cervical Screening Programme; those providing the cervical smear testing services; those advocating for women as well as women from a wide spectrum of circumstances, experiences, and understandings, on whose behalf the Programme, the services and the advocates all deem to be working.

The purpose of this evaluation has been to document the implementation process of the Canterbury Cervical Screening Programme and its effects on cervical screening practices, in terms of both providers and users of the services. An important focus for this evaluation has been on identifying the perspectives of these interest groups involved in the Cervical Screening Programme and on clarifying in the relationships between them in order to develop an understanding of interactions between them and the implications of these relationships.

The background study provides an overview of the relationships and the circumstances which contributed to the Programme's developmental phase and which have influenced its ongoing implementation. The history of the Cervical Screening Programme spans 30 years, in which there was considerable debate and tension. These tensions have been long established in the development of health services but have been exacerbated in this instance by the particular political and historical context of the development of the Cervical Screening Programme over the last five years, namely the Cartwright Inquiry.

Studies of the implementation of Canterbury Cervical Screening Programme and general practitioners' perspectives indicate that there has been unanimous agreement about the need for all women to have regular cervical smears to prevent cervical cancer. There is also widespread recognition of the importance of organised cervical screening. Both groups are concerned for the well being of women.

However there are differing rationalities for practicing depending on whether one is involved in implementing the Cervical Screening Programme, or providing cervical smearing services. The Cervical Screening Programme is concerned with equity and efficiency. It's primary tool is the Cytology Register and so an important measure is the number of enrolments on this register. The programme is dependent on general practitioners to make enrolment on the register available to women yet there is evidence that locally relatively few practitioners are systematically enrolling women on the Cytology Register. General practitioners are concerned with issues of professional autonomy and the privacy of the consultation relationship, fundamental to their practice. They are concerned that some of the policies of the Programme are not flexible enough to take account of their need to make judgements based on individual consultations. The Cervical Screening Programme recommendations for screening have been made to provide a population based service developed mainly from an epidemiological perspective. In contrast general practitioners work from a clinical base and are concerned to meet the needs of individual women.

The relationship between the two groups becomes one of competition and confrontation commonly described in terms of battles and fighting. In this environment there is little room for negotiation and reasonable compromise. Each position tends to blame the other with failure to comply with their position. In this instance the Cervical Screening Programme might blame general practitioners for not enrolling women on the
register while general practitioners might complain that the Programme is duplicating their services and intervening in the patient doctor relationship.

However, as a consequence of the implementation of the cervical screening programme general practitioners have focused more on cervical cancer and as a result they have increasingly invested in developing their recall systems and have raised the quality of their own smear taking.

The women's perspective indicates that in general most women want their general practitioner to be their smear taker. While very few women were aware of the Cytology Register, when informed of its function most women said they would want to be enrolled on it. However cost is an important issue and many women indicated that increasingly they were consulting their general practitioner only in emergencies or waiting until there were several issues to be dealt with. In these circumstances having a cervical smear taken is not a priority.

Maori women expressed their concern that both the Programme and screening services have little awareness, appreciation or respect for the needs of Maori women. They questioned the gap between the Area Health Board Policy Statement confirming a commitment to the Treaty of Waitangi and the empty gestures they frequently experience when they come face to face with people providing health services. They reinforced once again that there must be Maori health workers and marae based services. Resources to develop these initiatives should be more readily available. Maori should have autonomy over these resources.

As a result of the Cartwright Inquiry the boundaries between women and health practitioners have changed. Women have increasing expectations over what they may expect in terms of health care; these expectations have now to be consolidated into the health system.

Issues of informed consent and biculturalism continue to be fundamental issues to be addressed. If these operate to make management of health systems difficult that is no reason for removing or marginalising them. It means finding new solutions and processes for negotiating and co-operating.

The process will be neither easy nor straight forward. There are many tensions to be resolved. However the sustainability of the Cervical Screening Programme is dependent on the co-operation negotiated between these groups involved in resourcing, organising and providing cervical screening services.
APPENDIX 1  CHRONOLOGY OF EVENTS

1928 Dr Papanicolaou demonstrated that cancer cells could be detected by a vaginal smear examination.

1943 'Pap' smear able detected pre malignant cells in women who had no symptoms of disease.

