

**INFORMING THE DEVELOPMENT  
OF A COMMUNICATIONS  
CAMPAIGN FOR THE NATIONAL  
CERVICAL SCREENING  
PROGRAMME**

RESEARCH REPORT FOR

**NATIONAL SCREENING UNIT,  
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***AUTHORS***

Elizabeth Fisher - Lead Qualitative Researcher  
and New Zealand European Women's Research

Kataraina Pipi - Maori Women and Maori  
Community Key Informant Research

Jo Howearth - Maori Stakeholder Research

Nancy Sheehan - Pacific Women and Pacific  
Community Key Informant Research

Sinai Hemaloto - Pacific Women's Research and  
Pacific Stakeholder Research

Lisa Star and Kerry Murphy - New Zealand  
European Stakeholder Research

Dr Allan Wyllie - Director of Social Research

# CONTENTS

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|      |   |     |
|------|---|-----|
| 1.   | EXECUTIVE SUMMARY .....   | 3   |
| 1.1  | Introduction.....   | 3   |
| 1.2  | Service Users, Lapsed Users And Non-Users .....                               | 3   |
| 1.3  | Community Key Informants .....  | 6   |
| 1.4  | Stakeholders .....  | 6   |
| 1.5  | Overall Recommendations .....   | 7   |
| 1.6  | Recommendations For Maori Women .....   | 9   |
| 1.7  | Recommendations For Pacific Women .....                                       | 10  |
| 1.8  | Recommendations For Older NZ European Women.....                              | 11  |
| 2.   | INTRODUCTION.....   | 12  |
| 2.1  | Research Objectives.....  | 13  |
| 2.2  | Research Method And Sample.....   | 15  |
| 2.3  | Research With Service Users, Lapsed Users And Non-Users.....                  | 15  |
| 2.4  | Research With Community Key Informants .....                                  | 17  |
| 2.5  | Research With Stakeholders .....  | 18  |
| 3.   | RESEARCH FINDINGS: SERVICE USERS/LAPSED USERS/ NON-USERS .....                | 20  |
| 3.1  | Overall Context: Across Cultures, The Gisborne Enquiry Still Resonates .....  | 20  |
| 3.2  | Cultural Drivers And Social Norms .....                                       | 23  |
| 3.3  | 'Relationships And Type Of Connection' Impact Efficacy Of Communications..... | 30  |
| 3.4  | Two Key Drivers Underpin Attitudes To Cervical Screening .....                | 33  |
| 3.5  | Perceptions of The Screening Process.....                                     | 39  |
| 3.6  | Motivations Can Be Positive And Negative .....                                | 49  |
| 3.7  | Barriers Are Primarily Emotional With Several Working At Once .....           | 55  |
| 3.8  | Decision-Making; Things Change.....   | 65  |
| 3.9  | Using Positive Triggers To Overcome Barriers.....                             | 71  |
| 3.10 | Findings From The Regions .....   | 76  |
| 3.11 | Perceptions Of The Programme, New Legislation And Access To Data .....        | 78  |
| 4.   | EFFECTIVE COMMUNICATIONS.....   | 82  |
| 5.   | COMMUNICATION VEHICLES.....   | 87  |
| 5.1  | Overall .....   | 87  |
| 5.2  | Maori Women.....  | 87  |
| 5.3  | Pacific Women .....   | 90  |
| 5.4  | Older NZ European Women.....  | 91  |
| 6.   | RESPONSES TO CURRENT COMMUNICATION MESSAGES .....                             | 92  |
| 7.   | DISCUSSION .....  | 93  |
| 8.   | RESEARCH FINDINGS: COMMUNITY KEY INFORMANTS.....                              | 95  |
| 8.1  | Maori Community Key Informants .....  | 95  |
| 8.2  | Pacific Community Key Informants.....   | 102 |
| 9.   | RESEARCH FINDINGS: STAKEHOLDERS .....   | 104 |
| 9.1  | Knowledge/Understanding And Perceptions Of Programme .....                    | 104 |
| 9.2  | Concerns About The Programme .....  | 106 |
| 9.3  | Information Provided Under New Legislation .....                              | 109 |
| 9.4  | Support Needed To Deliver Appropriate Messages .....                          | 111 |

# **1. EXECUTIVE SUMMARY**

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## **1.1 INTRODUCTION**

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- This qualitative research was undertaken to inform the development of communication strategies to promote greater use of cervical screening services
- There was a particular focus on Maori and Pacific women, as they are under-represented among current service users
- Qualitative research was undertaken with 46 women who were service users, lapsed users and non-users (19 were Maori, 15 Pacific and 12 Pakeha)
- There were also interviews with seven Maori and three Pacific community key informants and 58 stakeholders, including 36 smarttakers and 22 influential others (e.g. media, NGOs)
- The research was undertaken between late September and December 2004

## **1.2 SERVICE USERS, LAPSED USERS AND NON-USERS**

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### **THERE ARE STILL MISUNDERSTANDINGS ABOUT CERVICAL SCREENING**

- Many women, Pacific especially, still think of cervical screening as a test for cancer. In general older NZ European women are more likely to understand the 'why and what', but even 'informed' women have incomplete information
- Women comment that they know little about the cause of cervical cancer and want to know how they can prevent it. Few women had heard of the human papilloma virus. The idea of a virus causing cancer was foreign and non intuitive. There is a feeling that everyone has cancer cells and that something 'just triggers' it
- Across cultures, women want to know how to care for themselves better

### **EMBARRASSMENT AND LITTLE DISCUSSION ABOUT CERVICAL COMPARED WITH BREAST SCREENING**

- While across cultures there is some uncertainty about 'what goes on inside' there is more spiritual significance accorded to the reproductive area for Pacific and Maori compared with NZ European. However for Pacific and NZ European especially, there is very little discussion about 'down there' or anything to do with the screening process. Combined with the strong emotional barriers to screening, not feeling able to talk about the process can deepen feelings of anxiety around subsequent screenings

### **A RATIONAL DESIRE FOR INFORMATION BUT EMOTIONAL RESISTANCE IS STRONG**

- The women talked to in the research are interested in knowing more about cervical screening but fear that knowing more will be distressing, thus they will rarely pick up brochures (especially lapsed users). In fact, when women are asked to look over the brochures, learning diminishes their fears. For example, they learn that abnormal smears rarely mean cancer and that cervical cancer typically has a long gestation

### **MOTIVATIONS CAN BE POSITIVE AND NEGATIVE**

- Life-stage has a huge impact on the decision to be screened. Child bearing women and younger women receive high encouragement from health professionals and, mothers in particular, have high motivation to be screened i.e. to be here for the children. Motivations such as fear of cancer and the health scares of family and friends can be both motivations or barriers, depending on individual attitudes

### **BARRIERS ARE PRIMARILY EMOTIONAL WITH SEVERAL WORKING AT ONCE**

- Decision making around screening can precipitate a subtle inner contemplation about death – misunderstandings about abnormal cells still terrify too many women. During decision making women welcome the efforts by others to encourage and support them to get screened
- Without primary motivations such as being here for the children or a personal health scare, women struggle to convince themselves that they need to be screened, emotional barriers predominate and users can quickly lapse

### **PERCEPTIONS OF THE PROGRAMME**

- There is greater awareness about the programme for Maori and NZ European women than Pacific
- The programme is often confused with other cancer prevention campaigns. The cervical screening programme currently lacks an identifiable image, a positive emotive 'essence' and a folklore of understanding. The programme needs a sense of 'collective' (we do this as women), importance and connection (we do this for ourselves and our whanau)
- The reminders to get screened are seen as a primary benefit of the programme
- Many women have no idea about the risk to NZ women from cervical cancer, or whether the programme is effective or not
- Across cultures, the Gisborne enquiry still resonates. Past negative publicity appears to have contributed to the current high coverage rates, rather than a

fundamental understanding of and commitment to the benefits of being screened. Due to the current misinformation and a lack of emotional comfort with screening, ongoing committed support is at risk. However the NCSP has been successful in creating a strong sense in women that “I should do this”. This is particularly so for older NZ European women

- Maori and Pacific women have felt less engaged with the programme due to lack of culturally appropriate services and communications that they can identify with

#### **ACCESS TO DATA AND AWARENESS OF NEW LEGISLATION**

- Attitudes to access to data are polarised. Maori women have heightened sensitivity to access and less trust that the system will respect their data
- In general, women across cultures were unaware of the changes to legislation. The right to opt off the register is already expected

#### **IT'S ABOUT THE WHOLE EXPERIENCE; BEFORE, DURING AND AFTER**

- When asked how the screening process could be improved in any way, women say that fundamentally it is difficult to make the experience better. However they comment on all the many small things that make them feel better about it. It is the small things that make women feel that they matter; that they are not just a ‘number’ to be processed, an illness waiting to be found
- There are many points within the decision making and actual screening process that have potential to be improved or used to pre-empt lapsing and to trigger more understanding and commitment

#### **COMMUNICATIONS WORK BEST WHEN THEY TRULY REFLECT THE VALUES OF THE TARGET GROUPS**

- Communications need to be perceived as being authentic – ‘If I cannot see myself in there then the message is for others’. The appropriate message and messenger is critical for Maori and Pacific. Provide the right information with the right messenger in the right environment and women will want to know. For respected information dissemination for Maori and Pacific, think in an oral and circular manner (face to face community talk) not written and linear (facts from distant authority)

## **1.3 COMMUNITY KEY INFORMANTS**

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### **PACIFIC COMMUNITY KEY INFORMANTS**

- Pacific Community Key Informants feel that there is insufficient marketing activity and engagement with Pacific women by the programme
- Another issue is the perceived lack of smear takers and health promoters that are available for Pacific women

### **MAORI COMMUNITY KEY INFORMANTS**

- The Maori Key Informants affirmed the need for support for the National Cervical Screening programme. They acknowledged the contributions of Maori practitioners and service providers in working together with Maori women
- The importance of establishing strong relationships with Maori women was a key factor in ensuring Maori women's needs are met. Determining Maori specific approaches to communications was recommended
- Support for regional approaches to screening, education for health professionals about working with Maori, about cultural safety and monitoring cervical screening service provision were highlighted as useful strategies for increasing the numbers of Maori women who are benefiting from the programme

## **1.4 STAKEHOLDERS**

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### **HEALTH PROMOTION**

- A national advertising campaign is needed to support the local work of health promoters by increasing the profile of the programme
- Whilst delivery methods are locally determined according to regional cultural contexts, messages need to be consistent throughout the country. To enable this, communication from the Ministry to local providers is required
- For targeting and planning purposes, health promoters need access to regional statistics

### **SMEARTAKERS**

- There is a need to find effective ways of informing primary care about cervical screening, especially any changes made to the programme. Communications

struggle to get attention from General Practitioners (GPs) and Practice Nurses (PNs) who are too busy to read everything they receive. Effective ways of informing primary care may include:

- Engagement through PHOs
- GP professional development credits
- GP and practice nurse education programmes
- Resourcing smarttakers with a straight forward pamphlet outlining the Health (National Cervical Screening Programme) Amendment Act 2004

## **MEDIA**

- By proactively informing media, the National Cervical Screening Programme (NCSP) profile may rise within media. This may help to:
  - Develop a relationship between NCSP and the media
  - Build media empathy with the programme
  - Counter remaining negative perceptions and prevent misinformed reporting

## **1.5 OVERALL RECOMMENDATIONS**

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### **FUTURE COMMUNICATION MESSAGES**

It's about:

- Self care
- Well health
- Being holistic - it's about the whole woman
- Taking care of each other as women, for women, by women – “hook a ‘sista’ up”
- A woman's intuition and self knowledge
- ‘Protecting love’ - me, my family, my daughters, my friends, our communities
- Life stage
- Cultural and spiritual significance
- Moving away from ‘shame’

### **COMMUNICATION VEHICLES**

- TV national campaign – use TV as a strategic anchor to bring the subject into the light, help create talk and encourage support and ‘nudging’
- Use community based vehicles – real life stories, opportunity to reflect and/or korero/talanoa (talk/conversation/discussion)
- Use places grounded in community – hairdressers, Plunket, supermarkets, housie, community news papers
- For stakeholders – greater emphasis is needed on creating clear processes to disseminate information both nationally and locally

### **CONSIDER A CHANGE IN DIRECTION**

- For Maori and NZ European women, turn the conversation around – make stronger connections with women’s wellness and self-empowerment. For Pacific women its about a sense of place and responsibility
- Create a stronger, warmer, more holistic identity and image
- Include men in the younger NZ European and Maori women’s conversations
- Consider setting up dedicated women's screening clinics (i.e. all types of screening)
- Ensure consistency of messages within the medical profession and the general public

### **ENSURE CULTURAL AUTHENTICITY AND RELEVANCE IN ALL COMMUNICATIONS**

- The right message, the right messenger, the right environment, at the right time
- Use life stage and culture to begin tailoring messages
- Make wellness and well health checks an everyday conversation
- Work with insiders to empower and resource local communities to deliver messages
- Think of information dissemination in a circular manner (community talk) not linear (facts from distant authority), think oral not just written
- Talk to the intuitive and unconscious as well as the rational - use real life storytelling, metaphor and symbolism, and present statistics in a holistic context
- Provide an emotional context and create a sense of personalised connection (real life stories) wherever possible
- Inspire more conversation and openness; make it personal, social, and fun



- Engage other voices - husbands, lovers and family, and encourage 'niggling' – have you been yet? "Hook a 'sista' up"
- Get creative – avoid an overly serious 'social marketing' feeling

### **USE ALL THE TOUCH POINTS BEFORE, DURING AND AFTER SCREENING TO HELP SHAPE POSITIVE RETURN ATTITUDES**

- Treat each experience with care – it only takes one bad experience for women to begin to disengage
- Find an easy user-friendly way to impart relevant information each time
- Ensure all communications work hard to allay emotional barriers
- Be proactive – get the clinics to create appointments for women (be highly personable and encouraging in this)
- Use 'affirm and nudge' tactics in environments that are emotionally comforting

### **AFFIRM, VALIDATE AND EMPOWER**

- Treat women with respect
- Ensure gender, age, and cultural safety at all times
- Remind women why this is important, why they are important – some need to be reminded to give themselves permission to look after themselves
- Communicate clear expectations regarding results
- Always affirm decision once screened and to continue screening
- Empower women's self awareness and health knowledge at every opportunity
- Women need to be reminded – they are busy

## **1.6 RECOMMENDATIONS FOR MAORI WOMEN**

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- Develop Iwi and Maori specific communications strategies
- Develop a communications package specific to Maori community that includes visual presentations and small group hui
- Ensure opportunities for Maori women to learn and discuss these issues have transport and childcare needs catered for

- Gather a series of Maori women's personal experiences, ensure a range of experiences is highlighted, that is, real and positive experiences from across the spectrum of Maori women
- Ensure that all messages to Maori women are affirming of them and add value to their wellbeing
- Don't use messages that are blaming and would make Maori women feel uncomfortable, embarrassed, guilty or feeling lesser than others
- Present the message in ways that are understandable and build women's confidence and self esteem
- Consider monitoring cultural safety to ensure a quality experience

## **1.7 RECOMMENDATIONS FOR PACIFIC WOMEN**

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- Talk about Pacific women's total health, e.g. self worth, breast and cervical screening – the "whole woman"
- Encourage women to share their knowledge and support others – engage advocacy on a personal level using real stories – In Pacific communities story telling is particularly powerful
- Pick community champions to put a 'face' to the message – this makes the issue feel more real
- Use face to face and same age groups for discussion, always include food, and ensure neutral venues that are understood as a sharing environment so that their personal stories can be heard
- Provide more opportunities for opportunistic smears – make it easy
- Pacific women are very practical, they are very busy - "Tell us what is important for us to know, not things we do not need to know"
- Encourage the use of Pacific women's groups e.g. PACIFICA as an entry point to communities and as a source of support, the network is national and has good opportunities to build leadership and advocacy channels
- For rational motivation – refer to external authority (health professionals)
- For emotional motivation – focus on where the values lie, on what is important to them, use a call to action that focuses on the benefits to their family's health and the connection with the importance of their own health, the health of future children and then their community wellness
- Always affirm their importance as women – they are their "family's heartbeat". Encourage women to see their needs as a priority, and advocate self worth and self care – even if it's in order to continue as the key caregiver

## **PACIFIC WOMEN NEED TO BE SUPPORTED AND AFFIRMED IN THEIR DECISION**

- They need family support – “yes we want you to go”
- They need community support – “tell me this is OK’
- They need programme support – “MOH or my doctor tells me this is important”
- They need encouragement for personal motivation, to know that; “I am important, and so is my family – I do this for me so I can be here for them”
- They need an emotional context in order to better understand medical words like cervix e.g. The cervix is the entry to the birth canal – this is where the children will come from – it needs to be healthy to have a healthy baby
- They need to know that this is the single most avoidable cancer
- They need post screening affirmation - tell me – “well done”
- For younger Pacific – use role models they know and look up to
- For older Pacific – use women who have respect, knowledge about what they are doing and have a position in their community

## **1.8 RECOMMENDATIONS FOR OLDER NZ EUROPEAN WOMEN**

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- Providers should be proactive in making appointments: this helps transform the latent potential of ‘I should’ into ‘I can and will’
- Provide a greater understanding of why screening is relevant to them at their age
- Couch messages in a context of: self care, quality of life, and the whole woman
- Communicate messages that show respect for their own self awareness, knowledge and decision making, that make them feel valued and that they still matter

## **2. INTRODUCTION**

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### **BACKGROUND**

The National Cervical Screening Programme (NCSP) already delivers a range of key messages about the programme and cervical screening through a variety of communication mediums. Most of this takes the form of information booklets and pamphlets distributed through health services, women's centres, libraries and other NGOs. Women can also contact the NCSP directly via the web or an 0800 freephone number.

More can be done, however, and the imminent introduction of the new Health Amendment Act prompted the National Screening Unit (NSU) to develop and implement a comprehensive communications strategy. The aim of this communication strategy is not only to conform to new legislation but to encourage more women - especially Maori and Pacific women - to participate in cervical screening.

The NSU commissioned this qualitative research to inform the development of the communications strategy. Research was required to ensure that the communication programme's messages are properly targeted, especially at high-risk groups such as Maori and Pacific women, and that the messages result in action (i.e., participation in screening). There was concern about the fact that Maori and Pacific women have lower participation rates in the NCSP and have higher rates of cervical cancer than non-Maori and non-Pacific women. The programme, in other words, is not achieving sufficient coverage of high-risk groups, and therefore is a contributing factor to the exacerbation of health inequalities for Maori and Pacific Peoples.

It was also acknowledged that the communication campaign will need to be supported by stakeholders to maximise its success. The "point of sale" efforts of many stakeholders (particularly providers involved in service delivery and women's centres) are needed to complement any mass media communication strategies. This is particularly important since it is likely that the communication strategy will aim to change some public attitudes (as opposed to the easier task of building awareness). Therefore consulting with and involving key stakeholders will be an important part of the research process.

The other key reasons for researching service providers was to identify what their current practices are and how consistent these are with the requirements of the new act to come into effect in 2005.

Another group of stakeholders of importance are those who influence opinions, both of the target group and other stakeholders. These we have labelled 'influential others' and include the media, women's health organisations and non-government organisations such as FPA and Maori and Pacific health organisations.

The Health (NCSP) Amendment Act 2004 introduced legislation to address quality control and public trust issues, by enabling the comprehensive evaluation of the NCSP.

This legislation will also require the NCSP to ensure that women entering the programme and programme-related stakeholders understand:

- The smear test procedure
- The importance of having regular cervical screening tests
- The objective of, and the risks and benefits of, participating in the programme
- Who has access to information on the NCSP-Register
- The uses to which that information may be put
- How a woman may cancel her enrolment in the programme, if she wishes to do so

## **2.1 RESEARCH OBJECTIVES**

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The overall objective was to obtain information to inform the development of effective communication strategies.

More specifically the research assessed:

- Current health-related behaviour patterns:
  - How, where and when do women seek information, advice and help about health and illness issues—and specifically about women’s health issues?
  - How does current participation in screening happen?
- Motivations, decision processes, triggers, barriers, attitudes and meaning:
  - What do women understand about cervical cancer, cervical abnormalities and cervical screening?
  - What does cervical cancer and cervical screening mean to women (non-rational associations)?
  - What are their motivations for participating in screening?
  - How do women make decisions to participate (or not) in cervical screening?
  - What are the barriers to participating in screening, including any concerns regarding safety?
  - What events or behaviours trigger participation in screening?
- Social context, culture and influence:
  - In what way are women discouraged or encouraged by family, peers and colleagues?
  - What are the cultural implications of cervical screening?

- In what way are health care givers, women's centres, the media and other stakeholders encouraging or discouraging screening?
- National Cervical Screening Programme:
  - What are women's attitudes toward the screening programme?
  - How much is known about the programme?
  - What are women's non-rational associations with the programme and how does it impact on women's behaviour?
- Communication concepts:
  - What are the key messages that resonate with women regarding the need to participate in screening?
  - How are women reacting to existing messages?
  - What new communication ideas could women and stakeholders come up with?
- Vehicles for communication:
  - What are the best channels for communicating with the target groups?

Specific objectives for the **stakeholder** and **community key informant** components of the research were:

- To identify their current knowledge/understanding and perceptions relating to cervical cancer and the screening programme
- To identify any concerns/ negative attitudes about the programme or the way it is implemented
- To identify their understanding of the information that women should be provided with under the new legislation and (for smear takers) the extent to which they already provide this information
- To identify what they need in the way of support to ensure delivery of appropriate messages

## **REPORTING FORMAT**

The research was undertaken in three parts and these have been reported separately in the sections which follow. The three parts are as follows:

- In-depth interviews and focus groups with women users and non-users or lapsed users of cervical screening services

- Interviews with Maori and Pacific community key informants
- Stakeholder interviews, with service providers and influential others

## **2.2 RESEARCH METHOD AND SAMPLE**

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### **RESEARCH WITH SERVICE USERS, LAPSED USERS AND NON-USERS**

#### **QUALITATIVE METHODS**

Qualitative research was used in this study to gain deeper understanding of the attitudes, motivations, triggers and barriers to cervical screening among the target groups. Qualitative research seeks to provide a neutral and stimulating environment in which to facilitate thinking and free discussion around a topic. The value of qualitative discussion is the freedom to explore issues that are meaningful to the target group rather than solely elicit answers to predetermined close ended questions that may be laden with assumptions.

A mix of qualitative methods were used; individual in-depth interviews, paired interviews and focus groups. It had been planned to undertake mostly single or paired interviews, in part to allow for the sample to be spread across a number of regions and across the different target groups, including younger and older women (the client requested a particular focus on women aged 50 to 69 years). For Pacific there was also the need to get a spread by Pacific ethnic groups and whether people were New Zealand or Island born. As shown in the table below, many of the non-Maori and non-Pacific interviews were undertaken as paired interviews, which the researcher found worked well. The large number of Pacific interviews were best managed as individual interviews. The Maori researcher had organised with the people doing the recruitment in different regions, using their local networks, for them to set up interviews with individuals or pairs. However, they arrived at two locations to find groups were present, as that was how people wanted to discuss the issue. These groups included both service users and non-users.

#### **DATA COLLECTION**

The interviews were undertaken between late September and the end of October. Maori and Pacific respondents were contacted via community networks. This usually involved the researchers making contact with personal acquaintances or organisations known to have good community networks. These people received a koha (donation) for assisting with recruitment and each respondent also received a koha. A recruitment company was employed to obtain the sample for the Pakeha/other component. They selected respondents from their panel, used networks, and made cold calls from the phone book.

