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**A CHANGING DIALOGUE WITHIN HEALTH  
COMMUNICATION IN NEW ZEALAND: A CASE  
STUDY OF THE WAIKATO SCREENING,  
MAMMOGRAPHY PROGRAMME**

A thesis  
submitted in partial fulfilment  
of the requirements for the Degree  
of  
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by

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# ABSTRACT

As part of changes in the health sector in New Zealand over the past decade, government has provided a number of community-based health interventions. The purpose of such interventions is to provide information and resources that will empower “well” individuals to participate in proactively managing their health, thereby contributing towards both cost and mortality savings.

In 1991, government introduced population-based screening mammography pilot programmes into two communities: one in Otago and Southland, the other in the greater Waikato region. As a community-based health intervention, the breast screening programme communicates with eligible women to encourage them to participate in screening mammograms every two years. The purpose is early detection and treatment of malignant tumours. However, to achieve mortality and cost savings the programme must attain a 70% participation rate of eligible women. The purpose of this research was to examine the ways in which the breast screening programme in the greater Waikato region communicates with women to encourage them both to participate in the programme and also return regularly. In turn, the ways in which a random sample of women responded to that communication were also examined.

To investigate the process, a triangulated approach to data collection and analysis was undertaken. First, a questionnaire survey was sent to a random sample of 1,085 women, stratified by age and ethnicity; 611 (58%) usable responses were returned. Following initial analysis of the questionnaire data, five focus groups were held with 41 women, and 3 individual interviews undertaken to further explore the outcomes from the questionnaire. Nineteen interviews were also held

with staff in the breast screening programme to identify the influences on the ways in which they communicate with eligible women who undergo the process of mammography.

The resulting data were analysed and interpreted using a combined quantitative and qualitative approach. Fisher's exact tests in 2x2 tables and chi-squared tests for independence in contingency tables were used to establish general trends in the data. Qualitative analysis was undertaken using interpretive thematic analysis (Owen, 1984) with a critical turn and reference to Ricoeur (1981).

The findings from this research emphasise the importance of effective communication in the process of screening mammography, to encourage both initial and ongoing participation. There were a number of discrepancies identified between the perception of staff and participants about the communication processes from the breast screening programme. The use of a random sample stratified by ethnicity further identified a number of statistically significant differences among ethnic groups in their responses to communication from the programme. The analysis identifies the divergent communication that women receive from staff in the breast screening programme.

The importance of communication in enhancing both the invitation and physical process for women participating in the population-based breast screening programme is highlighted in this research. Although the programme is provided as a community intervention there appears to be little consultation with participants. Accordingly, the diverse cultural needs of ethnic minority groups are not always recognised in the programme's practice. A willingness to both

recognise and incorporate the varied needs of women undergoing screening mammography would serve to not only enhance the process for participants but also assist the programme to attain the desired 70% participation rate of the eligible population.

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# LIST OF ABBREVIATIONS

## GENERAL

A	Asian
BSM	BreastScreen Midland
E	European
GNA	Gone, no address
HBM	Health Belief Model
HFA	Health Funding Authority (previously Regional Health Authority)
GP	General Practitioner
M	Māori
MRT	Medical Radiation Technologist
NHS	National Health Service (Britain)
NHSBSP	National Health Service Breast Screening Programme
NZ	New Zealand
PHA	Public Health Association
PCQ	Psychological Consequences Questionnaire
PI	Pacific Island
RCI	Royal Commission of Inquiry
RS	Reprinted Statute
WHO	World Health Organisation

## STATISTICAL

CI	Confidence interval
<i>P</i>	Significance level
$\chi^2$	Chi-square value
<	Less than

# CHAPTER 1

## INTRODUCTION

Over the past decade in New Zealand, communication in health care has gained increasing prominence as the emphasis has moved away from tertiary, hospital-based care to primary, community-based health interventions. This emphasis implies the need for medically-based services to enter the community and encourage the participation of a “well” population. The purpose is to provide information and resources that will empower individuals to accept responsibility for monitoring their own health and undertaking appropriate health-inducing behaviours. Such communication tends to address questions of responsibility for disease towards the “well” or “undiagnosed public” (Kirkwood & Brown, 1995, p. 61), employing a “language of choice” (p. 62). The success of such interventions is predicated on effectively communicating information which empowers a “well” population to participate in health-promoting behaviours. The intended outcome is early detection and treatment of disease or potential disease-causing conditions, thereby maximising the opportunity to enhance both cost and mortality savings.

The introduction of the health reforms in 1991 resolutely moved the focus on health care away from tertiary institutions (hospitals) into primary health services (such as general practitioners and screening programmes) in the community. Consequently, this placed a greater emphasis on the need to

understand the potential influence of persuasive communication about health care. This thesis is concerned with the communication processes of a recent community health intervention, the screening mammography programme, introduced in 1991.

As a community-based detection programme for breast cancer, screening mammography relies on effective communication for its success. Women must be encouraged both to participate in the programme, and also to return for regular mammography. Any focus on health communication requires that the form and content of the text itself be considered. The cognitive and emotional experience of those receiving the communication is of equal importance. Information is critical, but how people process this information is equally critical. Just as socially and institutionally constructed meaning will inscribe the communication from the programme, women in the target audience will also ascribe meaning to the same communication. Consequently, the meaning may differ between each group. At this time, there is no identified research that has studied the combined influence of the political, socio-cultural and institutional environment on the communication processes of a breast screening programme and analysed how, in turn, such variables have influenced the subsequent communication and eventual interpretation of meaning by a target audience.

Furthermore, the author recognises that the communication process is inevitably influenced by the heterogeneity of New Zealand's population. The national population mix increasingly includes diverse ethnicities which will bring their own cultural perspectives to health care interventions. The implications of ignoring cultural differences are revealed in the health statistics for New Zealand (Ministry of Health, 1999). The prejudiced health status of Māori reflect the outcomes of a health care system that is strongly established on an individualised western model which Durie (1994a & b) argues has displaced the holistic focus of

the indigenous Māori population. Such recognition emphasises the resulting moral imperative under the Treaty of Waitangi (1840) to work in partnership to attain research results that will be of equal relevance and benefit to both groups; an imperative that extends also to other ethnic minority groups represented in this study, such as Pacific Island and Asian women. As a literature search did not reveal any published research in this country that has provided data about the contrasting experiences and perceptions of various ethnic groups participating in screening mammography, this study provides important initial insights into these.

## **PURPOSE**

The purpose of this research is to explore the production and consumption of health communication from the Waikato pilot breast screening programme.

There are three questions relevant to this thesis:

1. How does the breast screening programme **communicate its presence to eligible women** in the community, and how do women receive this communication?

As a community-based initiative, the breast screening programme needs to signal its presence to the eligible population. This research question is concerned with how this outcome is achieved and how women respond to the initial invitation to participate in screening mammography.

2. What influences the way in which **staff** in the breast screening programme communicate with women who choose to participate?

This question relates to the way in which the institutional, socio-cultural and political context influences the way in which staff communicate with women during their participation in the breast screening programme.

3. How does the **target audience** receive and interpret the communication from staff in the breast screening programme during their participation in mammography?

The final question addresses the responses of women to the communication from the staff in the breast screening programme. This interaction is likely to influence women's decisions about whether they return for ongoing, regular mammography.

The primary focus of this study is on the communication practices and resources of the Waikato breast screening pilot programme, which was set up in 1991 and continued until December 1998. At that time, a national breast screening programme (BreastScreen Aotearoa) was introduced, which contracted with six organisations to provide mammography services for asymptomatic women between the ages of 50 and 64 years of age. As one of the successful contenders for a national contract, the Waikato pilot programme subsequently became BreastScreen Midland. Accordingly, there is inevitably some overlap with the introduction of the national programme and the ensuing adaptation from a pilot to a national programme, which required comprehensive changes in both the structure and operation of the organisation. The transition was still occurring during the data collection for this thesis, which commenced in April 1999 and was completed in March 2000.

## **SCOPE AND RATIONALE**

As Sharf (1993) points out, health care is both diverse and integral to quality of life; thus the concept of health communication is interwoven into the lives of most people in western society. The purpose for selecting the topic of health communication that drives this thesis was threefold. First, although there is an abundance of research under the rubric of health communication, much of it

focuses on dyadic interaction between health professionals, primarily medical staff, and their clients (for example, Cardello, Ray & Pettey, 1995; Conlee, Olvera & Vagim, 1993; Fisher & Groce, 1990 and West, 1990). Although many studies do reveal some interesting perspectives, such as the anxiety and the “strangeness” participants sometimes experience in the health environment, dyadic interactions often fail to recognise the influence of the broader institutional, socio-cultural and political environment that will in turn influence many facets of health communication.

Second, as pointed out by Atkinson (1995), little work has been done to reveal the critical influence on intragroup and intergroup communication processes between professionals within health organisations, and how these communication processes impact on clients. Third, as reflected in the extensive research that surrounds screening mammography programmes, the cogent influence of communication on the process also suffers from a lack of attention. Communication is often treated as a secondary issue, rather than a major part of the overall experience of mammography, a part that may make it more acceptable to participants. Despite a plethora of research about screening mammography programmes, much of it has focused on process issues, such as the influence of different strategies to encourage participation; (through health professionals, (Hurley et al., 1992); letters of invitation, (Williams & Vessey, 1989); or promotional materials (Mead, Rhyne, Wiese, Lambert & Skipper, 1995)), rather than the influences relevant to the production and consumption of communication from the programme.

As communication provides a basis on which eligible women will make informed decisions, both about a decision to participate and further decisions about ongoing participation in the screening programme, it is relevant to consider

all of the implications in this process, not just the resources provided. It is equally relevant to provide women who undergo screening mammography with the opportunity to reflect on the myriad of ways in which they responded to that same communication process. In addressing the importance of effective communication in a community intervention for a well population, however, the question of why it is desirable that women do choose to participate in screening mammography inevitably arises.

### **WHY SCREENING MAMMOGRAPHY?**

The incidence of breast cancer is increasing throughout the western, industrialised world, “even when earlier diagnosis and better cancer registration are discounted” (Forrest, 1991, p. 3). Women are dying from breast cancer in increasing numbers. For example, Forrest (1991) explains that 57,000 American soldiers died in Vietnam over a decade of combat. At the same time 330,000 American women died at home from breast cancer. He further explains that in Britain, 25,000 new cases are diagnosed each year, and one woman dies every 30 minutes from breast cancer.

New Zealand women are not immune, as this country consistently demonstrates one of the highest rates of occurrence of both pre and post-menopausal cancer of the breast (Kohlmeier, Rehm & Hoffmeister, 1990). The incidence of breast cancer appears to be increasing at an expeditious rate (Cox, 1995). For example, in 1997, 2,017 cases of breast cancer were diagnosed, and 620 women died from the disease. In 1998, 2,061 women presented with breast cancer, 628 of these have died (Jim Fraser, Ministry of Health, personal

communication, September 14, 2000).<sup>1</sup> It is anticipated that 2,300 New Zealand women were diagnosed with breast cancer in 1999 (Jim Fraser, personal communication, July 21, 2000). The disease remains the most common cause of cancer deaths among women aged 50 years and over (Armstrong & Borman, 1996; Ministry of Health, 1999).

Although some identified risk factors have been associated with breast cancer, as yet there is no known means of prevention. However, the impact of the disease can be minimised through early detection of malignant breast lesions, which usually results in more successful treatment outcomes. One means of identifying small, non-palpable breast cancers is that of breast X-rays, or mammograms. Over the past three decades, some clinical trials have indicated that mortality savings of up to thirty percent can be obtained from regular mammography in women over fifty years of age (for example, Shapiro, Venet, Strax, Venet & Roeser, 1982; Tabar et al., 1992). Women who do not attend breast screening programmes suffer higher rates of mortality overall (Frisell et al., 1991; Tabar et al., 1992). Therefore, women need to be increasingly encouraged to undergo screening mammography.

The premise of the efficient and effective use of mammography is based on its ability to locate carcinogenic breast lesions before they are palpable (Schmidt, 1990). Cancer presenting as a breast lump reaches a size of one centimetre before it can be detected manually (Love, 1990). However, screening mammography can locate lesions that are much smaller, perhaps only half a centimetre, in post-menopausal breasts (Forrest, 1991). As the risk of mortality declines with early intervention in the developmental phase of many breast

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<sup>1</sup>These are provisional figures provided by the Ministry of Health. There is a time lag in providing confirmed figures. For example, the incidence and mortality rates from breast cancer among New Zealand women for 1997 have yet to be confirmed.

tumours, screening mammography enhances the success of treatment outcomes (Armstrong & Borman, 1996; Campbell & Royle, 1992; Szeto & Devlin, 1996).

## **COMMUNICATING SCREENING MAMMOGRAPHY**

In 1991, in response to the increasing mortality of New Zealand women from breast cancer, government introduced two pilot screening programmes, one in Otago and Southland, the other in the greater Waikato region. A nationwide population-based screening mammography programme for eligible women followed seven years later.

Successful outcomes for any screening mammography programme in detecting breast cancer depend on women having regular screening mammograms (Austoker, 1994a; Austoker, 1994b; Hobbs, 1986). Thus, the effectiveness of any screening mammography programme is predicated on communicating with women to encourage them, first, to participate, and, second, to continue to participate. Without participation, there is no benefit. It has been estimated that at least 70% of women need to attend for screening if cost and mortality savings are going to be achieved (Adelson, Irwig & Turnbull, 1992; Austoker, Fagge, Gray & Patnick, 1995; De Koning, 1996; Sutton, Bickler, Sancho-Aldridge & Saidi, 1994). Both the effectiveness and efficiency of mammography relies on regular attendance of “at risk” women at breast screening centres. In turn, attendance relies on developing more effective health communication (Reynolds, West & Aiken, 1990).

The study of communication in screening mammography programmes suggests that there is no single, categorical means of effective communication. There are distinct phases in the mammography process, and women require different types of communication to allow them to make informed decisions about

screening mammography at each stage of the process, as pointed out by Bonevski, Perkins, Sanson-Fisher and Lightfoot (1996) and Gladding (1997). For example, it is unlikely that communication that will encourage a woman to initially undertake mammography will be equally effective in encouraging her to return for repeat screenings (Austoker & Ong, 1994). Women's experience of screening mammography will not only strongly influence decisions they make about re-attendance (Baines, To & Wall, 1990; Elwood, McNoe, Smith, Bandaranayake & Doyle, 1998), but also encourage those women to influence others in their social network through discussions about the experience (Elkind & Eardley, 1990; McNoe, Richardson & Elwood, 1996). Similarly, although not the focus of this research, the communication for women who require reassessment following an abnormal finding on their mammogram will need to be reconsidered (Austoker & Ong, 1994).

For the purpose of this thesis, the style of communication that is dominant in the two phases of communicating screening mammography may be further defined by the definitions of language provided by Brown and Yule (1983). They distinguish between language that expresses "content" or transactional, and that which expresses "social relations and personal attitudes" as interactional (p. 1).<sup>2</sup> Although, as the authors point out, the demarcation is not always complete, the dichotomy provides a useful distinction for this research. The first phase of communication to encourage women to participate in screening mammography is based primarily on print resources, such as pamphlets, posters and letters of invitation. These resources use transactional language to convey "factual or propositional information" (Brown & Yule, 1983, p. 2). The function of

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<sup>2</sup> Not to be confused with the analysis of interpersonal communication as a system, discussed by Watzlawick, Beavin & Jackson (1967).

transactional language is to efficiently transfer information, which in this case, is integral to providing the resources for facilitating the participation of eligible women in the breast screening programme. Although there is typically some interactional communication between women considering breast screening and health professionals in the community, interactional communication primarily occurs when women are interacting with the staff during the physical process of mammography. Accordingly, the second phase of communication in screening mammography is centred on interactional language where “interaction is characterised by the primarily interpersonal” (Brown & Yule, 1983, p. 3).

## **ANALYSIS**

This study combines both quantitative and qualitative research to explore the influences on the communication processes and outcomes, both internal and external to the breast screening programme. To investigate the process, a triangulated data collection and analysis method was employed, using a questionnaire survey, focus group interviews and individual interviews. Results from the analysis of quantitative and qualitative data were combined to provide the advantages of linking the two approaches, such as using the former to describe patterns and the latter to validate, clarify and illustrate findings, as suggested by Miles and Huberman (1994).

## **ORGANISATION OF THE THESIS**

To discuss communication in a New Zealand health organisation, the broader institution of health care needs to be introduced and placed in a social context. Chapter 2 provides a brief introduction to the development of the health sector in New Zealand, and the ideological shift away from a welfare to an

economic model of health care in the unprecedented reform process of 1991. A discussion of the relevant influences and decisions which resulted in the development of the breast screening programme in New Zealand follows. Finally, a review of international literature provides background information about the process, benefits and risks of mammography, including reference to the polemic debate that surrounds the process of screening mammography programmes.

Chapter 3 contains a review of literature relevant to this study of health communication. Literature which provides a theoretical framework of the different models of communication in a health care context, such as the biomedical and health promotion paradigms, is presented. The implications of communication that occurs within the changing context of health care are also summarised, integrating a discussion on the relevant socio-cultural influences, such as healthism and individualism. Finally, a range of literature that reveals the implications of communicating a programme to detect cancer is also discussed.

Chapter 4 outlines the methodology used in this study. An interpretive approach with a critical turn was adopted, using a single case study. The use of triangulation as a methodology, which combined quantitative and qualitative data collection and analysis as a form of validation, is discussed. The procedures used in the multiple-strategy approach to the collection of data, such the development and implementation of a questionnaire survey, and participation in focus group and individual interviews are presented. A discussion of each method incorporates the advantages and disadvantages associated with each, and the ways in which those that were apparent in this study were dealt with. Quantitative statistical analysis was performed throughout the research using SPSS.<sup>3</sup> The rationale for using tests of significance applying Fisher's exact tests in 2x2 tables

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<sup>3</sup> SPSS Inc., 1989-1997. SPSS Statistical Package for Windows. Release 8.0.0 22/12/97.

and chi-squared ( $\chi^2$ ) tests for independence in contingency tables is outlined. The process of qualitative analysis of resulting data using narrative themes (Owen, 1984) with reference to Ricoeur (1981) and a critical perspective is also presented. Finally, the limitations of this research are discussed.

As identified in prior literature, screening mammography programmes require different types of communication to both encourage and maintain participation. Chapter 5 presents the findings from the first research question which investigates how the breast screening programme communicates its presence to eligible women and in turn, how the women respond. This chapter provides background information on the primarily transactional, and also interactional, communication strategies designed to encourage women to participate in the screening mammography programme.

First, the key messages that predicate all communication from the programme are presented, followed by a discussion about the communication material (pamphlet and poster) used by the pilot programme to encourage participation. The communication material of the television promotional campaign produced for the national programme by BreastScreen Aotearoa, and the pamphlets that some women commented on in the research, are briefly introduced. However, the latter were introduced just prior to the survey. Therefore, most women had not seen the pamphlets, which accordingly, were not as relevant to this research. Finally, the role of general practitioners in encouraging women to participate in the breast screening programme is discussed.

Women's responses to the influence of introductory communication strategies from the programme are analysed, using quantitative data and anecdotal comments from the questionnaire survey, focus groups and participant interviews. Tests of significance were applied using Fisher's exact tests in 2x2 tables and

chi-squared ( $\chi^2$ ) tests for independence in contingency tables. The data are supported by relevant anecdotal comments women made in the questionnaire survey, focus groups and participant interviews.

The focus of Chapter 6 is the second research question which relates to the political and socio-cultural influences on the interpersonal communication between programme staff and women who are participating in screening mammography. The semi-structured interviews held with nineteen female staff members in the breast screen unit and the health promotion team are analysed using thematic analysis (Owen, 1984) with reference to Ricoeur (1981). The emergent themes are examined and the influence on the process of communication with the target audience discussed.

Chapter 7 addresses the final research question of how those in the target audience receive and interpret the communication from within the breast screening programme that is designed to encourage them to participate in regular, ongoing screening mammography. Findings from the questionnaire survey, focus groups and participant interviews are all drawn on in this chapter. The quantitative and qualitative analysis provides an examination of meaning ascribed to the communication processes during the process of screening mammography by participants, meaning which is most likely to influence their ongoing decisions about regular participation.

In Chapter 8, the identified discrepancies between the communication produced by the programme staff and the interpretation and reception by the target audience are discussed. The results are also considered in relation to other research in the area of health communication. The key findings of the research are highlighted and discussed in relation to the implications for appropriate

models for future communication about breast screening. Possible strategies to enhance communication within the breast screening programme are discussed.

The discussion in Chapter 9 outlines the converging findings revealed from the multiple sources of data and analysis undertaken in this research.

Implications that arise from conclusions drawn from the outcomes of this study are outlined. Opportunities for facilitating further research in devising appropriate and effective health communication for the screening mammography programme are also suggested.

## **CHAPTER 2**

### **THE BREAST SCREENING PROGRAMME: BACKGROUND AND LITERATURE**

The New Zealand screening mammography (breast screening) programme was introduced nationwide on 10 December 1998. To explain how and why the programme came into being invites a historical perspective of the health sector that produced the service. In this chapter, I first briefly outline the development of the welfare model of health service in New Zealand. Second, the radical reform process of 1991, which represented a response to environmental factors and a precursor to community screening programmes is introduced. Third, I discuss the increased incidence of breast cancer and the implications of rising mortality in the face of no known means of prevention or cure for the disease. An outline of the subsequent development of two pilot programmes, and one national screening mammography programme, in New Zealand then follows.

Subsequently, research relevant to the communication and experience of screening mammography is presented. As communication is central to the breast screening programme and to this thesis, I identify the international research that has explored various aspects of the process. Finally, I review the literature that focuses on the rationale, risks and benefits of screening mammography.

## **A HISTORY OF THE HEALTH SECTOR IN NEW ZEALAND**

In New Zealand, an integral thread in the development of the social and resource structure was a publicly-funded and largely free health system. Although it is likely that New Zealand was settled as early as AD 800-1100 by the Polynesian populations from neighbouring islands, the population never exceeded 100,000 (Davidson, 1992). The European population was not established until the wave of immigration from Britain in the middle eighteen-hundreds (Sinclair, 1980). In response to the need for organised health care in a growing population, the Hospital and Charitable Institutions Act was passed in 1885 which divided the country into 12, (later 28), hospital and charitable aid districts (Hay, 1989). However, the state played a minor role and government provision for medical care was modest. The poorly-funded hospitals at the turn of the century tended to be charitable, under-resourced institutions. The lack of facilities was exposed during public health crises, such as the influenza epidemics of 1838, 1889 and 1918, and the pandemic of bubonic plague which began in China and reached New Zealand in June 1900 (Hay, 1989).

In accord with the political and social climate of a post-depression country in the nineteen-thirties, a young politician, Dr McMillan, proposed setting up a national health service to provide all citizens with “free medical, dental, pharmaceutical, specialist, and institutional treatment” (Hanson, 1980, p. 35). The ideology underlying public funding was that the provision of health services was a public good that should be accessible according to need rather than ability to pay. Subsequently, the post-depression Labour Government was elected in 1935 on a platform of providing welfare benefits, including relatively inexpensive health care, in the form of the intended Social Security Act.

The pressures that instigated this legislation appear to be threefold. First, the country had experienced a severe economic downturn following a global depression in the nineteen-thirties that had affected levels of health and well being (Hay, 1989). Thus, health care was a highly valued means of retaining productive economic activity in an agricultural economy (Dow, 1991). Second, women were entering the workforce, which they continued to do in accelerating numbers over the war years, and were no longer available to provide home care for the sick and infirm (Olssen, 1992). Finally, the epidemics of plague and influenza had highlighted the need for an accessible and organised means of providing health services to the population in times of crisis (Dow, 1995).

Following nearly three years of parliamentary debate, the Social Security Act was introduced in 1938, and the publicly-funded health system was established. Over the past sixty years, reviews of the Social Security Act of 1938 have retained the premise of equality. A Royal Commission of Inquiry undertook the first significant reassessment of social policy in 1969. The Commission supported the Act of 1938, stating that:

[W]hatever the imperfections of the New Zealand health and medical services may be, the basic aims of universal benefits and readily accessible service at all levels have stood the test of time, have received widespread commendation overseas, and should be preserved (1972, p. 15).

A subsequent commission recommended further social policy to diminish poverty traps, and thus enhance the sense of community through increased social equality (Royal Commission on Social Policy, 1988). It was concluded that egalitarianism, in the sense of narrowing affluence and privilege, remained an intrinsic feature of New Zealand society.

## **THE HEALTH REFORMS, 1991**

With the global economic downturn of the late nineteen-eighties, the cost of providing publicly-funded health care to the New Zealand population came into question. The economic recession gave resonance to the claims of the New Right, whose policies reflected an aim of reducing welfare dependency and the high costs associated with the welfare state (Burrows, 1991). As the health service exists within a relationship of mutual interaction or symbiosis with the wider social, political and economic environment in which it operates, a number of variables have impinged on the direction of health care. Those that were notable in the past three decades are briefly discussed below.

### **Economic influences**

In the 1950s and 1960s New Zealand was enjoying full employment, and the agriculturally-based economy was prospering. However, in the 1970s the “oil shocks” reverberated throughout the global economy as the price of oil rose dramatically (O’Conner, Orloff & Shaver, 1999). The result was an inflationary increase in the price of virtually all commodities. Because of the increased cost of production, unemployment began to rise. The “think big” projects were recognised as being wasteful and unsuccessful as costs began to escalate, along with a shrinking tax take from those remaining in the workplace (J. Kelsey, 1993).

Britain, New Zealand’s biggest customer for the main export commodities of dairy produce, joined the EEC. Consequently, the traditional market diminished as Britain began to give preference to the milk, meat and wool products from farmers closer to home (Easton, 1997). At the same time, the technological age gathered pace and the job market receded even further as automation and computerisation provided the means to enhance efficiency.

Additionally, the children of the initial round of baby boomers from the nineteen-forties began to produce children and payments such as “family benefit” started to be questioned (Hawke, 1981). The efforts of the state to reduce fiscal cost gathered momentum, and radical restructuring of the public service in New Zealand inevitably included the health sector, as health care become constituted as an object of the market (J. Kelsey, 1993).

## **Political influences**

The Labour Party of 1984, the same party that instigated the Social Security Act of 1938, challenged the rights of all to many welfare services, including the right to public sector health care. In government, the party embarked on a path of radical reform, which included the corporatisation and subsequent privatisation of state agencies. In 1986, a review of the country’s existing public health services was commissioned. The committee had barely produced a report (Fougere, Marwick & Scott, 1986) before a taskforce chaired by Alan Gibbs was commissioned to investigate the public health system (Gibbs, Fraser & Scott, 1988). The resulting report had a strong focus on potential savings that could be made by dealing with the perceived inefficiencies in the existing system.

Although the Labour Government at the time rejected the controversial Gibbs report, the recommendations were subsequently espoused in the National Government’s health reform process. Evoking a scenario involving individual consumer choice and the beneficial effects of competition, the National Government introduced the *Green and White Paper* in the Budget on 30 July 1991. The then Minister of Health, Simon Upton, argued that there was a need for radical reform to address the “litany of incompetence” present in a “fragmented and uncoordinated [health] system” to ensure the availability of

accessible and affordable health services (NZ Parliamentary Debates, 1992, August 20, Vol. 258, p. 10783). Upton (1991) maintained that the “currently fragmented system was inefficient” (p. 18), and would be replaced by an alternative that offered “greater value for money” (pp. 13, 22 & 47), would “guarantee access” (p. 18), offer “greater choice and flexibility” (pp. 19 & 39) and be “more efficient” (pp. 31, 35, 37 & 47). The legislation to effect the changes, the Health and Services Disability Act 1993, was introduced to Parliament on 20 August 1991.

### **The influence of technology**

Technology has provided rapid and exponentially accelerating advances in the health service. Equipment and developments have allowed the previously unthinkable, such as multiple organ transplants, to proceed with increasing rates of success. As Foucault (1986) contends, technology establishes the role of the health sector as not simply one of curing, but as one of making curing increasingly possible. In so doing, there are implications for increasing cost:

Technology does not affect only the patients on whom it is used.

Using a CAT scanner, a computer, an artificial heart or kidney requires extraordinary integration of personnel, skills, finances and availability (Bates & Lapsley, 1987, p. 16).

Efficiency improvements from technological advances, however, may also lower cost to some extent. For example, the new lithotripsy procedure means that kidney stones are removed as an outpatient process rather than in an operation which requires extensive surgery and several days of hospitalisation (Renner & Palmer, 1998). Also, as Jecker and Pearlman (1992) note, technology has developed at such a rate that it has been argued that “today’s high technologies are

tomorrow's low technologies" (p. 83). Although the statement is true with regard to advances in certain treatment techniques, such as equipment for cardiac bypass surgery, it would be difficult to apply it to a development such as the oral contraceptive pill. The ongoing influence of convenient, sure contraception has had far-reaching and continuing social implications, enhancing women's flexibility to plan careers and lifestyles. Putting aside the ongoing risks of oral contraception, such as the incidence of stroke and thrombosis, the influence on the ability of women to plan their lifestyles is as relevant today as it was three decades ago when sure contraception first became readily available. Nevertheless, with progress comes an increased expectation for better healthcare. In conjunction with an inelasticity of demand for care, cost is likely to continue to rise (Cullen, 1998).

## **Demographic influences**

One of the key reasons cited for the recent reform process in New Zealand has been the aging "baby boom" cohort (Upton, 1991). The aging of society is seen as a demographic shift that "pushes us more quickly toward resource scarcity" (Daniels, 1988, p. 10). The baby boom aggregation of population is composed of the large birth cohorts born from the mid 1940s to 1970s (Pool, 1996). In New Zealand, the baby boom was preceded by a long period from 1875 to the 1930s in which fertility had declined to very low levels; it was also followed by a sustained drop in the birth rate (Pool, 1997). Both of these factors mirror the situation in other western countries (Daniels, 1988), and both have implications for the future. As a large cohort reaches retirement age, it will look to the following generation for fiscal support.

Demand for health care originates, in part, from demographic structures. The underlying issues are, first, who needs services and, second, who provides those services. Both are a function of population, and the first is delineated by the second; that is, by who is available to pay for the provision of the services (Pool, 1997). In New Zealand's case, there is a large cohort of people who, within the next decade, will begin to reach the age of typically high dependency on health care services (Fougere et al., 1986). By 2031 the numbers of baby boomers aged 65 and over will swell the ranks of the elderly population to 939,600; more than twice that of 1991, and more than the total population of the South Island in 1991 (Statistics New Zealand, 1995b). That same cohort of people is also followed by one comprised of a much smaller number of individuals who will be in the workplace to support the anticipated increase in demand.

### **Social and cultural diversity**

New Zealand is increasingly becoming a multicultural society. Although predominantly of European descent, the population comprises a significant proportion of Māori and increasing numbers of Pacific Islanders, Asians and other races. "Ethnicity" and "race" are variables defined with reference to their subjectively meaningful properties within a particular society. They are socially defined in terms of their meaning for actors and their situation in a particular society which makes these actors socially distinct groups in their own eyes and in the eyes of others (Bulmer, 1986). It is indubitable, however, that the progress of health care in this country has been firmly situated on a western model of health, which has undermined the notion of ethnic and racial equality.

For example, Durie (1987) explains that Māori health care is culturally determined by the community and maintained under the laws of "tapu" (p. 3).

Health is directly related to spiritual laws and the ascendancy of the family and collective interest. Models of indigenous Māori health care emphasise the holistic view. For example, the Māori model of *Whare Tapa Wha* compares health to the four walls of a house; the spiritual, the feelings, the physical and the family; these symbolise the supporting structures that are all equally necessary to ensure strength (Durie, 1994b). In contrast to the individual emphasis on health in the western model, the Māori family is central to the function of health care. However, with colonisation, a western approach emphasised a scientific, professional institution of health care in New Zealand. As a result, science dominated spirituality and separation caused depression when Māori families were unable to care for either their sick or their dead (Durie, 1994b). With ideas, attitudes and reactions shaped by a cultural heritage with concepts of tapu and “illness as an infringement against tapu” (Durie, 1994b, p. 68), Māori often suffer anxiety and depression while in hospital.

European colonisation was progressive. There were fewer than 100,000 people in New Zealand in 1840, but by 1860, there were 120,000. During that twenty-year period, however, the ethnic balance had shifted significantly from approximately forty Māori to every non-Māori in 1840 to “around parity by 1860” (Pool & Bedford, 1996, p. 3). By the 1890s, when European settlers were experiencing levels of life expectancy of between 50 and 60 years, lifespan for Māori was around 20 years. The greatest force of mortality was at the youngest ages: 25% of Māori girls born in the 1890s would not have reached nine months of life; half would have died before the age of seven (Pool & Bedford, 1996, p. 12).

Although not entirely, the responsibility for many of these deaths was a result of the introduction of foreign diseases such as measles and whooping cough

from immigrants. As the Māori population had never been exposed to these viruses, the complications were intense and disease often fatal. However, Māori who survived the nineteenth century epidemics developed some immunity and passed it to their descendants. Intermarriage between Māori and European also helped to transmit some immunity over time (King, 1992).

The western medical model has done little to incorporate the spiritual and health care models of the indigenous people. The costs are clear. When the Ministry of Health carried out the first national survey of health status in New Zealand in 1995, the experience of good health remained significantly worse for Māori (Triggs, Johnston, O'Connor & Wong, 1995). The survey reported that poor health status and correspondingly higher use of most health services were more common in Māori, who were less likely to be covered by health insurance and more likely to report an unmet need for health care. Triggs et al. (1995) showed that cost was the reason most often given for unmet needs and for late consultation. Accordingly, although Māori were found to be more likely to visit a doctor than other groups, they were also more likely to consult for serious conditions. The 1991 reform process was an attempt to address the health system bias of “a culturally constrained medical straitjacket” that was failing Māori (Durie, 1994a, p. 194). The situation, however, remains inequitable (Ministry of Health, 1999).

## **OUTCOMES OF THE REFORM PROCESS**

Although the reforms were introduced in July 1991 by the National Government, changes in health care had been occurring since the middle to late nineteen-eighties along with the Labour Government's restructuring of the public sector. As a result of the reform process, in response to the socio-political

influences outlined above, primary health interventions were introduced in an effort to move the emphasis away from more expensive hospital care (tertiary care) into the community (primary care). The underlying rationale is now one of a more efficient use of health resources by providing interventions in the community that may avert the need for more costly hospital treatment in the future.

To engender the necessary changes in the tertiary health service, a new “corporate identity” was introduced as hospitals became Crown Health Enterprises, and were charged with responsibility for making a profit. Although some of the initial strategies, for example user part charges, were eventually abandoned as they were both unpopular and uneconomic, the focus remained commercial (Easton, 1997). Government removed itself from health care by introducing a competitive tendering process through the establishment of Regional Health Authorities (now Health Funding Authorities). All hospitals, including the departments within them, were to operate as financially autonomous, and management salaries were linked to performance-related bonuses (Kelsey, 1997). The new focus was on how to manage the business, control the budget, and wherever possible, make a commercial profit (Ashton, 1995). Clinical professional identities became subordinate to business managers who controlled budgets and resource allocation within departments. Funding was restricted to a tender process, with public and private health organisations competing for available funds to provide surgical and medical services for the population.

In keeping with an increasing drive for efficiency in the health sector, the management of the health service encompassed a process that was required to promote the “best health gain for the resources required” (Cumming, 1996, p. 27).

The underlying premise of weak sanctions against inefficient performance under the old non-competitive, institutional health care system which did not provide the required levels of efficiency (Danzon & Begg, 1991), was replaced with financial imperatives to attain desired levels of health provision. In the competitive environment, organisations submit tenders to the Health Funding Authority to provide health services. They must undertake to provide an acceptable service within the financial constraints of an allocated budget. The weak sanctions of the “old” system have been replaced with the stronger commercial reality of an implicit lack of guarantee that contracts will be renewed if terms and conditions are not met.

Concurrently, in a further move to constrain the use of expensive tertiary services, programmes were introduced to detect, and wherever possible, treat disease and illness at a primary level in the community. In tandem with a social expectation of self-responsibility for one’s own health, which is discussed further in Chapter 3, screening programmes were introduced. For example, facilities such as blood pressure and blood glucose checks, for hypertension and diabetes respectively, were made available in the community to empower those who were willing to monitor their health. Individuals no longer needed to wait for symptoms to occur, neither did they need to visit their general practitioners to obtain some diagnostic services.

However, it is difficult for any government, even in the wealthiest country, to provide for every health need of a population. Accordingly, resources for screening programmes need to be targeted to the areas of greatest perceived need. As breast cancer was, and remains, the most frequent cause of death from cancer for New Zealand women, it was a legitimate focus for community intervention.

It was in this environment in 1991 that the pilot programmes for screening mammography were introduced in the Otago and Southland and Waikato regions.

## **BREAST CANCER**

The incidence of deaths from breast cancer in New Zealand has been consistently identified as a major factor in mortality rates for women (Armstrong & Borman, 1996; Ministry of Health, 1999). As noted in Chapter 1, an increasing trend in incidence of the disease is occurring (Cox, 1995; Elwood 1995b), which is reflected in the numbers of registrations for breast cancer among cancer registry figures (Ministry of Health, 1999). The diagnosis of breast cancer is one which is made in the knowledge that there is currently no known cure, only treatments that have varying rates of success for the multiple types and stages of malignant tumours that occur (Roberts, 1989). As breast surgeon, Susan Love (1990) writes; “Breast cancer is disease with a major psychological impact” (p. 238) and the diagnosis is “terrifying” (p. 238). Accordingly, in the current climate of community interventions, there is an analogous emphasis on both providing a screening intervention, and also providing information to women about the level of risk of contracting breast cancer. The aggregated purpose is to encourage women to adopt a proactive stance towards health-enhancing behaviours.

There are three types of risk referred to when discussing breast cancer: the first is absolute risk, the rate at which cancer occurs and the mortality from the disease in the general population. The average absolute risk of developing breast cancer by age 80 is around 10%, and the probability of dying of it is about 4% (Elwood, 1995b). The second is attributable risk, which looks at how much breast cancer could be prevented by altering known risk factors (Love, 1990). The third is relative risk, which measures the incidence and mortality of breast cancer

among those with risk factors, compared to other people who do not demonstrate the same risk factors. For example, in the case of breast cancer, ovarian hormones are believed to be a key factor in development (J. L. Kelsey, 1993). The risk may possibly even be determined very early with pre-natal exposure to high levels of oestrogen, a predisposing factor in the incidence of breast cancer in later life (Ekblom, Trichopoulos, Adami, Hsieh & Lan, 1992). Other identified hormonal influences are being childless or bearing children late in life (Helmrich et al., 1983; Kelsey & Berkowitz, 1988), not breast feeding (Brinton, 1994; Newcomb et al., 1994), early onset of menarche, and late menopause (Love, 1995), which may be positively correlated with the incidence of breast cancer.

However, the most consistent variables associated with an elevated risk of breast cancer are gender and increasing age (Chamberlain, 1984; Kelsey & Berkowitz, 1988; Love, 1995; Moolgavkar, Stevens & Lee, 1979). A family history of breast cancer appears influential, including genetic predisposition (Bethwaite & Smith, 1996; Eddy, 1989). Nevertheless, the discovery of a genetic influence on the development of breast cancer (for example, the BRCA or Tp53 genes) has been identified in less than 5% of women presenting with the disease (Love, 1995). The presence of benign breast disease may indicate increased risk (Boyd, Cousins, Lockwood & Tritchler, 1990). It has also been suggested that the incidence of breast cancer is more common in women in high socio-economic groups (Rimpela & Pukkula, 1987), although mortality is higher in lower socio-economic groups (Farley & Flannery, 1989; Lethaby, Mason, Holdaway & Kay, 1992; Solomon & Jackson, 1990).

It could be argued, however, that the only behaviourally modifiable risk factors above are those of child bearing age and breast-feeding. Nonetheless, such decisions may also be constrained by physical factors, lifestyle and goals that are

likely to supersede decisions about behaviours related to the perceived risk of breast cancer. However, it has also been noted that the use of hormone replacement therapy and oral contraceptives (which are both based on ovarian hormones) may also be associated with incidence of breast cancer (J. L. Kelsey, 1993). Once again, the options about the use of both may well be constrained by other life chances or choices.

Still, association does not imply causality, and risk factors are constantly being redefined. The debate will continue as knowledge develops. Miller, McNoe, Elwood and Doyle (1998) demonstrated that even the understanding of New Zealand doctors about the current relevant risk factors for breast cancer remains “limited” (p. 28). Meantime, many women continue to develop breast cancer, although there are no attributable risk factors present (Love, 1995). Currently, there is no known, feasible means of primary prevention.

Even in the case of behaviours that have been widely promoted as influencing life chances of ill health, or attributable risk, there is little evidence to even suggest a causal link. Although a possible link between breast cancer and factors related to high-fat diets, such as high meat consumption (Toniolo, Riboli, Shore & Pasternack, 1994) and increased alcohol intake (Willett et al., 1987) has been suggested, the evidence remains inconsistent, resulting in a call for more epidemiological data to corroborate such claims (Prentice et al., 1990). The exigency of such a request is emphasised by a number of more recent studies that have consistently failed to demonstrate a definitive association between health-related disciplinary behaviours of a controlled low-fat diet or lower alcohol consumption and freedom from ill health (Brinton, 1994; J. L. Kelsey, 1993; Lund, 1994). As Kaplan (1984) urges, “Risk factors should not be confused with the outcomes. They are only important because they bear probabilistic

relationships to outcomes” (p. 756). The author continues that those relationships “are not uniformly supported by research data” (p. 757) as demonstrated above. A clear principle that emerges from the above discussion is that there is currently no known means to prevent the occurrence of breast cancer. Those who are female and aging, over half of the population of New Zealand, cannot avoid the two highest, most consistently identified risk factors to date.

## **SCREENING FOR BREAST CANCER IN NEW ZEALAND**

Concern about the rising mortality rates from breast cancer in women aged over 50 years was expressed in 1987, when the Public Health Association and the Cancer Society convened a workshop to discuss early detection of cancer of the breast and cervix (Chetwynd & Clarke, 1988). Consumer groups addressed the matter of screening from various perspectives and agreed that whatever service may eventuate, it must be “affordable, accessible, acceptable and culturally-appropriate” (Chetwynd & Clarke, 1988, p. 176).

Later in 1987, a working group was set up to investigate the feasibility of a national screening programme for breast cancer in New Zealand. The group, chaired by Professor David Skegg, recommended that a population-based screening mammography programme offered the most effective means of lowering mortality from breast cancer. However, the working group also expressed concerns about the lack of available resources in terms of equipment and qualified staff to institute a nationwide programme. Accordingly, they recommended that two pilot programmes be set up initially (Skegg et al., 1988b). The pilots were to complete a two-year screening round by June 1994 (Brown, 1997). This would allow time to assess whether the benefits of a screening mammography programme would prove worthwhile in New Zealand.

In the continuing absence of either an effective means of primary prevention or the demonstration of a “statistical cure of symptomatic invasive breast cancer” (Forrest, 1991, p. 3), mammography or breast screening offered the best alternative for reducing mortality in women aged fifty years and over (Austoker, 1994a; J. L. Kelsey, 1993). Accordingly, the Ministry agreed to fund two pilot programmes within the terms of the Skegg report (Skegg et al., 1988a). The Cancer Society of New Zealand and the Health Research Council of New Zealand were to evaluate the programmes. Following assessment of submissions from a number of interested groups and appraisal by the Medical Research Council, the proposal for Otago and Southland was selected in 1989 (Elwood, Doyle & Richardson, 1991). Subsequently, funding was granted and two fixed screening units were established in Dunedin and Invercargill, and a third unit operating from a mobile van visited rural areas. Screening began at the fixed sites in September 1991, and the mobile service commenced a year later in September 1992 (Richardson, 1996). However, although Otago and Southland offered an appropriate population size of 20,000 eligible women, the region did not provide an ethnic mix conducive to assessing the acceptability of the programme for Māori women, as only two percent of the population in the area were Māori (Richardson, 1996).

A second pilot was subsequently established in the Waikato where there is a greater representation of Māori and Pacific Island women. Accordingly, an important outcome of the pilot programme was to establish “knowledge and understanding [through] evaluation of the different methodologies for targeting Māori women” (Brown, 1997, p. 72). Government directly funded a Māori community support organisation, Raukura Hauora O Tainui, to provide two half-time health promotion staff for promoting screening mammography. The other

half of their time was spent promoting cervical screening. Assessment of the Waikato pilot was linked to the Otago and Southland programme (Elwood et al., 1991).

The two pilots were subject to the assessment criteria of the evaluation committee set up by the Cancer Society and the Health Research Council to ensure that pre-set targets were met. Regular reviews indicated that the programme was operating cost-efficiently (Menon, Devlin & Richardson, 1994), and that it was acceptable to women (Richardson, McNoe & Bang, 1993). In 1995, an advisory group was convened to provide policy advice about breast screening to the Director-General of Health. Basing their decision on the evidence of international trials that screening reduces mortality, and was demonstrated to be cost-effective in New Zealand, the committee “recommended that the then National government pursue a strategic approach to breast cancer detection ... including the establishment of an organised, population-based screening programme for eligible, asymptomatic women” (Breast Cancer Screening Policy Advisory Group, 1998, p. 138).

Three years later, on 10 December 1998, the National government introduced the BreastScreen Aotearoa programme, which would provide a free nationwide screening mammography service for eligible women in New Zealand. There were six contracts allocated throughout the country. In the North Island, a private health provider, St Marks, was awarded the BreastScreen Auckland and North contract which serves the women of Auckland as far south as the Bombay Hills, and to Kaitaia in the north. BreastScreen Midland (formerly the Waikato pilot programme), covers the area of the greater Waikato region, which was amalgamated with the Bay of Plenty region under the national programme.

BreastScreen Coast to Coast, based in Palmerston North, provides a breast screening service for women from Taranaki to Gisborne. The fourth North Island contract is held by BreastScreen Central, based at Hutt Valley Health, providing breast screening for women in the greater Wellington region, as far north as Hastings South. In the South Island, one of two contracts is held by the Pegasus Group, a private provider based in Christchurch, who supplies breast screening services to the women in the top half of the island through to Timaru in the south. BreastScreen Healthcare (formerly the Otago and Southland pilot) which covers the greater Otago region, provides services for the remainder of the South Island; as far south as Invercargill.

## **THE PROCESS OF SCREENING MAMMOGRAPHY**

Eligible women are those who are aged between 50 and 64 years, and are considered “well” or asymptomatic. Women who present with a history of symptoms such as breast lumps, pain or nipple discharge are not eligible for screening mammography. These women will be referred for a diagnostic mammogram which may be combined with other procedures such as ultrasound or biopsy. If a breast abnormality is identified in women already participating in the population-based screening programme, they will be referred on for clinical assessment. If cancer is eventually found, those women affected will move on to the diagnostic programme for a minimum of five years. However, this research focused solely on those who were participating in screening mammography, which caters for well women only. As discussed in Chapter 1, there are distinct communication phases in communicating screening mammography programmes to eligible women. Accordingly, international research focuses on each phase

(Austoker & Ong, 1994; Baines et al., 1990). Two phases, inviting women to join the programme, and encouraging ongoing participation, are relevant to this thesis.

## **INVITING ELIGIBLE WOMEN FOR SCREENING**

The first stage of the screening mammography process involves identifying and inviting eligible women to be screened. As stated earlier, a community intervention that targets a “well” population requires communication so that women are both aware of the programme and willing to participate if targets are to be achieved. Accordingly, there has been considerable international research that has looked at various approaches to communicating with women to invite them to take part in a breast screening programme.

For example, with less than optimum levels of attendance in America (McBride, Curry, Taplin, Anderman & Grothaus, 1993), Australia (Turnbull, Irwig, Simpson, Donnelly & Mock, 1995) and Britain (Sutton et al., 1994), a number of research studies have focused on strategies of encouragement. Researchers in America and Britain have found that the more trusted and respected the source of encouragement, such as general practitioners, the more likely the invitation for screening will be accepted (Dorsch, Cheok & Ingham, 1991; Fallowfield, Rodway & Baum, 1990; Mandelblatt & Kanetsky, 1995; Rimer, 1992; Rimer, Keintz, Kessler, Engstrom & Rosan, 1989; Sienko et al., 1993). In New Zealand, Miller, McNoe, Elwood and Doyle (1998) and Richardson, Williams, Elwood, Bahr & Medlicott (1994a) found that the input from general practitioners in encouraging attendance at screening mammography programmes was an important influence for women in the Otago and Southland region. However, although general practitioners fulfil an important role, Hurley et al. (1992) also demonstrated that promoting the programme to this group provided

no detectable increase in the attendance of their female clients for screening mammography.

Further research has focused on the composition of letters of invitation that are sent from breast screening programmes to encourage attendance. For example, Taplin, Anderman, Grothaus, Curry and Montano (1994) found that a letter from the doctor had no influence on their sample of 1500 American women, although reminder cards from the programme doubled the likelihood of participation. Similarly, in Australia, Turnbull, Irwig and Adelson (1991) demonstrated that letters from the programme, that is from health professionals unknown to women, were just as effective as those sent from women's doctors in encouraging participation. Investigating the structure of the letter, Williams and Vessey (1989) demonstrated that including appointment times in the initial invitation encouraged attendance more than an open-ended invitation.

Research that provides a communication focus on the way in which information is "framed" includes that by Rothman, Salovey, Turvey and Fishkin (1993a), who investigated the role of internally oriented messages in influencing attendance at screening mammography. They found that self-attribution messages that emphasised "self" rather than "other" (health professionals') responsibility for participating in a screening mammography programme were more likely to encourage American women to obtain a mammogram. The same researchers later explored "gain" versus "loss-framed" messages in encouraging participation in mammography (Banks et al., 1995). They found that the same objective messages that focus on the disadvantages of not having a mammogram were more effective in encouraging participation than those focused on the advantages of participating in screening mammograms.

The diverse cultural communication needs of some groups have been researched by Skinner, Strecher and Hospers (1994), who demonstrated the importance of tailoring communication to suit recipients. Skinner et al. (1994) found that personalised messages were particularly effective with low socio-economic and minority ethnic groups. This outcome has implications in terms of the under-representation of ethnic minority groups of women undergoing screening mammography in America (Burack et al., 1989; Stein, Fox & Murata, 1991), Britain (Kernohan, 1996; Pfeffer & Moynihan, 1996) and New Zealand (Solomon & Jackson, 1990), and suggests issues of acceptability and availability. Women in ethnic minority and low socio-economic groups were also significantly influenced by the use of a “personal contact” programme trialed in America (Calle, Moss, Miracle-McMahill & Heath, 1994). In contrast, Turnbull and Irwig (1992) found that personal contact had no major effect on recruitment for their sample of Australian women.

More recent research has stressed the importance of interpersonal communication. For example, Taplin et al. (2000) have reported that reminder telephone calls are even more likely than letters to encourage participation. Similarly, Saywell et al. (1999) reported that a letter from the doctor had no significant influence on attendance for mammography, unless it was combined with a personal approach (such as a telephone call or visit). One study (Phillips, Kerlikowske, Baker, Chang & Brown, 1998) recently demonstrated that the “interactive nature of decision making” (p. 43) between women and doctors was a significant predictor of attendance for breast screening, whereas simply leaving educational materials in doctors’ waiting rooms was ineffective in increasing participation in the screening programme (Mead et al., 1995).

## **REGULAR ATTENDANCE FOR MAMMOGRAMS**

For those women who choose to accept the invitation to participate in breast screening, the second stage is having a mammogram. The purpose of screening mammography is to detect breast cancer early. However, women are not always prepared to attend for regular mammography. Also, just as they need to be encouraged to attend, women also need to be motivated to re-attend. One mammogram will only detect breast cancer at that time. As cancer can develop at any stage, regular screening is necessary if mortality savings are to be achieved. Reflecting the importance of regular breast screening, some international research has focused on why women choose not to return for mammography.

Those studies that have looked at women who have made decisions not to attend or re-attend for screening mammography show specific differences between the groups. For example, French et al. (1982) found that respondents who refused mammography saw the breast screening programme as a “place of risk” (p. 617), and reported they were anxious about their “lives being disrupted” (p. 617) through participation. Non-attenders also expressed more concern about exposure to radiation (Bastani, Marcus, Maxwell, Das & Yan, 1994; Rimer et al., 1989), as discussed below. They were also more likely to report previous screening experiences as embarrassing or distressing (Orton et al., 1991), recall higher levels of pain and “less courtesy and promptness during screening” (Baines et al., 1990, p. 1667). Hurley and Livingston’s study (1991) further illustrated the presence of possible barriers to participation, in the form of considerable personal, financial and opportunity costs for women attending for screening mammography, even when there was no charge for the service. However, the two most cogent factors in decisions not to re-attend are pain and anxiety.

International research has established a link between breast screening and anxiety about both the procedure and the possible outcome of detecting breast cancer (for example, Bull & Campbell, 1991; Cockburn, DeLuise, Hurley & Clover, 1992; Ellman et al., 1989; Gram, Lund & Slenker, 1990; Marteau, 1990; Munn, 1993; Richardson, 1990; Rimer, Lerman, Trock, King & Engstrom, 1991; Roberts, 1989; Wardle & Pope, 1992). When women present for screening, believing that they do not have cancer, any news that there is an abnormality creates an “abrupt transition from a perception of being well to serious illness” (Maguire, 1983, p. 284) which creates anxiety and fear. For example, Lightfoot et al. (1996) discovered that “intense fear and anxiety related to the screening process” (p. 148) were reported by 43% of women who had completed a questionnaire immediately post-screening. Nielsen et al. (1991) reported similar results for nearly half of their samples of women. Similarly, in New Zealand, Munn (1993) and Richardson (1990) both identified fear and embarrassment as perceived barriers identified by respondents. McNoe et al. (1996) and Richardson (1996) subsequently identified that women attended for reassurance and the early detection of breast cancer, although fear of the procedure or possible outcomes constrained decisions to participate.

Some contend that even publicity about breast cancer and invitations to be screened tend to raise anxiety levels and feelings of vulnerability in women (Gerard, Turnbull, Lange & Mooney, 1992). Such processes may increase fear-induced anxiety through reminders to women that they are at risk of breast cancer (Maclean, Sinfield, Klein & Harnden, 1984). For example, Dean, Roberts, French and Robinson (1986) found that 30% of their sample of British women reported increased anxiety merely from receiving an invitation to have a mammogram. As noted above, anxiety about the physical process of mammography can also occur,

as any X-ray requires exposure to doses of ionising radiation. In terms of the numbers of years that women are exposed to screening mammography and improved equipment that requires exposure to smaller doses of ionising radiation, it is estimated that there is a minimal and ever-reducing risk (Feig & Hendrick, 1997; Gohagan, Darby, Spitznagel, Monsees & Tome, 1986). Even though the risk appears small, anxiety about exposure to radiation is evidenced in research findings. For example, Bakker, Lightfoot, Steggle and Jackson (1998) and Irwig et al. (1991) identified concern about exposure to radiation in nearly 30% of their samples of women. Stein et al. (1991) also found it was a significant deterrent to attending breast screening and Bastani et al. (1994) reported that their sample of American women were two and half times less likely to have a mammogram if they were concerned about radiation.

However, in comparison to the volume of research that has revealed the anxiety associated with attendance at a screening mammography programme, there has been less focus on how communication strategies may alleviate that anxiety. The exceptions are Marteau (1990) and Marteau, Kidd and Cuddeford (1996) who identified how clear and simple information about the procedures influenced the level of anxiety women experienced during mammography. Also, Woods (1991) points out that once women have made a decision to participate in screening, they need clear explanations of procedures from courteous and supportive staff, but provides no further advice about facilitating the process. Baines et al. (1990) and Elkind and Eardley (1990) similarly support this contention. However, it is Marteau (1990) who provides specific advice about the need for staff to be aware of how to assess carefully whether women understand the details they are being offered. Facilitating understanding means asking women what their understanding is of what they have been told,

reinforcing important points, then offering the opportunity to ask questions (Marteau, 1990). Roberts (1989) argues for the need for the interaction to occur in a supportive environment. It is recognised that those who are able to communicate their emotions, such as anxiety, cope better both physically and psychologically (Planalp, 1999). However, they require an environment conducive to allowing them to do so.

A second cogent influence in decisions not to re-attend appears related to the physical pain that women experience when the breast tissue is compressed. The breast is a physically sensitive organ, and some women are distressed by pain or discomfort resulting from mammography (for example, Baines et al., 1990; Bakker et al., 1998; Eklund, 1991; Elwood et al., 1998; Fallowfield et al., 1990; Hugh, 1991; Keefe, Hauck, Egert, Rimer & Kornguth, 1994; Kornguth et al., 1993; Nielsen et al., 1991; Rimer et al., 1989). During a mammogram, the breast tissue is tightly compressed between two X-ray plates. Compression is necessary to smooth out the breast tissue so that it is well spread and any abnormality will be easily detected. Compression also “thins” out the tissue which reduces the exposure to radiation (Lightfoot et al., 1996).

However, there is some research that dismisses the claim of pain during mammography. For example, Stomper et al. (1988) and Rutter, Calnan, Vaile, Field and Wade (1992) assert that the majority of women undergoing screening mammography suffer only mild physical discomfort. Jackson, Lex and Smith (1988) go as far to assert that “radiologists should not hesitate to use vigorous compression” (p. 421). In contrast, Fallowfield et al. (1990) reported that 48% of women found mammography either very painful or very uncomfortable and Nielsen et al. (1991) also found that pain and discomfort were problems for over 47% of women in their study.

The physical pain that may be associated with screening mammography can prove a source of distress for women (Baines et al., 1990; Bakker et al., 1998), to the point where they are reluctant to undergo further mammography, even when they have already experienced one mastectomy for breast cancer (Hugh, 1991). As Elwood et al. (1998) demonstrated, the experience of New Zealand women is no exception: 46% of women who declined further invitations for mammograms made that decision because of the pain. Similarly, O'Halloran and Kalafatelis (1996) contend that many women who have experienced mammography in New Zealand have found it painful to the extent that they have "mocked the typical medical throwaway line that 'this may cause some discomfort' " (p. 17).

There has been recognition of various factors that influence the amount of pain and discomfort reported by women in a range of international studies; for example, experience of mammography (Stomper et al., 1988), daily caffeine intake, stage of the menstrual cycle at which screening is undertaken, (Jackson et al., 1988), race, breast size, anxiety (Nielsen et al., 1991), high rates of compression (Keefe et al., 1994), and the technical skills of the technician (Eklund, 1991; Stomper et al., 1988). However, there has been little reference to the ways in which communication may influence women's perceptions of pain during the process.

If pain is a significant barrier to regular participation in screening mammography programmes, as the literature suggests, perhaps the need to communicate validation of women's pain is required. As Keefe et al. (1994) argue, even the experience of pain may be under-reported because health professionals are not responsive to women who complain of pain:

Over the course of several mammograms, a patient may learn which individuals are likely to attend to complaints of

mammography pain. As a result, she may fail to mention having pain to the radiology technician who tends to minimize her complaints, while at the same time talking extensively about mammography pain with close friends (p. 257).

Thus, Keefe et al. (1994) contend that failing to provide a supportive environment which encourages communication results in women not only “avoiding further mammograms” (p. 257), but also facilitates their communicating with others about their experience of pain. Elwood et al. (1998) did reflect on the need for staff in breast screening programmes to express sympathy and to offer suggestions for coping, such as taking analgesia prior to the mammogram. However, many suggestions tend, once again, to overlook the communication process. For example, it has been argued that fostering a sense of control can be achieved by involving women in the physical process of controlling the descent of the plate during the process of mammography (Korniguth et al., 1993). The procedure helped to relieve pain to “acceptable levels” in 31% of participants. However, it has also been relevantly suggested elsewhere (not in relation to mammography) that “communicating about emotion can help provide a sense of control which is an important step in... coming to terms with any emotionally overwhelming experience” (Planalp, 1999, p. 114, emphasis added). A supportive environment can help to facilitate this interaction (Burlison & Goldsmith, 1998). However, there is little research that has revealed this level of emotional communication during the process of mammography.