1940's -1990's Screening programmes for cervical cancer introduced by various countries all over the world.

1946-1955 Some GP's taking cervical smears.

1955 National Women's Hospital Auckland established policy that all patients over 35 years of age attending the out patients department or admitted to the gynaecological wards were to have cervical smears taken.

1962-65 Royal New Zealand College of General Practitioners attempted to establish a population based screening programme which included a national cytology and histology register. The register ceased to operate in 1965.

1965-1970's Scepticism regarding the effectiveness of cervical screening being taught at the Post Graduate School of Obstetrics and Gynaecology Auckland Medical School.

1970-1980's National and International debate over these views. Some General Practitioners taking cervical smears.

1985 The New Zealand Society of Cytology developed Recommendations for cytology, minimum requirements for cytology laboratories and advocating a National Cytology Register.

1985 A meeting was called by the Department of Health and the Cancer Society of New Zealand on 5 November 1985 to discuss Screening For Cervical Cancer in New Zealand.


1897 June Metro magazine published an article 'An "Unfortunate Experiment" At National Women's.' by Sandra Coney and Phillida Bunkle

1987 10 June The Minister of Health, Hon. Michael Bassett, instituted an investigation and appointed Judge Sylvia Cartwright to pursue the inquiry.

1988 5 August The "Cartwright Report" was released recommending in Term of Reference Nine that a nationally planned population based cervical screening programme should be implemented immediately.

1988 August A deadline of November 1989 was set for the launching of the programme.

1988 6-8 December National Hui on Cervical Screening at Porirua Police College.
1988-89  Pilot studies of four community projects: Kaikohoe and Wanganui - Maori women; Kawerau and Nelson - low income women.

1989 April  The National Cervical Screening Implementation Unit established within the Department of Health. Cytology registers by Area Health Boards were piloted in Marlborough and Wanganui.

1989 November  Ministerial Review Committee Reported on The Implementation of A National Cervical Screening Programme.

1989 December  The Expert Committee established.

1990 February  Restructuring of Department of Health.

1990 5 June  National Co-ordinator took up her appointment.

1990 July  Review of the National Cervical Screening Programme in New Zealand by Dr Judith Stratton, Division of Public Health University of Western Australia.

1990 23 July  The Manager of the Canterbury Area Health Board took up her appointment.


1990 November  General Election

General Practitioner contracts were a controversial issue. Women's Health Issues and cervical screening a topical issue.

1991 February  The Expert Group was disbanded

1991 May  Advisory Committee appointed to monitor the evaluation and implementation of the Cervical Screening Programme.

1991  Standards of Competency for Smear Takers and Guidelines for the Training of Nurse, Midwife and Lay Smear-Takers published. (Had been issued previously).
APPENDIX 2  TELEPHONE QUESTIONNAIRE

code no [   ]

TELEPHONE QUESTIONNAIRE

Hello. My name is ...(name of interviewer)... Could I speak to ...(name of woman)... please. Thank you.

(If not available, arrange time when appropriate to call back)

...(name of woman)..., my name is ...(name of interviewer).... Did you receive a letter last week about the cervical screening programme?

If did not receive letter give a verbal summary (see card 1).

Are you happy to talk to me about this study. (If 'no', conclude the telephone call with thanks)

Is it convenient to talk now, or would it suit you better if I phoned another time. It will take about 20 minutes. (If inconvenient arrange another time to call and conclude the telephone call with thanks)

Before we go any further, the study includes women aged between 20 and 69 years. Are you within that age group?

(If 'no' explain that for this particular study their information is not required and conclude the telephone call with thanks).

OK. We'll get started then. If there are any questions you don't wish to answer please just say so and we will move onto the next question.
SECTION 1.

We want to know what women know about the cervical smear test so the first questions are about that.