All the Maori interviews were undertaken, analysed and reported on by a Maori researcher and two Pacific researchers (Fijian and Tongan) undertook a similar role with the Pacific peoples.

The interviews were usually of two to two and a half hours duration. Respondents were sent information sheets and consent forms prior to their interview. The interviews were taped with the respondent's consent, for listening back to during the analysis phase. Respondents were given \$50 as a koha or donation to cover expenses. Some interviews were transcribed.

Each of the researchers working on this project has a different 'voice', so variations in reporting style and description are evident, but the findings work in harmony together to tell an insightful story.

## SAMPLE

In total 95 persons were interviewed in this component of the research, with 32 Maori, 35 Pacific and 28 Pakeha/Other Eligible participants were women aged 20 to 69 years. The table below shows the ethnic and regional distribution of the sample for both users and non-users/lapsed users. It should be noted that the users and non-users are grouped for Maori, for the reasons explained previously.

|  | Maori  | Pacific Peoples   | NZ European/ Pakeha   |
|--|--|---|---|
| Service users  | 1 South Auckland group<br>1 Provincial group (Huntly)<br>1 Rural group (Te Kauwhata)                                     | 6 Auckland interviews<br>4 Porirua/Hutt interviews<br>2 Provincial interviews (Hamilton)                                      | 1 Auckland paired interview<br>1 Christchurch paired interview<br>1 Provincial paired interview (Hamilton)  |
| (Service users and non users in same groups for Maori) | 1 Auckland central paired interview<br>1 Provincial group (Hastings)<br>1 Auckland interview<br>2 Rural group (Raupunga) | 3 Provincial interviews (Tokoroa)   | 1 Provincial paired interviews (Rotorua)<br>1 Rural paired interviews (Rangiora)<br>1 Rural paired interviews (Waihi)   |
| Service non-users                                      |  | 10 Auckland interviews<br>4 Porirua/Hutt interviews<br>3 Provincial interview (Hamilton)<br>3 Provincial interviews (Tokoroa) | 7 Auckland interviews<br>1 Christchurch interview<br>1 Provincial interview (Hamilton)<br>1 Provincial interview (Rotorua)<br>4 Rural interviews (Rangiora)<br>2 Rural interviews (Waihi) |
| <b>Total</b>   | <b>5 groups and<br/>1 paired interview</b>   | <b>35 single interviews</b>   | <b>6 paired interviews and<br/>16 single interviews</b>   |



The following table shows the numbers in each of the service user/non-user groups and the second table the distribution across the two age groups. To classify as a lapsed user, the person had to have used cervical screening services, but not in the last five years.

| Type of User/ Non-User                  | Maori     | Pacific   | Other     |
|---|-----------|-----------|-----------|
| Service user                            | 19        | 15        | 12        |
| Lapsed user -intending to continue      | 3         | 12        | 5         |
| Lapsed user - not intending to continue | 3         | 6         | 7         |
| Non-user                                | 7         | 2         | 4         |
| <b>Total</b>                            | <b>32</b> | <b>35</b> | <b>28</b> |

| Age Group    | Maori     | Pacific   | Other     |
|--------------|-----------|-----------|-----------|
| 20-39 years  | 13        | 16        | 8         |
| 40-69 years  | 19        | 19        | 20        |
| <b>Total</b> | <b>32</b> | <b>35</b> | <b>28</b> |

| Pacific Groups | Total     | New Zealand Born | Island Born |
|----------------|-----------|------------------|-------------|
| Samoan         | 15        | 10               | 5           |
| Tongan         | 5         | 2                | 3           |
| Cook Islands   | 9         | 8                | 1           |
| Niuean         | 3         | -                | 3           |
| Tokelauan      | 3         | 1                | 2           |
| <b>Total</b>   | <b>35</b> | <b>21</b>        | <b>14</b>   |

## RESEARCH WITH COMMUNITY KEY INFORMANTS

This was a small component consisting of eight Maori and four Pacific community key informants, to provide a wider geographic spread than was possible with the in-depth qualitative research with the service users, lapsed users and non-users. Participants were identified through networks and were selected as people who had a good knowledge of their community's perceptions and attitudes towards cervical screening.

## RESEARCH WITH STAKEHOLDERS

There were 58 phone interviews undertaken with stakeholders spread across the country, as shown in the table below.

| SERVICE PROVIDERS                               | Maori    | Pacific  | Other     |
|---|----------|----------|-----------|
| GP  | 2        | 2        | 7         |
| Practice Nurse                                  | 3        | 3        | 3         |
| Gynaecologist                                   | -        | 1        | 2         |
| NCSP <sup>1</sup> Regional Services             | 1        |          | 5         |
| Managers - Independent Service Provider         | 1        | 1        | 1         |
| Health promoters - Independent Service Provider | 2        | 1        | 1         |
| <b>Total</b>                                    | <b>9</b> | <b>8</b> | <b>19</b> |

| INFLUENTIAL OTHERS           | Maori     | Pacific   | Other     |
|------------------------------|-----------|-----------|-----------|
| Media - Press/TV/Radio       | 1         | 1         | 4         |
| Magazines                    | 1         |           | 3         |
| Health publications          |           |           | 2         |
| Women's health organisations | 1         | 1         | 1         |
| NGOs                         | 3         | 3         | 1         |
| <b>Total</b>                 | <b>6</b>  | <b>5</b>  | <b>11</b> |
| <b>Total</b>                 | <b>15</b> | <b>13</b> | <b>30</b> |

The schedule of interviews was designed to incorporate Maori and Pacific voices speaking from both mainstream and Maori and Pacific services. Some stakeholders were both smartakers and health promoters and their comments are included in whichever role they spoke from.

All interviews were undertaken by phone. This allowed a greater coverage in terms of regions and number of interviews. Because of the less in-depth nature of the interviews, many of them were undertaken by experienced senior interviewers. In all cases the Maori interviews were undertaken by a Maori interviewer and in all but one case the Pacific interviews were undertaken by a Pacific interviewer.

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<sup>1</sup> National Cervical Screening Programme

The interviews took place between mid October and early December 2004, although most were completed by mid November. The interviews lasted between 15 minutes and up to an hour, with half an hour being a typical duration. Respondents were sent information sheets and consent forms prior to their interview. The interviews were taped with the respondent's consent, for listening back to during the analysis phase. Respondents were given the chance to win vouchers of their choice as a thank you for participation.

### **3. RESEARCH FINDINGS: SERVICE USERS/LAPSED USERS/ NON-USERS**

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#### **3.1 OVERALL CONTEXT: ACROSS CULTURES, THE GISBORNE INQUIRY STILL RESONATES**

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Older NZ European and Maori women in particular remember and care about what happened to other women as a result of the cervical screening mis-readings. Educated NZ Pacific had more memories of the Gisborne experience than other Pacific women; this is linked with their comfort with general media.

Comments about the inquiry were more likely to arise when women were prompted during the interviews about issues of trust in the programme and access to data. While the topic of the Gisborne inquiry elicited a diverse range of attitudes and opinions, the incident has left a residue of mistrust for the entire medical profession rather than the cervical screening programme alone. In response to questions about trust, women typically say, “what choice do you have? You just have to trust”.

Pacific women trust the health system but, as for all women, their trust is reframed at every interaction; one bad experience can undermine trust.

*“I trust the system enough that it is supported, a lot of that thinking is comforted through my relationship with my doctor and that is a reflection of the health system”* Samoan urban user mid forties

#### **PAST NEGATIVE PUBLICITY IS LIKELY TO HAVE CONTRIBUTED TO THE HIGH COVERAGE RATES BUT COMMITTED SUPPORT IS NOW AT RISK**

Listening to the expressions of dislike of the screening process, combined with lack of knowledge as to the cause of cervical cancer, it is likely that the Gisborne inquiry created high awareness (which converted into high screening coverage for NZ European and Maori) rather than a fundamental understanding of ‘why I need to do this’, and therefore commitment to the process. Thus for many women, lapsed users especially, committed support in the future is at risk without better understanding or motivation.

#### **FOR ALL WOMEN, LIFE-STAGE HAS A HUGE IMPACT ON THE DECISION TO BE SCREENED**

It was evident across all cultural groups that life stage plays an important role in motivating or distancing women in terms of being screened.

Younger women and mothers are generally more in contact with the medical profession or health professionals because of contraception needs or obstetric attention. Because of this they receive active encouragement to get screened.

Life stage provides strong internal motivation; many mothers are responsive to being screened or in fact doing anything that will enhance their chances of 'being here for the children'. Maternal motivation enables women to jump the emotional barriers to screening that can put off older women.

The older women talked to in the research were less likely to be in the medical and health sphere of influence and were often left to their own devices.

### **THE SAME BUT DIFFERENT**

Across cultures, there are, at a psychological and physical level, more similarities than differences in terms of women's knowledge, attitudes and experiences of cervical screening. The absolute differences are the differing cultural contexts, which have particular implications for communications. Each culture and age group responds to some messages and messengers more readily than others.

### **SIMILARITIES OVERALL; SOME UNCERTAINTY ABOUT WHAT GOES ON INSIDE**

Many women feel uncertain if asked to draw or name parts of their reproductive system. Cervix is not a word women identify with emotionally or readily understand, it is seen as a medical word with little spontaneous emotive imagery attached to it. This can make discussions using the word cervix feel distant; compared with, for example, the word 'breast'.

### **SILENCE FOR SOME, REVERENCE FOR OTHERS**

While NZ European women feel they are more open to discussion than their mothers were, there is still a silence around discussions about things like cervical screening and their 'private parts', a silence that they themselves find at odds with 'showing all' during childbirth.

Many Maori women associate the cervix with reproduction (te whare tangata – the house of the people). This has spiritual and cultural significance because the cervix is the entry point to the womb, where life begins. Maori cultural stories tell us that this is where Maui died, and so is referred to by some as the beginning and the end of life.

Many older traditional Pacific understand that the cervix is the top part of the birth canal. Pacific women did not have any specific words – it's all 'down there' or 'that place' accompanied by 'a giggle' for the younger ones – who are not comfortable talking about it at all.

*"The church has a lot of influence on women's views. I'd like to think we could be more open within church communities or*

*whatever we could be more open about how we approach these things*" Tokelauan, urban non user late twenties

Pacific women often feel alienated from western medical terms e.g. they often confuse 'cervix' with vagina.

*"When I first got my period I didn't know what was wrong with me, my mother never talked to me about anything to do with down there you know"* Pacific rural lapsed late forties

### **A LACK OF "CELEBRATION OF WOMANHOOD" FOR MANY**

Many of the NZ European women talked to in the research lacked an easily expressed language or any sense of ritualised experience around their feelings of their reproductive system. For some women this was viewed with sadness, especially when they compared their cultural knowledge with their perceptions of Maori and Pacific knowledge.

*"Western women and I'm talking basically white women here ... I've actually witnessed it with one of my daughters, they stand in front of the mirror and say, oh I hate these stretch marks and I hate this stomach that I've got ..., and you know there were years when I was paranoid and thinking, oh I haven't got my figure back and things like that. Who cares? Once you're a mother, you know it's part of the territory. Whereas other cultures, they love the round tummies and the stretch marks, they represent something. Like the body is looked upon as a temple and it's idolised and respected. Whereas we don't have anything, do we? Nothing"* NZ European rural lapsed forties

*"I don't know, it's something we don't do. I mean I could understand where they're coming from with Pacific people, they're a very spiritual type of people. They're a lot more, I don't know how to put it, they believe a lot more I suppose in themselves as a spiritual being compared to us"* NZ European rural user early twenties

For Pacific women - the "stealing" of tapu (all that is sacred) creates a sense of lost relationship and identity with "down there".

*"It's very sacred for women to expose themselves to someone else unless it so for a medical reason"* Niuean urban user late sixties

When words that are traditionally used in private conversations become everyday language, they are often removed from the cultural protocols, and can be used in a derogatory way. This has happened with the Pacific language where women's body

parts are now used colloquially as swear word. This only adds to the loss of context and of the respect and dignity usually accorded.

Maori women have an increasingly strong sense of place and spiritual connection to the concept of Mana Wahine, that is, the special place and role of women within the community, particularly as child-bearers. The reproductive system is referred to in a traditional sense as Te Whare tangata - the gateway of future generations.

For all women, there is a strong desire and need for information and affirmation as women, especially when they participate in the screening process.

*“My doctors explain it each time (I have a smear), explaining every time that it is important, it just keeps reminding me”* Cook  
Island urban user mid forties

## **3.2 CULTURAL DRIVERS AND SOCIAL NORMS**

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### **MAORI WOMEN**

#### **Pay heed to the dignity of women**

The late Mira Szaszy, at a national conference of the Maori Womens Welfare League, proposed the theme of the conference focus on the notion of paying heed to the dignity of women (me aro koe ki te ha o hineahuone). This focus was partly suggested due to the blatant disregard of Maori women by the health system and a desire for Maori women to be reminded of their special place, as mothers, as grandmothers as those who play a significant role in ensuring the well-being of the family.

*“I want to have a doctor who recognises how things are tapu to Maori and that our private parts are to be treated with respect not like a factory line. I would like doctors to be given this message, it’s all about dignity”* Maori urban lapsed sixties

#### **Older Maori women**

For many older Maori women there are strong beliefs regarding the sacredness of the body – te tapu o te tinana. Thus there can be more resistance to engagement with cervical screening services particularly where there is uncertainty around the safety and protection of the reproductive system.

This resistance has also been caused by previous degrading and humiliating circumstances experienced by Maori women whereby they have felt they are either at the mercy of someone else or culturally unsafe.

*“When the operation was to happen, I did not realise a pack of male students would be shown what to check while all looked on.”*

*I felt so stink. From there I had a fear of being in a vulnerable position where a Dr can do what he likes. They did not respect my privacy”* Maori urban lapsed sixties

Often older women relate best to older women. Acknowledgement of kuia (older woman) status and cultural norms is important. In the mainstream health system there are (for some Maori women) multiple levels of discomfort that women subject themselves to when they have to deal with someone who is not only non-Maori, but young, perceived to be inexperienced and male.

*“The doctor has talked to me since about having a smear and said a lady Dr can do it – but too late, not interested, the lady Dr was too young as well and I don’t think she appreciates how older women feel. As a kuia I expect them to know how I might feel”* Maori urban lapsed sixties

The due regard and respect that older women want is not complex.

*“It would make a difference for me if they were to say ‘Kia Ora, I appreciate that your private parts are sacred to you, how can we make this comfortable for you?’”* Maori urban lapsed sixties

### **Issues of concern to all Maori women**

Maori Women want to live long and healthy lives. They want to be treated with respect and feel safe within the health system. Maori women remember negative messages they have received as a result of what they perceive to be abusive and hurtful experiences at the hands of the medical system. These experiences, memories and the associated feelings stay with them for life.

*“There have been shocking dealings that we’ve had imposed upon us as Maori women. I remember a personal experience with a doctor where I fell pregnant at the age of 14. I’d only just started menstruating. Teenage pregnancies were about getting into relationships. I remember being treated by that Dr as a slut and being looked down upon and feeling disempowered as a young girl who is going through this amazing experience and being raised to trust your Doctor”* Maori provincial user thirties

*“I was always told that cervical cancer was caused by not being cleaned out properly after having a baby. I have concerns for young women these days having babies; they are encouraged to leave hospital much earlier. In the old days, you were looked after, you were No. 1, you were pampered. These days it’s in and out”* Maori provincial user forties



These kinds of experiences have given negative messages to Maori women about themselves and about the health system. This reinforces notions of Maori women as under-valued, worthless and not worth the time of day.

At the same time, over the past 20 years emerging Maori perspectives on health, the strong voices of Maori women within the health field, the numbers of Maori initiatives that have a pro-Maori and pro-Maori women focus, have paved the way for Maori women to expect high quality care from the health system. Culturally safe practice is an imperative and for some non-negotiable.

*“I remember back in the 80’s Mum and Aunty encouraging us to get active, be motivated, be vibrant as Maori women. That had an impact on us. All the way down the track and 5 – 10 years later there’s mum and aunty again telling us you’re beautiful Maori women. Then there’s the other aunty telling us that our periods are a river of life and how to take that concept from being rubbish to something that’s treasured”* Maori provincial user thirties

Furthermore, poverty distracts Maori women from caring about themselves. The health message goes unheard clouded by the reality of day-to-day survival.

The difficulty is in promoting health when so many other issues, caused primarily by poverty, impact on many whanau.

*“Maori women carry the burden for the health and well being of the family and often because the whanau is in poverty, self-care is not a priority. It slips off the day-to-day agenda”* Maori urban user forties

What is clear is that where a good relationship exists between the provider of healthcare and Maori women there is more likelihood of women receiving the type of care they are deserving of.

## **PACIFIC WOMEN**

### **Value motherhood above all else**

Children are the centre of the family unit in the Pacific. The family and the extended family is the primary focus for women in prioritising their time followed by their community.

The degree to which Pacific women feel obligation to their extended family and community however is influenced by how they are raised. This sense is stronger for Pacific born and raised where traditional concepts of obligation are tied to and reinforced by community events; births, deaths marriages and sometimes through their

church. For Pacific women who are born and/or raised in NZ this sense is somewhat diluted. But their sense of family is still strong.

For women who have full nests, their commitment is to their children. For grandparents the priority becomes the grandchildren, as the children (who are now parents) can take care of themselves. All actions in life are 'for the children'.

*"I want to be healthy to live longer to see my grandchildren grow up"* Rural lapsed grandmother

### **Put everyone's needs first**

Pacific women will run themselves into the ground looking after others – they often have a very wide network of people they feel obligated to: getting the kids to school and cooking for the community, the church and the family.

*"I think we are naturally really healthy and really staunch we don't worry about it, it's something that just happened, you see your parents, to some people you know you don't want to burden anybody, it's a pride issue or a fear ... I can do anything"* Tokelauan urban non-user late twenties

Pacific women rarely look for acknowledgement; putting other's needs ahead of your own is the norm, it would *ma* (shame, embarrassment) for Pacific women to expect any overt credit.

*"You know I'm busy all the time, I do everything in the house, I cook and do the washing I take kids to their school activities, I help do their homework, I'm very tired at night"* Auckland Tongan young mother

Personal resources are stretched by a social obligation to be seen to give and help with food, money for the church and/or community regardless of personal circumstances.

### **Use the knowledge in the community first**

Pacific families are often located within low socio-economic areas; household resources are often strained, so community networks are important points of access for information. These groups are often age-relevant so more than one point of access is important.

*"We should have workshop in own group, in PACIFICA (Women's Network) young women do not really turn up, but they have their own sport and culture groups and that's the way for the young"*

*people, otherwise they do not have comfort to come with their mums to have group talk” Tokelauan urban user late fifties*

Communities with a collective mindset invariably resource internally. Personal experience is valued and shared openly because of the sense of empathy they have with their own.

*“Pacific women will look after themselves if they have the right information. They have to have a one to one session, it depends how you deliver the message” Niuean urban user late sixties*

Health information coming into the community often enters through health professionals within the community. Otherwise active interface with other Pacific community health professionals or agencies has proven to be useful.

*“When the health nurse comes again we just organise ourselves, or our women’s group. We are lucky that we have a health worker. Women like to come together, then we have someone come and we can talk about these things” Tokelaun urban user late sixties*

Pacific women naturally share information as equals as support for each other. The sharing of health information by health professionals, information that women legitimise through personal experience, is very powerful for Pacific communities. Many of the Pacific women interviewed commented that Pacific health professionals had provided technical information through community meetings at either a local or national level.

### **Urban Pacific have greater access to health resources via insiders and media**

Pacific women living in larger urban areas have more access to health information; population funded services are more readily available where there are large concentrations of Pacific people. This has a direct impact on the numbers of Pacific people working within health services and the range of services offered and in turn the capacity of these services to work within Pacific ethnic communities. In addition access to suburban/community newspapers, especially in urban areas, provide a good source of information of the different services available for Pacific women.

National Pacific language radio is also a key source of quality information for communities in that it provides a safe forum for dialogue of complex issues and easier access to professionals and experts who can communicate within Pacific language constructs.

### **Pacific women take a holistic view of the body**

Pacific (and Maori) women do not separate the parts of their anatomy when talking about screening; breast and cervix are essential to their sense of 'womanliness'. But they do have a different sense of appropriateness between the two.

*"(Breasts are) for vanity reasons really, the concept of being a women, it's part of my woman hood, that we keep and are quite happy to keep public (but) the cervical area is an area which is private"* Samoan urban user mid forties

### **The concept of prevention is not commonly understood in Pacific communities**

Traditional Pacific do not want to hear about prevention, they are essentially very practical, if the ailment is not perceived as limiting them they often require visual proof of an ailment. Pacific invariably wait until a crisis before getting something seen to. Other research has shown that this may be due to access issues (cost, information or time) and cultural appropriateness of services.

Cervical screening is not undertaken in the island countries – due to lack of resources and emphasis, so women who have moved to NZ within their adulthood may not have a family appreciation and commitment to cervical screening.

Pacific women have smears as part of their antenatal procedures, often assuming that this is part of the antenatal process. However they tend not to keep them up later or understand and appreciate that this should be a regular check.

### **Mothers and daughters are often uncomfortable talking about it together**

Of the Pacific women talked to in the research, very few Pacific daughters discuss intimate matters with their mothers, especially anything related to sex. Often a very practical discussion took place at the onset of puberty, in terms of what to do when your period came, and never continued from there.

Daughters often don't want to worry their mothers, or have their mothers realise they are sexually active so they will talk with their older sisters or friends first.

*"I didn't want to worry my mum, she's got some health problems, my father used to beat her up and now if I have any problems I will talk to my sister"* Cook Is rural lapsed young

Mothers are used to being the strong ones and are reluctant to show any weakness.

*"My Mum is so used to being, you know, like the strong one, when it's sort of your turn and you are so used to doing things for everyone - it's a Mother thing too"* Tokelauan urban non user late twenties

Women's issues are kept separate from men's issues, yet men are important sources of support for their women.

*“Partners are the most important support – but some men have nothing to do with it”* Niuean urban user mid sixties

### **Respect for authority**

Pacific women will respond to internal cultural authority e.g. the wives of community leaders or church ministers, to discuss personal issues or to take advice from.

*“We only have the minister’s wife to work along side with because we trust her, she is known to the community that she will keep things confidential”* Niuean urban user mid sixties

*“We tried to get the Minister’s wife to get our women together but she didn’t. You know it’s quite hard for us to work without her help, she knows the women in the community and they will listen to her, it’s quite frustrating”* Pacific rural user mid fifties

*“If it was recommended I would do it”* Tokelauan urban non user late twenties

Most Pacific people are usually aligned to a church. Even for NZ born Pacific, it may not be the church you were brought up in, or that your parents go to, but the benefit of a sense of community and common values remains through the generations.

## **OLDER NZ EUROPEAN WOMEN**

### **Self assurance and deep realisations: doing it for themselves**

Of the NZ European women in the research, many older women (over 45), and particularly lapsed users, had a deep sense of who they are, what and who they trust and what they will tolerate. They value their experiences and lessons in life and are likely to trust their own intuition and make their own decisions in regards to health.