## **THE DEBATE ABOUT SCREENING MAMMOGRAPHY**

The provision of a screening mammography programme seems to be a contentious issue, particularly among the medical community (Dines, 1997).

Evaluation of the benefits and costs of screening mammography has resulted in a dialogue in which positions appear to be resolutely polarised. That both benefits and costs exist is not a contentious issue in itself, and these are outlined below.

The efficacy of screening mammography for detecting breast cancer has been investigated through a number of randomised and non-randomised medical trials. Comprehensive overviews of these are offered in Campbell and Royle (1992) and Richardson (1996). Of particular note in the Skegg report (Skegg et al., 1988a) were two randomised controlled trials which had previously demonstrated that mortality from breast cancer could be reduced by thirty percent in women aged between fifty to sixty four years of age who underwent screening mammography. The first trial was undertaken in 1963 by the New York Health Insurance Plan, and the 30% mortality difference between the control and treatment groups has been maintained over fourteen years of follow-up (Shapiro et al., 1982). The second was the 1977 two-county trial in Sweden, in which randomised samples were selected at community level (Tabar et al., 1992). The outcomes of these two trials were also instrumental in the favourable decision of the Forrest committee to introduce screening for breast cancer in Britain (Austoker & Sharp, 1991; Gerard, Brown & Johnston, 1997).

However, the two trials in which a thirty percent mortality gain from screening mammography was reported have also been followed by some that have not demonstrated the same level of efficacy, for example, the Malmo trial, undertaken in Sweden in 1977 (Andersson et al., 1988) and the Edinburgh trial (Roberts et al., 1990) where the demonstrated 20% reduction in mortality for women undergoing screening mammography was not high enough to reach statistically significant levels. Some outcomes remain a subject of debate, such as the higher total mortality in the study group of the Malmo trial (O'Hagan, 1991),

where interestingly, 25% of those in the control group had already had a mammogram (Tabar & Duffy, 1999), or the influence of low participation rates or low sensitivity of the screening test on the Edinburgh trial (Roberts, et al., 1990).

Many outcomes are probably broadly explained by the recognition that trial results will depend on variables such as the degree of compliance of participants assigned to randomised groups (Glasziou, 1992) or the evaluation of available expertise and resources for the research (Andersson et al., 1988). The debate about the true reduction in mortality from screening mammography looks likely to continue as ongoing research both questions (Mayor, 1999) and defends (Tabar & Duffy, 1999) the methodology of prior studies.

As discussed above, however, regular participation in screening mammography currently offers the most effective means of identifying breast cancer early. Nevertheless, it is recognised that potential benefit from participation in the programme is also offset by some measure of cost or risk, which is discussed below.

## **RISKS ASSOCIATED WITH MAMMOGRAPHY**

The first identified risk of undergoing screening mammography is the possibility of false negative results. A false negative result occurs when cancer is present at the time of screening and remains undetected. A mammogram does have limitations as only the accessible area of breast tissue can be filmed. Accordingly, as the periphery of tissue on the breast wall will not be included, the fact that mammography is not 100% effective is well recognised in medical research (Campbell & Royle, 1992; Love, 1990; Wilson, 2000). A tumour may be inaccessible by X-ray, too tiny to identify in accessible breast tissue, or simply

missed on radiological survey. This outcome, should the tumour be treatable, will significantly influence the life expectancy of the woman (Moskowitz, 1992).

Further, in the two or three year interval between screening, cancer could develop at any time, the incidence of “interval cancers” being reported as high as 17% (O’Hagan, 1991, p. 122). It is likely that approximately 10% of “interval cancers” could possibly have been false negatives (Wilson, 2000). That is, when prior mammograms are reviewed, the abnormality can be detected, although it was not noted as significant at a prior reading. However, it has also been argued that the incidence of interval cancers may be the result of the willingness of women to ignore a palpable breast lump when they have had a previously negative breast screen (Moskowitz, 1992). In like manner, O’Hagan (1991) contends that a clear mammogram result may induce a false sense of security that will encourage women to ignore any breast lumps that may subsequently develop. The tendency of women to regard a mammogram as an “insurance policy” was demonstrated by Elkind and Eardley (1990, p. 18). Other women may regard mammography as a prevention programme (French et al., 1982). From a medical perspective that is highly critical of screening mammography, Schmidt (1990) argues that such false reassurance may prove more harmful to women than any perceived benefits from screening mammography may be.

The second risk is the potential for false positive results. The incidence of false positives does not appear to be widely documented. However, in New Zealand the breast screening programme has a target of an incidence rate of no more than 5% false positives, compared to a target of 10% in Britain (Chapman, Brown & Snodgrass, 1995). A false positive result occurs when a woman who has a benign lesion in her breast, such as an atypical hyperplasia, is incorrectly diagnosed as having a malignant abnormality (Campbell & Royle, 1992).

Similarly, the situation may occur if inexperienced teams produce poor quality films or incorrectly identify tumours that are in reality, non-existent on repeat readings (Baum, 1988). As Elmore, Wells, Lee, Howard and Feinstein (1994) demonstrated, radiologists can differ substantially in both their interpretation of mammography films and their subsequent recommendations for treatment.

In such cases, women are normally referred on for diagnostic follow-up which may involve diagnostic investigations such as further mammography, biopsy and needle aspiration. Such outcomes tend to be associated with increasing levels of anxiety, which may continue long after the diagnostic follow-up has produced a negative result (Lindfors, O'Connor, Acredolo Liston, 1998; Wright, 1985). For example, Gram et al. (1990) demonstrated that anxiety about breast cancer was ongoing in 29% of their sample of 126 women who had previously experienced a false positive result from their mammogram. The level of anxiety was also more prolonged in women who have been recalled for follow-up in the research of Ellman et al. (1989), regardless of outcome. Lerman et al. (1991) found that worry affected the mood of 26% of women who had received a false positive report following mammography, even three months after receiving the report. Similarly, Brett, Austoker and Ong (1998) found that this worry persisted up to five months after the last screening appointment.

Even though anxiety may not reach pathological levels, it appears to increase with recall because of an "uncertain" screen, or because surgical procedures, such as biopsy or fine needle aspiration, are required (Bull & Campbell, 1991). It has been argued that "morbid anxiety", or prolonged anxiety may develop in women awaiting diagnostic results; they may become preoccupied with the possibility of developing breast cancer, which potentially results in varying states of psychiatric depression (Fentiman, 1988), and may have even

resulted in two women committing suicide in Britain (Weil & Hawker, 1997). Nevertheless, women who undergo screening and receive a negative result without delay do not appear to develop morbid levels of anxiety (Ellman et al., 1989). The critical factor appears to be the existence of delays through inconclusive results.

The third risk from screening mammography is the potential to detect pre-malignant lesions that would be unlikely to progress to invasive cancer, or detect true cancers early that are not responsive to early treatment. Therefore, lesions are detected and treated which would not, under different conditions, have required intervention during the woman's lifetime (Campbell & Royle, 1992). As a result, women live with a feared disease for many years, often without any trade-off in terms of treatment, or alternatively, "over-treatment" of non-malignant tumours (Austoker, 1994b; Valentin & Leitz, 1988). It has been argued from a more critical perspective that screening mammography, as an intervention targeting a "well" population, has a propensity to "make patients out of well people" (O'Hagan, 1991, p. 121). The result is what has been referred to as "medicalisation" of societies, which compounds the intrusion of the biomedical model on the social structures within which we live. This event is explained by Auge and Herzlich (1995) as a social trend in which "medicine has itself become one of the major expressions of 'social reality' " (p. 165). An increasing number of processes and events are placed within a medical frame (Neubauer, 1992). It has subsequently been argued that screening as an intervention in a "well" population, by definition, may give rise to ethical concerns (Guttman, 1997).

Finally, it has also been suggested that it is not only women who undergo screening mammography who suffer from anxiety. There is a potential cost in anxiety to women who are denied access to the programme (Sutton, 1997).

Breast cancer is rare before the age of thirty (Valentin & Leitz, 1988), and there is some debate about the value of screening younger women because the density of pre-menopausal breast tissue makes it difficult to detect any abnormality. There is some support for screening 40 – 49 year olds (Smart, 1994), provided the interval between screenings is shorter, due to the faster progression of pre-menopausal tumours (Tabar et al., 1995). Overall, it appears that, as yet, there is uncertain benefit to be gained from screening younger, pre-menopausal women (Elwood, 1995a; Shapiro, 1994). There are, however, known benefits of screening mammography for women who are older than 64, as increasing age is currently the most predictive variable of the incidence of breast cancer (Chamberlain, 1984; Kelsey & Berkowitz, 1988; Love, 1995). Accordingly, women of 65 years of age and over could rightly argue that their risk of breast cancer is greater than that of women in their fifties (Sutton, 1997). Although screening is effective in women aged over 65 years the decision not to include them is that they are likely to have “other health problems which may make screening inappropriate” (Breast Cancer Screening Policy Advisory Group, 1998, p. 140). However, with studies demonstrating significant mortality savings from screening mammography in 65-74 year olds (Chen, Tabar, Fagerberg, & Duffy, 1995), these women may have some difficulty in making sense of their exclusion from a national screening mammography programme.

## **BENEFITS OF SCREENING MAMMOGRAPHY**

As mentioned above, the discussion about screening mammography is polarised. Austoker and Sharp (1991) reflect that breast screening is controversial, resulting in a polemical debate where:

[F]acts are intermingled with uncertainties, statistics with emotions.

There has been a tendency to obscure what could be a healthy debate under a veil of rhetoric, irrational prejudices and vested interests (p. 166).

On one hand it is argued that a decision to undergo screening mammography offers women the opportunity to identify whether they suffer from a disease for which there is no known cure (Roberts, 1989). However, it is also indisputable that, depending on the type of cancer, the earlier these treatment options are undertaken, the greater the saving in mortality will be (Moskowitz, 1992).

The purpose of a population-based screening mammography programme is to reduce mortality from breast cancer. This outcome is achieved through identifying a cancer, or malignant tumour, early in its stage of development which then increases the chance that treatment can be successfully applied. Early intervention is the most important benefit because it allows treatment to commence before tumours are large enough to become “clinically symptomatic” (Elwood et al., 1991, p. 259). When a cancer establishes itself, it tends to metastasise. In other words, the cells break away from the primary tumour and are transported by the lymphatic system throughout the body where they are catalysts in the development of further tumours (Forrest, 1991). Biopsy of the lymph nodes closest to the tumour (in the case of breast cancer, the brachial plexus nodes under the arm) can help to indicate the status of likely metastases. For example, a distinction is made between individuals considered to have a moderate risk of metastases (one to three brachial lymph nodes involved) or a high risk (four or more nodes involved) (Canellos, Hellman & Veronesi, 1982).

Of course, outcomes depend on the effectiveness of follow-up interventions (Harris, Lippman, Veronesi & Willett, 1992; Mason et al., 1994).

There are currently three ways in which a breast tumour can be identified; through breast self-examination, clinical examination by a health professional, and X-ray or mammography. However 70% of those detected by mammography are not able to be palpated (Elwood, 1995b). Thus, the propensity of a mammogram to detect small tumours far exceeds the first two methods of breast self-examination by women or clinical examination by health professionals, both of which depend on palpation to detect any noticeable lumps in the breast tissue.

Mammography was first suggested in 1956 by Gershon-Cohen and colleagues who suggested that X-rays might be useful in detecting small, presumably early, breast cancers (Roebuck, 1986). Since that time, equipment and techniques have developed and there have been multiple improvements in both. Thus, screening for breast cancer is “especially attractive in today’s environment... [in which] we have failed to reduce the population mortality from breast cancer in the course of this century” (Campbell & Royle, 1992, p. 1).

Any discussion about the potential risks and benefits must occur in recognition of the absolute outcomes of screening mammography programmes, as central to any debate is the principle that screening mammography is offered to women on the “ethical basis” that “the benefits outweigh the risks and costs” (Elwood et al., 1991, p. 260). Despite the mixed findings of the studies briefly mentioned above, a meta-analysis of six international randomised trials of screening mammography revealed that on average, a 28% mortality benefit has been consistently demonstrated (Elwood, 1995b). A recent longitudinal study to assess the impact of the population-based screening mammography programme in Britain recorded a 21.3% reduction in mortality from breast cancer among eligible

women between 1990 and 1998 (Blanks, Moss, McGahan, Quinn & Babb, 2000). Reduced mortality is a crucial benefit. As Roebuck (1986) contends, the probability that screening mammography does significantly decrease mortality is so high that it “could be considered unethical and unfair to deny women the opportunity to participate” (p. 224).

Women who attend screening programmes have lower mortality than those who choose not to attend (Frisell et al., 1991; Tabar et al., 1992). In European cities where the screening programmes were introduced in the 1970s, mortality from breast cancer has fallen compared to cities without screening mammography programmes (Day et al., 1986). Women’s lives have been extended because specific and treatable tumours have been detected through screening mammography. If women with breast cancer present early, the tumour can often be treated before it spreads or metastasises to other areas of the body. Smaller tumours mean that breast-conserving surgery such as lumpectomy (surgical removal of the tumour only) may be possible, and consequently more aggressive surgery such as mastectomy (surgical removal of the entire breast) may be avoided (Campbell & Royle, 1992). Also, the need for other therapies such as radiotherapy and chemotherapy may be reduced (Campbell & Royle, 1992). Moody et al. (1994) demonstrated that the first three years of the national population-based screening mammography programme in Britain resulted in “a greater awareness of the disease with earlier presentation, smaller tumours, and a higher local excision rate” (p. 259).

Even if it is only those women whose mammograms identify breast cancer who benefit from screening mammography, their potential gain is substantial. The evidence is that the survival rate in women who present with early-stage treatable breast cancers (Stage 1) far exceeds that of those who present with

advanced (Stage 4) tumours (Austoker, 1994a). Thus, screening mammography can prolong life, thereby offering benefit for women who may choose to undergo screening, which should not be disregarded (Austoker and Sharp, 1991). To help to place this benefit in perspective, a woman in her fifties has a 1 in 40 chance of dying of breast cancer and screening can reduce this risk to 1 in 55 (Campbell & Royle, 1992, p. 18).

Mammography is not ideal. Some cancers will be missed, and some women will undergo the unnecessary anxiety associated with abnormalities being detected on their mammograms that are benign. However, it is the best detection system available to address a significant disease of women. The advantages of the population-based screening programme in New Zealand eliminate many of the decisions that women may need to make about the provision of facilities if they attend private screening clinics. It is clear from the disadvantages outlined above that the risks of false negative and positive results are directly related to the skill of the technicians and the quality of the equipment. The importance of the Waikato and Otago and Southland pilot programmes was to establish that the government could provide an appropriate level of technical expertise and dedicated equipment so that women could be assured of a high quality service. Strict criteria were set in place in the *Interim National Quality Standards* (1996) which provide set guidelines for the practice of all personnel involved in the screening mammography programme. The standards are regularly reviewed by a multi-disciplinary team to ensure that the contents remain up-to-date. The programme thus “meets all the criteria of a valuable service which should be available to all eligible women in New Zealand as part of the general health service” (Elwood, 1995b, p. 29). There is currently no better available alternative that provides evidence of benefit.

## CONCLUSION

This chapter has detailed the contextual development of the breast screening programme in New Zealand, which arose as a result of an ideological shift from a firmly established welfare model to that of a market model of health care. As detailed, the health reform process of 1991 was the catalyst in the development of a population-based breast screening programme which resulted from a political emphasis on community-based primary health care interventions. As such interventions were established on a market model which emphasised efficiency; they were developed to target high-incidence diseases. Breast cancer, which is the major cause of death from cancer among New Zealand women aged over fifty years, presents difficulties in controlling a disease for which there is no known means of prevention or cure; a disease for which the only known risk factors of increasing age and gender cannot be influenced. The rising incidence of breast cancer among women in New Zealand, alongside the lack of an identified cure have meant that a screening mammography programme provides an effective means of intercepting the development of many cancerous breast tumours.

To encourage a “well” population who are free of symptoms to attend, the breast screening programme relies on effective communication processes to allow women to make informed decisions about participation. The role of effective communication in inviting women to participate in the screening programme is crucial to the success of the programme, and a number of international studies have explored various perspectives related to the process. It appears that women respond more positively to personal approaches such as face-to-face interaction or telephone conversations, rather than simply to letters of invitation. However, letters of invitation from the breast screening programmes were an equally or

more effective means of recruitment than letters from general practitioners in a number of studies.

Similarly, research related to the ongoing participation of women in the programme included reference to the influence of communication on the process of breast screening, which tends to be one associated with varying levels of pain and anxiety for some participants. However, there is a paucity of research that addresses the ways in which communication strategies may help to alleviate the negative association of pain and anxiety for participants. The deficit is most apparent when considering the needs of cultural minority groups, as the approach appears to be one of a uniform message for women, who are meant to respond appropriately.

There remains a polemic debate surrounding the provision of population-based screening mammography programmes, and it is apparent that as a medical procedure, screening mammography is not without some level of risk. Also, there are a number of benefits which participation provides for eligible women. However, although many medical and para-medical practitioners have entered into the debate about the level of value provided by the breast screening programme, there is less discussion about the need to ensure that this information is provided to women in the community in a way that they are able to make an informed decision about whether they will participate or not.

It also needs to be recognised that just as the health service exists in a political, social and economic environment, so too does the communication process occur within an institutional context. The following chapter will look at the implications of the environment in which communication occurs within the provision of the health service in New Zealand.

## **CHAPTER 3**

### **LITERATURE REVIEW**

The purpose of this chapter is to discuss the theoretical concepts that form a frame of reference for this thesis. The focus of the discussion is on the influences relevant to communication that occurs within a health care setting. A breast screening programme relies on communication at every stage of the process. Although the communication process takes place within a community programme, screening mammography is provided as a medical intervention staffed by health professionals; thus communication occurs within a clinical context. Accordingly the implications of communicating from a biomedical paradigm will be explored.

In this chapter, I first examine the ways in which health professionals communicate with target audiences from within the institutionalised biomedical model that dominated health communication in the past. Second, the increasing influence of less institutionalised primary interventions, such as models of health promotion, is introduced. The following discussion examines the significant influence of the changing socio-cultural context, for example the individualistic focus of self-responsibility, as a catalyst in the changing communication of health services. Finally, I consider the implications of communication when a screening programme is offered to a “well” population to detect cancer; a feared and often fatal condition.

## COMMUNICATION IN A HEALTH CARE CONTEXT

When interpreting any communication, we “use mediating devices on the basis of relevant cultural models” (Gesler, 1999, p. 14). The process of interpretation is determined by one’s social identity as a group member. Kleinman (1986), a medical anthropologist, argues that health care systems are experienced from within social, professional and community arenas. This experience helps to construct distinct forms of social reality for participants. The resulting communication is thus socially and culturally inscribed, distributed and interpreted within an institutional framework. As a legitimated institution, health care stands apart from the community as a basis for interaction. As Drew and Heritage (1992) explain:

A central theme in research on institutional interaction is that in contrast to the symmetrical relationships between speakers in ordinary conversation, institutional interactions are characteristically asymmetrical. Underlying this research is a widespread acceptance that ordinary conversation is premised on a standard of “equal participation” between speakers and that this standard is departed from in talk in institutional settings (p. 47).

The language of health professionals is distinguishable from that of “everyday” talk. Different texts associated with professions such as law or medicine tend to reflect an “order of discourse” (Fairclough, 1993, p. 135) or communication that is shaped by institutionally available repertoires of associated experiences and languages, as discussed further in Chapter 4. As a discourse that constitutes medical language is familiar to health professionals, it soon becomes commonplace to them. However, it is often wrongly taken for granted that others, who do not have the same everyday repertoire of experience, will understand it.

The familiar experiences that inhabit our everyday existence, or “lifeworld”, prescribe our interpretations and interactions, and thus orient us towards expected outcomes as Habermas (1988) explains, (promoting the concept of Husserl’s (1964) “lifeworld” which reflects the everyday, commonly experienced taken-for-granted social reality). Habermas (1988) defined this in terms of Schutz’s (1970) “common-sense knowledge” of our everyday existence as follows:

The foreknowledge handed down in everyday language is intersubjective; in it is constituted the world in which I can take the perspective of the other. This foreknowledge consists of prescriptions for what I can typically expect in interaction with others and in encounters with the natural environment. It also orients me to the relevance of behaviors and events. Thus the lifeworld is articulated in culturally determined and differentially distributed contexts of meaning that circumscribe the scope of intentionality within which social action can occur (p. 107).

The world of social reality that we inhabit has specific meaning and relevance for us. We interpret the world that we experience as the reality of our “common-sense” daily existence (Schutz, 1970, p. 272). Accordingly, Maynard (1991) explains, as individuals move from home and community to interact with health care systems they “develop and employ cognitive value orientations that embody personal and community meanings” (p. 476). As they interact with health professionals who “use impersonal, objective, and scientific frameworks, this results in frequent problems of communication” (Maynard, 1991, p. 476). When communication occurs within an institutional environment where people typically operate in specialised fields, the rhetoric of health professionals tends to develop a technical and specialised language that is not only socially constructed

(Fox, 1993), but also somewhat removed from that of the everyday life of the broader population.

## **The scientific rationality of biomedicine**

Individuals manage their daily affairs by using a background of understanding that reflects the social reality of the group and is thus reflected in the language used (Berger & Luckmann, 1966). However, the significant progress made in health care in the nineteenth century was firmly established on scientific principles. This emphasis resulted in a predominant “doctrine of specific aetiology” (Conrad & Schneider, 1990, p. 145) and the essence of the dominant western paradigm of the scientific “biomedical model” focused on the presence of disease and pathology was enduringly incorporated in health care. Nettleton (1995) explains that the biomedical model is based on five key assumptions: first, the doctrine of specific aetiology; second, the dualism of Descartes, or separation of the mind and body; third the belief that the body is like a machine composed of separate anatomic parts. Consequently, fourth, is the belief that the body is treated like a machine under “a technological imperative” (p. 3). Finally, the focus is on biological structures, or “biological reductionism” (p. 3) that neglects wider social factors.

The “absolute, universal truths” of biomedicine are firmly grounded in the principles of science and technology and professionalism. The development of X-ray, the discovery of penicillin and vaccines and improvement in living conditions in the twentieth century have been part of innumerable advances that have moved medical knowledge and practice forward at an accelerating rate (Conrad & Schneider, 1990). Consequently, many of the diseases that were feared, such as smallpox and tuberculosis, have virtually been eliminated,

although new challenges in the form of cancer and auto-immune diseases fill the void. Meantime, the world of biomedicine continues as one that is orderly and predictable, where an advent of disease-causing viruses or bacteria can be experimentally surveyed and outwardly corrected. As Kaufert (1988) explains: “Above all, it is a world which is knowable, but only by those who honour the rules of scientific method” (p. 331).

Advanced knowledge also underpins the analogous tenet of professionalism associated with biomedicine. Membership of a profession is not only defined by a level of complex skill, judgement and knowledge, but also by a fiduciary duty when the complexity of skill and knowledge which exists in treatment outcomes cannot be evaluated by the layperson (Freidson, 1994). The formalised roles of health professionals within the health service are solidified and entrenched in the bureaucracy developed to provide health care services, employing rules and procedures for its operation (Atkinson, 1995). Within this bureaucracy, Maseide (1991) argues that health professionals represent the authority of the knowledge and skills base which essentially legitimises the institution of health care because of the underlying need for expertise. Maseide (1991), a medical sociologist, asserts that the authority of health professionals is “necessary and constitutive” (p. 545) to provide appropriate health care. Thus, without the unequal distribution of expertise and authority, the result would be an inadequate health service.

A sociological perspective on health care was first introduced by Talcott Parsons, whose seminal work provided a structural-functional account of a number of institutional roles. Parsons (1951) examined the relationship between doctors and patients and maintained that there were four major components to the relationship. First, those who are unwell are exempted from the “normal social role” provided they are not “malingering” (p. 436). Second, they are exempted

from blame for their malady. Third, this exemption relies on patients having an “obligation to get well” (p. 437), and as social “actors”, being motivated to act in accordance with the defined roles in an orderly social system. Finally, they are obliged to seek the “technically competent” (p. 437) help of the doctor to get well. In other words, those who are unwell are socially vulnerable, and require the socially beneficent doctor to validate their current role. In turn, doctors are legitimised in their central and potent role.

Talcott Parsons (1951), however, ignored the power relationship, describing both doctor and patient as part of a social system, to which they were equally subject. According to Parsons (1951), the “physician [was] a technical expert qualified to help the patient in a situation institutionally defined as legitimate” (p. 439). The emphasis was purely on technical needs. However, as Foucault (1980) contends, knowledge and power are inseparable. Just as the power of the health professional is based on scientific knowledge; in turn, that relevant, specialised knowledge creates power, which “institutionalizes, professionalizes and rewards its pursuit” (Foucault, 1980, p. 93).

From a critical philosophical perspective, Foucault (1986) argues that the development of the scientific discourse and the associated rise of professionalism of institutional health care were firmly inaugurated on power. He maintains that the institutional formalisation of health care arose from “the organization of a politics of health” (p. 273), as the maintenance of health in the population became a political and economic problem. The organisation of health care was thus predicated on “an administrative system and the machinery of power” (p. 283). Governments established hospitals as formalised structures which Foucault (1973) argued could thus provide surveillance of the population under the “medical gaze” (p. 51). Foucault (1973) explains that these “intersecting gazes form a network

and exercise at every point in space, and at every moment in time, a constant, mobile, differentiated supervision” (p. 31) of the population. The disciplinary power or hegemony of government was thus exercised through its invisibility. “It is the fact of being constantly seen, of being able always to be seen, that maintains the disciplined individual in his subjection” (Foucault, 1977a, p. 187). Medical staff in hospitals thus provided “medico-administrative” surveillance in return for “social power” (Foucault, 1986, p. 283). The underlying hegemonic power of biomedicine was enduringly established.

However, the positivist epistemological assumption that bioscience is objective and universal has been challenged, and the communication processes of biomedicine have been central to this challenge. For example, an increasing ideological emphasis on communicating in the “lifeworld” as the connection between the biological and the social has increasingly recognised health care as a socially influenced institution (Auge & Herzlich, 1995). As Habermas (1990) contends, “Reaching understanding in the lifeworld requires a cultural tradition that ranges across the whole spectrum, not just the fruits of science and technology” (p. 18). Attention to individual agency through acknowledging the experiential knowledge of those who encounter ill-health and the need for informed consent are just two examples. In this tradition, Garfinkel (1967) put forward an ethnomethodological perspective which argues that when health professionals use the voice of scientific rationality, it creates another set of presuppositions than that of the “lifeworld” of their clients.

Garfinkel (1967) explains that the presuppositions underlying these voices “do not shade into each other, they produce logically incompatible sets of events” (p. 276). He continues:

[S]cientific rationalities can be employed only as ineffective ideals in the actions governed by the presuppositions of everyday life. The scientific rationalities are neither stable features nor sanctionable ideals of daily routines and any attempt to enforce conformity to them will magnify the senseless character of a person's behavioral environment and multiply the disorganised features of the system of interaction (p. 283).

That is, we must be able to bring to bear from our previous experience knowledge associated with the use of a specific dialogue. Lupton (1994b) contends that a health care environment can be strange and stressful:

As the "experts" in the medical encounter, doctors and other health professionals must advise patients how to behave in the encounter, direct their bodily movements in clinical examinations, prepare them for surgical procedures and advise them on behaviours relating to their health problems and treatment regimes, for as "non experts" the majority of lay people simply do not know what to expect or do (p. 118).

Over the past two decades, there have been a number of studies that have explored various perspectives on the interaction between the lifeworld and the institution of health, particularly medicine. As Turner (1985) claimed:

The weakness of the philosophy of medicine is that it too frequently and too glibly separates the question "what is disease?" from the question "what is the function of medical knowledge in the context of medical professionalisation?" (p. 208).

Extensive research has been undertaken on interpersonal communication in health by many, including sociologists, anthropologists and linguists. Although much of

it has focused on conversational analysis of doctor-client interaction (such as Cardello et al., 1995; Conlee et al., 1993; Fisher & Groce, 1990 and West, 1990), the outcomes are equally relevant to other health professionals (Joos & Hickam, 1990). However, much of this body of research tends to be limited to analysis of types of conversation. As a result, Wodak (1996) contends that many studies offer “only limited interpretation” (pp. 36-37) of health communication in a wider context. Fisher (1991) also argues that researchers have “overwhelmingly ... concentrated on the asymmetry between provider and patient, by an almost exclusive concern with medical topics to the nearly total exclusion of the social, biographical context of patients’ lives” (p. 158), which tends to limit the perspectives of analysis within dyadic interactions.

Atkinson (1995) further points out that there is “a rich diversity of social action and interaction that escapes the obsessive focus on doctor-patient dyads” (p. 33). Accordingly, there has been some research on the communication processes that health professionals use to discuss their patients among themselves within an institutional framework (such as Atkinson, 1994). An earlier narrative analysis of the presentation of medical case studies by Anspach (1988) illustrated the propensity of health professionals to discuss their clients in impersonal, scientific terms of biomedical “processes” that exist quite independently of “people” (p. 372). For example, Anspach (1988) argues that the advances in diagnostic technology further separate patients from health professionals, who attend more closely to the process of using and interpreting the diagnostic information, than to the person at the end of the process. As Smith (1993) contends, although tests are run and examinations carried out, these “stand alone, separated linguistically from any act by any human being. We do not learn who examined, tested, or decided” (p. 128).

Similarly, Frankel (1995) also argues that health professionals are so focused on the process of solving health problems that they fail to address the needs of clients in any other context. As a result, they may also overlook indications of a lack of understanding from those clients, without a domain of shared meaning as “the concepts, terms and logic of medicine as a bioscience, represent a technical and specialised language clearly and markedly distinguished from the everyday language of the lifeworld” (Mishler, 1984, p. 171). For example, Kavanagh and Broom (1997) demonstrated that although women in their study wanted to be involved in decision making about their cervical abnormalities, they were not only confused about the information but also felt unable to question their doctors about anything that was unclear in the explanations they received.

However, that is not to say that health professionals never talk in the voice of the “lifeworld” (Silverman, 1987). It is simply that they tend to adopt a discourse using terminology that excludes lay people whenever it is used without clarification. In the words of Joos and Hickam (1990):

[A] fundamental purpose of communication in the health care setting is to transmit information. However the literature shows that a large proportion of patients do not understand and are unable to recall what they are told (p. 220).

Despite an increasing emphasis on the importance of involving individuals in planning of their own health care and treatment (Shackley & Ryan, 1995), in practice, the tendency is towards scant input from anyone other than health professionals in their ascendant and regulating role (Cegala, Marinelli & Post, 2000; Entwistle, Sheldon, Sowden & Watt, 1998; Fox, 1993; Gesler, 1999; Grace, 1991; Gubrium, 1980).

The imbalance of knowledge and power between clients and health professionals is a common theme which has been identified. For example, Mishler (1984), borrowing the concept of “voice” from Silverman and Torode (1980) carried out a narrative analysis of multiple interactions between doctor and patient, illustrating how the decontextualised “voice of medicine” ignored the biographical narrative of the “lifeworld” of patients and thus served to lessen the effectiveness of medical interaction. Medical sociologists and critical communication theorists contend that health practitioners appear to frequently restrict the flow of information (Taylor, 1988; Waitzkin, 1985; Wodak, 1997), and that medical questions, by their placement in the discussion, by their form and their selective focus of attention, control the content and direction of communication (Waitzkin, 1989; West, 1990). Communication theorists argue that health professionals “prefer to communicate to patients rather than with patients” (Kreps & Kunimoto, 1994, p. 74, emphasis in original). Wodak (1996) contends that unequal power relations are reinforced by a language that is “impenetrable and intimidating to patients” (p. 2). The outcome is described by Wodak (1996) as “disorders of discourse” which

result from gaps between distinct and insufficiently coincident cognitive worlds: the gulfs that separate insiders from outsiders, members of institutions from clients of those institutions, and élites from the normal citizen uninitiated in the arcana of bureaucratic language and life (p. 2).

The gaps arise because the relevance and appropriateness of information are defined through what health professionals choose to attend to and ask about (Anspach, 1988). It has thus been argued from a Foucauldian perspective that expert domination is the result of a medical discourse which is encapsulated

within a biomedical model (Armstrong, 1984). Psychologists, Leventhal and Cameron (1987), describe the roles in the biomedical perspective:

In this framework the patient is likely to be viewed as the recipient and performer of regimens that are to be accepted and obeyed.

Non-compliance is often seen as the direct result of personality aberrations of the patient, with little or no emphasis given to the patient's understanding of the treatment setting (p. 119).

The outcomes that often result are feelings of confusion, anger and frustration for participants, because people feel “they [are] not being listened to” (Jones, 1988, p. 2) as “worlds of knowledge and interests collide with one another, and those who possess linguistic as well as institutional power invariably prevail” (Wodak, 1996, p. 2). The sense of impotence that may result is eloquently described by DiGiacomo (1987) who related her feelings about a proposed treatment for cancer as

being bullied into accepting more treatment with the most effective of threats, that I had been made to submit, to comply, through the strategic manipulation of information (p. 325).

She described a laborious “fight for every piece of information” (p. 323) in her quest to be recognised by health professionals as a relevant participant in decisions regarding her treatment.

It has been argued from a critical perspective by Taussig (1980), that health professionals often fail to take account of the search for explanation and meaning that typically accompanies even the possibility of ill-health. Consequently, questions of “why me?” are disregarded. However, within interpretive research, the native-view paradigm of Geertz (1983) affirms that those questions are an essential component of how individuals conceptualise and cope with a newly

imposed reality. How people make decisions about responding to a situation that may result in negative information is shaped by the ideology of illness produced in the social context.

Health care systems are experienced within social, professional and community arenas that help construct distinct forms of social reality. That is, they organise particular sub-systems of socially legitimated beliefs, expectations, roles, relationships, and transaction settings which create a socially legitimated context of sickness and care, which I shall refer to as “clinical realities” (Kleinman, 1986, p. 31).

From a sociological perspective, any health communication initiative must recognise and substantially incorporate the reality of the lifeworld rather than the clinical. As Turner (1985) contends, ill health is a social incident. He argues that although there may be highly variable individual manifestations of ill health, they will be, in part, culturally imposed. Therefore, an appropriate response from health professionals not only depends on knowledge of cultural understandings about health and ill health (Turner, 1985), but also needs to incorporate a willingness to “hear” the person’s own interpretive view (Armstrong, 1984, p. 743). Although Baruch (1981) contends that people consistently defer to the opinions of health professionals, alternatively, Gabe and Calnan (1989) and Calnan and Williams (1992) demonstrated the willingness of both men and women to participate in decisions about their health care treatment. However, Posner (1991) argues that the opportunity to do so is infrequent, which means that for many women, “their health status is defined for them in a way that is disempowering and unhealthy” (p. 186).

Conversely, as Fisher (1991) convincingly demonstrated, when health professionals are willing to provide a non-authoritarian environment which allows people to express themselves outside the constraints of a biomedical model, understanding and benefits are enhanced for both. As Greenfield, Kaplan, Ware, Yano and Frank (1988) found, greater patient participation and sharing of information between clients and health professionals are associated with better outcomes. They suggest that their intervention to increase collaboration and client participation might have improved outcomes by enhancing patients' feelings of mastery and control. As Mishler (1984) pointed out, the normative character of interactions in health settings and a research bias anchored in "the voice of medicine" create an unnecessary prejudice. He contends that in order to break free of the bias of a consistently scientific, biomedical interpretation of health, to open up new perspectives and help to understand how to change a pattern of misunderstanding, the focus of health professionals must be on the cogency of the voice of the patient's "lifeworld".

## **SOCIAL INFLUENCES ON HEALTH COMMUNICATION: HEALTHISM AND INDIVIDUALISM**

Health communication is not encapsulated within an institutional context; it is also inevitably influenced by the socio-cultural environment in which it occurs. Over the past three decades, in tandem with the changing social, political and cultural context discussed in Chapter 2, an emphasis on primary health care interventions has evolved. Neubauer (1992) contends that as well as addressing issues of the "cost of sickness" (p. 6), this emphasis has also been reinforced because of a change in disease patterns and the advent of degenerative diseases throughout the western world. From the beginning of the twentieth century, the

principal sources of mortality have been shifting from infectious to chronic disorders. Starr (1982) explains that as cures are found for the epidemics of smallpox, tuberculosis and poliomyelitis, societies focus more on diseases such as cancer and heart disease. At the same time, cumulative research has linked individual behaviour to risk factors in the development of chronic disease (McLeroy, Gottlieb & Burdine, 1987). The outcome has been the

development of a strong, officially-sponsored ideological perspective which emphasises the personal responsibility of the individual citizen in the maintenance of their own health and the avoidance of chronic disease (Davison, Frankel & Smith, 1992, p. 675).

Consequently, critical theorists argue that ideas about what defines “health” have undergone a gradual, though distinct, transition. For example, Crawford (1980) revealed the emergence of “health” as a significant value which he defined as the “new health consciousness”, labeled “healthism” (p. 365). His argument is that the dominance of “healthism” contains moral imperatives which demand certain behaviours. For example, a moral imperative of self-determination can be seen in the stance of one of the most forthright biomedical theorists, Knowles (1990), who argues for a rigidly controlled lifestyle, because “over 99% of us are born healthy and suffer premature death and disability only as a result of personal misbehavior” (p. 386). He continues that “the individual has the power - indeed the moral responsibility - to maintain his own health by the observance of simple prudent rules of health.” (p. 386).

Under the prevailing discourse of “healthism”, Crawford (1980) argues that the pursuit of good health has become an end in itself rather than a means to an end. The maintenance of good health is the responsibility of the individual.

Thus, any subsequent right to health care becomes mediated by the duty to be “healthy”. As Skrabanek (1994) contends, “To be healthy is politically correct and the duty of a responsible citizen” (p. 17). Good health is represented as a personal, rational choice in which “categories of health and illness have become vehicles for the self-production and exercise of subjectivities endowed with the faculties of choice and will” (Greco, 1993, p. 357). Health is defined as an individual attribute that can be controlled through the way in which individuals behave or live. As it is “considered ‘good’ to be healthy, and ‘bad’ to be ill” (Kamm, 2000, p. 251), everyone has a duty to remain healthy. Greco (1993) explains:

If the regulation of life style, the modification of risky behaviour and the transformation of unhealthy attitudes prove impossible through sheer strength of will, this constitutes, at least in part, a “failure of the self to take care of itself” - a form of irrationality, or simply a lack of “skilfulness”. The mastery of the self is thus a prerequisite for health; the lack of self-mastery, accordingly, is a “disease” prior to the actual physical complaint (p. 361).

Good health, or at least the effort to maintain good health, is now perceived as a visible sign of attendance at the gym, daily exercise, low fat food in the supermarket trolley and eight glasses of water a day. As Lupton (1995) argues, good health is now perceptible through the “lean, taut, exercising body” (p. 71). The communication of self-responsibility appears to begin at an early age, as exercise and healthy eating dominate definitions of health as early as primary school (Kirk & Colquhoun, 1989). The logical outcome, according to Petersen and Lupton (1996), is that citizenship “emphasises both the rights and the obligations of individuals to take up and conform to the imperatives of ‘expert’

public health knowledge” (p. 61). In a capitalist western democracy, health becomes a capital that has value because incapacity prevents work, thus “health” becomes relevant as a variable in the rationale of economic enterprise (Pierret, 1993). Fit, healthy individuals are able to produce output, pay taxes and thus have value as productive, useful citizens. Pollock (1993) contends that this ideology may explain why it appears that people are more willing to assume some responsibility for good health when they are well, and take a different attitude when they suffer from illness. If illness is a result of failing to take due care, then it follows that it is irresponsible, thus socially unacceptable, to become ill.

It would be difficult to argue against the value of encouraging individuals towards the benefits of lifestyles that incorporate exercise and healthy eating. However, as Glassner (1989) points out, there are unfortunate outcomes: “The physique has become a cardinal sign of the self. ... The information a person gives off by being fit is meant to be both economically and globally favorable for the self” (p. 184). Nevertheless, as Greco (1993) contends, such goals are more achievable for some, both genetically and in terms of lifestyle imposed by economic necessity. Greco (1993) points out that good health is not always a choice:

A health that can be “chosen”, however, represents a somewhat different value than a health one simply enjoys or misses. It testifies to more than just a physical capacity, it is the visible sign of initiative, adaptability, balance and strength of will. In this sense physical health has become to represent, for the neo-liberal individual who has “chosen” it, an “objective” witness to his or her suitability to function as a free and rational agent (pp. 369-70).

Wallack, Dorfman, Jernigan and Themba (1993) argue that a focus on individual responsibility for health may well obscure social deficiencies, such as poor housing and access to adequate resources, which further influence the choice of risky lifestyles. An emphasis on volitional health behaviour assumes that people will always be free to act in their best interest and only assume risks knowingly and willingly. However, as Dougherty (1995) asks, how can the social and physical conditions that are beyond individual control be denied?

In a socio-cultural environment where the rights and needs of “individuals” are emphasised (Tesh, 1988), the new rhetoric of “healthism” prevails (Crawford, 1980; Lupton, 1994b), with the implications discussed above, and health is promoted as being within the control of all regardless of living conditions. The end result, according to Fitzgerald (1994), is that when “illness and culpability are so intertwined” (p. 197), illness may easily become a form of deviance. Being responsible for one’s “health” by acknowledging that there are certain behaviours that do impact on health, such as smoking cigarettes, is likely to have positive outcomes. However, Turner (1985) argues that this may not be the case if any potential illness results in a “devaluation of the self [as] the maladies of the body become the stigmatisation of the person” (p. 237). Goodman and Goodman (1986) explain:

Moralizing health concerns by treating them as foci of discipline and surrounding them with prudential counsels generates a context of expectations in which any tragic outcome may seem incomprehensible unless it can be ascribed to infraction of some hygienic rule (p. 35).

Nevertheless, it has been argued from a sociological perspective that it is essential any notion of individual responsibility is balanced with biological limits

which are genetically (Angell, 1985), and often socially and politically (Crawford, 1977) imposed. Thus, if good health is a personal, rational choice, ill health will be synonymous with guilt (Brownell, 1991), or even worse, with a “personal failing attributable to defects of character or will” (DiGiacomo, 1992, p. 121). As Marantz (1990) appeals, “Why isn’t it possible to just get sick without it also being your fault?” (p. 1186).

## **COMMUNICATING HEALTH CARE IN THE COMMUNITY**

According to Boot (1990), one of the underlying tenets of the shift towards individual responsibility for health appears to be that providing people with appropriate information will encourage lifestyle changes to promote good health and thus provide efficiency gains. As Russell (1986) contends from a health promotion perspective, the “general proposition [is] that lifestyles that fit the accepted norms of healthy living are indeed associated with better health and lower death rates” (p. 80). Healthy people do not require “sickness” interventions (Davison et al., 1992). Certainly, the models of health care before the late seventies were not focused on any of these activities. For example, Parsons’ (1951) seminal work on the sociology of the “sick role” of patients that required the validation of expert physicians, did not incorporate any mention of health promotion.

Communication about health protection, maintenance and promotion appears to be a concept that arrived in the late 1970s when “wellness” was socially constructed as an ideal, as discussed above. Nevertheless, just as Parsons’ model incorporated the obligatory need for the “desire” to be well, the new individualised health promotion model equally requires the “willingness” to behave in a manner that will promote health. However, the latter approach relies

heavily on the communication of information to “empower” various publics in a community setting. As Wilson and Olds, (1991) relate, communication is designed to encourage individuals to adopt responsibility for their own health, and to take actions that will promote good health.

Such communication interventions are well suited to the current social environment with the increasing significance of preventing illness and disease through working with communities to promote behaviour that is conducive to “health”. Lupton (1995) explains that the major focus is on fostering health, through prevention of illness rather than treatment. Prevention strategies are designed to “market” appropriate behaviour to “communities” to encourage the development of “healthy” environments (Lupton, 1995, p. 51).

To encourage a response from publics, health communication is transmitted through various channels. For example, the media have been used to inform members of the public about health hazards, motivate them to reduce health risks, encourage them to adopt healthier life-styles, and persuade them to assume more responsibility for maintaining their own health (Scherer & Juanillo, 1992). Some forms of public health communication are strongly reinforced by law, such as the wearing of seat belts or driving under the influence of alcohol. Others, such as anti-smoking campaigns, have no legal constraints apart from age control at point of sale or the allocation of certain “no smoking” areas in nominated public and work places. Alternatively, some campaigns promote voluntary behaviour, such as blood pressure checks, cholesterol testing or screening for cervical and breast cancer. Individuals may or may not decide to participate. Overall, health communication is primarily designed to encourage behavioural changes that are believed to be conducive to health.

## **Health promotion**

### ***Social models of health promotion***

Many descriptive models to promote health in a primary, or community context have been proposed during the past few decades (Burrows, Nettleton & Bunton, 1995). Promoting the health of populations, however, is not new; it has been a principle of programmes that have addressed issues of disease, poverty and hygiene since the early 1800s (Terris, 1992). Emphasis has been on improving health by addressing fundamental causes and conditions. The approach incorporates that of a social or systems model. Within this “macro-social” framework, over the past three decades, there has been an increasing emphasis on encouraging primary intervention at community and national level to promote health in the population. Policy is designed to foster the well being of communities through social interventions that will provide the environment for health-promoting actions (Glanz, Lewis & Rimer, 1990a).

International discussion on the means to achieve this end has resulted in significant documents such as the *Ottawa Charter* (1986) and *Alma Ata* (1978) of the World Health Organisation (WHO). The *Declaration of the Alma Ata* (1978) was a WHO initiative designed to provide “a historic collective expression of the political will of governments to improve the health of their peoples in the spirit of social equality in health matters” (Mahler, 1988, p. 75). Within the declaration, health was considered a fundamental human right and an international social goal. Primary health care was defined as an integral function of every country’s health system, a function essential to the social and economic development of every community. The promotion of health and prevention and treatment of illness were stressed as a global strategy, which was adopted by the World Health Assembly in 1981.

The *Ottawa Charter* (1986) which followed, provided a comprehensive list of prerequisites for health. These include “food and education; shelter; a stable ecosystem and sustainable resources; peace; equity and justice” (Tones & Tilford, 1994, p. 9). All of the above depend on the coordinated action of governments, social and economic sectors, industry and the media, as well as the health sector (Terris, 1992). Clearly, there is not only a need for community, but also for government intervention, to ensure that environmental requirements are conducive to achieving “health”:

One key aim of health promotion is to “engineer” those various environmental factors in order to maximize opportunities for health and the avoidance of disease and disability. In so doing, “healthy” decision making is potentiated: the healthy choice becomes the easy choice (Tones & Tilford, 1994, p. 7).

Although the *Ottawa Charter* involves population-based strategies, there is also an emphasis on providing education and enhancing possibilities for individual options so that people are able to choose options that are conducive to their health (Terris, 1992). One relevant example of an application of this model of health promotion is that undertaken to address escalating levels of breast cancer in Israel. The role of environmental contaminants was linked to the incidence of breast cancer in Israeli women. Subsequently, following a ban on organochlorine pesticides between 1976 and 1986, significant reductions in the contamination of this chemical in both cows’ milk and in the breast milk of lactating women were noted. Contemporaneously, Israeli women experienced an 8% saving in mortality rates from breast cancer (Westin & Richter, 1990).

## ***Individual models of health promotion***

However, health promotion also has a marked interest in cognitive appraisal and information processing paradigms. Although it can be viewed in social, cultural, political, institutional or economic terms, health promotion can also be regarded from an individual perspective. Behaviour is implicated as the cause of many diseases that have resulted from lifestyles (Egger, Spark & Lawson, 1990). Such a perspective is reflected in models of health promotion that have been developed that primarily focus on the “micro-individual” approach, or the development and change of individual lifestyles to enhance health. As Glanz et al. (1990a) explain:

The increased interest in behavioral determinants of health and disease has drawn attention to the importance of health behavior and change and spawned numerous training programs and public and commercial programs (p. 5).

Individual health is associated with lifestyle and behaviour. As Raeburn and Beaglehole (1989) explain, the more recent individualistic health promotion approaches developed from the disciplines of health education and disease prevention. For example, one early and enduring health promotion model, the Health Belief Model, was developed “in an attempt to understand the failure of people to accept disease preventives or screening tests for early detection of disease” (Boddy, 1992, p. 173). The foundation of individual health promotion models is a hypothesis that people need a “reasonable level of health motivation and knowledge” (p. 173) to participate in health promotion. For example, the Health Belief Model hypothesises that health-related action will depend on the simultaneous occurrence of four factors: sufficient motivation, threat or belief that one is vulnerable to a health problem, belief that an intervention would prove

beneficial and the restriction of perceived barriers (Rosenstock, 1974). According to the Health Belief Model, health behaviour is directed, in an almost rational way, by a set of health beliefs (Rosenstock, 1974). Thus, if a woman believes that she is susceptible to breast cancer, which may be symptomless, and that she will receive benefit from mammography, then she will participate in the programme. Her participation will depend on the presence of perceived benefits to act as cues to action, and the absence of barriers such as cost. However, subsequent variability in results from a number of studies using the model has resulted in adaptations, such as the addition of “self-efficacy” as an explanatory variable (Rosenstock, Strecher & Becker, 1988).

Communication of information is integral to health promotion. As Wallack (1990) remarks:

[I]mplicit in much health education reasoning is that if we can only get the right message to the right person in the right way at the right time, then the frequency of risky behavior will surely diminish (p. 370).

Providing information is important for its contribution to the desired behavioural outcome (Tones & Tilford, 1994). It has been assiduously maintained that providing information to women about screening mammography is part of a “health promotion” role that will encourage a proactive response. For example, Adams (1991), Champion (1994), Fallowfield et al. (1990), McBride et al. (1993), Reynolds et al. (1990) and Rutledge, Hartmann, Kinman and Winfield (1988) have used the Health Belief Model as a framework to discuss participation in screening mammography. This model, broadly based on health promotion tenets of perception, process and outcome, has been frequently used to ascertain why individuals participate, or not, in other health-related activities such as breast

self-examination (Kuhns-Hastings, Brakey & Marshall, 1993; Salazar et al., 1994) and cervical screening (McAvoy & Raza, 1991).

## **Prevention of disease**

There are a number of different models of health promotion founded on a tenet of health representing the absence of disease, which often comprise “the overlapping spheres of health education, prevention, and health protection” (Naidoo & Wills, 1998, p. 59). Accordingly, programmes designed to prevent disease are integral to the process. Such interventions are founded on the tenet of a “wellness” model with a focus on optimal levels of well being:

The overall goal of health promotion may be summed up as the balanced enhancement of physical, mental, and social facets of positive health, coupled with the prevention of physical, mental and social ill-health (Downie, Fyfe & Tannahill, 1990, p. 25).

Tannahill (1997) further explains that disease prevention interventions have been a “cornerstone of most strategies for health promotion to date” (p. 169), where activities are directed towards risk factors that are associated with disease. Downie et al. (1990) explain that prevention programmes have four foci: prevention of the onset of a disease process through risk reduction; prevention of the progression of a disease; prevention of avoidable complications of a disease; and prevention of recurrence. For example, such activities could include reducing obesity for heart disease, using condoms to avoid sexually transmitted disease or applying sunscreen to minimise the risk of skin cancer. Screening mammography may also be promoted by some as a “preventive service” offered at national level (for example, Tannahill, 1997). In accordance with the tenets of

health promotion, the underlying principle is encouraging information-based behaviour change. Tones and Tilford (1994) put it this way:

If people are provided with health information, they will act on the knowledge gained and behave “rationally”. In this case rational action is assumed to involve the adoption of medically approved preventive behaviours. ... The provision of knowledge is not important for its own sake but only for its contribution to the approved behavioural outcome (p. 16).

Accordingly, the underlying assumption is that women will assimilate the information that an intervention provides. The underlying message of prevention campaigns is that action taken today will prevent occurrence of future disease. Preventive innovations involve taking an action in the present to lower the probability of some future consequence that may not occur (Rogers, 1994). Accordingly, they have a tendency to create some ambivalence about the need for current action. Preventive actions, for example having an immunisation, require action at a time when the impetus is not always a strong variable. Therefore, Rogers (1994) contends that the inconvenience, cost or discomfort of having a treatment that has no immediate effect may outweigh the impetus to action at the time.

In meeting the challenge of empowering people to make informed decisions about participation in proactive health behaviours, some limitations have been observed in health promotion interventions. For example, Grace (1989, 1991) has argued from a critical stance that health promotion is merely the “expert” model of biomedicine sustained in another guise. Grace (1991) further contends that health promotion involves “ ‘experts’ developing, planning, implementing and evaluating” most community programmes on the basis of “their own value

systems” (p. 331). Raeburn (1994) believes that if health communication is to succeed, rather than being controlled by “experts”, it should be directed by the community. However, Grace (1989) maintains that, despite the claims of health professionals that their activities are focused on “empowering” communities in promoting health, the power remains firmly in “expert” hands, thus the goal is adaptation to the prescribed activity. As Tones and Tilford (1994) state:

A rapid scan of the patient education literature conveys an impression of effort directed towards the achievement of compliance. Compliance describes the extent to which people’s health behaviours are in tune with the advice of health professionals (p. 161).

Also, Duff (1994) points out that a number of lifestyle choices are constrained by ethnicity, class and access to resources. As discussed above, there are practical and ideological limitations on individual responses that cannot be ignored; simply providing information and education is not enough to instigate changes (Miller, Kitzinger, Williams & Beharrell, 1998).

It has further been argued that the positive focus on health can also make ill-health or disability a “negative” value (Grace, 1994; Nettleton & Bunton, 1995). Thus health promotion practice is seen as supporting the individualistic victim-blaming stance discussed above. Browning, Kendig and Teshuva (1994) provide a relevant example, pointing out how a focus on “health” often discriminates against older people who may demonstrate a high level of chronic illness. If there is an underlying assumption that given the right information, people will make healthy behaviour choices, should individuals “choose” a certain lifestyle, they are thus “responsible” for the ill health that may result. Health promotion has also been criticised by Kelly & Charlton (1995) for “medicalising”

people's lives far more than biomedicine did – by intruding on communities to “empower” them even when those communities had never even thought of it being necessary. Therefore, what is rational and healthy is informed by biomedicine (Nettleton, 1995). Thus, despite rejection of biomedicine, health promotion interventions still remain vested in scientific rationalities. Similarly, it has been argued that health promotion maintains Foucault's “surveillance” of populations which creates not only healthy lifestyles (Armstrong, 1993), “but also healthy minds and healthy subjectivities” (Nettleton & Bunton, 1995, p. 47). Finally, Chapman (1996) contends that health promotion can also be “hijacked” into supporting the marketing of remedies that may prove only to be effective as a source of revenue rather than as effective treatment.

## **Detection of disease**

A further approach within the literature that incorporates both a cognitive and affective influence is that of disease detection. Disease detection programmes provide information about the presence or absence of a condition or disease, and contrast with those of health promotion and disease prevention. For example, health promotion strategies can prevent unwanted outcomes, such as applying sunscreen to lower the risk of skin cancer (Rothman, Salovey, Antone, Keough & Martin, 1993b). Prevention of disease, or even potential complications, can also avert an unwanted outcome (Downie et al., 1990). However, Maddux (1993) argues that disease detection programmes differ in that they have the potential to influence health only individuals have access to treatment for the condition (Maddux, 1993). Thus, the underlying assumption is one of the availability of effective treatment. On the basis that there is no cure for breast cancer, screening mammography is occasionally referred to as a disease detection programme.

Also, in contrast to health promotion, a disease detection approach essentially incorporates recognition of the levels of affect or emotion (Millar & Millar, 1996); in this case anxiety, often associated with screening programmes. For example, medical sociologists and physicians such as Daly (1989) and Stewart-Brown and Farmer (1997) suggest that participation in any screening programme has potentially negative outcomes in terms of increased anxiety. As McDonald, Daly, Jelinek, Panetta and Gutman (1996) found, even those who participate in a screening programme and receive normal test results and reassurance from health professionals may still experience high levels of anxiety. They assert that health professionals may fail to reassure those they describe as “the worried well” (p. 329), whose anxiety may have resulted from simply participating in a routine examination.

The variance between disease detection and health promotion interventions has also been illustrated at a cognitive level. For example, Boddy (1992) explains that health promotion and disease prevention activities to promote health rely on cognitive factors as the primary elements of behaviour, including “the importance of health to the individual, perceived control, self efficacy, definition of health held and perceived health status” (p. 175). Therefore, Downie et al. (1990) state that as feelings, beliefs, and values are all important determinants of health-related behaviour, it is therefore a central tenet of health promotion to consider what attitudes are and how they can be changed, so that they can be employed in health promotion initiatives.

However, Millar and Millar (1996) illustrated the influence of anxiety on cognitive functioning when people were confronted with the possibility of detecting the presence of a disease over which they had no control. They found that the participants in their study consistently demonstrated “defensive

avoidance” (p. 411) towards threatening information. They noted “significant differences in response times” (p. 410) towards disease detection and health promotion information, and suggested that this finding may reflect differences in how accessible attitudes are in memory. Accordingly, they asserted that attitudes are unlikely to be accurate predictors of disease detection behaviours when they cannot be quickly accessed. Cognitive psychologists, Fazio, Sanbonmatsu, Powell and Kardes (1986) found that attitudes that take a long time to access from memory play a lesser role in motivation of behaviour, thus they tend to be poor predictors of behavioural outcomes. According to Roskos-Ewoldsen and Fazio (1992), because individuals typically try to “maximize positive outcomes and minimize negative ones” (p. 210), attitudes that are likely to result in positive outcomes are typically more readily accessible than those associated with negative evaluation. For example, Meyerowitz and Chaiken (1987) found that the reluctance to address anxiety-provoking threats to health was prevalent in their study of the influence of message framing on women’s attitudes towards breast self-examination.

As cognitive processing is also influenced by emotional arousal, Perry et al. (1990) argue that it is difficult to process information when emotions are heightened. Accordingly, when emotionally aroused, individuals may find it difficult to attend to communication from health professionals. They contend that the reason for the difficulty is that anxiety will trigger defensive behaviour which in turn serves to lower the anxiety. The outcome of not thinking about the feared process or outcome should thus reduce anxiety (Croyle & Sande, 1988). In this way, individuals may resist information that may require them to address anxiety-provoking threats to health. For example, Millar and Millar (1993) found that merely the threat of detecting something wrong was enough to generate a strong

emotional reaction. A further study also indicated that even just the thought of performing a disease-detection behaviour was enough to produce a negative mood change in respondents (Millar, 1995). They concluded that motivation to avoid the negative feelings may result in lower levels of compliance with disease-detection behaviours.

## **Social Marketing**

Any activity which promotes health-related learning that produces changes in understanding is often referred to as health education (Tones, 1986). The health communication interventions discussed above rely on the process of providing information to an audience, information that is integral to decision making about appropriate healthy behaviours. An increasingly popular method of disseminating this information is through social marketing, where marketing techniques are used to design a communication strategy and implement a programme. Wallack et al. (1993) explain:

Social marketing assumes that power over health status evolves from gaining greater control over individual health behaviors. It provides people with accurate information so they can better participate in improving their own health (p. 24).

Congruent with the move towards a more individualistic focus in health care where information should result in the desired action, the design and implementation of interventions have been increasingly predicated on theories of “consumer behavior” or “social marketing” (Novelli, 1990, p. 343). Wallack et al. (1993) contend that the primary goal is to “reduce the psychological, social and practical distance between the consumer and the behavior” (p. 21). The authors further state that the underlying premise of social marketing as a health

communication strategy is to make it as attractive as possible for individuals to comply with health communication and demonstrate the effects of not following the desired course of action.

Social marketing integrates “the ideal marketing mix of the right product, price, promotion, and place” (Wallack et al., 1993, p. 22). However, rather than selling tangible goods, social marketing campaigns more frequently focus on “sell[ing] a service, idea or attitude” (Pollay, 1989, p. 187). The desired outcome is that individuals will be willing to participate in whatever is being promoted, perhaps at some financial or personal cost, to obtain some benefit (Wallack, 1990).