1. Have you heard of the term cervical smear?
   1. yes
   2. no
   8. not sure
   9. refused

If "no" give an explanation of cervical smear test (see card 2) and go to question 6, page 4.

2. Here are some statements about cervical smears. Could you tell me how true you think each of these statements is. First I will read out the possible replies.

   1. definitely true
   2. probably true
   3. not sure
   4. probably not true
   5. definitely not true
   8. don't know
   9. refused

2a. A cervical smear is a preventative test for cancer.

2b. A cervical smear requires an internal, vaginal examination.

2c. Only doctors can take cervical smears.

2d. Other properly trained health workers may take cervical smears.
3. The next set of statements are about which groups of women need to have cervical smears. I will read out each statement then will ask you how true you think it is.

3a. Older women, say over 60 do not need a cervical smear.

3b. Women who have never had children do not need a cervical smear.

3c. Any woman who has ever had sexual intercourse should have a cervical smear.

3d. Women who have had a hysterectomy do not need a cervical smear.

3e. Women do not need a cervical smear after menopause/change of life.

4. I will now read you some statements about how often cervical smears need to be taken and again ask how true you think each statement is.

4a. Women who need cervical smears should have them taken regularly.

4b. Women who need cervical smears should have one about once a year.

4c. Women who need cervical smears should have one about every three years.

5. Where did you get your information about cervical smears from? Tick all that apply

1. personal networks - family/friends
2. self research - reading
3. doctor
4. nurse
5. other health professional - specify:
6. Media - TV radio
7. other - specify
88. don't know
99. refused
Have you ever had a cervical smear taken?

1. yes
2. no
88. don’t know / not sure / don’t remember
99. refused

If ‘yes’ go on to Section 2: question 7 page 5.

If ‘no’ or ‘don’t know’ go on to Section 3: question 20, page 13.

If ‘refused’ check that the woman is willing to continue with the interview. Encourage her to answer the question. If she still does not wish to answer the question go to Section 5, question 29, page 19.
SECTION 2.

7. Do you have a smear taken regularly?
   1 yes
   2 no
   99 refused

If 'yes' ask question 7a, otherwise go to question 8.

7a. About how often?
   1 more than once a year
   2 about once a year
   3 about every eighteen months
   4 about every two years
   5 about every three years
   6 between 3 and 5 years
   99 refused

8. How long ago did you have your last smear?
   1 within the last year
   2 between 1 and 2 years ago
   3 between 2 and 3 years ago
   4 more than 3 years ago
   88 don't remember or don't know
   99 refused

If answer is 'more than 3 years ago', 'don't remember', 'don't know' or 'refused' ask question 8a, otherwise go to question 9.
8a. There are a number of reasons women give for not having had a cervical smear taken. I will read a list of these. Could you tell me if any of them apply to you?

*Tick all that apply*

1. I didn't think it was necessary to have another smear taken
2. I didn't know where to go
3. forgot
4. too busy
5. I'm not sick
6. transport is a difficulty
7. embarrassed / shy - didn't like to ask
8. it costs too much
9. it may hurt
10. I'm afraid of the result
20. I didn't want a man to do it
30. I didn't want a woman to do it
40. the doctor didn't suggest it
50. I didn't want my GP to do it
60. money for my children's health come first
70. I couldn't get anyone to look after the children while I went to the doctor
80. I've have had a hysterectomy

**Are there any other reasons?**

90. other - specify

.................................................................
.................................................................
.................................................................
88. don't know
99. refused
9. **Who took your last smear?**

1. female GP
2. male GP
3. practice nurse
4. specialist
5. Family Planning Clinic
6. independent nurse
7. other - specify
8. Don't remember
9. refused

10. **Last time you had a smear taken did you arrange an appointment especially for that?**

1. yes
2. no
8. don't remember
9. refused

*If 'no' ask question 10a and 10b otherwise go to question 10c.*

10a. **When you had your last smear taken did you ask for it to be taken or did your doctor/nurse suggest it?**

1. self
2. doctor/nurse
8. don't remember
9. refused
10b. Was it part of a post natal visit, to do with contraception or family planning matters, or change of life - in other words to do with 'women's' matters?