Most of the women talked to were big on prevention and self care. They had high awareness of their needs and were clawing back their personal identity after child rearing, divorce or life change. In addition they typically now had more time to think about their decisions in regards to health and had learnt how to access knowledge to aid their decision making.

### **Often radical shifts in terms of their relationships with men, society, and their own self image**

Older NZ European women had typically gone through a reassessment of their relationships with men and their own role as women in society. They expressed a strong desire to reclaim their body from society, men and child bearing. They were also more likely now to be questioning traditional or authoritative structures (medical,

government). Thus their relationships with and attitudes to health professionals, for example, were also in a process of change; they were more likely to see their doctor as an advisor in decision-making, not an absolute authority.

Despite the sense of empowerment from the women this attitude was rarely expressed overtly as a feminist philosophy, rather, post child bearing, it is a renewed sense of self and ongoing discovery.

### **Attitudes to screening shift with age**

The older a woman becomes the more screening becomes a highly personal decision i.e. even if a women is being hassled by friends to go, or if she has a family member or friend with cervical cancer she may still resist.

Due to misconceptions about the need to be screened, older NZ European women are less likely to perceive they are at risk. Considering the increased barriers that arise for older women, it is likely that screening coverage amongst older NZ European women will go down unless their perception of need changes.

## **3.3 'RELATIONSHIPS AND TYPE OF CONNECTION' IMPACT EFFICACY OF COMMUNICATIONS**

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### **THE INTERVIEW PROCESS HOLDS LEARNINGS – THE OPPORTUNITY TO TALK WAS WELCOMED**

The interpretation and understanding of ones role in whanau and community differs for each culture and underpins the efficacy of communication messages and vehicles.

For Maori and Pacific there is a strong sense of sharing information for the benefit of others in extended whanau. This is less so in the more individualised NZ European culture.

In the interviews, opportunities to talk were welcomed. In both the Pacific and Maori interviews, interested others came of their own accord or women got themselves into focus groups when they knew an 'insider' was coming to talk with them about cervical screening. They wanted knowledge. Pacific women in particular appreciated a 'safe space' to talk.

For NZ European women the idea of bringing along others to the interview was only mentioned once in a rural community. However several of the NZ European interviews were with pairs of friends who appreciated the opportunity to discuss the topic with another woman. Even women who had known each other for a long time expressed surprise that they had not discussed this together before.

## **PROVIDE THE RIGHT INFORMATION WITH THE RIGHT MESSENGER IN THE RIGHT ENVIRONMENT AND WOMEN WILL COME**

For Pacific and Maori it's about being face-to-face with people you know and trust. Relationships are critical in Maori and Pacific women's health issues. It's all about who you know, for example, with some of the Pacific interviews, groups of friends turned up. With some of the Maori interviews a number of women in the one whanau turned up to do this together.

## **WHANAU KORERO (TALK) BEST DONE AMONGST WHANAU**

Pacific and Maori women's 'talk' within whanau and community is the most important information carrier. It's all about the level of connectedness and insider relationships. Women's talk is shared in communities, particularly in smaller communities and especially when facilitated.

*"If they could just talk to us. Level with us instead of ordering us. They don't like explaining things to us they expect us to do as we're told"* Rural user early twenties talking about the women in their community

## **INFORMATION DISSEMINATION - THINK CIRCULAR AND FACE TO FACE**

There was wariness from some Maori about the information collected in the research. Maori women wanted to know how the research information was being collected, by whom, for whom and what analysis mode was being used.

Maori were expressing a desire for the protection, accountability and appropriate contextual analysis of the information. There was a cultural need for the information to build on what has already been found and for it to be presented back to the community.

This need to build on community knowledge was also evident in the Pacific interviews. Researches are 'duty bound' to educate and share their knowledge resources in exchange for dialogue, it's part of 'what you do'- impart information as you go, share the knowledge around the community.

In this regard information gathering and dissemination on the 'ground' is holistic, less hierarchal or one way than we habitually think in social marketing. The learning here is to think circular and face to face rather than linear or hierarchical, and oral rather than written.

## **IMPLICATIONS FOR COMMUNICATIONS**

- Communications need to be authentic – 'If I cannot see myself in there then the message is for others'

- Life stage is an important factor in readiness to hear certain messages
  - Pacific and Maori are eager to know more but prefer to talk it through with insiders rather than confront this via the written word
  - Engage or work with local insiders in each community – they hold the community knowledge
  - Be aware of the socio economic conditions – for some, self care is almost a luxury
  - Engage Maori women's desire to be a role model to younger women
  - Engage Pacific sense of 'duty' to be a role model and share knowledge within the community especially
- Wrap cervical information within a holistic women's well health knowledge context and look for opportunities to "cross-sell" cervical screening messages and other health promotion messages

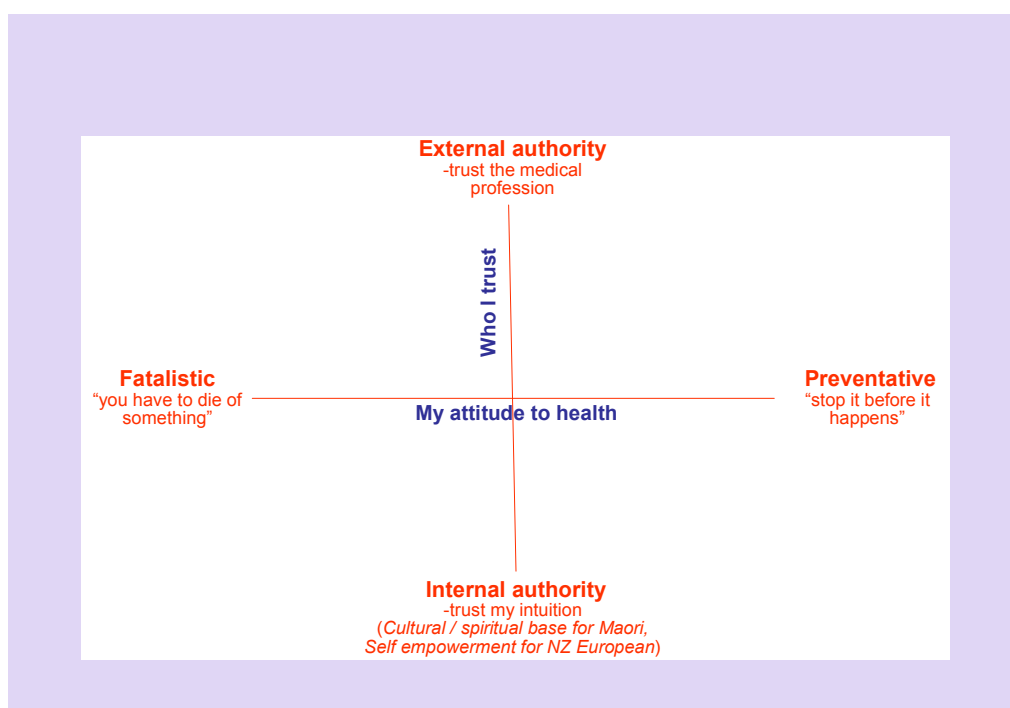


### 3.4 TWO KEY DRIVERS UNDERPIN ATTITUDES TO CERVICAL SCREENING

#### ATTITUDES TOWARDS HEALTH AND TRUST POINT THE WAY TO UNDERLYING MOTIVATIONS AND BARRIERS

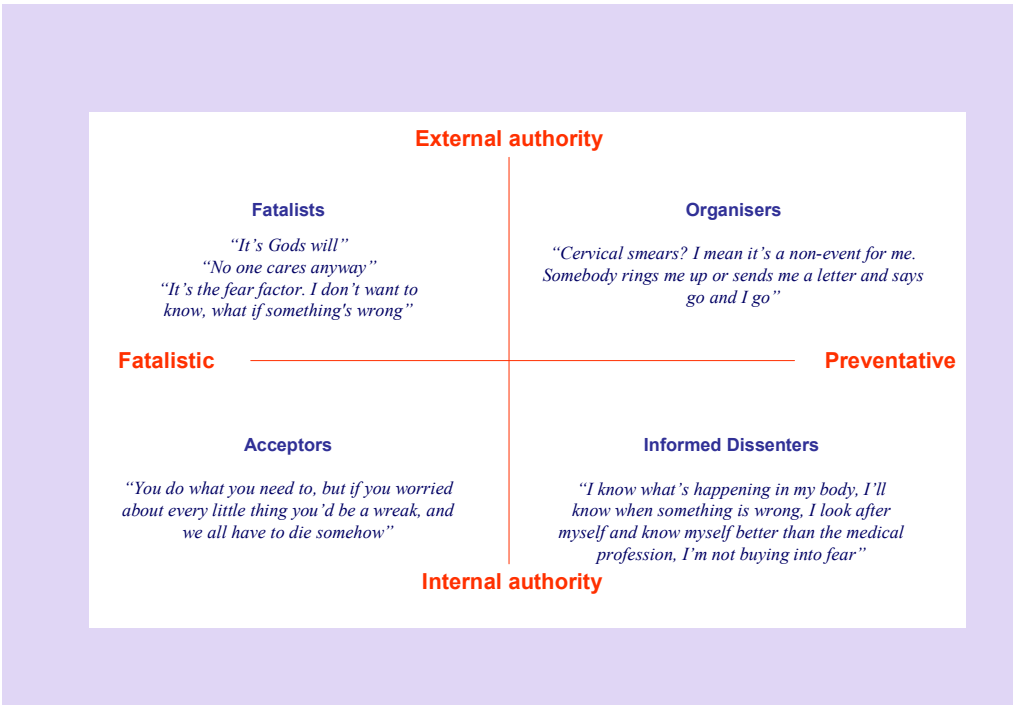
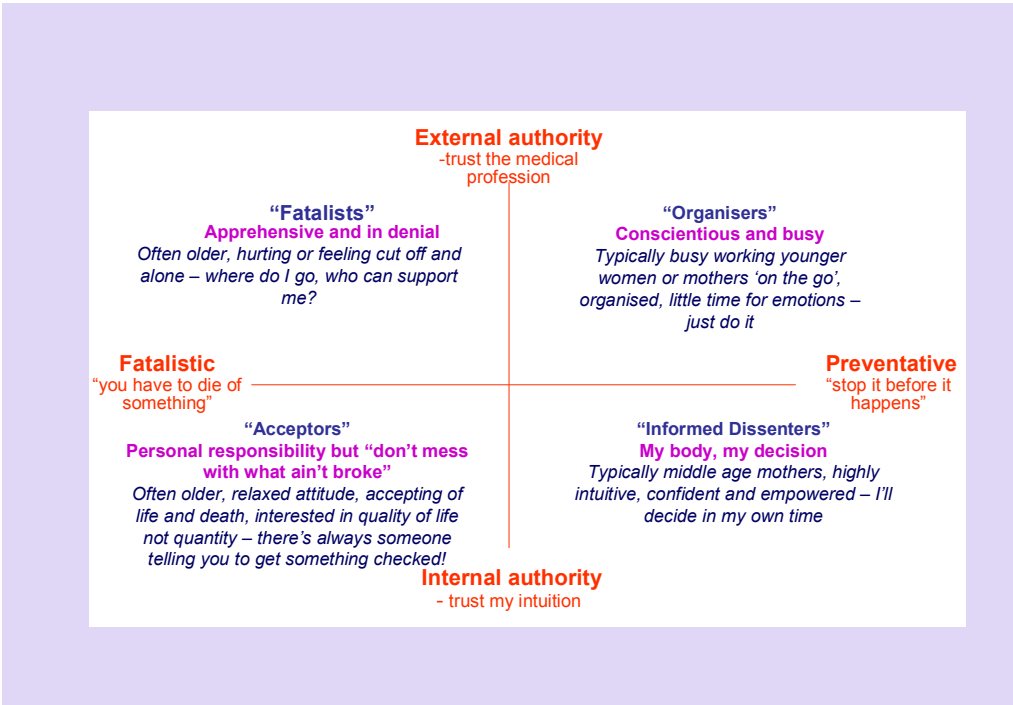
In listening to women speak in the interviews, two key themes emerged that can be seen to underlie a women’s attitude towards cervical screening. One theme is an individual’s attitude to health, where at one end of the continuum women take a preventative approach and at the other end a woman may take a more fatalistic approach.

The other theme revolves around ‘trust’. At one end of this continuum a woman has high trust in external authority (others), at the other end a woman may place higher trust in an internal authority (myself, my culture).



The diagram above shows how the common themes expressed by the women in the research create two continuums which reflect the underlying attitudinal drivers in terms of responses to cervical screening.

As shown in the two diagrams below, the continuums create qualitative segments of women who express similar motivations in their attitudes to cervical screening.



### **‘ORGANISERS’ ARE TYPICALLY BUSY MOTHERS WITH LITTLE TIME TO THINK**

Organisers typically just put screening on the list and get it done. They are often busy women typically putting other people’s needs before their own, their motivations for looking after themselves is to keep healthy for others.

*“It’s never been a problem for me, I just do it along with getting the groceries in”* NZ European user rural mid forties

Organisers will respond particularly well to having the appointment made for them, anything to make things easier.

### **‘INFORMED DISSENTERS’ HAVE MADE THEIR DECISION**

Informed Dissenters have weighed up the information, the experience, the risks and the options and have decided that cervical screening is not for them. These women have made their mind up and want respect for their decision; they resent efforts to challenge their thinking. Their decisions are not made lightly; they involve a plethora of concerns and reflect, in their perceptions, an informed philosophical or political stance.

Informed Dissenters will respond to communications that show respect for their self-knowledge and decisions but also offer new facts or information.

*“I’m one of those very determined people. I just said enough is enough, you know. The reality that my gut feeling is always right, like for being in charge of myself and I don’t like sort of succumbing to being part of that system out there. I don’t mean that I don’t want to know, and I’m closing my door to what’s out there. What I’m saying is that I want to make my decisions. If my decisions are bad that’s my decision. I’m not an irresponsible person, I’m a very responsible person. The thing is that I like to know that my responsibility counts for something, not having the system saying we saved you, you know, this is my life”* NZ European rural lapsed mid forties

### **‘ACCEPTORS’ TYPICALLY HAVE AN AWARENESS OF THEIR BODY AND THE WAY IT WORKS BUT ALSO ACCEPT ITS LIMITATIONS**

Acceptors have weighed up the odds and are determined to live in the present and accept whatever the future may bring. They are typically older and have confidence in their health. They look after themselves and experiment in a somewhat faddish way with supplements and different approaches to health. They are interested in quality of life not quantity.

Acceptors will respond to communications that talk about simplicity of process and quality of life in the present.

*"I can see that some people might say, I wouldn't have chemotherapy and I wouldn't have radiation so why do I need to be screened. .... I don't want to know myself because if I do have it, am I going to do anything about it, I doubt it, I would just accept it"* NZ European urban lapsed early sixties

### **'FATALISTS' JUST DO NOT WANT TO KNOW – WHAT YOU DON'T KNOW CAN'T HURT YOU**

Fatalists are typically less empowered and informed, believing that others know better than they do. Fatalists will be the last ones to seek help for their own needs. They are often fearful and imagine the worst case scenarios.

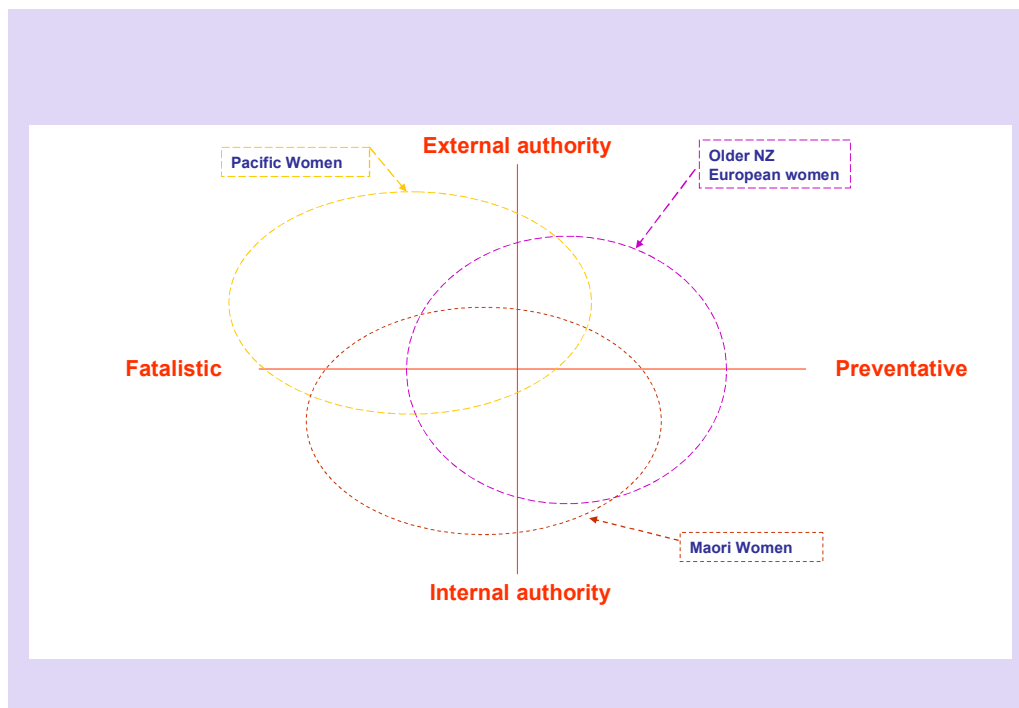
*"I'm really terrible in some ways because I don't pay too much attention to health issues. I am a diabetic, so I should, but I don't. I've never thought about it really. I've had a friend die of breast cancer, sort of thing, and I am aware of it sort of thing, but I don't know whether I'm too chicken. Do you know what I mean, I'm just too chicken to even think about it"* NZ European non user mid thirties

Fatalists will respond to the personal touch, gentle persuasion, encouragement and care. Scare tactics will frighten them.

### **SEGMENTS ARE DYNAMIC: LIFE STAGE AND CULTURAL INFLUENCES CREATE CHANGE**

The women from each culture expressed cultural norms in their attitudes to health that were subtly different from another culture.

While these attitudes are always dynamic and in a process of change, the diagram below depicts the relative weight in a qualitative sense of the attitudes as expressed in the research.



**Traditional Pacific women** have tended to be more deferential to authority: pastor and parental word is law. They typically ‘do as the doctor says’. Traditional Pacific have a high level of trust of health professionals in NZ. This is less so for NZ born Pacific.

Pacific women have lost some of the preventative ideas; they are only just being recognised because, as the NZ Pacific population ages, the community now sees the impact of illnesses like diabetes. This creates a sense of urgency as people become more aware.

**Maori women** are diverse, and tended to have more trust in Maori driven health services than mainstream medical profession; taking action in regards to health is dependent on feelings of self worth. Cultural and spiritual factors are also significant.

Compared with Maori and Pacific the **Older NZ European women** talked to in the research were more proactive in taking care of themselves and were better versed in preventative ideas. In part this reflects their greater comfort with mass media information and the cultural values that extol the virtues of self-attention via consumerism, “because you’re worth it”. However this is also because older women have learnt through experience what works for them and they know that they have to do this for themselves. As previously mentioned older NZ European women are also increasingly less trusting in the medical profession as a whole.

## **IMPLICATIONS FOR COMMUNICATIONS**

- In general the prevention message will resonate more readily with NZ European and Maori
- Referring to external authority (health professionals) will resonate with Pacific
- Both Maori and Pacific will listen to community insiders before outsiders because of the relationship of trust
- Iwi and Maori health driven services are critical because they can engage Maori women and are trusted in general
- Older NZ European and Maori women will respond to messages that acknowledge their own power and intuition and promote self care
- Pacific women are typically less motivated by notions of 'self empowerment' but will respond to a message advocating self worth and self care

## 3.5 PERCEPTIONS OF THE SCREENING PROCESS

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### TOUCHING THE RAW SILENT SOUL OF WOMANHOOD

Women do not spend time thinking or talking about cervical screening, but when they are offered the opportunity, discussions can unleash a whirlpool of emotions.

As women age, at its emotional core, the cervical screening process touches a woman's relationship with her children; her partner; her past; herself; the medical profession; her perception of her role in society and her hopes for the future. Thus the older a woman becomes the harder it is emotionally to participate in cervical screening.

### FOR ALL WOMEN - A GROAN AND MOAN ...AND THOUGHTS OF DEATH

Women do not like the cervical screening process. It is embarrassing, uncomfortable and often painful.

*"You're vulnerable. You feel vulnerable and you're out of control. They're in control aren't they? You feel almost stupid. I worry, worry, worry, worry, I'm anxious, anxious and then when it's done you think, what was all that about. It is silly. I think why do I have to go through this. Why do women have to go through this"* NZ European urban user early sixties

*"I'm thinking Ok, yuk, because my sister was justifying her reasons why she doesn't get a cervical smear and she was saying it really hurts, it really hurts"* Tokelauan urban non-user

Decision making around screening can also precipitate a subtle inner contemplation about death. Misunderstandings about abnormal results still terrify too many women.

*"They send me a letter that my smear was abnormal, gee I thought, I got cancer, scared shitless"* Cook Island urban user young

### WHAT WOMEN UNDERSTAND ABOUT CERVICAL SCREENING

Too many women, Pacific especially, still think cervical screening is a test for cancer. In general NZ European older women are more likely to have some information and understand the 'why and what', but even 'informed' women have incomplete information. In general, Maori women understand it as a process linked to cancer, but don't know a lot about the what and why.

For all women there is little consistency in terms of how often one should go – 6 monthly, 1, 2, 3, 5 years?

## WHO IS IT FOR?

Any woman? Those who are sexually active? Do nuns get it? While women were unsure exactly who screening was for, there was a strong feeling for all that young women (sexually active minors) should be getting screened.

*“A lot of our young girls now are having sex at an early age like 12yrs, more often than most of us older folks. Shouldn’t be targeting them rather than us”* Tongan urban user

*“I think they should be targeting the younger girls, I don’t know how they should be doing it, but they don’t want to do it through high schools or anything. There are a huge number of sexually active kids at school. I think they should start having cervical smears early”* NZ European urban user late forties

Maori women in particular feel that screening should include younger Maori women as many are sexually active at an early age.

## HOW DO YOU GET IT?

While there is a sense of cervical cancer being something to do with sex (and promiscuity), there is also a feeling that everyone has cancer cells and that something ‘just triggers’ it.

For Maori women, many commented on feeling misinformed and had many questions. Their awareness has come from stories they’ve heard or personal experiences with family members.

*“Is sex what causes cervical cancer?”* Maori urban user early forties

*“I always thought cancer starts with the heart”* Maori provincial user  
fifties

## PERCEPTION OF RISK AND EFFICACY OF SCREENING

Most women have no idea about the percentage of risk to NZ women from cervical cancer or whether the programme is effective or not. They presume it must be because otherwise, they ask, why would the programme be in existence.

When shown the numbers of deaths and lives saved, many women across cultures are hopeful and feel that it is working. However for some, the numbers can feel small and therefore raise questions as to why this is deemed to be more important than many other health risks.