The usual definition of social marketing is the communication of persuasive information to serve the public interest, which can imply that the social marketer is acting in the interest of the target group. Although the “four P’s” of business marketing apply,<sup>4</sup> Kotler (1975) points out that there are three critical differences between social and business marketing. First, social marketers try to change attitudes or behaviour, rather than meeting needs and wants of consumers. Second, there is usually no profit motive. Third, business marketers promote products and services, whereas social marketers market ideas. Accordingly, Dignan et al. (1991) argue that it is important to carry out a thorough analysis of the community prior to any social marketing intervention, so that the target audience is well defined. Also, the marketing of health promotion and disease prevention is nearly always correlated with other interventions that encourage behaviour change (Novelli, 1990).

However, from a critical perspective, there is also the influence of the organisation promoting the product or service to consider. A social marketing

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<sup>4</sup> Product, price, promotion and place.

orientation from a health organisational perspective has been described by Kotler and Clarke (1987) as one that

holds that the main task of the organization is to determine the needs, wants and interests of target markets and to adapt the organization to delivering satisfactions that preserve and enhance the consumer's and society's well-being (p. 32).

Thus, the organisation plays a direct role in deciding what will “enhance” the well-being of the target audience. This outcome may not always be for the benefit of the audience. For example, Sheaff (1991), in his discussion of marketing the National Health Service in Britain, explained how social marketing can be used as damage control, for example in dealing with outcomes of cost containment on the quality of services. He considers that this can be achieved through defining the “distinction between needs and wishes” (p. 39), and continues that social marketing requires access to the media, as “it is critical to try to set the terms of the debate” (p. 133). Successfully framing an issue is likely to construct the terms of discussion. However, the principle of benefit appears strongly related to the organisation in this instance.

Furthermore, as with health promotion, social marketing has also been criticised for reducing health to individual risk factors, thereby emphasising risk factors as under the control of the individual when they are a result of complex environmental factors (Wallack, 1990). Thus, it has been suggested by Browning et al. (1994) that any campaign that applies a reductionist approach will not only be ineffective, but also victimise individuals who are not able to control environmental factors.

## COMMUNICATING CANCER

As discussed above, from a critical perspective it is difficult to dissociate disease from the social context of human agency, cultural interpretation and moral evaluation (Turner, 1985). Radley and Billig (1996) argue that we all construct our health status, including ill health, as part of our social identity. Such events are part of our social reality; therefore, according to Prior and Bloor (1993), the physical processes that occur have meaning that is collectively influenced by our culture. As they are members of a social group, what individuals communicate about both health and illness will reflect social constructs. For example, Auge and Herzlich (1995) point out that in the past communities suffered epidemics and phthisis (tuberculosis or “consumption”). Ill health was a community affair. However, now the plagues and epidemics of the past have been replaced in the west by cardiovascular disease and cancer. We are now ill alone.

Accordingly, Radley (1993) suggests that the “healthy” aspects of a person’s life are reconstructed in relation to the domain of illness they have come to symbolise (p. 113). Consequently, he suggests that metaphors are a powerful means not only of reflecting, but also socially transforming, individual identities as people cope with illness, such as cancer. Lakoff and Johnson (1980) explain in their seminal work on the importance of metaphor:

Since much of our social reality is understood in metaphorical terms, and since our conception of the physical world is partly metaphorical, metaphor plays a very significant role in determining what is real for us (p. 146).

As language can reveal individual perception of social reality, the way in which metaphors are used can also enhance understanding. It has even been argued that metaphors are so pervasive that we even construct reality as “we signify things

through one metaphor rather than another” (Fairclough, 1992, p. 194). For example, Sontag (1979) illustrated the consistent use of metaphors of war when discussing the “invasive” nature of cancer, or “fighting” cancer (p. 64). Sontag’s (1979) work also illustrated that the myths that surround cancer today similarly encompassed tuberculosis in the past. Whereas passionate artists were “consumed” with tuberculosis in the past, those with cancer today are “invaded” by alien cells (Sontag, 1979, p. 14). Lerner (1998) has illustrated how the use of metaphors of war persists as “particularly prominent” (p. 74) in any discussion of breast cancer, to the point where “it is now almost impossible to discuss breast cancer without using military terminology” (p. 77), despite pleas to “eliminate battle imagery” (Clark, 2000, p. 8) from those women who are contending with the disease.

Nevertheless, Sontag (1979) did argue that once a cure has been found for cancer, the disease will be demystified, and thus will lose its metaphorical power just as tuberculosis did with the discovery of the tubercle bacillus and an effective treatment. Meantime, for most, cancer remains a disease to be feared and to be fought. As Sontag (1979) explains:

It is not naming as such that is pejorative or damning, but the name “cancer”. As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have (p. 7).

This influence also tends to apply to others involved with the person who experiences a diagnosis of cancer. Bolwell (2000) suggests that in encountering the disease in another, individuals may also find they confront their own mortality. Blaxter (1983), in her study of women talking about disease, identified the level of discomfort surrounding cancer:

Cancer had replaced TB as the incurable disease, the disease to be dreaded, the disease to be mentioned without any discussion of its cause. Cause was unknown, and speculation not only fruitless, on the whole, but also uncomfortable (p. 67, emphasis added).

As Stacey (1997) despaired, “The cultural imperatives of secrecy and disguise are a constant reminder of the price of living with a stigmatised illness” (p. 67).

Women living with breast cancer experience feelings of vulnerability (Elder, 2000), depression (Matheson, 2000) and anger (Matthews, 2000). Anxiety and depression tend to occur regardless of post-diagnosis treatment (Schain, Angelo, Dunn, Lichter & Pierce, 1994). Breast cancer is associated with high rates of depression and anxiety, or “psychiatric morbidity” (Lovestone & Fahy, 1991, p. 1219). As DiGiacomo (1992) contends, the illness is inseparable from its prescribed cultural meaning.

Also, physically, cancer is an insidious disease that presents a number of forms that can be easily ignored. For example, breast cancer is usually painless and develops without detection for many years. Stacey (1997) reflects:

Cancer deceives. It silently makes itself at home and waits. The body which appears healthy hides the imminent truth of its mortality (p. 73).

The eventual diagnosis may mean that sufferers will be forced to contend with a variety of physical changes. For example, pain, energy loss, nausea, disfigurement and hair loss are associated with treatment of the disease.

This suggests that when a community programme is established to detect a disease such as cancer, it is important to question how people comprehend the experience of “cancer” as a possible part of their own life situation. There are potential influences both from using a word with the identified fearful and

emotive implications discussed above and also from the socio-cultural environment in which the service is being offered. For example, it has been suggested that in the current social context that involves a strong emphasis on self-responsibility, acceptance that one may have a disease that may have been avoided through “a healthy lifestyle” (as promoted by Knowles, 1990; Maibach, Davis, TerMaat & Rivera, 1998, and Parsons, Clarke & Bradley, 1994), may add a new dimension of accountability and often, enhanced anxiety (Barsky, 1988; Crawford, 1994), self-blame (Linn, Linn & Stein, 1982) and declining satisfaction with personal health (Barsky, 1988). Inglis (1981) points out that since 1845, there has been a lingering notion that it was because women harboured grief and anxiety that they developed breast cancer. Researchers have found that this idea persists, for example, C. Chen et al. (1995) assert that women who present with breast cancer are likely to have experienced stressful life events in the preceding five years. The theme of individual self-responsibility for the development of cancer is also clearly depicted in Quilliam’s (1990) and in Clarke’s (1992) analysis of diverse media products. Sontag (1979) contends that:

Punitive notions of disease have a long history, and such notions are particularly active with cancer. There is the “fight” or “crusade” against cancer; cancer is the “killer” disease; people who have cancer are “cancer victims”. Ostensibly, the illness is the culprit. But it is also the cancer patient who is made culpable. Widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well. And conventions of treating cancer as no mere disease but a demonic enemy make cancer not just a lethal disease but a shameful one (p. 57, emphasis added).

Within the context of the current climate, it is argued that self-responsibility is promoted as an individual duty and virtue. Stacey (1997), an academic sharing her intuitive and thought-provoking experience of cancer, writes that she was “so young for cancer and so fit” (p. 14, emphasis added). Similarly, Bolwell (2000) writes “[I]f someone as ostensibly fit, healthy and ‘young’ as I am can get breast cancer...” (p. 20). These sorts of statements reflect the ethic of self-responsibility, where “good” health equals “good” people. As Del Vecchio Good, Good, Schaffer and Lind (1990) demonstrated, communication about cancer is “powerfully influenced by societal and institutional contexts” (p. 60). However, Simms (1989) contends that an ethic such as individual responsibility for ill-health potentially creates “victim blaming”, which in turn creates barriers in communication from the tension inherent in analysing health problems in terms of the deficiencies of the individual.

Lupton’s (1994a) study of discourses on breast cancer in the Australian press concluded that “the discourse of victim-blaming was central [as] the overweening message was that ‘women should do something to protect themselves’ ” (p. 85). If they failed to do so, it was implied that women were “irresponsible and neglectful of their own health” (p. 85). It has been further argued by Pinell (1987) that the end result of such an emphasis may result in women who present with cancer describing themselves as feeling “humiliated”, “isolated” and “condemned” (p. 35) as reported in her study of women with cervical cancer.

An approach of self-responsibility for ill health also obscures the reality of biological influences. Wardle and Pope (1992) contend that, as part of the ethic of self-care, the concept of risk factors that are statistically associated with a disease has become predominant as reflected in the discussion of risk factors for breast

cancer in Chapter 2. These risk factors, however, are also multiple and still open to debate. Unfortunately, with a disease as insidious as breast cancer which is difficult to detect, diagnose and treat, women will remain vulnerable to any suggestion of a panacea, such as *The breast cancer prevention diet* (Arnot, 1998). Morgan, Sharma, Lukachko and Ross (1999) point out that some of the information in this publication is scientifically unfounded and that following Arnot's diet "could disrupt healthy eating habits" (p. 245).

Nevertheless, Clarke (2000) states that the focus remains on modifying lifestyle and behaviour, even though the outcome of the ongoing debate about risk factors for breast cancer may be needless anxiety for those women who overestimate the importance of those risk factors, or the false sense of security it may engender in those who do not have many risk factors (Love, 1990). Love (1990) asserts that there is clearly an interaction which has not yet been identified, and the disease continues to increase in both incidence and mortality, despite the emphasis on the individual maintenance of "health".

The tendency to locate the responsibility for the cause and the remedy of health problems in the individual has three underlying assumptions, according to Becker (1993). The assumptions are:

[P]ersonal health-related behaviors are discrete and independently modifiable; anyone can decide to alter his/her behavior and then go on to do so successfully; and everyone has a personal responsibility to "live well" through self-discipline and behavior modification (p. 3).

In what Becker (1986) calls the "tyranny of health promotion" (p. 15), he argues that "an introspective approach to health which fosters victim-blaming and stigmatization, ignores critical social, economic, and environmental issues which

may have major impacts on health” (p. 20). The contention is that underlying assumptions may not only fail to correlate with the known aetiology of disease, but recommended interventions may also prove damaging to health. For example, for years women have been exhorted to carry out regular breast self-examination as a means of identifying suspicious lumps. However, progressively over the past decade, this has been amended to “breast awareness” (for example, see Austoker et al., 1995), primarily because research has identified no objective evidence that self examination is either effective or efficient at reducing mortality through detecting breast cancer (Arroll, 1990; Elwood, 1995b; Love, 1990). Therefore, Moss (1992) maintains that no matter how methodical or consistent the behaviour, it may only result in unnecessary anxiety. Maguire (1983) contends that anxiety can sometimes reach the point of an obsessional ritual associated with cancer phobias. It appears that confidence in the procedure may well prove misplaced. In 1992, the National Advisory Committee on Core Health and Disability Support Services advised that reliance on breast self-examination “as an effective means of early detection is not likely to be effective” (National Advisory Committee, 1992, p. 11). McKinlay (1993) reflects that the lack of positive influence from undertaking similar health-focused interventions has disillusioned people when the outcomes often prove to be less optimal than originally believed.

Inevitably, it is important in this debate to bear in mind that all viable human bodies are subject to the physical processes of birth, decay and death; these are simply part of living. In Foucault’s (1973) words,

Degeneration lies at the very principle of life, the necessity of death is indissociably bound up with life, and the most general possibility of disease (p. 158).

However, as Sontag (1979) argues, in the midst of life, “cancer is a metaphor for what is most ferociously energetic; and these energies constitute the ultimate insult to natural order” (p. 68). Furthermore, nobody is immune:

Cancer appears to lurk in every aspect of daily life: the air we breathe, the water we drink, the food we eat, the homes we live in, the substances we touch, and the work we do (Feinstein & Esdaile, 1987, p. 113).

Fear is not an unreasonable response, nor anxiety an unexpected symptom “when the entire world seems to view cancer as the most dread and hellish circumstance that one can imagine” (Brown, 1989, p. 2690).

## **CONCLUSION**

The preceding discussion has demonstrated the significant influence of the socio-cultural and institutional context in which health communication occurs. In particular, the structural functionalist paradigm of scientific biomedicine has been challenged by anthropologists, medical sociologists and critical communication theorists. Analogous with social-cultural pressures for change, the outcomes from this challenge underpin the changes in health communication processes that have occurred. Certain health communication models have developed as a result of this period of transition, and a number of different models such as health promotion, disease prevention, disease detection and social marketing are used to attempt to empower individuals in a “well” population to take responsibility for their own health status.

Also, there has been a potent social influence on the development of health care, primarily in the form of “individualism” and “healthism”. Research has been presented from several theorists who have argued that because such

perspectives do not take account of environmental influences, they invoke a “victim-blaming” stance. However, there has been little research that has focused on whether such influences are equally influential among all cultures, for example, individualist and collective cultures. Furthermore, there are social and cognitive influences which need to be recognised when health communication is designed to encourage “well” women to undertake a behaviour that may result in the confrontation of a feared disease such as cancer. Once again, there appears to be little differentiation in available research about the reception of that message among diverse groups of women.

As outlined in Chapter 1, the purpose of this thesis is to investigate the production and consumption of the communication process from the breast screening programme. Now that the contextual framework for the process has been outlined, the way in which this research was undertaken will be discussed in the following chapter.

## CHAPTER 4

### METHODOLOGY

The aim of this chapter is twofold: to provide a theoretical framework for the research methodology and outline the method on which this study of communication in the breast screening programme is based. In the first section I outline the development of the interpretive approach and discuss the critical turn adopted for this research. The influence of the role of language within the critical and interpretive paradigms, including the context of thematic analysis is also discussed. The use of triangulation as a research method and form of validation is outlined, including mention of the criticisms of this multi-strategy approach.

The second part of the chapter describes the method, including the background to the development of the research project, and the procedures used in the multiple-strategy approach to the collection and analysis of data. The research methods which comprised a case study using questionnaire surveys, focus group interviews and individual interviews to obtain data from those who participated in the programme, both as providers and clients, are discussed. The benefits and disadvantages of each method as they relate to this research are presented.

The analysis of the resulting data, including the use of quantitative analysis and the qualitative approach of interpretive analysis applying Owen's (1984) method of thematic analysis, with a critical turn and reference to Ricoeur (1981),

is outlined. Finally, I discuss the limitations that arose from the above approach to this research.

## **METHODOLOGY**

### **THE INTERPRETIVE APPROACH**

The three research questions central to this thesis required a means of interpreting and explaining the communication processes of both staff and participants in the breast screening programme. The interpretive approach was selected as the appropriate framework to underpin the study. Based on the hermeneutic tradition, an interpretive approach focuses on questions related to experience and meaning, which provides a way of approaching subjects as self-informed, autonomous individuals whose own understanding of the world is valid (Burrell & Morgan, 1979). An interpretive approach views reality as socially constructed, where outcomes are firmly grounded in the social context in which they occur. Burrell and Morgan (1979) explain that this approach involves understanding “the very basis and source of social reality” ... [or] “the essence of the everyday world” (p. 31):

The interpretive paradigm is informed by a concern to understand the world as it is, to understand the fundamental nature of the social world at the level of subjective experience. It seeks explanation within the realm of individual consciousness and subjectivity, within the frame of reference of the participant as opposed to the observer of action (Burrell & Morgan, 1979, p. 28).

The development of the interpretive paradigm is grounded in Husserl’s (1964) classic phenomenology, which identified the relationship between the nature of meaning and human existence. Through Gadamer (1976) and

Heidegger (1967) the notion of a hermeneutic circle of interpretation developed which included recognition of the role of language in shaping the interpretive process. Hermeneutics is thus defined through language within the “linguistic circle” (Gadamer, 1976, p. 17), which recognises the process of dialogue between speakers as they seek mutual understanding. Language is “the middle ground in which understanding and agreement concerning the object takes place between two people” (Gadamer, 1975, pp. 345-346); thus, “understanding is language-bound” (Gadamer, 1976, p. 15).

Language is not merely a code for communication. It is inseparably involved with processes of thinking and reasoning in which versions of the reality of the social world are constructed. The social world is both explained and constructed through the way in which individuals produce, organise and define their life situations. As language is central to the production of meaning and social reality, the competing discourses that result from the process of creating meaning can therefore represent multiple perspectives (Richardson, 1994). One means of interpreting data is to analyse the content of texts, either spoken or written. However, the influence of the “social” may not always be paramount in the use of text for interpretation, in for example, quantitative content analysis, a method of comparing documents or transcripts to quantify occurrences of specified data (Manning & Cullum-Swan, 1994).

Some theorists have challenged what Krippendorff (1980) calls the “somewhat simplistic notion of scientific objectivity” (p. 14) of quantitative content analysis, a challenge which resulted from a growing interest in the influence of media and the emerging “empirical methods of inquiry in the social sciences” (p. 15). For example, it was argued by Weber (1985) that a quantitative reduction of information precluded much of “the richness and detail” (p. 41) that

could be achieved through a qualitative approach. Similarly, the “multi-dimensional” nature of language meant that “frequency-counts of straightforward, surface meanings rarely go deep enough to answer in-depth questions” (Carney, 1972, p. 48).

As Holsti (1969) contends, content analysis “has been marked by a diversity of purpose, subject matter, and technique” (p. 42); thus qualitative approaches have developed as equally valid to the once-dominant quantitative process. An approach that has subsequently developed from the archetype of content analysis which recognises both quantitative and qualitative influences, is identification and analysis of themes, or thematic analysis (Owen, 1984). Holsti (1969) argues that themes provide a “most useful unit of content analysis” when conducting research on “values, attitudes, beliefs, and the like” (p. 116) which underlie communication. Within an interpretive framework discussed above, meanings “evolve from interaction processes and the ways that individuals make sense of their talk” (Putnam, 1983, p. 40). Law (1994) further contends that narratives are a “mode of ordering [that are] recursively told” (p. 259), often differ, are incomplete and regularly interact. Accordingly, narrative themes can provide a valuable catalyst in focussing analysis on the processes by which meanings are produced and sustained through communication; the way in which individuals “make sense” of their world through communicative behaviours.

Analysis of narrative themes that emerge from research data is based on the interpretive approach which Owen (1984) used to focus on how people discursively made sense of their emotional relationships. The purpose of Owen’s (1984) interpretive study was to attempt to understand the discourse that participants use to describe their experience to expand understanding of how participants conceptualised their relationships. Owen’s (1984) use of thematic

analysis illustrates that narrative themes may be identified which will help to understand how individuals explain personal experiences.

The same approach was also successfully used by Wood, Dendy, Dordek, Germany and Varallo (1994) in a study of how differences contribute to close relationships. They point out that thematic analysis is “doubly interpretive” as “it not only probes symbolic constructions, but also relies on discursive accounts as the primary data that reveal the meanings” generated by participants (p. 116). Similarly, using thematic analysis Weller (1996) provided a sensitive description of early medical school relationships, both in a personal and organisational context, as male students integrated into medical school. The approach has also been applied in an organisational context by Zorn and Ruccio (1998), who used thematic analysis to reveal influences on employee motivation in a sales-oriented setting.

As interpretive research, it is a goal of this study to obtain the “rich data” or “thick description” (Geertz, 1973), that “consists in trying to rescue the ‘said’ of such discourse from its perishing occasions and fix it in perusable terms” (p. 20). In other words, the aim is to interpret, understand and accurately reflect the social reality of participants. The goals of the researcher are explanation and understanding (Ricoeur, 1981). Ricoeur (1981) explains that the correlation between understanding and explanation and explanation and understanding is the “hermeneutical circle” (p. 221), referred to above. Thus, a correctly applied interpretation of the data generated from this research will facilitate understanding and explanation of the communication experiences of both the staff and the women participating in the breast screening programme. Nevertheless, in recognition of the fact that communication does not occur within an institutional vacuum of the breast screening programme, but rather within a broader political

and socio-cultural context, I needed a supplementary approach to provide a wider analysis. Thus, a critical perspective was added to the research.

## **A critical turn**

The introduction of a critical perspective provided an opportunity to offer a new dimension to the study, because where interpretive research seeks to describe, critical research demonstrates how discourse influences social identities. That is, where interpretive research has a focus on the way in which shared meaning is developed, a critical perspective attends to the ideological formation of meaning. Thus, Mumby (1988) argues that social reality is examined on two levels: the “surface structure” which reveals the overt, routine activities, and the “deep structure” which maintains various power interests that provide the underlying system of rationality on which the “taken-for-granted” surface structure rests. As Mumby and Clair (1997) explain, “[T]he interpretive approach works at a descriptive level, focusing on the way in which members’ discursive practices contribute to the development of shared meaning” (p. 182). However, norms and values will be expressed through discourse that will point to underlying or “deep” structures of meaning. Thus, to reveal such norms and values that underlie communication, language “should be studied in [its] social, cultural and political contexts” (van Dijk, 1994, p. 435).

A critical approach will focus “more closely on the [underlying] question of power and control” (Mumby & Clair, 1997, p. 182), which includes the closely related concepts of ideology and hegemony. Ideology is important to critical theory (Littlejohn, 1996). The common-sense world of everyday existence is ideological. The shared meaning that underlies social reality espouses practices through which an ideology, or understanding of what is acceptable, is both

embodied and expressed (Eagleton, 1991). The acceptance of a particular framework of definitions has such a taken-for-granted nature that we tend to be unaware that an ideology is even there as we share fundamental interests, values and concerns (Hall, Critcher, Jefferson, Clarke & Roberts, 1978). Ideologies exist in many forms and consistently reflect the social structure they inhabit. As Bourdieu (1991) contends, “Ideologies owe their structure and their most specific functions to the social conditions of their production and circulation” (p. 169).

The issue of why some interests are rationalised and thus legitimated as dominant to others gave rise to questions about the shaping of consent that results in their taken-for-granted acceptance. In other words, questions arose about the way in which dominant power is maintained in a way that “rationalize[s] and legitimate[s] particular courses of action upon the actions of self and others” (Smart, 1986, p. 164) without coercion. Gramsci (1971) defined the framing of definitions to allow dominant groups to exert authority over subordinate groups as “the organization of consent” or “hegemony” (Barrett, 1994, p. 238). Ideology “plays a central role in this process” (Littlejohn, 1996, p. 229) as it shapes the way in which people understand and interpret their experience.

Hegemony is a potent means of social control because it imposes impressions of social consensus rather than dominance (Stanfield, 1994). The universe of possible meaning and the power relations in a social group are encapsulated by the term “hegemony”, in which practice depends on consensus for ideas which express the needs of the dominant group. As a definition that carries a stamp of legitimacy, the hierarchical distinctions which result in group dominance appear as a natural and inevitable part of the social order. Hebdige (1993) explains that consent is won, not always through controlling subordinate

groups, but at least containing them “within in ideological space which does not seem at all ‘ideological’: which appears instead to be permanent and ‘natural’, to lie outside history, to be beyond particular interests” (p. 366).

Hegemony is not a form of coercive determinism. As Hall (1989) explains, hegemony is a “concept of ruling ideology that comes from outside and superimposes its own highly homogeneous perspective on people” (p. 51).

Activities and policies are reproduced discursively in ways that serve the interests of the dominant group, not through coercion, but through the production of active consent of both the dominant and dominated. Thus “compliance and stability are passively achieved” (Deetz, 1994, p. 177). Nevertheless, a hegemonic state is not stable, but is subject to challenge and struggle. As Hall (1989) cautions, the power is always shifting in a social order held in equilibrium by a moral and intellectual consensus that is diffused throughout the group, and will thus be revealed in the resulting communication.

One way in which hegemonic shifts can be revealed is through critical discourse analysis which exposes ideological struggles through the study of the “properties of ‘text’ in relation to context” (van Dijk, 1994, p. 436). The relationship between the material and discursive environments is a dialectical one, as demonstrated by Fairclough (1992); discourses do not just reflect social relations, they also construct them. The dialectical nature means that language is never seen as unitary; it both influences and is influenced by social beliefs and contexts. Discourse also positions people as social subjects within institutional and organisational contexts. For example, Jurgen Habermas (1971), an eminent critical theorist from the Frankfurt School, recognises the social influence of discourse as he argues that the technical rationality found in scientific paradigms underlie ideologies of expertise which create a “rationality of domination” (p. 85).

The achievement of repression through such ideologies “consists in the inconspicuous manner in which communication is systematically limited” (Habermas, 1976, p. 112).

Of relevance to this research is the way in which the socio-political critique provided by the critical approach to discourse analysis focuses on power and dominance as they are reproduced through discourse (van Dijk, 1994). The link between power and society is mediated through the underlying conventions of “orders of discourse” (Fairclough, 1993, p. 135). The order of discourse of some social or professional domain is the totality of its discursive practices and the relationships between them. However, there may be points of conflict and contestation in which one particular discourse has primacy over another, to cause an ideological shift as “meaning is mobilised in the interest of particular individuals and groups” (Thompson, 1984, p. 73). Accordingly, the texts will reveal evidence of a discursive struggle as power relationships are being enacted and orders of discourse will shift in the texts to reveal what Fairclough (1992) refers to as “the contradictory and unstable equilibrium which constitutes a hegemony” (p. 93).

In turn, texts are constructed, reconstructed or subsumed through other texts as a result of the intertextual or interdiscursive change which reveals hidden connections and causes discursive, social and cultural change which are “typically not transparent for the people involved” (Fairclough, 1992, p. 9). Fairclough (1992) further argues that evidence of power relationships are manifest in orders of discourse, as when the ideologies that reside in texts become “naturalised and win widespread acceptance” (p. 10), they constitute a form of hegemony.

One of the more prominent philosophers of the twentieth century, Michel Foucault (1977b), describes the power relations of institutional discourses that

underpin discursive practices which are “embodied in technical processes, in institutions, in patterns for general behavior, in forms for transmission and diffusion, and in pedagogical forms which, at once, create and impose them” (p. 200). Accordingly, when communication takes place within the context of a health care institution, certain influences will significantly dominate the interaction, as discussed in Chapter 3. In the words of Forester (1993):

In the staging of communicative action, we are confronted with the causal influences of institutional context and history. In the enactment and utterances of communicative action, we are confronted with the actors’ own theorizing, interpretations, articulations of self and others (p. 2).

When staff and participants provide oral or written feedback about the breast screening programme they are not merely speaking; they are discursively constructing their accounts from within historically constituted, specific, socio-cultural and political contexts. Thus critical analysis of discourse provides a means of examining the discursive dimension of language as the resulting orders of discourse reflect the ways in which relationships are enacted and discursively shift as discourses are assimilated into others within the breast screening programme.

## **TRIANGULATION OF DATA**

Once the theoretical perspective of this study had been established, decisions were then required about the appropriate methodology for the research. The option of using a combination of methods in the study of the same phenomena was selected, described by Burgess (1982 & 1991) and Denzin (1970) as triangulation. The underlying premise is that all single research methods

contain inherent strengths and weaknesses, and that the weaknesses in one method will be compensated for by the strengths of another (Jick, 1983).

Triangulation is described by Patton (1990) as a term that metaphorically calls to mind the “world’s strongest geometric shape” of the triangle (p. 187). He continues that the term derived from surveying of land. The use of two landmarks allows surveyors to take bearings in two directions, which enables a position to be precisely located (Tones & Tilford, 1994). However, the term “triangulation” does not limit the researcher to only three sources of data, but allows the selection of multiple sources that will converge as the study proceeds (Janesick, 1994). There are four different types: data triangulation, or the use of multiple data sources; investigator triangulation, or multiple investigators in a study; theory triangulation, or the use of multiple theoretical perspectives and methodological triangulation, using multiple methods of study (Janesick, 1994).

A combination of triangulation of theoretical perspectives, data sources, methods and analysis was chosen for this study to provide enhanced research opportunities. As Wolff, Knodel and Sittitjai (1993) maintain:

From the standpoint of advancing research agendas, two independent measures of the same phenomena, particularly if they involve separate methodologies, should yield not only greater analytic leverage than one approach alone but very likely conflicting, inconsistent, or unexpected results that naturally prompt the development of new explanatory hypotheses (p. 134).

The process also provided the advantages of combining both quantitative and qualitative methods of data collection to enhance the validity and reliability of the research (Frey, Botan, Friedman & Kreps, 1991). The debate about the value of using either of these approaches to the exclusion of the other has been a

protracted one, overtaken by another which recognises that both approaches have value which is predicated on the integrity with which the research is conducted (Denzin & Lincoln, 1998).

The combination of qualitative and quantitative approaches can enhance the process of data collection by adding greater variety, and also enhance the process of data analysis as different exploratory approaches can be applied. Glanz, Lewis and Rimer (1990d) explain:

The use of focus groups and open-ended exploratory interviews can give the health educator a window to the world of the target audience. But that is not sufficient. Deductive methods help assure that conclusions are based on a larger context and are therefore generalizable to some known group. The most meaningful data are often those that emerge from a combination of quantitative and qualitative methods (p. 430).

Nevertheless, the merit of triangulation as a methodology has been challenged. For example, Bloor (1997) questions the claims of enhanced methodological rigour because, he argues, every situation is context-bound. Just as some social elements can be generalisable, others are “situation-specific” (p. 37); therefore any attempt at direct comparison will give rise to problems. However, as Silverman (1993) contends, triangulation is a beneficial approach when looking at the difference between the public accounts of an “agency” and the private accounts of individuals regarding the same event; a context highly relevant to this study where the perceptions of participants in the breast screening programme are contrasted with those of staff within the organisation. Ultimately, however, the value of any study will be determined by attention to detail. As

Patton (1990) argues, the credibility of any research project relies on “rigorous techniques” (p. 461) in the gathering and analysis of data.

## **METHOD**

### **BACKGROUND TO THE RESEARCH INVESTIGATION**

As a health professional working in a regional base hospital of 800 beds as a nurse manager during the introduction of the health reforms in 1993, I had experienced the implications for tertiary health providers who supplied hospital care for the “sick”. The new environment of reform resolutely emphasised the urgent need for shortened “bed-occupancy periods” to enhance efficiency. It was no longer enough to either treat the disease, or alternatively, to surgically remove or repair the affected organ. Accordingly, an increasing emphasis was placed on education and communication between health professionals and their publics. Hospital staff were required to provide information about preventing possible recurrence of the condition to their “clients” (previously “patients”) and to community health professionals, such as district nurses, whose roles increasingly included the care of those in the community who had previously been hospitalised for longer periods of time.

At the same time, in the attempt to move health services into a more efficient environment, health professionals who worked in the community were also involved in developing programmes to provide “primary” health care. An emphasis developed on community programmes for disease prevention, education and detection, such as screening “well” populations to potentially detect disease early, thus facilitate early treatment and alleviate the demand for expensive tertiary or hospital care. Such programmes are predicated on the voluntary participation of a “well” population. Having always observed the dependence of

individuals in a tertiary health care setting, I had an interest in how they would adapt to the new environment, whether communicating health information at a community level would indeed empower them to make autonomous choices that might influence their own health status.

Health Waikato had implemented a community health intervention to detect breast cancer in the form of one of two national pilot programmes for screening mammography between 1991 and 1998. The organisation had subsequently been approved as one of the six primary providers of screening mammography services to the women of New Zealand on 10 December, 1998. The staff were interested in knowing how effective their communication processes were in ensuring that women received appropriate information that would encourage them both to attend for screening mammography, and to return on a regular basis. As they had been running one of the two national pilot programmes since 1991, staff had clear communication procedures in place; however, they believed that their objectives were not always being met. First, some women were either registering with the programme and not attending for mammography. Second, some women were attending once and not returning for subsequent mammograms.

At our first meeting in April 1999, the manager of the breast screening programme discussed the pending integration of the Bay of Plenty into the BreastScreen Midland region that had occurred with the allocation of the regional contract. As there had been no prior organised programme in the Bay of Plenty, she believed it would be helpful to obtain some idea of women's knowledge about breast cancer and mammography in the area before the programme was introduced. This would provide a useful baseline from which to analyse future trends and measure different aspects of the programme. However, approval for the research that informed this thesis had not been received from the Waikato

Ethics Committee by the time the programme was launched in the Bay of Plenty. Also, some promotional activity had already been autonomously undertaken in the area by one of the resident health promotion team. Accordingly, the intended survey would have generated results that were confounded by intervening variables.

As it was not possible to conduct the proposed research, following further discussion, a decision was made that I would work with the health promoters to design a questionnaire survey relevant to women who had already experienced screening mammography in the Waikato region. This would provide feedback about women's perceptions of the programme's strategies of transactional and interactional communication that may have influenced decisions about participating in, and returning for, ongoing mammography. As well as providing the basis for the research for this thesis, the influence of the communication process was also of interest to the organisation. The manager asked if I would use the data generated from the research to prepare a report for them to assist in establishing strategies for effective communication in the future. The report was completed during the course of this research (Brunton, 2000).

There were three research questions that drove this research, and the data were intended to answer the research questions that were explained in Chapter 1. These were developed from a review of relevant literature and consultation with staff in the breast screening programme. The resulting questions were:

1. How does the breast screening programme **communicate its presence to eligible women** in the community, and how do women receive this communication?
2. What influences the way in which **staff** in the breast screening programme communicate with women who choose to participate?

3. How does the **target audience** receive and interpret the communication from staff in the breast screening programme during their participation in mammography?

### **Ethics approval**

As the research required the use of human subjects in a health organisation to complete survey questionnaires and participate in interviews and focus groups, I was bound by the regulations of both the Human Research Ethics Committee at the University of Waikato and the Waikato Ethics Committee. Application was made to the Waikato Management School Ethics Committee in May 1999 and the Waikato Ethics Committee in August 1999, and approval subsequently obtained from both organisations.

### **RESEARCH DESIGN**

As outlined above, my intention in this research was to adopt an interpretive approach with a critical turn. The underlying philosophy was one founded on consultation to allow participants to collaborate in the research process as much as possible. The purpose of doing so was threefold. First, participation assisted in establishing a foundation to meet one of the three goals of critical research, which are “understanding, critique and education” (Deetz & Kersten, 1983, p. 148). The goal of education is enhanced through encouraging “ownership” of the research by participants (Haig-Brown & Archibald, 1996), thereby increasing the possibility of greater understanding and positive change. Second, as suggested by Guba and Lincoln (1989), credible outcomes depend on the extent to which trust is established between the researcher and those participating in qualitative

research. Trust is predicated on consultation and understanding which can be facilitated through participation of subjects in debates as central to the study.

Finally, as Te Awekotuku (1991) and Roman (1993) demonstrated from an anthropological perspective, and Finch (1984), Kauffman (1992) and Oakley (1981) from a feminist point of view, participation also challenges the hierarchical position of researcher and researched. The consensus from the above researchers is that challenging this relationship through participation of subjects in debates about the study will enhance the resulting outcomes of the research. Accordingly, in light of the number of identified advantages, I adopted a participative, flexible response to participants, which incorporated “the need to negotiate with those being researched in a culturally sensitive way” (Spoonley, 1999) as explained further below. As women who took part in the questionnaire survey could not logically be involved in the development of the research tool, I needed to rely on the input of those who were their advocates in the organisation, such as the health promoters and community educators as co-participants for the study.

Various methods were available to carry out the research; however, the prohibitive resource and cost requirements of methods such as telephone surveys or personal interviews precluded these options as primary data sources in this study. Considering the time and financial constraints of the project, a consensus was reached with the organisation that the most efficient and effective method to provide feedback on the communication process would be the use of a mail-out questionnaire survey. Individual interviews and focus group interviews, as agreed by participants, were also used, not only to validate and augment the survey data, but also to investigate issues that were not explained from the quantitative research. Interviews with staff members provided a further opportunity to explore

the relevant influences on the source and nature of the communication from the breast screening programme.

The chronology of the research project constituted an initial development and distribution of a questionnaire survey to eligible women to discover how the breast screening programme communicates its presence to eligible women to encourage participation and ongoing attendance. Overall, the responses from eligible women would address the first and third research questions about how they received and interpreted the communication about participation and ongoing attendance. Although I would have preferred to hold focus groups to identify issues important to respondents before developing the questionnaire, this possibility was precluded by the need to submit the questionnaire as part of the approval process for the Waikato Ethics Committee prior to commencement of the study.

When the questionnaire was distributed, it was accompanied by an invitation to participate in individual or focus group interviews (see Appendix 5, page 386). Women were asked to provide only their first name and either telephone number or residential contact details to arrange the meeting. This invitation provided a “yes” or “no” tick box for those women to indicate their willingness or not to participate. For those who did wish to take part, they were also asked to select their preferred interview option. The purpose of the invitation was to provide an opportunity to further explore issues arising from the survey data. Once patterns did begin to emerge from the survey data, I began to hold focus group and individual interviews with women who had indicated their willingness to participate. Finally, individual interviews were held with staff in the breast screening programme to address the second research question which related to the production of communication. The focus of the interviews was on

examining the influences on the way in which staff in the breast screening programme communicated with women to encourage ongoing attendance.

## **Case study**

This research used a “single-case study” (Huberman & Miles, 1994, p. 435) or “intrinsic case study” (Stake, 1998, p. 88). Huberman and Miles (1994) contend that single case studies can provide relevant instances of social processes aggregated in a setting. Thus, the approach provided the opportunity to investigate a current situation in a context relative to a topic of interest; in this case, health communication. A case study also provided a framework within which a variety of evidential approaches could be undertaken to enhance rigour, as suggested by Yin (1994). Yin (1994) argues that various origins of evidence are “highly complementary” (p. 78). Thus, the use of “as many sources as possible is desirable for a good case study” (p. 78). As a primarily qualitative research approach, Yin (1994) also contends that the construct validity and reliability of a case study will be enhanced by the use of a formal database and using multiple sources of data to provide a “chain of evidence” (p. 99) for the reader. Applying multiple sources of evidence in a case study enables a wider range of “historical, attitudinal, and behavioral issues” to be investigated through “converging lines of inquiry” (Yin, 1994, p. 92).

However, Huberman and Miles (1994) do caution that there is some “tension” in reconciling the particular characteristics of a case to “the universal” (p. 435). This lack of generalisability is defended by the unique perspective of the case study, which Stake (1998) argues, makes a lack of replicability irrelevant. In an attempt to overcome this limitation, a triangulated data collection process that incorporated quantitative analysis of survey data was integrated to enhance

the tools for optimising the external validity or generalisability of the findings from this research.

## **Questionnaire survey**

A self-administered questionnaire survey was used to obtain information from participants in the breast screening programme. There were two critical issues of interest to this research investigated through the survey: first, the communication processes that had encouraged women to attend; second, the communication experiences within the programme that encouraged their return.

### ***Rationale for using a questionnaire survey***

There were a number of advantages in using a mail questionnaire. As mentioned above, part of the rationale behind the decision to use a mail survey was determined by constrained resources, as the approach provided a low cost collection option of obtaining a good spread of responses. Further, because respondents complete mail questionnaires in their own environment without the external influence of an interviewer's responses, the questionnaire survey thus avoids the potential of bias inherent in interviews (Oppenheim, 1992).<sup>5</sup> Provided the questions in the survey document are well designed, respondents should be able to comprehend them quickly and with ease (Frey et al., 1991). If this criterion of clear understanding is met, a self-completed questionnaire also enhances the likelihood that the responses are an accurate reflection of respondents' opinions and perceptions, as they record their own data (Oppenheim, 1992).

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<sup>5</sup> In this study, some of the questionnaires were hand-delivered to ethnic minority groups, which means that some of the responses may have been influenced by the participation of the health workers as they provided assistance to respondents.

However, there are also disadvantages in using mail questionnaires which need to be addressed as fully as possible prior to distribution (Statistics New Zealand, 1995a). For example, once mail questionnaires have been put in the post, respondents have no opportunity to clarify any questions they may not understand (Babbie, 1998). Therefore, mail questionnaires are unsuitable for those with poor literacy (Oppenheim, 1992). Similarly, the researcher has no opportunity to collect observation assessments (Oppenheim, 1992). Furthermore, the questions are likely to reflect the biases and preconceptions of the researcher (Leathar & Roberts, 1985), which in turn restricts the ability of the respondent to tell their own stories (Morrison 1998; Wolff et al., 1993). Furthermore, questionnaires are limited by eventual response rates and the consequent response bias this may introduce to the study (Frey et al., 1991). Although a random sample may be carefully selected, a researcher has no control over non-response, which is not a random process (Moore, 1991). However, McDonald and Daly (1992) contend that careful attention to validity and reliability throughout the design process can reveal many sources of bias. The approaches integrated into this research to address issues of possible bias are outlined in the discussion below, along with the limitations of this study.

### ***Consultation process for the development of the survey***

Several meetings were held with the health promotion team both in Hamilton and Toi Te Ora in Tauranga to discuss the research project and survey design. This was an important step in ascertaining what resources were available for the research and what the staff intended to do with the results. Also, as New Zealand is a multi-cultural society, women of Māori, European, Pacific Island and Asian descent needed to be included in the development of the survey to ensure

that the orientation was carefully developed so that participants would feel as comfortable as possible. As Temple (1997) contends, understanding across cultures requires recognition of different forms of cultural expression. It also requires the development of research processes and analyses that “challenge white privilege and question how such privilege may shape research experiences” (Anderson, 1993, p. 51) through the inclusion of all ethnic perspectives.

Consultation was also based on recognition of the rights of Māori under the Treaty of Waitangi (1840). Consultation is essential “if a research project is on a topic relevant to a Māori health issue or Māori are to be involved as participants” (Health Research Council of New Zealand, 1998, p. 7). The Treaty has been recognised as a suitable framework in which Māori health objectives can be attained. Consultation with Māori participants should not only “begin as early as possible in the research project [but also be] ongoing throughout the project” (Health Research Council of New Zealand, 1998, p. 8). Furthermore, I believed that there was also an ethical responsibility to include Māori as much as possible in the process. As detailed in Chapter 2, the health of Māori in this country is significantly disadvantaged. Thus, this population suffer a higher rate of illness and premature mortality than Europeans. Te Awekotuku (1991) and Smith (1999) contend that an integrative approach to research can reclaim power for Māori. To facilitate the process, research must recognise the need to facilitate a process of “centring our [Māori] concerns and world views and then coming to know and understand theory and research from our own perspectives and for our own purposes” (Smith, 1999, p. 39, emphasis added).

That there were issues involved for Māori and other ethnic minority groups in the provision of the breast screening service was evidenced by their significant under-representation on the database, as discussed in Chapter 5. To avoid basing

the research on the assumptions of a dominant mainstream perspective (in this country, European), meetings with Māori, Pacific Island and Asian health promoters were held early to ask for their participation and support in the research. In addition, the purpose was to ensure that the research tools would be presented in a way in which respondents would feel they were being treated with dignity and that their responses would be interpreted within a relevant and acceptable cultural context and integrated into the research project appropriately and positively.

There was close liaison with the Māori representatives of the funded provider, Raukura Hauora O Tainui. The coordinator for the health promotion team provided further contacts with the Pacific Island health promoter (coordinated through Te Rapakau Health) and the Asian community adviser to ensure a consultative approach in establishing guidelines for data collection within each group. The Māori, Pacific Island and Asian health promoters and community advisers were independent of the screening programme. At an early meeting I asked whether separate survey tools would be helpful to facilitate language and cultural differences. However, the Māori health promoters who were present at the meeting where this issue was raised (Tauranga meeting, 18 June 1999), were adamant that their people did not want to receive different questionnaires from those they described as the “mainstream”, or dominant cultural group of Europeans. One explained that this approach had been taken with earlier research and had been perceived negatively by the community.

Subsequently, representatives of Māori, European, Pacific Island and Asian groups were involved in discussions about ways in which questions could be asked that would both encourage a response and not cause offence. In recognition of my limited knowledge of the cultural beliefs and influences of the

Māori, Pacific Island and Asian groups, they were invited to discuss the questions, a number of which centred on issues that had been of specific cultural significance to them. The health promoters were also included in regular reviews of the questionnaire, as they perceived the importance of the opportunity that the research provided for them to have “a voice” both in expressing what was important to them and also in discussing what would represent effective communication in a culturally acceptable manner.

Also, consultation was a mark of respect for those with whom I was conducting the study. As Haig-Brown and Archibald (1996) stated of their research, my purpose was to “seek respectful and ethical knowledge production” (p. 247) through a process of consultation with all ethnic minority groups. Thus, to both recognise the importance of their input and to reduce potential bias, information was sought from members of minority ethnic groups to enhance my understanding of their needs and perspectives.

### ***Formulating the questionnaire***

In this research project, the primary concern was those questions related to how women experienced the transactional and interactional communication from the breast screening programme, as they were encouraged to participate in, and return for, ongoing screening mammography. The parallels between the communication processes and the responses of women about how they interpreted and responded to the outcomes guided the development of the questionnaire survey. Accordingly, the questions were generated from an extensive review of literature to classify the key issues that had been previously identified as relevant to women’s experiences of screening mammography, which related as closely as possible to the research questions.

Questions that were related to the two underlying variables of interest - the communication phases referred to above - were mixed throughout the survey. The key topic sections were: first, the way in which women had responded to the introductory transactional and interactional communication from the breast screening programme; second, their experience of the programme interface with the community; third, their experience of the process of mammography; fourth, the information resources both internal and external to the programme and finally, their attitudes and emotional responses towards screening mammography. (A copy of the questionnaire survey can be found in Appendix 4, page 377).

The majority of questions in the survey were directive or closed, including those which used a Likert scale that related to the programme interface. Closed questions allowed women to respond to a series of tick boxes. Each section of the questionnaire provided opportunities for comments, of which many women took advantage. From these sections, 1248 confidential comments, which comprised several pages of open and detailed feedback, were generated. Also, open or non-directive questions were asked when it was believed to be important that women could describe various outcomes, for example, perceived information deficits.

Demographic data were sought on age, ethnicity, residence, work, income and level of education to obtain information about the characteristics of the population that had responded to the questionnaire, and how representative this sample was. The Māori and Pacific Island health promoters were resistant to information about income and education being included. However, they accepted that the demographic information would assist in establishing what population had taken part in the survey, and agreed to the inclusion of these questions. Such questions were clearly a contentious issue for many Māori women, who expressed

concern about the amount of health research they have participated in with either little recognition or result, as reflected in Campbell and Bryant's (1996) report.

There has been an overall perception of Māori being "over-researched" for little gain, not only in the health sector. As Smith (1999) points out:

Years of research have frequently failed to improve the conditions of the people who are researched. This has led many Māori people to believe that researchers are simply intent on taking or "stealing" knowledge in a non-reciprocal and often under-handed way (p. 176).

The author explains that the outcome is now a "deep distrust and suspicion" (p. 173) of the research process which has resulted in a negative attitude of Māori communities. Such perceptions mean that barriers need to be recognised, validated, and carefully negotiated during any research project.

Recognising that feelings, attitudes and values are central to communication theory (Littlejohn, 1996) and underlie health communication outcomes (Downie, Fyfe & Tannahill, 1990), there were a number of subjective questions in the survey about women's feelings, opinions and attitudes towards breast screening, and inevitably, breast cancer. They were asked about the various levels of anxiety associated with different phases of the mammography process, such as waiting for their appointment (question 5), the physical process of mammography (question 10), and waiting for the results (question 6). (See Appendix 4, pages 378 & 379).

Questions relating to resources for the programme also included the way in which the information was presented. Responses to the presentation of information were explored with two framed messages in question 26 (see Appendix 4, page 383). Framed messages can present the same objective message in a context of benefit to be attained through undertaking a behaviour, or

alternatively, what may be lost through failing to undertake a behaviour. The framed statements in the survey were adapted from Banks et al. (1995) who found in their research that women demonstrated significant differences in their responses to framed messages about screening mammography, as discussed further in Chapter 5.

### **Reliability and validity of the questionnaire survey**

To generate information that will accurately reflect the views of the target population at any one time, it is important that a questionnaire is both valid and reliable. Validity is the measure of whether a research instrument is indeed measuring what it is supposed to measure. Relevant to this study was external validity, or the extent to which the findings are representative of the population from which the sample is drawn. A random sample was selected, as it provides an accurate way of ensuring external validity. That is, the sample is most likely to be representative of the population in question (Babbie, 1998).

A further influence is that of content or face validity, which means that researchers need to recruit “qualified people” to either generate questions or alternatively, to assess whether available questions provide accurate measures of the variables of interest (Frey et al., 1991). In this study, the latter approach was undertaken. The questionnaire was discussed with the programme’s affiliated research nurse (involved in an international breast cancer study) and a surgeon who consulted for the breast screening programme, to ask for their feedback. Content validity was also ensured by an extensive review of relevant literature.

Silverman (1993) suggests that a way of maximising reliability is to ensure that questions are both clearly worded and require fixed-choice responses as much as possible so that each respondent understands the question in the same way. Therefore, according to Frey et al. (1991), “good” survey questions are not

double-barrelled (ask about more than one issue), are not leading (do not encourage the respondents to answer in a particular manner) and avoid using emotive language. Accordingly, to enhance reliability of the survey questions, thorough pre-testing was required. As discussed further below, this involved distributing the draft questionnaire to a small number of people, preferably those who were not intended as subjects, to ascertain their understanding of the questions. Discussions about the clarity and appropriateness of questions revealed important issues that might otherwise have affected the reliability of the outcomes, as illustrated below.

***Pre-testing procedure for the questionnaire survey.***

A pre-test was conducted in two stages among varied groups of 60 women. The first stage was a distribution of five questionnaires to members of the academic community who were experienced in designing and implementing questionnaires. As a result, some questions were refined and others reformatted to make them read more simply.

The final phase of pre-testing followed a fortnight later. Fifty copies of the questionnaires were distributed among the health promoters. Ten copies each were given to the Māori, European (2), Asian and Pacific Island health promoters. The process of pre-testing was discussed with them to ensure that they understood what was required of them, and a checklist was attached to each questionnaire to ensure that the appropriate information was obtained (see Appendix 6, page 387). I retained a further five copies to distribute to women who I knew had experienced screening mammography, but were not currently participating in the regional breast screening programme. Of the 60 copies from both stages of the pre-test, 53 were returned complete.

The process resulted in a number of alterations to the questionnaire:

- A further addition resulted from interest in the involvement of general practitioners in actively encouraging women to attend the programme.
- The “health worker” category was added to the checklists in questions 1 and 3 which referred to sources of information and influence related to breast screening, as 12 women nominated this category in the pre-test.
- The category “own decision” was added to question 3, as 15 women indicated they already participated in regular mammography and did not relate to any of the specified sources of influence in the programme.
- A number of “I don’t remember” categories were added.
- Some ordering of the questions was changed.
- Question 22, asking women about named pamphlets was amended from a tick box selection to an open-ended question as I discovered that the BreastScreen Aotearoa pamphlets that the question asked about had been available only in the past five months. Accordingly, women in the pre-test had not seen them.

The most outstanding remaining concern was the length of the six page questionnaire. However, agreement was reached with the health promoters that all of the questions were equally important, and a decision was made to leave the document intact.

### ***Sample selection for the questionnaire survey***

Alternative ways of obtaining a sample were initially explored among the health promoters in Hamilton and Tauranga. Following an explanation about the importance of obtaining maximum validity, or generalisability of the data from the study, the selection of a random sample was agreed. As Babbie (1998) states:

A basic principle of probability sampling is the sample will be representative of the population from which it is selected, if all members of the population have an equal chance of being selected in the sample (p. 169).

The team accepted that, in order to increase the likelihood of a representative sample and allow estimates of the sample's accuracy to be made, a random sample was required. In this case, within current constraints, the most effective way to obtain a probability sample of women who were most likely to have experienced screening mammography was to obtain a random sample from the women currently registered on the programme database.

### **The sampling frame**

At the time of selecting a sample for the research project in August 1999, there were 30,412 women recorded on the programme database. When the pilot programmes first began in 1991, in Otago and Southland and Waikato, the intention was to trial different methods of obtaining registration. The Otago and Southland programme worked directly with the regional general practitioners to obtain names for the target age group. As a health-focused research-based initiative of government, the Waikato programme was given access to an age-specific electoral roll to enable them to contact appropriate women. Both sources are now invalid because of the intervening Privacy Act 1993 that prohibits access to personal information without individual consent.

Thus, registrations currently result from self-referral or responses to external influences such as letters sent out from general practitioners and also from promotions carried out by programme staff. Once eligible women have registered, they are sent an invitation to attend either a fixed or mobile clinic in two-yearly cycles or rounds. As mentioned above, sometimes women who

decided to register have not come forward for screening. In addition, a number of women who have attended one round of screening have not returned for another.

Of the 30,412 women recorded on the database in August 1999, just under half (14,392) were in the eligible screening age group of 50 to 64 years, and had attended the third round of screening. The remaining 16,020 women on the database included those who had either moved over to the diagnostic system because of a positive result or those who were now ineligible for the breast screening programme, as they were older than 64 years. There were also a number of women who had originally been put on the database from the electoral roll, but had not responded to an invitation to attend. There were others who were unable to be reached as their addresses had changed in the interim and records had not been updated. Other women had since died. Once a name is put on to the screening database, it is removed only by written request.

The available population of women comprised those who had participated in Round 3 of screening, which had commenced on 1 November 1995 and finished on 30 October 1997 for the fixed screening site. For the mobile screening service, the third round had commenced on 27 May 1996 and was completed on 23 April 1998. Both fixed and mobile screening sites are required as the greater Waikato area covered by the breast screening programme includes areas from the top of the Coromandel Peninsula in the north to Taumaranui in the south (as illustrated in Appendix 7, page 389). As the majority of women in the study (71%) had been screened in the past year, there was clearly some overlap with the commencement of Round 4.

### ***Obtaining a representative sample***

To allow the population of women on the database to be reconstructed, a representative sample of all Waikato women of eligible screening age on the

database was required. However, as both confidentiality and anonymity were ethical prerequisites of the study, any access to women's details was precluded to an outside researcher, and the sample selection could be obtained only by request. The initial request to the manager of the information support service for Community Health, who oversees the management of the database for the screening programme, was for a random sample of 1,100 women.

The purpose of selecting a sample of an appropriate size was to estimate percentages within known margins of error. The margin of error on a percentage is the half width of a 95% confidence interval when the percentage is 50%. The formula for the margin of error results from dividing one by the square root of the sample size, then multiplying by 100. For example, a sample size of 1,000 would provide a margin of error of  $\pm 3\%$  (Levin & Rubin, 1980). However, even a sample size of 500, which was probably a more realistic goal for a mail questionnaire survey, would still provide a margin of error of  $\pm 4.5\%$ . To counter the usually low response rate of mail questionnaires discussed above, and potentially reduce the impact of response bias, a decision was made to obtain a stratified random sample of 1,100 women from the database.

### *Stratifying the sample*

To obtain data of known precision for certain subdivisions of the population, a sample was subsequently drawn from the population of women represented on the screening database from the area of the greater Waikato. The sample was divided into strata of district, age and ethnicity, and units selected at random from each stratum.<sup>6</sup> As Levin and Rubin (1980) explain:

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<sup>6</sup> The reason for stratifying by district was to eliminate the Bay of Plenty region that had recently been introduced with the national screening programme, where a number of women had recently registered, but not yet attended for a mammogram.

Stratified sampling is appropriate when the population is already divided into groups of different sizes and we wish to acknowledge this fact. The advantage of stratified samples is that when they are properly designed, they more accurately reflect characteristics of the population from which they were chosen than do other kinds of sampling (p. 232).

The nature of the population, that is women of 50 to 64 years of age, who were on the database because they were eligible for the programme, meant that the sample was necessarily stratified by age. However, the groups were further divided into three for the survey; 50-54, 55-59, 60-64 years to identify any differences that may occur among the groups.

To be in a position to make sensible statements about any population, a sample size of at least 100 is required, as this proportion will provide a margin of error, or variance of  $\pm 10\%$  (Lapin, 1980). However, in the case of ethnic minority groups, with the exception of Māori, the number of women on the database did not exceed 100. Accordingly, a census sample of Pacific Island ( $N=100$ ), Asian ( $N=74$ ), and Indian ( $N=58$ ) women was requested. A sample of 379 (35%) Māori women was requested, and 481 (4%) European and 8 (4%) of those women who chose to define their ethnicity on entering the programme as “other”, a total of 1,100. Requested variables such as prior experience of screening or family history were not available from the database.

### ***Administration of the questionnaire survey***

Once approval was obtained from the Waikato Ethics Committee, 1,100 copies of the questionnaires, introductory letters (in which the breast screening programme manager introduced the study – see Appendix 1, page 373), the

information sheet which provided details and contacts for information (see Appendix 2, page 374), a consent form to sign and return (see Appendix 3, page 376) and invitations to participate in focus groups or individual interviews were prepared (see Appendix 5, page 386), along with reply paid envelopes addressed to the University of Waikato. Questionnaires were put in the mail to coincide with a weekend mail delivery in the expectation that the selected women may be more apt to put aside time to answer the questions when they were less likely to be at work.

The sample that had been provided by the staff in the information support service comprised European 476 (481 requested), Māori 370 (379), Pacific Island 77 (100), Asian 64 (74), Indian 50 (58), Other 11 (8). In all, a total sample of 1048 was provided. A request was made for the balance of the requested sample to bring the total to 1,100, which was provided one week later. On the first working day following the mail-out, 48 questionnaires were returned with “gone, no address” (GNA) on them. As a decision had been made to mail out the questionnaires in Health Waikato envelopes, to ensure that women would know that it was a bona fide study, mail was always returned to the organisation’s address printed on each envelope. The 48 GNA surveys were replaced by additional surveys sent to women from the further random sample by clerical staff, without my knowledge.

To protect the anonymity of the women on the database, I was not allowed to access any of the data, including this batch of returned mail. As a result, I had no information about the ethnicity of the women who had not been reached by the mail survey. However, one of the health promotion team analysed the second random sample and found that, with only four exceptions, it comprised European women only, which had an inevitable influence on the resulting sample. A

subsequent request was made for a more representative sample. However, this was unavailable for some weeks. Accordingly, a further 37 questionnaires were distributed from the sample, a total of 1,085 questionnaires.

### ***Response to questionnaire survey***

By the middle of November, 426 questionnaires had been returned. At a subsequent staff meeting in November, the total response of 426 questionnaires was discussed. Subsequently, to minimise non-response bias, (as suggested by Stout, 1994), a reminder letter was prepared and this was sent out in November to the (then) 659 women who had not responded to the questionnaire. (See Appendix 8, page 390). A further 213 responses were received.

In recognition that not even a high response rate can provide confidence about the non-response, which is unfortunately not a random process (Moore, 1991), each questionnaire had been coded, both to allow an assessment of the response bias and also allow reminders to be sent to non-responders. To ensure confidentiality, the staff from the programme put a number on each questionnaire and matched each number to the list of names from the database. When the questionnaires were returned in the reply-paid envelopes addressed to the university, I collected them and listed the code on the back of each questionnaire. Each week I sent the list of codes to the programme staff, who subsequently crossed off the corresponding names on the list, which thus provided an accurate reference for those requiring reminder letters. Coding also provided valuable information about the characteristics of those who both responded late, and chose not to respond at all, which allowed a comparison of populations to assess which groups had responded late and how they differed from “early” responders as discussed below.