   1 yes
   2 no
   88 don't remember
   99 refused

10c. Before you had your last smear taken did you get a letter or phone call beforehand reminding you to have the test done?

   1 yes
   2 no
   88 don't remember
   99 refused

11. Next time you have a smear taken will you go back to the same place?

   1 yes
   2 no
   88 don't know
   99 refused
12. How satisfied are you with the way in which the test was done? I have a number of options. Which one would you choose?

1. very satisfied
2. satisfied
3. dissatisfied
4. very dissatisfied
88. unsure / don't know
99. refused

Comment.................................................................................................................................
...........................................................................................................................................

13. Did you receive information giving you the result of your cervical smear?

1. yes
2. no
88. don't remember
99. refused

If 'no', 'don't remember' or 'refused' go to question 15.

14. How satisfied are you with the way the results were explained to you? I have a number of options. Which one would you choose?

1. very satisfied
2. satisfied
3. dissatisfied
4. very dissatisfied
88. unsure / don't know
99. refused

Comment.................................................................................................................................
...........................................................................................................................................

15. Have you had any follow up tests such as a repeat smear or another examination?
1 yes
2 expect to have a follow up test
3 no
88 don't know
99 refused

If 'yes' or 'expect to have a follow up test' ask question 15a, otherwise go to question 16.

15a. What did you have done / expect to have done? There are several possibilities. Could you tell me which applies to you? Read out the options. Tick all that apply.

1 repeat smear
2 colposcopy, that is where the specialist looked at your cervix through a microscope
3 cone biopsy, that is where the specialist removed a cone shaped section of your cervix while you were under an anaesthetic.
4 other (specify)
88 don't know
99 refused

Now we are about half way through.
16. Do you know of any other places where you could have a smear taken?

   1 yes specify
   2 no
   99 refused

17. In the future which person would you most prefer to take your smear? I will read out the complete list of possibilities first, then go back to each one separately. Give just one answer. Would it be: (Read out complete list before getting response)

   1 own GP
   2 another GP who is female
   3 another GP who is male
   4 Practice nurse
   5 Family Planning Clinic
   6 A Maori woman from your community who has been trained to take cervical smears
   7 A Pacific Island woman from your community who has been trained to take cervical smears
   8 A woman from a community health clinic who has been trained to take cervical smears

Are there any other options you would prefer?

   9 other - specify
   88 don’t know
   99 refused

17a. Can you tell me why you would prefer this person?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
18. In the future which place would you most prefer to have your smear taken? Again I will read out the complete list of possibilities first, then go back to each one separately. Would it be: (Read out complete list before getting response)

1. GP surgery
2. specialist rooms
3. Family Planning
4. a clinic at work
5. a clinic at the Marae
6. in your own home
7. with a group at a specially arranged place
8. at a women's health centre in the community

Are there any other options you would prefer?

9. other - specify
88. don't know
99. refused

18b. Can you tell me why you would prefer this place?

Comment...........................................................................................................................
...........................................................................................................................

19. Has the cost of going to the doctor ever put you off having a cervical smear test?

1. yes
2. no
88. don't know
99. refused

Comment
...........................................................................................................................
...........................................................................................................................

Section 3 concerns women who have never had a cervical smear taken so go next to Section 4: question 25, page 16.
20. There are a number of reasons women give for not having had a cervical smear taken. I will read a list of these. Could you tell me if any of them apply to you? Tick all that apply.

1. I didn’t know about it (cervical smears)
2. I didn’t think it was necessary (to have a smear taken)
3. I didn’t know where to go
4. forgot
5. too busy
6. I’m not sick
7. transport is a difficulty
8. embarrassed / shy - didn’t like to ask
9. it costs too much
10. it may hurt
20. I’m afraid of the result
30. I didn’t want a man to do it
40. I didn’t want a woman to do it
50. the doctor didn’t suggest it
60. I didn’t want my GP to do it
70. money for my children’s health come first
80. I couldn’t get anyone to look after the children while I went to the doctor
90. I’ve have had a hysterectomy

Are there any other reasons?