*“I was talking percentages before, wasn’t I? I don’t think that helps your campaign at all. People look at that and go, wow it’s not many so why are we worrying about it. Unless you’re one of*



*those women, I'm not one of the 85. It's not going to happen to me. That doesn't help their campaign at all. That would make me forget about going altogether. That would just make me think, phew, I'm not one of the 85 and I'm never going to be. It's such a small percentage"* NZ European urban user mid forties

*"Um, 85 women die from it every year, oh that's worth taking note of, that's a noticeable amount, it's not like 3. The fact that 230 of them are diagnosed and they don't die from it, yes that's good. but those numbers don't really mean that much to me because then you've got to think about it and the population and then I've got to try to do maths and then the brain doesn't work"* NZ European urban user early twenties

*"I hate them (statistics) because it takes away, it sort of reaffirms to me that I'm having less and less control over who I am and what my body is all about, I hate statistics"* NZ European rural lapsed never to return mid forties

*"I think that a lot of women think that this doesn't really kill a lot of women. I wouldn't know how many. I did see a thing in here when I flicked over, so it's not that high on the list. There is breast cancer, there's heart disease, there's all sorts. You see very little about cervical screening and you sort of assume that it's not that big an issue. That not that many women are dying of it"* NZ European urban lapsed late forties

For a small number, another concern is the potential harm caused by scraping.

*"The other thing that concerns me with the regular screening is that the cervix is quite a delicate little organ and changes from woven to unwoven throughout your menstrual cycle. They don't know what doing that many scrapings is going to do to that mechanism"* NZ European rural lapsed never to return late forties

## **HOW CAN YOU PREVENT IT?**

Across cultures, women want to know how to care for themselves better. In discussions about their attitudes to cervical screening women comment that they know little about cause and want to know how they can prevent cervical cancer.

Some Maori women ask why Maori statistics are so high, without greater knowledge around cause they are less aware of why they are at risk and so they are less motivated to see screening as a health priority.

For many women, screening is not generally seen as 'real' prevention. Prevention is knowing how to avoid risk in the first place. In the absence of knowledge, for many women, keeping healthy "down there" is about "being hygienic" (showering).

## **'YOU CATCH A VIRUS, YOU DON'T CATCH CANCER'**

Very few women had heard of the human papilloma virus. The idea of a virus causing cancer was foreign and non intuitive.

*"Human what? No idea what you're talking about. I've never heard of such a thing. All I know about a virus is catching a cold, and you can spread it too, so is this virus catchy?"* Maori provincial non-user fifties

*"A virus is something you catch, cancer is something that's already in your body, but only comes out maybe in certain people or because of a certain thing. Maybe you've eaten certain types of food, or you're not eating certain types of food. To me a virus is a catchable thing and cancer is not a catchable thing"* NZ European rural lapsed late fifties

When told about the connection between HPV (genital warts) and cervical cancer it makes more 'sense' to women. When NZ European and Maori women hear about the virus they do mental summersaults about the implications. They then see themselves as being more or less at risk. Women in a stable and long term relationship see themselves as being less at risk, whereas women who have had several partners begin to feel themselves at higher risk.

## **PACIFIC WOMEN NOT TALKING ABOUT STIS**

Pacific women typically do not make the connection to thinking about risks from their partners – they do not want to think about the implications. STIs are not talked about nor are they understood so women find it difficult to connect cervical cancer with STIs. As many Pacific women did not know or were unsure of what and how you catch the HPV – many didn't understand the connection with STIs and cervical screening, even those who were regular users.

Some Pacific women were apprehensive that their men would then say 'why do you want this 'check', don't you trust me'? Or "what is it that you've been doing that you need to get yourself checked out?" This further reinforces the need to make this a supported decision for women and Pacific women in particular.

## **BRING THE MEN IN ON THE CONVERSATION**

Although expressed in vague terms, the underlying sense that cervical cancer is caused 'by sex' motivates, in part, some women to suggest that men need to be 'brought into the conversation'.

*"My husband is pretty good, some things you pick and choose, but he's usually pretty happy (to engage about women's issues).*

*He's come from a family of just being him and his Mum, no father, no siblings. So ...he's a bit more sensitive to us, you know to our side of things because he's had to hear about it most of his life, so he's good...and he is the one that will nag me in to going to get screened"* NZ European rural user early twenties

### **MAORI WOMEN SAY 'GET THE MEN INVOLVED AS SUPPORT' BUT OLDER NZ EUROPEAN AND PACIFIC WOMEN AREN'T SO SURE**

Maori women say the programme needs to get men involved because 'it's about whanau' so it affects everyone. Specifically some have referred to the role of men as 'carers and protectors' and the willingness of many to support their partners on this issue.

*"It's important to put the message out to our men about how they can be a part of nurturing te whare tangata"* Maori provincial user forties

*"It's important our men know about it too. If more of our men saw other Maori men behind their women to do this, it would make a difference"* Maori provincial user fifties

Younger NZ European women are more open to the idea of including men in the discussions and are likely to say 'this is for all of us'. Older women however can feel less comfortable about this, for them it can be a closed and private subject. Pacific and older NZ European say their men are rarely interested in 'women's business'.

*"Our men they don't care about these things all they care or worry about is themselves and all they do is go to fai kava"* Auckland Tongan late thirties

*"I would never, I don't think I've ever discussed it.... it just never occurred to me to talk to my husband about whether or not I'd go to have a smear. He certainly wouldn't discuss it with me. I can't imagine what we'd say"* NZ European urban user sixties

*"Yes, it's hard to talk to him about it. He'll just turn off and not want to know about it"* NZ European urban user early fifties

*"I wouldn't talk about it. No, because my husband is very anti, he's not interested in any kind of medical solutions to things either really, so I probably wouldn't"* NZ European rural user early forties

However a better understanding about cause, in terms of the virus being sexually transmitted, is likely to create a greater desire for men to need to be included in the conversations around cervical screening.

## **A RATIONAL DESIRE FOR INFORMATION BUT EMOTIONAL RESISTANCE IS STRONG**

The women talked to in the research were interested in knowing more about cervical screening but they fear that knowing more will be distressing, thus they will rarely pick up brochures (especially lapsed users).

In fact, when women were asked to look over the brochures, learning diminishes their fears, for example, they learn that abnormal smears rarely mean cancer and that cervical cancer typically has a long gestation and so forth.

*"I like this information because I have had the experience of having an abnormal smear. Makes me see what it actually meant"*

Maori provincial user fifties

*"You know I didn't know this, (referring to the information brochure) this makes it not seem as bad"*

NZ European urban user mid late forties

## **WOMEN GET TOLD INFORMATION BUT OTHER PRIORITIES CLOUD THE MEMORY**

Women are not always being reminded why screening is important. Typically they have been told at some stage but without a sense of urgency around the information it gets relegated to 'back of mind' and women forget.

The timing of the conversation is important since the primary focus for women at the time of screening is to 'get it over and done with as quickly as possible'.

## **IT'S AS MUCH PSYCHOLOGICAL AS IT IS PHYSICAL AND FUNDAMENTALLY ABOUT SELF ESTEEM AND CONTROL**

Without primary motivations such as being here for the children or a personal health scare, women often struggle to convince themselves that they need to be screened. For many women making the decision to be screened is wrapped up with feelings of self esteem. While on one hand, women dread going to be screened and want to forget the experience as soon as possible, on the other, they feel proud when they have done it, proud for having overcome their fears.

*"Afterwards you feel jubilant because it's out of the way, and funnily it boosts your confidence because you did something you didn't want to do in the first place. Because you have achieved it you feel really good. It's the thought of it, it's like feel the fear and do it anyway"*

NZ European urban lapsed sixties

Emotionally, cervical screening asks a lot of a woman; it lacks the beauty and joy of the similar "loss of dignity" that accompanies childbirth. The disempowering feeling of "invasion" and "loss of control" can outweigh the perceived benefits. It is relatively

easy to forget the physical discomfort, it is the uneasy emotions that can resonate for a long time.

*“In 1980 I had an experience that shocked me and made me more determined I would not be put in an awkward position again. The Dr made me lie in this position and he went away. There were glass windows and I felt like I was being watched. I was left naked from the waist down and it made me feel so vulnerable and powerless. He didn’t talk to me and I didn’t know what I was meant to do. I do not remember what happened next. I just remember the horrible feeling”* Maori urban lapsed sixties

*“It’s probably more psychological. Maybe our daughter’s generation won’t be like that. We grew up with our mothers and their attitudes. Maybe the next generation who go through won’t have that sort of disempowerment thing. They might not have that. It may be different”* NZ European urban user early fifties

*“I suppose when you’re fearful you’re a bit tense. You do get cold, but my doctor is very good, very gentle and everything. I can’t see how she can do things any different. It’s just embarrassing, for me, it’s really the mental thing rather than the physical”* NZ European urban lapsed early fifties

*“I think for myself actually to be able to go back it would have to be a mind over matter thing for me. I would have to conquer my own thing inside of me. I know it’s not a huge massive thing to have done, it’s just something that takes about 5 or 10 minutes of your time, it’s whipped in whipped out, it’s really quick and simple and everything like that, it’s more my psyche”* NZ European urban lapsed early fifties

*“It feels horrible, it is like someone has grabbed hold of your intestines and they’re butting them, it’s bizarre because you’ve never felt pain there before... Usually I think she puts some sort of gel on that thing to make it easy to go in. That’s all uncomfortable as well. She gives you tissues and you feel a bit funny wiping yourself down there. It’s like wiping yourself once you’ve been to the toilet. Like slimy. You’re sitting there wiping your bottom with your pants off”* NZ European urban user early twenties

*“I’m not so keen, I do feel violated when it’s been done. I do feel that I’m at a severe disadvantage”* NZ European urban user late forties

## **FOR PACIFIC AND NZ EUROPEAN, VERY LITTLE DISCUSSION COMPARED TO BREAST SCREENING**

Unlike breast screening women rarely talk about their cervical screening – words fail them! A groan says it all. Breasts are visible, talked about, known, perceived as part of a women’s identity. The cervix is unknown, mysterious, out of sight, forgotten about.

NZ European and Pacific rarely discuss with others the need for cervical screening or their experience.

*“It will come up in conversation about a smear test, or something, or one of us is going for a mammogram and if it’s a mammogram it’s like oh, you poor thing and invite you around for coffee... you all sort of sympathise with them. But cervical screening - it’s a bit embarrassing. Like I say, it’s not something I’ve been brought up to talk about. No even with my friends. You don’t talk about it”* NZ European urban user forties

*“You can joke about having a mammogram, whether you’ve got big breasts or littlies, women and breasts are quite often a topic of conversation but you never talk about the other area”* NZ European urban lapsed early fifties

### **NEED TO CREATE A POSITIVE, EASY CONVERSATION**

Not feeling able to talk about the process deepens feelings of anxiety for next time around. Cervical screening needs to be repositioned in such a way that it can be talked about and ‘worn with pride’ i.e. self worth and self care not embarrassment and silence.

*“If I say anything I’ll just say I’ve had a smear. I never say I can’t stand it when his hand goes up there and that cold thing is there and I bleed afterwards and I can’t stand it. That’s how I feel about it but I would never talk about it”* NZ European urban user mid fifties

*“You think it is just you. You kind of want a buddy to go along with you so you can both get them done at the same time, or discuss it afterwards. But it is something that you go by yourself and then you’re quiet, it is not something you talk about afterwards. It is kind of you shut up and you feel kind of like, sort of invaded. Because afterwards you’re not going to feel particularly strong when you come out, you feel a bit gross and icky. I did, just the fact that I couldn’t go blabbering and tell someone everything that they do straight afterwards. If I could have talked to someone about it straight afterwards and say they did this and it was really gross. Did they do that to you. It’s invaded your system. It’s sort of like at work when you’ve had something happen and then you go home and you just want to get it off your chest and just babble it all out and then you feel good again. You go in and you feel very powerless and like there’s nothing you can do, you’re on the table and they’re going to do their thing. So it is sort of like being at the dentist, there’s nothing you can do, you just have to sit there and open up your mouth and let them do it and it’s horrible. I come out and I want to talk it out to get rid of that feeling”* NZ European urban user early twenties

## COPING STRATEGIES

Women have several ways of coping with the physical process of being screened. Some women will just 'book it and do it' as quickly as possible to avoid having to think about it, others have small 'before and after' rituals that help prepare them for screening and help process their feelings afterwards.

Preparing beforehand is generally around building self-esteem and self confidence via self-talk or waiting until one feels emotionally 'bolstered' or 'strong enough' to cope.

*"It's not the kind of thing you can do if you're not feeling 100%"*  
NZ European urban user early fifties

Before-hand preparations also include reminding oneself why you're doing this – "think of the children".

Preparing oneself physically is also common: showering, 'smelling nice', having clean underwear on and so forth.

*"Well I have to make sure I don't put too much powder on. It's the whole thing, you've got to start the minute you wake up, put the deodorant on, clean knickers. You have a shower and everything. You make sure your period isn't due"* NZ European urban user early fifties

*"There's no way I'd do anything like that before I'd had a shower, oh yuk. Well I would say definitely because I mean I'm very conscious of being overweight, plus I wouldn't go in at a time when I was feeling bad I don't think. I suppose you just feel a bit vulnerable doing it and exposed and you need to be on top of things"* NZ European rural lapsed mid forties

During screening many women try and switch off in order to distance themselves emotionally.

*"I keep saying to myself look she's probably seen a thousand and mine is no different from anybody else's. You think to yourself, where are we going on holiday"* NZ European urban lapsed early sixties

*"You detach yourself entirely from what's happening. It actually surprises me that I am still slightly uncomfortable with it, after having children. You know you would think that after you've had children that it would just be a total and utter non-event but I guess it probably was easier, just after we had children when we were used to exposing ourselves constantly for one reason or another and then we've sort of got out of the way of that, I don't really like to expose myself these days"* NZ European urban user early fifties

It is during screening that the interpersonal skills of the smear taker are so important. Some women talked of the strained conversations and sense of shared embarrassment between doctor and patient, where they felt depersonalised and uncomfortable, as if something bad had happened. Other women talked about doctors who were upfront, sensitive and professional, where, as women, they felt cared for and respected throughout the process.

*“I felt comfortable because the nurse talked to me all the way through, telling what was happening, she made me feel warm, she was caring and it wasn’t a long drawn out session, she walked you through it and was reassuring”* Maori provincial user forties

There is a great sense of relief for women when it’s over. Thus some women will often give themselves a small treat or reward afterwards; even time out for a coffee can help dissipate the negative and often intangible emotional feelings. Other women will do things like have a shower to wash off negative feelings.

For some women, in all cultures, going with a friend or family member for support has appeal, but busy schedules often mean that it is difficult to do this.

Reminding oneself that ‘other women do this too’ can be comforting.

*“It’s healthy to actually talk about it in a way or go with someone. It makes you feel that you’re not on your own. I mean every single woman in the world has to go through exactly what we do, even the Queen, everyone, it’s not just me but no one says anything...Get rid of that whole medical feeling, even though it is medical, it’s quite sterile. I know that I had to psych myself up to do it. Reassuring myself that it was good, it was something I needed to get done, it was going to benefit me and it wasn’t a big deal, it was a small issue, everyone gets them done, I get into a real state”* NZ European urban lapsed mid sixties

However the idea of taking support is not for everyone.

*“I mean it is all very nice about taking a support person to have a smear. I mean how realistic is that for a European woman? I mean I cannot imagine taking a support person in to have a smear test done. It’s so, I mean you know we’re kind of highly individualistic, private, you know ‘I can do anything’ kind of culture”* NZ European urban lapsed early forties

For some Maori women, it’s about ensuring that the relationship with the smear taker is a good one. Where possible, going back to the same trusted person is desirable.

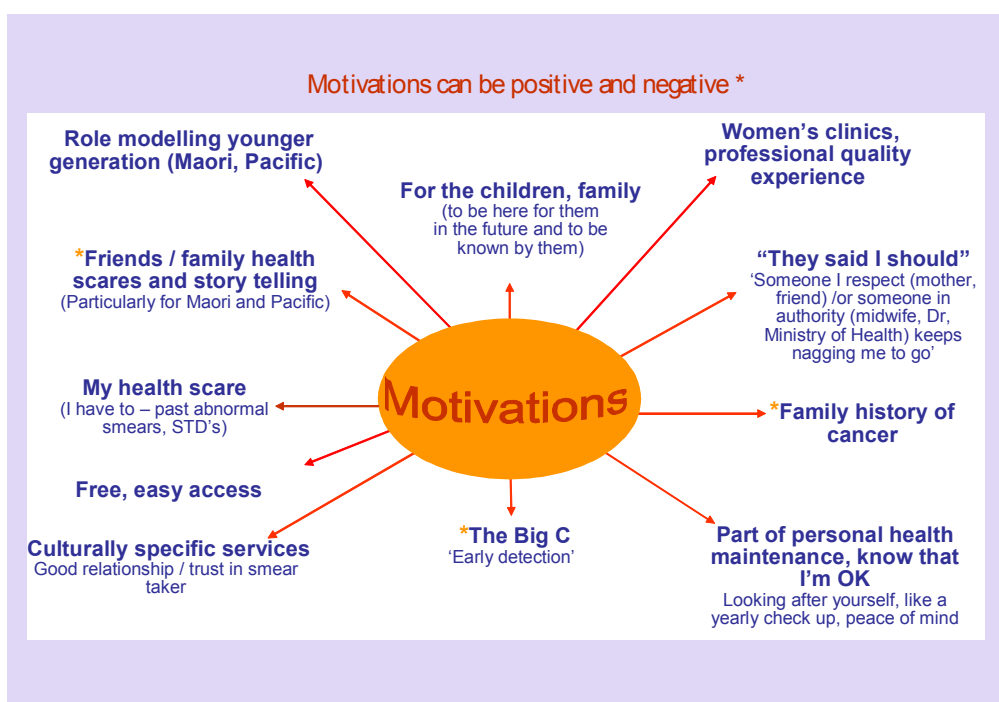
For other women, the power of prayer (karakia) is important. This ritual is often something that women will do of their own accord in preparation for a screening.



### 3.6 MOTIVATIONS CAN BE POSITIVE AND NEGATIVE

Motivations, as expressed by the women in the research, are not as plentiful as barriers. Some triggers can be both motivations and barriers, for example, the perceived risk of cancer; health scares and the perception of family predisposition to cancer can be motivating for some women and act as a barrier to others.

The diagram below summarises the factors that help motivate women to get screened.



#### CULTURALLY SPECIFIC MOTIVATORS

For Maori women some of the cultural motivators have to do with people, place, information and activities.

**People** – Iwi and Maori specific services where they can be supported by Maori. For some the presence of kuia and Kaumatua (elders) is comforting. Some women would choose a Maori specific service if they were aware it was available. Others wouldn't. Having the choice is the key.

**Place** – For some women, having screening in a 'Maori space' motivates them to participate and also where transport and childcare is offered.

**Information** – For those who are fluent in the Maori language, the use of te reo Maori is a motivator. It is through the language that Maori concepts and values can be portrayed.

**Activities** – Having a range of activities that support and nurture women through the screening experience such as wananga or learning forums where women can learn more about cultural aspects of being women, Mana Wahine activities that highlight the specialness of Maori women.

## **ROLE MODELLING**

Feedback from Maori women to a Maori specific pamphlet which had a kuia promoting the message was seen as a positive aspect. Maori mothers and grandmothers are mindful of the value of positive role modeling.

## **HEALTH SCARES OF FRIENDS AND FAMILY**

For Maori women health scares within the whanau are very motivating. This is often the time when women and the whanau at large learn most about health issues, that is, when it has happened to someone close to them. Shared experiences of looking after loved ones with cervical cancer prior to their passing and being with the whanau during the tangi, listening to the talk and asking questions often motivate women to take action as a result.

*“My cousin died at the age of 25. I was around her for the last 3-4 months. It certainly was the most undignified way to go. We dressed her when she died and I saw her body. I remember the horrible smell, we had to use industrial aerosols. Her mother had died a matter of months before too, I saw her body as well. That’s always in the back of my mind”* Maori provincial user forties

Pacific women are also sensitive to what’s happening to their community. Pacific women within church or ethnic communities are often related or connected through tribal links. This reinforces the sense of community and ready emotional and practical support when a health scare is evident. These stories are traded and used to reference the life lead or their own lives in order to make sense of the crisis. As communities are made more aware of the prevalence of these health risks support for action becomes stronger.

*“With the church group you had it all taken together, then they (the smear takers) came back the next year to do a new group, that was positive, because in that time people had died”* Samoan urban lapsed mid forties

In the more individualistic NZ European culture, the health scares of others are not as strongly motivating. There were several stories of women who knew others with cervical cancer or women who had scares. For some women, this was a wake up call

and motivation to get screened, but for others, even women with close contact with these stories, there was still the sense that – ‘this won’t happen to me’.

*“I feel that you know when something is wrong. I know that is not always true but I have the impression that I know when something is wrong with me and that’s when I go and eventually do something about it and maybe that is too late. I have a brother in law who died of cancer so I should be more sensible. If I’m feeling healthy and feeling well, I think why should I have to go and have the tests. I hardly have them”* NZ European rural lapsed mid forties

*“I have a friend who had cervical cancer but I still don’t want to go”* NZ European urban lapsed mid forties

Women with abnormal results in the past are more likely to be proactive and diligent.

### **THE BIG C - AS A MOTIVATOR**

For most women cervical screening is about ‘early detection of cancer’ and as ‘knowledge is power’, early detection must be good, it offers peace of mind and, for many women, a sense of control. Screening is part of keeping a check on your body and a feeling of control over your life.

### **BEING HERE FOR CHILDREN, FAMILY**

Child bearing and rearing is an absolute motivation to be screened. During this time women typically have input from health professionals prompting them to be screened and so awareness and encouragement is high.

Women carry enormous fear during pre school years when children are unable to fend for themselves – ‘what if something happens to me, who will look after them?’

*“Yes, peace of mind I suppose is one (benefit). The other thing, the same as with a lot of things I suppose, is to make sure you’re there for the kids and stuff like that. I have so many more fears now than I had. I never used to be afraid of anything until I had my first son. You know it just changed everything”* NZ European rural user mid twenties

This fear is exacerbated by the enormity of information on health and disease in the media. Carrying fear is the fall out from heightened awareness. Several NZ European women expressed their dismay at the fear and worry that heightened awareness had triggered in them or their loved ones.

*"My daughter is convinced she has cancer"* NZ European urban user  
early fifties

*"It's everywhere, breast cancer, I think about it every day"* NZ  
European urban user mid twenties

### **'THEY' SAY I SHOULD**

Women, NZ European in particular, often comment that cervical screening is something 'I should get done'. They often do not completely know why they should but, 'everyone tells you that you should'. 'Everyone' being the doctor, TV advertising or friends and family.

However 'shoulds' do not mean 'I will'. The personal decision making around screening can be very complex. While many women would rather not think about it, the background 'should' means that the inner dialogue is hard to silence and women will sometimes tussle with their contradictions and fears for months before finally deciding to go. The feeling that I 'should' for NZ European women is a latent motivation waiting to be triggered by encouragement and things that 'make it easy to commit'.

### **IT'S PART OF LOOKING AFTER YOURSELF – 'TELL ME I'M HEALTHY'**

Some women and particularly younger women accept cervical screening as part of basic health check ups. Knowing that 'I'm ok down there' is empowering and positive knowledge; information that women want (i.e. they want to be told they are healthy directly not indirectly by the absence of a recall letter). These women are often proactive and seek regular health checks.