Of the 639 (60.5%) questionnaires returned, 611 were completed satisfactorily, providing a usable response rate of 58%, as detailed below in Table 4.1.

**Table 4.1. Sample demographics**

	Questionnaires sent out				Returned		
	Total	Notified GNA* or deceased	Nett	% of nett	Number	% returned within ethnicity	% of total
Asian	64	2	62	5.9	42	67.7	6.9
European	505	7	498	47.2	348	69.9	57.0
Maori	370	11	359	34.0	155	43.2	25.4
Other	11	0	11	1.0	11	100.0	1.7
Indian	64	0	64	6.0	4	6.3	0.7
Pacific Island	71	9	62	5.9	51	82.3	8.3
	<b>1085</b>	<b>29</b>	<b>1056</b>	<b>100.0</b>	<b>611</b>	<b>57.9</b>	<b>100.0</b>
	Incomplete / unusable				28	2.6	
					<b>639</b>	<b>60.5</b>	

\*GNA (gone, no address) excludes the 48 questionnaires replaced from initial returns.

The composition of the population referred to as “other” was combined with the sample of Indian women because of the extremely low response rate for the latter group. It could be asserted that women who chose to nominate their ethnicity as “other”, then described themselves as “British”, “English” or “Scot” could feasibly be combined with the “European” category. Indeed, “British” includes “Scot” and “English” nationalities.

However, in deciding to nominate themselves as “other” and then giving specific nationalities, these women distinguished themselves in the sample population. Therefore, to combine them with another group would have introduced a possible source of bias to the study. As illustrated below in Table 4.2, the responders comprised the following.

**Table 4.2. Ethnicity of those returning completed questionnaires.**

American	1	0.2	Indian	4	0.6
Asian	42	6.9	European	348	57.0
British	2	0.3	Maori	155	25.4
Canadian	1	0.2	Not stated	1	0.2
English	3	0.4	Pacific Island	51	8.3
Fijian Indian	2	0.3	Scot	1	0.2
			<b>611</b>	<b>100.0</b>	

Twelve questionnaires were answered by telephone. Although that option had not been suggested in the questionnaire, in the mail-out I had provided contact details of available people if women required assistance (see Appendix 2, page 374). Accordingly, as some women did not feel confident with written responses, they telephoned to request assistance. Every attempt was made to present the questions in a systematic manner and ensure that there was no oral response from the interviewer that would indicate bias by either perceived acceptance or non-acceptance of any answer provided by the respondent.

Three questionnaires were returned unused and four returned with letters saying that participants were now living overseas. One telephone call was received from an Asian male asking why he had received a questionnaire. When the pilot programme commenced, women were invited from an age-specific electoral roll. Therefore, it was possible that this gentleman's name had been placed on the database from the electoral roll and his inclusion may reflect some cultural misunderstanding or misinterpretation by those involved in the selection of names from this source.

Eight notifications were received by telephone that women who had received questionnaires were deceased, which reflects the difficulties that programme staff experience in attempting to update the database. Possible reasons for this are discussed in Chapter 5. Although the initial 48 GNA letters

were replaced from a further random sample of Waikato women from the database as discussed above, another 21 GNA letters were returned. For simplicity, the 28 (2.6%) questionnaires that were incomplete were eliminated.

## **Focus group interviews with women who had experienced mammography**

As discussed above, survey respondents were also offered the opportunity to participate in either individual or focus group interviews. Focus groups are described by Hughes and Dumont (1993) as “in-depth group interviews employing relatively homogeneous groups to provide information around topics specified by researchers” (p. 776). The groups may comprise any number between three (Kitzinger & Barbour, 1999) and twelve people (Bristol & Fern, 1993), and provide an opportunity for researchers to observe social interaction of the collective group as well as obtain information on specific topics (Kitzinger, 1995; Morgan & Spanish, 1984). It has been suggested that focus groups are “especially appropriate” (Rogers, 1994, p. 214) for health communication research because of their propensity to produce an improved understanding of health problems. As Basch (1987) explains:

Focus groups interviews are particularly well suited to collecting in-depth, qualitative data about individuals’ definitions of problems, opinions and feelings, and meanings associated with various phenomena (p. 434).

The interaction among group members can serve as a catalyst in producing unique data. According to Morgan (1988); “The hallmark of focus groups is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group” (p. 12).

In this research, focus group participants were selected from two sources. The first source, based on considerations of their willingness and ability to participate, was survey respondents who indicated that they would like to be included in a group discussion of issues related screening mammography. Although women were offered the option to attend focus groups or have an individual interview as an alternative to completing the questionnaire, the latter option was nominated on only one occasion.

The second source of focus group participants was women who had indicated to the Māori and Pacific Island community health promoters their willingness to participate, and were subsequently included subject to their availability. These health promoters are employed by external organisations that are independent of the breast screening programme. As advocates for their communities, the health promoters were able to provide essential input into assisting with appropriate venues for the focus groups where Māori and Pacific Island women would be most likely to feel comfortable. The intention was to organise small groups to facilitate close rapport among the participants. Each group was designed to be as homogeneous as possible to facilitate rapport, as suggested by Hughes and Du Mont (1993). To try to reduce the possibility that participants would find the setting inhibiting (a possibility suggested by Stewart and Shamdasani, 1990), arrangements were made so that the groups met in a familiar, safe environment where respondents could feel as comfortable as possible. As Small, Yelland, Lumley and Rice (1999) demonstrated, an approach that is flexible and sensitive to ethnic minority populations in a familiar research environment will enhance the outcomes.

Focus groups were chosen as an option in this research to provide an environment where women could speak openly, express a wide range of ideas and

opinions, and benefit from the support of one another. The primary goal was to provide a forum in which underlying issues and concerns of importance to participants could be explored, thereby avoiding “one of the common failings of questionnaire research, which is exploring only those issues judged to be important by the researcher and thus reflecting his biases and preconceptions” (Leathar & Roberts, 1985, p. 669). Thus, the opportunity to “uncover important understandings serendipitously” (Basch, 1987, p. 433) is enhanced. The potential of focus groups allows participants freedom from a role of being “passive objects of the researcher” (Johnson, 1996, p. 519), encouraging them to provide relevant and useful information. Accordingly, focus groups are frequently used in health research as they provide a forum for obtaining information relevant to uncovering “consumer-responsive” needs (Basch, 1987, p. 423). The process is a valuable tool in exploring individual responses to health care (Wilkinson, 1998) and identifying pertinent reasons why health care services may not be meeting clients’ needs (Basch, 1987), which was relevant to this research.

Depending on analysis of the questionnaire survey data alone would have meant that opportunities for understanding issues would have been missed. As Hughes and DuMont (1993) contend, the interaction within the group provides researchers with access to the language that participants use, the social interaction of those in the group and a range of shared cultural knowledge. Many issues were picked up and expanded on through listening to the group discussion that resulted from pursuing topics of interest to respondents. The contention of Morgan and Krueger (1993) was demonstrated in the research for this thesis:

It can be dangerous to oversimplify human motivation. By comparing the different points of view that participants exchange during the interactions in focus groups, researchers can examine

motivation with a degree of complexity that is typically not available with other methods (p. 16).

The questionnaire data revealed dissatisfaction with various areas of the breast screening service, such as hours available for screening and understanding of oral information. However, women did not specify why they were dissatisfied. It would have been easy to make assumptions about this. For example, there was a large number of working women in the sample, which suggested that they might require more flexible hours outside working hours to attend. However, quantitative analysis indicated that other occupational groups of women were also dissatisfied with the hours and days offered for appointments, although there was no indication why this was the case. However, in the focus groups, respondents were able to explain how they fulfilled family roles of looking after grandchildren or very elderly parents who could not be left while their carers attended appointments. In some cases, women were reluctant to state that they needed to rely on others for transport, or alternatively, often needed emotional support from family members who were in the workplace.

Furthermore, the focus group interaction provided a forum that helped to clarify why some women had trouble with the oral communication processes in the breast screening programme. This provided particularly valuable insight into cultural aspects of each ethnic group, as suggested by Hughes and Dumont, (1993), highlighting subtleties in personal meaning that Basch (1987) contends are not readily obtained through other methods. For example, the data indicated that although women perceived that the staff nearly always explained the procedures associated with mammography, further questioning revealed that a smaller number believed they had received clear explanations, as discussed in Chapter 7. In the focus groups, Pacific Island women were able to explain that

although they “nod their heads and answer, ‘yes, yes’ ” they don’t really understand, but don’t wish to “offend” by asking questions. Māori women likewise explained their reluctance to question the staff during their mammogram. Accordingly, because “the staff assumed that [their] silence implied understanding”, they just carried on. In this way, focus groups helped to elaborate or clarify the underlying complexity of issues that produced some seeming inconsistencies in the data. As Wolff et al. (1993), explain:

On those occasions in which surveys and focus groups examine different dimensions of the same underlying concepts ... the results may lead to deeper insights in to the nature of those concepts than would be possible using either methodological approach alone (p. 133).

Without the use of focus groups, such issues would never have been revealed. As Kitzinger and Barbour (1999) stated of their research into attitudes towards AIDS which also used focus groups, the method provided an ideal medium to explore the “experiences, opinions, wishes and concerns” of women, and allowed them to “pursue their own priorities on their own terms, in their own vocabulary” (p. 5).

However, although the use of focus groups is predicated on the belief that group dynamics are a valuable aid in eliciting information (Lederman, 1990), those dynamics may tend to bias the information. For example, when subjected to enhanced self-awareness in a group setting, people’s attitudes tend to become more polarised, an effect which dissipates beyond the group setting (Bristol & Fern, 1993).

Furthermore, focus groups may also be subject to participation bias. That is, some people in the group may tend to dominate the discussion (Bloor, 1997).

Therefore, it is important that a well-organised discussion where everyone has the chance to be heard is recognised as a “key to a successful focus group” (Rubin, Rubin & Piele, 1993, p. 196). Furthermore, as Basch (1987) points out, findings rely heavily on those facilitating the process, and the standards by which to judge the authenticity of conclusions from the groups are often unclear.

A further disadvantage of a focus group setting can be the influence of group censoring and subsequent conforming. That is, group members may not wish to share their experiences and ideas that they perceive are divergent from the group “norms” (Carey & Smith, 1994). Therefore, it is most important that the process is well mediated by the facilitator. The role of facilitating group dynamics to encourage dialogue and self-disclosure requires careful management (Hughes & DuMont, 1993).

A further limitation of focus groups may be through selection, which is usually achieved through obtaining a purposive sample of those who are willing to participate (Lederman, 1990). Purposive sampling results in a group that does not represent a total population, but some distinct population which has been drawn on the basis of characteristics relevant to the study (Davidson & Tolich, 1999). For this reason, the sample is not necessarily representative of a specific population and therefore generalisability of the data cannot be inferred.

Nevertheless, the two methods of questionnaire surveys and focus groups can be complementary (Bertrand, Brown, & Ward, 1992). Both Bertrand et al. (1992) and Ward, Bertrand and Brown (1991) demonstrated that variables included on both survey data and focus groups yielded similar results, although the focus groups provided additional detail. In this study, the advantage of being able to use focus groups in conjunction with other research methods was that

additional information became available to complement the generalisable data of the questionnaire survey.

### ***Focus group method***

Although all survey respondents were offered individual interviews or focus group interviews, the latter were the primary choice of all those individuals who did respond, regardless of their ethnicity ( $N=146$ ). The one exception was Asian women who did not indicate their willingness to participate in either. As the Asian community health educator was on an extended overseas vacation at the time, I was unable to coordinate any interviews with respondents through her. Also, as the focus groups were eventually held at a time when women were busy preparing for holidays and Christmas, a number of respondents who had indicated their willingness to attend were unavailable at the time of the request.

Focus groups were also the preferred choice for the researcher because, as mentioned above, it was recognised that “focus groups offer a stronger mechanism for placing the control over this interaction in the hands of the participants rather than the researcher” (Morgan, 1988, p. 18). Thus the groups provided a both valid and useful medium to explore the social reality of cultural groups within the constraints of my own ethnicity as a researcher. As Smith (1999) argues, from a Māori perspective:

What makes ideas “real” is the system of knowledge, the formations of culture, and the relations of power in which those concepts are located... These ideas constitute reality. Reality cannot be constituted without them (p. 48).

Recognising the need to allow participants to express their own ideas and reality meant that a semi-structured interview approach was adopted. That is, a schedule

of open-ended questions was devised to encourage intragroup discussion about a number of issues that related to the research questions. This included having a discussion outline which had been carefully devised around the research questions, as well as attempting to facilitate a non-threatening and positive climate in this study to encourage participation, as suggested by Basch (1987).

In total, five focus groups were held with 41 women between November 1999 and March 2000. Two focus groups were held with Pacific Island women, one in Tokoroa with fourteen members of the Pacific Island community in November 1999 and one in Hamilton city in December 1999, with six participants. Although the first group was larger than desired, it was a close-knit church group with participants who interacted well together and were supportive of one another. The first focus group with eight Māori women was held in November, the second with a further group of six in late February 2000. Asian women did not indicate their willingness to participate in either focus groups or interviews. One final focus group was held with seven European women in Hamilton city in early March 2000.

As mentioned above, focus groups were held at times and in preferred locations nominated by participants. The meetings varied in length from between 60 – 155 minutes. Prior to the focus groups, participants received a brief description of the study, and signed a consent form to indicate their willingness to participate (see Appendix 3, page 376). Also, in an effort to establish initial rapport with each participant, each meeting was preceded with light refreshments (some were generously provided by the breast screening programme). During this time, I made sure that I introduced myself to each participant. As with the individual interviews, focus group interview sessions were audio recorded. The tapes were transcribed and then erased. The transcribed material was stored in a

password-protected database to ensure confidentiality. In all focus groups there was an emphasis on assuring respondents of confidentiality.

Material was prepared for the focus groups that converged on issues identified as relevant by each group in the questionnaire survey. Although it was important to identify these issues, women were also encouraged to talk about anything at all that was important to them about the process of mammography or relevant issues, such as breast cancer. Without exception, all women agreed to the group discussions being recorded which enabled me to concentrate on the input and interaction. This ability was further enhanced as the Māori and Pacific Island health promoters consented to being present during each of their own group's meetings. The purpose of this request was so that in the event of any participant becoming upset and needing to withdraw from the group, there would be someone available to provide necessary support. As the health promoters for European women were employed by the breast screening programme, they were not asked to attend the focus group for those women. Another health professional not associated with the screening programme agreed to attend in a support role. However, there were no issues that arose that could not be handled in the groups at any time.

From the beginning, it was made clear to participants in the focus groups that my role was not one of representing the organisation of BreastScreen Midland. I was an independent researcher with an interest not only in trying to understand the issues, but also in obtaining feedback on how women perceived an outcome could be achieved that would meet their needs. The focus group interviews also provided a forum for women to express perceptions that they had not been able to describe in the questionnaire. Such discussions did reveal the process of group members attempting to make "collective sense" of individual

experiences as suggested by Morgan and Spanish (1984, p. 259). The group interaction enhanced my access to the “opinions” and “tacit, uncodified and experiential knowledge” of participants (Johnson, 1996, p. 521). As described above, the evidence from the groups did confirm many of the survey findings and reflected some of the complex issues that underlay the results.

Although there were no difficulties during the focus groups that required intervention, on any occasion that I perceived a participant had signaled any perceptible level of distress during the discussion, I made sure that I approached her after the group had ended to provide an opportunity to talk further about anything that may have arisen during that time. Two women were appreciative of the opportunity to talk quietly without interruption, and in recognition of the confidential nature of these discussions, none of the material is included in this study. Following each focus group, the discussion was orally summarised to ensure that I had not misunderstood the discussion. Written summaries of the discussion were also offered to participants. Only one respondent asked for a copy of the material relevant to her cultural group, and a summary of the group discussion was delivered to her on completion of the data collection along with an invitation to discuss any queries with the researcher. Following a short discussion at the time, no further queries were raised.

### **Individual interviews with participants and staff in the breast screening programme**

A further means of obtaining feedback from those currently involved in the communication role is the use of individual interviews as a research tool. Interviews are undertaken as a means of eliciting individual “accounts” to

generate data related to a research topic. The term “accounts” was popularised by Garfinkel (1967), to explain how people make settings and procedures “account-able” (p. 1). A commonly used form of interviewing technique is a semi-structured interview in which a question guide is used to guide participants who are provided with latitude to discuss those issues they also perceive are relevant to the question. This was the preferred option in this study.

Semi-structured interviews provide a means of understanding the “meaning and significance” individuals provide for their actions (Jones, 1985, p. 46). At the same time, to obtain accurate accounts, it is important that interviews are prepared and carried out in a systematic way to allow for understanding of the interpretive and cognitive processes people use. Properly administered, interviews will provide a first-hand report of everyday experience (Garfinkel, 1967).

Any interview research involves a relationship between the researcher and the researched. Burgess (1991) warns of the danger of “over-rapport” (p. 101) in order to prevent bias occurring. On the other hand, it is also important to develop the confidence of respondents to ensure that they will engender enough trust in the researcher to confidently express themselves. This secure environment is described by Patton (1990) as “empathic neutrality” (p. 58). Such neutrality is not always easy to attain. For example, the cultural orientation of the interviewer will inevitably influence the research (Littlejohn, 1996) and other characteristics “such as gender, personal experience, age and social status” (Burgess, 1991, p. 105) will also impinge on the relationship between interviewer and interviewee, a perspective I attempted to recognise in the participative approach to this research.

Breast cancer is a form of cancer that is rare in men and therefore the breast screening programme targets women. Accordingly, without exception,

participants in this research were women. Finch's (1984) study of clergy wives illustrated some of the ethical problems involved in women interviewing women and the development and potential exploitation of trust in the interview situation. Following Oakley (1981), Finch (1984) recommended the use of less structured interview strategies "to avoid creating a hierarchical relationship between interviewer and interviewee" (p. 72). Furthermore, as Anderson (1993) contends, obtaining feedback that accurately reflects individual experiences requires challenging "assumptions that the knower [researcher] is the ultimate authority on the lives of those whom she or he studies" across cultures (p. 50).

Eliciting a "native" point of view is paramount in a process of generating understanding, which requires trust. The guiding principle of any research containing an interpretive component is founded in the statement from Geertz (1983), that "the world is what the wide-awake, uncomplicated person takes it to be" (p. 89), which requires sensitivity in the language and behaviour of the interviewer to ensure that this "world view" can be presented. Guba and Lincoln (1981) explain that the search for this meaning

is a search for multiple realities, truths, and perceptions. Those multiple realities are contained in the unique, the singular, the idiosyncratic, the deviant, the exceptional, the unusual, the divergent perceptions of individuals (p. 157).

There is some caution expressed about the interview as a source of information, however. Richardson (1992) points out that there has been no evaluation of whether the preferences stated in the context of an interview will correspond with the authenticity of real choice. A number of researchers, such as Bloor (1997), Dingwall (1997) and Radley and Billig (1996) also point out that the purposes of respondents are not necessarily those of the researcher. As

Bloor (1988) and Scott and Lyman (1968) clearly demonstrated, people's accounts are typically a socially constrained process. As individuals are motivated to demonstrate their competence in their current role, their accounts are likely to be constructed. Therefore, a researcher must be aware that interviews will reveal experience and perspectives rather than factual accounts (Emerson, Fretz & Shaw, 1995; Silverman, 1973).

### ***Interview method***

In this study, interviews were all held at a time and location nominated by participants, who had signed a consent form beforehand (see Appendix 3, page 376 & Appendix 10, page 392). The interview sessions varied in length between 45 minutes and 2 hours. With only one exception, where permission to record was declined, interview sessions were recorded, immediately transcribed from audiotape, the tapes erased and the computer file secured.

### **Interview at the Health Funding Authority**

In an attempt to clarify some of the background development of the programme, an interview was held in June 1999 with Elizabeth Bang who had been the previous manager of the Otago and Southland pilot programme. Ms Bang was currently employed with the Health Funding Authority to oversee the BreastScreen Midland programme along with other public health responsibilities.

The Health Funding Authorities (previously the Regional Health Authorities) were set up as a result of the 1991 reform of the health sector to act as intermediaries for government in the contracting process. Staff are responsible for ensuring that health services are provided to their regions in the most effective and efficient way possible. Elizabeth Bang provided useful material, both spoken and written, as she had earlier participated in the review process of the Waikato

pilot programme and had been awarded a Churchill Fellowship, visiting Britain and Europe to observe established breast screening programmes. She also supplied the names of further contacts. The communications manager at the Health Funding Authority in Auckland, Sally Hughes, who was responsible for overseeing the formulation and adoption of nationwide communication strategies for the breast screening service, also provided background information about some of the more recent BreastScreen Aotearoa media communication, but declined an interview.

### **Interviews with mammography unit staff**

When the questionnaire data was almost collected and some trends were emerging, it was late November and an appropriate time to conduct staff interviews as the screening programme was winding down for the Christmas break. All staff involved with women who attended for screening were asked to participate in an individual interview. All agreed, and interviews were held with unit staff members as follows:

- 4 reception staff
- 1 support staff (for clerical and technical support)
- 3 medical radiology technologists (one further staff member who had commenced work in the previous two weeks declined an interview).
- 3 clerical staff who handled the 0800 calls.
- 1 registered nurse (the only participant who declined taping of the interview).

## **Interviews with health promotion staff**

Further interviews were held with all of the health promotion staff, who comprised:

- 1 regional health promoter for the Midland region (the second European health promoter left the organisation in early November).
- 2 Māori health promoters under contract to Raukura Hauora O Tainui, an externally funded health provider. The health promoters were responsible for women in the greater Waikato region (north and south) under a 50/50 contract with the cervical screening programme.
- 1 Pacific Island health promoter under contract to Te Rapakau Health, a community organisation which facilitates health education for the Pacific Island community.
- 1 Asian community educator.
- In addition, the general manager for the cervical and breast screening programmes and the breast care unit manager also granted interviews.

The purpose of talking with all staff was to obtain data to disclose the unique organisational and environmental factors that influenced the approach of breast screening staff involved in communication from the programme. From the commencement of the research in April/May 1999, until the data collection and analysis was completed in March 2000, I attended the regular monthly staff meeting to provide an outline of, and answer queries about, the intended research. Although this was a time-consuming process, I appreciated the opportunity to establish rapport with staff in the hope of engendering their trust. Participants were provided with the background to the evolving research, and the process was updated with them regularly. In early November, staff were asked to leave their names with the Breast Care unit manager and the regional coordinator for the health promoters, if they were willing to participate in planned interviews. At the

time, a schedule of questions was also provided to give future participants some idea about likely questions (as outlined in Appendix 9, page 391). I also believed that this would provide staff with an opportunity to discuss the proposed schedule among themselves in an environment where they were likely to feel more comfortable about either querying or refusing to broach particular issues. The intention was to provide a safe, comfortable environment for them to discuss their perceptions of the process of communication in the breast screening programme.

The purpose of staff interviews was to obtain qualitative data about the messages they provided for women throughout the breast screening process in their roles as organisation members. The goal was to elicit relevant and useful data, or “thick description”, a phrase discussed above and derived from Geertz (1973). Although the interviews could follow the designated schedule, the intention was to allow staff to explore whatever they felt was relevant to their communication roles within the organisation. Consequently, there was an emphasis on providing opportunities for open-ended feedback as much as possible, using semi-structured interviews, as described above.

The semi-structured approach was also used as a guiding principle to facilitate an in-depth inquiry into a “native” point of view, consistent with an interpretive approach. The “native” point of view was introduced by Gregory (1983), who argues that you can only understand culture from participants’ points of view or conceptual worlds. Accordingly, although the schedule was used as a general guide, I preferred to allow participants to discuss whatever they believed was pertinent to issues of communication, and in so doing, was able to develop a “feel” not only for their priorities in their various roles, but also for the culture of the organisation.

## **Interviews with women who experienced mammography**

As discussed above, women who received the questionnaire survey were invited to participate in either individual or focus group interviews. In three instances, respondents requested individual interviews (in one case, in preference to completing the questionnaire), instead of attending a focus group. In each case, there was a high level of distress expressed around issues that had arisen and caused concern for these three European women as they had participated in the breast screening programme. As a result, none of them had chosen ongoing participation in the programme.

These three interviews were conducted in the homes of two women, and at the workplace of the third, as requested. The sessions lasted between 45 minutes and 100 minutes. All three interviews were focused on allowing women to express their feelings and to take the discussion in whatever direction they believed appropriate. The women were pleased to have had the opportunity to discuss their feelings, and each of them suggested that it had been “a relief” to have been able to talk about situations that they did not believe had “been heard by the programme”. As Eckermann (1994) found in her group interviews with women who attended general practitioners, “[T]hey wanted to be listened to, not prescribed to” (p. 292). Similarly, Hunt (1994) records the point of difference in women’s health centres as “we listen” (p. 391).

## **ANALYSIS OF DATA**

In this study, both quantitative and qualitative analysis were combined to provide the advantages of “linking” the two approaches, described by Miles and Huberman (1994), such as using the former to describe patterns and the latter to validate, clarify and illustrate findings. Further advantages of complementary differences in the two types of analysis include the provision of greater detail and

enhancing corroboration through triangulation (Rossman & Wilson, 1985), as discussed above. Furthermore, in this study, the staff interviews also brought new data to the study which provided information about the influences on the production of communication.

## **Quantitative analysis of the questionnaire survey data**

Quantitative or statistical analysis was used in this study to provide a summary of the patterns and responses of the sample population as they experienced the communication processes of the breast screening programme. The choice to use this research strategy was founded on my goal of examining the research questions related to first, how the breast screening programme communicates with women both to encourage them to participate in, and to return for, screening mammography, and second, how women respond to this communication. The research was carried out using a sample stratified by age and ethnicity and a quantitative approach provided a means of identifying differences in the way in which different groups of women received and interpreted the communication from the breast screening programme. The approach also provided statistical generalisations to establish whether the results yielded “typical” patterns that could be related to the social and cultural frameworks further identified through qualitative data collection (as suggested by Bogdan & Ksander, 1980). In this way, the two methodologies were used to complement one another as suggested by Silverman (1993) and Miles and Huberman (1994). Tests of significance provided an objective yardstick against which to test the significance of associations between variables that relate to communication during mammography, such as pain and anxiety.

Exploratory quantitative analysis of the data from the questionnaire survey was carried out to incorporate the advantage of being able to extract a structured overview of the population, as suggested by Maindonald (1999). This could not have been achieved through a solely qualitative approach to data analysis. In recognition of the limits of distinguishing association from cause and effect, inferential statistics were used to draw cautious conclusions and demonstrate generalisability about the experiences of different groups of women who had mammograms. For example, questions were asked about whether variables (such as ethnicity and a reluctance to question staff) simply occurred together, or was there an association between them? Tests of significance were applied using Fisher's exact tests and chi-squared ( $\chi^2$ ) tests for independence in contingency tables to assess the relationships between demographic characteristics and participation variables, and evaluate responses to the programme, further discussed in Chapters 5 and 7.

As the survey data generated primarily nominal data, chi-square was an appropriate choice (Davidson & Tolich, 1999). Similarly, the use of Fisher's exact and chi-square tests for independence were appropriate to assess any possible association between variables. The chi-square test is a theoretical probability distribution, based on the assumption that there is no association between variables; they are independent, as demonstrated in a set of expected frequencies (Lapin, 1980). However, it is always possible that even if an association between variables is demonstrated, it may have resulted from normal sampling error. Accordingly, the chi-square test is based on the same sampling assumptions as that of confidence intervals, that is, a sufficient number in the sample to lower the possibility of sampling error (Levin & Rubin, 1980), as discussed above. In this research, categories "other" ethnic group and "over 65"

age group, with only 15 and 12 women completing the survey respectively, were not included in the chi-squared analysis of contingency tables or Fisher's exact 2x2 tables because of the small number of women in those categories.

In the case of chi-square, the sample size must be large enough to guarantee the "similarity between the theoretically correct distribution and the sampling distribution" (Levin & Rubin, 1980, p. 367). Therefore, the minimum number of expected frequencies in any one cell must be at least five to meet the underlying assumptions. If possible, where appropriate, in cases where the cell frequencies are smaller than five, categories are collapsed into one. In this study, for example, sometimes "very satisfied" and "satisfied" may become a single category.<sup>7</sup> The chi-squared statistic is the sum over all cells, of the quotient of the squared difference between the observed and expected frequencies, divided by the expected (Frey et al., 1991). Analysis will not only indicate the strength of the observed relationship ( $\chi^2$ ) but also determine the statistical significance of the observed relationship ( $P$ ). Fisher's exact test provides the same information, but can be used only when there are 2 categories of information for each variable (a 2x2 table). In this research, the nominal 5% significance level is used for a significant result.

Initially, the collected data were entered into a dedicated database designed in Microsoft Access. The questionnaire data resulting from the initial pre-test were used as a trial basis to provide insight into the efficiency and reliability of the data entry process. Some amendments, such as an audible alarm sounding if an incorrect key was struck, were made to ensure that every opportunity to safeguard reliability was taken. Silverman (1993) suggests that reliability will be

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<sup>7</sup> Wherever categories have been collapsed for statistical analysis in this thesis, it will be noted.

enhanced through consistency and accuracy in coding of data. Accordingly, regular checks were put in place to maximise consistent accuracy of data entry. For example, at the end of every week, a random ten percent of that week's coded questionnaires were checked for accurate coding. Also, at the completion of coding, a random check of the data entry was carried out by another graduate researcher in return for a reciprocal random check of her own data entry. An exceedingly low error rate was identified.

The coded data were subsequently put into frequency tables and graphed to try to identify any patterns that were occurring. Various tests were run as an exploratory data mining process, to identify relevant data trends, with a heavy dependence on the use of graphs. In the words of Levin and Rubin (1980), "graphs of frequency distributions are useful because they emphasise and clarify trends that are not so readily discernible in tables" (p. 28). As graphs work in the same way to "attract a reader's attention to trends in the data" (Levin and Rubin, 1980, p. 28), they have also been used in preference to tables whenever possible in this study. Whenever ethnicity or age were variables of interest, either frequency histograms or stacking graphs are used to illustrate data. Because of the variation in sample sizes of ethnic groups, percentages were used to clarify the trends in the data. The exceptions were multiple-response categories where totals did not equal 100%, as respondents could nominate more than one variable.

Nevertheless, as Bogdan and Ksander (1980) caution, the very act of "counting is an attitude we take toward people, objects, and events ... [which can be used to] exaggerate the degree to which ours is a world of 'facts' " (p. 303). Therefore, although quantitative analysis was used to establish data patterns, it was also enhanced with the use of qualitative interpretation to clarify and expand the analysis of data in this research.

## **Qualitative analysis of survey, focus group and interview data**

As Guba and Lincoln (1981) point out, quantitative methods may not necessarily result in useful and meaningful outcomes for all research questions. Interpretive research, which typically focuses on how people respond in particular settings, requires more than mere quantification. The feedback from the questionnaire surveys, focus groups and staff interviews provided the material for qualitative analysis in this study. The questionnaire survey generated 1248 comments from respondents. Of these, 685 were prompted responses solicited about various communication products, such as pamphlets, posters, radio or television. The remainder, however, were unprompted responses made in the various comments sections provided throughout the survey questionnaire.

Further insight into basic questions about interpretations of what individuals may reveal through their communication can be attained through qualitative approaches such as analysis of narrative themes, as discussed above and outlined below.

### ***Thematic analysis***

The three criteria adapted by Owen (1984) for identifying narrative themes are repetition, recurrence and forcefulness. Repetition is an explicit, repetitive use of the same “key words, phrases, or sentences” (p. 275). Recurrence may be identified when the “same thread of meaning” (p. 275) occurs, even though this meaning may be embodied in different words. Forcefulness refers to “the underlining of words and phrases, the increased size of print or use of coloured marks” in written material, or “vocal inflection, volume or dramatic pauses” (pp. 275-276) in spoken dialogue. Also, as with any form of content analysis, the

most important requirement is that the coding of categories (in this case, themes) “must adequately reflect the investigator’s research question” (Holsti, 1969, p. 95). The approach to analysis was threefold, as illustrated below in relation to identifying themes relevant to participants.

First, to ensure familiarity with the material, the transcribed interview and focus group material and the comments from the questionnaire survey were read on several occasions over a number of weeks. As Ricoeur (1981) recommends to interpretive scholars, “to understand is not to project oneself into the text but to expose oneself to it” (p. 95). Repetitiveness and recurrence were identified after several readings of the data to identify those themes relevant to the research questions. For example, in this study, although the word “anxious” was used repetitively as a descriptor, associated words such as, “worried”, “stressed”, “upset” and “frightened” were also used to describe the type of anxiety experienced by respondents; therefore these words were identified as recurrent descriptors of anxiety.

The third criterion of “forcefulness” was identified where respondents underlined or capitalised words, or used any number of exclamation marks in the questionnaire survey responses. As all comments and punctuation were transcribed directly from the questionnaire, forcefulness was immediately apparent. In the focus group or interview transcripts, forcefulness was indicated by a raised tone of voice, repetition, pauses or marker phrases. Oral emphasis was indicated by capital letters in transcription. The process was repeated with the transcribed interview material from staff interviews. As mentioned above, one further criterion emphasised in this study was that only themes that were related to the three specified research questions were included.

Although Owen's (1984) framework was helpful in organising the data, it offered little input into the process of interpretation; consequently, I looked further afield for assistance. In attempting to identify a framework to enhance the process of interpreting the data, I looked to one of the most noted interpretive scholars who incorporates an interpretive and critical approach, Paul Ricoeur. Ricoeur (1981), talks about "narratives" as being "reduced to a combination of a few dramatic units which [are] the paradigms of action" (p. 156). He explains:

A sequence is thus a succession of nodes of action, each closing off an alternative opened up by the preceding one. Just as the elementary units are linked together, so too they fit into larger units. To explain a narrative is to grasp this entanglement, this fleeting structure of interlaced actions (p. 156).

To begin the process of further identifying narrative themes, I first adopted a retrospective approach, which Ricoeur (1981) refers to as " 'dechronologising' the narrative" (p. 156) and looked for "nodes of action" that would be likely to contribute to narrative themes, which I describe as outcomes. For example, an identified outcome was that over 50% of Māori and Pacific Island respondents described the breast screening programme as either "scary" or "isolating", or both. The next step of identifying the "elementary unit" or the manifestation of the theme that resulted in the above experience revealed an expressed need for personal contact that the same women reported as lacking in the programme. The "larger unit", or the "entanglement" of the "interlaced actions" was a perception of a *lack of recognition*. The theme was thus categorised under a "structure" or "larger unit", which resulted from the "interlaced actions" of the women's experience as *unrecognised cultural needs*, discussed in Chapter 7. The same

approach was used to interpret and organise the remaining data, and the resulting themes are illustrated in Tables 6.1 and 7.1 in Chapters 6 and 7 respectively.

Finally, as noted above, it is of significance that all interviewees in this research were women. Altheide and Johnson (1994) and Gal (1991) assert that meanings are also communicated through both the cultural context and prior experience of participants. “It is the context that provides for interpretive meaning” (Altheide & Johnson, 1994, p. 496). Accordingly, in recognition of the sociological perspective that illustrates socialisation processes where “women are socialised to be nice, polite, quiet,” (Smith, 1991, p. 12) and thus “may be unwilling or unable to express strong emotions like anger” (Planalp, 1999, p. 57), interpretation was not just a matter of listening to what was said, but also to that which was not said. A theme that illustrates this propensity most clearly is that of *ambivalence*, which is discussed in Chapter 7.

Themes were important to this study as there were a number of participants (611 survey respondents, 44 focus group and individual interview participants and 19 staff interview participants), and the method not only provided an interpretive framework, but also a means of organising large batches of data. To assist readers to distinguish various themes, the relevant phrases that have been selected as representative of those themes in this thesis are presented in italics.

Transcriptions of interview quotations incorporate a slight hesitation as (-).

Pauses are indicated by a series of round dots; one round dot equals a one second delay (thus, a 4 second delay would be indicated as °°°°).

Emphasis resulting from a raised tone of voice, pause, marker phrase or repetition in the focus group and individual interviews is accentuated in the text by the use of capital letters.

As the responses to the questionnaire were directly transcribed, forcefulness indicated by underlining, capital letters and exclamation marks is immediately

apparent. Although identifiers have been provided in the interview excerpts from staff respondents, there are no identifiers used in the quotations from survey respondents. In the case of staff interviews, to protect the respondents' anonymity, only excerpts from the transcripts were used.

### **Secondary interviews**

A further goal of interpretive research is understanding, a dialectic process which occurs as meaning is produced between people (Deetz & Kersten, 1983). Accordingly, it is a central tenet of interpretive research that "accounts should be plausible to organizational actors" (Deetz, 1982, p. 145; Koch & Deetz, 1981; Potter & Wetherell, 1987). As a researcher, I was aware that I had obtained only "snapshot" views of the organisation in my periods of interaction with staff, and had relied on anecdotal examples in interview material as a source of data.

It has been suggested that conducting multiple interviews will provide a means of checking on the validity (Frey et al., 1991; Morse, 1994), or credibility (Kincheloe & McLaren, 1994; Tompkins, 1994) of the research. To enhance the validity (or credibility) of the interpretation of qualitative data in this study, identified emergent themes from the questionnaire survey were discussed in the focus group and individual interviews with forty-four respondents. Furthermore, five staff from the breast screening programme were interviewed for a second time in June and July 2000. The purpose was to ensure that my interpretation of emergent themes was consistent with the interpretation of those who participated in the staff interviews. If, as Zorn and Ruccio (1998) suggest, analysis of themes allows the researcher to identify common themes while still "preserving individual perspectives" (p. 480), it was important to ensure that, wherever possible, the narrative themes identified in this study did indeed provide a genuine representation of the perspectives of all interviewees. Accordingly, their

responses to identified themes would help to identify instances where I may have imposed my own thinking as a researcher, that is, introduced a possible source of bias. The secondary interviews with staff lasted between 90 and 120 minutes. With only one exception, staff substantiated identified themes as being representative of their organisational experiences. However, the most predominant theme of *the business of screening* elicited some measure of surprise and resistance from both groups. The responses from staff in the breast screening programme to all identified themes are discussed in Chapter 6.

## LIMITATIONS

It was recognised that although obtaining a random sample of women who had participated in Round 3 from the breast screening database provided a sample of women who had been exposed to the communication from the breast screening programme, it also eliminated those who had not attended. Taking only those women registered on the database introduced a source of bias to the study, meaning the results may not be generalised beyond the database to Waikato women in general.

Additional bias resulted because the respondents, 61% of those surveyed, were self-selecting. That is, they were the women in the sample population who had made a decision to respond to the questionnaire. To account for the non-response bias, the 213 surveys returned after the reminder letter was sent in late November were coded as “late returns”. The responses from this group were separated in SPSS, analysed and compared with those of earlier returns. The only identifiable difference between the two groups of “early” and “late” returns was that there were 11% more women in the workplace who returned their questionnaire “late”, or subsequent to a reminder letter. Also, there were 9%

more Māori women and 12% more Pacific Island women who returned their questionnaires in the “late”, rather than in the “early”, group. There were, however, no significant differences among variables between respondents in the “early” and “late” groups, such as experience of satisfaction, anxiety, pain or reassurance obtained from mammography, which suggests that the sample was likely to be representative of the remaining population of non-responders in this study.

In obtaining a sample stratified by ethnicity, I attempted to recognise that ethnicity has an important influence on health status. As noted by Kilgour (1991), however, ethnic minority groups typically comprise only a small percentage of the population. Therefore, “representative samples may not include enough members of minority groups to allow for meaningful statistical analysis” (p. 21). Although a census sample was taken, the under-representation of ethnic minority groups on the database meant that numbers were small even though the response rates were higher than expected. It is interesting to note the low response rate for Indian women (4), who do not have a community worker. In this study, where the resources were available, every effort was made to adopt a personal approach that would maximise the response of Asian, Māori and Pacific Island women. Rohipa (1994) asserts that New Zealand has a multicultural population and if communication has been “developed from an individualistic point of view” (p. 15) that typifies a European style, it will not be accepted. Accordingly, “Strategies must be implemented to overcome the barriers which result from the different environments” (p. 15). In this study, health promoters delivered and collected as many questionnaires as possible to some Māori, Asian and most Pacific Island women. Nonetheless, it is also recognised that the ensuing interaction between

those delivering and completing the questionnaire may have influenced the responses from those women.

Furthermore, the women who chose to respond to the questionnaire were highly committed to screening, with 99% considering that regular mammography was important, which illustrates a possible voluntary response bias. As Moore (1991) contends, those who choose to respond to questionnaire surveys tend to be individuals who have strong feelings about the issues at hand. This tendency is further demonstrated in the polarity of responses in the data resulting from the questionnaire survey.

The process by which this study was generated, interpreted and communicated was inevitably influenced by the researcher. As Thomas and Veno (1996) point out, “research is embedded in the values of researchers and cannot be a value neutral activity” (p. 289). The development of the research questions, the process of analysis and thus the outcomes of this study were ultimately shaped by my personal prejudices and values. Influence was also likely to result from the preconceptions of health care and communication I had developed over my twenty-five years of experience as I progressed from a trainee nurse to a nurse manager in the private and public health sector in New Zealand. However, this experience did provide the advantage of being what Kasper (1994) refers to as being an “informed researcher” (p. 269), which she asserted was essential in helping to understand the terminology the 29 women in her study used to explain their experience of surgery following breast cancer.

Although I had no experience in community health programmes, I did have knowledge of medical terms which helped to facilitate a flow of information, uninterrupted with requests for clarification or explanation of medical terms that may have been necessary for someone who lacked familiarity with the language.

This was an important benefit during the process of developing, pre-testing and implementing the questionnaire, as I was able to readily relate to terms in the literature, and descriptions from both staff and respondents. Also, during staff interviews, there was no interruption when medical terms were used, as participants explained the intricacies of the world they inhabit as they carry out the procedures of breast screening. Equally so, in the focus groups and individual interviews, my prior knowledge, both as a woman and health professional, helped to facilitate understanding of explanations about both the medical and the social world of those involved in screening mammography.

However, as Gadamer (1976) asserts, “[T]he prejudices which make understanding possible also entail possibilities of misunderstanding” (p. 121). I believed that participants were bringing considerable knowledge and skills with them into this research and my need to develop understanding was critical to the interaction. But I also recognised that this research was inevitably influenced by my ethnicity that constrained my ability to comprehend some differences that were expressed by participants, particularly in focus groups, and sometimes clarification was necessary. Smith (1999) rightly points out that researchers bring their own dominant cultural orientation into a study, which may confound understanding.

Furthermore, I realised the need to be ever aware of imposing my own cultural orientation, values and conceptualisations on the expressed reality of the group participants. My goal was to attempt to give ascendancy to alternative conceptions or “ideas [that] constitute reality” for minority cultures (Smith, 1999, p. 48) and thus obtain relevant feedback. However, as Ehrenhaus (1983) reflects, “Making sense simply does not mean making sense accurately” (p. 268) when

communicating across cultures. Although every attempt was made to work empathetically with ethnic minority groups throughout the research process, as Stanfield (1994) contends:

[A]utobiographies, cultures, and historical contexts of researchers matter; these determine what researchers see and do not see, as well as their ability to analyze data and disseminate knowledge adequately (p. 176).

Furthermore, consistent with an interpretive approach that recognises that any interpretation is inevitably “a product of perspective” (Littlejohn, 1996, p. 223), it could be argued that the narrative themes identified in this study are not only a result of the emphasis and repetition of organisational members; they are also a result of my own interpretation of the data.

Although it is recognised that the qualitative analysis in the following chapters may provide only one possible interpretation of the data, the rigour of the analysis to ensure the veracity and credibility of the research is outlined above. Every effort was made to establish a trustworthy interpretation, which Guba and Lincoln (1989) and Janesick (1994) contend can be met in two ways; credibility, through verifying the results of the research analysis with participants and dependability, through an audit of the data, as explained above. To ensure credibility, I consulted available interview participants to ensure that the interpretation was credible to them. To make sure that the themes identified from the staff interviews were consistent with the interpretation of the nineteen participants, secondary interviews were held with five staff. Their feedback on identified themes is included in Chapter 6. Also, results from the analysis of the questionnaire survey were verified through discussion of identified issues with 44

women in five focus groups and three individual interviews. A number of their comments are included in Chapters 5 and 7.

It was also recognised that completion of the questionnaire survey in this study relied on retrospective self-reports of prior experience of mammography. Self-reporting inherently depends on women's ability to comprehend and accurately report these behaviours; therefore it is important to assess the validity of self-reporting. King, Rimer, Trock, Balslem and Engstrom (1990) demonstrated that they were able to verify 94% of records for women who reported having recently participated in mammography (within the previous year). Similarly, Zapka et al. (1996) validated 83% of reports related to the mammography experience across ethnically diverse groups of women. In the current study, 71% of respondents reported having had mammograms within a year, 15% could not recall when they had their last mammogram, and only 14% had been screened at an earlier date.

Finally, although every precaution was taken, and every attempt made to enhance the rigour and validity of the research, the scope of the study was also constrained primarily by time and cost. However, this is typical of research projects. Although research may be carried out with the utmost rigour, Patton (1990) reminds us:

There are no perfect research designs – there are always trade-offs because of limited resources, limited time and limits of human ability to grasp the complex nature of social reality (p. 162).

Nonetheless, restrictions in resources and time do not need to imply that research cannot be carried out well.

## CONCLUSION

This chapter has provided the background methodology which underpins the theoretical perspective, data collection and analysis for this research. The interpretive approach, which developed from classical phenomenology through philosophical hermeneutics, provides an approach that is consistent with the goals of this research, which focus on interpretation and understanding of the communication processes in the breast screening processes. As there are various participants in the breast screening programme, who occupy a number of roles, there was a need to allow their individual perspectives to surface. The need to facilitate this process was an important focus, not only because of the different roles of participants, but also because of the socio-cultural differences within the groups which impacted on the way in which the communication would be interpreted. Such differences were important to the questions that underpinned this study.

As there were a number of issues inherent in health communication, such as institutional and professional power, a critical perspective was also adopted to reveal the underlying “deep” meaning of communication in the study. The framework of triangulated methodologies provided an opportunity to allow a multiple approach to data collection and analysis. This not only provided multiple sources of data, but also allowed data from one source (such as the questionnaire survey) to be verified or differences explored through other methods (such as focus group interviews).

The second section presented the background that influenced my decisions to carry out this research and those perspectives that were responsible for my decision to incorporate a consultative approach to participants. The various methods of data collection, with their inherent advantages and disadvantages, and

the ways I dealt with those followed. The case study approach was used to help to define the parameters of the research. Within these parameters, the process of designing, developing and implementing a mail questionnaire survey to obtain a wide spread of responses from women participating in the breast screening programme provided a confidential and accessible means for women to relate their experiences. The five focus groups and twenty-two individual interviews also generated further data that provided information about the perspectives of both the staff and the women who had participated in screening mammography.

The eventual analysis of the resulting data, which combined qualitative narrative thematic analysis and quantitative statistical analysis using Fisher's exact test and chi-square tests for independence in contingency tables provided a complementary multi-method approach. Such an approach not only highlighted general trends, but also gave precedence to the individual experiences of communication within the breast screening programme. The findings that resulted from the above approach are presented and discussed in the following Chapters 5, 6 and 7.

## CHAPTER 5

### THE COMMUNITY INTERFACE: ENCOURAGING ELIGIBLE WOMEN TO ATTEND

As explained in Chapter 2, the breast screening programme is a disease detection intervention promoted in a community context. The purpose of this chapter is to provide insight into the interface between the programme and community, thereby addressing the first research question guiding this research: How does the breast screening programme communicate its presence to eligible women in the community, and how do women receive this communication? As discussed in Chapter 2, the breast screening programme has a two-fold goal in communicating with eligible women: first, to encourage initial participation, and second, to encourage ongoing, regular participation. The first goal of encouraging women to join the programme is the focus of this chapter.

The programme interface with the community can be identified as relying on two distinct approaches to encourage women to participate in the screening mammography programme; “transactional” and “interactional” communication (Brown & Yule, 1983, pp. 1-3), as outlined in Chapter 1. There are nine “key messages” that underlie all communication from the programme. These are discussed in the first part of this chapter. Second, the transactional resources used to convey information about the breast screening programme - the pamphlet, poster and letter of invitation - are outlined. A brief discussion follows about the

recent BreastScreen Aotearoa resources of the pamphlet and television advertising campaign that were also identified by women in the questionnaire survey. As outlined in Chapter 4, the resources for the national programme were being released at the time of the research. Accordingly, most respondents had not seen any of the material.

The second section of this chapter primarily focuses on how women respond to the communication from the breast screening programme. As the two phases of communication from the breast screening programme (transactional and interactional communication) outlined above are so distinct, analysis in this chapter will focus on the first phase of communication which occurs in a community context. This discussion contrasts with that in Chapter 7, in which I discuss women's responses to the communication experiences with staff in the breast screening programme, which are more likely to relate to decision making about ongoing participation in screening mammography.

As the social context of respondents inevitably influenced the data produced in this research, the demographic population comprising the sample is described in terms of its significance to the responses generated by participants. Women's awareness and understanding of the nine "key messages" referred to above are then assessed. Following this, responses of the target audience to various transactional strategies are examined to assess both the visibility and the influence of each approach.

Because the breast screening service is founded on a medical paradigm of early detection of disease, there is an inevitable interface between the target audience and community health professionals such as general practitioners. Accordingly, the influence of interactional communication which expresses interpersonal communication between respondents and general practitioners in a

community context is briefly discussed. Analysis of relevant quantitative data generated from the questionnaire survey is outlined. The quantitative analysis is supplemented by some of the anecdotal comments originating from the questionnaire survey, focus groups and individual interviews with participants. These comments have been directly transcribed and are presented in the format explained in Chapter 4 (page 156). Finally, the overall success of the communication process is evaluated through comparison of the most recent regional census population with programme participation data.

## **COMMUNICATING THE SCREENING PROGRAMME**

### **Key messages**

As Austoker et al. (1995) contend, the effectiveness of a breast screening programme is directly linked to providing information from which women can make informed decisions. Any informed decision making process relies on not only available, but also accurate, information. In communicating with eligible women, the breast screening programme employs specific resources to provide information about mammography. All material for the national programme, such as pamphlets, posters and health education kits, is provided through the Public Health Coordinator for the Health Funding Authority in Auckland, and is based on nine “key messages” that communicate the presence of the population-based screening programme to a target audience. Information is also provided through health personnel to help facilitate decision making in the community.

In 1996, subsequent to the announcement about a national breast screening programme, the Business Research Centre was commissioned by the Prevention Policy Department of the Ministry of Health to identify what messages were pivotal to successfully communicating screening mammography. The stated

purpose was to target three “priority groups”: those eligible women who had not taken part in the programme, those who were ineligible (under 50 years or over 64 years of age), and those women who were currently participating in the programme (O’Halloran & Kalafatelis, 1996).

Material from the Cancer Society’s Breast Information Programme was used to develop a programme of key messages for all organisations that are involved in providing screening mammography services, by the authors, O’Halloran & Kalafatelis (1996). They state that the objective in establishing communication guidelines for the programme was to develop “consistent and recognisable key messages” (p. 10) that would be appropriate to specific groups of women. The resulting strategies and resources (such as pamphlets, posters, and health education materials) are all allocated through the Health Funding Authority.

The nine key messages are these:

1. Nearly 10% of women in New Zealand develop breast cancer.
2. The risk of developing breast cancer increases with age.
3. Free mammograms (breast X-rays) are available for women aged 50 to 64 through the National Breast Screening Programme.
4. Screening mammograms detect breast cancer before you can feel or notice anything unusual.
5. Early detection and treatment can save lives.
6. Mammograms need to be repeated every two years.
7. Most women who have mammograms will be reassured they don’t have breast cancer.
8. Most women who develop breast cancer have no relatives with the disease.

9. Women of any age who feel or notice anything unusual about their breasts should seek advice from their doctor.

The purpose of the key messages was to provide “key emotional benefits” for each group of women (O’Halloran & Kalafatelis, 1996, p.3). For example, the authors anticipated that women who had not yet participated in the breast screening programme would respond to the key messages in this manner:

When I take part in the breast cancer screening programme by having a mammogram, I will receive reassurance and feel confident about monitoring my breast health. Therefore I am being responsible and taking good care of myself (p. 4).

The messages recognised the “three key areas of misperception” identified at the time: first, an exaggeration of the incidence of breast cancer; second, a lack of understanding of the cause, with an over-emphasis on family history; and third, an over-emphasis on breast cancer occurring at a younger age than it does (O’Halloran & Kalafatelis, 1996, p. 11). A further purpose of the key messages was to address these areas of misinformation.

## **Resources for communicating the breast screening programme**

### ***Pamphlet and poster for the pilot programme***

When the Waikato and Otago and Southland pilot programmes commenced in 1991, no key messages had been established. One pamphlet was designed and printed, and the front of the pamphlet used as a template for a poster that staff used to promote the programme. The pamphlets and posters were designed by each of the two pilot programmes. Otago and Southland produced their version based on information from overseas and guidance from the Ministry of Health (E. Bang, Health Funding Authority, personal communication, August 14, 2000).

The Waikato pilot followed the same format in producing their pamphlet (see Appendix 11, page 393). The poster was a larger replica of the front page of the pamphlet.

The pamphlet was included with the letter of invitation sent out to women when they had registered with the breast screening programme. The outside cover of the pamphlet was a pale blue-green, with black and white print. The cover/poster had at its focal point a black and white photograph of four women of different ages and ethnicities. One Māori woman who appears to be in her early fifties, one Pacific Island woman, of about the same age and two European women, one perhaps in her early fifties, and one who appears to be in her sixties were on the cover. The younger European woman was standing at the back with her hands on the shoulders of the Māori woman and the older European woman. In turn, the older European woman had her hand resting on the shoulder of the Pacific Island woman who was seated in the chair. Thus, the impression of a “group” was sustained.

Across the top in large capitalised print were the words “A BREAST X-RAY” then on a line below “is a positive personal statement that you care about your health”. Under the photograph of the women, there is a statement saying “Take Part in the Waiora Waikato Free Pilot Breast X-ray Programme for Waikato Women aged from 50 to 64 years”. It appears that making “a positive personal statement” is linked to an obligational clause to “take part”. The Health Waikato Logo “Caring for Life” was on the bottom of both the pamphlet and the poster. The latter had a white square inset for staff to write relevant information. As these posters were often distributed a week or two prior to the arrival of the mobile screening van in a rural area, the date and time when the van would attend were often written in this space.

The inside of the foldout pamphlet contains black print on a white background, apart from the heading and questions which were presented in the same blue/green colour as the cover. Inside, a question and answer format addresses questions that relate to mammograms. It is clear and straightforward, using simple language. The word “mammogram” is introduced in parenthesis and the more common, probably more easily recognisable phrase, “a breast X-ray” leads the opening comment, which is introduced as “a safe, easy way to care for yourself”.

Most of the answers are personalised with the use of “you” and “your”. The first answer, which responds to the question, “Why should I have a breast X-ray?” includes a final comment that is italicised, the only sentence in the brochure that is. It states, “Most changes detected in breast tissue are not cancer.” That point remains an important message from the programme, and perhaps that is why it was highlighted in that manner. However, this pamphlet was sent to women over 50 years of age, a population in which 50% of women who present with lumps will experience a diagnosis of cancer (Moskowitz, 1992).

All other responses are similarly personalised using “you” or “your”, thus are strongly individualised, which is in direct contrast to the group of women presented on the front cover. An individualised stance is in line with the “discursive economy of market research ... [in which] discourses of nationality and race shape the information produced” (Astroff, 1997, p. 130). As a result, the tenets underlying the western, capitalist model of health care were ascendant.

In the pamphlet, issues of eligibility are discussed second. The pamphlet states that “the benefits of screening have so far been demonstrated only for women in this [50 to 64 years] age group”. However, this ignores the body of research that demonstrates that breast cancer has always increased in incidence

with age and those 65 years of age thus benefit more than those of 50 years of age from regular mammography (H. Chen et al., 1995; Sutton & Balmer, 1994).

The third question in the pamphlet is “When can I take part?” Women are told that they will receive an invitation in the mail with an appointment date. The pamphlet contains a request for women to telephone to confirm a time. This assumes that all women have access to a telephone, and if they do, also have the language skills that enable them to communicate easily.

The pamphlet also assures women that the service is free and costs “only a little of your time”. The fact that it is “absolutely free” is further emphasised by underlining. However, as Hurley and Livingstone (1991) demonstrated, there are numerous psychological and financial costs, such as travelling and opportunity costs to women who attend even a free breast screening programme.

The next question in the pamphlet is: “What happens when I have a breast X-ray (mammogram)?” The response is, “You will be welcomed by our friendly staff” and further “asked to prepare for the X-ray by undressing from the waist up”. This is followed by reassurance that the “programme is staffed solely by women”. A further question: “How is the X-ray taken?” is answered with a description of how the breasts are “placed between two plates on the X-ray machine and the pictures will be taken. This will allow all the breast tissue to be seen in the picture”. However, there are two deficiencies in this statement. For one, all the breast tissue cannot be exposed to X-ray, hence part of the reason for the false negatives described in Chapter 2 (Love, 1990). Second, the breast tissue is “peeled” up from the chest wall on to the plates by gradually applying pressure and an upward motion to the chest wall below the breast. The same process applies a downward motion to the top of the breast. Accordingly, the medical radiation technologists (MRTs) need to handle the breast to an extent that some

women may find excessive. It is an important part of ensuring a comprehensive mammogram. Nevertheless, it could be argued that women would benefit from knowing that beforehand. As Marteau et al. (1996) demonstrated, clear, simply-phrased education booklets that outlined procedures beforehand helped to alleviate anxiety about health care procedures.

The question: “How does it feel?” receives the response, “You may find it uncomfortable because the breast is held quite firmly for a few seconds while the X-ray is taken”. However, this fails to acknowledge that research has demonstrated that women also find it painful. For example, they describe the plates as hard and cold and the compression excessive (Eklund, 1991; Keefe et al., 1994). On the basis of the information in the pamphlet, women would be totally unprepared for anything other than discomfort.

The response to the question, “Is the X-ray safe?” is affirmative, and assurance that benefits “far outweigh any risks” of the procedure follows. The further two questions relate to the length of time at the clinic and when results will be available. There is a brief reference to the possibility of a follow-up, which is qualified by a statement in capital letters, “REMEMBER – MOST WOMEN CALLED BACK DO NOT HAVE BREAST CANCER”. Once again, the message is one of reassurance. Otherwise, the pamphlet does not acknowledge the fact that research has identified that anxiety is associated with breast screening, as described in Chapter 2. The final three questions relate to whether the doctor will be involved, prior mammograms, and women who have had a previous mastectomy. There is a directional map on the last page.

Overall, the pamphlet appeared to provide relatively little information about the process of mammography. For example, for radiology purposes, it is important that women do not use talcum powder or deodorant prior to their

mammogram. An MRT explained that the aluminium in powders or deodorants shows up as white flecks, which mimic calcium deposits on film, often an indicator of the presence of cancer (V. Smith, personal communication, December 1, 1999). Although women were told not to use talcum powder (on the very last page), there was no mention of deodorant. However, the pamphlet may also have been influential on another level. It could be argued that a personalised, individualised approach introduced the possibility that, if attending for a mammogram is a “positive personal statement” implying self-responsibility, it logically follows that choosing not to take part is the opposite.

### ***Letter of invitation***

The letter of invitation is sent to eligible women who have enrolled in the programme. A template of the letter that was current at the time of the research is in Appendix 12 (page 397). The template is personalised with the woman’s name; however, apart from the manager’s name at the bottom, there is no personalisation of the programme in the contents. The letter opens with the not very welcoming capitalised statement, “IF YOU ARE OVER THE AGE OF 65, PLEASE DISREGARD THIS LETTER”. That statement is followed by another in bold, issuing an invitation to attend the unit “situated in the Waikato Hospital grounds”. The “free service” is emphasised, and followed by a statement that “finding breast cancer early offers the best chance of cure”. However, that is only likely to be the case if, one, the cancer has not yet metastasised, and, two, if the tumour is treatable (Moskowitz, 1992).