95. other - specify
88. don’t know
99. refused
21. Do you know of places where you could go to have a smear taken?

   1 yes - specify: ........................................
   2 no
   99 refused

22. If you were to have a cervical smear taken in the future which person would you most prefer to take it? I will read out the complete list of possibilities first, then go back to each one separately. Give just one answer. Would it be: (Read out complete list before getting response)

   1 own GP
   2 female GP
   3 male GP
   4 Practice nurse
   5 Family Planning Clinic
   6 A Maori woman from your community who has been trained to take cervical smears
   7 A Pacific Island woman from your community who has been trained to take cervical smears
   8 A woman from a community health clinic who has been trained to take cervical smears

Are there any other options you would prefer?

   9 other - specify
   88 don't know
   99 refused

22a. Can you tell me why you would prefer this person?

........................................................................................................................................
........................................................................................................................................

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23. If you were to have a cervical smear taken in the future which place would you most prefer to have your smear taken? Again I will read out the complete list of possibilities first, then go back to each one separately. Would it be: (Read out complete list before getting response)

1. GP surgery
2. specialist rooms
3. Family Planning
4. a clinic at work
5. a clinic at the Marae
6. in your own home
7. with a group at a specially arranged place
8. a women's health centre in the community

Are there any other options you would prefer?
9. other - specify
88. don't know
99. refused

23a. Can you tell me why you would prefer this place?
Comment.................................................................................................................................

24. Has the cost of going to the doctor ever put you off having a cervical smear test?
1. yes
2. no
88. don't know
99. refused

Comment
.................................................................................................................................

We are about half way through
SECTION 4
Now I have some questions about the cervical screening register that is being set up around the country.

25. Have you heard about this register?

   1 yes
   2 no
   88 not sure
   99 refused

If 'no', 'not sure' or 'refused' give information about the register (see card 3) and go to question 27a.

If 'yes' ask 26:

26. I would like to read some statements about the cervical screening register. Could you tell me how true you think each of these statements is. I will read out the possible replies:

   1 definitely true
   2 probably true
   3 uncertain
   4 probably not true
   5 definitely not true
   88 don't know
   99 refused

I will now read out the statements:

26a. Every woman who has a cervical smear taken will be automatically enrolled on the register.

26b. The register will ensure that women are reminded to have another smear taken when it is next due.

26c. Women are able to find out what information is on register about themselves.
27. Are you enroled on the cervical screening register?
   1 yes
   2 no
   88 don't know
   99 refused

If 'no' or 'don't know' ask question 27a, otherwise go to question 28.

27a. Would you be willing to be enroled on the cervical screening register? I will read out the options first. You tell me which applies to you.
   1 yes, I am willing to be enroled
   2 yes, but first I need more information
   3 no, I am not willing to be enroled
   88 don't know
   99 refused

28. Now I have some few questions about cervical cancer.

28a. Can you tell me whether among New Zealand women cervical cancer is: Read out the options.
   1 increasing
   2 decreasing
   3 staying about the same
   88 don't know
   99 refused
28b. Cervical cancer is the most common form of cancer among New Zealand women. Is this: 
Read out the options.

1 definitely true
2 probably true
3 not sure
4 probably not true
5 definitely not true
88 don't know
99 refused

28c. Cervical cancer can usually be prevented from developing if it is detected in the early stages. 
Read out the options.

1 definitely true
2 probably true
3 not sure
4 probably not true
5 definitely not true
88 don't know
99 refused
SECTION 5.

To finish could you give me some personal details to provide some general background for the study and to make sure our replies are representative of the population as a whole.

29. Do you mind telling me about your age? I will give you some ranges. You can tell me where you fit.

   1 20 - 24 years
   2 25 - 34 years
   3 35 - 44 years
   4 45 - 54 years
   5 55 - 64 years
   6 65 - 69 years
   99 refused

30. What ethnic group do you belong to?

   1 New Zealand European/European
   2 New Zealand Maori/part Maori
   3 Pacific Island group
   4 Other (specify) ....................
   99 refused

If 'Maori' or 'part Maori' ask questions 30a otherwise go to question 31.