*"Preventative I think would be just keeping yourself safe and making sure there's nothing there, keeping yourself healthy.... keeping your cervix healthy...That would be really good if someone actually told you what that meant or told you what that was. Because I think that's actually really quite a good thing. That's something that I think would be a good thing to come under the prevention, because I think prevention is the best thing anybody can do for themselves"* NZ European rural lapsed mid forties

*My awareness is around being healthy in that part of my body. A smear is someone examining you internally and letting you know I'm OK. At the end of the year I normally go to the doctor for a check up. I won't go into a new sexual relationship until I know I am alright"* Maori provincial user late thirties

### **WELL HEALTH PACKAGES HELP**

Some women are being offered and are being screened as part of an overall 'well health' check or 'package'. Many women appreciate the idea of a package. They see

this as a more positive and holistic women's well health approach and it is convenient. It allows them to get it all done in one go.

*"For the last 10 years, I think, the doctor has always said that for \$25 you can get your smear, your weight, breast feel. That feels a bit better. She does, she does your weight, your blood pressure, she examines your breasts and does the cervical smear. It's sort of a package. I like the idea of a package. It's just the fact that you don't have to make an appointment that's brilliant, it's really good"* NZ European urban lapsed sixties

*"Back to that one stop thing. It would be really good to be able to get everything done, your moles, your bones, your cervical and mammogram"* NZ European rural user mid twenties

*"It takes me so long to get there, I reckon they should do everything in one go, after all it's best to deal with the whole body at once"* Maori urban user fifties

*"Well you could have women's health centres where you could go, specifically for women's health and you can go and have the mole map. Maybe you could get your breasts checked there and smear and all the rest of it. I think they should have a one stop shop. Otherwise you get a compartmentalisation thing, you go somewhere else for this and that"* NZ European urban user mid fifties

While health packages had appeal for many, some women raised concerns about increased costs and the potential to exacerbate emotional discomfort.

*"Just easy for me I think. Time-wise and just getting it all over and done with in one hit. But I suppose if there was no cost involved. I mean cost would be an issue, like if you had to pay for all these things at once"* NZ European urban user early twenties

*"I'm actually a very open-minded person so I can deal with that but there's a lot of women out there that find it hard enough just to open their legs and have somebody put a spatula up or whatever. So they actually, all of a sudden they're saying that someone is going to feel around on their boob as well, I don't think emotionally they could actually handle a package deal"* NZ European rural lapsed mid forties

## **WOMEN'S CLINICS WITH EXPERIENCED SCREENERS**

Knowing that women had easy access to dedicated women's clinics with competent experienced screeners would allay much of the intangible anxiety that women feel. In the research several women were not aware that they had an option.

*"I think some kind of, somewhere like family planning which is some sort of a setting where it's about females, it's about birth, and you know all of those kinds of things, where the staff are*

*used to dealing with women, so you're not being in a situation where someone has just taken blood and now you're walking in and they're going to give a smear, do you know what I mean? You're part of some sort of conveyor belt of testing, so somewhere which is much more about women's, you know, reproductive medicine. So somewhere with babies, and you know, women's health, a women's health centre I guess" NZ*  
European urban user mid thirties

### 3.7 BARRIERS ARE PRIMARILY EMOTIONAL WITH SEVERAL WORKING AT ONCE

#### WHAT PUTS WOMEN OFF BEING SCREENED?

Barriers are primarily emotional and personal and there are usually several barriers working at once. Women rarely have one issue that puts them off screening; rather it is a combination of factors that intersect with their needs and world view at that time.

The diagram below summarises some of the many barriers for women in the decision making around screening.



#### LACK OF CULTURAL SENSITIVITY

There are varying degrees of cultural sensitivity. All women deserve to be and want to be treated with respect as a human being. However for Maori women, there are many examples where they feel that they have not been treated with respect in terms of their cultural values, beliefs and practices.

*"I felt terrible, it was an invasion of my essence as a Maori, it was unsafe and I couldn't wait to get out of there"* Maori urban user forties

Many women spoke positively about the presence of Iwi and Maori providers within their communities particularly as they had a relationship with the people and were

confident that their cultural needs would be taken care of. In rural areas and smaller towns, women talked about how well they knew the surgery and at times how they take care of their own needs as they know where things are.

*“At our clinic, there is privacy, we know where the tissues and the sheets are and we help ourselves. I feel comfortable in the environment because it’s Maori”* Maori rural user fifties

*“I took the moko with me last time and it was pai, she could hear all the korero and it was OK to have whanau there. That’s important to me, we’ve got to teach them young.”* Maori provincial user fifties

## **EMBARRASSMENT**

While embarrassment is an issue for all women, NZ European women do not have a spiritual equivalence of the area ‘down there’ as being tapu. However despite bearing all during childbirth, NZ European women say that screening never gets easy and nether does ‘talking about it’.

*“Initially I was quite uncomfortable and the way that I felt when the whole procedure was being done was that I was a turkey and I had no more respect or dignity than a turkey. Reach up there, and kind of embarrassing, but I mean you get over that and I suppose, I haven’t had children and I suppose that would be a lot worse, and this would be nothing”* NZ European urban user early twenties

*“It’s such a personal thing, that’s why we know from our networks that women will not go to their GP to get a smear test, it’s uncomfortable we need to make it easier for them”* Samoan urban lapsed mid forties

For Maori women, whakama (embarrassment) is seen as a potential barrier to healthcare. It is one of the reasons that prevent Maori women from participating in screening and for those who do, this is what often prevents them from saying what they think and feel. According to Cram, Smith and Johnstone<sup>2</sup> this highlights the importance of a health practitioner taking time to put patients at ease, as whakama will decrease as a relationship is built.

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<sup>2</sup> NZMJ 14 March 2003, Vol 116 No 1170

URL: <http://www.nzma.org.nz/journal/116-1170/357>



## NOT AT RISK

Misinformation is high. Women generally imagine that sexual promiscuity is 'wrapped up' with cervical cancer and so they put themselves on or off the 'at risk' list. They feel themselves to not be at risk if they; have only one partner; a trusted partner; if they are not having sex or they do not currently have a partner; if they are 'not having much sex'; if they have been through the menopause or if they have no history of STIs.

*"I've only had one partner so I'm not at risk"* NZ European urban user  
early twenties

*"I suppose if you've never had an STI, you think that it's never going to happen to me. And multiple partners and things like that"* NZ European rural lapsed early fifties

## BODY IMAGE

Women who perceive something wrong with their body shape, size, hair growth or anything, find it very embarrassing to take their clothes off.

*"Is it really that necessary? Oh, it's sort of, do I really want some doctor looking up there. You know, it's basically invasion, you know. Because I'm a large person too. I mean I don't like looking at myself in the mirror"* NZ European urban non user mid thirties

*"At the size I was. It's not as bad now, but it was definitely a weight issue when I was younger. It would have helped if she had been a big nurse that was older and she might have said come on, get your bottom up there, but she's a lovely trim sexy looking girl"* NZ European urban user late forties

*"When you're older unfortunately the body looks a bit strange, it's baggy and it's saggy and I don't like showing my body to a young and thin looking person, they might think funny things"* Maori urban non-user sixties

*"It's just taking your clothes off in front of somebody else. For me, in particular, I am very private and I find that very difficult and yet that is silly after having children and being in that situation but then again, that is a different situation. I suppose if you are overweight and I have been and still am at the moment, but it's like you don't want to lie on the bed looking like that. That's silly too because I know they see all sorts of people. That is just the way you feel about it. A natural part of it"* NZ European rural lapsed early forties

## OTHER PRIORITIES AND PRACTICAL ISSUES

For many women, there are other priorities and practical issues that prevent them going, including availability of time, work commitments, transport and cost.

*“It’s a bit like a mammogram isn’t it You know they say oh you can go and get it done and I’m thinking, oh well the inconvenience of having to go, no, I’m not, nothing wrong with me, I’m right. It does, because it means I’ve got to take time off work to go and get it done and I hate that. I hate asking for time off”* NZ European urban lapsed early fifties

*“It’s pretty much looking after yourself. It’s saying you’ve got to have a smear test to look after yourself. It probably is important but I’ve put it further down the ladder, lower down. To me, the fitness and the eating are more important and again, it is my body and my decision”* NZ European rural lapsed mid forties

*“When the stack of mail comes in the letter box and they’re all bills but the reminder letter to get screened is there too I think, have I got \$30 to put some petrol in my car to get to town to the doctor, nah, the bills are on top for me.”* Maori rural lapsed thirties

*“Your lifestyle is such that you go through a lot of things in your life, new things, and that (screening) is not a priority. You know you get one letter and then you get another I wouldn’t remember which letter it was, I mean you just read it, but it only stays in your mind for the next 20 minutes”* Samoan urban user mid forties

## **WHAT CAN I EXPECT AS A FIRST TIMER?**

Women who have never had a smear know what is done but not really how it’s done. They typically rely on sisters or health professionals to guide them through the process.

*“Do I need to shave myself?”* NZ European urban non user early twenties

*“You see I don’t know what they do. Do they use stirrups or what, what happens, I don’t know what they do”* NZ European rural non user early twenties

## **THE PAST**

Carrying emotional scars from the past is inevitable but the screening process can trigger emotions that women are left to struggle with alone. Several stories of past sexual abuse were told by NZ European women. For these women the cervical screening process is too confronting to participate in without emotional support before and after. The women talked to in the research were not aware that the NCSP offers support for women who have been sexually abused.

*“For me, it’s like it’s my body, I don’t want them to do it, I don’t want them to go anywhere near me. Like I’ve had bad experience in my life with males and stuff, so it sort of freaks me out every time they go to do it. There’s a lot of people out there, it’s not just me, there’s a lot of people that have had bad experiences with*

*males and stuff and it might make them feel a lot better knowing that there's a female actually there to talk to you and whatever, like to keep your mind off what's actually happening"* NZ European rural user early twenties

*"If you've had a history of sexual abuse, I don't know, maybe they should have a support line or something. I think you're actually losing a lot of women due to that factor alone. It's almost like saying to someone who has been through something incredibly traumatic, here get back on this ship. It's not the real thing, it's only a little fake of it. You're not going to get people in there. I don't think it makes a huge difference whether it's women or men that take the smears"* NZ European rural lapsed opted off register

### **THE BIG C – AS A BARRIER**

In general, ideas about cancer are that it is aggressive and deadly, few women talk about slow growing cancers. This heightens anxiety around cervical screening, 'what if they find something'.

*"As soon as they find it, you're dead in 6 weeks, would they be dead if they hadn't found out?"* NZ European rural lapsed mid forties

Cancer is seen as aggressive: women perceive that it can develop very quickly, so they often do not understand why screening needs to take place only every three years.

*"What surprises me (upon reading the information in the cervical brochure) is that it's really slow, if you do get cancer it's a really slow, slow, process. I think I have this every 3 years, I should be having it every year, every 6 months. Cancer is supposed to be really quick. I honestly thought that when they scraped it, they were scraping cancer cells. That's why I couldn't understand why it was every 3 years. I thought cancer spread so quick"* NZ European urban user mid forties

*"My body is all right, I mean my body is overweight and all the rest of it, but as long as my body is functioning, why should I tangle with it. then you see, there's also the idea, well it used to be didn't it, that if you got cancer, once they opened you up that was it. So if you don't know about these things, they don't have to open you up to take that bit out to start with..... three years! I would think that was stupid because you're going to get cancer it doesn't take three years to get there does it. I mean you could have it done, you could have a smear done and then three months later you could have cancer cells couldn't you, couldn't you? I don't know how quick they form, I don't know, but to me three years is, oh it's a long time"* NZ European urban lapsed mid fifties

## **FEAR, FEAR AND MORE FEAR**

For some women, fear works. They comment that they need to be 'scared into it'. They can even picture the scenes of loss to the family that would make them 'do it tomorrow'.

*"For me the reluctance is not knowing exactly why you're doing it and not having enough information. There are pamphlets on cervical screening and they are telling you that you should have this done but there is not enough information in there to scare me. Probably letting a woman know that her kids are at risk if she is not there. Probably for me to be really sick or to see something which showed the loss. Because actually that's what I don't have any sense of, the consequences. I really don't. I don't know what it's about"* NZ European rural lapsed forties

*Our mother died of cancer, the doctor got all us girls together and said, if you don't want to die like your mother you better do something about it. That scared the hell out of me."* Maori rural lapsed forties

Fear would create the sense of urgency that some women feel is lacking, however while it can be effective in the short term using fear to trigger action will heighten resistance for others and can undermine mental and emotional well being.

*"I really hate the scare thing, because every time you do anything, it doesn't matter what you do, there's a scare tactic, do you know this will happen.... I think a lot of people have the angst of a society that has so much coming at it, that anything that can be kept low key, is probably going to work better"* NZ European urban user mid fifties

*"I'm pretty ignorant about it I think. I think as soon as you become sexually active I think you're at risk of cervical cancer. It's a kind of a "should", one of the things that as women we should be doing, you know, getting regular smears and I don't. I can't explain why I don't do it exactly, I just don't see the benefit, I can't see a benefit for me to be honest. ... I guess in a way I don't want to wander around, you know, with a series of fears on my shoulder, like shit I might get cervical cancer, or I might get melanomas, or I might get, you know, I might have breast cancer. It's like a whole lot of stuff. I guess the case hasn't been made strongly enough for me about the risk benefit for me of cervical screening, and I think probably when I think about it, which I don't usually, I feel it is somehow attached with that whole women's movement kind of grip on the area and this is speaking as someone who was a very strong feminist. That whole ideology belongs to cervical screening for me. I don't like it"* NZ European urban lapsed late forties

*"It's raising your fears. I never used to like using the word cancer. I mean you don't. It brings up all sorts of messages to you. Now people are talking about it more. You used to call it*

*the big C and you didn't talk about it at all did you? It was just a whisper. I think there is still that, it's not a comfortable subject"*  
NZ European urban lapsed mid sixties

### **BAD EXPERIENCE LAST TIME**

It is not just the tangible experiences that can put women off - (like having a speculum caught in your cervix while the doctor panics and leaves you in the room bleeding and frightened, or having people wander in and out of the room) – it is also the intangible, the subtle sense for some of feeling judged or treated impersonally.

*"I had a trainee who didn't know what she was doing. It took half an hour, it was sore and I got told I had to go back because she didn't do it properly. I haven't been back since cos she scared me and hurt me."* Maori provincial lapsed thirties

Several women had stories to tell of less than satisfactory experiences but others were overt in acknowledging the sensitivities and professionalism of some of the doctors they had been screened by.

### **WAITING FOR RESULTS - ABNORMAL RESULTS ARE CAUSING HAVOC**

Misunderstandings about what 'abnormal' results mean still cause serious emotional trauma. Too many women have as much anxiety waiting for the results as they do deciding to get screened. Many ring to ask about their results because they can not stand the anxiety of waiting.

Some women are very angry and feel misled when they are told that abnormal results do not indicate cancer and can be caused by very ordinary changes in the cervix.

*"I actually had two friends who went through exactly the same thing, two separate people had failed results, or abnormal results. they both absolutely freaked out, had this big emotional melt down because it's huge, well it would be the first thing you'd think wouldn't it. Because you go in for a cervical check, then you get an abnormal smear, what does that mean to you? The first thing that would go through your mind, I know it's probably not the best way to think about it, you always think of the worst things, you do. They were absolutely beside themselves the pair of them, no three, three of them, because another one was only just very recent. But she rung me up and it put her almost into this like depressive state sort of thing, she cried for two days, she was so terrified. She was so, so, so, upset and then to go back, But she went back again for another check because they wanted just to make sure and all of this sort of stuff. I don't know if she got another one after that, or whatever but it's all fine. I mean these people have gone on these emotional roller coasters for nothing.*

*All three of them were absolutely relieved over the moon and everything like that, but wild, they were so angry*” NZ European rural user late twenties

*“All I know is that over my life there have been women at various points who have said to me and have come in for a smear, I’ve had a smear and I’ve been told I’ve got an abnormal smear. The panic and they’ve gone on and it’s all been OK after all. But the panic!, why would you want to put yourself through that. I don’t see why”* NZ European rural lapsed forties

In a similar vein, Pacific women who had received news of abnormalities were aware of the purpose of the screening – early detection of cell changes but many jump forward and develop a sense of dread that this is actually cancer.

*“When I first got the news I felt frightened that it was cancer. I didn’t know what was going to happen, I didn’t really know what the process was”* Cook Island urban user mid forties

### **IGNORANCE IS BLISS – DENIAL LETS ME SLEEP AT NIGHT**

Women intuitively ‘weigh up perceptions of risk’ and put some things on the ‘back burner’ in order to concentrate on others. While women joke about their ‘denial’, it is a form of protection.

*“I just deny it, I’m just in denial about the whole thing. I just put it to one side and it might pop up from time to time, but essentially my way of dealing with whatever my negative feelings are about this whole thing is just to kind of put it out of my mind”* NZ European urban never mid thirties

*“I think well if you’re healthy why tempt fate. I mean if I found something imagine how devastated I’d be, so I think well if I don’t know about it I don’t have to do anything about it. Leave well enough alone”* NZ European urban lapsed sixties

At a deep emotional level, women perceive cervical screening more in terms of ‘risk of death’ rather than well health. This means that at a deep level ‘buying in’ to screening means potentially having to think about consequences i.e. ‘what would I do if something is wrong’.

Screening is about state of health and potential consequences. This is why women want a ‘good health’ report not just an ‘abnormal cells’ report.

## **WOMEN'S INTUITION**

Women's intuition is about self: self awareness, self knowledge, and self confidence. "I'll know when something's wrong" is a common expression. Women can feel that screening undermines their sense of faith in their own knowing because screening instills fear of 'what if'.

A women's intuition is a powerful sense to harness in the campaign – again it's about turning the conversation around to a more empowering, holistic and well health approach.

*"I don't really want anyone to say to me your body is this and that. No, I will say, I know my body. Don't tell me what my body's not doing. I'll tell you"* Maori provincial user late thirties

*"Early detection, for me it's just total self-intuition. You know for things like that, there's, I don't know how to explain it really, for myself it's just like you know something is not right, whether it's a niggle or a twinge or a sniffle"* NZ European rural user mid twenties

*"OK I've got a gut feeling, intuition, call it whatever you like. Your gut feeling is your first instinctive feeling, it is never wrong, you can pull it to bits, you can analyse it, you can change it, you can twist it around, you can even go against it, but you'll find that right from that first instinctive gut feeling it will always hit you back in the face...I've had an example recently, I had symptoms. I said, no, no. for a year I put off getting screened, a year it kept niggling at me and I thought to myself, well hey I'm going to have more kids and what if this happens and you know, and I thought no, and I was fighting against myself and I didn't want to have it done. I got so angry about it and my husband said, go and have the thing done. I said, no. He said, go and do it. I sort of said OK, and I got angry with myself for giving in, because I knew it would come back clear. I knew that because all my tests have come back clear. So I got angry at myself because I knew my body, I knew who I was, I knew that it was just because I was in the wrong position or it was that time of the month where it was tender"* NZ European rural lapsed late forties

There are other women who have an absolute belief that they are healthy and don't see the need to go as they believe it is unnecessary to do so.

*"I didn't feel I ever needed to do it. I just don't think there's anything wrong down there, I'm healthy"* Maori rural non-user

## **NEGATIVE MEDIA STORIES**

Negative media stories can undermine the strength of a woman's decision making process and trust in the medical profession and male practitioners in particular. Even

when women trust their male doctor, these stories plant seeds of doubt and exacerbate the feelings of embarrassment.

### **HEALTHY READINGS**

Some women interpret the absence of an abnormal result, especially a few years in a row as 'I'm fine, I don't need to bother'.

*"A lot of women in our age group that don't want to go back, it's because they have a long term relationship with one partner and they've been clear all this time and so why bother"* NZ European urban user fifties

*"For several years my tests were positive and I decided I would take the risk and not have to suffer the embarrassment and uncomfortableness and that included the breast screening as well"* Maori urban lapsed sixties

### **MISINFORMATION – WHY ARE WE REALLY DOING THIS?**

Generally, a large number of Maori women did not recall hearing or receiving information about cervical screening and therefore felt misinformed and had many questions.

*"It's hard to cure – isn't it? Can it be cured?"* Maori provincial lapsed forties

*"Is sex what causes it?"* Maori provincial lapsed thirties



### **3.8 DECISION-MAKING: THINGS CHANGE**

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The number and depth of the emotional barriers means that subsequent screenings often create more anxiety than the first screening, where typically, women do not know what to expect.

*“It didn’t worry me the first time, because I didn’t know what I was expecting. But then the guy who did it after, who is no longer my doctor I must say, he was as rough as guts. The little clampy thing they use, it pinched and he didn’t let it go. I’m going ow, ow, ow, and he’s going oh just hang on a minute and he was pinching me in the clamp. Oh my god I was like bruised for I don’t know how long and the swab thing he poked and shoved and scraped and I was just sitting there crying. I was in so much pain. it was revolting”* NZ European rural user mid twenties

As women age, they are particularly sensitive to emotional barriers, their attitudes to health change and they are often in a process of reframing past experiences. Thus each screening involves a decision making process that is ever changing in the variables being weighed up.

#### **THE TYPICAL SCENARIO – GETTING ‘ROUNTUIT’**

As mentioned, some segments, particularly younger or busy women are typically well organised because they have to be, they take a just ‘do it’ approach, book it in, get it done and forget it.

Other women however are likely to put the letter on the ‘to do’ pile. The letter will then be reassessed a week later and thrown out or put on another pile! However during this time there is often a ‘constant niggle’ and inner dialogue as women tussle with their feelings. The screening letter rarely gets consciously thrown out, women just try and remove it from their vision. At a rational level they want to ‘be good’ and get screened but at an emotional level they just do not want to do it!

*“When the letter comes it’s a good reminder and I think oh it’s that time again and then I lose it, and then I do all sorts of other things before I finally get round to going.”* Maori urban user forties

#### **A CONSTANT WEIGHING UP OF CHANGING VARIABLES AND EMOTIONAL TRIGGERS**

Without primary motivations such as ‘doing it for others’, emotional barriers predominate and users can quickly lapse.

*“It never used to worry me. I used to go and have it done and I was never fantastically happy to have it done, but it was*

*something I had to do. I was a lot more settled about it. In the last few years I've got less happy about it and I'm not too sure why. It may be that I know my doctor, I maybe know the doctor too well. Last time I had one he wasn't there and a woman did it. I was happier with that. Although I personally knew the doctor, I was happier having her do it. It may be just my relationship with him, which was a bit odd in a way, it's a lot more personal. To me it was so important to make sure you were completely healthy before I had children, and when they were younger perhaps. Over the last however many years, I've felt much more defensive about it. I'm not as relaxed about it"* NZ European urban user fifties

During the 'weighing up' women are very open, and in general welcome the efforts by others to encourage them and 'give them a push'. Advertising has an important role to play in nudging women along.