Once again, as in the pamphlet, women are given a telephone number to call to arrange a time. This letter was sent to women throughout the greater Waikato region from Coromandel to Taumaranui. A number of those women may not

have had access to telephones. Others may not have been able to afford the cost of a toll call. The letter provides an appointment day only, and women are exhorted to “cancel”, so that “we may offer it to someone else” if they are not planning to attend. Perhaps such directives are not terribly welcoming or comforting if a person is experiencing some apprehension about the process that lies ahead. The letter concludes with the salutary, “We look forward to hearing from you soon”, which once again requires access to a telephone.

### ***BreastScreen Aotearoa resources***

#### **Promotional material**

As mentioned above, with the advent of the national screening programme in December 1998, a decision was made to establish a set of resources that would meet the needs of women throughout the country. However, as the majority of women in the questionnaire survey were not aware of this material, it will be only briefly outlined.

In the middle of 1999, BreastScreen Aotearoa, the national programme, distributed a comprehensive range of educational material, including presentation kits comprising a video, booklet and flipchart to the six national contract holders. The kits were provided for health promoters to use in their presentations in the community. However, as these resources were still being distributed throughout the greater Waikato region when this research was in progress, only six respondents referred to the “new” pamphlets. This discrepancy was picked up in the pre-test for the questionnaire survey which had a question detailing each of the new pamphlets, asking women for their responses. Nobody identified any of them in the pretest. Further, another question (question 21, see Appendix 4, page 382) which partly related to how easy it was to understand these types of resources was so seldom completed in the final questionnaire survey, that it was the one question

that was excluded from the final analysis of the data as the non-response rate was so great (in excess of 60%). At the time of this research, none of the educational kits had been released. However, some of the pamphlets and posters had filtered through to public areas such as pharmacies and health centres and were specifically noted by six women in the questionnaire survey.

The pamphlets and posters were produced for the ethnic groups of Māori, European, Pacific Islands (Cook Island and Tongan) and Asian women. Once again, the posters are a larger copy of the front page of the pamphlets. They are all founded on the nine key messages outlined above, and although the primary information came from the Health Funding Authority and technical advisors, the material was designed to turn the technical language of breast cancer and mammography into “people-speak” (H. Kizito, Folio Communications, personal communication, November 8, 1999). During the six month time-frame allocated to the task, extensive pre-testing and consultation took place throughout the country.

In contrast to the pilot programme pamphlet, the BreastScreen Aotearoa material is multi-coloured and full of information (see Appendix 13, page 398). It is presented in the same question/answer format, but provides information on “chances of getting breast cancer”. The advantages of mammography are promoted, and the possibility of false positives and negatives mentioned, though not quantified. The pain that some women experience is recognised in the statement; “Many women find [mammography] uncomfortable: a few find it painful.” However, the description of the physical process remains the same as in the pilot pamphlet.

Eligibility and results are explained, and one page is devoted to the Health Information Privacy Code. The back page provides information about talcum

powder and deodorant, appropriate clothing, an invitation to discuss concerns with staff and to bring a “support person” if desired. The pamphlet contains more information than the earlier version for the pilot programme. However, it tends to be full of small print, which may be a little overwhelming for women who do not have the time or the desire to read. It also provides an 0800 telephone number that is clearly presented on two occasions in the text.

Over 50% of the eight flip sides of the pamphlet are covered in text. The second page is purely promotional, which sets the tone for the remainder of the pamphlet. There is a clear logo on the bottom of the first page which reads, “Early detection is your *best* protection” (emphasis in original). The pamphlets are distributed throughout the community, for example to health groups and pharmacies. They are also mailed out in the letters of invitation to eligible women who respond to promotion about the programme.

### **Television advertising campaign**

As early treatment of breast cancer means a higher possibility of enhanced longevity, regular screening mammography can prolong life. However, women must be convinced, not only that attendance at screening mammography is desirable, but also that they need to attend regularly to obtain the benefit of the programme. In the absence of a means of directly inviting women through invitation, the programme needed to inform eligible women that a national breast screening service was available. Whereas the pilots had been able to access records from medical practitioners and the age-specific electoral roll, these sources of information were precluded by the Privacy Act 1993. Accordingly, BreastScreen Aotearoa ran a promotional television advertising campaign during August to November 1999 and February to May 2000, to advertise the presence of the programme to eligible women throughout New Zealand.

The television advertising campaign promotes the service to eligible women. First, a message in white print appears on a black background on the screen: “This is a free offer for all women aged 50 to 64”. Second, using “snapshots” of different ethnic groups of women, the format is divided into four segments, each one signaling interaction and relationships. For example, the first segment comprises a group of Pacific Island women who are admiring a young child of about 18 months old on the steps of a church, identified as Freetown Church.

The Māori segment focuses on a Māori woman walking on a windswept beach with rough seas. Four young adults, aged perhaps ten to early teens, probably mokopuna (grandchildren), accompany her. The beach appears remote and there are the remains of a bonfire nearby. The group has a four-wheel drive motorbike with fishing gear. The children are running and skipping and there is an air of excitement as they finally catch two large fish.

The European segment includes an Asian woman. It shows two women arriving at the “Freemont Community Hall”. The doors are pushed open and a welcome extended by another woman from inside. The following scene inside the hall shows the ceiling layered with flags. Eleven European women and one Asian woman are taking part in an aerobics session. The focus is clearly on the Asian woman in the central front row who keeps getting her steps wrong in the midst of a scene full of activity and laughing. The final segment introduces an attractive European woman with her male partner (and thirty-something daughter) with a young boy and girl (grandchildren) preparing food in a kitchen setting – a very happy, relaxed setting with a flow of interaction between the five people. They are preparing four large serving platters of “healthy” food such as carrot sticks and lettuce, apparently an alfresco meal as the daughter picks up one plate

and heads outdoors with it. At the same time the male puts his arm around his partner as he reaches for food on one of the plates. She laughs at him, and then leaves the group and picks up the telephone. The female voiceover urges women to “call the BreastScreen Aotearoa programme now to make an appointment” at the same time as the 0800 number comes on to the screen.

There are four final visual segments that accompany the final voiceover, one of which is incorporated in every advertisement. Each of the four includes either a Māori, European, Pacific Island or Asian woman picking up the telephone. There is also a shortened version that simply presents the written message on the screen, followed by one of the four women representing the ethnic groups picking up the telephone with the voiceover to call the breast screening programme.

Alternatively, sometimes just one of the segments for each ethnicity would play, which is followed by the matching segment for the ethnic group picking up the telephone. Without exception, the background music contains one word only: “free”. That word is set to music and repeated continually throughout every segment, until the voiceover at the end asks women to call for their “free” appointment.

The television advertising campaign run by BreastScreen Aotearoa is a social marketing campaign that demonstrates how the planning variables can be extracted from the marketing mix and reinterpreted for health issues. In terms of the marketing mix which targeted “consumer behaviour”, the “product” was mammography, which was promoted as an invitation to eligible women. The “price” was emphasised and attractive; the product was undoubtedly free. Women merely had to pick up the telephone and call to arrange for an appointment. The “free” service was the key message in the background, the voiceover and the print on screen. The thrust of the “promotion” of the product

meant that the campaign was built around this key message, for example, “freedom from worry, freedom from embarrassment, freedom to get on with, and enjoy life” (S. Hughes, Health Funding Authority, personal communication, July 15, 1999).

Throughout, the messages “free to enjoy life”, “free from embarrassment”, “free to get on with life” and “free from worry” run on the bottom left or right hand corner of the screen. Even the names of the Freetown Church and Freemont Community Hall emphasise the “free” message. Finally the “place” is only a freephone number away. It couldn’t be easier; a number of Pacific Island, Māori, Asian and European women who exercise to keep fit and prepare healthy food say so on the promotional advertisements. To have a mammogram is promoted as a positive and beneficial health behaviour choice for women. However, just what the process or the logic of having a mammogram entailed, or exactly why women need it other than because it is liberating (“freedom from...”) and “free” is not specified.

Similar social marketing campaigns from other sources ran concurrently. For example, during October 1999, St Marks Breast Centre, the Auckland providers for the population-based screening mammography programme, ran a televised campaign promoting not only mammography, but also breast reduction and enhancement. Southern Cross also ran a campaign, which provided women with details about the incidence of breast cancer, and attempted to provide a context for some semblance of informed choice. However, access to this service is determined by membership of the private health insurance group.

The Breast Cancer Foundation also briefly ran a television advertising campaign that promoted Lois Muir, the former Silver Ferns netball coach, as a spokesperson for women who have experienced breast cancer. The key message

of the campaign was the familiar one of BreastScreen Aotearoa: “Early detection is your *best* protection”. These campaigns all addressed the key principle of social marketing, “to reduce the psychological, social, economic, and practical distance between the consumer and the behavior” (Wallack, et al., 1993, p. 21).

All the above sources were external to the breast screening programme; they were designed to encourage women to participate. As illustrated, the resources were primarily transactional, that is used to convey information, in this case to encourage women to participate in the breast screening programme. To assess how influential the communication was in achieving this goal, the following section will address women’s responses to these resources.

As the sample for the research was stratified by ethnicity, a number of the results of the quantitative analysis demonstrate differences between these groups. Accordingly, when describing results, the following abbreviations are used: Māori (M); European (E); Pacific Island (PI) and Asian (A). As noted in Chapter 4, the “other” population and “65+” age group were excluded from statistical analysis because of the small numbers of women in these categories.

## **WOMEN’S RESPONSES TO COMMUNICATION**

### **SAMPLE DEMOGRAPHICS**

It is consistent with the interpretive approach to recognise the influence of background values, culture and subsequent interpretations of their experience on individual reports from respondents (Holstein & Gubrium, 1994). Accordingly, an interpretation of the findings of this study, the socio-demographics of the sample which are enumerated in Table 5.1 below need to be taken into account. The limitations of this sample were outlined in Chapter 4.

**Table 5.1. Demographic characteristics of questionnaire survey respondents.**

<i>Age groups</i>	No	%
50 to 54	231	37.8
55 to 59	208	34.0
60 to 64	160	26.2
65 plus	12	2.0
	<b>611</b>	<b>100.0</b>

<i>Occupation</i>	No	%
Wages or salary	274	44.8
Unpaid work in home	128	20.9
Self employed	72	11.8
Retired	137	22.5
	<b>611</b>	<b>100.0</b>

<i>Ethnic groups</i>	No	%
Maori	155	25.4
European	348	57.0
Pacific Island	51	8.3
Asian	42	6.9
Other	15	2.4
	<b>611</b>	<b>100.0</b>

<i>Household income</i>	No	%
Less than \$15,000	143	23.4
\$15,000 to \$30,000	150	24.5
\$30,001 to \$50,000	105	17.2
\$50,001 and over	69	11.3
Do not wish to answer	144	23.6
	<b>611</b>	<b>100.0</b>

<i>Residence</i>	No	%
In city	195	31.9
In a rural town	323	52.9
In the country	93	15.2
	<b>611</b>	<b>100.0</b>

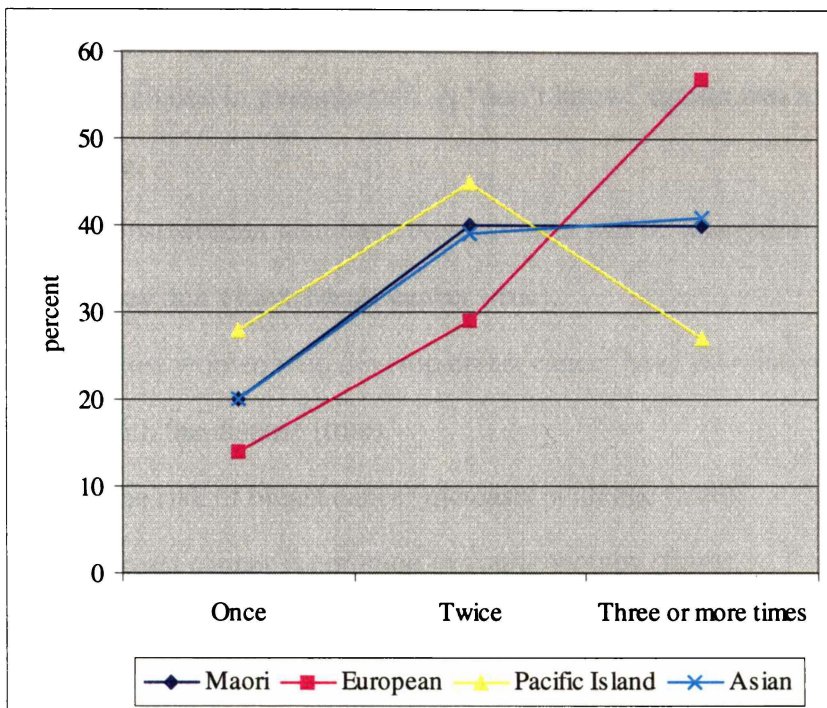
  

<i>Level of education</i>	No	%
Primary school	29	4.7
Secondary school	380	62.2
University	73	11.9
Trade or polytech	45	7.4
Other sources	24	3.9
Do not wish to answer	60	9.9

<i>Location of mammogram</i>	<b>Residence</b>				
	No	%	City	Rural town	Country
Hospital	314	51.4	188	87	39
Mobile van	295	48.3	7	235	53
Other	2	0.3		1	1
	<b>611</b>	<b>100.0</b>			

As well as the differences illustrated above, these women inevitably had varying levels of experience of screening mammography. When asking women about their experiences of the screening programme, it was important to know what level of experience they had. To ascertain respondents' level of experience, they were asked about the number of times they had attended for screening. As shown in Figure 5.1, the respondents in this study were an experienced group, with over 80% having participated in two or more mammograms.



**Figure 5.1. Number of mammograms experienced by respondents by ethnicity.**

Wherever relevant, to avoid confusion for women who had multiple experiences of mammography, they were asked to comment on their most recent experience. In 5 cases women detailed differing experiences between each of their mammograms. In each case, the most recent result was recorded.

## **RESPONSES TO KEY MESSAGES**

As the key messages were designed to provide consistent information to educate women about breast cancer and the role of breast screening, the questionnaire survey asked respondents about their awareness and knowledge of the identified key messages. Three of the key messages discussed above were included in the questionnaire survey (1-3 below) to try to ascertain whether respondents had a correct understanding of each statement. One was a general knowledge category about the incidence of breast cancer in young women (4).

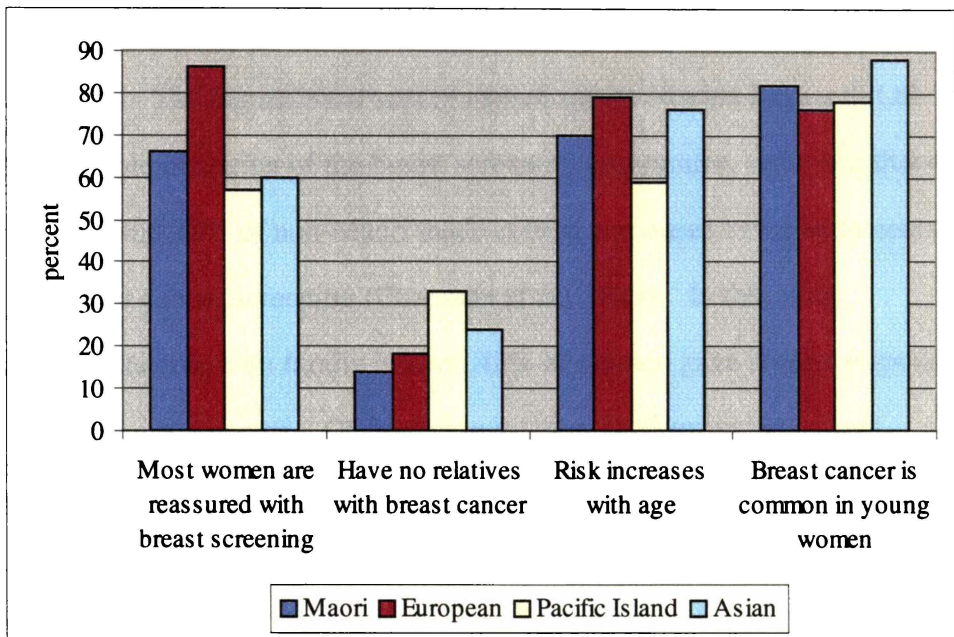
Respondents were asked whether the following were true or false (correct responses are included in parenthesis). A “don’t know” option was excluded to force a response.

1. Most women who have breast X-rays will be reassured they don’t have breast cancer (true).
2. Most women who develop breast cancer have no relatives with the disease (true).
3. The risk of breast cancer increases with age (true).
4. Breast cancer is common in young women (false).

Previous regional studies, carried out by market Research Ltd, have included the statement “Most lumps in the breast are harmless” (true), along with statements 1 and 3 above (Chapman et al., 1995; Chapman & Brown, 1997). However, the sample for this research comprised a population of women that were over 50 years of age. In this group, over half of those presenting with breast lumps will face a diagnosis of cancer. Accordingly, although this statement would have provided an interesting contrast to earlier regional research, in recognition of the importance of not influencing any possible decisions to disregard breast lumps as “harmless”, I considered it was imprudent to include this statement in the questionnaire survey.

However, as O’Halloran and Kalafatelis (1996) had previously identified that there was some confusion about whether many young women experienced breast cancer, I included a relevant statement. The inclusion of this statement also offered an interesting comparison between “general knowledge” and that specifically related to key messages. That is, were the key messages predominant in the communication about breast cancer and screening, or were other messages

just as conspicuous? Correct responses to the selected four statements are illustrated in Figure 5.2.



**Figure 5.2. Correct responses to key messages by ethnicity.**

As shown above, overall knowledge levels were high for two of the key messages with 450 (74%) respondents recognising that most mammograms would reassure them that they did not have breast cancer. Similarly, 447 women (73%) understood that breast cancer increased with age. In response to the general knowledge statement, 469 (77%) were aware that breast cancer was not common in young women. However, only 112 (18%) realised that most women who develop breast cancer have no relatives with the disease. As illustrated, the correct responses to the general knowledge statement exceeded that of the three key messages which suggests that the “key messages” may be no more prominent than other information related to breast cancer and breast screening.

Over all groups, only 8% of women were accurately aware of all four statements. Clearly, a consistent misunderstanding about family history influenced this outcome. If this variable is excluded, knowledge levels have

substantially improved from initial surveys. Prior to the implementation of the breast screening service, Market Research Ltd had been commissioned to find out women's knowledge level and attitude towards breast screening in the greater Waikato region. The unpublished survey carried out by Market Research Ltd prior to the implementation of the breast screening programme, indicated that only 10% of Māori and 38% of non-Māori made correct responses to the statements related to breast cancer screening (Chapman et al., 1995). In this study, excluding the statement on family history, 48% of women gave correct responses to the other three statements. Of European women, 58% provided correct responses to all three statements. Overall, 40% of Māori women, 31% of Pacific Island and 31% of Asian women gave correct responses to all three statements.

### **Confusion about the variable of family history**

The confusing nature of the variable of family history tends to exist even at policy level. For example, the policy discussion paper (Cancer Society of NZ & Ministry of Women's Affairs, 1991) contained the statement: "Having a mother or sister who has had breast cancer can increase a woman's risk of developing the disease" (p. 4). The same paragraph continues, "However, most women who develop breast cancer have no known family history of the disease" (p. 4). Although technically, these statements are well founded, it appears that they confuse some respondents, since only 18% are familiar with the key message that most women who develop breast cancer have no relatives with the disease.

The subsequent outcome of the misunderstanding was that twenty-four respondents asserted that there was "no need for worry" with no family history involved in their cases. For example, "We have no family history, so there is nothing for me to be afraid of," and, "Coming from a family with no history of

cancer gives me a relaxed feeling about myself.” Also, the one woman in this study who refused screening because it was “not important” gave the same reason for her refusal to have further mammography. The misunderstanding about family history appeared to be potentially discouraging some women from participation in the screening mammography programme.

### **Influence of age in response to key messages**

The only significant variation over age groups in response to the key message about the incidence of breast cancer in young women was that women aged 50-54 years (83%) and 55-59 years (81%) were more aware than women aged 60-64 years (71%) that breast cancer is not common in young women ( $P=0.009$ ), as illustrated in Table 5.2.

**Table 5.2. Respondents’ awareness of key message about incidence of breast cancer in young women by age.<sup>8</sup>**

		Age			
		50 to 54	55 to 59	60 to 64	Total
Breast cancer is common in young women	No	192 83%	168 81%	113 71%	473 79%
	Yes	39 17%	40 19%	47 29%	126 21%
Total		231 100%	208 100%	160 100%	599 100%

( $\chi^2 = 9.5$ ,  $df=2$ ,  $P=0.009$ )

### **Influence of ethnicity in response to key messages**

There was some variation among ethnic groups in response to the key message about the reassurance women experience when they have a mammogram.

As shown in Table 5.3, European women (84%) were more aware of the

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<sup>8</sup> As noted in Chapter 4, the “over 65” age group, with only 12 women completing the survey, was not included in the chi-squared analysis of contingency tables or Fisher’s exact 2x2 tables because of the small number of women in that category.

reassurance of screening mammography than either Māori (66%), Pacific Island (57%) or Asian (59%) women ( $P<0.0005$ ).

**Table 5.3. Respondents' awareness of key message about reassurance by ethnicity.<sup>9</sup>**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Most women are reassured when they have a breast xray	No	53 34%	54 16%	22 43%	17 41%	146 25%
	Yes	102 66%	294 84%	29 57%	25 59%	450 75%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 38.43$ ,  $df=3$ ,  $P<0.0005$ )

European women were also more likely to be correct about the increasing incidence of breast cancer with age (79%) than Māori (71%,  $P=0.04$ )<sup>10</sup> or Pacific Island (59%,  $P<0.005$ ) women ( $P=0.006$ ). See Table 5.4.

**Table 5.4. Respondents' awareness of key message about incidence of breast cancer increasing with age by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
The risk of breast cancer increases with age	No	46 30%	72 21%	21 41%	10 24%	149 25%
	Yes	109 71%	276 79%	30 59%	32 76%	447 75%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 12.41$ ,  $df=3$ ,  $P=0.006$ )

There were significant differences in responses to the family history statement, demonstrated below in Table 5.5. Pacific Island women (33%) were

<sup>9</sup> As noted in Chapter 4, the "other" ethnic group, with only 15 women completing the survey, was not included in the chi-squared analysis of contingency tables or Fisher's exact 2x2 tables because of the small number of women in that category.

<sup>10</sup> Fisher's exact tests were applied to pairs of all groups within the overall analysis to ascertain whether there were significant differences between them. However, only percentages are provided in further tables.

more aware that most women who develop breast cancer have no relatives with the disease than Māori (14%) or European (18%) women ( $P=0.018$ ).

**Table 5.5. Respondents' awareness of key message about significance of family history in development of breast cancer by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Most women who develop breast cancer have no relatives with the disease	No	133 86%	285 82%	34 67%	32 76%	484 81%
	Yes	22 14%	63 18%	17 33%	10 24%	112 19%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 10.02$ ,  $df=3$ ,  $P=0.018$ )

### Cultural diversity in response to information

It is also apparent from this research that different groups of women do respond differently to the way that information about the breast screening programme is presented ( $P < 0.0005$ ), as depicted in Table 5.6. For example, ethnic minority groups such as Māori (52%) and Pacific Island (51%) women were significantly more likely to respond to a loss-framed message than either Asian (14%) or European women (15%).

**Table 5.6. Response to loss-framed message by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Loss framed message	No	75 48%	294 85%	25 49%	36 86%	430 72%
	Yes	80 52%	54 15%	26 51%	6 14%	166 28%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 87.32$ ,  $df=3$ ,  $P < 0.0005$ )

A “loss-framed” message, (taken from Banks et al. (1995), who demonstrated the influence of framed messages in encouraging participation in mammography), is illustrated in statement 1 of question 26 in the survey (see Appendix 4, page 383). As discussed in Chapter 3, the difference between loss and gain framed messages is that the same message is presented in terms of what may be lost (in this case, through not having a mammogram), rather than in terms of benefits gained (through having a mammogram). Loss-framed messages are based on the prospect theory of Kahneman and Tversky (1979), which suggests that people will respond differently to messages depending on how the messages are framed (Kahneman & Tversky, 1982, 1984). Messages framed around objectively equivalent situations can be couched either in terms of benefits or losses (Rothman & Salovey, 1997). For example, participation in screening mammography can be presented as an opportunity to detect breast cancer early, or non-participation as a lost opportunity to detect breast cancer early. It may be that it is too difficult, because of the anxiety inherent in the breast screening process, to consider participation as a gain. However, perhaps the risk of lost health – or even life – may provide a strong inducement to participate.

The findings of this research may reflect those of Lauver and Rubin (1990), who argue that the relative value of potential losses and gains regarding health may be different for advantaged and disadvantaged groups. Whereas advantaged groups focus on long-term gains or benefits, those who are socioeconomically disadvantaged may not. Furthermore, the research of Meyerowitz and Chaiken (1987) and Banks et al. (1995) demonstrated a significant response towards loss-framed messages for women performing both breast self-examination and attending screening mammography. Although loss-framed messages may be perceived as “negative” when discussing screening mammography as suggested

by Gladding (1997), they are simply different presentations of the same objective message.

The results of this research suggest that, if used appropriately, they may also hold a key to presenting a more persuasive message for some groups of women. Perhaps the possibility of averting a loss also may be a cogent factor in establishing a modicum of control which may help to alleviate anxiety. As Allen, Sorensen, Stoddard, Colditz and Peterson (1998) demonstrated, self-efficacy, or confidence in one's ability, was significantly related to participation in mammography.

Self-efficacy is related to other health behaviours such as breast self-examination (Maibach & Murphy, 1995). Banks et al. (1995) did not find that message framing influenced self-efficacy in their research; however, one of the researchers commented that they "may not have measured it optimally" (Professor P. Salovey, Chairperson, Department of Psychology, Yale University, personal communication, September 28, 1999). As there has been no particular approach that has successfully identified why women choose to resist screening mammography, despite a plethora of international studies, many important and unresolved research questions remain. Therefore, it is suggested that alternatives such as loss-framed messages not be merely disregarded, but rigorously analysed and assessed for their value in the process.

Nevertheless, overall, it is most important of all that any messages about screening mammography are measured against their relevance to non-European cultural groups such as Māori. Rohipa (1994) poses the question: "Are messages being created from a Māori world view or are they being promoted from a non-Māori interpretation of Māori needs or from a non-Māori perception of Māori

needs?” (p. 11). The answer to that question on behalf of all ethnic minority groups is foremost in any culturally-appropriate communication strategy.

## **REQUESTS FOR INFORMATION**

Respondents to the questionnaire survey and participants in the focus group interviews asked a number of questions about various aspects of breast screening and breast cancer. Responses to the questionnaire survey indicated requests for information – for example, women wanted to know about the influence of hormone replacement therapy, “lumps” and the associated procedures, the influence of breast feeding on the risk profile of developing breast cancer.

Questions included (numbers in parenthesis):

If age is a risk factor, why does screening stop at 64? (66)

What *are* the overall risk factors? (62)

What is the risk of hormone replacement therapy? (51)

How do I do self-examination correctly? (45)

What are these “lumps” they talk about? (37)

What is the risk of being exposed to X-rays every two years? (22)

Is not breast-feeding a risk factor? (16)

Why isn't mammography 100% reliable? (11)

Thirty-two women made comments, such as they “just want to know about it all”, or “would value more information”. When interviewed, the call centre staff confirmed that women sometimes telephoned with “questions about breast cancer and screening” (I:U3). One explained that they “tried to put them through to someone who could answer them” (I:U4); however, there did not appear to be a designated procedure for these inquiries. Twenty-six other respondents to the

questionnaire said they were “too afraid to ask”. Clearly there were information needs not being met within the communication strategy for the programme.

Eighteen respondents in this study not only had a number of questions about risk factors, but also queried processes involved in both the procedure and outcomes of mammography. However, as the confusion about family history indicates, both the effectiveness and efficiency of the way in which information is presented need to be reassessed. As Austoker (1999) suggests, information must be research-based if it is going to provide women with an appropriate decision making tool. It appears from the results of this research, that despite the intention to present a clear key message about family history, some women in the community are not accessing the correct information. An emphasis on consistency of the message and absolute accuracy and dependability of information offered will enhance the acceptance and usefulness of the material.

For example, in July 1999 BreastScreen Aotearoa had released an information booklet, *More about breast screening*, which contains general information about breast cancer and screening, including possible risk factors, such as hormone replacement therapy and exposure to radiation during mammography, the procedures and possible outcomes. In the focus groups, discussion about requests for information sometimes focused on this booklet. When women were asked for their responses to the booklet, which was distributed prior to the focus group and some pre-tests, their answers tended to emphasise an affective as well as an intellectual response. For example, although some women described the book as “helpful” and thought it was “timely”, others reacted to the information in the booklet by saying:

“I feel demoralised about it now.”

“Why bother with screening, after reading this?”

“There’s clearly too much inconvenience for too little result.”

“I never knew it was so risky.”

“It’s not going to do much good (having a mammogram).”

It is recognised that the number of women (41) who comprised the purposive sample of respondents in the five focus groups precludes making any valid generalisations. However, in light of the anxiety that is associated with screening mammography as discussed in Chapter 2, the way in which relevant information is presented appears to be critical. For example, of the five focus groups, three groups of women discussed their apprehension about hormone replacement therapy. Women in four of the focus groups spent some time talking about the depth of concern they shared about exposure to radiation.

On the other hand, the booklet did not appear to address these cogent issues accurately. Some medical consultants associated with the screening mammography programme throughout the country have expressed their disquiet regarding what they believe, in light of current research, to be factual inaccuracies in the booklet (I. Campbell, Breast and General Surgeon, Health Waikato, personal communication, November 15, 1999). Some identified concerns relate to the quoted levels of risk from both the use of hormone replacement therapy and exposure to radiation in the booklet. At the monthly screening advisory group meetings, the consultants stated their belief that the risks were overstated. The medical staff have subsequently asked for the book to be withdrawn until it is revised and accurate research-based information is provided. In reviewing in excess of 500 journal articles related to breast cancer and screening for this thesis research, I was unable to identify any data which supported that in the booklet.

Any information presented to women must be supported by recent, relevant research of a high standard. It is unfair and unethical to provide anything less if

there is a commitment to informed consent. As Coulter (1998) suggests, it is imperative that information moves beyond the fallibility of simple standard readability formulas, “conforms to the highest standards of scientific accuracy [and is] tested for relevance and comprehensibility” (p. 225). Furthermore, the way in which the material is presented is also crucial to acceptability. An emphasis on simplifying material may not always achieve the most useful result that meets both the information and reassurance needs of the reader. As Meade and Smith (1991) illustrated, although “readability” of material must be considered, an emphasis on readability formulas might make it easy to overlook the motivation and knowledge level of women, which are integral to their communication needs.

To be useful, quality information is required that facilitates women’s choices about participation in screening mammography. To achieve this outcome, available evidence needs to be presented in a form that is both accurate and acceptable (Entwistle et al., 1996; Raffle, 1997). As well as being “accurate and unbiased” (Anderson & Nottingham, 1999, p. 227), information resources also need to state the variables that are not yet known.

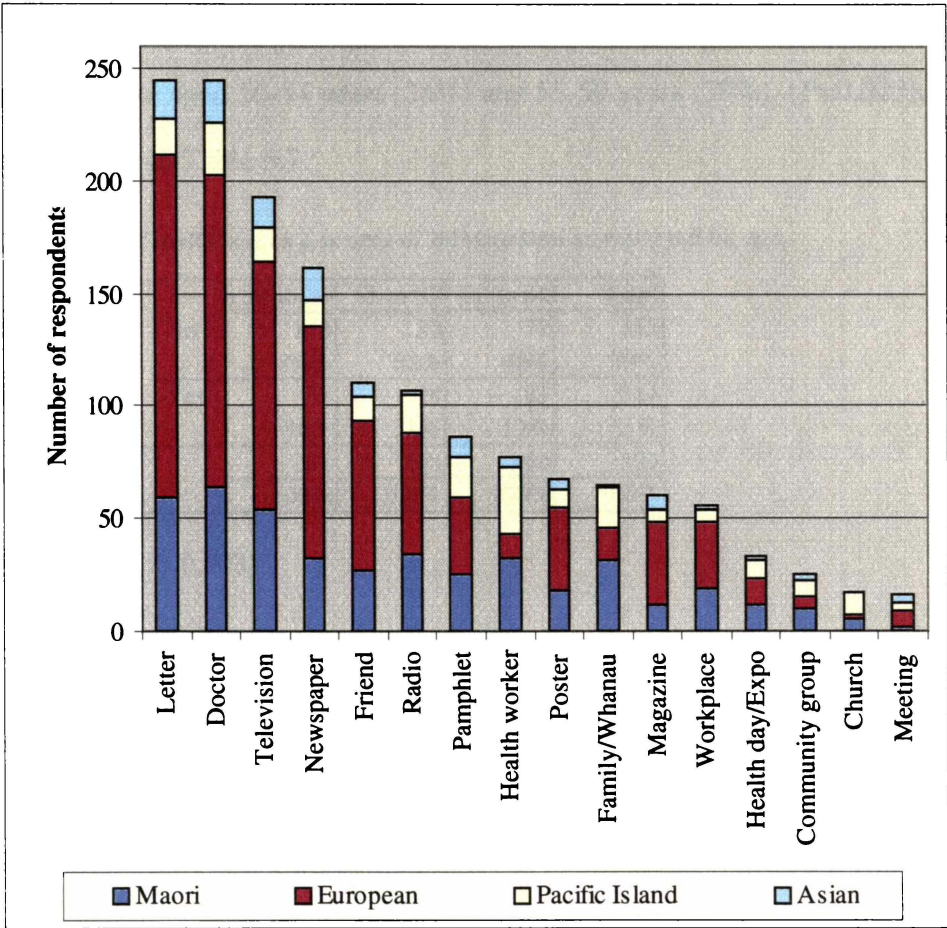
## **REACHING ELIGIBLE WOMEN**

The above discussion has focused on the resources that are used to communicate with women about participating in the breast screening programme, and their responses. A brief introduction of the key messages that are incorporated into all communication from the programme was also included. However, if a target audience is not aware of a screening programme, it is unlikely to participate. As women must participate in regular screening mammography if they are to benefit from the mortality savings, the success of any

population-based breast screening programme is founded on its ability to communicate its presence to eligible women. The following discussion assesses the response of women to the communication strategies employed by the programme to encourage participation.

### SOURCES OF AWARENESS

To provide some indication of the “visibility” of the various approaches used to communicate screening mammography to the eligible population, the questionnaire survey asked respondents how they found out about the programme. Their responses are enumerated in Figure 5.3.



**Figure 5.3. How respondents found out about the programme by ethnicity.**  
 (Numbers exceed 611 as respondents could nominate more than one category).

In this study, more women found out about the breast screening programme from the letter of invitation ( $N=251$ ) than from any of the other sources. A similar number obtained information from their doctors ( $N=249$ ), who consistently provided information across all ethnic groups ( $M=41\%$ ,  $E=39\%$ ,  $PI=45\%$  &  $A=27\%$ ). Television advertising was a source of information for 198 respondents.

### **Influence of age on response to sources of information**

The increased use of media over the progression of the pilot programme may be reflected in the variation across age groups in response to sources of information. For example, women over 60 years of age (52%) were more likely to have received information about the programme from the letter of invitation compared to those aged 50-54 years (36%) and 55-59 years (38%), ( $P=0.003$ ), as illustrated below in Table 5.7.

**Table 5.7. Letter of invitation as a source of information as reported by age.**

		50 to 54	55 to 59	60 to 64	Total
Letter of invitation from programme	No	148 64%	130 62%	77 48%	355 59%
	Yes	83 36%	78 38%	83 52%	244 41%
Total		231 100%	208 100%	160 100%	599 100%

( $\chi^2 = 11.33$ ,  $df=2$ ,  $P=0.003$ )

Similarly, 47% of women who had experienced two or more mammograms had heard about the programme from the letter of invitation, compared to only 23% of those who had had only one. In contrast, as shown in Table 5.8, women who were aged 50-54 years were more likely to nominate television advertising (41%) as a source of information than the other age groups ( $P=0.003$ ).

**Table 5.8. Television advertising as a source of information as reported by age.**

		50 to 54	55 to 59	60 to 64	Total
Television advertising	No	136 59%	153 74%	113 71%	402 67%
	Yes	95 41%	55 26%	47 29%	197 33%
Total		231 100%	208 100%	160 100%	599 100%

( $\chi^2 = 11.91$ ,  $df=2$ ,  $P=0.003$ )

Younger women (aged 50-54 years) were also more than twice as likely (24%) to hear about the programme from friends than were those of 60+ years (11%).

### **Awareness of BreastScreen Aotearoa campaign**

Women were specifically asked about their awareness of the recent television advertising campaign for BreastScreen Aotearoa. The campaign was screening at the time of the research, along with similar productions from Southern Cross and the Breast Cancer Foundation as discussed above. The 390 (64%) respondents who had viewed the recent television campaigns of BreastScreen Aotearoa, Southern Cross and the Breast Cancer Foundation were positive about them. European (67%) and Māori (63%) were the most likely to have viewed the television advertising advertisements.

The percentage of women who identified television advertising as a source of information about the programme reflects the introduction of the nationwide screening mammography service and subsequent airing of the television advertising campaign which began in October 1999. Although the awareness rate of the television advertising campaigns was 64% in this sample, all participants were part of the programme before the campaign started. Accordingly, the level of visibility suggests that future research may show an increase in this variable as

a source of communication about screening mammography if BreastScreen Aotearoa makes a decision to continue with television promotion. The campaign has been monitored by Research Solutions Ltd, and future strategies will be decided on the basis of this information (S. Hughes, Health Funding Authority, personal communication, December 8, 1999). Seventeen women referred to the format of the BreastScreen television advertisements in an evaluative manner, describing them as “too short”, “too brief”, “too soft” and “not hard-hitting enough” from one respondent who thought that “screening should be compulsory for all women”. Fourteen respondents thought that they were not informative enough and made comments such as: “A little more detail would have been helpful”.

Once again, in response to the importance of attending for breast screening, the influence of misunderstanding about the variable of family history was apparent. Nineteen women commented that, because they did not have a family history of breast cancer, they “tuned-out”. For example, as one respondent wrote, “With no history of breast cancer in my family, these ads were not aimed at me.” Such misunderstanding illustrates the detrimental effects of ineffective communication about breast cancer on the breast screening programme.

### **Influence of ethnicity on response to sources of information**

Ethnic groups varied in that Pacific Island (59%) and Māori (21%) women were more likely ( $P < 0.0005$ ) to find out about screening from health workers than Asian women (10%) or European women (3%), depicted below in Table 5.9.

**Table 5.9. Health workers as a source of information as reported by ethnicity.**

		Ethnicity				Total
		Maori	European	Pacific Island	Asian	
Health worker	No	123 79%	337 97%	21 41%	38 90%	519 87%
	Yes	32 21%	11 3%	30 59%	9 10%	77 13%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

$$(\chi^2 = 133.6, df=3, P<0.0005)$$

Both Pacific Island (31%) and Māori (38%) respondents were the least likely of the ethnic groups to learn about the screening programme from the letter of invitation. Pacific Island women tended to nominate family (35%) and friends (22%) as primary sources of information, and were also most likely to have used radio (33%) and community interventions such as health days (16%) and church (20%) to obtain information. Māori women were inclined to favour family (20%) and television advertising (35%) as sources of information, whereas Asians and Europeans preferred print media. For example, the Asian group was the most likely to identify magazines (14%) and newspapers (33%), and both groups identified letters of invitation (E=44%, A=41%) as sources of information.

When asked about their preferences in the focus groups, Māori women expressed some dissatisfaction with print resources. For example, they reported their discomfort with the pamphlet for various reasons, such as the illustrations and Māori phrases (see Appendix 14, page 402). The material had been prepared using extensive pre-testing (H. Kizito, Folio Communications, personal communication, November 5, 1999). However, the process was apparently undertaken among Māori communities in the north and accordingly depicted one Māori woman in traditional dress, which did not sit comfortably with those Māori living in the urban areas of the Waikato, who “refuse[d] to behave in line with

what certain narratives have identified as the rules of their culture” (Astroff, 1997, p. 129). A health promoter explained:

Our Māori women detest the Māori pamphlet. They want to know how come there are real women on the Pakeha one, and WE have to fake it. The pretesting was done up north, and the women liked the Māori one, but now it’s finished and they see the two together [Māori and European pamphlets], women say it doesn’t look like reality – Māori women, the generation we’re talking to don’t look like THAT – and you had to have wedding rings on! The majority of our women are widows or solo mothers °°°° so that’s the downside to the pamphlet. And what’s more the Māori sayings that are in there °°° everyone interprets those differently and it’s not hitting on a message that is the same – you can have your own interpretation depending on where you have been brought up.

The front of the pamphlet (the same as the poster) stated in Māori “Kotahi te ha o nga whakatupuranga e toru” (“the general knowledge and wellbeing of health spread through three generations”), which referred to the three women in the drawing. However, apparently for the same message that Māori in the Waikato refer to as “wellbeing”, the interpretation would be “beauty” in the North. In Rotorua, the same interpretation would result in “goodness”. One respondent explained, “With the Māori language, you have to listen to the whole thing – the essence of what is being said – and then interpret it.” As one of the health promoters explained, a number of women do not speak Māori, including some community educators; therefore have difficulty with the pamphlet.

Apparently advice was sought from the Māori Language Council in the design of the pamphlet, and the proverbs that are inside are “common text” to

most groups. They address anxiety, “ina te pai o te tautoko mai a te whanau” (“in the support of your whanau all is well”), and “otira, kia kaha wahine ma” (“we know you’re frightened, but be strong”). Women are encouraged to talk, “he mea nui tonu te korero ki tetahi atu” (“the more we talk about it the easier it becomes”), which relates to the tradition of men standing to talk on the marae to solve problems (I:P16). The penultimate statement recognises the right of women to choose; “tera te ra kei tua o tawauwau e whiti mai ana” (“at the end of the day through all we’ve done together and all the information gathered it’s up to us to make the choice”). The final statement says “nau mai, piki mai ki runga i tenei kaupapa nui” (“come listen, you need to understand - this is a really big subject”).<sup>11</sup> The rest of the information in the brochure is presented in English.

Although the women accepted that there were potential difficulties with interpretation, the most disagreeable influence of the pamphlet was the presentation of the cover. The Māori pamphlet and poster had a drawing of three generations of Māori women on the cover in contrast to all other pamphlets and posters, which had photographs. One of the Māori women was dressed in a traditional cloak and two had wedding bands on their fingers. The whole presentation of the pamphlet was described by respondents as “off-putting”, and “difficult to get past”, even though the messages inside were intended to be compassionate and understanding and presented in bullet point format so that the text was minimised (I:P16).

In contrast, the Pacific Island women welcomed the pamphlets in their own languages, especially Cook Island and Samoan women. The pamphlets were a direct translation of the European version (I:P18). They reported feeling far more comfortable with these than the European pamphlets, as English is primarily their

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<sup>11</sup> Translations by Elaine Preston, health promoter for Raukura Hauora O Tainui.

second language, although some of the women in the focus groups did say that they “still needed help” as some of the information was “confusing”.

However, the recent European poster produced by BreastScreen Aotearoa invoked a unanimous response among Māori and Pacific Island women in the focus groups that the “individual” message of “it’s time to take care of ourselves” did not sit well with them. They explained that their motivation was their families and therefore the message on the poster “wasn’t for them”.

The discussions in the focus groups and many of the comments in the questionnaire related to the influence of family for Pacific Island women, who tended to define their most important role as “mothers”, and often referred to the “other mothers” when they talked about encouraging other women to attend the breast screening programme. Most references were made in relation to the importance of family. For example, one woman explained how she talked to another Pacific Island woman about screening:

I need[ed] to make her understand – to make it EASY for her to understand that if she loves her kids and her family °° that it is time °°°° that she must do what is right to do [have a mammogram].

Members of the family were also described as an important catalyst in ongoing participation in screening for these women. For example, when describing a negative screening experience, one respondent stated, “Only because of my family did I put up with it”. Accordingly, it was difficult for Pacific Island women to relate to communication that focused on an individualistic autonomous need to care for themselves, when they identified with such needs primarily in a context of being part of a family group. The inability of this cultural group of women to relate to communication that espouses western “individualised” approaches reflects their strong commitment to their role in a community or

family. As Hofstede (1997) relates, there are distinct differences between collective and individualised approaches:

Individualism pertains to societies in which the ties between individuals are loose: everyone is expected to look after himself or herself and his or her immediate family. Collectivism as its opposite pertains to societies in which people from birth onwards are integrated into strong, cohesive ingroups, which throughout people's lifetime continue to protect them in exchange for unquestioning loyalty (p. 51).

The extended family group is central to Pacific Island women, and any effective communication would need to be structured with that in mind. Nevertheless, the need for further investigation is evident, as there is a paucity of useful and current research for this group of women (A. Aumua, Pacific Island advisor to the Ministry of Health, personal communication, September 19, 2000). Māori women are part of a collective culture as well. In Rohipa's (1994) words, "In Māori terms to be totally independent and separate is regarded as unhealthy" (p. 12). Whereas there is an emphasis on physical health and illness in western culture, Māori emphasise spirituality over other aspects, where good health equates to recognition of the influence of others, the dead, the environment, and links between them (Durie, 1994a). As Durie (1994a) explains: "Poor health reflect[s] an absence of a personal or collective spirit, and no degree of physical fitness [can] compensate for an impoverished soul" (p. 196).

Furthermore, as Bathgate et al. (1994) point out, the health of Pacific Island women is compromised in a western model of health care by their cultural reticence to discuss anything to do with reproduction (breast and cervix) in a society where programmes rely not only on discussing, but also revealing, these

parts of the body to strangers. Once again, this same cultural ethic of the sanctity of the organs of reproduction is reflected in Māori culture (Campbell & Bryant, 1996). Failure to recognise such cultural importance is encapsulated in the description of Smith (1999):

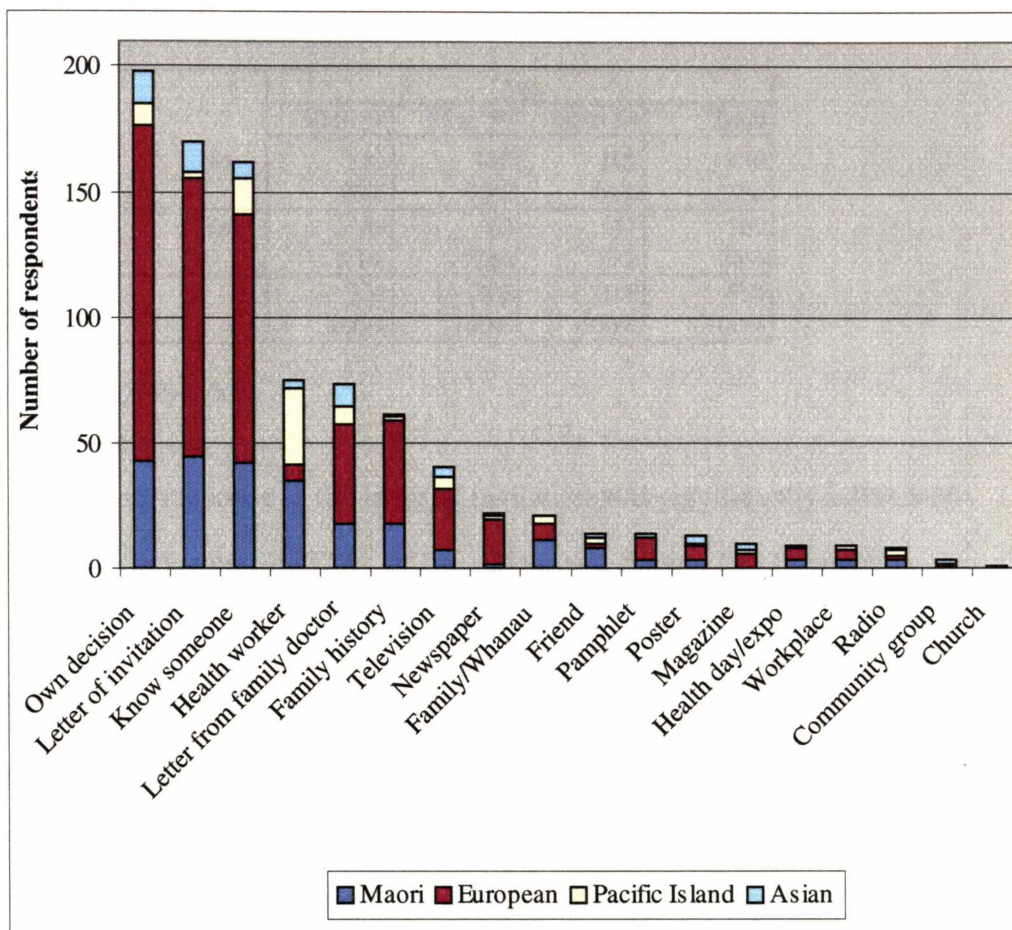
Research “through imperial eyes” describes an approach which assumes that Western ideas about the most fundamental things are the only ideas possible to hold, certainly the only rational ideas, and the only ideas which can make sense of the world, of reality, of social life and of human beings (p. 56).

Smith (1999) continues that the approach “conveys a sense of innate superiority” (p. 56), which is not only offensive, but also fails to reach the intended objectives, in this case, encouraging Pacific Island and Māori women to participate in the breast screening programme.

## **SOURCES OF INFLUENCE**

Although the above methods demonstrated levels of programme visibility to women in the community, it was also important to understand which sources of communication women perceived to be influential in helping them to make a decision about participating in screening mammography.

Accordingly, women were asked what helped them to decide to take part in the breast screening programme. Their responses are enumerated below in Figure 5.4.



**Figure 5.4. Sources of influence to participate in programme by ethnicity.**  
 (Numbers exceed 611 as respondents could nominate more than one category).

### Letter of invitation

Once again, letters of invitation ( $N=174$ ) provided the most common external impetus to take part in the programme for 29% of women. There was significant variation between age groups with women over 60 years of age (36%) more likely to respond than women aged 50-54 years (21%) to this source ( $P=0.006$ ), as illustrated below in Table 5.10. Also, this result correlated with experience of screening, where women with two or more mammograms were more likely to respond (33%) than those who had only one (16%).

**Table 5.10. Letter from programme as a source of influence as reported by age.**

		Age			
		50 to 54	55 to 59	60 to 64	Total
Letter of invitation from programme	No	182 79%	145 70%	103 64%	430 72%
	Yes	49 21%	63 30%	57 36%	169 28%
Total		231 100%	208 100%	160 100%	599 100%

( $\chi^2 = 10.72$ ,  $df=2$ ,  $P=0.006$ )

In addition, response to the letter of invitation was significantly influenced by ethnicity, with European (32%), Māori (28%) and Asian (29%) women responding to the letter, compared with 6% of Pacific Island women ( $P=0.002$ ), as Table 5.11 shows.

**Table 5.11. Letter from programme as a source of influence as reported by ethnicity.**

		Ethnicity				Total
		Maori	European	Pacific Island	Asian	
Letter of invitation from programme	No	111 72%	237 68%	48 94%	30 71%	426 72%
	Yes	44 28%	111 32%	3 6%	12 29%	170 28%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 14.77$ ,  $df=3$ ,  $P=0.002$ )

Pacific Island women explained that they disliked the impersonal approach of the letter of invitation. One respondent explained that when she received her letter of invitation from the programme; “I just threw the letter I got in the bin.” Another woman in the same focus group related:

I didn't know who these people were or anything about them. If it had come from my doctor I may have responded °°°° yes, I would respond to that °°°° but if it just comes from someone doing their

job who picks up my name from who knows where from and  
send[s] me a letter °°° I want to know where they get my name.

Furthermore, in the focus groups Māori and Pacific Island women described how they had “missed” appointments through misunderstanding the invitation letter. As a Māori health promoter explained, “When you say you are ‘inviting’ a Māori woman to have a breast screen, she waits for an invitation to arrive.” The invitation letter asked women to telephone to make an appointment.

Consequently, some women had not responded and had missed out on having a mammogram, because of cultural misunderstanding. This outcome reinforces the need for communication strategies to be founded on the relevant “social and cultural environment” (Campbell & Bryant, 1996, p. 10) in facilitating attendance.

Similarly, Smith (1999) argues for a need to centre on Māori “concerns and world views” (p. 39) in research. Perhaps such an approach to developing relevant communication resources would have indicated a strategy suited to the needs not only of Māori women in the programme, but also Pacific Island and Asian women. In turn, an appropriate approach would not only have met the “needs and purposes” (p. 39) of the women, as suggested by Smith (1999), but ultimately, those of the programme.

### **Autonomous decision making about participation in programme**

A further 27% of the respondents knew someone with breast cancer, a factor that had encouraged them to undergo screening mammography. However, 33% of women believed they had made their own decision about participation, irrespective of external influences. As noted in Chapter 4, this category had been added as part of the pre-test. There was significant variation between age groups.

As shown in Table 5.12, European women (38%) were more likely to do so than either Māori (28%) or Pacific Island (18%) women ( $P=0.009$ ).

**Table 5.12. Respondents reporting making their own decision about participation by ethnicity.**

		Ethnicity				Total
		Maori	European	Pacific Island	Asian	
Own decision	No	112 72%	215 62%	42 82%	29 69%	398 67%
	Yes	43 28%	133 38%	9 18%	13 31%	198 33%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 11.69$ ,  $df=3$ ,  $P=0.009$ )

Of the 200 respondents who reported making their “own decision”, 115 reported this as a sole category of influence on their decision to participate in the breast screening programme (M=37%, E=68%, PI=22%, A=54%). A further 85 respondents nominated between one and seven other influences as well as making their “own decision”. The most commonly nominated other category of influence was “know someone with breast cancer” (37). The letter of invitation was nominated together with making their “own decision” by 30 women, television by 20, family history by 13, and all other categories were nominated on fewer than ten occasions.

### **Health workers as a source of influence**

Health workers influenced 12% of women to participate in screening mammography, as illustrated below in Table 5.13. There were significant differences between ethnic groups ( $P<0.0005$ ), with health workers primarily influencing Pacific Island (61%) and Māori (23%) women to participate. Once again, these groups of women responded to a more personalised approach.

**Table 5.13. Health workers as a source of influence as reported by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Health worker	No	120 77%	342 98%	20 39%	39 93%	521 87%
	Yes	35 23%	6 2%	31 61%	3 7%	75 13%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 160.233$ ,  $df=3$ ,  $P<0.0005$ )

Overall, health workers were an important prompt to action for many Pacific Island and Māori women. Twenty-two percent of these groups of women commented in the survey about their reliance on the health workers for decision making. Some women commented that they would “never have come” without the support of the health workers, and that they “rely on them” for ongoing support throughout, particularly with their difficulties in attempts to communicate with programme staff. For example, the Māori organisation funded by government to supply health promotion services for Māori women in the community, Raukura Hauora O Tainui, operates a block booking system. The health promoters make a list of names for the Māori women who want to have a mammogram. The health workers, who are familiar with the system, telephone and make the booking on behalf of eligible women. The health worker explained:

The reason we have set up our own system that is currently used is because when women were ringing themselves they could not understand the questions being asked, and in most cases agreed to something they did not understand. Consequently, many women missed their appointed times and this caused some tension between individuals and the Breast Unit. Another reason was the time it took to get through. Many women would try two or three times to

no avail, so would give up and not ring back again, missing out on even going.

However, the influence of the health workers did decline from 17% to 8% with the increasing age of respondents ( $P=0.019$ ) as depicted in Table 5.14.

**Table 5.14. Health workers as a source of influence as reported by age.**

		50 to 54	55 to 59	60 to 64	Total
Health worker	No	191 83%	185 89%	147 92%	523 87%
	Yes	40 17%	23 11%	13 8%	76 13%
Total		231 100%	208 100%	160 100%	599 100%

( $\chi^2 = 7.97$ ,  $df=2$ ,  $P<0.019$ )

As one Māori health worker explained, older Māori women resisted anything that would possibly result in removing any part of their body. Therefore, mastectomy (removal of the breast) was anathema:

In traditional Māori terms you go out as you come in. They want to be complete – people have limbs removed and it is buried °°° that is where they will be buried. I still remember an aunty who died of breast cancer – the smell was terrible – but to that generation, you die with dignity. Unfortunately. °°°°° When the men speak about the whakapapa we belong to the earth, and in a Māori sense it is easy to relate to. What annoys me is that mainstream technicians think that is stupid – it’s a whole lot of hogwash, because “we can save you”. But it’s about the mana of choosing the way in which you die. At times I have felt really upset about it, but if that is their choice °°°°° our worst hassle is that if “I’m OK, I’m fine”, and they won’t go to the doctor.

However, she continued that the older women did encourage younger ones to attend for screening. It just simply did not fit with their own set of beliefs for their own health. Nevertheless, they had no difficulty in promoting the perceived benefit for others.

Similarly, Ma'ia'i (1992) contends that a number of Pacific Island women also believe, "[I]f God wills one to get cancer then it would be presumptuous to try and alter it" (p. 68). Once again, the cultural relevance of communication is highlighted in this research. The communication is established, presented and justified in terms of the dominant, westernised, individualistic model of health care that has been ascendant in New Zealand. Although there are many advantages for those who may be comfortable with the cultural model, it fails those who are not. As Smith (1999) explains, social reality underlies all of our cultural experiences, even though the ideas that are the foundation of that reality may not be the same for all of us:

These ideas constitute reality. Reality cannot be constituted without them. When confronted by the alternative conceptions of other societies, Western reality became reified as representing something "better", reflecting "higher orders" of thinking, and being less prone to the dogma, witchcraft and immediacy of people and societies which were so "primitive" (p. 48).

Accordingly, cultural and social reality, firmly grounded in years of tradition and respect, is met with a culturally diverse response that communicates that it is perceived as "hogwash" or "stupid" by the majority ethnic group. It appears that Smith's (1999) contention; "Western culture constantly reaffirms the West's view of itself as the centre of legitimate knowledge, the arbiter of what counts as knowledge" (p. 63) can be applied to the resulting miscommunication.

The ideal would be that one informs the other, and thus both are supported and validated to allow the needs of all to be met. As Hofstede (1997) contends, cultural understanding “does not imply normlessness for oneself, nor for one’s society” (p. 7). However, he further argues that “it does call for suspending judgment when dealing with groups or societies different from one’s own” (p. 7).

The health workers appeared to occupy an integral role in encouraging participation and helping to bridge cultural gaps in understanding between the community and the programme. Health workers also demonstrated an effective role in providing support and information in Kernohan’s (1996) research among 1,000 ethnic minority women of Asian, African and Eastern European descent in a British community. Although not using health workers, Burack et al. (1989) demonstrated how a more personalised approach can assist in recruiting ethnic minority groups in America. However, in further British studies, health workers had no influence on encouraging Asian women to participate either in cervical screening (McAvoy & Raza, 1991) or screening mammography programmes (Hoare et al., 1994).

## **GENERAL PRACTITIONERS**

The role of general practitioners has long been recognised as an influential one in women’s decisions about participation in breast screening programmes (Dorsch et al., 1991; Fallowfield et al., 1990; Giveon & Kahan, 2000; Mandelblatt & Kanetsky, 1995; Rimer, 1992; Rimer et al., 1989; Sienko et al., 1993). Interestingly, letters from their doctor accounted for only 12% of women deciding to take part in the programme in this research. As the first community health professionals women often consult with are their family doctors or general practitioners, their role, as perceived by respondents, was investigated. There are

a number of possible scenarios about ways in which doctors may interact with eligible women. To explore some of the alternatives, women were asked about the role of their doctor in informing them about the programme, how influential that variable was in their decision to participate, and whether they perceived that their doctor had encouraged them to take part in the programme.

The results from this study demonstrate that most of the women who either heard about the programme (80%) or had been influenced to attend the programme (86%) through their doctor, were also encouraged by them to take part, as illustrated below in Table 5.15.