30a. To which tribe or tribes do you belong?

   specify 1 ..............................
   2 ..............................
   3 ..............................

If a tribe(s) is named ask question 30b otherwise go to question 31.
31. Who are the persons that usually live in the same house as you? I will read out the possibilities you tell me which apply to you. Include children and babies:

1. husband/partner
2. my children
3. other related adults
4. other related children
5. other persons (such as flatemates or boarders)
6. I live alone
99. refused

If children ask question 31a.

31a. How many dependent children do you have?
Code by number
32. Can you give me an indication of your income? (If you and your husband/partner share a combined income estimate the total income bracket). Again, if I give you some income brackets you can tell me where you fit?

1 Under $20,000
2 $20,000 - 29,000
3 $30,000 - 39,000
4 $40,000 - 59,000
5 $60,000 or over
88 don't know
99 refused

32a. Do you have access to money for your own personal use for things such as going to the doctor

1 yes
2 no
99 refused

32b. Are you receiving a Social Welfare, an Education or an A.C.C. benefit?

1 yes - specify ....................
2 no
88 don't know
99 refused

If 'no' or 'don't know' ask question 33, otherwise go to question 34.
This next section is about work

33. Are you in paid work at the moment?
   1 yes
   2 no
   99 refused

If yes ask question 33a, otherwise go to question 34.

33a What is your main occupation?
Get details and code later.
Specify ......................

34. Finally I want to know about schooling and training. What is your highest level?
   1 no formal qualification
   2 school certificate
   3 university entrance/6th from certificate
   4 7th form qualification
   5 tertiary qualification eg teachers college; nursing; university qualification
   6 other - specify
   88 don't know
   99 refused
Those are all the questions from me. Thank you very much for your time. You have been very helpful.

Is there anything you want to ask me now.

If you have any queries or feel uncomfortable about any of the questions later on please do not hesitate to contact Valerie Norton. You have her name and phone number on the letter. Do you want those details again? (3382-678)

There is a Department of Health pamphlet on cervical screening available. Would you like it to be sent to you?

yes/no (note on list)

It will be about 2 months before the report from this study is finished. Would you like to receive a short summary of the main results then.

yes/no (note on list)

Should it be sent to this address or would you like it sent somewhere else?

Alternative address

Thank you. Goodbye.
Card 1.

Introductory Information: Summary of Letter

*If did not receive letter give a verbal summary*

I am involved in a study about cervical screening services in Canterbury for the Department of Health research unit. I want to find out what kind of cervical screening services women in Canterbury would like.

I am telephoning now to ask you to help plan these services in the future by answering some questions about your use of cervical screening services and whether there are ways in which the services could better meet your needs. It will take about 20 minutes of your time.

Your name has been selected from the 1990 electoral roll along with 700 other women. Even if you have never had a cervical smear, or do not know what it is about, your opinions on health services are an especially important source of information.

I assure you that anything you say will be totally confidential.

Card 2.

Question 1. Do you know what a cervical smear is?

*If answer is "no" give an explanation of cervical smear test*

A cervical smear test is a way of checking the health of the cervix (or neck of the womb). Using either a small wooden spatula or a tiny brush some cells are gently wiped from the surface of the cervix which are sent to the laboratory for testing. A cervical smear will show if there have been any changes in these cells which could develop into cancer. If changes are found treatment can be given to remove the changed cells and prevent cervical cancer from developing.
Card 3

Question 25. Have you heard about this register?

*If "no" give information about the register*

The national register provides a back up to the services already provided by your doctor (or the person you choose to take your cervical smear).

Enrolment on the register is voluntary. Women sign a consent form to confirm their agreement to be enrolled.

Information about your cervical smear will be sent to you and your doctor. The register will ensure that women are reminded by their doctor (or the person chosen to take the cervical smear) to have another smear taken at the right time and that when a woman has an abnormal smear she is given adequate treatment.
REFERENCES CITED


Holmes A. Canterbury Area Health Board. (Unpublished Report)