*"My Mum and my friends are always encouraging me. And its the publicity thing – it was like a solidarity thing, women looking after ourselves."* Maori provincial user forties

The diagram below summaries some of the key motivations and barriers for non-users, users, lapsed and lapsed hope never to return.

| Non Users   | Users   | Lapsed  | Hope Never to Return  |
|---|---|---|---|
| Limited understanding about how the body works                            | Doing it for the children or have had a health scare    | Often immobilised by emotional barriers: embarrassment, poor service, fear of cancer      | Philosophical / political stance  |
| Less aware - Cervical screening? means nothing                            | Often a greater understanding about how the body works  | Or do not see themselves at risk  | Highly unsatisfactory screening experiences or unhappy emotional memories, cultural and spiritual   |
| What do they do and why do they do it?<br>Do I have to prepare something? | Part of personal responsibility to take care of oneself | Still have a constant niggle – I know I should do this (NZE) – <i>want to be pushed</i>   |   |
| Want encouragement, direction and support from friends and family         | Already 'in the medical system'                         | Want help / encouragement overcoming emotional barriers and clearer understanding of risk | Some want their decision to be respected and to be left alone, others need a high degree of one to one support and encouragement to overcome barriers |
|   | Need encouragement from health professionals, midwives  | Want acknowledgement of cultural and spiritual values (Maori)                             |   |
|   | Users have potential to be advocates in Pacific         |   |   |

## **IMPLICATIONS FOR COMMUNICATIONS**

- Emotional barriers often overwhelm motivations and the ‘best of intentions’ – currently most users are ‘potential lapsed’
- Communications need to work hard to help women feel supported. Women need a sense of togetherness in this, like the collective sense of the breast screening campaign. At the moment, emotionally, women feel they are ‘doing it alone’ and compared with perceptions of the breast screening campaign...it’s no fun!!
- Use all ‘customer touch points’ before, during and after screening to shape understanding, commitment and positive ‘return attitudes’ e.g. affirm women in having made the right decision
- Inspire women to talk about it and proactively support each other – *“have you been ...”*

## **IT’S ABOUT THE WHOLE EXPERIENCE; BEFORE, DURING AND AFTER**

There are many points within the decision making and actual screening process that have potential to be improved or used to pre-empt lapsing and to trigger more understanding and commitment.

### **BEFORE...**

It is important to remember that each woman brings a particular context with them to the screening process. The context they bring predisposes them to some fears rather than others, for example, whether they are married, divorced, single, have a history of STIs, a family history of cancer, whether they have had abnormal smears before, and so forth will contribute to the comfort or worry that women feel.

In addition, the level of their understanding as to why they are getting screened aids or inhibits their sense of ease i.e. if a woman is doing this because “I’ve been told that I should” rather than owning the motivation: “I am doing this for my peace of mind and well being”, she is less likely to be committed to the process long term.

Practical preparations also play a role: women often struggle to fit in the time to get to the clinic for open hours, they have to get the kids somewhere or get time out of work and in many cases, for rural and non-European, they have to organise transport and so forth.

Money is also a consideration; many women find it hard enough to find time and pay for doctor’s fees when they are sick let alone making an appointment when they are well.

The letter or phone call advising women that they need to make an appointment is of enormous importance and is currently underutilised as a potent communications vehicle in terms of providing encouragement.

### **DURING...**

As noted below in section on 'what makes a good screening experience', there are many small things that can be done to make women feel more respected and cared for.

There is room to ensure that in closing or finishing each individual screening session that women receive some encouragement or affirmation about having made the right decision to be screened; *"you've done the right thing, well done"*, *"see you back in three years unless we ring, here's a reminder"*. This is also an opportunity for women to take away some well health information that strengthens their own understanding about women's health and why screening is important.

### **AFTER...**

As previously discussed, the manner in which women receive results and the expectations they have around results also has potential to substantially allay fears and provide more empowerment in terms of knowledge.

Women need to be told very clearly at the end of a screening; how the results will be communicated to them, what 'abnormal' means, how common abnormalities are and what kinds of things can make cell changes look abnormal, when they can expect to hear about the results and what they can expect in terms of communications around the results i.e. being rung or sent a letter or not receiving any communication at all.

Explanations and communications need to be in simple everyday language, and given a context, visual image or metaphor to help women really understand.

Even when results are clear women want to know rather than being left to assume that everything is fine because frequently, if women hear nothing, instead of being assured that they are fine, they often imagine that 'the letter was lost in the post' and something terrible has been found!

*"Well if I didn't have a choice, if he just said, get up on the table we'll do it now. Oh OK, I'd do it but then you see I'd worry, I'd walk out of there and I could imagine myself being so stewed up about it that I could probably be violently sick. Because now I've got this wait"* NZ European urban lapsed mid sixties

*"You start to wonder if you don't get a phone call, how come they haven't rang you, is it abnormal or with me having them as abnormal for so long, it makes me wonder sometimes when the doctor doesn't ring me or whatever I have to ring them myself to make sure for myself"* NZ European rural user early twenties

## **A GOOD EXPERIENCE? IT'S THE SMALL THINGS THAT COUNT**

When asked how the screening process could be improved in any way, women say that fundamentally it is difficult to make the experience better. However they comment on all the many small things that make them *feel better* about it.

It is the small things that make women feel that they matter; that they are not just a 'number' to be processed, an illness waiting to be found.

### **At a rational level**

- Competency, experience, professionalism
- Gentleness, sensitivity to need e.g. large towel, screen, a special room, blinds down, a closed/locked room - no nurses or staff wondering in
- Bringing a nurse in if with male doctor (don't ask just do it)

### **At an emotional level**

- Gender, age and cultural safety
- Music, flowers, warmth, kindness, privacy
- Treating me like a real person and with respect
- Being reminded why I need to be doing this and what will happen regarding results
- Being affirmed in making the right decision to have been screened and to continue screening

For Maori women the cultural and spiritual aspects impact on emotions in a big way, particularly due to the significance of and values and beliefs around the reproductive area. Acknowledgement of cultural factors is important for Maori women, particularly where women have a belief of trusting only their own women.

*"It matters for me that we can have this done at the marae, it is where I feel safe. Our kuia are there and it's a familiar environment with support of other women."* Maori provincial user fifties

## **IMPLICATIONS FOR COMMUNICATIONS**

- It's the small things that matter
- For Maori acknowledgement of cultural and spiritual values and beliefs is critical
- Reframe the process in a context of wellness (rather than current illness focus)
- Treat every 'customer touch point' as an opportunity to enhance understanding and confidence and shape positive 'return attitudes'

- Communications should be encouraging and supportive. Tell the good stories - highlight positive experiences
- Use 'affirm and nudge' tactics; one of the biggest roles of advertising for cervical screening is to remind and prompt lapsed users (while affirming and encouraging users)
- Use 'affirm and nudge' tactics in environments that are open, comforting and ordinary e.g. hairdressers, women's groups, weight watchers groups, kindies, schools, supermarkets, markets, churches, sports events
- Be careful about using things like the back of doors in women's toilets – for older women it can reinforce the feelings of 'secret women's business'

## 3.9 USING POSITIVE TRIGGERS TO OVERCOME BARRIERS

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### MAKING IT EASY

- Access - timing, parking, transport, childcare
- Location with options - GP clinic, marae, Maori health clinic, private home
- Decision-making - increase opportunistic screens (while you're here....), make my appointment for me
- Relationship - trust and professional competency
- Dedicated women's clinic, knowing I have a choice about where to go. Sometimes women feel uncomfortable asking where else they can go as though they are being disloyal to their doctor (male)
- Make payments affordable/free – cost is an issue for many women

### SHORT CIRCUIT THE SELF-TORTURE – MAKE THE APPOINTMENT FOR THEM

Use the reminder letter to make an appointment that women then have to break. 99% of NZ European women in the research said that if their reminder letter had a time and date allotted they would go!

They comment that ringing up to cancel would require almost more courage than going. This is especially so when the letter or phone call has come from a health professional one knows reasonably well like the doctor's nurse, and especially so when one lives in a smaller rural community when you are likely to see one another often.

*“You get your first reminder, or your second reminder, time to go for your cervical smear. I feel guilty and another one comes. I then get around to doing it. I'll go in and I apologise and they don't care. Perhaps they could give me the option of going somewhere. I think in a way, what would make it a lot easier for me would be to say, we have made an appointment for you to come in next Wednesday at 4.00 pm and if you can't make it, please ring us to make an appointment to come in. That would make a huge difference to me, because I have to get in touch with them and I would have it done within 10 days. That would make a big difference to me. That would make me move and make me do it. Even if I said I can't make it, but I will do it next week and I'd be in there and have it done in the first 2 weeks”* NZ European urban user mid fifties

It is also important to use the reminder letter as an opportunity to highlight a few succinct and age appropriate paragraphs about why screening is important.

## **CREATE WOMEN'S HEALTH PACKAGE OPTIONS**

Women particularly like, and spontaneously mention, the idea of including cervical screening in with other mandatory health checks like skin moles, breast lumps, cholesterol, and blood pressure. This diminishes the uncomfortable focus on the 'big event' and feels more empowering as an overall health check.

*"Maybe they should combine the 2, then have a package. I would still go, I don't care, even though I've got this fear thing, I would still in the end do it, and the same with mammograms. Even though I don't like it, I still do it, even though it's a bit late"* NZ European urban lapsed mid sixties

For Maori women, this option is even more attractive when there is an element of pampering and fun. The health checks don't seem to be so onerous when surrounded by a 'good time' with others.

*"Take us on a retreat, give us a nice hot tub, a really nice massage, tell us we're awesome, build us up, let us know as Maori women we are special. Do it to Maori women by the busload - it matters that we feel valued."* Maori provincial user forties

## **SIGNIFICANT INFLUENCERS – "A WORD IN YOUR EAR"**

Encouragement from others, whether professional, family or friend, is needed and works.

*"Aunty has been so consistent in her encouragement over the years, she deserves a medal. And when I see her face, she is always a reminder about screening and about strong healthy Maori women too, and I like that"* Maori provincial user forties

## **SOME MUMS TALK, SOME DON'T**

Talking about screening with daughters means talking about sexual activity so attitudes are polarised in terms of mothers passing information on to daughters.

Some women make an effort to talk openly with daughters about sex and contraception (but often forget about smears). Others do not talk about at all.

*"I kind of lost my virginity at an early age, and since then we don't talk about that. She's kind of angry at me and we haven't really talked about it. So I kind of took over myself and looked after it since and I've talked to other people. I do have health professionals I talk to, but no Mum wouldn't want to talk about that"* NZ European urban user early twenties



For most Pacific young girls they learn about sex and STI's from school and friends as this is not an open subject to talk to with their mothers, this however doesn't guarantee they understand it, or retain it.

*"I remember reading about it, I think in a pamphlet at school but I don't know what it is"* Tokelauan urban non-user late twenties

For Maori women, the increased publicity and focus on Mana Wahine (women's prestige), through events such as Mana Wahine week, through the education Maori children are receiving in kohanga reo (kindergarten) and kura kaupapa (school) is now reinforcing the value of Maori women. Iwi and Maori providers have a stronger presence in some communities and are actively promoting Maori women's health. As a result, more women are openly sharing with one another in hui and other forums information pertaining to the health of Maori women.

#### **GROUNDED IN THE WHANAU EXPERIENCE**

Experience and knowledge of mainstream health professionals was not overly positive. In many cases either they or a close relative had not received good treatment and sometimes this resulted in a relative dying. Suspicion and fear of the health system was therefore often grounded in the whanau experience and not solely the experience of an individual. Some women are more comfortable with their doctors and practice nurses who know them and their whanau.

#### **RAPPORT AND QUALITY RELATIONSHIPS ARE THE KEY**

Women like doctors who take the time to find out about them and their families, are genuinely interested and don't talk down to them.

*"In smaller towns, whanau have more of a personal relationship with Dr's. There's the connection with the families. I remember Dr....., he looked at families with acceptance regardless of whether they were pohara or not. He was not into playing God. There were certain Dr's who were well respected in the community"* Maori rural user thirties

*"I remember feeling comfortable with my doctor because she made me feel warm, had me covered in private and she took time to talk to me before she got on with the job, she was reassuring for me"* Maori user rural forties

## **MAKE IT PERSONAL AND FUN**

Maori women enjoy opportunities to talk amongst themselves, particularly as a whanau or in close-knit groups where they can have intimate discussions around these issues. Often they will make fun of the topic in order to 'make light' the aspects which are somewhat heavy topics.

*"If I was to do it again, (have a smear) I would like it in a group situation where it's not just cervical screening, it's introduced along with other interesting happenings, a challenging atmosphere, but fun cos we love to laugh"* Maori urban lapsed sixties

Women suggested a tupperware type of party where women come together at someone's house, talk, have fun and be together as screening is done would be another approach.

## **PACIFIC WANT ENCOURAGEMENT AND OPTIONS**

There are many differences within the Pacific peopled communities. Some women may prefer to go to a non-Pacific doctor because they feel just as comfortable in a non-Pacific environment. Other women prefer non-Pacific doctors because of privacy; Pacific communities are small and everyone knows everyone else. As such Pacific women want options.

*"I can access Pakeha media and I translate that into my Pacific way of thinking and how that is important for me as a Pacific person, but we need to package the information in a Pacific way. We have to be somewhat sensitive to what they (the Pacific Community) will prefer to be exposed to it. My doctor is a mainstream doctor, I don't think we have to be brown to appreciate how to communicate brown"* Samoan urban user mid forties

Pacific women want to know that they are doing the right thing. Community-based reassurance provides a context of support and normalcy. Strong support from family and encouragement of the decision to have a cervical smear is important – so as not to defer the decision.

## **IMPLICATIONS FOR COMMUNICATIONS**

- Women are lapsing unnecessarily, many current users are potential lapsed. There is opportunity both in the process and in advertising for more proactive encouragement to shape positive return attitudes
- Engaging other voices - husbands, lovers and family will help normalise screening

- For all users, incidental advertising and communications work to remind and prompt women, acting as a nudge to make that appointment
- Accentuate the positive. Position screening in the positive; women want 'healthy cervix' reports. All communication opportunities can be used as a vehicle to encourage and empower self knowledge and self care
- Talk about the women who survive because they were screened. This provides a strong emotional and positive context in which to understand risk
- Talk about the numbers of women who do get screened, for some women knowing that 'every woman' does this is comforting and gives them courage. Consider an 'x thousand women do this' style of communication - reminding women that women of all shapes and ages do this - your neighbour, granny, friend, your sporting icons
- Talk about Maori for Maori service provision
- Local people know what works best in terms of overcoming barriers within their communities
- Clear up understandings around the results as they are creating emotional havoc. Work needs to be done on expectations, language and understandings about abnormalities. Keep it clear and simple, use everyday language, explain clearly and succinctly what an abnormal result and call back means, consider communicating this information visually if possible, indicate clear timeframes, repeat the messages more than once, have ways of checking understanding, use a frequently asked questions sheet to prompt and pre-test potential scripts

### **3.10 FINDINGS FROM THE REGIONS**

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Women in rural areas are likely to have a close relationship with the health provider as they bump into them in the shop and at school. This creates a continual prompt and banter. Often the relationship with the local nurse can be quite personal and together the nurse and the community work out how best to get the results.

*“The nurse used to come around and chase everyone, because if you’re behind, it puts her behind. She’s a bit of a Hitler, but we feel comfortable with her”* Maori rural user forties

There is a certain language and mode of communicating that is unique to small communities - locals know best.

*“I prefer my doctor to do my smear he knows everything about my health, he’s been my doctor for years”* Samoan rural user late fifties

#### **WHEN IT’S APPROPRIATELY RESOURCED IT WORKS BETTER**

Women in areas that have the equivalent of the district nurse or a community based health provider have closer access and more buy-in, as they are on your door-step. In some areas where Iwi and Maori service providers are present, they have a particular knowing about how best to serve their communities. There are examples now of where screening rates are increasing due to a concerted effort by local providers and clinics working together. All women want a “personal relationship” based approach at the time of the service.

#### **REGIONAL VARIATIONS - MAORI**

Common to all regions was the positive impact in communities of strong Maori women as role models and Iwi and Maori service provider contributions to health services. Everybody knows what goes on in small rural communities.

*“Back in the 80’s there were two Aunties in particular who were encouraging of us to get active, be motivated and vibrant as Maori women. That had an impact on us, they were like a strength of well-being in themselves because of what they did and how they did it”* Maori provincial user fifties

*“For Maori Women, they are more likely to overcome emotional barriers with the support of staff who are whanaunga (related).”*  
Maori rural user forties

*“There was ....who taught us the concept of treasuring ourselves, where Dr’s had no regard for this, they rubbished it”* Maori provincial user forties

There is an increased awareness and consciousness around health and wellbeing in Maori communities. Traditional healing was and still is very common in the whanau in particular communities. There is also an increased focus on rongoa Maori (Maori healing methods) as whanau begin to further reclaim family traditions.

*“We want our healing ways back. In the previous generation, everybody had a nurse in the whanau and a lot was past down from our parents. The old medicines were much stronger”* Maori rural lapsed fifties

### **3.11 PERCEPTIONS OF THE PROGRAMME, NEW LEGISLATION AND ACCESS TO DATA**

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#### **GENERAL AWARENESS ABOUT THE PROGRAMME FOR SOME**

Most NZ European women had awareness that screening is a national programme. They imagined the benefits as: keeping track of women and data for timely recall, quality control and research data.

The screening reminders are seen as a prime benefit because women do forget especially if they are going three yearly. Women who are going more often are more likely to have formed a habit, an internal clock that reminds them.

However the comfort of the campaign reminders can also mean that women avoid 'ownership' of motivations and knowledge. Belonging to the programme can mean that women 'forget it' i.e. they take less proactive ownership of the process: remembering to have a smear, and have less motivation to take on board the 'why' information. Instead they trust a paternal authority to tell them where and when.

#### **MAORI WOMEN EXPRESS A WIDE RANGE OF FEELINGS**

Not many Maori women were aware of the programme, those that were, associated it with raising awareness about screening and some recognised it as a monitoring system which keeps a track of screening for and on behalf of women.

Others were misinformed and associated it with the Gisborne "botch up".

Some felt that the programme was unaware of Maori women's needs.

#### **PACIFIC TOO BUSY TO WORRY ABOUT IT**

The common response from many Pacific women is that they are too busy concentrating on what is in front of them thus Pacific women have less awareness of the programme and have less understanding of what this means.

*"A health worker from the Hutt Valley she came and told us (about the register), if I remember after that we were put into different ethnic groups and then we came together"* Tokelauan urban user late fifties

Pacific women had little awareness of the changes to legislation. When explained, Pacific women had more tendency to trust other "experts" - belief in external authority. Pacific women are pragmatic – 'they know what they are doing so get on with it'.

Of the Pacific women interviewed, the ones who had previous abnormalities detected and had experienced other parts of the programme, e.g. specialist care, colposcopy, more regular smears, were more knowledgeable about the programme and its purpose and were able to convey this understanding. This however, didn't necessarily translate into community advocacy for the programme.

### **DISENGAGED FROM PROGRAMME**

Pacific women often feel disengaged from Government communications and initiatives as the language, services or issues are not perceived to be directed towards them as Pacific women, they may consider these messages as more relevant to other groups.

*"If it doesn't concern my world directly, I'm not interested"* Samoan urban user mid forties

*"I think you need to be sexually active and I'm not, that's what I think, I also think it's also for older women, you know, from TV you have to be 45 (confusion with breast cancer adverts)"* Tokelauan urban non user

### **ATTITUDES TO ACCESS OF DATA ARE POLARISED - TRUST IS ALWAYS ON THE LINE**

There are some concerns about access to data. Access is imagined to be for research purposes and most women are comfortable with this especially if the data is unnamed.

Women that indicated unease often have less trust in the medical system as a whole and therefore take a cautious approach.

*"I never trust anything. Anything can be exposed, or overt, or assumed. I would never say I would have 100% confidence in anything"* NZ European urban user fifties

*"I think that it should be consented. Well, there has been quite a bit over the last couple of years when people's confidentiality has been breached. I think it's a personal and private thing unless you've given your consent. And if it was for the good, like a research programme that was going to help other people, of course it wouldn't worry me"* NZ European urban user mid fifties

*"It's just a courtesy to say the least, that I get your permission"* NZ European rural user early twenties

For some the issue is about respect and privacy. For others it's about potential embarrassment with past STIs.

Women in smaller communities (either geographic or cultural) are particularly wary of who has access to online information. There is often a fear that other private information will be accessed.

## **MAORI WOMEN HAVE HEIGHTENED SENSITIVITY TO ACCESS**

There generally seems to be less trust in the system by Maori women. There are perceptions of misrepresentation and misinterpretation of data and not enough evidence to satisfy Maori that the system has due regard for Maori information.

Maori women want control of their data as they are also wary of the deficit perspective.

*“I don’t trust the medical profession or scientists, there are so many technical heads out there that can skewer the information, I want to know that our information is going to be safe”* Maori provincial user mid thirties

## **WHAT LEGISLATION? ABILITY TO OPT OFF EXPECTED**

Most women were not aware of the legislation but had presumed that they could opt off the register if they wanted. For one woman the reminders amounted to ‘harassment’ and combined with the stress of a false positive result, she made an informed decision to opt off.

## **TRUST? “YOU JUST HAVE TO”**

Trust in the programme has in part been undermined and bolstered by the Gisborne investigations. Women comment that human error is always a risk but there is a feeling that such a scandal ensured that quality has been heightened.

*“I know there’s been issues in the past, but you know I think they were hopefully just one off situations. I also think that things will have improved with time. Well I assume that they’re going to pick up any trends or anything else that’s happening, anything unusual or if there’s anything that can be done. But you entrust it (your data) and you’ve just got to, you’ve got to hope that whatever they’re doing is being done properly and that they follow procedures. Most of the time I don’t really even think about it to be honest”* NZ European rural lapsed late forties

Women ask ‘how can you ever tell’? Continual exposés of professional misconduct whether at an individual level or process level continue to undermine trust.

*“Oh you know, you think what’s the point, they’re likely to get it wrong. It would take a lot to build people’s confidence back up. It wasn’t a New Zealand wide thing was it, it was only in certain places that it was misread, but you would still have that doubt there thinking, well there really isn’t any point in doing this, is there, because it could be wrong. So if they say, yes well you have got cancer, well it’s wrong isn’t it? How do you know it’s*



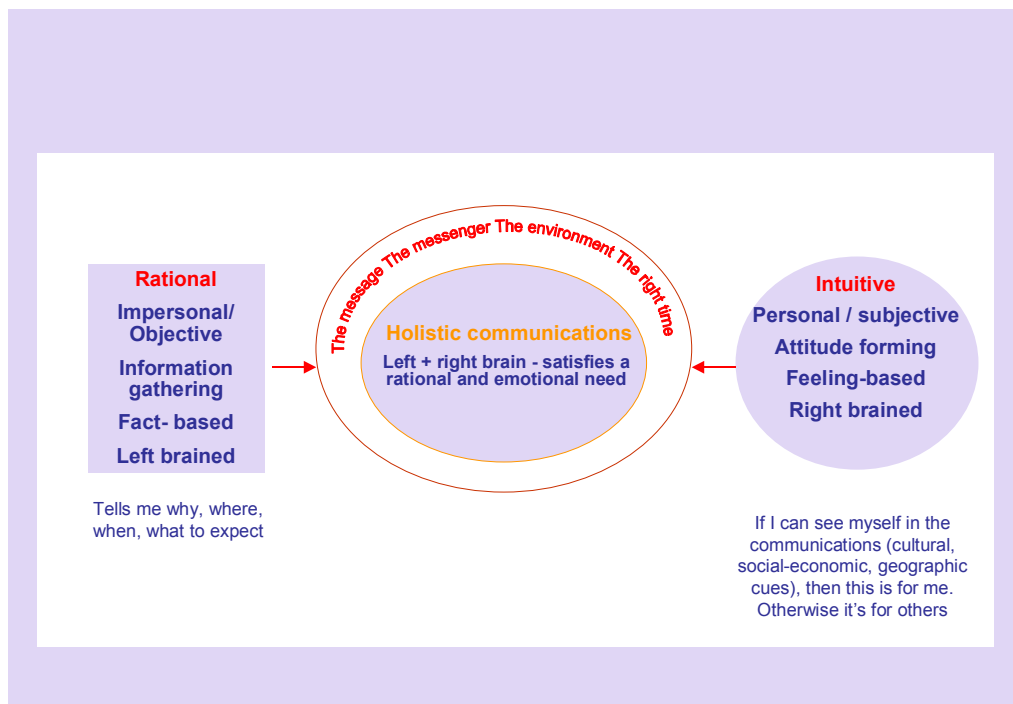
*right? How many times have you tested it. To me the doubt would  
be there” NZ European urban lapsed late sixties*

### **IMPLICATIONS FOR COMMUNICATIONS**

- The trust issue is as much about the medical profession as a whole as the cervical screening programme
- There is a tension between raising the awareness of the use of women’s data and not creating apprehension (big brother)
- Better to communicate information as ‘non-identifiable data’ rather than ‘confidential’

## 4. EFFECTIVE COMMUNICATIONS

In issues of health many women say they want facts based information but there is also a need to address the emotional context as well. Thus, as outlined in the diagram below, effective communications need rational and emotional triggers, and a cultural context.