**Table 5.15. Crosstabulations of respondents' reported input from family doctor.**

<b>Did family doctor encourage you to take part in programme</b>									
		No	Yes	Total			No	Yes	Total
Heard about programme from family doctor	No	255 70%	107 30%	362 100%	Letter from family doctor	No	297 55%	241 45%	538 100%
	Yes	52 20%	197 80%	249 100%		Yes	10 14%	63 86%	73 100%
Total		<b>307</b> 50%	<b>304</b> 50%	<b>611</b> 100%	Total		<b>307</b> 50%	<b>304</b> 50%	<b>611</b> 100%

However, among respondents, 50% either did not recall, or did not receive, encouragement from their doctors to participate, and there were no significant differences across ethnic or age groups. This outcome has held constant with the 1991 baseline survey in the Waikato, which revealed that only 50% of general practitioners routinely recommended screening mammography for women (Chapman et al., 1995). However, with many women who responded to this survey entering the screening programme without encouragement from their general practitioner, it was difficult to obtain information on what effect doctors were having without access to data about whether non-attenders either did not receive information or encouragement from their family doctor, or alternatively, received either information or encouragement, or both, and chose not to respond.

## **Prior survey of general practitioners**

As it was unclear whether women had received letters and not responded, or alternatively had not received letters, I investigated the results of a prior survey conducted in the South Waikato towns of Mangakino, Tokoroa and Rotorua by the breast screening programme in late 1999. The health promoters had written to all general practitioners reiterating the fact that the programme had no access to a population-based register to invite eligible women, and asked whether they wanted packages of relevant material to assist in the registration process for breast screening. The packages contained a letter of introduction ready for the general practitioner to sign, coded registration forms, information pamphlets, and post-paid envelopes. These were to be sent out to eligible women in each practice. In the target area, the practices which responded were sent a total of 1848 registration packages.

It appears from a recent manual count of available coded registration forms that only 130 (7%) were returned from women registering with the breast screening programme, assuming that all were distributed. However, due to the inadequacies of the information support system it is not possible to identify how many women in the designated areas chose to respond by telephone. Because of this, the outcomes were inconclusive.

## **Prior research on the involvement of general practitioners**

The pre-screening survey of Waikato doctors undertaken in 1991 did reveal “a high level of support” for the programme (Chapman et al., 1995, p. 27), with 92% of respondents saying they would “encourage eligible women in their practices to take part” (p. 23). Similarly, in Otago and Southland, the population-based screening mammography programme was supported by 95% of medical

respondents (Miller, McNoe, Elwood and Doyle, 1998). Therefore, it may have been possible that women answering the questionnaire for this research were choosing not to consult with their doctors about their decision to participate in the breast screening programme.

### **Consultation of publics with general practitioners**

The health reforms introduced in 1991 have encouraged an environment of primary health services such as screening mammography in which a “well” population is empowered by information and an opportunity to decide about participating in proactive health-inducing behaviours. Rather than women waiting to be directed towards the services their doctors consider appropriate, in an attempt to guide asymptomatic women towards monitoring their own health status, the breast screening programme goes into the community to present the option of regular screening mammography to eligible women, and encourages them to register.

Accordingly, over the past decade or so, it is possible that women are responding to the new environment of health care and are becoming more independent about making health care decisions without any input from their doctors. To assess whether this may be the case, respondents were asked whether they preferred to make their own health care decisions, confer with their doctor, or leave decisions up to their doctor. The response from women across all age groups (64%, 95% CI 58 to 66) was that they primarily wished to confer with their doctors about health care decisions. As illustrated below in Table 5.16, European women were more likely to want to consult with their doctor (70%) compared to Māori (53%) or Pacific Island (47%) women ( $P < 0.0005$ ).

**Table 5.16. Respondents' reported desire to consult with their doctors about health care decisions by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
I like to include my doctor in any health decisions	No	73 47%	106 30%	27 53%	19 45%	225 38%
	Yes	82 53%	242 70%	24 47%	23 55%	371 63%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 19.64$ ,  $df=3$ ,  $P<0.0005$ )

Women expressed reliance on the expertise of their family doctors in the focus groups, describing their desired input as “important”, “necessary”, or even “essential”. For example, in the words of one, “If my doctor hadn’t hassled me I wouldn’t have bothered”. Only 18% of women wanted to be responsible for their own health care decisions. European women were almost twice as likely to want to take responsibility for their own health care decisions (20%) than either Māori (11%) or Pacific Island women (11%), although the trend abated with advancing age. There were differences among the 18% of women who preferred to leave health care decisions entirely to their doctor ( $P<0.0005$ ). Pacific Island women were significantly more likely to do so (39%) than Māori (31%), Asian (31%) or European women (6%). See Table 5.17 below.

**Table 5.17. Respondents' reported desire to leave health care decisions to their doctor by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
I prefer to leave health care decisions to my doctor	No	107 69%	327 94%	31 61%	29 69%	494 83%
	Yes	48 31%	21 6%	20 39%	13 31%	102 17%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 74.32$ ,  $df=3$ ,  $P<0.0005$ )

Although the desire of women in this study to consult with their doctors is clear, the reason for the doctors' apparent lack of involvement in recommending the breast screening programme is less so. General practitioners are well positioned to encourage women to attend screening mammography, although auditing records and sending out letters of recommendation do involve compliance costs for practices (Dr L. Rademaker, GP, Glenview Medical Practice, personal communication, March 3, 2000).

The results of this study indicate that there are marginally fewer than 50% of general practitioners providing encouragement to respondents to participate in screening mammography. In a telephone interview, the doctor who is the regional representative who liaises with the breast screening programme on behalf of all general practitioners in the greater Waikato region, stated her belief that some doctors still think that women are automatically sent a letter of invitation (Dr L. Rademaker, March 3, 2000). It is possible that there may not be a high level of awareness of their influence and their need to support the programme among general practitioners in the region.

## **EFFECTIVENESS OF COMMUNICATING SCREENING MAMMOGRAPHY**

The purpose of the above strategies is to encourage women to regularly participate in regular screening mammography. Furthermore, if 70% of the eligible population must participate to ensure the goals of cost and mortality savings are achieved, as suggested by Adelson et al. (1992); Austoker et al. (1995), DeKoning (1996) and Sutton et al. (1994), the programme must be able to communicate its presence to the target audience in the most efficient and effective

way possible. Accordingly, it is appropriate to question whether this goal is currently being met.

The most recent New Zealand Census of Population and Dwelling (1996) records the target population of eligible women in the greater Waikato region as follows:

**Table 5.18. Census population (1996) of women aged 50-64 years of age.**

Ethnicity	Number	% of total population	Desired screening rate (70%)
Maori	3,000	12.0%	2,100
European	20,574	82.0%	14,402
Pacific Island	285	1.1%	200
Asian	393	1.6%	275
Other	852	3.3%	596
	<b>25,104</b>	<b>100%</b>	<b>17,573</b>

The population of eligible women who were registered in the screening mammography programme in August 1999 is shown below in Table 5.19.<sup>12</sup>

**Table 5.19. Representation of population on the screening database.**

Women eligible for screening in Round 3					
Ethnicity	No	% of total	Desired screening rate (70%)	Surplus / shortfall	Under represented by:
Maori	1,087	7.6	2,100	-1,013	48%
European	12,881	89.5	14,402	-1,521	11%
Pacific Island	101	0.7	200	-99	50%
Asian	74	0.5	275	-201	73%
Other	249	1.7	596	-347	58%
	14,392	100.0			

As illustrated above, the data provided for this study indicate varying levels of under-representation on the breast screening database of all eligible population

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<sup>12</sup> All details relating to Waikato women on the programme database were provided by the information support staff from the breast screening programme to the researcher in August, 1999.

groups in the region. This suggests that there are a number of eligible women in the region who have either not been identified, identified but not invited or aware of the programme, or identified and declined. As the biggest barrier in attaining a 70% participation rate is identifying and communicating with the target population in the most effective and efficient way possible, the introduction of the Privacy Act 1993 may have interfered with the process of recruitment. Respondents in this study primarily learned about the screening programme and were influenced to participate through letters of invitation. As Hurley et al. (1992) demonstrated, letters of invitation are the most effective and efficient means of recruitment. However, they cannot be used without an identified population.

There is a resulting anomaly in government policy that provides a population-based screening programme which is designed to be as barrier-free as possible for women, but then places a resolute deterrent in place for that programme which precludes any effective and efficient way of identifying the target population. Although identification of the eligible population for the pilot breast screening programme was primarily through access to age-specific electoral rolls, less than two years into the process the Privacy Act of 1993 precluded this source of identification.

The adherence to the legislation continues to adversely affect not only the effectiveness but also the accountability of the health system. For example, during the cervical cancer screening inquiry in July 2000, Professor Skegg proposed an audit of all cases of cervical cancer in the Gisborne area where women were dying from invasive cancer of the cervix after their diagnostic slides had been misread. The intention was to identify other cases as quickly as possible. The Privacy Commissioner, Bruce Slane, warned that care must be

taken “not to break promises of confidentiality ... [otherwise] people would lose confidence in the system” (Privacy pledges, 2000, p. A10). The opportunity to identify further potentially life-threatening errors was subjugated to the perceived need for privacy.

A further difficulty in achieving ongoing participation through current, accurate records is demonstrated in the 69 (11%) letters returned for this questionnaire survey because women were no longer at the specified address, and had not left a forwarding address. This suggests that 11% of women who are sent recall notices from the breast screening programme to attend for a two-yearly mammogram will possibly not receive them. Once again, access to a current, population-based register is required to ensure that contact details for women are as accurate as possible if mortality savings are to be achieved through ongoing participation in the breast screening programme.

## **CONCLUSION**

In this chapter, the external means by which the screening mammography programme communicates with publics has been described. The resources of the pamphlet, poster and letter of invitation used by the pilot programme have been outlined, and brief mention made of the more recent BreastScreen Aotearoa pamphlet and television advertising campaign that some respondents identified in their responses to the questionnaire survey. Although the national strategy for communicating with the target audience incorporates key messages, responses from the questionnaire survey and focus group interviews indicate misunderstanding about the critical variable of family history, which is having an important influence on women’s attitudes towards screening mammography. If the implications of this misunderstanding are to be overcome, clear, accurate

communication is required that provides some feedback mechanism so that the outcomes can be assessed and appropriate future strategies developed.

There is also an identified paucity of information sources for women about issues relevant to breast cancer and breast screening. Letters of invitation were the most frequent sources of information and influence on women to participate in the breast screening programme (as was also found to be the case by Hurley et al., 1992; Taplin et al., 1994 and Turnbull et al., 1991). In recognition of the influence of letters of invitation in facilitating participation in screening mammography revealed by this research, the programme letter is currently being revised and pre-tested with the health promotion team. For example, one intervention being tested is that used by Hurley et al. (1992), Turnbull et al. (1991) and Williams and Vessey (1989) who demonstrated that including appointment times in the initial invitation encouraged attendance more than an open-ended invitation.

The evidence suggests that this provision is an effective means of encouraging participation in screening mammography programmes, provided requested changes of appointment are accommodated willingly. The results of this study also indicate that a tailored message with a strongly personalised approach, as Skinner et al. (1994) found, would also be likely to enhance the influence of invitation letters among ethnic minority groups. However, political constraints on communication also exist in the form of government legislation, which precludes the use of letters of invitation because of the lack of access to a current population register, unless women respond to the television advertising campaign.

Women have expressed their disappointment that resources from the breast screening programme are not more informative, for example, the recent television

promotional campaign. However, an attempt to address some of the deficiencies in the recent booklet, *More about breast screening* revealed responses that indicated the contents invoked anxiety in some women in the focus groups. All age and cultural groups of women have indicated that they wish to consult with their general practitioners about participating in the breast screening programme. In this research, the involvement of general practitioners in an advocacy role is less clear.

Furthermore, the use of a stratified sample by ethnicity demonstrated preferences and differences in responses to communication strategies from Māori and Pacific Island women that are significantly different from those of European and Asian women. These communication needs are not only significantly influenced by ethnicity, but do not appear to be accommodated in the communication interface of the breast screening programme. Māori and Pacific Island women have demonstrated a clear preference for personal contact and have responded well to health workers. They also responded differently to the way in which introductory communication was framed, which suggests that the information provided by the breast screening programme did not accommodate the cultural needs of ethnic minority groups.

However, there is a further interface of the programme with participants, which occurs when women present for the physical process of screening. It has been argued that this interface is critical, as their experience of screening mammography will strongly influence decisions women make about re-attendance (Elwood et al., 1998). It will also influence the intragroup communication about the process among those women eligible for breast screening (Elkind & Eardley, 1990). The following chapter will explore the influences on the communication

that takes place between staff in the breast screening unit and women participating in mammography, and identify the consequences of such influences.

## CHAPTER 6

### ENCOURAGING ONGOING PARTICIPATION IN THE BREAST SCREENING PROGRAMME

In this chapter I address the second research question: What influences the way in which staff in the breast screening programme communicate with women who choose to participate? As discussed previously, the programme has a two-fold goal in communicating with eligible women: first, to encourage initial participation, and second, to encourage ongoing participation. Women must participate in the programme if it is to succeed in reducing mortality from breast cancer. Regular attendance for screening mammography is also essential as breast cancer can develop at any stage.

The discussion in Chapter 5 focused on the external communication interface of the breast screening programme that is designed to primarily use resources founded on transactional language to encourage women to participate in screening mammography, alongside some input from health professionals, such as general practitioners. In contrast, the overall purpose of the following analysis is to provide a closer examination of the interpersonal or interactional communication processes internal to the programme, processes likely to influence women's decisions about returning for regular mammography.

To provide insight into the ways in which the staff involved in the programme communicated with women, semi-structured interviews were held with the nineteen female staff members who interfaced with publics. Thirteen staff worked in the breast screen unit; five worked either as health promoters or community health educators; one was the programme manager. Staff in the breast screening programme work in different buildings and in different ways. The call centre staff are involved in the telephone interface with women who call the 0800 number, alongside unit staff who carry out the physical process of mammography, either at the fixed site on the hospital campus or in the mobile van. The health promotion staff primarily work in the community, encouraging women to participate in the breast screening programme. They have an office in the nearby Community Services building, along with the manager of the cervical and breast screening programmes.

In the interviews, all staff were asked to describe their perceived role in communicating with women who participated in the breast screening programme, as outlined in Chapter 4. The interviews were transcribed and analysed using the interpretive approach of thematic analysis (Owen, 1984) with reference to Ricoeur (1981). The way in which the themes, their manifestations and outcomes, were extracted and are presented was described in Chapter 4 (pages 156-158). To distinguish various themes in the text, these are presented in italics.

Five staff participated in secondary interviews to provide feedback about the researcher's interpretations. Their feedback is included in the discussion below. In response to the second research question in this study, six primary influences on the interactional communication process between staff and participants in the breast screening programme during women's attendance for mammography were identified. The resulting themes are illustrated below in Table 6.1.

**Table 6.1. Narrative themes**

<b>Theme</b>	<b>Manifestation</b>	<b>Outcome</b>
1. The business of screening	Ensuring efficiency Screening as a commodity	Working to justify the cost A dominant emphasis on completing the screening round on time
2. Technical expertise	Submerging other narratives Primacy of expertise	Subsequent communication submerges narratives of participants Communication processes subordinate to task completion
3. A troubled transition	Feeling disenfranchised Separated from prior promotional tasks Lacking recognition	Unit staff report a perceived lack of recognition at national level Unit staff report feelings of a lack of commonality with new staff Unit staff report lack of validation and recognition for past work
4. Synthesising screening	Integration Segregation	Health promoters practise a role as a community “link” Subsequent attempts made to devolve ownership of programme to community Separation from technical role of unit staff Lack of control of process for women invited for screening
5. Lacking consultation	A top-down process	No opportunity for input into policy. No recognition of cultural differences
6. A divergent culture	Communication from conflicting paradigms	A fragmented or “web” culture

The first theme was consistent across all 19 interviews: *the business of screening*, which appeared to reflect the market influence of the strategic reform process which has occurred in the health sector in New Zealand over the past decade. The resulting importance which interviewees placed on “efficiency” indicated how success in the breast screening programme was measured in volume regardless of the effect of screening one woman every 10-15 minutes.

The result was that there was little time to spend addressing other contextual needs of participants in the programme. A further two themes were apparent in interviews with the breast care unit staff: *technical expertise*, which involved the development and maintenance of a discourse of excellence, closely related to the biomedical paradigms with its associated mechanistic approach to health care, and *a troubled transition* as staff in the screening mammography pilot were coping with both transition into a national programme and internal organisational restructuring.

Two visible themes emerged across interviews with the health promotion staff: *synthesising screening*, as they worked to incorporate screening as a healthy option to enhance the overall wellbeing of eligible women and *lacking consultation*, as they encouraged ethnic minority groups to participate in the programme. A final theme, *a divergent culture*, resulted from the conflicting paradigms of technical staff in the unit, who employed a biomedical perspective, which directly contrasted with the community-focused approach of the health promotion staff. As a number of themes filtered throughout the interviews, they tended to “cross” over others. Consequently, some themes coherently weave together throughout the following discussion.

## **THEME 1: THE BUSINESS OF SCREENING**

As stated above, the one narrative theme that emerged across all staff interviews (19), including unit staff and health promotion staff was that of the “business” of screening. The breast screening programme was presented in the interviews within an economic discourse of justifying cost and ensuring efficiency, for example, ensuring that X number of women were screened during a specified period of time. Accordingly, discursively presenting the programme in

a commercial context moved the emphasis away from a service ethic towards one of achieving efficient outcomes. As suggested by Barrett, Thomas and Hocevar (1995), when the language changes, the organisation changes. In the breast screening programme it appears that the economic rhetoric managed, at times, to discursively displace the reported effort to attain a “woman-centred” service as staff were required to be “aligned to the *business* of the clinic” (I:P18).

The commercial context is highly relevant to the political influences on the breast screening programme. As discussed in Chapter 2, over the past decade in particular, those in the health sector have been required to work in a market model which has influenced the way in which services are provided (Ashton, 1995). In this case, the repositioning of health care as a commodity influenced the way in which staff communicated with participants as discussed below.

### **Ensuring efficiency**

The focus of screening as a business was an important influence on the way in which the service operated, as within the market model of health, the future of the breast screening programme depended on efficient outcomes. It was essential to reach financial targets in terms of even justifying the existence of the programme, thus ensuring that the contract would be renewed. Staff focused on the need to

work to *justify the cost* °°° the concern I have is that you **MUST** expect staff to work *effectively* and *efficiently* °° it’s just that the system won’t work if you can’t justify the *cost* – but that’s not always easy (I:P17).

The need to focus on both working efficiently and justifying cost was not expressed as either a positive or negative aspect by respondents. It was described

as a “common-sense” discourse (Fairclough, 1992) which six respondents explained was integral to the programme. As one respondent reflected, “We have cut our teeth on the *business* and we know it so well”. However, there were also pressures as there was “a constant need to work *efficiently* to complete the screening round in time” (I:U12).

The need for efficiency dominated the process of communication between staff and the women who were experiencing mammography. Control was perceived as necessary by staff because of the pace of appointments that precluded discussion with women. One staff member explained:

“It’s quite hard sometimes ○○○○○ you sense you could have a bit of a chat but you have to cut off. You’re talking to the lady and your eyes are creeping towards your equipment ○○○ or you talk and do things – I know that’s distracting (I:U11).

There also appeared to be some conflict reported by staff as they coped with the need for efficiency when dealing with the anxiety that some women exhibited in an unfamiliar environment. When discussing the apparent need of some women to talk about the process when being screened, one staff member explained:

I guess it is incorporating that into the *business of the clinic* and screening women every ten minutes – the practicality of building that [talking with women] into other questions and explanations (I:U9).

Efficiency was integral to the successful attainment of performance criteria. Success was measured in ensuring that an optimum number of women were screened “as there is hundreds of thousands of dollars worth of equipment in this place that shouldn’t be idle” (I:U8). The equipment should be “made to

pay its way” (I:U8). By default, that means the staff who operate the equipment are also required to “pay their way”.

Providing all eligible women in the population with a mammogram every two years means that a certain number of mammograms must be completed each week. However, this creates an imperative of having only a minimal amount of time to carry out each mammogram. Staff explained that, for a number of women, ten minutes was enough time. However, they also discussed how sometimes women wanted time to reconsider their options, requested extensive explanations about the process, or alternatively, just wanted time to “catch their breath” between the compression of each breast (I:U11 & 12). If the staff went over time because of a delay, all the subsequent appointments ran late.

Similarly, on the mobile van, staff are allocated a certain period of time to conduct mammograms at a given location. However, with the aging of the baby boom cohort, large numbers of women are now turning 50. For example, in the recent screening round in Huntly, there were eighty new registrations. That trend is likely to continue, and it is likely to be nationwide. Consequently, the service is facing the reality of screening increasing numbers of women within the same available time frame, using the same resources. As Yeatman (1990) argues, “[T]he emphasis on ‘efficiency’ and ‘accountability’ contains ideologically mobilised values of economic rationalism” (p. 17). In other words, making public sector organisations function in a market model redefines their identity and thus the way in which they function (du Gay, 1996). The value of a service predicated on rational values is legitimated, where “accountability ... is strongly led by considerations of financial efficiency, and by cost-related numerical performance targets” (Freedland, 1994).

Performance targets have been introduced into the market place of health through initiatives to ensure such targets are met. Organisations providing services to the national breast screening programme are evaluated through audits carried out by the Dunedin-based external monitoring committee, which regularly assesses and compares the “performance” of the six organisations under contract to the government-funded BreastScreen Aotearoa programme. From the initial conception of the breast screening programme, the criteria for evaluation were established as accessibility, acceptability and cost effectiveness (E. Bang, Health Funding Authority, personal communication, June 24, 1999). In their discussion of the British health care system, which has undergone a similar restructuring process, Heelas and Morris (1992) argue that it is no longer possible to simply provide a service without paying attention to the cost, without accountability being measured in expenditure. They state that it is a requirement that health professionals “have to think in terms of an economic culture that requires operations to be properly budgeted” (p. 5). The idea is that “inefficient” health organisations will have “a challenging future” (p. 6). The imperatives of meeting financial targets are clear.

It can be argued that monitoring, in terms of ensuring a cost-effective service within the requirements of the health reforms, incorporates the rules governing the production and consumption of a commodity. Fairclough (1992) explains:

“Commodification” is the process whereby social domains and institutions, whose concern is not producing commodities in the narrower economic sense of goods for sale, come to be organised and conceptualised in terms of commodity production, distribution and consumption (p. 207).

The service of breast screening was reconceptualised in a market framework, and thus required to reach economic utility through what Cheney (1998) refers to as “today’s obsessive business pursuit, efficiency” (p. 31). The emphasis was clear: “We MUST complete the round [the period allocated to screen all eligible women in a given population area] in time” (I:P18). The resulting imperatives include maintaining efficiency within both time and cost constraints, with needs of participants possibly subjugated to the exigency of meeting targets. As Plant (1992) points out, the market context can influence the service ethic:

It can also lead to some changes in behaviour among those in the public sector, which might, paradoxically, harm the service offered to the client, patient or customers, for if the service ethic is displaced by a contractual or market one, there is a danger that people whose self-understanding is that they are offering a service, but are being constrained to behave as if they were in a market or a quasi-market, might then act only within the terms of the contract (p. 94).

In this study, the ascendant need for organisational efficiency to obtain the “competitive edge” described by Keenoy (1997, p. 835), influenced actions that were required to meet such ends.

### **Screening as a commodity**

Of critical note in this study is that staff interviewees themselves neither questioned nor criticised the market context in which they were expected to operate. The discourse tended to maintain an uncritical stance of presenting breast screening in the context of a market model. As Traynor (1996) noted in his study

of the British health sector, even the traditions of a rational science of health care can be “pushed to the margins and excluded by a new language of rationality and measurement” (p. 337); that of the cost of providing health services. The process that Fairclough (1993) refers to as “commodification” of a state service has occurred through positioning, or what Bakhtin (1981) refers to as “saturation”, of language within an economic framework until it is accepted as a “given”. In Bakhtin’s (1981) words:

The whole matter consists in the fact that there may be, between “languages”, highly specific dialogic relations; no matter how these languages are conceived, how they may all be taken as particular points of view on the world. However varied to social forces doing the work of stratification - a profession, a genre, a particular tendency, an individual personality - the work itself everywhere comes down to the protracted and socially meaningful saturation of language with specific and consequently limiting intentions and accents (p. 293, emphasis added).

However, it is also worthy of note that *screening as a business* was the only theme identified by the researcher that was queried by all participants in the secondary interviews. One respondent replied with a question, that because the breast screening programme “has gone out and actively recruited these women, surely there is an obligation to be efficient?” (I:S1). In other words, if someone had made an appointment, they were entitled to be seen on time. Also, the same respondent argued that “the breast screening pilot programme was part of an epidemiological study to assess how effective the programme was in New Zealand” (I:S1). Accordingly, staff must complete the two-yearly screening round on time to protect the validity of the study. At the end of this particular

interview, however, the respondent also asserted that efficiency was integral to the overall approach:

The programme HAS to be *operationalised* °°° it can't entirely move in the warm, fuzzy paradigm [of health promotion] otherwise it would never happen °°°°° it would just be a mess (I:S1).

The response from the health promoters in the secondary interviews was, in the words of one of them, one of “being blown away by the thought” of screening as a commodity as they reported that they “worked SO hard to keep the service women-centred” (I:S4). The same respondent continued that she “made a conscious effort NEVER to talk *in terms of money*” (I:S4). However, health promotion staff agreed that their contracts were “written in *quantitative terms*” (I:S3) and that their performance was consequently “measured in terms of numbers” (I:S4).

I suppose *money IS the bottom line* and if the contract [with the Health Funding Authority] is not met then it will get pulled – that is simply the reality of the situation we work in (I:S4).

There are at least two explanations for the level of discomfort expressed by respondents to the identification of this theme in the research. First, it may be that I am imposing my own thinking as a researcher in constructing the theme. Alternatively, the economic rationale may have been such a logically coherent or “common-sense” ideological discourse that staff were unaware of its influence. As J. Kelsey (1993) argues, the health reforms were the most radical representation of the “intrinsic superiority of the market place” (p. 79) in the reform of state sector organisations in New Zealand. It was inevitable that those operating within such an environment were enculturated, at least into the language, if not into the ethical imperative of the market place. A decade into the

reform process of progressive commodification of breast screening as a business, economic discourse did appear to be inevitably and simply presented as a natural part of the discussion, to the point where nobody was aware of its existence. It thus transcended other texts in the organisation, through the seamless process of interdiscursivity. Fairclough's (1992) words come to mind:

Change "catches on" and becomes solidified into an emergent new convention, and stylistically contradictory texts come to lose their patchwork effect and be "seamless". Such a process of naturalisation is essential to establishing new hegemonies in the sphere of discourse (p. 97).

Although participants in the secondary interviews reported that they were not happy with thinking about health in a market context, it was recognised that: "At the end of the day we have to deal with numbers" (I:S4). As van Dijk (1993) asserts, "[D]ominance may be enacted and reproduced by subtle, routine, everyday forms of text and talk that appear 'natural' and quite 'acceptable' " (p. 254). It appears so natural that the reproduction loses its strangeness. In the "common-sense" world, individuals align with specific bodies of knowledge which affects their interaction with others. Accordingly, the development and maintenance of socially constructed reality, or a "taken-for-granted" consensus is established at a deep structure (Mumby, 1988), which often results in an ideological consensus. Reality is socially constructed; however, this occurs in such a taken-for-granted way, that consensus may occur which enhances the power relations of one over another. When this happens, a hegemonic shift has occurred as staff predicate their service on "a need to be *efficient* and paying our way" (I:U6). In this case, numbers became the criteria of measurement for successfully meeting the goals of the organisation. The economic discourse

appeared to be an inevitable outcome of a political environment where “health was simply another commodity to be bought and sold on the level playing field of its particular market place” (J. Kelsey, 1993, p. 87).

Despite the expressed discomfort of staff about my identified theme and the associated economic discourse, the interviewees did appear to express an economic ideology underlying the “value of *efficiency*” (I:U12), which was diffused throughout the organisation. Such consensus legitimised a framework of definition that sustained a hegemonic shift towards economic rationality. As Grace (1994) argued, the message from government about the basis for “reform” in the health sector was clearly the “need to restructure the system in the interest of greater efficiency, greater effectiveness and increased consumer responsiveness [where] better value for the dollar [was] the favourite slogan” (p. 271). One of the underlying features of the reform process has been the strategic use of language to reposition health care in order to influence public opinion about the commonsense notion of cost.

Economic ideology represents a set of values about social and economic organisation that espouses individualism. Inherent in this ideology is support for privatisation of public property, and the use of private sector management techniques in the public sector. Such an ideology views the “problem” of public welfare expenditure as a burden for taxpayers. The “burden” can be reduced by converting state production to private provision of services for welfare “consumers” (Kelly, 1991, p. 127). Therefore, it could be argued that staff also worked within a role that was not only internally, but also externally, imposed because of a developing “public” expectation of increased service for decreased cost. As one respondent reported, “We are expected to make this thing work ◦◦◦ to provide an *efficient* and safe service for women” (I:U9). The subsequent

influence on both the language and the values transferred to the interaction between the staff and participants in the breast screening programme, as Christensen (1995) suggests, will occur within a consumerist discourse.

## **THEME 2: TECHNICAL EXPERTISE**

A recurrent and repetitive narrative theme that emerged from interviews with all (13) breast care unit staff was the centrality of *technical expertise* to their service. This theme was nominated by the thirteen staff as being of the greatest consequence in their interaction with women. However, it also covertly influenced the discursive interaction between staff and women having mammography. The resulting discursive positioning of the primacy of “expertise” was firmly grounded in the rationality of biomedicine, which privileges the exigency of carrying out a process focused on the physical “at the expense of social, cultural and biographical” contexts (Atkinson, 1988, p. 180).

The unit staff perceived a focus on expertise as critical to the breast screening process, not only to meet the safety needs of women through reducing the risk of false positive and negative findings, but also to reassure women that they were “entering a *professional, expert* environment” (I:S1). Each participant in the group expressed the importance of developing an expert approach to enhance the ongoing success of the centre. One respondent described the unit as

“a centre of *excellence*”, where staff are immersed in mammography. I believe that our level of *expertise* is so high because we do nothing else and we focus our energies (I:U10).

There was an interlinking focus between “expertise” and “excellence” throughout ten interviews as illustrated in the above quotation. One appeared, at

times, to imply the other, and both were clearly desirable. As one respondent explained:

This IS a centre that has an established reputation of *excellence*, it's got a tremendously high level of *expertise* – we should be telling people that. We should be making it known (I:U8).

The culture of “excellence” was popularised in management texts such as those by Peters and Austin (1985) and Peters and Waterman (1982), based on adaptability and initiative. The drive to achieve excellence as an organisation was promulgated as the “new way”, or as “very much a crusade” (du Gay, 1996, p. 68), which has had an enduring influence on the workplace and those in it. In this research, staff strove to provide “*excellence* in everything we do” (I:U7), although as another explained, “Sometimes it's so hard just keeping your focus on giving your lady the best you can” (I:U4).

However, as Rose (1999) argues, the cultural transition which results from a discourse of excellence may also negatively impact on people who strive towards that goal. The downside of such a crusade is that striving for excellence may dominate people's lives not only at work, but overall, as the discourse of excellence inevitably links the productive with the political and to the personal, as it overflows into values such as “self-realisation, the skills of self-presentation, self-direction and self-management” (Miller & Rose, 1990, p. 27). In Foucauldian terms, the technologies of power merge with the technologies of the self (Foucault, 1988, p. 18). In this case, the outcome was reported as “a high level of burnout among the staff that is a constant worry” (I:U8).

## Submerging other narratives

The importance of making sure that the resulting X-rays from each mammogram were properly exposed was seen as integral to controlling risk, and tended to override other considerations as discussed below. During the interviews, one staff member expressed concern about participants in the process as well:

I feel really worried that women are having false negatives – and you wonder whether you are really doing women a service. But it's not perfect °°° it's really well °°° you will always have human error (I:U12).

However, this concern occurred as an isolated comment. As Leventhal, Nerenz and Steele (1984) describe, the biomedical perspective is one which promotes clinical aptitude as dominant to any other consideration, and in this study, the theme of task expertise tended to be pervasive over other considerations.

Biomedicine is a reductionist model which exists in a clinical mode; individuals are merely “passive sites of disease manifestation” (Atkinson, 1988, p. 180), rather than whole people. Accordingly, health professionals focus on the task at hand, which logically excludes anything other than the task: establishing whether disease (breast cancer) is present or not. In this research, the reported perception of unit staff was that women simply needed to understand “how important” it was to have regular mammograms. Then they would attend.

I think the biggest barrier is not being educated, to know it's for their benefit (I:U6).

The staff did not perceive that there would be any reason not to attend for screening. For example, one stated, “We can't solve the problem [of breast cancer] if women won't come in for screening” (I:U1). However, the contextual

needs of participants, such as anxiety and pain experienced, will also influence their decisions about participation in voluntary health interventions. Sometimes, a biomedical focus is so intent on expertly addressing a particular health problem that health professionals often fail to recognise such needs (Frankel, 1995).

### ***Communicating discomfort***

The discourse of expertise was privileged above others in the narratives of those involved in screening mammography. For example, there is a dilemma inherent in the physical process of obtaining a mammogram. The breast must be compressed; otherwise the quality of the resulting film is reduced. In response to discussion about the discomfort participants may experience with mammograms, an argument was presented by unit staff in favour of the overriding importance of “*expertise [as] the primary requisite*” (I:U8). The criterion was firmly grounded in the requirement to obtain a satisfactory task outcome; for example, one technician explained, “You can *tell by looking* how hard you have to press” (I:U10). That is, the need for optimising the technical outcome was paramount, as outlined in Chapter 2. Technical outcomes do strongly reflect the risks of participating in screening mammography programmes. However, the perspective of the participant is equally important. If women are refusing ongoing, regular screening, as the literature suggests they are, because of an unacceptable level of pain (for example, Baines et al., 1990; Bakker et al., 1998; Elwood et al., 1998; Hugh, 1991; Rimer et al., 1989), mutually appropriate outcomes appear to be a trade-off between technical excellence and an acceptable experience for women.

Nevertheless, further probes about assessing levels of discomfort for participants were negated by the perception of pain as a “myth”. Technical staff perceived a “need to explain the procedure to them [participants] – obviously

there is a lot of myth going around about it” (I:U7). Staff assiduously commented on the discomfort associated with the procedure as “necessary” to ensure that the process was carried out as effectively as possible:

We’re not doing it to make it uncomfortable – it is *for the individual’s benefit* – we just can’t do any more °°°° you know?

(I:U6).

However, staff believed that once women had experienced mammography, they were quite happy about the process. For example:

I think once they’ve had one mammogram, then they tend to accept it and get on with it and go. At least 80% of the ladies don’t find it as bad as it is said in public. I don’t know where they are getting it from °°°° the media must be getting this from the wrong source I think (I:U12).

The findings of this study, along with numerous others referred to in Chapter 2, did not support that hypothesis, and the respondent was not able to provide evidence of the assertion other than it “was [her] impression that this [was] the case” (I:U12).

Staff did appear to be genuinely perplexed about the apprehension women expressed about the pain of the process, especially those women who had not experienced mammography before. There is no doubt that pain was a dominant concern for some respondents in this research, just as it has been in other studies, as mentioned above. However, the opinions of respondents may reflect the influence of treatment focused on expertise. Keefe et al. (1994) contend that women having mammograms may not mention pain to clinical staff because of their tendency to “minimize complaints” (p. 257). Thus, women tend to “talk extensively about mammography pain with close friends” (p. 257), and probably

others in their social network. As McNoe (1996) illustrated, 20% of women in her Otago and Southland sample were influenced by negative reports from other women. It was possible that women were not reporting pain to staff, either through a lack of opportunity or their lack of willingness to do so. Subsequently, staff in the breast screening programme appeared unaware of the level of discomfort that women later reported in the questionnaire survey and in individual and focus group interviews.

### ***Communicating cultural needs***

Questions of how the service incorporated the cultural needs of different groups of women evoked a similar response, that “the most important thing to ALL women is an *expert service*” (I:U8). As discussed in Chapter 3, when health professionals focus on working within the scientific framework of a biomedical model, the result often is problems in communication (Maynard, 1991). Underlying such problems of miscommunication is the propensity of health professionals to transpose the scientific paradigm on to people, and discuss their clients in impersonal, scientific terms of “processes” that exist quite independently of “people” (Anspach, 1988, p. 372) where, “ethnicity isn’t the issue, it is people KNOWING what they are doing” (I:U10). To ensure effective outcomes that lowered the risk of false positive and negative mammograms, expertise took precedence over other needs of participants.

Health services in this country have been historically founded on a western scientific model which is anathema to ethnic groups who are culturally grounded in a community model (Durie, 1994a & b). However, unit staff reported that they believed that they “provide[d] a welcoming environment” (I:U7) and thus interventions to assist different groups to assimilate into the programme were

“unnecessary” (I:U6), as “ALL women [were] in the same boat” (I:U1). For example, one respondent commented that she did not feel there was any value in recently introduced large-size floral gowns to try to help Pacific Island women feel more comfortable:

Quite frankly, I don't think a culturally sensitive gown will do it. I think this is a very multicultural comfortable environment. There is no cultural theme running through it. If they DON'T want to come in there's nothing you can do about it, but I think it's a real shame they won't take advantage of it (I:U2).

The above quotation serves to illustrate the misjudgment inherent in “cultural imperialism” (Te Awekotuku, 1991, p. 11) that assumes the natural dominance and “rightness” of the ascendant western perspective. In this case, those in the dominant European culture are setting the breast screening environment in a way in which the needs of ethnic minority cultures are not being accommodated. However, in the midst of doing so, staff are also establishing (or re-establishing) their stance as the arbiter of what is right and what is proper. In Smith's (1999) words, they are “the centre of legitimate knowledge” (p. 63), or claim the right to know what is appropriate. For example, as Rohipa (1994) points out, the physical, economic, political and social environment of many Māori is different from that of most non-Māori. Accordingly, she argues that the different environments cannot be ignored, and demand different strategies if resulting barriers are to be overcome. After all, an expert outcome counts for little if few women are willing to participate.

## The primacy of “expertise”

The narrative theme of *technical expertise* was consistently described as a key criterion in communication with women undergoing mammography. As one staff member reported, the need to assure women of expertise was essential, regardless of the situational context:

I don't have a problem with people at all, no matter what. Even the aggro ones, they're a challenge! You have to realise that they are anxious or something happened in their life and you're just the dumping ground. We ALWAYS reassure them that everyone is *expert* (I:U8).

The value of the service was invariably predicated on a “tremendously high level of *expertise*” (I:U5). Armstrong (1984) suggests that a persistent focus on expertise reflects the underlying premise of a rational and scientific biomedical model. However, in recognition of the “expert” role, participants who are receiving the expert treatment are often expected to subjugate themselves to the medical process which tends to minimise any activity other than that of effective and efficient diagnosis and treatment. In the words of one respondent, “It can be quite hard to allow them to ask and answer without hurrying them [participants] because you NEED to get on” (I:U9). Similarly, there were occasions when it seemed inconvenient, or perhaps too tiring to engage in conversation.

Sometimes you sense it [women want to talk] and you just *don't allow it* to happen °°°° it just depends how your day's going – you think, I'll talk because I need a break (I:U12).

As Fox (1993) demonstrated, a biomedical environment is imbued with both knowledge and power which shape unequal experiences for those providing and participating in treatment. The choices are not equal, even those about how and

when to communicate needs. Lupton (1994b) explains that the institutional health environment is typically a strange and stressful one for lay people as “non-experts”. Consequently, lay persons often feel vulnerable about what they will be asked to do, and also about the possible outcomes.

Although screening is promoted as a primary or community intervention, the process is undertaken by those who have generally worked in tertiary health sector organisations, such as hospitals. For example, Medical Radiation Technologists (MRTs) who take the X-rays must train in a clinical environment to complete their qualifications. Thus, they are used to functioning in specific task-focused roles where the emphasis is on the outcome of a process that is independent of the recipient of the service. As suggested by Anspach (1988), technology separates the patient from the health professional. In this case, the focus is on ensuring high quality films.

In the secondary interviews, the need for expertise was reinforced as essential to engendering the trust of women that they will encounter a safe, acceptable experience:

If we do inferior mammography we are doing women a disservice as we are increasing their risk. I think it's important that we focus on *expertise*. I think it's comforting. I'll make the assumption that it's very important to women that they walk into an *expert* environment (I:S1).

As the “expert” model dominated the practice, it also dominated the perspective of staff in the unit. Accordingly, that perspective was transposed on to women who were attending for screening. For example, the prominence given to expertise in this study, as in prior research, meant that health professionals did appear to restrict the flow of information to participants, as suggested by Taylor (1988);

Waitzkin (1985) and Wodak (1997). They also controlled the content and direction of the communication (Waitzkin, 1989; West, 1990), preferring to “communicate to patients” (Kreps & Kunimoto, 1994, p. 74, emphasis in original).

Such an emphasis on both an expert and efficient service did appear to override further considerations that diminished other contextual needs of participants. Communication involves not only “content” but also “relationship dimensions” which affect how communication is both transmitted and interpreted (Kreps & Kunimoto, 1994, p. 44). In this case, communication with breast screening participants appeared subordinate to expert task function as the “rationality of domination” (Habermas, 1971, p. 85) of the scientific paradigm prevailed. The implications, as perceived by participants in the screening programme, will be discussed in Chapter 7.

### **THEME 3: A TROUBLED TRANSITION**

The transition of the pilot to the national programme had influenced the communication that took place between staff and participants in the breast screening programme. In the past, the unit staff had carried out all of the promotional activity. Consequently, women received communication from the same group of people in the same context, from their introduction to an invitation for breast screening until completion of the physical process. However, as discussed in Chapter 2, in December 1998, the then National Government announced a national screening mammography programme for New Zealand women aged 50 to 64 years. Six contracts were allocated for tender throughout the country and the Waikato pilot was successful in its bid to provide breast screening services to the women of the greater Waikato region. The process of

transition that followed meant that the staff who had been involved in the pilot were not only required to integrate into a national programme, but also encountered internal organisational changes introduced by Health Waikato through the appointment of additional health promotion staff.

As a result, the breast screening organisation made structural changes which integrated a separate group responsible for the promotion of the breast and cervical screening programmes. As well, the programme manager, who had been with the organisation for some years, had resigned, and a new manager was appointed just prior to the staff interviews for this research. Nine unit staff mentioned some difficulty with the transition process, although they were usually reticent about doing so. This theme also tended to evoke a somewhat emotional response from respondents in four of the interviews, as unit staff expressed some reservations about how their contribution to the programme was perceived by those they referred to as “outsiders” (I:U8) involved in the process of establishing the national programme.

### **Feeling disenfranchised**

The process of change had not been an easy one. Although authors such as Kanter (1990) and Peters (1987) extol the excitement and challenge of the opportunities inherent in a rapidly changing work environment, others such as Ezzamel, Lilley and Wilmott (1993) and Zorn, Christensen and Cheney (1999) have pointed out that change is not exciting for everyone: it is often used as a controlling mechanism, and can be a source of stress, as indicated in this research. For example, unit staff expressed a sense of ownership for the breast screening programme:

Right from the word “go” there was a shared sense of vision for the service. People who came in were so strongly focused on making a go of this thing and making it successful that they came in and gave it their all (I:U8).

However, they also expressed a sense of feeling disenfranchised from others involved in the administration of the national programme:

The centre has done the mile and developed a great deal of expertise and we NEED to be bold enough to say that. It’s that tall poppy syndrome – I think when you have done a really good job you SHOULD be able to say appropriately that we ARE expert.

Whereas I sometimes feel like – even at a national level- *that has been viewed as an inappropriate* thing or feeling to have (I:U8).

After eight years of being responsible for organising the entire presentation of the breast screening programme, unit staff suddenly had to adapt to an externally imposed model of “how things were going to be done without reference to the fact that [they] had done them damned well in the past [as they had] forged the way for the nation” (I:U8) in the pilot programme. The change to a national programme did not appear to be exciting, stimulating or enjoyable, but rather a stressful and unwelcome imposition.

### **Separation from prior tasks**

The same feelings were also expressed about the new personnel involved in promoting the screening programme. Just before the implementation of the national programme, the health promotion team had expanded, including the appointment of a full-time coordinator in August 1999. The health promotion

staff occupied existing offices in the adjacent Community Services building where the cervical screening staff were already located.

However, six interviewees described some difficulties that had been experienced in the process of integrating health promotion staff with existing personnel. One breast care unit staff member explained:

When we were just ourselves [the breast care unit] *everyone was aware* of what was going on. There was this feeling that everybody to a greater or lesser degree had a finger on it °°° um °°°° because at staff meetings *information was brought back about everything* so people could pick up on the big picture. Now there is that feeling that, my god, it is all happening – *we don't know HOW it's happening* – *we don't have the control* that °°°° perhaps a SLIGHT feeling of *being a bit scared* that things might be happening that we are unaware of and we only become aware of them when they blow up in our face (I:U8).

Unit staff explained that during the first seven years of the pilot programme they had coordinated the promotional activities along with the timetable for the mobile van. Consequently, they “just *ALWAYS knew* what was happening” (I:U5). There was a sense of feeling separated from earlier responsibilities with screening processes being fragmented into a more specialised service. The outcome was that unit staff expressed feelings of being disenfranchised and thus separate from the health promoters who they perceived had detached them from their prior tasks.

The impact of the national screening programme has been quite big. Because of the fact that things had to be *fragmented* – we have

a close team at the centre - *we don't really have anything in common* with the others [health promotion staff] (I:U9).

Without exception, all thirteen unit staff throughout their interviews reported that they were part of a “close team” (I:U11), and identified strongly with the “team” ethic, and it was agreed in secondary interviews that this theme provided a relevant assessment of their work environment. Nevertheless, one staff member relayed how that closeness might be perceived as difficult for others. “We have a VERY strong team here which *may be quite intimidating* as we are very close knit” (I:U2). However, as Robbins and Barwell (1994) point out, when a close team is asked to work cooperatively with another that is dissimilar, there is a high probability of conflict developing. The authors explain: “[A]s soon as organisations begin to divide up work ... the seeds of conflict are sown. Differentiation, by its very nature, creates a ‘them’ versus ‘us’ mentality” (p. 357), which was reflected in this research.

## **Lacking recognition**

There were a number of integral differences between the two groups in the way that they approached the breast screening service. Accordingly, the unit staff not only expressed dissatisfaction with losing control over promotional tasks, but also with not being recognised for what they considered to be their years of experience and hard work. This was compounded at the time of interviews by a strong feeling that there was no regard for their level of experience and expertise. The perception was that the worth of accepted practices and meanings associated with the organisation was being discounted.

There's a need to acknowledge again that this centre has in fact gone the mile and learnt a lot in that process and we have got some

stuff that is worth hearing – and I suspect that at the moment the staff in the unit don't feel that they are getting a hearing um um um um that a lot of good work has gone on – a lot has been achieved, but maybe at the moment, um um um um because we are so busy pushing forward and advancing the service um um um um but that's fine – the service is only where it is because of all the hard work that has gone before (I:U8).

The difficulties experienced in the interface with the health promoters were specifically described by six staff members. Their concern was encapsulated in the words of one:

There are a lot of very *experienced people* here that have so much knowledge, some feel that the new people [health promoters] who've come aboard *haven't recognised* that (I:U2).

The focus was consistently one of a lack of recognition and validation as unit staff struggled to make sense of an order of discourse that did not reflect the “expert” orientation but rather that of a distinct set of meanings that was difficult for them to interpret. Tensions between the health promoters and unit staff had developed an increasingly antagonistic stance, which Robbins and Barnwell (1994) contend sometimes occurs when there is mutual task dependence between teams which creates “a definite escalation in the potential for conflict” (p. 356). The conflict between the two groups from the perspective of health promoters is described below.

Efforts to bring in an independent arbitrator to facilitate a better working relationship between the two groups “had not been successful” (I:P17).

Secondary interviews confirmed that the situation was not resolving and that there was a sense of disappointment on the part of unit staff that there were “still people

out there promoting something they don't understand" (I:S1). The sense of disenfranchisement had not diminished.

#### **THEME 4: SYNTHESISING SCREENING**

In contrast to the clinically-oriented biomedical model described above, the overall approach of all five health promotion staff in their interviews was one of integrating the programme with the target audience through advocacy of a community-based health promotion model. The outcome was an inconsistent message for women in the community which is discussed further below.

Although nobody used the term "synthesis" during the interviews, during the secondary interviews, health promotion staff agreed that it was an accurate thematic representation of their perceived role.

In terms of Rosenstock's (1974) Health Belief Model, health promoters explained their role as one of "*removing barriers*" so that women in the community could make an "*easy and comfortable transition*" into the screening programme (I:P17). Within the description of Downie et al. (1990), health promotion is "the balanced enhancement of physical, mental and social facets of positive health" (p. 25). Therefore, as a "wellness" model, health promotion tenets advocate involving individuals to encourage information-based behaviour change.

#### **Integration**

Congruent with health promotion principles, the health promoters appeared to be actively involved in devolving ownership of the programme from the internal organisation to the external locus of the community with a consistent discourse which emphasised autonomous choice, "I think EVERY client has the

*right to question anything they want to*” (I:P15). The health promoters worked in the community, meeting once a month in the cervical screening building to discuss various issues. They also met regularly with the newly integrated Bay of Plenty health promotion team at Toi Te Ora, the public health organisation for Pacific Health in Tauranga. The region had been included in the BreastScreen Midland area with the introduction of the national programme in December 1998. As community-based workers, the health promoters stated that they were exposed to a considerable amount of feedback from women about various aspects of the programme.

The health promoters related their role as a “link” between the women and the programme. However, they were very aware of their position as external to the technical process of mammography. This was reported as an area of concern as their tasks included inviting women in for screening. However, from the moment these women reached the door of the screening unit, the welcome they received was completely outside the control of the health promoter who had issued the invitation. Subsequent feedback from breast screening participants resulted in reported perceptions from health promoters that, on occasions, unit staff could be “cold and uncaring” (I:P15) towards those they dealt with. The concern about the service participants in mammography received served to “deplete [their] energy” as promotion staff “tried to deal with the fallout” (I:P14) of processes that health promoters perceived tended to “segregate” rather than “integrate” (I:P17).

## **Segregation**

One health promoter explained that with the cervical screening procedure, they were able to recommend culturally-appropriate services to women. Trained

health providers are easily able to set up a cervical smear service in the community with little cost, as equipment is minimal. Many clinics are able to cater for smear taking, either as a dedicated service, or more commonly as an adjunct to others, such as general medical services. Therefore, health promotion staff can recommend those whom they believe will provide an acceptable service to comply with the individual and cultural needs of women.

Breast screening, however, requires large, expensive machinery; thus the more community-oriented approach is not so achievable. Accordingly, one health promoter explained the subsequent lack of control over what were perceived as barriers to the screening procedure:

With the breast centre we can only go to the front door – then THEY [unit staff] dictate where you [breast screening participants] go, what you need to do. “This is what you’re going to do now” °°° I know straight away when they [participants] go in that will happen – it’s a real thing of control and it REALLY bugs me!  
(I:P16).

The emphasis of unit staff on a task-focused need to provide an “expert” service to reduce clinical risk was in dissension with that of the health promoters, who wanted to provide a “wellness check” in the context of the community. Consequently, the perception of all health promoters was of a clinical coldness that even infiltrated the way in which the breast screening programme contacted women for screening.

The system doesn’t have that touch of contact, of touching you and saying, “Did you know?” – it’s just a letter °°°°° but what else could we do? I didn’t like the process that we had to use, but that’s what we did (I:P15).

This comment epitomised the low response rate of Pacific Island women to the letter of invitation discussed in the previous chapter. The individualised print media approach did not appear to meet the needs of this cultural group. However, if the health promoters did convince women to respond to the invitation for screening, when the women telephone the service, some interviewees suggested that they experienced further barriers.

They think they're really good and they ring up [to enrol in the programme] and somebody's rude and mucks them around. So they just hang up. So this support that we create for them is *thrown out the window* when they hit the 0800 number. As efficient or whatever that unit may be it just *lacks the personal demeanor*. Consequently, women are saying, "At this stage of my life I *just DON'T expect* to be treated in that way". So they decide *just not to come back* (I:P14).

The decisions that respondents in this study made about not to participate are discussed in the following chapter. Meantime, as Kreps and Kunimoto (1994) assert, interpersonal relationships are integral to providing health care. The vulnerability imposed by the health sector environment, because of the loss of certainty usually experienced in accustomed, everyday settings, may be enough to create dissonance about the process of screening. Negotiation and cooperation to achieve mutually acceptable outcomes are cogent variables in the process. As one health promoter appealed, "Is it too much to ask for? It's just so nice to walk in somewhere and know that you'll be *treated with respect*" (I:P16), a critically important variable in Māori culture. Smith (1999) explains:

The term "respect" is consistently used by indigenous peoples to underscore the significance of our relationships and humanity.

Through respect the place of everyone and everything in the universe is kept in balance and harmony. Respect is a reciprocal, shared, constantly interchanging principle which is expressed through all aspects of social conduct (p. 20).

The Māori health promoters “just want[ed] to have some input and have their views respected” (I:P15). Two weeks before the secondary interviews in June 2000, health promotion staff had attended a national conference in the Bay of Plenty. Three health promoters reported they were surprised to find that the feelings of isolation they experienced with other health “experts” were common to other health promoters from other regions. In the words of one:

It is because the experts don't seem to think we are doing it [promoting breast screening] properly. They say you should be doing it THIS way or THAT way (I:S3).

The new environment of health care has required health professionals to interact with other occupational and cultural groups who do challenge the premise of the scientific rationality of biomedicine, as outlined in this research. Within health organisations, there are various professional groups who have distinct functions and goals. Health care providers are “socialised through their educational and work experiences to develop strong professional identities” (Kreps & Kunimoto, 1994, p. 65). These identities are strong influences on beliefs, attitudes and values and the distinction is reflected in language. In Wodak's (1996) words:

There exists not one discourse in the institution, but a whole set of interwoven, conflicting discourses which construct and establish multiple relationships (p. 12, emphasis in original).

In health organisations poor interprofessional communication can prove a major impediment as the ethnocentric cultural biases can limit cooperation among health professionals (Kreps & Kunimoto, 1994). In this case, the ultimate outcome was perceived by all health promoter interviewees as one that affected the women who were having mammograms. One explained:

They [the women] are saying, “Who do I listen to?” So I have a fear now that our credibility is on the line – we are now in damage control because we are not getting alongside our colleagues. I thought it was just us, but it’s actually quite widespread °°° it’s nationwide (I:P15).

Intergroup communication occurs as an interface between two separate systems of rules and meanings (Collier & Thomas, 1988). Therefore the potential for communication problems to exist between different groups is high. For example, Stewart (1985) asserts that communication problems may be the cause of dissatisfaction in an organisation because professionals speak their own technical language that is misunderstood by management. They, in turn, use their own “administrative reason” (p. 218), which is misunderstood by health professionals). The manner and rationality of the decision making process will contain values and assumptions which may not be acceptable to one group or the other. As one health promoter acknowledged, at the conference she “suddenly realised what was happening”, and just how “vital it was that they started to talk to the experts”. She explained:

A lot of people at conference said that they now want to stand aside from the screening programme because the message is so conflicting – health promoters are saying one thing, the experts are saying another (I:S3).

This was perceived by all health promoters as creating a difficulty for women as the same women saw health promoters as part of the same breast screening service, not as separate entities. After all, they were promoting the same service, so that was not an inappropriate conclusion for women to reach. However, feedback received by health promoters from some women who had gone through the process of mammography had indicated that what they had been told by health promoters and what had happened were different. As a result, one health promoter “wonder[ed] if the unit staff and us are on the same wavelength, and whether the things we talk about are even the same?” (I:S3).

There was evidence of a discursive struggle between the unit staff and health promoters to establish a meaning system in which one view would be privileged over the other. The order of discourse within the biomedical model was being challenged by the health promotion order as a preferred meaning system. However, the outcome was that energies were being consumed in professional conflict. As Keleher (1994) states, health professionals “must believe in their ability to work within participative and collaborative models” (p. 373). Energy should be focused on advocacy, not dissent. However, a cooperative stance needs first to be established.

## **THEME 5. LACKING CONSULTATION**

*Lacking consultation* was a major narrative theme in only three interviews, all with health promotion staff. It was also present as a minor narrative theme in the other two interviews with health promoters. However, as it tended, when it occurred, to be a theme that was both dominant and forceful, it could not be ignored, especially considering the historical context. Previously identified issues, such as a lack of appreciation of cultural differences, have not been

recognised for ethnic minority groups in the programme in the past (Campbell & Bryant, 1996). The outcome was perceived as one of an ethnocentric model of health care based on the dominant European paradigm; therefore, ethnic minority groups did not easily integrate into the breast screening programme.

A primary reason for locating one of two pilot programmes in the greater Waikato region was that there was a significant Māori population in this area (Richardson, 1996). With increasing recognition of the poor health of the Pacific Island community, the coordinator of a culturally-based health organisation was also asked to assist in establishing promotional strategies among Pacific Island women. However, some frustration was expressed by the Māori (2), Pacific Island (1) and Asian (1) health promotion and community education staff at the programme's perceived lack of consultation with ethnic minority groups. From the outset, there has been an ongoing desire for consultation among Pacific Island women (Devlin & Singsam, 1994) and Māori women (Campbell & Bryant, 1996). However, consultation has not been perceived as occurring. In the words of one Māori health promoter:

The pilot programme was signed, sealed, delivered, like it or not. What was required was *NOT the programme we wanted* to develop. It was *what THEY wanted*, how THEY wanted, whether THEY wanted, for God's sake! I am REALLY angry °°° we had a pilot programme and had the opportunity to make changes for Māori, but there was never ANY input allowed from us at management level (I:P15).

There was a perceived disregard for the needs of the indigenous group who were supposed to be an important part of the process. Although government had made provision for Māori to integrate into the breast screening process, the

outcome appears to be a token inclusion. True integration would have included recognition of everything Māori, from the way in which the service was negotiated, through the provision, and an emphasis placed on acceptability for these women. Thompson (1990) describes the process of true cultural recognition as comprehending the

meaningful actions and expressions, of utterances, symbols, texts and artifacts of various kinds and of subjects who express themselves through these artifacts and who seek to understand themselves and others by interpreting the expressions they produce and receive (p. 122).

In other words, a truly integrative process would have involved consultation within parameters that were acceptable to all parties.

### **A top-down process**

The top-down process that eventuated in the breast screening programme lacked consultation, which is antipathy to Māori protocol. As Patterson (1992) explains, Māori approach activities on a group basis, “where everyone involved knows what is being done and why” (p. 41). The outcome was that all Māori and Pacific Island health promoters perceived an “inflexibility” of the programme in accommodating the needs of women (I:P17). Māori and Pacific Island staff further expressed an ongoing need to be involved with, and be a part of understanding, where the programme came from and where it was going. However, there was a clear frustration with perceived bureaucracy that interfered with their need to be both consulted and allowed to participate in a consultative process with others.

Bureaucracy still gets in the way, and there were many times that *we weren't happy about decisions* that were made. *We were challenged* every day because we had to cope with a system that was imposed on us, °°°°° they have just GOT to understand that there are just some *things that we do differently* (I:P14).

Patterson (1992) points out that traditional Māori ventures are co-operative, where “decision making involves consensus, not top down command” (p. 41). Accordingly, Māori perceived that they were being ignored in what was a market-driven, top-down model. They were frustrated at the lack of consultation which was established as their right under the partnership principle of the Treaty of Waitangi. When the contents of this chapter were discussed in the secondary interviews, there was an ongoing frustration expressed at the constraints put in place by their provider contracts with the screening programme. As one Māori health promoter related:

They are doing our contracts the mainstream way – they look at traditional [biomedical] medicine and no ethnic minorities are allowed to address things in their own way. We have no choice but to put things in the monocultural way of mainstream (I:S2).