### THE MESSENGER IS AS IMPORTANT AS THE MESSAGE

When the information is delivered in the right way by the right messenger women want to know. Each culture has respect for particular messengers.

### APPROPRIATE MESSAGE AND MESSENGER CRITICAL FOR MAORI AND PACIFIC

The message and the messenger go hand in hand for Maori women. When women were asked for examples of appropriate messages they gave forthright, strong messages that were expected to provoke action. There was no desire or need to “soft sell” the messages.

*“Cervical cancer affects our whakapapa”*

*“Do it - You’ll get to know what’s going on down there”*

*“Cervical screening can save a life”*

*“If you want to be around for your babies you better get on and do it - have a smear!”* Maori provincial user/lapsed forties

Maori Women felt that some women needed reassuring about the quality of service that they might receive and that they would be cared for in the process.

*“You are a Woman of Mana and we can’t afford to lose you”*

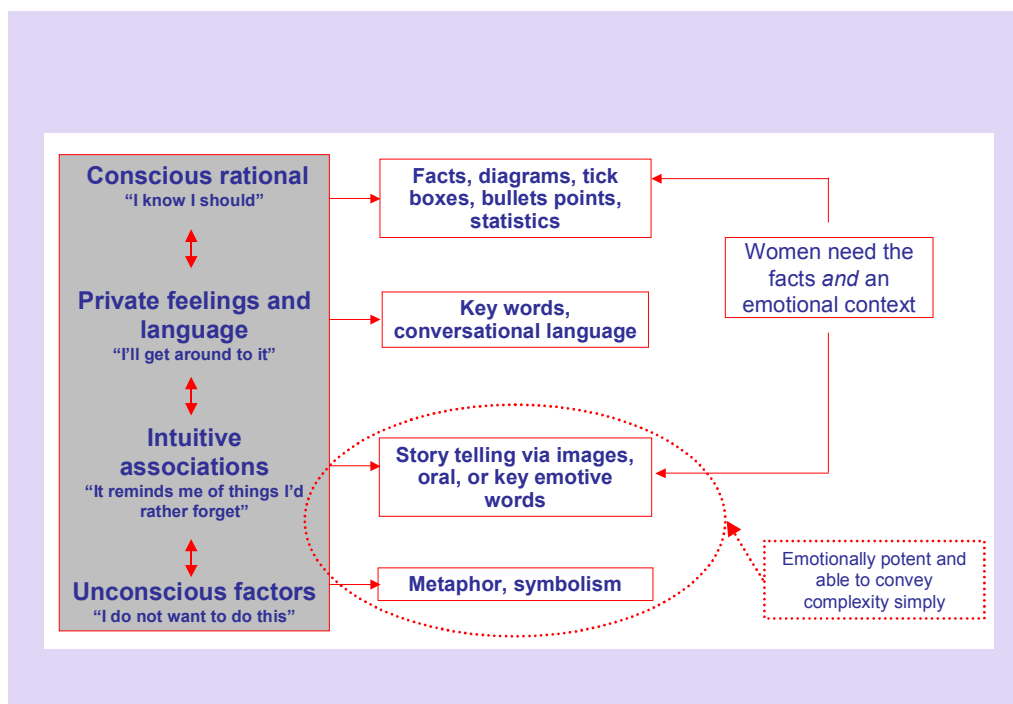
*“Now it’s safe to have a smear, we’ve found you a provider who is culturally safe”*

### **DIFFERENT COMMUNICATION DEVICES REACH VARYING DEPTHS AND HELP WHEN TRYING TO COMMUNICATE COMPLEXITY**

Different communication devices are needed to communicate to the emotional and rational levels, or to the left and right brain.

Understanding the ‘why’ around cervical screening can be complex so brochures are not the easiest medium to convey information, especially for women who are not comfortable with written information.

Creating emotional connections by community story telling via emotionally comfortable mediums, (women’s magazines, community papers, interest group newsletters, group korero) is the best way to speak to ‘ordinary’ women.



## **THE POWER OF METAPHOR**

For all cultures, but particularly for Maori and Pacific, information relayed through visuals is powerful.

Complex concepts which are informed from outside the culture, “we have no word for that”, work better through metaphors or experiences common to the culture, for example, ‘a mango may look juicy on the outside but if you turn it around it can be bad on the other side’. This is an experience understood in the Pacific to convey the need for internal examinations in cervical screening.

*“None of us women know anything about our bodies unless we have these well-health checks, because you might think ‘oh there is nothing wrong for me’, but that’s the whole thing, like if I give you an example, like when you pass the road and see a pawpaw or mango tree and you see this fruit and you think oh! what a beautiful fruit, but you don’t know if the whole fruit is nice or not, till you go and pick it and check it out, you could turn it around and the other side is all rotten, it’s just the same with our bodies, we won’t know what is happening inside our bodies unless we check it out”* Niuean urban user sixties

## **OVERALL MAKE IT REAL, RELEVANT AND WARM**

### **At a rational level**

- Avoid medical terminology, long blocks of text
- Ensure it’s short, succinct, simple, colourful
- Communicate in an active conversational voice, simple colloquial language
- Statistics work for some...but keep them close to home – ‘out of x families, x number of women’
- State the facts but wrap them in a story or an emotional context

### **At an emotional level**

- Tune in – be alert to the small cues that will help women identify and feel that these communications are authentic (and therefore important)
- Remember that without a supportive context the emotional discomfort can quickly over ride the facts
- Empower and acknowledge female intuition by accentuating wellness and self awareness (know more about yourself)
- Ensure cultural authenticity
- Use humour for Maori and Pacific
- In first languages for Pacific and Te Reo for Maori

- Ensure age relevant information

### **PERSONAL IS BEST**

Women want help in making the decision, the more personal and encouraging the approach the better. A letter from the NCSP is too distant and clinical and gives women less sense that someone really cares. Lapsed users especially need the sense that someone they know cares whether they get screened or not. Maori and Pacific women in particular would rather talk it through with peers.

*“Information needs to be either one on one or in groups with your own people delivering it in a fun situation. A professional person is not capable of coming down to that level”* Maori urban lapsed sixties

### **THE MAORI PAMPHLET (ATAWHAITIA TE WHARE TANGATA) WORKS WELL**

Maori Women appreciated having a Maori specific pamphlet containing Maori images, Maori concepts and philosophies and the use of the Maori language.

The fact that the primary focus of the pamphlet was a celebration of Maori women, that it informed women about te whare tangata and included Maori men, was appealing.

Overall, there were a number of reasons why this pamphlet worked compared with the general pamphlet which many said they could not relate to as it did not contain words and pictures that were relevant to them.

*“As a Maori I can associate with this pamphlet – she’s an old kuia and there’s a younger wahine. It makes me think about myself and my daughter. For me, it’s who she is and where she’s from, that makes a difference”* Maori provincial non-user fifties

*“It’s important for us to be able to relate to the picture, I could see myself taking this home to my husband. Because of te reo Maori, he would want to share in it”* Maori rural user fifties

*“The information about the wananga on wahine atua is neat. We can use it as a basis of our korero as Maori women”* Maori rural user fifties

*“The male/female photo is good, that puts the message out there to our men about how they can be part of nurturing te whare tangata”* Maori provincial user thirties

### **SOCIAL MARKETING SENDS ITS OWN MESSAGE**

The genre of social marketing is beginning to be understood and recognised by people. Unfortunately there is an unconscious weighing up of importance i.e. the bigger the

dollar spend the more important this issue 'must be'. Therefore drink driving, attitudes to mental illness and breast cancer are important but cervical cancer 'can't be that important'.

## 5. COMMUNICATION VEHICLES

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### 5.1 OVERALL

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- Use vehicles that will get the subject out of the back room and ‘women business’ and into the light as part of women’s health and self care
  - TV
  - Community newspapers
  - Radio
  - Health magazines, women's magazines
  - Face to face, or at least a sense of personalised connection, works better so put the message in environments where women are talking and relaxed; pubs, casinos, housie, hairdressers, kindies, church, sports groups, community libraries, community education classes
- A range of different and sometimes unconventional environments will help ‘bust’ the subject into the open and normalise the topic
- Innovative and creative approaches in and of the communities, culturally grown and delivered by the women of that culture or community

### 5.2 MAORI WOMEN

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A common theme from Maori women about vehicles was to portray a whanau message by showing mother/daughter, wives of NZ celebrities, all the whanau – husband, wife, children, grandparents, our men, our grandchildren, highlighting the fact that all members of our whanau are potential vehicles for the message to Maori women.

Many felt that Iwi and Maori specific vehicles are most effective as it enables the use of dialect, images specific to the varied audiences and often has a person accompany the message.

*“The message and the messenger has to relate to different age groups and their realities”* Maori provincial user thirties

Hui and Whanau korero by Maori faces in Maori places with kaupapa Maori was also suggested. Well known programmes such as Shortland Street, which are diligently watched by a high number of Maori women could have a focus on screening where the desired messages could be written into the script.

Maori Television and Maori Radio were recognised as a powerful medium for Maori communities particularly as local people can then promote the message in ways that are most effective locally.

There is a more visible presence and acceptance of pro-Maori women focused activities within the Maori community. There are more songs heard on Maori radio, and Maori television is playing an important role in portraying Maori women in a positive light.

*“In Maori communities there are key people. Those ones are the closest naturally to our whanau. There’s Nanny Mihi who does the morning show on Iwi radio, all those old ones listen to her”*

Maori rural non-user fifties

Other suggestions made were:

- Mobile and marae based clinics
- Music, Drama, Sport, Waka Ama
- Humour - positively funny!
- The pamper trail - retreats, the courtesy car
- The use of song
- Kapa Haka

## **WOMEN’S HEALTH AND WHANAU EXPERIENCE**

A shift from the traditional Maori view of health may be required in this context whereby the health of individual Maori women is promoted alongside the holistic and whanau centered health messages. This is why more and more Maori women are attracted to the pampering retreats where the package deal includes pampering, the environment is peaceful, the company is great.

The whanau is the basic support structure for Maori and an integral part of Maori health and wellbeing. Whanau experiences are where learning takes place and many Maori women are influenced by events that occur for family members.

*“If it has happened to a family member, I am likely to read the whole pamphlet, it’s got to relate to them or me”* Maori provincial user  
thirties

## **IWI AND MAORI SERVICE PROVIDERS - A KEY**

There are key workers in Maori communities who know the people well and are able to utilise their networks and build rapport with Maori whanau.



*“In our work, we are moving in many areas, we have to walk the talk, there are people that turn to us for guidance and support. We’re a vehicle for them”* Maori provinces user thirties

### **THE CREATIVE APPROACH**

Some say get creative! - every song tells a story. Spread the word through song, movement and dance. The more mediums the further the reach.

*“We need to use all the mediums that will engage Maori - music, kapa haka, waka ama, netball, Maori television, Maori women”*  
Maori provinces user thirties

## 5.3 PACIFIC WOMEN

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- Talk about Pacific women's total health (e.g. self worth – breast and cervical screening) that includes cervical screening – what is important for us to know?
- Face to face with small same age groups
- Pacific women are attracted to visuals and stories that relate to them, seeing ‘people like me’ in communication vehicles supports the sense of belonging, of being part of something, of community

*“When there is a picture of a Pacific Island family or people I feel that I belong, I feel good, I feel happy, I feel part of this country”*

Tokelauan user urban late fifties

- All information provided however also needs to reinforce the reality that women make choices based on available information and constantly changing realities

*“No matter how much information you give women they still need to make that choice”*

Niuean urban user mid sixties

- Older women in particular want face to face interaction to help with understanding and to overcome sense of discomfort – language that conveys respect and care, visuals, oral story telling, humour
- In neutral places: traditional Pacific women won’t be comfortable having their brother, father, husband in the next room. They need intimate but safe places in the community to have this discussion
- Mobile caravans that can visit the communities

## **5.4 OLDER NZ EUROPEAN WOMEN**

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While older NZ European women typically have fewer family connections in their community compared with Maori and Pacific, they still keep an interest in what is going on and are often very involved in a voluntary capacity.

For information they use the:

- Local pharmacy and local medical centre
- Radio
- Community notice boards
- Community papers
- Localised interest groups, local coffee shops
- They will stop and talk to women running information stands at craft shows, events, school fairs
- They will read flyers in letterboxes if they have local content / stories
- They will also notice posters and so forth in libraries and community education classes and attend talks in the same kind of venues
- Internet

## **6. RESPONSES TO CURRENT COMMUNICATION MESSAGES**

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### **RESPONSES TO CURRENT MESSAGES**

Some of the current messages were looked at during the research to assess how relevant they were to women.

#### **Regular three – yearly cervical smears are a woman’s best protection against developing the most common types of cervical cancer**

- Some of the women talked to in the research were going two yearly or less and were surprised that the recommendation was 3 yearly

#### **Regular cervical smears are recommended for all women aged between 20 and 70 who have ever had sex, including lesbians**

- Why not younger? Why past menopause? Why are lesbians singled out?

#### **Cervical smears closer than three yearly give very little extra protection**

- Did not add up with commonly held assumptions about cancer being aggressive, and the fact that some women were going more often

#### **An abnormal cervical smear result almost never means cancer**

- “Not what we’re led to believe”!!

#### **Changes in the cell walls of the cervix are quite common and many will disappear without treatment. If treatment is needed it is usually simple and effective**

- Cell walls and cervix is medical talk – what does it mean in everyday language
- A cream is simple and effective, is it this easy?

#### **The risk of developing cervical cancer increases with age**

- “...didn’t know this, that makes a difference”
- “ Well the risk of anything increase with age”

#### **Annually about 85 women die from, and 230 women are diagnosed with, cervical cancer**

- Can seem small to some, significant to others – needs to be put in an emotive context; families, friends, mothers

## **7. DISCUSSION**

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### **IN NEED OF A MAKE OVER**

The current cervical screening programme lacks a positive emotive 'essence' and folklore of knowing. However for some (NZ European in particular), it does have a strong call to action prompted by past publicity – "I know I 'should' get screened".

The programme needs a greater sense of 'collective' (we do this as women), and importance and connection (we do this for ourselves and our whanau).

### **FEAR WORKS FOR SOME BUT DON'T USE IT**

As more health risk information is available the potential for fear rises. The prevalence of social marketing to talk in terms of 'risk of death' is having a detrimental effect on mental health and well being. Fear is a barrier as much as a motivator in cervical screening. It can undermine emotional and mental health because it creates high anxiety in a situation where women feel powerless.

Fear also encourages the 'how many deaths' approach where some women say 'well 85 deaths compared to 100's with Breast screening?' Cervical screening is competing for mind space with breast screening and as a result cervical screening is being interpreted as 'not as urgent'.

### **FEAR IS A PATERNALISTIC WEAPON BUT EMPOWERMENT IS DEMOCRATIC**

Fear tactics have been effective in some arenas, for example, meningococcal immunisation. Fear works for parents taking responsibility for others, it is less effective when acting for self. It works for the 'worried well' and 'Organisers' (mothers) but it has a short life span as a campaign platform – people get blasé.

The 'disease' or deficit approach is counter to the rising interest in preventative measures – do not talk illness without talking about 'how to care for' or prevent.

It is better to take a slower longer term approach and build on a platform of self empowerment, and capitalise on self knowledge.

It is also important to remember that all Ministry of Health social marketing initiatives are basically selling health. We need to ensure that each separate initiative works towards` a combined and future whole i.e. inspiring a more proactive and empowered movement towards self knowledge and self responsibility in health for all.

## **REDEFINE THE CONVERSATION**

The separation of 'body parts' (breast screening, cervical screening) and therefore campaigns is non intuitive to many women. A combined women's health check that included a mix of screenings: skin/moles, diabetes, breast etc would reorient the conversation to holistic wellness.

## **EMPOWER WOMEN THROUGH EVERY PART OF THE PROCESS**

Women want to know about women's health in a way that is emotionally accessible and relevant to their lives. Each part of screening is shaping a woman's future attitudes - acknowledge women's power and self awareness of their own bodies – empower them through the process. Greater attention to gender and cultural sensitivity is critical.

## 8. RESEARCH FINDINGS: COMMUNITY KEY INFORMANTS

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### 8.1 MAORI COMMUNITY KEY INFORMANTS

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The seven Maori key informants interviewed came from the Gisborne, Hamilton and Wellington regions. The majority of them were well informed about screening practices within their regions, two had a historical perspective of Maori participation in screening and one had a specialist focus on the impact of screening on women who have been sexually abused.

#### HOW THEY FEEL ABOUT THE PROGRAMME

The majority felt that the programme needs to be supported and needs to have more Maori on board.

*“Historically Maori were marginalised during the development of the programme. Millions of dollars were spent on the technical side of the programme and a small amount in developing the community side which involves Maori women”* Key Informant Maori Waikato

*“Given that we’re Gisborne based. Thank goodness it exists because people who have got a bad deal out of the disaster are reasonably common, so working in Gisborne is a place that thinks thank goodness we have a programme that is up and running and whereby we can plug into the centralised results. If ever there is anyone we don’t know we can get on the phone and ring someone and find out what’s happened”* Key Informant Maori Tairāwhiti

Many felt that the programme could serve Maori needs better than it was currently doing and suggested that allocating more resources and support for Maori to develop the programme to serve Maori needs would be advantageous for Maori women and the programme as a whole.

Key Informants acknowledged positive developments to date as including; the establishment and resourcing of the Kaitiaki group, the programme working alongside iwi and Maori health providers, enabling face to face visits in small communities and progress towards working out the ‘best fit’ for each community, as they say – there is no one size fits all.

*“We have the worst outcomes as Maori. If the programme is going to serve anyone well, it must serve those who have the worst outcomes”*

*“There is high mobility of patients in our area and often we have people’s history who we do not know. Having a monitoring and*

*tracking system and easy availability of the data is important for us*” Key Informant Maori Tairawhiti

*“When you’re a nurse in a GP clinic, you have to send out recalls, letters don’t always work. What works is having people visit communities where women are”* Key Informant Maori Tairawhiti

## **PERCEIVED STRENGTHS OF THE PROGRAMME**

Maori Key Informants considered the strengths of the programme to be:

- It’s free
- The availability of data as a back-up and a tracking mechanism
- The Kaitiaki group oversight of ethics
- Maori practitioner involvement
- The proactive nature of the programme
- The commitment of Maori women to the programme

*“The programme is very proactive in the sense that women are very much encouraged to be screened and with the follow up that practitioners do regarding regular screening”*

*“There has been an incredible commitment from a core group of Maori women that have held the kaupapa. That’s been its biggest strength”* Key Informant Maori Tairawhiti

## **PERCEIVED WEAKNESSES OF THE PROGRAMME**

The perceived weaknesses of the programme from Maori Key Informants included:

- The inability of the programme to sell itself causing misunderstandings about the programme
- Respect for existing relationships with GP’s – the need for alternative approaches to achieving programme outcomes for those who don’t buy in
- Lack of promotion of Maori values and beliefs
- Practitioners losing access to regional faces to the programme

*“Maori Women often don’t want to be part of the programme, they have a relationship with the Dr and often they want that private stuff kept with him. There are odd ones that want their stuff with iwi.*

*If Maori women want to keep that stuff with the Dr then the NCSP can link in to the Dr’s stuff and pull out the stuff if they have permission. NCSP needs to let go and start addressing those*



*issues and not saying you have to do this and that*” Key Informant  
Maori Waikato

The cervical screening programme was seen as an effective way to prevent cancer for Maori women provided that there are coordinated and effective relationships with doctors, health professionals and Maori community to achieve outcomes. Supporting innovative and culturally appropriate approaches was also affirmed.

*“The potential is there for us. If they didn’t have the programme I doubt whether they would have got as many Maori women to have their smears”* Key Informant Maori Wellington

### **AWARENESS OF LEGISLATION**

The majority of Maori Key Informants were also not aware of recent changes to the way cervical screening is done in New Zealand nor the Health (National Cervical Screening Programme) Amendment Act 2004, however it was mentioned that evaluators access to the database should be restricted to the programme and not individual women’s records.

### **POSSIBLE MESSAGES FOR MAORI WOMEN**

With regard to messages being provided to Maori women about screening, the importance of establishing the relationship before the message was seen as critical. Giving women as many choices with regards to their safety, the procedure, the position and engagement with the programme was highlighted. The notion of giving the messages, with care was mentioned as well as the benefits of constantly highlighting the importance of screening while reinforcing the value of Maori women.

*“Maori women need to hear that screening is useful. It’s healthy, it’s a good thing to do. Your data can not be identified”* Key Informant  
Maori Tairāwhiti

The need to ensure that there is a way of checking that the information is heard as was intended to be was also considered useful as some people need to hear it more than once and often will interpret the information differently.

*“The biggest thing is to make sure they heard what you said, like ask them, tell me what you heard me say”* Key Informant Maori Tairāwhiti

There was also a point of view that stated that the responsibility is on the programme to know about Maori women as opposed to Maori women needing to know about the programme.

*“There’s stuff that the programme needs to know about Maori women. The responsibility lies with the programme.*

*The bottom line information is about their wellbeing. Maori women aren’t all that keen on CS and maybe it’s not a cultural practice. Some women will go along because I think they have been sold that message. It is not something they would normally do in their hearts. It’s about staying well for your family. The whanau thing”* Key Informant Maori Waikato

The kinds of messages that Maori respond to most according to Key Informants are positive messages about wellbeing, a message that says it’s free or affordable and those that are direct, use humour and highlight the treatable aspects.

*“Positive messages about wellbeing. Anything that’s going to be enhancing to their wellbeing and to their whanau. That’s why the Quit smoking campaign seems to be successful.*

*They’re doing something like that for breast screening. It is such a private and personal aspect of ones physiology. I would come at it from te whare tangata aspect I think that’s what Maori women relate to, even if Maori women don’t have a deep understanding of it. It’s about giving due respect and regard to that part of the body in the sense of rather than thinking about sex and the physical nature of the body its thinking about the cultural and spiritual aspect and what it actually means. Even though there are women who choose not to produce children it is still that thinking which gives us that particular importance and our power as women”* Key Informant Maori Tairāwhiti

## **WAYS TO SUPPORT MAORI WOMEN**

There were a range of ways that Key Informants saw the services as being supported to provide these messages including additional resourcing to implement Maori specific approaches, the opportunity to test mobile smear taking services or an outreach programme, training for Maori and the encouragement of innovative approaches. It was felt that people are the main resource and this reiterated the point about the message going hand in hand with the messenger.

*“I really find that face to face korero for me is the best way for Maori to take on board and understand. I’d love to see for example some kind of a facilitated group provided in an area where women could go along and learn about it together and have a few laughs and have something to eat”* Key Informant Maori Wellington

Key Informants reinforced the need for men to be part of the conversations too.

*“Doing promotions – don’t believe in closing korero off to anybody, we’d mahi in the whare hui. Our men need to be there, it’s part of the manaaki role”* Key Informant Maori Waikato

## **ISSUES AND CONCERNS**

The concerns that Maori women have about cervical screening were largely related to loss of dignity and respect, invasion of personal space vulnerability, fear of the outcomes and the triggering of emotions due to past abuse.

*“I would imagine the concerns are more about being really vulnerable and being exposed and not necessarily being treated with the respect and sensitivity that would allow them to walk away with their dignity”* Key Informant Maori Wellington

*“There are a % of the women who are as cool about it, but as soon as you get to the women to have been abused, they close up”* Key Informant Maori Tairāwhiti

Key informants agreed that the main motivations for Maori women to participate in screening were a combination of self interest, for the good of the whanau, as a result of what’s happened to other whanau members and early detection. In one instance the power of traditional Maori healing was mentioned.

*“Know of one woman who had cancer, in her mind she was going to die anyway, she got hoha with the need to go every year and then cut them off and went to a tohunga (Spiritual healer) and then went back a couple of years later she had no cancer”* Key Informant Maori Wellington

## **BARRIERS TO SCREENING**

The barriers for Maori women were similar to those previously mentioned with the combination of barriers being particularly apparent.

*“She goes to have a smear, she’s been raped, the smear taker is harsh she doesn’t go back again”* Key Informant Maori Waikato

*“Money, getting there from A to B, finding the time to put aside for doing something like that because a lot of the time Maori women are not always good at prioritising themselves, they might be good at getting the kids to the doctor but not themselves”* Key Informant Maori Tairāwhiti

Ways of overcoming barriers focused on the need for education of health professionals about working with Maori and holistic health and for culturally appropriate services. In

addition, regular reviews to ensure close monitoring of cervical screening service provision was seen as important.

*“I worked for a GP clinic where they thought they were running an effective service. They weren’t for Maori. The underlying issue was that they would lose some of their power and their money. They need to be educated”* Key Informant Maori Waikato

*“It’s important to have staff who Maori women are able to relate to where either Maori women themselves or other staff are there who have some training that enables them to be more welcoming”* Key Informant Maori Wellington

*“Having regular reviews, having an audit on something is not a bad thing. Make sure everyone is being monitored all along the way so that mistakes are less likely to happen. Don’t mean to do harm. CS is horrible and unkind”* Key Informant Maori Tairāwhiti

Maori Key Informants each saw themselves as having a role to play in overcoming the barriers. For some that role was related to the deconstruction of inappropriate policies, for others the giving of a voice to the most marginalised, and education leading to quality service delivery to Maori Women.

*“The namer of names is the father of all things. (Quote by Moana Jackson) Once it’s written it’s real. The medical profession has changed as a result of policy over the years. I first started nursing 30 years ago when govt gave money to provide services. Today it is more competitive you have to show you are providing a service people want. There are hidden things. When they write policies, the dominant voice of women and Maori are marginalised. So my role is about deconstructing those policies that are developed by white male mainstream people. Flipping it up so that Maori women’s voices are the dominant voice where it affects them”* Key Informant Maori Waikato

*“The barriers for sexually abused women are body image, the fear of being vulnerable of exposing themselves. It can trigger a lot of their traumatic reactions. People need to be aware that there’s some education that needs to happen about that. For Drs and Maori providers, all service providers”* Key Informant Maori Wellington

## **ACCESS TO DATA**

Regarding access to records Key Informants felt that Maori women were very concerned about who has access to their information

*“Most want their stuff with doctor that is one who they have a 15 year relationship with.*

*Maori Women are very concerned about that. We have a history of having information used against us, it's part of our whakapapa (our past)*" Key Informant Maori Waikato

Maori women will respond to the changes under the new legislation in different ways. Firstly, there will obviously be no response if they are not informed and those that do respond will do so differently dependent on who gives the message. It was felt that the resistance would be around concerns with regard to institutionalised racism.

*"I believe in women being able to make choices. I am never ever convinced about what the medical world says. We have enough information that enables us to make the decision. We are better at doing that as we've had to think a lot more about things that are imposed on us. It's like there's Maori who don't vote and people think that's so because we're dumb and sometimes its because we're making a choice.*

*When Maori women have all the information and the circumstances are right, they can make the right choices. They must feel they have as much power to make the right choices for themselves"* Key Informant Maori Wellington

## **8.2 PACIFIC COMMUNITY KEY INFORMANTS**

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The Pacific key informants interviewed held both key positions within community networks or organisations and have several access modes within various Pacific community groups to inform their response.

### **HOW THEY FEEL ABOUT THE PROGRAMME**

Pacific Community Key Informants differed in their sense of the effectiveness of the campaign, depending on their level of interaction or history with it

*“(The cervical screening programme effectiveness is) very limited, I don’t think enough is done in terms of marketing, marketing the information so that our women can participate and understand the seriousness, we understand when things go wrong though”* Samoan Key Informant

### **WHAT THE ISSUES ARE**

There is a sense with Pacific community key informants that there are issues with engagement with Pacific communities and capacity with the relevant health workforce. This has been informed by either their own experience or that of women within their networks.

*“Some of the weaknesses is that some of the numbers that have been included in this process have been quite limited, it’s not going out to enough of the Pacific women, the problems around engaging people and accessing communities in a way that people want to be proactive in the programme, there are too many people who don’t know how to engage the women, the way we get people exchanging information is how we engage people”*  
Samoan Key Informant

*“We have enough (smear takers) in terms of numbers but perhaps the capacity of those can be strengthened, need support in the terms of capacity of those we have”* Cook Island Key Informant

### **WHAT COULD BE BETTER**

Pacific community key informants have a good understanding of the success of programmes becoming part of their community, because they work within it on a daily basis, they also get a strong sense of when it’s not working and why.

*“A lot of women we know have a limited knowledge of everything about it (the programme), it’s important to know the benefits of the programme, also there are a lot of in-consistencies in how the*

*programme is delivered. We have got a chance here for early detection but we tend to minimise it because of the lack of information, its really like having a cup of coffee a lot of people know how to make a cup of coffee because they do it all the time, it's got to be like that, it's got to be common knowledge, you prioritise your life with cervical screening"* Samoan Key Informant

*"We understand them (the community) enough to know that we can't tell them about the message until they are ready, willing and able to take part"* Cook Island Key Informant

### **POSSIBLE MESSAGES**

Not all key informants were satisfied with the current communications vehicles and their ability to convey a suitable message, about a complicated process to an increasingly diverse community.

*"With all those posters, I had a reservation, that all that we are doing is browning the image, but you need to convey the concept I don't know that you can do that with that poster"* Samoan Key Informant

*"It's about the right information, if you start looking at all the different types of cancer people can get confused, a lot of people don't know enough. They have to be in an environment that is familiar to them and with people they have confidence in, these are key considerations. We are lucky that this is an area where we can do something through early detection, we need to go into homes, develop resources, develop a workforce and then giving them the resource to do that"* Samoan Key Informant

### **CAN'T ASSUME PACIFIC ARE THE SAME EVEN WITHIN PACIFIC COMMUNITIES**

The communication messages cannot assume that all Pacific women are the same. Even educated Pacific women find some of the nuances of the programme hard to fathom, because it is about prevention rather than a direct cure. Women need to understand the purpose to continue to be engaged in the message.

*"There is a new generation of women that have been more informed about sexual health through other services, but even when you explain the whole programme, I don't think that women know what you mean, you can't assume that even the younger women know anything about it. I think there is misinformation or no appreciation of what happens and why it needs to be done, there are news through the media. I would certainly be walking someone through it a little bit"* Samoan Key Informant

*"This is something that gets done to you but there are no immediate results"* Samoan urban user mid forties

## 9. RESEARCH FINDINGS: STAKEHOLDERS

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### 9.1 KNOWLEDGE/UNDERSTANDING AND PERCEPTIONS OF PROGRAMME

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Overall stakeholders believe the programme is generally very good.

*"I think it does a fantastic job, we were going to have an epidemic of cervical cancer"* Pakeha Health Promoter

*"It's effective because it can pick up any abnormalities. I'm aware that the actual test is not 100% but for now that probably is the best prevention programme we have"* Pacific GP

*"Awesome, when the inquiry came up there was a lot of gaps. As a nation it shows that we can progress from that"* Maori Health Promoter

#### **SMEARTAKERS**

Smeartakers are made up of GPs, gynaecologists, practice nurses and smeartakers at Independent Service Providers and NCSP Regional Services. Their understanding of the programme is generally focussed on the delivery of the cervical smear in a practice environment and the 'programme' to them is the 'register' which they view as a tool to assist with providing this service.

Smeartakers believe that the programme is very valuable as it reduces rates of cervical cancer and the register acts as a back up to the practices' own recall practices. The national register is also perceived to be useful as a "one stop shop", where smeartakers can look up when women last had a smear and the results of previous smears more easily.

There is confusion around issues such as the time of first smear (with some GPs believing women should have smears as soon as they become sexually active, even 13 or 14 year olds) and timings of smears (some GPs advocate yearly or two yearly smears).

#### **HEALTH PROMOTERS**

Health promoters also agreed that the programme was important and they tended to concentrate on bigger picture issues. Some stakeholders are both health promoters and smeartakers and their comments tend to reflect this 'big picture' view.

*"A strength of this programme is that despite this being a complex area with lots of different players with different*



*viewpoints, we all have a common goal which is to save women's lives"* Pakeha health promoter

They commented that language, concepts and practices were developing around women's health. Some examples given were *whare tangata*, *hauora*, *mana wahine*, well women, well women clinics and well women checks.

There is also the perception that over the last few years there has been an increased uptake by women, improved training of *smeartakers* and increased funding by the Ministry of Health.

### **PACIFIC/MAORI**

Maori and Pacific health promoters explained that creating intimate spaces (e.g *marae*, *fono*) for Pacific and Maori women to discuss these issues is important. Intimate spaces are best when they are women only while bigger groups can be in the form of 'family days' with involvement of partners/husbands and children.

Health promoters find that health promotion groups work if they include a prayer and encourage women to go for smears together in a group.

### **MEDIA**

The perception media have of the cervical screening programme usually includes the Cartwright and/or Gisborne inquiries. There is a feeling that the Gisborne enquiry hangs over the programme, which in spite of the negativity surrounding this, they feel it did have the effect of heightening awareness amongst women generally. There is an increasing feel of confidence in the programme since the Gisborne enquiry as it is thought the weaknesses exposed by the enquiry (e.g. labs, monitoring and auditing) have been addressed, thus creating a safer programme.

## **9.2 CONCERNS ABOUT THE PROGRAMME**

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### **SMEARTAKERS**

The 15 minute appointment time available to GPs is too restrictive to complete the smear test as well as provide information. The information requirements under the Health (NCSP) Amendment Act 2004, will result in additional pressure on time.

*"There's not a lot of time, it takes over 15 minutes just to do the smear"* Pakeha GP

*"Hard enough to tell them about the procedures without the Act, bombarding them with information will lead to confusion, a lot of them still do not understand the programme so to have it all done at once is too much. These things shouldn't be rushed"* Pacific GP

### **PACIFIC**

Amongst Pacific smeatakers there is a concern about sending letters home to unmarried women, that is, assuming that a woman is sexually active when culturally it is inappropriate to be so until marriage. Some Pacific smeatakers also feel uncomfortable with the idea of opportunistic smeataking with unmarried women.

*"The names of these young ladies come up automatically when they turn twenty and I do not agree with sending out letters to them that they are due for their smears. We have a policy that we ask any young woman from 20-25 years. I cannot do that with my traditional upbringing and I think there's a huge risk there culturally and I'm not sure a lot of GPs are aware of that"* Pacific PN

### **RESOURCING SMEARTAKERS**

Staffing resources are available at practice level by using PNs to explain and/or take smears freeing up GP time. Because they are sharing smeataking, consistent training for GPs and PNs is necessary to provide a consistency of messages to women. Smeatakers noted that funding is stretched due to the additional complexities of smeataking and health promotion with Maori and Pacific women. Maori smeatakers provide services as part of their holistic approach to service for which they are not funded (e.g. providing transport).

### **HEALTH PROMOTERS**

Health promoters note a lack of proactive and positive media coverage and the need for national advertising to support health promotion work done locally.

*"I think we're too passive [with media] and the result of that is that then misinformation becomes ingrained and it's so much harder to try and re-educate"* Pakeha Health Promoter

*"The lack of marketing... I'm comparing it to breast cancer, it's in your face continuously, they have a lot of celebrities on board, they are on TV, in magazines, there's fundraising exercises going on, walks, the little pink ribbon pin in shops"* Pakeha Health Promoter

There is also a feeling that 'prevention' and cervical screening can be hard to 'sell' for various reasons:

- Some women don't have a word in their language for the cervix
- Some women don't know where the cervix is
- Cervix and cervical are scary, too 'medical'
- Some women don't think in terms of their specific body parts
- Women don't go to the GP unless they are sick

*"PI women, they go when they're sick for diagnostic procedures but the screening concept doesn't sink in"* Pacific Doctor

By repackaging communications with more holistic concepts embracing wellness, such as well women, mana wahine and hauora, and encouraging provision of services reflecting this concept, e.g. comprehensive well women checks and education programmes, prevention and cervical screening may be easier to sell. This fits with the shift in health delivery as Primary Health Organisations (PHOs) facilitate a more preventative focus in health care amongst communities and health practitioners.

## **MAORI/PACIFIC**

Both Maori and Pacific health promoters comment on a lack of demographic data feedback from the programme, such as coverage rates with break downs by ethnicity and locality.

*"I don't know how good or bad we are doing unless we've got something to compare with"* Pacific PN

Health promoters also note that funding can be stretched due to the additional complexities of smarttaking and health promotion with Maori and Pacific women and the additional complexity of trying to deliver services that work for Maori and Pacific women from within mainstream structures or practices. Those working outside

mainstream service providers face additional barriers in securing funding for programmes.

*"Mainstream control the funding, we have to prove ourselves, if we come up with an idea, we work it and then have to prove to mainstream it's great"* Maori Health Promoter

*"Too much of a palagi way of doing things....The weakness of the programme is the deliverance of the programme to our PI women, it is all wrong"* Pacific Health Promoter

## **PACIFIC**

Pacific health promoters noted that translation of resources was an issue, with literal translations often being used.

*"The translation that is done now is too technical for PI women to understand, we've taken the raw context from palagi straight to our language and it's done word for word"* Pacific health promoter

## **MAORI**

A concern for Maori health promoters is the lack of trained women smarttakers and health promoters from local iwi. This is especially felt in rural areas.

*"Train and hire people like ourselves and get them to go home and work, Pakehas can't get into their homes"* Women's health organisation

It is felt that more iwi input is needed in the programme generally, specifically input from local iwi as different iwi have different kawa (protocol).

## **MEDIA**

There is concern amongst media that the cervical screening programme only has a high profile amongst younger white middle class women. Media feel that they are not proactively contacted by the National Cervical Screening Programme (NCSP) in comparison with other health issues, examples given were breast cancer and asthma. They would like to be proactively contacted but state that they will/do contact the NCSP if they feel they need information. The media perceive their role as reporting all the news, good and bad.

*"I would like to add that it's not up to the media to encourage women to have cervical smears, our job is to tell stories whether they are good, bad or otherwise"* Mainstream media

## **9.3 INFORMATION PROVIDED UNDER NEW LEGISLATION**

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Most stakeholders are not aware of new legislation and feel they need information about this. Those who are aware are generally hazy on the details and still feel they need more information. There is a very small group of stakeholders who know the Act well and have strong feelings of concern about privacy issues.

### **HEALTH AMENDMENT (NCSP) ACT 2004 - CONCERNS**

Some stakeholders are concerned about the aspect of the new legislation that allows for women who develop cervical cancer (even those who opt off) to have their records accessed. Some stakeholders believe more women will opt off under the new system and that some women will stop getting smears. This was in relation to Maori and Pakeha women only. Some stakeholders believe women will initially react negatively to the new legislation and then get over it.

### **HEALTH AMENDMENT (NCSP) ACT 2004 - SUPPORT**

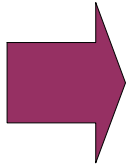
Some stakeholders support the new legislation for its ability to provide a clinical overview and auditing. Pacific stakeholders are not aware of the new legislation but most of them think that the average Pacific woman will be unfazed by it.

### **INFORMATION PROVIDED BY SMEARTAKERS REGARDING THE HEALTH (NCSP) AMENDMENT ACT 2004**

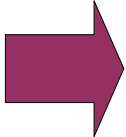
Smear takers already routinely discuss some but not all requirements under the Health Act, currently covered under the Health and Disability code of compliance.

The requirements of the Act, highlighted with arrows in the figure below, shows the relative frequencies with which they are discussed. The importance of having regular cervical screening tests and the objectives of, and the benefits and risks of participating in, the cervical screening programme are routinely discussed. The smear test procedure is discussed slightly less often but relatively more often by Pacific smear takers with their Pacific patients. The 'risks' of participating in the programme are not routinely discussed by Maori and Pacific smear takers, with the emphasis on encouraging and welcoming. Who has access to information on the Register, the uses to which that information may be put and how a woman may cancel her enrolment in the programme if she wishes to do so are discussed very infrequently across all ethnicities. Going on the register is presented as the 'default' option, and the register is not discussed further unless a woman asks for more details.

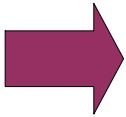
## Information provided to women by smartakers under Health Amendment Act



The importance of having regular cervical screening tests



The objectives of, and the benefits and risks of participating in, the cervical screening programme



The smear test procedure (More so amongst Pacific)

Who has access to information on the Register

The uses to which that information may be put

How a woman may cancel her enrolment in the Programme, if she wishes to do so

### **HEALTH (NCSP) AMENDMENT ACT 2004 - NEED FOR INFORMATION**

Most smartakers need information for themselves relating to the Health (NCSP) Amendment Act 2004 to ensure they pass on to women.

One organisation had made a resource to hand out to women, but have stopped giving it out until the Act is discussed in the media as women are not aware of it and *"It was a non-entity to them"*. Pakeha health promoter.

Stakeholders recommend GP and PN education programmes and ask to be provided with a straight forward pamphlet or flip chart outlining the Health (NCSP) Amendment Act 2004.

## **9.4 SUPPORT NEEDED TO DELIVER APPROPRIATE MESSAGES**

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### **ENSURE MESSAGES ARE CONSISTENT FROM ALL SOURCES**

Ensure that GPs, PNs, smartakers, health promoters and national advertising are providing consistent messages to women. This appears to be especially important for issues where historically there has been confusion around issues such as the time of first smear (either at 20 years old or when women become sexually active) and timings of smears (some GPs advocate yearly or two yearly smears).

Some ways to achieve this may be:

- National strategy planning alongside local services
- Listen to all women's voices not just the loudest
- Communication to enable local messages to reinforce national messages and vice versa

### **HEALTH PROMOTERS - HELP US ENSURE THE RIGHT MESSAGES ARE REACHING THE RIGHT AUDIENCE**

- Proactive positive media and national advertising to support health promotion work done locally

Previously local television advertising has been shown to produce increased enrolments.

Comparisons are drawn between Cervical screening and Breast screening. Breast screening is seen to have a higher profile, especially amongst older women (a target group for the NCSP). This is credited to the national media campaign and the campaign's persistent and positive messages.

*"Health is a market now, advertising will change behaviours"* Maori  
GP

- Information about changes to the Act proactively advertised.

Currently regional services are put in a position where they need to respond to media half 'truths'. Proactively advertising changes to the Act may help ensure the correct messages are being disseminated.

Suggestions for additional information resources needed include:

- Straight forward flyer in different languages to give to women

- 0800 line for enquiries about the Health (NCSP) Amendment Act 2004 for both health professionals and women
- Information designed for health professionals
- Thorough pre testing of resources to be used
- A celebrity could relate an experience through media
- Mana motuhake - supporting by Maori for Maori services

*"Have to have the people on the ground level doing the mahi, women want the information kanohi ki te kanohi"* Maori health promoter

- Strengthening links between Maori and mainstream services - work alongside each other

### **GPs AND PNs - HELP US TO ABSORB INFORMATION EASILY AND DELIVER THE RIGHT MESSAGES WITHIN THE PRESSURE OF A PRACTICE ENVIRONMENT**

GPs are generalists, therefore the NCSP needs to compete for their time and attention along with all the other health issues they face in their practices.

*"We're given so many things to do and I would have to prioritise and to me it's awful to say but a cervical smear will have to go to the bottom of the list because we're looking at a 10 year process for the cancer, whereas if you look at immunisation you have to do in a certain time period so they don't run into another batch of immunisation, that is more urgent, I'm not saying it [a cervical smear] is not important but if we have to prioritise that [cervical smear] is the last thing for me to worry about"* Pacific PN

It is important to make messages as easy for them to access and integrate as possible. Information about cervical screening may be lost in the paper trail and office email inboxes. Workshops could be set up through PHOs with professional development credits as an incentive. GPs also need support to deliver messages to women due to the time pressure of a 15 minute appointment.

Some ways to support may be to:

- Encourage the increased use of PNs in all aspects of cervical screening delivery and information provision
- Resource them heavily with print resources in different languages to give to women
- Support them with a national advertising campaign. Higher awareness of the need for cervical screening amongst women will make the GPs and PNs role easier
- Nurturing practice relationships with mobile smear providers (Maori and Pacific)



- Many Pacific women go to palagi smeartakers. These smeartakers need to be supported to provide information to Pacific women who may not read brochures (even in their first language) and may not ask their smeartakers questions

### **HEALTH (NCSP) AMENDMENT ACT 2004 - SMEARTAKERS**

The Health (NCSP) Amendment Act 2004 will add an additional learning pressure for GPs and PNs and extra time pressure in delivery of service. Nearly all smeartakers need information relating to the Health (NCSP) Amendment Act 2004 for themselves to increase the likelihood that they pass on ALL required information to women and in appropriate forms for women.

- Provide GP and PN education programmes and resource them with a straight forward pamphlet outlining the Health (NCSP) Amendment Act 2004
- Information about the Act may be lost in the paper trail and office emails so workshops could be set up through PHOs

*"I don't know how we can do this. I guess if it is very important for us to know then maybe the Ministry can set up workshops to inform us about changes that have happened or about to happen so every one is aware of it"* Pacific GP

### **MEDIA**

Media are interested to know more about what is happening with the NCSP.

There is a need to 'fax' media information, for example, press releases.

*"I don't get any faxes from them. Is there a mailing list they [NSU] could put me on"* Pakeha Health reporter

As the NCSP cannot control whether the media will contact them in relation to fact checking and given that the media has no inherent motivation towards supporting the programme, the option of proactively contacting the media seems like it may be the best tool to prevent misinformation. This will, in turn, help to support regional services who are often at the forefront of delivering accurate cervical screening messages amongst women and health professionals.