The entire service appears to have been predicated on the individualised westernised model of health of the dominant European population. For example, the national programme had produced kits for all health promoters which were congruent with the key messages discussed in Chapter 5. The kits included brochures, a video, posters and a flipchart that were to be used to present the breast screening programme to eligible women. However, as the Māori health promoter stated, “We might not like having to bring back this message from our communities but they are saying, ‘Hey, teacher, get lost’ ” (I:S3). She explained

that “presentations” where information is directed at people are not appropriate to Māori women who are “used to holding a hui” where they discuss general health concerns, “not bits of the body” (I:S3). However, Māori had been denied input into the formulation of policy:

We always came in half way down the track – we never had any input – but all of a sudden *we had to do this* °°° we wanted them [the programme] to know this was NOT the way Māori projects work (I:P15).

Māori, Pacific Island and Asian health promotion and education staff expressed their belief that the ongoing lack of consultation has had far-reaching effects on how their groups of women perceived the screening process as they struggled to adapt to an individualistic western health model. As one stated:

Their thinking [in the programme] is if they keep it nice and safe then it’ll be OK, but they have damaged a whole community °°°° if they could *allow us to be part of the process*, I think it can only enhance the outcomes (I:P16).

Such comments direct attention to the cultural context in which people are situated. As Lewis and Slade (1994) point out, variances in language, in values and in patterns of behaviour provide prevalent sources of breakdown in intercultural communication. For example, although the Asian women who responded to the questionnaire survey did not express high levels of dissatisfaction with the programme, the community health educator explained that they would be “too shy” to do so (I:P19). She explained, “The language barriers make some women frightened that someone will question, or even speak to them, and they won’t know what they’re saying” (I:P19).

Furthermore, as “health is not a unitary concept, [neither] does it have meaning outside a cultural context” (Durie, 1994a, p. 200). Accordingly, health care interventions must be appropriate in presentation and process to all groups of women. Health professionals are not necessarily the best people to decide what is appropriate for others. As Kreps and Kunimoto (1994) explain:

The meanings individuals assign to their health status are strongly influenced by their cultural backgrounds and experiences, and these culturally based meanings strongly influence the health care choices and decisions they make, their relative confidence in their health care providers and treatment regimen, and even their actual physical responses to health care treatment (p. 18).

Unless crucial cultural orientations are incorporated into the infrastructure of health care activities, positive outcomes are unlikely to be achieved. This requires input at primary policy stage from all cultural groups. It also requires respect for alternative views and a willingness to incorporate resulting recommendations.

## **THEME 6: A DIVERGENT CULTURE**

One primary narrative theme in staff interviews was that of a divergent organisational culture. The conflict was evident throughout the interviews. Although both the unit staff and health promoters demonstrated internal values and beliefs that were homogeneous and unitary as individual groups, the same values and beliefs did not tend to exist across the organisation. The breast care unit staff consistently articulated the conventions of the biomedical model of provider/recipient, which was, as Gesler (1999) suggests, “often expressed in language or discourse” (p. 15).

In contrast, health promotion staff were promoting screening as a service from a community-based health promotion model where women were “facilitated into decision making” (I:P17). Viewing screening as an equally important physical and psychological process incorporates the recognition that regular participation will depend on women’s “own experiences, expectations and mood as well as on the nature of the procedure involved” (Weinman & Johnston, 1988, p. 209). This context creates direct inconsistency with a biomedical model that is grounded in achieving an optimum process. Although nobody would be likely to dispute the importance of skill and aptitude in a health care context, the health promotion team had a strong emphasis on incorporating individual needs into the process as well, which may become secondary when the focus is on the optimal completion of a task.

Throughout the interviews, both groups did convey a cohesive message in which they indubitably positioned breast screening as a “healthy” choice. There was never any conceivable question about the value of mammography in reducing mortality from breast cancer. However, the approach differed in how the modifiable social factor of choice should be conveyed. One group emphasised “expertise” as a benefit of the service; the other group emphasised “choice”. Consequently, there was divergence created from the juxtaposition of two different paradigms which ensconce significant differences in approaches to their goal of encouraging women to participate in screening mammography. It could be argued that one encompasses a model of *dependency* where women are reliant on a short-term task process which is source-oriented. In contrast, the other is one of *autonomy* where women are recognised as part of a long-term process. The latter approach is typical of a focus on health promotional strategies, where making sense of the process in a supportive environment encourages

long-standing changes in health behaviours and attitudes (Scherer & Juanillo, 1992). As Cioffi (1991) asserts, it is not the actual or objective features of a health event, but rather the features that people attribute to the event that are of lasting importance.

There is no reason why the programme should not offer a service that incorporates both equally desirable aspects of expertise and participant autonomy. However, it appears that the two professional groups from the same organisation are expressing different, even oppositional, discourses. As Kreps and Kunimoto (1994) relate, health care providers develop professional identities that have a strong influence on beliefs, attitudes and values. The distinction is reflected in various discourses. The discourse of biomedical practitioners is typically dominant, and resistant to challenge (Gesler, 1999). In this case, the resistance seems to be founded on claims of who “speaks the truth” about what priorities should be in the breast screening service. Where the health promoters expressed their role as promoting screening through “*advocacy of women*”, (I:P16) the unit staff established their role as one of “*providing an expert service for their [women’s] benefit*” (I:U6). The two different discourses revealed anomalous words and meanings, developed from divergent paradigms, which created a major barrier to communication within the organisation.

The difficulty in trying to establish a middle ground was conspicuous. The resulting interface was dysfunctional, as there was ongoing opposition to any suggested change. The eventual outcome was that many new suggestions from health promoters were reported as being resisted by unit staff, “It’s just so hard to get anything done” (I:P17).

Here I am trying to facilitate – to get things going – but they just say: “No, that’s not going to happen, not at all!” Their [unit staff]

attitude is “you women out there should feel lucky we do this for you” (I:P17).

For example, issues raised about practical concerns by one group were treated as signs of disruption, as illustrated in the following example. A health promoter described how women in a rural town had expressed their discomfort with a perceived lack of privacy because the mobile van was parked next to a polytechnic institution. Accordingly, the health promoter had suggested an alternative site. In explaining their negative response to this request, one unit staff member stated:

It’s all very well to WANT all of these things, but it’s just NOT that simple! We can’t just move the van every five minutes and just go anywhere. We just can’t accommodate that °°°° a lot of people just don’t understand that we can’t just park down the road... (I:U7).

Resistance typified the interaction with both parties. Just as the unit staff held steadfastly to the routines that had existed for the past eight years, the health promotion staff similarly resisted consultation about strategies that had been the responsibility of the other group for almost a decade.

Because I don’t want them [unit staff] to critique [interventions], they’re offended. But I don’t NEED their opinions and I’m NOT going to do it. It’s not that I don’t respect them, but I don’t NEED to know. They will always be biased because they work there (I:P17).

The dissent between the two groups resulted in a common perception of not being heard by the other party. One health promoter reported that they all felt they were “*not being listened to* despite the fact they knew their ladies really well”

(I:P17). Similarly, unit staff members made statements such as; “We have some stuff that is worth hearing, you know °°° and I suspect that at the moment the staff in the unit *don't feel they are getting a hearing*” (I:U8). As Miller and Holstein (1993) explain, organisational members who are in dispute will cast themselves as responsible professionals and justify organisational roles and routines.

Reality within an organisation is socially defined in organisational roles. The construction of common-sense knowledge “constitutes the ‘fabric of meaning’ ” (Berger & Luckmann, 1966, p. 27). Thus the common-sense world, or the culture of the breast screening organisation aligns with specific bodies of knowledge that influence interaction with others. According to Pacanowsky and O'Donnell-Trujillo (1982, 1983), such meaning is reflected through organisational communication. The cultural environment described above appears to reflect what Meyerson and Martin (1987) refer to as a fragmented “web” culture where “differences in meaning, values, and behavioural norms are seen as incommensurable and irreconcilable” (p. 637).

This definition compares to more typically integrated descriptions of culture, for example, that of Schein (1991) who maintains that the stability of any organisation will depend on the existence of shared understanding of experience and interpretation. This allows routine daily activities to assume a taken-for-granted nature. Coordinated action is facilitated through the development of shared meanings.

Culture is shared. Shared assumptions, invented, discovered or developed by a group as it copes with problems of external adaptation and internal integration that has worked well enough to be considered valid and is thus taught to new members of the

groups as the correct way to perceive, think and feel in relation to those problems (Schein, 1991, p. 247).

However, the interpretive orientation consistent with this study views the development of organisational culture as a result of individual agency rather than simply an organisational process, as discussed in Chapter 4. The interpretive processes involved in creating social reality are central to the way in which interpretivists conceptualise organisations. An interpretive approach seeks to demonstrate “how the supposedly hard, concrete, tangible and ‘real’ aspects of organisational life are dependent upon the subjective constructions of individual human beings” (Burrell & Morgan, 1979, p. 260). Organisational culture thus comprises the “interpretive acts” that both create and assign patterns of meaning, and subsequent behaviour within the organisation. As Putnam (1983) explains:

Individuals shape their own realities; hence they act with a sense of choice and free will about their options. Although behavior is voluntaristic, people enact regularized sets of relationships that reflect back on their ongoing actions. The processes they create become accepted practices that impact on everyday interactions. These habitual actions are not cast in cement; ongoing activities alter them. Thus, in the interpretive view, process and structure merge together over time (p. 44).

The interpretive view of culture thus espouses a dialectic process where meanings evolve from interaction processes. Nevertheless, even this more differentiated perspective of an organisation as a culture still implies another, albeit less standardised, level of certainty.

In contrast, a fragmented “web” culture does not work towards minimising ambiguity (Meyerson & Martin, 1987). The ambiguity that typifies a web culture

is reflected in the breast screening organisation. Differences in meaning and values reflect the “lack of consistency, lack of consensus, and ambiguity” (Martin & Frost, 1996, p. 609) that represent a fragmented culture. However, in the breast screening organisation, ambiguity is not accepted by either group as inevitable. Neither do staff appear to perceive that it is functional. Thirteen of the nineteen participants mentioned their awareness of the need for overall “co-ordination” of the programme. For example, in the words of one health promoter:

If we want to be serious about this, we have to be as positive as can be – and there ARE times when the programme has been fantastic, and at the end of the day do you want this to work or don't you? All we have to do is sit down and take a look at things. It is not a new programme any more °°° they [the staff in the unit] have to change °°°°° because women simply don't have a choice [about available venues for the breast screening programme] (I:P14).

One individual encapsulated the responses of unit staff by saying that it had been “a bit of a rocky road” (I:U6) to try to synthesise the organisation as a whole, and eight participants from both groups expressed their disappointment at the lack of integration and overall management support. Both groups were aware of the problem, described by one health promoter:

There are barriers that have to be dealt with by management °°° because I have a concern that there are some staff who make the programme look really bad and we've got no way of talking. The manager has to break that barrier for us – she is the one person who SHOULD facilitate breaking down the barriers (I:P15).

However, six months later, at the time of writing this study, the situation remains unresolved. As Mumby (1993) states, organisations are not simply neutral sites of meaning formation. They are produced and reproduced in the context of struggles between competing interest groups and systems of representation. Organisations are thus political in the system of practices that make them up and reflect the struggle to institutionalise the dominance of certain groups and meaning structures over others. Despite recognising the need for change, staff found themselves bound in a discursive construction of division and conflict, which so far they appear unable to bring to a positive conclusion.

## **CONCLUSION**

This chapter has examined the organisational and environmental influences that were revealed in staff interviews as influencing interactional communication from the breast screening programme to participants. There are three primary sources of influence identified. First, the breast screening organisation exists within a setting of a health sector in a socio-political context of change. The setting is one where health professionals, who have operated in the egalitarian philosophy of a welfarist model of health care provision, are being aligned to a competitive market model. As Harrison and Cameron-Traub (1994) comment, cost control in health care has had an enormous influence on the way in which services are provided. The discourse of economic rationality has “subsume[d] many political and social discourses” (Cheney, 1998, p. 31) in order to redefine everything in “purely economic terms” (p. 31). In this study, an economic ideology also exacerbated the efficient task approach encapsulated in the biomedical model. Accordingly, as De Cock (1998) suggests: “In constructing

the organisation as one thing as opposed to another, certain lines of action [were] invited and others discouraged” (p. 2).

Introducing a market model measures “the efficiency of health services by turning their endeavours into cash equivalents” (Miller & Rose, 1990, p. 7) through the use of an economic discourse which inscribes it “in such a way as to make the domain in question susceptible to evaluation, calculation and intervention” (p. 7). The dogma of the market model is in authority, and thus practices are inevitably predicated on the rationality of efficiency, which has further served to undermine the morale of many in the health sector in New Zealand (Ashton, 1995; Wills, 1991).

Second, the organisation has a responsibility to communicate effectively with all cultural groups. Health care is organised within the parameters of particular cultural systems that contain meaning and any action needs to recognise the symbolic as well as the physical elements of that care. The influence of culture cannot be disregarded. However, the texts of unit staff revealed little recognition of difference for those whose cultural values are not based on a dominant western way of thinking. The result is an oversight of the effect on those with cultural values which are not based on an individualistic context of undergoing screening alone, subjugated to staying “on time”, at someone else’s direction. Within the hierarchical distinction and dominance of providing an “expert” service, other meanings and values may inadvertently become an artifact.

Finally, the organisation is in transition and adapting to the constraints of a national programme. As it expands, there is some conflict as both the old and the new staff work to both discursively define and legitimate their institutional activities. Consequently, the organisation communicates from a site of conflict. Although the organisation shares a common goal of encouraging women to

participate in screening mammography, priorities about how to reach that goal differ. The institutional order of professional roles is one of divergence with two separate systems of rules and meaning. There is incoherence between competing discourses, which are both in competition for ascendancy.

It may be that the two paradigms that underlie the competing discourses together would form a closer “ideal” of a consumer service under a market model. However, in that case, one cannot be ascendant to the other. Nevertheless, as Fairclough (1992) points out in his discussion about medical discourse, any shift “away from overt authority and expertise ... towards the consumers or clients ... is not smooth” (p. 148). Practice from within a biomedical model of specialised role-specific knowledge focused on expertise creates an institutional order of subordinated participants. Thus a means/end relationship is established that is logically incompatible with devolving the power or ascendancy to the “lifeworld” of participants.

The divergent culture of the organisation is generated and reproduced through the articulation and tacit affirmation within each group of opposing paradigms. The outcome is conflicting communication about how to both present issues and position participants in the breast screening process. Each group advocates an approach that is incompatible with the other. So how does this influence the resulting communication? The organisational and environmental influences on the process of communication may result in women receiving an underlying discourse of contested and conflicting information in the communication about where they “fit” in the process of mammography. The resulting ambiguity means that there is likely little opportunity for them to explore any discrepancies in the discourse. Thus, they are at the end of a communication process hindered by antagonism, vulnerability and separation.

However, just as the communication process filters through the organisation, it will also filter through the “fabric of meaning” (Berger & Luckmann, 1966, p. 27) or socially perceptive process that individuals use to establish their own “objective reality” (p. 77). The only way in which to examine the women’s perception of the communication they receive from the breast screening programme when undergoing screening mammography is to ask them for their responses, which are presented in Chapter 7. Therefore, the following chapter explores how respondents received and interpreted the communication during their experience within the breast screening programme.

## CHAPTER 7

### THE REPORTED EXPERIENCE OF RESPONDENTS WHO PARTICIPATED IN THE BREAST SCREENING PROGRAMME

When communication is meant to be both educational and persuasive, it is the response of those at the end of the process that will provide the most relevant measure of its influence (Kirscht, 1990). The purpose of this chapter is to explore the experience, opinions and perceptions of women who choose to undergo screening mammography, and thus address the third question driving this research: How does the target audience receive and interpret the communication from staff in the breast screening programme during their participation in mammography?

As in Chapter 5, data relevant to this chapter are drawn from the questionnaire survey, which provided women with an accessible and confidential means of expressing their opinions and perceptions about the communication which had influenced their decisions about participating in regular screening mammography. Data are also included from the focus group and individual interviews with participants in the breast screening programme. As the responses of women to the predominantly transactional introductory communication strategies of the breast screening programme were outlined in Chapter 5, the following discussion will focus on their responses to the largely interactional, or interpersonal, communication process that accompanied the physical experience

of mammography. Whereas women are encouraged to take part in breast screening through means external to the programme, their decisions to return will be more likely to relate to the interactional processes that occur when they take part in the physical process of mammography within the organisation (Baines et al., 1990; Elkind & Eardley, 1990; Elwood et al., 1998).

In contrast to the qualitative analysis approach of the previous chapter, in this chapter results are provided using a combination of both quantitative statistical analysis, using chi-squared and Fisher's exact tests and qualitative interpretive thematic analysis (Owen, 1984), with a critical turn and reference to Ricoeur (1981). Once again, thematic analysis was used to help categorise and interpret the data, which revealed the shared sense-making attributions of participants as they communicated their needs, feelings and perceptions in the survey and interview data.

As in Chapter 6, the way in which the themes, their manifestations and outcomes were identified and presented is outlined in Chapter 4 (pages 156-158). In the case of responses to the questionnaire survey, forcefulness was identified from the use of capital letters, underlining and exclamation marks used by respondents, as all comments, including emphasis, were copied directly from the written responses on returned questionnaires. Forcefulness in the interview transcripts (indicated by a raised tone of voice, repetition, pauses or marker phrases on the tapes) is distinguished by the use of capital letters. Also as in Chapter 6, various themes are distinguished in the text by the use of italics.

Combined analysis of quantitative and qualitative data provided a converging picture of respondents' perception of the interactional communication process of screening mammography. Five narrative themes emerged, as identified in Table 7.1.

**Table 7.1. Narrative themes.**

<b>Theme</b>	<b>Manifestation</b>	<b>Outcome</b>
1. Communication-induced anxiety	Breakdowns in communication  Anxiety awaiting appointment  Anxiety about physical procedure and pain of mammography  Anxiety about results  Anxiety about outcome	Increased levels of anxiety  Lack of reassurance from abrupt, unhelpful telephone interface  Perception that staff were unsympathetic to complaints of pain – women felt invalidated  Results not always received  Propensity of mammogram to relieve this source of anxiety
2. Unrecognised cultural needs	Need for cultural recognition  Different information needs	Increased anxiety caused by individualised programme  Difficulty experienced in understanding explanations from staff
3. Rejecting the market rhetoric	Concern about women excluded from the programme	Reported need for explanation of targeting process
4. Communicating acceptance and rejection	Value of the breast screening programme by some participants  Reconsideration of further mammography by some participants	Feeling of gratitude for programme and impressed with staff  Pain or stress overlaying positive experiences
5. Ambivalence	Reluctance to complain  Reluctance to criticise health professionals	Hesitation to complain in case identified or service is withdrawn  Perception by respondents that they should just accept “free” service

The first major theme was *communication-induced anxiety*, as women reported their experience of anxiety at a number of stages in the screening process. However, respondents’ descriptions of the anxiety they felt appeared to be more closely related to the interactional processes with staff in the organisation, rather than to the procedures themselves. *Unrecognised cultural needs* was the second emergent theme. In particular, Pacific Island and Māori

women had difficulty integrating into a western, monocultural model of health care that not only failed to provide a supportive and comfortable environment for these women, but also failed to recognise other relevant needs, thus compounding their anxiety. The third theme was one of *resisting the market rhetoric* as women expressed their discomfort, particularly about the targeted nature of the programme, and their anxiety about those who were excluded.

The final two major themes were *communicating acceptance and rejection* of screening mammography, which revealed the polarised responses of women in this study towards the breast screening programme, and finally, *ambivalence*, a theme that recognises that meanings depend on context. As Holstein and Gubrium (1994) explain, interpretive practice is “organizationally embedded” (p. 268). In other words, “interpretive activities are simultaneously in and about the settings to which they orient, and that they describe” (p. 265, emphasis in original). For example, the social world contains knowledge that is not articulated, or “tacit knowledge” (Altheide & Johnson, 1994, p. 191). Therefore the purpose of interpreting the participants’ experience includes more than simply what is said. Although unstated, this theme was strongly reflected in the reluctance respondents exhibited when criticising either the breast screening service or the staff. As noted in Chapter 6, a number of themes will tend to infiltrate through texts associated with other themes to create a synchronous link in the data.

## **THEME 1. COMMUNICATION-INDUCED ANXIETY**

Anxiety was a dominant theme mentioned by 64% of survey respondents and consistently juxtaposed with other emergent themes in the data as women explained their perceptions of the process of screening mammography. The

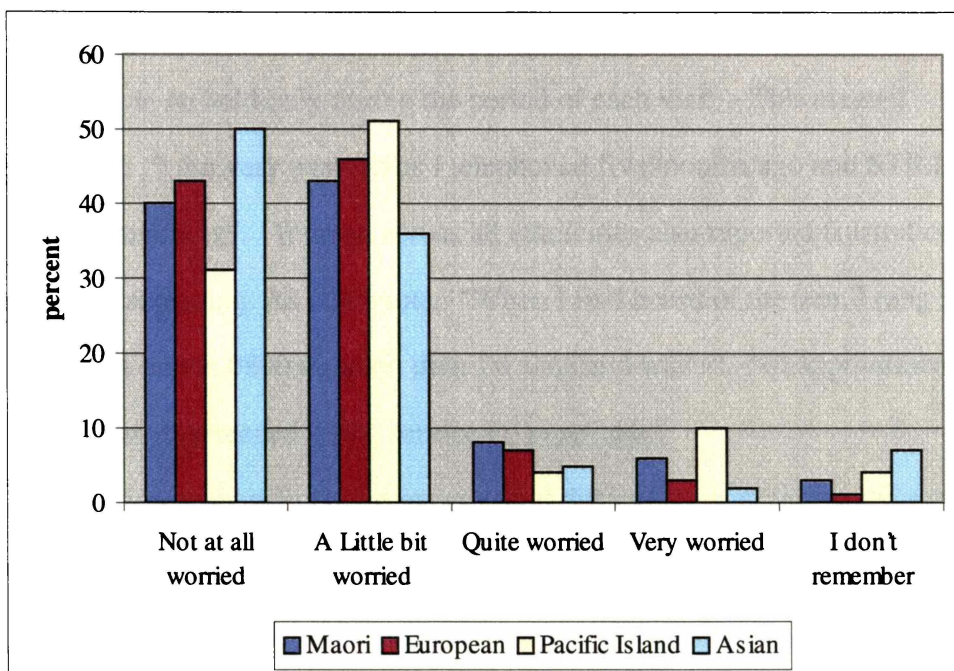
propensity of breast screening programmes to raise levels of anxiety has been associated with different phases of the process, such as heightened apprehension while awaiting the appointment, stress during screening and worry while awaiting results (Gerard et al., 1992). There is also a premise that the underlying anxiety relates to possible outcomes, that is, a potential diagnosis of breast cancer (Keefe et al., 1994). Accordingly, survey respondents were asked about their experiences at each phase of the process and how worried they normally felt about getting breast cancer.

As outlined below, the data generated from this research revealed that the anxiety that women described was more closely related to issues of communication than those of process. For example, women reported predominantly low levels of anxiety awaiting their appointment. However, those women who did report anxiety at this stage also reported difficulties in the communication interface. Similarly, the anxiety associated with the physical process of mammography related more to a perception of a clinical, cold environment where there was minimal communication from staff rather than to the process itself, as discussed below.

### **Anxiety awaiting appointment**

Although there is no evidence in the literature that breast screening will increase psychiatric morbidity (Dean, Roberts, French & Robinson, 1986), as discussed in Chapter 2, it is known that it can still be an anxious and distressing process for some women (Austoker, 1994b). For example, some contend that even public communication about breast cancer and invitations to be screened tend to raise anxiety levels and feelings of vulnerability in women (Gerard et al., 1992). It is suggested that such processes may increase fear-induced anxiety

through reminders to women that they are at risk of breast cancer (Maclean et al., 1984). Accordingly, respondents were asked to describe how worried they felt while waiting for their appointment. Their responses are shown below in Figure 7.1.



**Figure 7.1. Level of worry experienced while awaiting appointment by ethnicity.**

Among respondents, 41% reported feeling no worry at all, and 46% reported feeling “a bit worried” while awaiting their appointment. Only 6.5% felt “quite worried” and 4% “very worried”. Fifteen women (2.5%) did not recall how they felt.

However, during the focus group and individual interviews, among the 44 participants, the 26 who expressed anxiety reported incidents that appeared to relate more to communication experiences rather than the period of waiting for the appointment. Similarly, in the questionnaire survey, fourteen women reported anxiety about their experience of communicating with the programme when they tried to make an appointment. In particular, nine Pacific Island women found it

“*distressing*” that they would telephone either the unit or the 0800 number, only to reach an answerphone, even though it was during working hours.

On occasions, their messages were never recognised and they subsequently missed out on having a mammogram because no appointment was made. (The mobile van visits each rural town and district on a two-yearly cycle, and appointments can be held only during the period of each visit). This created further anxiety. “I am very *worried* as I telephoned five months ago and **STILL** haven’t heard anything”. Women across all ethnicities also reported frustration and barriers to screening. As one wrote, “When I first heard of the van, I rang for an appointment on the 0800 number, then I waited and waited. No appointment arrived, so I wasn’t screened – [the service is] unreliable!”

Eight survey respondents also experienced difficulties with the recording of messages on the answerphone and one suggested, “The telephone should be monitored manually instead of recording messages, because being poor and *not owning a phone is too stressful*.” Six respondents related their problems in, first, accessing a telephone, second, having to try on a number of occasions before they could get through, and finally, if they were successful, not having a contact number to leave. However, similar difficulties were also arising from the external monitoring service that operated on the 0800 number after hours. For example, staff explained that some of the details passed on to them from the monitoring service were incorrect, and consequently it was impossible to contact the women who had asked to be called (I:U2). Once again, the result was that nine women reported feeling “*upset*”, “*stressed*” and “*unimportant*” because they had never received a response to their requests for appointments. The respondents reported feeling that their communication needs were unrecognised.

Their experience may also reflect the biomedical paradigm in which the way the service operates is related more closely to efficiency than to the recognition of needs of participants. As Fairclough (1992) suggests, discursive practices are ideologically invested to sustain relationships of power. Although the ideology of unequal power relationships between health professionals and women participating in the programme are unstated, they are nonetheless prevalent to the point where the programme fails to meet the needs of women, and at the same time, fails to meet its own objective of a 70% participation rate.

Twenty-nine respondents also reported stressful situations when they had managed to get through on the telephone. One reported, “My initial phone call was *very abrupt and off putting*.” Others complained that the telephonist was “*very abrupt and short*”, “*needed PR skills*” and expressed disappointment with a perceived lack of flexibility with appointments. Comments indicated that nineteen respondents reported that they believed they were not treated with consideration, as one reported she was “dismissed abruptly” when she asked if she could change appointment times. She explained: “I had to change my appointment. The lady kept sighing and really didn’t know what she was doing. After that *I felt most dissatisfied* with the whole thing.” Another respondent also expressed this feeling that the initial communication had been disturbing.

The woman who answered the 0800 number was very abrupt, most uncooperative. I most certainly would NOT have made an appointment if I had not already been for a mammogram. Other friends have had a similar experience and have not pursued the screening programme – so if *communication breaks down* so immediately, the following [advertising] is a complete waste of time.

The above experiences reported by respondents do reflect a service provided from within a biomedical framework constrained by a lack of recognition of the needs of women for an environment that was welcoming and accommodating. As Maynard (1991) stated, in general terms, the biomedical environment effectively suppresses client experience “in favour of a clinical perspective” (p. 450), which “ignores the life-world concerns” (p. 448) of the clients. The overriding attitude reflects a context where the hegemonic “cement” of the ideology of professionalism and of technological expertise legitimates the dominance of health professions and their autonomous right to determine how services will be offered: a process firmly grounded in it being “in the public interest for it to occur in this way” (Willis, 1994, p. 17). The outcome, for some women who were communicating with the service, was a perception of an unwelcoming and unaccommodating interface which did little to facilitate the positive relationship issues that D’Orsi and Debor (1995) have argued are so important to establish a positive experience for women participating in breast screening programmes.

Similarly, although many of the comments from respondents referred to the ease of access to the mobile screening service, twenty-seven women reported anxiety because of the difficulty in scheduling appointments. For example, one respondent stated, “The screening hours provided by the mobile are not always convenient for working women.” Another explained, “Nowadays it is important that we hang on to our jobs – I was trying to find a time that suits my work hours – I was *hoping* that the hours could be *more flexible* with the Xray.” Working women also expressed difficulties with time off work because they had experienced long delays, as the following statement illustrates: “It seemed to be *hours of waiting* - even though I had an appointment I was there for two hours.”

Another related, “My experiences at the hospital clinic (twice) were of very long waits. This was *extremely frustrating* – it appeared that too many women had been called in at the same time. At that point I switched to private care. I couldn’t afford to do otherwise.”

Over half of the respondents in this study were in the workplace, either working for wages and salary (45%) or self-employed (12%). Even though a recent monitoring report completed for the Health Funding Authority noted that the overall experience of mammography was lower in those who work full time (Hall, 1999), at the time of this study the service primarily operated within standard working hours. The need for extended hours for working women (Adelson et al., 1992) is accentuated with the increasing regional trend of women participating in the workplace which has occurred in the greater Waikato region. For example, in 1986, the New Zealand Census of Population and Dwelling identified 36% of women aged 50-64 in the workplace in the Waikato region. In 1991, there were 41%, and in 1996, 51% of women in this cohort were in the workplace (New Zealand Census of Population and Dwelling, 1991, 1996).

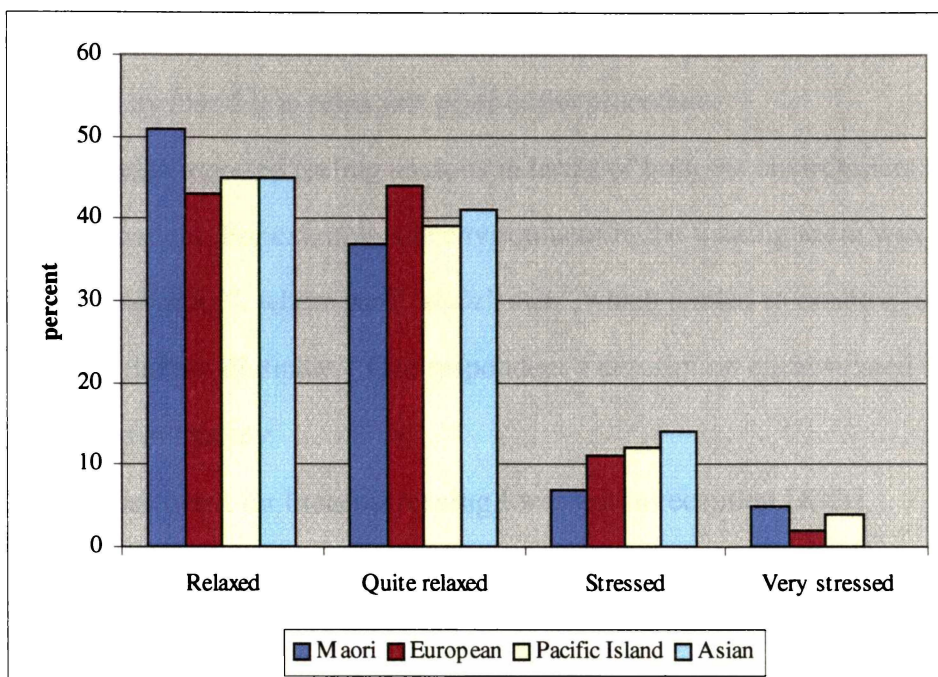
It has been shown that both the location of a breast screening service and the availability of appointment times may create practical difficulties for women who want to attend (Baines et al., 1990). The mobile service helps to address issues of location. However, prior research unanimously indicates how important it is that women require both access and convenience to create an accessible service (Rimer et al., 1989). As one respondent in this research commented, “It is all very well to make us think about breast cancer, but what can we do if we are unable to do anything about it because we are so busy?” In other words, the presence of the service created a desire to participate; however barriers to access served to enhance anxiety.

Similarly, in New Zealand, McNoe et al. (1996) identified practical difficulties of convenience as a barrier to participation with non-attenders finding it almost twice as difficult as attenders to fit in an appointment for screening. Richardson (1990) also found that 17% of respondents required appointment times outside normal working hours. Elwood et al. (1998) contend that “flexible and convenient appointment times” (p. 180) would help to improve participation in breast screening programmes. Earlier surveys of non-attenders in the Waikato region have also identified “inconvenient appointment dates” (Chapman et al., 1995, p. 110) as a deterrent to attendance, and recognition that the “adoption of flexible working hours and initiatives appropriate to each area will provide a service acceptable to each community” (p. 50).

Once again, across all occupational groups, over a third of this sample of women have requested a greater choice of screening times and days. Working women needed greater flexibility to allow them to attend outside working hours, Pacific Island and Māori women experienced transport difficulties and Asian women were caring for grandchildren, and unable to attend during working hours. Because of the worrying nature of the examination, all ethnic minority groups wanted family members to accompany them, which also placed a restraint on their attendance during working hours.

### **Anxiety about the physical process**

To indicate how many respondents found the physical process of breast screening stressful, they were asked in the questionnaire survey what level of relaxation or stress they experienced during their mammogram. Their responses are illustrated below in Figure 7.2.



**Figure 7.2. Respondents' level of relaxation/stress experienced during mammogram by ethnicity.**

The majority of respondents in this study, both across age and ethnic groups, reported feeling either relaxed (45%) or quite relaxed (42%) during their mammograms. Only 10% felt “stressed”, and 3% “very stressed”. This result confirms the findings from earlier regional surveys that fear of the actual procedure itself appears to be a minor factor for respondents (Health Waikato, 1993, p. 16).

However, a number of survey respondents did report feeling stressed for various reasons. For example, sixteen women commented that as a “wellness” initiative the breast screening unit did not always sit comfortably within the hospital grounds. Fourteen further respondents described the environment inside the unit as “clinical” and “cold”. The anxiety experienced by some women in this study tends to be reflected in comments they made about feeling “isolated”, and perceptions such as, “they actually forgot I was there”. One woman explained her response to the process; “I felt just like a number when I came into

the room – but for me it was a big thing.” Twenty-eight respondents also related how difficult they found it to relax just prior to the procedure.

Respondents reported feeling anxious in terms of both the environment and staff communication. For example, the environment in the waiting room was described as “*isolating*”, where staff “*didn’t talk*” which tended to create a level of anxiety that did not dissipate. One respondent’s description encapsulated a sense of pervasive anxiety:

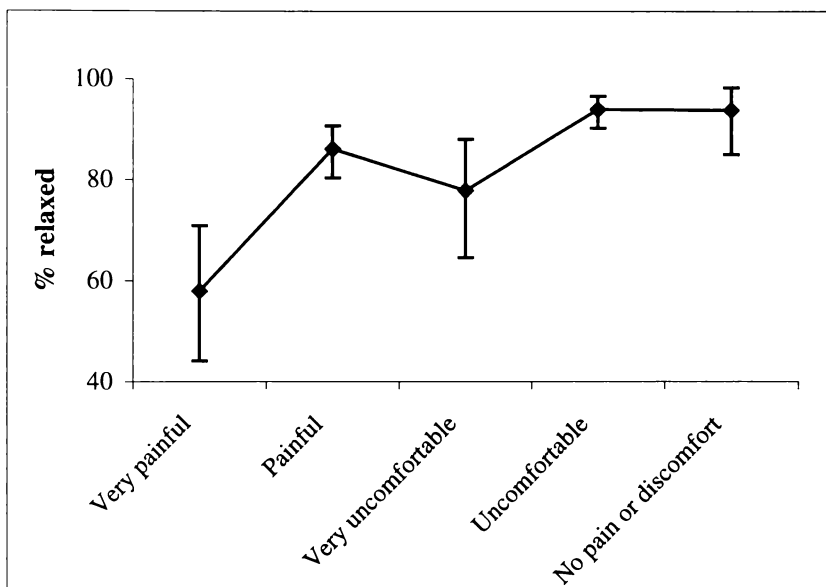
When I first went for breast screening I was left in reception [with] no one to *reassure* me. [I was] then taken to a cubicle to strip off - still *no reassuring words*, taken in for the procedure, *nothing reassuring there* either. [I was] left in cubicle again, then some time later told that I could leave. SURELY a smile, a few *reassuring words*, even a bit of friendly banter couldn’t hurt? It would certainly help me. It is difficult for some people to uncover parts of their bodies, let alone giving a stranger the opportunity to squeeze the heck out of them. *Reassurance*, a friendly smile and some friendly banter would go a long way to helping relieve the stress. TRY IT!!!!!!

For nineteen women the apprehension associated with the environment also related to the period after the mammogram, when women wait to find out whether their films need to be repeated. The “*waiting time* in the cubicles” was described as “*incredibly long*”, “*frightening*” and “*lonely*”. One woman explained, “Cancer is *life threatening*. I felt being left alone in the waiting room both before and after the mammogram a bit like a horse at the knacker’s yard.” It appears that anxiety related more to the environment and possible outcomes rather than to the physical procedure of the mammogram.

The impersonal, objective and scientific framework from which health professionals interact did appear to cause problems with communication as Maynard (1991) suggests. The absolute, universal tenets of biomedicine are firmly grounded in science, technology and professionalism (Nettleton, 1995). However, the result was an environment that was perceived as cold, anxiety-provoking and isolating that caused a level of distress in some women, which was clearly conveyed in the comments they made about the process. The comments of some respondents above challenged the biomedical framework where individuals are “viewed as the recipient and performer of regimens that are to be accepted and obeyed” (Leventhal & Cameron, 1987, p. 119). However, only four women also reported expressing their feelings to staff.

Although Maseide (1991) may argue for the authority and skills base to legitimise the expertise required in health care, there is also a place for bridging the gulf between the required expertise and the equally cogent need for validation expressed above by women participating in mammography. In other words, to establish communication “with” participants as suggested by Kreps and Kunimoto (1994, p. 74).

In this research, the level of relaxation or stress during the procedure of mammography was not significantly related to ethnicity or experience of mammography. Those who had one or two mammograms reported feeling stressed more often (15%) than those who had experienced three or more (11%). However, women aged 50-54 years were almost twice as likely (16%) as those aged 60-64 (9%) to feel stressed ( $P=0.006$ ). The level of reported stress was also significantly related to levels of reported pain, as discussed below, and demonstrated in Figure 7.3.



**Figure 7.3. Percentage of respondents (with 95% confidence intervals) who are relaxed during mammography related to their comfort or pain level during mammography.** (Moderate & 'slightly' painful and uncomfortable categories were collapsed into 'painful' and 'uncomfortable' categories, respectively).

### **Anxiety associated with pain**

It has previously been suggested that anxiety is associated with the amount of pain or discomfort women experience during mammography. Lightfoot et al. (1996) found that those women who reported “fear and anxiety related to the screening process” (p. 148) were significantly more likely to have experienced discomfort during their mammogram than those who were more relaxed. Nielsen et al. (1991) also reported that anxiety was significantly associated with the pain experienced by women in their sample during mammography. Women in this study who did feel stressed during mammography (13%) reported significantly higher levels of mammography feeling “painful” and “very painful” (62%) than those who were “relaxed” or “quite relaxed” (38%), providing evidence in support of the findings of Lightfoot et al. (1996) and Nielsen et al. (1991).

In this research, pain was one of the most recurrent, repetitive and forcefully described themes associated with anxiety. In the questionnaire survey 85 women

made comments about the intensity and duration of the pain they experienced. As stated in the previous chapter, there is a dilemma inherent in mammography. The breast is a physically sensitive organ, which mammography requires to be tightly compressed during exposure to ensure that a clear image is obtained and exposure to radiation reduced. The outcomes of mammography depend on the technical quality of the images produced. If the quality is reduced through inadequate compression, as described in Chapter 2, the risk of both false positives and false negatives is increased. However, compression is sometimes described as painful (for example, Keefe et al., 1994).

In the questionnaire survey, women were asked to report what level, if any, of pain and discomfort they experienced during mammography. The results indicate that mammography was “slightly uncomfortable” for 26% of respondents, “moderately uncomfortable” for 14%, and a further 9% of respondents reported their experience as “very uncomfortable”. Of those who experienced pain, 17% reported slight pain and 14% moderate pain; a further 9% described the process as “very painful”. No pain or discomfort was experienced by 11% of women in this study.

The level of recalled pain in this research is within the expected range of 5- 15% of women who report severe pain on mammography (Elwood, 1995b). Nevertheless, the pain experienced was still of concern to eighty-four survey respondents, who referred both to the intensity of the pain, such as, “GHASTLY”, “beyond painful”, “VERY painful”, or stating, “It was BLOODY SORE.” Twenty-eight respondents also recalled the length of time pain was experienced, for example, “I was tender for a week afterwards”; “It was 6 weeks before I could sleep at night,” or, “I was painful for days afterwards.”

Reporting pain was intertwined with a theme of anxiety related to communication issues, such as, “I felt the nurse *did not listen* to me when I told her it was sore;” “She was *neither gentle nor sympathetic*;” “The staff person *snapped at me*” and, “Staff *did not appreciate my concerns*.” Although one respondent explained that she realised staff were “under pressure to keep things moving”, she also wrote that she “didn’t want to feel processed from abrupt handling during the Xray procedure”. Thirty-eight respondents also directly associated staff performance with the theme of anxiety and pain, such as, “Staff were *rough* and it was very *upsetting*,” or, “She [the technician] pressed too hard,” or was “rough”, and the plate was “lowered so heavy *I couldn’t breathe*”.

There was also an overlapping theme of anxiety about the possible outcomes as twenty-two women in the survey expressed some concern about exposure to radiation. A further fourteen women reported disquiet about the possibility of physical damage from the pressure of the mammogram. Eight of these women referred to the risk of “developing breast cancer from the swelling and bruising” following their mammograms. As one respondent stated, “I felt that if I didn’t have breast cancer before the Xray, I would by the time they finished.”

As outlined in Chapter 2, pain during mammography is a source of well-documented distress for some women. However, this research also reflects distress that is associated with the way in which the health professionals failed to validate women’s experience of pain. Elwood et al. (1998) contend that women may be “more willing to report pain to a neutral person than to clinical staff” (p. 182). Perhaps, as Keefe et al. (1994) suggest, women do not complain because they have learned that health professionals will not be receptive to their complaints of pain. However, the same women will talk about their experiences to friends and others who will be receptive to them, as reflected in this research.

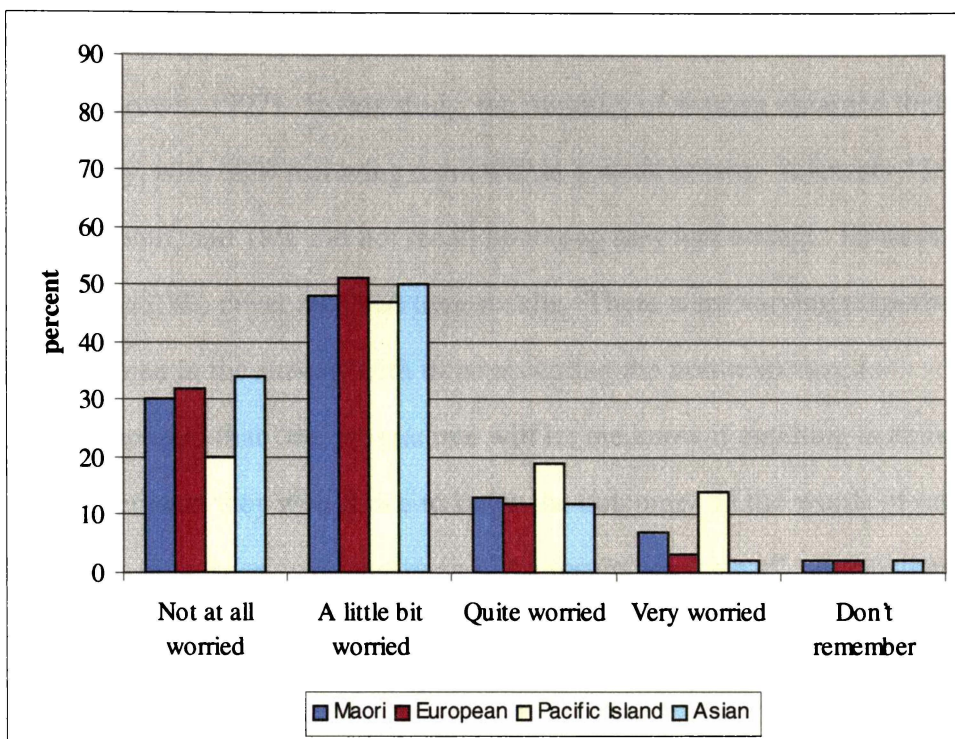
For example, of the eighty-five women who commented in the survey on the pain they experienced, twenty-two also wrote about talking to others about their experience. As one respondent wrote, “Pain is certainly the main topic of discussion when talking about screening, rather than the benefits.”

Aro, de Koning, Absetz and Schreck (1999) found that even an expectation of pain at mammography is predictive of non-attendance, which is probably a result of what Pearlman et al. (1997) describe as an interactive information environment. Information sharing about the experience of mammography is not just unidirectional from the programme to women, but also interactive. Women not only seek information from, but also provide information to, others about their experiences. Such processes may be a direct outcome of a failure on the part of health professionals to accept and validate women’s experiences during mammography, as suggested by Keefe et al. (1994).

### **Anxiety awaiting results of screening**

Respondents were also asked how worried they felt after having their mammogram and awaiting results. Consistent with the trends demonstrated in research subsequent to the completion of the earlier two rounds of screening in the Waikato region (Chapman et al., 1995; Chapman & Brown, 1997), women did report increased levels of anxiety between waiting for their appointment and awaiting their results, although not significantly so.

Their responses are demonstrated in Figure 7.4 below.



**Figure 7.4. Levels of worry while waiting for results, by ethnicity.**

In this study, 29.8% of respondents were “not at all worried”, 50.9% felt only “a bit worried”, 12.8% felt “quite worried” and 4.9% “very worried”. Ten women (1.6%) did not recall how they felt. Those with a family history of breast cancer experienced more worry ( $P=0.001$ ) while awaiting results (11%) than those without (4%).<sup>13</sup> In this research, as Richardson, Elwood, McNoe and Bang (1994b) also found, the same women expressed higher levels of worry both waiting for their appointment and results.

Speed of communication is an important factor to allay anxiety in the breast screening process (Ellman et al., 1989). As demonstrated by Wilson et al. (1998), early notification of results is associated with significantly higher levels of satisfaction with the experience of mammography. To alleviate anxiety, it is

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<sup>13</sup> Using Fisher’s exact 2x2 table combining “not at all worried”, “a bit worried” and “quite worried” vs “very worried”.

desirable that 85% of women should be notified of their results within ten days (Chapman & Brown, 1997). In this study, the majority of women obtained their results promptly, with 69% receiving them within a week or two. A further 11% waited for a month, and 18% did not recall how long they had waited. However, fourteen women (2%) never received their results. There were varying responses from these women in the survey, with three accepting the non-response, for example one reported that “the programme will let me know if anything is amiss”. However, eleven said they would like to know the outcome. In the words of one, “I would *like to have been contacted* even if the results were clear”. As another respondent explained, she “*needed to know* everything was OK”.

However, in the focus groups a further three women commented that they just accepted the lack of communication. One reported that she “didn’t like to trouble the busy staff” by telephoning about results, and two reported that they accepted that “no news is good news”. Once again, the expert ideology was reflected in the discourse, thereby dominating the communication needs of participants. The lack of communication that typifies the dominant biomedical paradigm was accepted by many respondents as naturalised, and thus not open to challenge.

### **Anxiety about the outcome**

Keefe et al. (1994) suggest that the fear of cancer is “one of the most powerful sources of anxiety during mammography” (p. 255). To further assess whether this was the case for respondents in this study, they were asked how worried they had normally felt about getting breast cancer before participating in the programme. Women reported experiencing higher levels of worry about the possible outcome of a diagnosis of breast cancer than they did about the stress of

the physical process of screening mammography. Twenty-three percent of women reported no worry about breast cancer. Of the remainder, the same number of women reported feeling “very worried” (14%) and “quite worried” (14%) about breast cancer. Nearly half of the respondents (49%) felt only “a little bit worried”, which is consistent with the findings of earlier research in New Zealand (McNoe et al., 1996) and internationally (Sutton et al., 1994), that women who are either very worried or not at all worried about breast cancer are less likely to attend for screening than those who experience more moderate levels of worry.

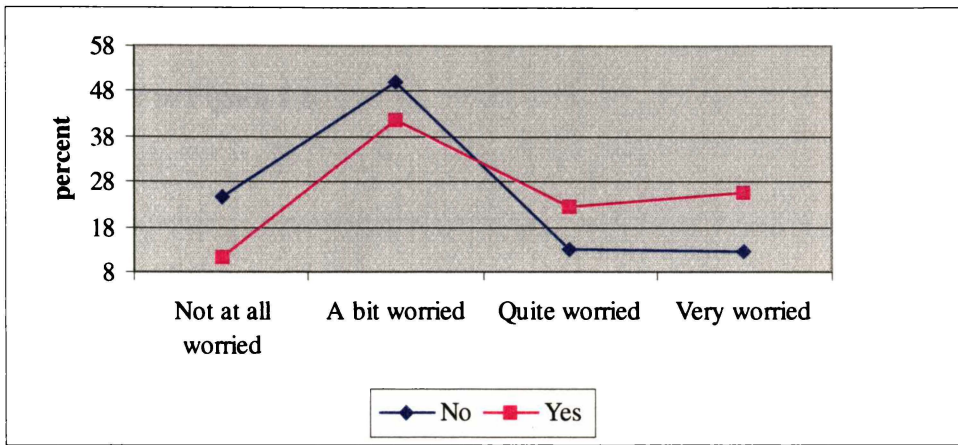
Although respondents in this study were more worried about possible outcomes than they were about the physical process of mammography, those who were either “quite” or “very” worried about the possibility of breast cancer did experience significantly higher ( $P<0.001$ ) levels of stress during mammography than those who were only “a bit” or “not” worried, as illustrated in Table 7.2.

**Table 7.2. Reported stress or relaxation during mammogram by level of worry about breast cancer.**

		Worry about breast cancer		
		Slight worry	Very worried	Total
Feelings during mammogram	Relaxed	396 90%	134 79%	530 87%
	Stressed	46 10%	35 21%	81 13%
Total		442 100%	169 100%	611 100%

( $\chi^2 = 11.3$ ,  $df=1$ ,  $P=0.001$ ) “Very” and “quite” worried and “a bit” and “not at all” worried were collapsed into “very” and “slight” worry respectively.

It has also been suggested that women with a family history of breast cancer may be so worried that they are less likely to participate in regular screening mammography (Lerman et al., 1993). In this study, those women who reported a family history of breast cancer were significantly ( $P=0.001$ ) more worried about breast cancer. See Figure 7.5.



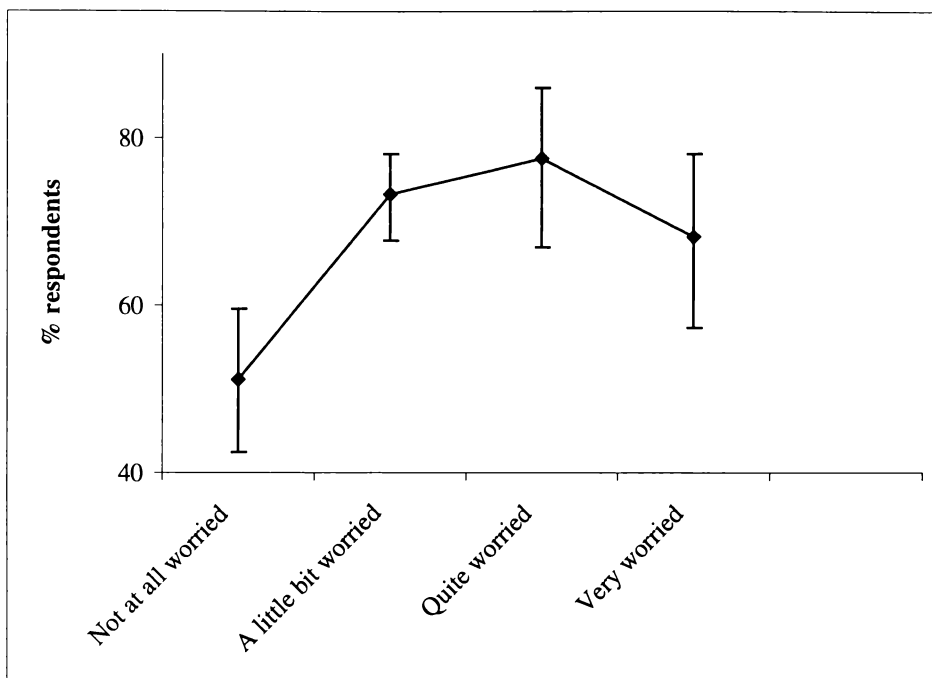
**Figure 7.5. Worry about breast cancer by family history of breast cancer.**

Although most respondents did not report high levels of anxiety at any stage of mammography, the question still arose that if the process does induce any anxiety at all, then why would women choose to participate? Reasons for continuing to undergo screening across all age and ethnic groups appeared to relate to the high level of reassurance participants obtain from screening. In this research, 68% of women felt “reassured” after their mammogram, 31% “felt much the same”, and only 1% felt more worried. The seven women in the last group also explained their anxiety was because they had been notified by the programme that they had something on their mammogram that indicated some abnormality.

***Alleviating anxiety about the outcome***

There is also a need to consider whether mammography had the propensity to influence all levels of anxiety that women experience about breast cancer. For example, perhaps those women who are “very” worried are less likely to obtain reassurance from their mammograms, and therefore resist participation. As a measure of whether respondents were experiencing “outcome anxiety”, that is, anxiety about the possibility of breast cancer being detected, they were asked whether having a breast Xray had influenced this worry. Their responses were

looked at in relation to their reported level of worry about breast cancer as illustrated below in Figure 7.6.



**Figure 7.6. Percentage of respondents (with 95% confidence intervals) who obtained reassurance from mammography related to their initial level of worry about breast cancer.**

Women across all levels of worry about the possibility of breast cancer obtained reassurance from mammography. Overall, 73% (95% CI 69 to 77) of all those with some level of worry about breast cancer were reassured by having a mammogram, and the three groups were not significantly different. Furthermore, 51% (95% CI 43 to 60) of those who reported they were not at all worried still obtained reassurance from their mammogram. As similarly identified by McNoe et al. (1996) in the Otago and Southland population, by Wolosin (1989) in America, and Orton et al. (1991) in Britain, most women in this research gained reassurance from having a mammogram. Accordingly, any propensity of the various stages of the process to increase anxiety levels in some women appears to

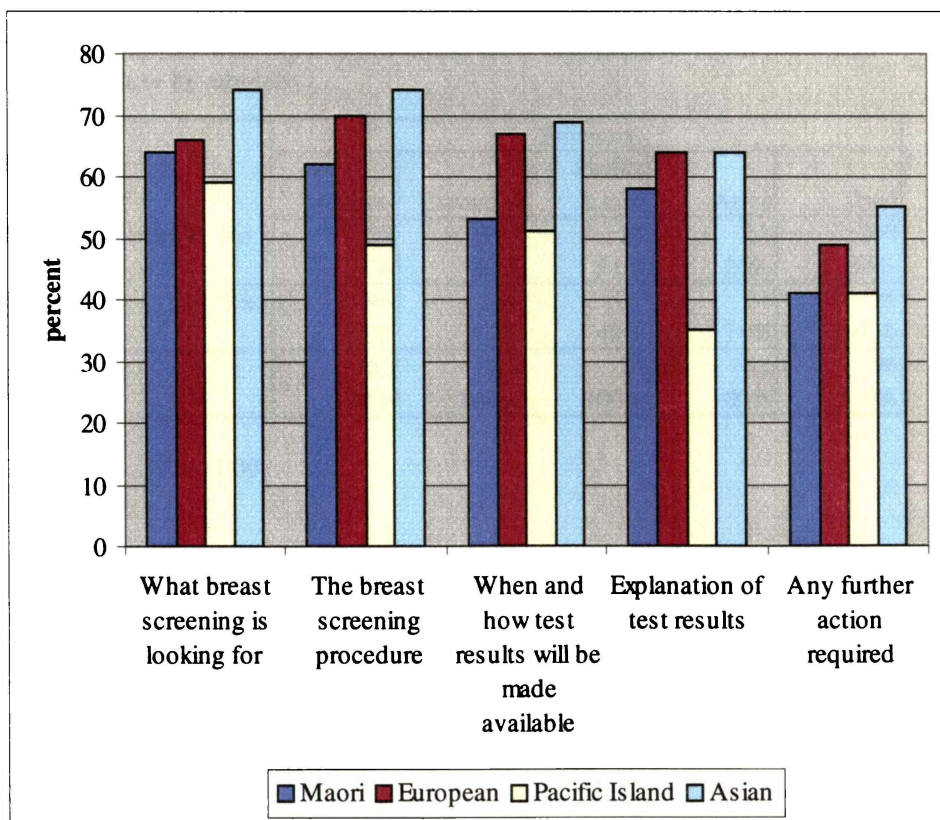
be well compensated for by the relief of anxiety once the outcomes of the mammogram are known, provided no abnormalities have been detected. As one respondent explained; “I have to have this Xray whether I want to or not. The risk’s just too big – regardless of how one feels.” However, eleven women reported their concern about the fallibility of the process. For example, one was “shocked” to learn that “some tumours are missed”. Another reported “disbelief” that mammography “is not 100% true”, and asked for “more openness about risks”. Once again, the deficit in relevant information to facilitate informed choice is apparent. As Fairclough (1992) points out, discourses do not merely reflect social relations, they construct them and thereby position people as subjects. Thus, by exclusion from relevant information, women in the breast screening programme were constituted as participants who were subjugated to a process without truly informed consent.

Nevertheless, it also appears that the propensity of the breast screening programme to ultimately relieve anxiety in participants is far greater than the anxiety that occurs during the process. Perhaps, in some instances, the colonisation of the discourse with “expertise” from programme staff served to naturalise and sustain power relationships that helped to overcome the apparent information deficits. For whatever reason, it is important to understand how the anxiety experienced by some women during mammography may be reduced.

### **The role of effective communication in reducing anxiety**

The anxiety associated with the process of breast screening creates what Baines et al. (1990) refer to as “an underlying ambivalence in some women about mammography” (p. 1668). In this study, respondents related anxiety associated with the unfamiliarity of the environment and a perceived lack of communication. As mammography is typically not a routine, everyday experience, participants

rely on health professionals to communicate various requirements and procedures to them. Therefore, it was relevant to this research to question if, and how, the way in which information was communicated could influence participants' perception of the process. For example, it has previously been suggested by Marteau (1990) that if women understand about the purpose of screening, the accuracy of testing and the implications of possible outcomes, they will be less anxious and thus more able to recall and act on advice offered. Implicit in Marteau's (1990) work is that providing clear and relevant information, in an appropriate format that ensured that participants understood what they were being told, would effectively reduce anxiety in women undergoing mammography. Marteau's (1990) research identified that clear explanations about the areas illustrated below in Figure 7.7 are pertinent to this outcome.



**Figure 7.7. Respondents who reported receiving clear explanations about information related to the breast screening process by ethnicity.**

Although 70% of respondents in this research stated that staff always explained procedures, only 65% of women reported receiving a clear explanation about what breast screening is looking for, and 66% about the procedure. The nature of the test results were believed to be clearly explained by 60% of respondents, and availability of the same results perceived as clearly explained by 62% of respondents. A clear explanation of future action required was noted by 47% of respondents.

There were no significant differences across age groups, or levels of worry about breast cancer. However, there were differences among ethnic groups. Pacific Island (49%) women were less likely to state they had received a clear explanation of the procedure than European (70%) or Asian women (74%), ( $P=0.009$ ). See Table 7.3.

**Table 7. 3. Respondents who reported receiving clear explanations about the breast screening procedure by ethnicity.**

	Ethnicity					
	Maori	European	Pacific Island	Asian	Total	
Clear explanation of breast screening procedure	No	59 38%	104 30%	26 51%	11 26%	200 34%
	Yes	96 62%	244 70%	25 49%	31 74%	396 66%
Total	155 100%	348 100%	51 100%	42 100%	596 100%	

( $\chi^2 = 11.48$ ,  $df=3$ ,  $P=0.009$ )

Similarly Pacific Island women (34%) were less likely ( $P=0.001$ ) to report receiving a clear explanation about the test results than either European (64%) or Asian (64%) women, as demonstrated in Table 7.4 below.

**Table 7.4. Respondents who reported receiving clear explanation of test results by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Clear explanation of test results	No	65 42%	124 36%	33 65%	15 36%	237 40%
	Yes	90 58%	224 64%	18 34%	27 64%	359 60%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 16.32$ ,  $df=3$ ,  $P=0.001$ )

The outcomes were the same for information about the availability of test results ( $P=0.010$ ) as shown in Table 7.5 below, with Pacific Island women (51%) less likely to report receiving a clear explanation than European (67%) and Asian women (69%).

**Table 7.5. Respondents who reported receiving clear explanations about how and when test results will be made available by ethnicity.**

		Ethnicity				
		Maori	European	Pacific Island	Asian	Total
Clear explanation of when and how test results available	No	72 47%	116 33%	25 49%	13 31%	226 38%
	Yes	83 53%	232 67%	26 51%	29 69%	370 62%
Total		155 100%	348 100%	51 100%	42 100%	596 100%

( $\chi^2 = 11.44$ ,  $df=3$ ,  $P=0.010$ )

The above results illustrate that ethnic minority groups did not perceive that they had received clear explanations about important issues in the process of screening. However, the reasons were unclear. As various Māori and Pacific Island women in the questionnaire survey and focus group interviews described themselves as “*shy, scared*” and “*very private people*”, who are “*somewhat reserved to ask personal questions*” and “*feel embarrassed about exposing their*

bodies to others”, it was possible they did not feel comfortable about questioning procedures.

### The role of a supportive environment in facilitating communication

It has previously been suggested by Roberts (1989) that a critical factor in a mammography setting is that women are encouraged to ask questions in a supportive environment. Accordingly, survey respondents were asked about the comfort level they felt about asking questions. Their responses are illustrated below in Figure 7.8.

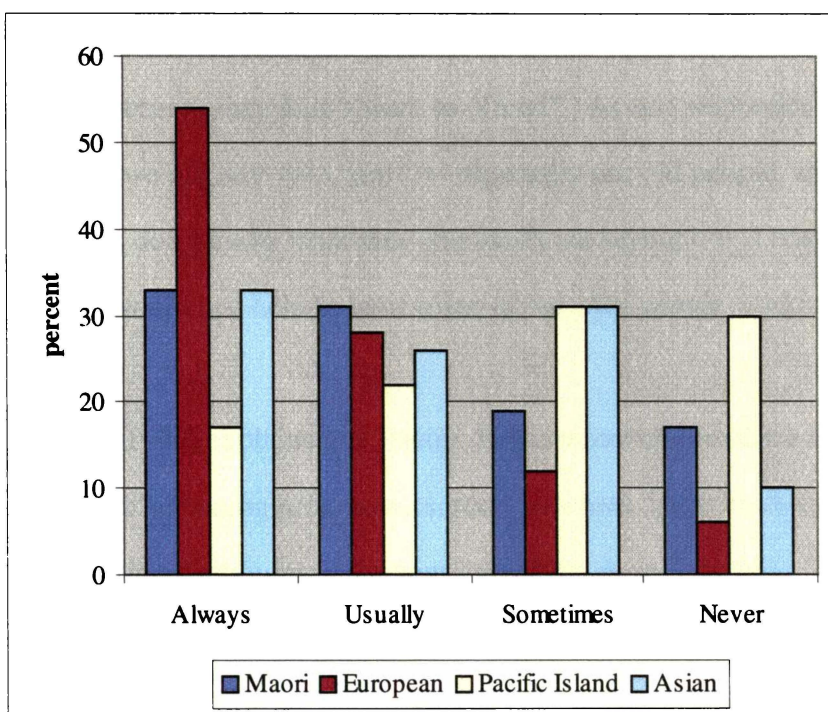


Figure 7.8. Comfort level asking staff questions by ethnicity.

Overall, a number of women felt comfortable “always” asking questions (44%), “usually” (28%) or “sometimes” (17%). A few women (11%) did not feel they could ever question. There were no significant differences among age groups. European women appeared to be the most comfortable with asking questions with 82% “always” or “usually” (M=64%, PI=39%, A=60%)

comfortable with questioning. Pacific Island women were the most reluctant ( $P < 0.0005$ ) to question, with 61% feeling comfortable about asking “sometimes” or “never” (M=36%, E=18%, A=40%).

When asked to clarify the difficulties they experienced, several Māori women confirmed their reluctance to participate with staff, whose “attitude *failed to reassure*”. Six respondents commented in the focus groups that while the procedures were explained to them, they felt “there was no room for questions”, and more importantly, as one explained, “Staff took the silence to mean that I understood what was being said when I did not respond, and continued” with the process. On the other hand, four Pacific Island women said they “tended to nod and say ‘yes’ because they didn’t want to offend”. As one respondent explained,

Because we just say “yep, yep” °°° especially our old people, and really we don’t know what they [the staff] are saying °°°° I really think it would just help to have some of our own people working there.

Ma’ia’i (1992) explains that Pacific Island women experience many difficulties with screening programmes, most of which “stem from shyness, modesty, traditional attitudes, behaviour and ethnic belief” (p. 69). When asked to participate in a programme that asks women to be self-directed, not only in decisions about participation, but also about communicating during the process, these women may find that cultural barriers make such a process stressful and unlikely to be repeated. As Durie (1994a) comments, on behalf of Māori, their involvement is integral to the success of any infrastructure for communicating health care. Otherwise, “an active attitude towards health [is] unlikely to gain popular support or sustained momentum” (p. 199). In the words of Kreps and Kunimoto; “No matter how ‘rational’ the goals of a health care campaign are ...

cultural roots run deep” (p. 97) and thus inevitably influence the perception of a target audience.

There were also significant differences between women with varying levels of worry about breast cancer ( $P=0.011$ ). Those women who felt “quite” or “very” worried (28%) about getting breast cancer were less likely to report feeling comfortable about asking questions than those who were only “a bit” or “not” worried (72%).

To further explore Roberts’ (1989) contention that it is important that women are encouraged to question the breast screening process, the responses from women who believed they had received clear explanations were analysed to see if they depended on their comfort level about asking questions, as demonstrated in Table 7.6.

**Table 7.6. Comfort level of asking staff questions by clear explanations received.**

Source of information	Comfort level asking staff questions		Significance level
	Always/ Usually	Sometimes/ Never	
Received a clear explanation of what breast screening is looking for	78%	22%	$P < .0005$
Received a clear explanation of the breast screening procedure	79%	21%	$P < .0005$
Received a clear explanation of when and how test results will be made available	78%	22%	$P < .0005$
Received a clear explanation of the test results	77%	23%	$P < .0005$
Received a clear explanation of any further action required	78%	22%	$P < .0005$

The results from this study confirm that the perceived clarity of each of the above sources of information was significantly related to the comfort level respondents felt about asking staff questions, as illustrated above. The women who were most comfortable about questioning ultimately believed they had received clear

explanations far more often than those who did not feel comfortable asking questions. The outcomes indicate that the opportunity to question is an important variable in effectively transmitting information in a screening mammography environment. The reluctance of Māori and Pacific Island women to question may underlie their perception of not receiving clear explanations. In turn, this propensity may also relate to the higher levels of anxiety these groups report.

As Planalp (1999) points out, when individuals are able to communicate emotions like anxiety, they cope better with situations, both physically and psychologically. However, in an unfamiliar environment, when women are awaiting an outcome that potentially influences the rest of their lives, and they are being asked to submit to a painful, invasive process, there is little that is conducive to communication. That is, unless women are fortunate enough to interact with people who have the time, willingness and ability to facilitate such interchange. In this study, it appears that the uncertainty and discomfort are compounded by a lack of cultural sensitivity, which compounds the anxiety for Māori and Pacific Island women.

## **THEME 2. UNRECOGNISED CULTURAL NEEDS**

The foregoing theme of anxiety was complemented by another emergent theme of *unrecognised cultural needs*. The connection was crystallised through the apparent struggle of ethnic minority groups to integrate into the programme reflected in comments from over 80% of Māori and Pacific Island women. In particular, both of these groups have demonstrated clear differences in their response to screening mammography. Such differences are reflected in their responses to the invitation to participate through to their interaction with staff during the various stages of the process.

## **Need for cultural recognition**

For 61% of Pacific Island women and 23% of Māori women, the health worker provided the catalyst for their participation in the breast screening programme ( $P < 0.0005$ ), as illustrated in Chapter 5. This interaction also appeared to be the most likely reason for the exceptionally high response rate (82%) to this questionnaire from Pacific Island women, as many of the questionnaires were hand delivered, as explained in Chapter 4. The importance of personal interaction may also help to explain the lack of response to the influence of letters of invitation from Pacific Island women (6%), which came from a source personally unknown to the women.

The under-representation of ethnic minority groups of women undergoing screening mammography in America (Burack et al., 1989) and Britain (Kernohan, 1996) suggests that there should be increased efforts to target this group in New Zealand (Solomon & Jackson, 1990). However, it is also apparent that social norms and values superimpose health beliefs and values. For example, individualism as a tenet has long been part of a capitalist ethic (Hofstede, 1997). However, individualism as an inherent value in any health policy conflicts with the values of Polynesian groups (Patterson, 1992). Thus any interventions that focus on changing individual behaviour, such as asking women to respond to an invitation to attend a screening programme, may invoke resistance when they are presented in a way which conflicts with cultural norms and values based on group consensus. The difference between the societal norms of individualism and collectivism is closely linked to the structure and functioning of many types of institutions including health care (Hofstede, 1984). Therefore, “because they are tied to value systems shared by the majority, issues of collectivity versus individualism carry strong moral overtones” (Hofstede, 1984, p. 149).

## Increased anxiety

For example, an individualistic focus may well increase feelings of isolation, and thus compound the higher levels of anxiety Māori and Pacific Island women have reported in this study. Although the findings from this research support the contention of McNoe et al. (1996) and Sutton et al. (1994) that women who have chosen to attend for screening predominantly report a more moderate level of anxiety about the possibility of breast cancer, Pacific Island (59%) and Māori women (35%) experienced significantly higher levels of feeling “very worried” about breast cancer than did other ethnic groups ( $P < 0.0005$ ), as shown in Table 7.7.

**Table 7.7. Worry about breast cancer by ethnicity.**

	Worry about breast cancer		
	Slight worry	Very worried	Total
Maori	101 65%	54 35%	155 100%
European	277 80%	71 20%	348 100%
Pacific Island	21 41%	30 59%	51 100%
Asian	30 71%	12 29%	42 100%
Total	429 72%	167 28%	596 100%

$$(\chi^2 = 37.59, df=3, P < 0.0005)$$

Increased levels of anxiety were reported by Pacific Island and Māori women throughout. For example, as illustrated in Figure 7.1 above, Pacific Island women (10%) and Māori women (6%) expressed higher levels ( $P = 0.03$ ) of feeling “very worried” than Asian (2%) or European women (2%) while awaiting their appointment.<sup>14</sup> The higher representation of Māori and Pacific Island women in

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<sup>14</sup> Using Fisher’s exact 2x2 table (M + PI vs A + E).

this sample may reflect the overall marginally higher levels of worry than those reported for the first two rounds of screening in which 95% of the sample were European and 5% “other” (Chapman et al., 1995; Chapman & Brown, 1997). Higher levels of anxiety were also reported by Pacific Island and Māori women while waiting for the results of their mammogram. Pacific Island women (14%) and Māori women (7%) tended to report feeling “very worried” more frequently ( $P=0.001$ ) than Asian (2%) and European women (3%).<sup>15</sup> The experience of breast screening is one that appears to compound their anxiety. As one Pacific Island woman explained, “It is a great thing to be cancer free but the *stress and fear of the unpleasant experience* that I had was awful.”

The need for personal contact may suggest why over 50% of Māori and Pacific Island women described the process of mammography as “*lonely and isolating*”. As one respondent explained, “I thought it was *impersonal*. Actually, to me it took over. It was a *lonely, scary, isolating experience* °°°° just put you in there waiting your turn. And then they use the big words – *I don’t know what they mean*.” In two focus groups, women asked why they couldn’t plan for themselves as a cultural group. One woman stated, “At the moment the van comes from Hamilton and the *times and days suit their programme*, not ours.”

It is recognised that there is an important need for efficiency to ensure optimum benefit from the breast screening programme for all women. As illustrated by Facione (1999), however, desired participation levels also require a culturally sensitive delivery of the service which may require a less structured approach. Māori and Pacific Island women appeared to need a more personal setting than Asian and European women. This may explain their desire to attend in groups at a time that fits in with other commitments. A similar approach of

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<sup>15</sup> Using Fisher’s exact 2x2 table combining all worries vs very worried and PI & M vs A& E.

allowing “drop-ins” (without appointments) for mammograms was described as “successful” (Chapman et al., 1995, p. 36) in Tokoroa during the first round of screening.

Facilitating this approach may well encourage higher comfort levels among some groups of women and increase participation in those women who are reluctant to attend as illustrated by Doyle, Jacobson, Parker and McNagny (1996). They found that a high proportion of “hard to reach” American women who had refused an appointment for a mammogram at another facility were prepared to attend a drop-in centre. It is likely that any increase in participation of ethnic minority groups will require ongoing, culturally acceptable interventions. As Chapman et al. (1995) reported in earlier Waikato surveys, “Anxiety lessened when [Māori] women went to appointments in groups or with whanau” (p. 91).

### **Different information needs**

The groups of Māori, Pacific Island and Asian women in this research consistently demonstrated different information needs. They experienced difficulty with the introductory verbal information and the way in which it was explained. For example, Asian, Māori and Pacific Island women were inclined to describe spoken information as “*confusing*”, “*too fast*”, “*overwhelming*”, or complained of not receiving any. One Pacific Island woman wrote, “English is my second language and staff (mostly) took things for granted when it came to explanation.” However, this situation will remain difficult. For example, as another Pacific Island woman stated in the focus groups, “We just nod our head, and say ‘yes, yes’, but we don’t like to say that *we just don’t understand.*”

Even though both Māori and Pacific Island women recognised that their need for “expert” mammography is a high priority, they also wrote that they

would feel “more comfort” and “relief” if there was someone “of our own” available to them who could perhaps speak their language and understand their culture. As one Māori woman commented, “There was no conversation to put me at ease. *I felt very uncomfortable.*” Another wrote, “They simply *do not cater for Māori.*” Rohipa (1994) explains, “It is easier to gain a rapport with the consumer if both [provider and consumer] are Māori. This allows for a friendlier, more intimate discussion, an assurance of understanding and lack of whakama” (p. 66). In other words, the cultural need for personal contact is strong, and it appears to remain unmet in the current programme.

When asked in the focus groups about their needs, women stated that their preference would be “to *feel welcome*”, something they put down to “all *staff having the right attitude*” of “smiling” and “*accepting their cultural differences*” as legitimate and permissible. As one respondent explained, “It doesn’t matter about the colour of the face, the age, or even how shy I feel. All of those things would be *overcome* with a *genuine* smile and a warm welcome – in a word, *attitude.*” As Facione (1999) demonstrated, perceptions of prejudicial treatment on the basis of ethnicity present a barrier to participation in breast screening programmes. Just because an environment is comfortable for the majority cultural group does not mean that it is so for other groups of women. For example, as Durie (1994a) argues, any intervention that is biased towards a western model of health care cannot succeed in Māori communities. It lacks not only “an appreciation of a cultural context” (p. 194), but also “the active involvement of communities in their own health and on terms they [can] appreciate” (p. 194). Second, Durie (1994a) argues, that “by imposing their own world-views, health professionals very often create fresh problems, expecting their patients to fit into a culturally constrained medical straitjacket” (p. 194).

### **THEME 3. REJECTING THE MARKET RHETORIC**

Finally, although women demonstrated some degree of shift towards their role as health “consumers” through their willingness to provide several pages of open and detailed feedback in the survey, the market ideology of screening as a commodity did not always sit comfortably with 68 survey respondents, suggested by comments about the restricted age eligibility for the programme. A further 14 respondents also challenged the authority of an interdiscursive reconfiguration of health care by an underpinning economic rationality with comments such as, “We pay our tax. I feel health is a countrywide issue, not a community one,” and, “I realise this is a government problem, but we do pay our taxes.” Women in this research rejected the idea of the need for rationing through an emphasis on financial imperatives that had been brought to the fore in the reform of the health system in the nineteen-nineties. As one respondent reported, “The issue of health care is too important to be subject to the mighty dollar.” Cheney (1998) points out that when the market dominates, people become “consumers”, thus positioning moral responsibility “outside the domain of consideration” (p. 39). However, the hegemonic shift to displace a welfarist notion of health care through the construction of a text or “order of discourse” of economic rationality was challenged by women participating in the breast screening programme. The acceptance of staff towards the colonisation of health care by a discursive positioning of an economic discourse was not reflected in the responses of participants.

There was a persistently expressed concern that women aged under 50 and over 64 years are excluded from the population-based screening mammography programme. Sixty-six women who responded to the survey directly questioned the message about “increasing age means increasing risk”, which along with

gender, is consistently the most predictive variable of the incidence of breast cancer (Armstrong & Borman, 1996; J. L. Kelsey, 1993; Kelsey & Berkowitz, 1988; Lethaby et al., 1992; Love, 1995). Accordingly, women of 65 years of age and over rightly argue that their risk of breast cancer is greater than that of women in their fifties (Sutton, 1997). With research demonstrating significant mortality savings from screening mammography in 65-74 year olds (H. Chen et al., 1995), these women rightly question their exclusion from a national screening mammography programme.

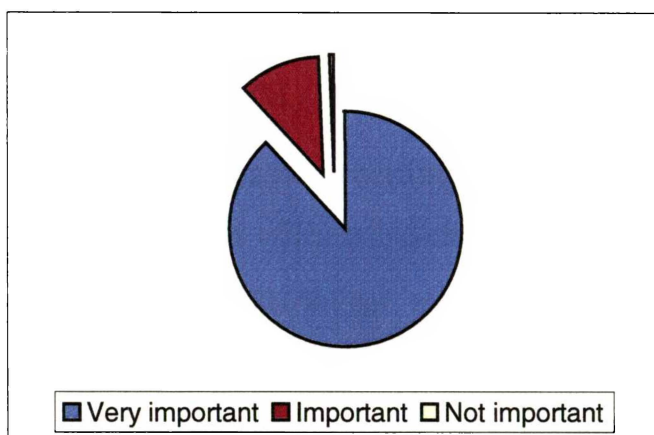
There was also reference to “the number of young women getting breast cancer”, by over 10% of women in the study. Forty respondents expressed anxiety about both their daughters and mothers, asking for “an explanation” about the age barriers in the breast screening programme. In the words of one, “Why do you say that risk increases with age, but then that there is no screen available for my 74-year-old mother?” There was also some resentment expressed by thirty-two women as they reported that they felt they were considered “past their use-by date” and “seen as obsolete” over the age of 64.

#### **THEME 4. COMMUNICATING ACCEPTANCE AND REJECTION**

Respondents expressed varying levels of acceptance or rejection of the breast screening programme. First, the positive side of the theme emerging from feedback received from those women who embraced the programme (over 90% of which were European) will be presented. Second, the theme emerging from the reported comments of those who were unwilling to participate further will be presented.

## Acceptance of the breast screening programme

This study comprised a highly committed sample of women who were very supportive of the need for screening. The majority (88%) viewed screening mammography as very important or important (11%) as illustrated below in Figure 7.9.



**Figure 7.9. Perceived importance of regular mammogram.**

Comments throughout the survey indicated strong advocacy among respondents for the programme. Fifty-two willing participants spontaneously offered comments about their acceptance of the programme and those who ran it. They stated how much they valued the service and the people who provided it. For example, these women described themselves as “lucky” to be part of “*a brilliant service*” which one respondent depicted as “one of the few *shining lights in the public system*”. They described the breast screening programme not only as “*well-run and businesslike*, but lovely and friendly” and were consistently pleased to be participating. Many women welcomed the “convenience and warmth of the mobile” and its “discreet and compassionate staff” and considered that “all women would be *extremely grateful* that this excellent programme exists”.

Respondents were “*impressed with*” and “appreciated the friendly, kind, thoughtful” staff, who were described as “*very professional*”, “caring” and

“understanding”. On occasions, women even passed on comments from those who had not been part of the research, but wanted to say thank you. Such comments included, “I wanted to take the opportunity to say *how grateful I feel* for this programme”, and, “I would like to say *thank you all* from the bottom of my heart for everything you’ve done for me.” There was an underlying theme of gratitude for the service that had been provided.

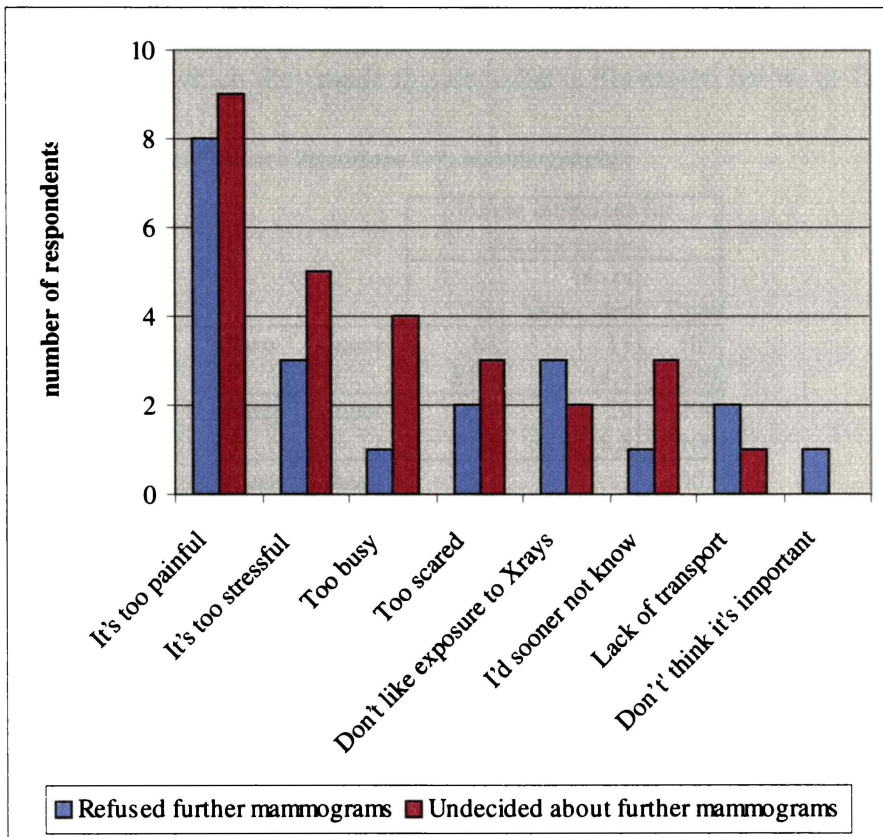
## **Rejection of the breast screening programme**

The premise of the efficient and effective use of mammography is based on the ability to find malignant tumours at an early stage so that they can be treated (Szeto & Devlin, 1996). The underlying success of a programme such as screening mammography has a premise of participation. As Rothman and Salovey (1997) contend:

[T]he impact of appeals that emphasize personal vulnerability is predicated on the assumption that people will adopt an available, effective behavior to reduce the likelihood of experiencing an unwanted outcome (p. 3).

However, the population-based screening programmes service an eligible population that is largely self-selected. At any stage, women may choose to “select” themselves out. As mentioned in Chapter 2, those studies that have looked at women who have made decisions not to attend or re-attend for screening mammography show specific differences. Overall, these women suffer higher rates of mortality (Frisell et al., 1991; Tabar et al., 1992). They are far more reluctant to participate in research (Baines et al., 1990; Fallowfield et al., 1990; French et al., 1982). Bastani et al. (1994) and Rimer et al. (1989) found that non-attenders expressed more concern about exposure to radiation. They also tended

to be less likely to participate in the health system overall (Rutledge et al., 1988), report previous screening experiences as embarrassing or distressing (Orton et al., 1991), recall higher levels of pain (Baines et al., 1990; Mastroberti & Stein, 1996), and complain of “less courtesy and promptness during screening” (Baines et al., 1990, p. 1667). The breast screening programme was seen as a “place of risk”, and they were anxious about their “lives being disrupted” through participation (French et al., 1982, p. 617), as the threat of breast cancer is perceived as such a serious one (Naidoo & Wills, 1998). Similarly, they would “prefer not to know if they have a potentially life-threatening disease” (Kamm, 2000, p. 251). In this study, reported reasons for possible non-participation in the breast screening programme in the future are illustrated below in Figure 7.10.



**Figure 7.10. Reasons for non-acceptance or indecision about future mammography from 44 respondents.** (Respondents could nominate more than one reason).

In this sample, there were a small number of women who indicated that they were either undecided about ( $N=22$ ; 3.6%), or had made a decision not to accept, further screening ( $N=22$ ; 3.6%). Respondents in this group who had decided against mammography were evenly spread across age groups; however, those who were undecided were more likely to be aged between 55 to 59 years ( $N=10$ ), than 50 to 54 years ( $N= 7$ ) or 60 to 64 years of age ( $N= 5$ ). Their ethnicity is shown in Table 7.8.

**Table 7.8. Women who refuse or are undecided about further mammograms by ethnicity.**

Ethnicity	No	Undecided
Maori	6	6
European	10	11
Pacific Island	3	3
Asian	3	1

The point at which they made this decision is illustrated below in Table 7.9.

**Table 7.9. Respondents' future intentions for mammography.**

			Future intentions for mammography		
			Yes	No or undecided	Total
No of mammograms	Once	Count	89	15	104
		%	85.6	14.4	100
	Twice	Count	186	18	204
		%	91.2	8.8	100
	Three plus	Count	292	11	303
		%	96.3	3.7	100
	Total	Count	567	44	611
		%	92.8	7.2	100

Of the 104 women who have had one mammogram, 14% had either made, or were considering, a decision not to return. Among the 204 respondents who have had two mammograms, 9% had decided similarly. Of the 303 respondents who had experienced three or more mammograms, there were 4% who were either undecided or had made a decision not to continue. It could be argued that the fact

that only a small number of women (7%) chose to reconsider returning for screening mammography in this sample precludes any valid attempt to generalise from these results. Nevertheless, the above trend is worth noting. Furthermore, as Elkind and Eardley (1990) suggest, the reasons for deciding not to participate are probably aligned to those of a larger population of non-attenders, a population that is not represented in the responses of attenders who are clearly committed to screening mammography.

In this study, pain was the primary reason for refusing further screening, as Elwood et al. (1998) found in Otago and Southland. Furthermore, thirty women who commented on the pain they experienced in the survey did not believe it was necessary, because of the variance between mammograms. One woman reported, “My first X-rays were done in a hospital – very gently. My second lot were in the mobile in ... VERY rough handling and it’s put me off any further X-rays.” For some women, the stress of one negative experience was enough to overlay any future experience. For example, one respondent reported that she had one very “rough and painful mammogram, and was too upset to return”. However, on the next screening round her friend told the staff in the mobile about her and they promised “they would be very careful” if she would return. She did so and explained, “They were very good. However, I didn’t go back for my third as I just couldn’t stop thinking about my first experience.” Nineteen women complained of distressing situations, such as “severe pressure”, “excessive stretching, squeezing and bruising” and “bad handling” to where one participant reported that she “nearly fainted with the PAIN”.

Another related her distressing experience of both the process and the communication that followed:

My first screening was a pleasant experience and I went back two years later quite relaxed. However, the second screening was *very unpleasant*. I had to go to work that evening and *couldn't stop crying* because of the pain. It was six weeks until I could sleep at night. When I mentioned this at work I found two other women who had had similar experiences. I wrote to the Breast Screening Programme about my concerns and in a telephone conversation was told it must have been “psychological”. I have never experienced such pain, or any pain inflicted so casually by someone else. Although I realise the importance of breast screening I am unwilling to put myself through that experience again. ○○○○○○ That sounds emotional and it is ...

The above quotation reflects not only an expression of anxiety, but also the lack of validation perceived by women that punctuated a number of accounts. As the above respondent continued;

If I had known that they had just LISTENED ○○○ I would have liked to think that what I said had an impact – that they would care enough to talk about it as a group and make some changes. There was a whole attitude thing that culminated in the telephone call ○○○○ I think their attitude on the telephone symbolised what was wrong with the whole process.

This perception was also reported by thirty-four other women. For example, “On commenting, (with tears of pain in my eyes on one occasion), I was told a mammogram shouldn't be painful.” Similarly, “It took a lot of courage to come back”, “there is so much stress and fear” associated with the procedure, and, “I can't face the awful feeling” of the procedure. The result for some women, were

dilemmas, expressed in ways such as this: “Although I want to go again, I’ll find it very difficult because of the intense pain I experienced.”

Decisions not to attend are a result of choice. However, the level of commitment demonstrated by respondents suggests that the choice not to re-attend was not an easy one. In this sample, only 1% of women viewed mammography as unimportant. Accordingly, it is likely that among the 44 respondents who report either refusal or reconsideration of further screening, there are some that are making that choice with some disquiet. In the words of one respondent already quoted above, “I was so proud that the pilot was a programme for women, run by women; that it was in Hamilton, and most of all, that I could be part of it all. I wanted to support it.” However, her subsequent experience was such that she was “unwilling” to put herself through breast screening again. She explained, “It was an awful experience °°° I haven’t been back and that worries me because I care about my health and don’t want to be a problem to others because my health goes.”

As noted in earlier research, participants in health care programmes often perceive that they have no say in their treatment because of their lack of knowledge (Harrison & Cameron-Traub, 1994). Nevertheless, the breast screening programme went into the community and extended a welcome to women to attend. The premise that a screening mammography programme must be offered to women on the “ethical basis” that “the benefits outweigh the risks and costs” (Elwood et al., 1991, p. 260) may be open to question in at least one case described above.

## THEME 5. AMBIVALENCE

Similarly, reports throughout this study revealed a notable theme of *ambivalence* that women displayed in reporting their feedback; a less pronounced theme that perhaps revealed more about what has remained unsaid, rather than that which was disclosed. For example, 107 respondents indicated by apologetic precursors to their complaints, their reluctance to complain or criticise health professionals in the breast screening service. Their subservience to the enduring biomedical model of health care, in which one was a passive recipient, was reflected by one respondent in her comments that “women should just leave it all to the experts”. This attitude was present in comments from forty-two survey respondents such as, “I don’t like to complain, but...” or, “It’s probably only me...” Thirty-three requests for improved service detailed in the survey were preceded by “maybe”, “perhaps” or “it would help”.

The reluctance of individuals to criticise health professionals is a disposition that has been recognised previously (French, 1981; Koch, 1994). When twenty-seven women commented on staff behaviour in this research, all but six also made comments such as, “I don’t like to be picky...” or, “I have been guilty of the same behaviour myself, but...” The discourse of some women also reflected the ambivalence of their “new” position as health “consumers”. For example, eighty-five expressed a high level of concern about the pain they had experienced as outlined above. Nonetheless, although pain was frequently, and often intensely, described, twenty-two women still apologised for expressing their feelings. For example, one woman who refused further mammography because of the painful procedure she experienced stated, “I think you all do a wonderful job, but [I] wish there was a more comfortable way to have the Xray.”

Eleven respondents were also reluctant to criticise a “free” service. They reported that they did feel some hesitation in complaining, as one stated, “[they] should be grateful”. Also, they expressed concern that the “free service could get taken away if they complained” about it. Similarly, six women also reported that they were worried that they would be identified because of their complaints. Consequently, they felt apprehensive about returning for further mammograms as they had complained about the service on prior occasions. For example,

I am afraid to come back because [I] am not sure how I will be received as I made a complaint when the van was last in my area. ... is a small town. Everyone knows everyone and word did get around, particularly among the Māori population, that the staff were rough and that it was very painful. I personally know of several ladies who chose not to go for this reason.

Even though this incident reputedly influenced a number of women, the respondent still felt uncomfortable about making a complaint, and subsequently, about her future attendance. This reticence may be as much a result of socialisation as the health care environment, as suggested by Smith (1991). Women are expected to be polite and are thus reluctant to express negative emotions (as suggested by Planalp, 1999). However, it was also likely to be a reflection of a biomedical environment where participants felt unsure and uncomfortable about what was expected of them and whether it was acceptable for them to express their concern. Whatever the cause, the outcome was not one that facilitated free and open reciprocal communication that encouraged ongoing participation for some women who felt disenfranchised with a process that they perceived was not meeting their needs.

## CONCLUSION

The findings from this research confirmed those of earlier studies that have identified the importance of clear communication in a supportive environment (such as Marteau, 1990 and Roberts, 1989). The process of participating in a screening mammography programme was underlain with anxiety for some women. However, the anxiety reported in this research appeared to relate more to communication issues than to the phases of the process, such as awaiting appointments. For example, only 11% of women were more than “a bit” worried while waiting for the appointment. Some of those who reported feeling anxious had experienced the stress of an unreliable and unaccommodating interface. Such experiences resulted in perceptions of a service that was inflexible and unwelcoming.

Likewise, the physical process of mammography was stressful for only 13% of women, which suggests that the “expertise” environment appeared to help participants to feel relaxed about the procedure itself. However, the same approach appeared to inhibit relaxation throughout the waiting that accompanied the process, as outcome anxiety was heightened in an environment that some women reported was clinical and contained little to reassure them. Comments from women such as “I felt just like a number” and “they forgot I was there” reflect feelings of a lack of recognition. Furthermore, those women who found mammography painful also experienced higher levels of stress. Pain was the primary deterrent for those who chose not to return.

While awaiting results, only 18% of respondents reported higher levels of anxiety. However, nearly all women did receive reassurance along with a clear result. That was not the case for the fourteen women who never received their results. The fear of a positive finding was reflected in many of the comments

women made throughout the research; anxiety about a possible outcome was heightened for those with a family history of breast cancer and for many Māori and Pacific Island women.

Māori and Pacific Island women experienced difficulty with both process and communication issues which appeared to be aligned to their needs for personal contact and a community approach that were unmet in the current programme, despite being pointed out earlier by Chapman et al. (1995).

Differences among ethnic groups in response to explanations demonstrated different information needs were also reflected in the response of Asian, Māori and Pacific Island women to written and spoken information.

Sixty-eight women also resisted the economic rationality of targeting the service, which they reported was discriminatory and unfair. Nevertheless, although women in this study did not always find the experience of mammography “easy” to undergo, they did not fail to recognise the value of having access to a service which 99% considered “important”. The responses from women in this study attest that the breast screening pilot has provided a service which contributes a valued resource for the Waikato region. Ultimately, screening mammography needs to be provided in ways that eligible women perceive are acceptable, accessible and effective if it is to succeed in the goal of reducing mortality rates. The following chapter will look at possible ways to enhance this outcome, such as the creation of working partnerships in defining the way in which the breast screening programme is provided, and subsequent recognition of the importance of providing real choice through incorporating appropriate communication strategies.

## CHAPTER 8

### ENCOURAGING ONGOING PARTICIPATION IN SCREENING MAMMOGRAPHY

The previous discussion in Chapter 6 has focused on the ways in which communication has been created and disseminated by the breast screening programme, as staff have attempted to meet the challenges of empowering women to make informed decisions about participating in regular screening mammography. In turn, the reception and interpretation of the communication by members of the target audience as they decide whether to participate in, and return for, screening mammography have been outlined in Chapters 5 and 7. The purpose of this chapter is to discuss the discrepancies revealed in this research between the intended communication from staff and the resulting perception of the same communication by participants in the screening programme and to suggest changes that may better facilitate the process.

First, the interactional communication from staff in the breast screening unit that was predicated on a biomedical model will be contrasted with the perception of participants. Second, the communication from the health promoters will be discussed. Although in comparison to a biomedical approach, health promotion tenets offered a community-centred approach that was more conducive to the reality of the “lifeworld” of participants, the use of this model will be questioned because it does not appear to place sufficient emphasis on the affective predisposition of the target audience.

Accordingly, I will argue that the health promotion paradigm appears to manifest important deficits in delivering effective communication to provide relevant information to women about breast screening. I focus on the importance of considering the form and content of the text when communicating information, and argue that it is important to frame communication in a context that is appropriate both to the nature of the message and those to whom it is directed. Subsequent suggestions are made about ways in which communication can be enhanced at both stages of the decision making process that women undertake about whether to participate in the breast screening programme, and whether to continue to attend.

### **COMMUNICATION WITHIN A BIOMEDICAL MODEL**

Evidence that a biomedical focus on expertise and task may result in anxiety, discomfort and subsequent difficulties with communication for participants was manifest in the comments from participants as they described their experiences in Chapter 7. The value of the service described by unit staff in Chapter 6 was invariably predicated on a “tremendously high level of expertise” (I:U5). Armstrong (1984) states that a persistent focus on expertise reflects the underlying premise of a rational and scientific biomedical model. However, in recognition of the “expert” role, participants who are receiving treatment are expected to subjugate themselves to the medical process which tends to give priority to the completion of an effective and efficient diagnosis, as illustrated in Chapter 6.

As Kamm (2000) points out, there is a critical need to establish rapport with women undergoing screening mammography so that they feel secure during the process; a need which did not always appear to be met through a biomedical focus

on successful task completion. In this research, the unit staff appeared to transpose their own focus on completing the task on to participants. For example, one staff member stated, “They [the participants] just want to have it, [the mammogram]. I don’t think they’re worrying about what they might find, rather it is ‘what are they going to do to me NOW’ and then they worry about the other bit later” (I:U10). However, in this research, women reported that they were more worried about the outcome (77% experienced some level of “worry about breast cancer”) than stressed about the procedure (13% were either “stressed” or “very stressed”).

It is further possible that the emphasis on the power and status of practitioners working in an “expert” biomedical model inhibited participants from openly communicating their feelings. In the investigation for this thesis, there was a reticence on the part of some women to question staff or procedures. The unit staff did represent the authority that Maseide (1991) argues is “necessary and constitutive” (p. 545) for health professionals to practise effectively. However, as Planalp (1999) points out, power and status are important influences on emotional restraint. The specialised knowledge and tasks asked of the “expert”, in turn, simply require compliance from those who seek a cure; an enduring tenet. For example, Harrison and Cameron-Traub (1994) noted in their research that patients were clear that they had no say in their care because they did not perceive themselves as having the knowledge of the health professionals. In turn, there was also an apparent misunderstanding and lack of awareness from unit staff about some of the perceptions and experiences of women having mammograms, as they encountered the technical and specialised discourse of health professionals described by Fox (1993).

This study has revealed the setting in which communication occurs during mammography as one that is overlain with what Drew and Heritage (1992) describe as a “characteristically asymmetrical” (p. 47) interaction, typical of an institutional environment such as that of the breast screening programme. The communication appeared to be dominated by health professionals, and this research revealed frequent misunderstandings between staff and participants, misunderstandings which staff did not appear to recognise. For example, where respondents reported their experience of the physical environment in the unit as “cold” and “isolating”, this contrasted with the perception of unit staff who considered that the service provided, in the words of one, a “homely, womanly place” (I:U2).

Similarly, despite the view of the unit staff that pain was “unavoidable” and “at least 80% of the ladies don’t find it as bad as it is said in public” (I:U12), some women in this study referred to the pain and the accompanying lack of validation they experienced during their mammograms as a source of concern. The culture of health care that contrasts with that of the lifeworld of participants is thus reflected in this research. As Kreps and Kunimoto (1994) describe:

Unfortunately, modern Western health care systems tend to be very ethnocentric and bureaucratic, proselytizing consumers to “comply” with formalized, often technologically based, and scientifically justified forms of treatment. Such treatment strategies are likely to violate many consumers’ personally held cultural beliefs about health care and can result in strong resistance to prescribed health care regimens, especially if there is not sensitive intercultural communication between providers and consumers (p. 9).

The findings in this research further illustrate a power differential between the authority of the unit staff who expected willing attendance from those eligible to participate. Six unit staff expressed genuine perplexity about why women would possibly choose not to undergo mammography. In the words of one, “Half an hour out of your day every 2 years to save your life? – for goodness sake!” (I:U2). Another stated; “It is just a question of ‘should I save my life?’ It’s a simple choice for them” (I:U6). The reported viewpoint of unit staff was that once women understood “how important” (I:U2) it was to have regular mammograms; once they knew “it’s for their benefit” (I:U6), they would attend. Thus, “they could solve the problem [of breast cancer] for women” (I:U1). However, this research indicates that the responses from participants in screening mammography focused more on describing a process that could be both anxious and painful, to the point where 7% were reconsidering future attendance. As noted earlier, these decisions about future non-attendance were likely to be difficult ones for participants.

Any decision on the part of women not to participate was encountered as incomprehensible by unit staff. As one explained, “If they don’t want to come in there’s nothing you can do about it, but I think it’s a real shame they won’t take advantage of it” (I:U2). As Foucault (1978) contends, “[P]ower is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society” (p. 93). It therefore resides in the knowledge that epitomises the institution of health, the “expert” body of knowledge that defines those who know from those who do not (Foucault, 1973). The power of health professionals is thus used to allow them to disassociate themselves from the influence that is incumbent in their position, by claiming that the choice women make to

participate or not in the breast screening programme is somehow unrelated to their own practice in providing this service. Furthermore, the discursive stance of self-responsibility is also clear in the above discourse. Women, in other words, had a moral duty to attend the breast screening programme, as it was a responsible, rational action for them to undertake. As Meyer (1986) describes, individualism is a “social doctrine” (p. 209). The resulting outcome is the obligation of individuals to “conform” (p. 209). That includes being “responsible” about attendance at health care interventions provided by health professionals as Petersen and Lupton (1996) suggest.

The “expert” focus was prevalent as unit staff consistently described their role was one of “provid[ing] expertise as an important and comforting need” (I:S1) for women undergoing screening mammography. However, as discussed in Chapter 7, participants in this research reported feelings of vulnerability as they experienced the programme, in Lupton's (1994b) words, as “non-experts” (p. 118).

Nevertheless, a focus on expertise is pivotal to health care professions, where practice is based on scientific rationalism. Thus the “expert” system is widely stressed as essential to “professional” performance (Daniel, 1994). However, the underlying trust in the performance of expertise, integral to the practice of health professionals (Freidson, 1994), is vulnerable to the practice and responsibility that the same health professionals display towards publics. At the time of this research, the same trust was being challenged by media portrayals of cervical, breast and prostate screening programmes in New Zealand which had failed to provide both competence and integrity.

For example, in November 1999 it was revealed that a pathologist who was contracted to the national cervical screening programme had produced almost a decade of misread slides and it was only when the mortality rate of women in the

Gisborne area increased markedly that anything was done about this. Professor David Skegg gave evidence during the televised trial that he believed: “We have a breast cancer screening programme which runs the risk of getting into just some of the problems we’re discussing in this inquiry” (Gillespie, 2000). Shortly after this statement, the breast screening programme in Otago was suspended pending an inquiry into why staff had failed to notify women of positive findings of cancer identified on their mammograms two years previously (Cancer women win, 2000). Furthermore, the information was not made public until some months after staff had identified the error.

At the same time, it was also revealed that some men who had tests for prostate cancer were given incorrect results because a “senior technologist ... had misused chemicals involved in prostate testing” (Mold, 2000, p. A8) in a laboratory in a Gisborne hospital. As Daniel (1994) argues, trust in the authenticity of expert knowledge relies on acceptance of the integrity and good intentions of the practitioner. However, in New Zealand, the events of the past year alone have demonstrated that sometimes the expert system indubitably fails, as standards of competence, care and responsibility fall well short of expected levels. The “expert” system not only failed to meet many needs of those who were participating in such systems; it also failed to uphold the tenets on which it is firmly established.

## **COMMUNICATING HEALTH PROMOTION**

One way in which the attempted devolution of health care has been undertaken is the transition towards promoting “health” rather than treating “disease”, as outlined in Chapter 3. In this research, women did appear to feel more comfortable with the community-focused approaches of health promotion

which, at least initially, removed them from the stress of the technical rationality of biomedicine. However, as pointed out in Chapter 4, this research was limited to a sample of those women who had chosen to respond to an invitation to participate in the breast screening programme. Accordingly, those who may have chosen not to respond to health promotion messages were likely to be excluded from the sample selected for this study.

The role of health promoters is one of working in a community setting to encourage “well” women to attend for mammography. The underlying premise, encapsulated on the logo on the BreastScreen Aotearoa promotional material is “*Early detection is your best protection*”. The communication is founded on encouraging participation so that any tumours will be detected and treated early. At no time was there any question from staff in the programme about the benefits for women participating in the programme. In contrast, Dines (1997), a nurse who works in the British screening mammography programme, described “ethical dilemmas” (p. 120) that she faced about the “paternalism” (p. 114) inherent in the paucity of information provided for women to facilitate “informed consent” (p. 114). However, such dilemmas were not an issue for staff in this research. They were committed to encouraging women to participate. Accordingly, the breast screening programme is presented by health promoters as a positive addition to empowering health-inducing behaviour.

However, it is equally possible that women who choose not to attend may suffer some level of guilt-induced distress, or “victimisation” that they would not have experienced had the breast screening programme not been promoted as an imperative of personal responsibility. As Petersen and Lupton (1996) contend:

[A]s the philosophies of the new public health have gathered force, the “right to health” is rephrased as taking on personal

responsibility for one's health by accepting and adopting the imperatives issuing forth from the state and other health related agencies concerning the maintenance and protection of good health (p. 65)

For example, Skrabanek (1994) argues that anxiety is an unfortunate side effect of health as a marketable commodity which is "delivered" to the "consumer" through issuing an invitation to healthy people to attend for screening, when their computerised records show they are "due" (p. 29). The result, he argues, is that consequent non-attendance becomes "non-compliance" (p. 29), indicating an element of recklessness and irresponsibility. The implication that good health is a choice, as Greco (1993) suggests, may be reflected in a discourse which promotes "early detection as your best protection". Thus, to choose otherwise is to implicitly choose to reject an opportunity to protect one's health, thereby, as Pollock (1993) contends, to act irresponsibly. As any subsequent disease becomes intertwined with culpability, the infraction of the rules of "good" health behaviour becomes a form of deviance (Fitzgerald, 1994). However, to provide a basis to assess the validity of this claim accurately, it would probably be more useful to talk with women who have chosen not to attend for screening mammography, who were largely excluded in the current sample.

For those women who did choose to attend for screening mammography, it is further apparent that the conflicting communication strategies of the health promoters and the biomedical premise of expertise created conflicting communication for some women as they encountered the different stages of the process of the breast screening programme, as pointed out by one health promoter in Chapter 6 (page 261). An example of how this situation may easily occur is provided by contrasting the positive, relaxed, supportive context of the

advertisements for the BreastScreen Aotearoa television promotional campaign outlined in Chapter 5 with the experience of mammography reported by some women in this study in Chapter 7. It could be argued that promoting the breast screening programme in such a manner is doing little to address the information deficit so apparent in the reported experience of respondents. Furthermore, it may serve to compound the anxiety that some women experience when they face the reality of a procedure that they have not been adequately prepared for. In the words of one respondent, the experience “blew me away to a point where I struggled to even drive home”.

O’Hagan (1991) contends that when you ask the majority of a population to undergo screening “for the benefit of the few” (p. 121), any advice about screening must be honest and presented in a way that recognises the cultural, social and intellectual diversity of women in the community. Screening mammography in population-based programmes is offered to eligible or “well” women who have no symptoms and have no obligation to attend (Maclean et al., 1984). However, it has been argued by Siminoff and Fetting (1991) that women may decide on alternative approaches once they have received specific information, which may not be consistent with the need to encourage women to participate in the national breast screening programme. Baum (1995) contends from a critical stance that “true informed consent for an invitation to screening” (p. 1003) may well reduce acceptance rates:

In absolute terms, less than 1% of women who are invited for screening will benefit from it, whereas a greater percentage will have to face the problems of false alarms, unnecessary surgery, unnecessary labelling as having cancer, and a lead time in the diagnosis of cancers whose natural course is unaffected by “earlier

detection”. In other words, true informed consent for an invitation to screening might reduce rather than increase acceptance (p. 1003).

However, the results of this research attest that it is also equally valid to argue that the majority of the other 99% will benefit from the reassurance they receive from a clear mammogram. Nevertheless, there is no argument with the need for informed consent, and the results of this research also emphasise the need for the information to first be provided to facilitate decision making. However, the way in which that information is presented is also important, and it is possible that the tenets of health promotion, although popular, may not provide the best “fit” with the requirements for successfully communicating screening mammography.

## **FRAMING THE MESSAGE**

The term “health promotion” is often used in health communication literature. Kirscht (1990) refers to the “health promotion juggernaut” (p. 423), which has resulted from the “explosive growth in programmes [of health promotion] ... [which] is the crusade of the 1990s” (p. 423). However, I contend that there are certain principles that are integral to health promotion which are largely excluded from screening mammography. Thus, it brings into question the use of this model as an effective paradigm within which such programmes should be communicated to eligible women.

The World Health Organisation (WHO) definition of health has been consistently recognised as one of the most internationally influential and long lived (Tones, 1986). As discussed in Chapter 3, health is viewed by WHO as an eclectic combination of the social, physical and mental, and this definition is

included in most discussions about health promotion in one context or another. The premise of the definition contained within the WHO documents of the *Declaration of the Alma Ata* (1978) and *Ottawa Charter* (1986) is to enable individuals to increase their control over, and thereby improve, their health (Raeburn & Peters, 1987). In 1984, WHO promoted five principles considered integral to social models of health promotion. These are:

1. Health promotion focuses on whole populations.
2. Actions are addressed to the total environment.
3. Health promotion requires full community participation.
4. Health promotion requires a wide variety of strategies and agencies.
5. Health professionals have a part to play, though primary health care is most important (Tones, 1986, p. 5, emphasis in original).

The breast screening programme as a community intervention fits only one of the above five criteria, as it uses a variety of strategies to promote the programme. For example, in relation to the first criterion, the programme does not focus on the entire population. It selectively targets a population of women aged between 50 and 64 years of age. The rest of the population of children, men, and those women who are either symptomatic or both younger than 50 years and older than 64 years of age are excluded. Second, there are no environmental applications provided by a screening mammography programme; women are simply invited to attend screening at a fixed or mobile facility. Third, there is no community involvement in the programme as it relates only to a specific population, although the health promoters do attempt to include family members and partners in the process of encouraging eligible women to attend.

Fourth, the screening programme does attempt to use multiple strategies to encourage attendance and health professionals are involved, as discussed earlier.

Fifth and finally, screening for breast cancer reflects the lack of success in identifying primary prevention strategies. If more was understood about the causes of breast cancer, then greater emphasis could be placed on identifying risk factors and associated prevention strategies implemented. Until that time, screening mammography appears to offer the best available option of early detection.

Accordingly, within the terms of the WHO criteria of health promotion programmes, the screening mammography intervention, although it occurs in a community setting, does not fulfil the accepted criteria to promote health as a community intervention. Neither does the procedure either promote, or even maintain health for individuals. For example, those who have had a skin cancer such as melanoma may maintain their current level of health by consulting with their dermatologist for annual skin checks. However, a mammogram has only the propensity to reveal existing disease. The procedure simply provides information for health professionals to advise on possible courses of future treatment. In so doing, it could be argued that mammography ultimately offers individuals choice about future actions which may possibly maintain or prolong life. However, such actions depend on the prescriptive intervention of health professionals, and those prescriptions may result in treatment that is debilitating, such as radiotherapy, chemotherapy or radical mastectomy. Alternatively, some breast tumours do not respond to any treatment (Campbell & Royle, 1992). A mammogram itself offers nothing other than detection of what is already present. As Maddux (1993) points out, a disease detection programme only influences health status when an individual can obtain treatment. In the case of breast cancer, whether treatment can or will be offered depends on the type of tumour identified (Campbell & Royle, 1992).

Neither will screening mammography prevent breast cancer (Roberts, 1989), despite “the appeal of the (often misused) concept of prevention” (Goodman & Goodman, 1986, p. 37). As Russell (1986) explains, to be detected the disease must essentially be established beforehand. In contrast, a valid preventive intervention such as vaccination provides a direct health benefit as it averts what Downie et al. (1990) describe as an unwanted outcome. Unwanted outcomes can be avoided through undertaking the necessary protection (for example, immunisation) to prevent a potential health problem (such as measles, mumps or tetanus). In contrast, screening mammography simply identifies people who have breast cancer. Regardless of the intervention, some women who have the disease will die from it (O’Hagan, 1991). The rationale is one of early detection and various treatment options.

In terms of health communication, the distinction between the underlying tenets of the various approaches described in Chapter 3, such as health promotion and disease detection, is a crucial one. As Millar and Millar (1996) explain:

One of the dimensions that differentiates disease detection behaviors from health promotion behaviors is the extent to which they may threaten perceptions about good health (p. 402).

For example, applying sunscreen is an individual health promotion behaviour that allows individuals to take action to alleviate the health threat of skin cancer that may be causing anxiety. This action was promoted over the past two years by the “slip, slop, slap” health promotion campaign of the Cancer Society, which exhorted people to cover up with hats and clothing and apply sunscreen to protect themselves from the harmful effects of solar radiation. However, a disease detection behaviour, such as having a mole biopsy to determine whether a skin cancer such as melanoma is present, in itself, does not provide any plan of

individual action. The outcome depends on the diagnostic process and prescriptions of health professionals. Therefore, disease detection behaviours are more inclined to generate anxiety (Millar & Millar, 1998), because individuals are confronted with the possibility of finding a problem over which they have no control. Thus, any reference to the optimistic definitions, often associated with a premise that providing relevant information is enough to prompt action within health promotion tenets, tends to overlook the influence of the critical variable of anxiety on the processing of health communication.

For example, the Health Belief Model described in Chapter 3 is a health promotion model founded on tenets of rational decision making behaviour. The emphasis in the Health Belief Model is that beliefs about susceptibility will result in a perceived threat. In turn, individuals will be likely to respond to the threat by adopting the recommended action. As Rosenstock (1990), who proposed the model argues, “[T]he failure to believe in the possibility of having an asymptomatic problem may help explain poor response to cancer screening programmes” (p. 41). The Health Belief Model underlies the approach of the health promoters in the breast screening programme, whose role is to encourage women to participate in screening mammography. The underlying precept is one of providing information through various forms to promote the programme. For example, the health promoters use educational materials which demonstrate the size of a tumour able to be detected by a mammogram compared with the larger size of a palpable tumour. Such an approach is designed to establish a belief in asymptomology; that is, the possibility that a tumour may be present in the breast without anyone knowing. This approach is consistent with the underlying tenets of the Health Belief Model. The health promoters present the information to women in the community and encourage them to build mammography into their

lifestyle as a “healthy choice”. Their stated “desire for the women is that they are barrier free” (I:P17).

However, the influence of fear can provide a complex variable that interferes with a straightforward decision making process. Despite persuasive presentation of rational information, people may simply stop processing communication when facing “bad or scary news about a health threat” (Witte, 1994, p. 288). In an effort to alleviate anxiety, individuals try to keep from thinking about the threat (Croyle & Sande, 1988). However, this action of “avoidant thinking” (Rippetoe & Rogers, 1987, p. 596) which diminishes fear of the threat, concurrently weakens intentions to adopt any “adaptive response” (p. 596). For these reasons, it is crucial that this anxiety is taken into account when formulating disease detection communication, as it will directly influence the ability of the listener to integrate the information into existing background knowledge. As Lazarus (1991) explains, the emotional and cognitive are intertwined:

The functional relationships between cognition and emotion are bidirectional. As an effect or dependent variable, emotion is the result of appraisals of the significance of what has happened for personal well-being. It is always a response to cognitive activity, which generates meaning regardless of how this meaning is achieved (p. 353).

Therefore, an affective response such as anxiety may interfere with cognitive processing or thought processes.

Anxiety is not restricted to screening mammography. It is typical of other screening programmes. For example, Quilliam (1990) stated that high levels of anxiety for women undergoing cervical screening were related to fears about both

the process and possible outcome. However, the author further contends that a sensitive, informative communication environment helps to reduce anxiety levels. Accordingly, as communication strategies used by health care professionals play a key role in determining health outcomes (Kreps, O'Hair & Hart, 1995), it is important that communication is framed within an accurate and perceptive context that recognises high levels of anxiety. As discussed in Chapter 2, increased anxiety is associated with the risks of mammography, which may well be analogous with the "delay" of up to three months in reporting breast symptoms that occur in 20% to 30% of women who suspect they may have cancer (Jones, 1999). The same source of apprehension may underlie the process of mammography for women.

In light of the anxiety associated both with the process of screening mammography and the possible outcome of a diagnosis of cancer, it is possible that the difficulty in retrieving information that is associated with high-anxiety conditions, suggested by Millar and Millar (1996), may well exist. Therefore, they argue that health communication that increases anxiety will be less effective than that which reduces anxiety in promoting disease detection behaviour. As Kahl and Lawrence-Bauer (1996) assert, messages that attempt to scare women into having a mammogram result in an overload of anxiety that often prevents action. High levels of apprehension may mean that people choose to avoid the threatening situation altogether. As Lazarus (1991) explains, if the cognitive cause of the emotion disappears, so does the emotion, in this case, fear. Even though avoiding anxiety (by avoiding a mammogram) translates into an increased risk of disease (breast cancer), the temporal remoteness of such longer-term considerations is likely to make them less salient than the current situation (Meyerowitz & Chaiken, 1987).

Such responses may explain why theories predicated on a rational correlation between understanding, belief and behaviour have limited success in predicting women's acceptance of screening mammography. For example, Rutledge et al. (1988) contend that levels of knowledge and understanding about breast cancer will positively influence participation in screening mammography. However, in contrast Turnbull et al. (1995), in a two-year prospective cohort study in Australia, demonstrated no significant relationship between knowledge, prior experience or level of information and attendance for screening. A similar result was illustrated by Clover, Redman, Forbes, Sanson-Fisher and Callaghan (1992), who found no significant difference in attendance rates for women who received either a simple recommendation or extensive education based on health belief principles about screening mammography.

In Britain, Hoare et al. (1994) discovered that "explanations about breast screening were not a successful strategy for promoting uptake" (p. 179) of screening mammography to Asian women. Lerman et al. (1991) found that health beliefs did not predict adherence to a screening mammography programme. Neither did such beliefs predict either the frequency or thoroughness of breast self-examination (Wyper, 1990). Perhaps the influence of anxiety on the cognitive process confounds the outcomes of these studies. For example, French, et al. (1982) found that their sample of women all had broadly similar beliefs and understanding about breast cancer. However, the difference between those who chose to attend screening mammography and those who did not, was that non-attenders were all anxious about the disruption to their lives of a positive diagnosis of breast cancer.

Recognising that "health promotion" has suffered from being currently perceived as a "highly fashionable term which has, unfortunately, been used in

many different ways without clarification of meaning” (Downie et al., 1990, p. 64), approaches such as the Health Belief Model may not provide a consistently reliable means for encouraging participation in screening mammography.

Discrepant findings suggest that adopting specific health behaviours may not be a strictly rational process. As Calnan (1984) concluded from the results of his research, “[T]he predictive power of the Health Belief Model is generally low” (p. 829). He thus maintained; “The results from these analyses cast doubt on the value of the HBM for predicting the use of different types of services for the early detection of breast cancer” (p. 829).

The reason for the popularity of health promotion may be the result of a competitive environment, where in terms of obtaining funding and political support, the term “health promotion” is both powerful and desirable (Caplan, 1993). As a result, the term is now “bandied about somewhat glibly, without clarification of underlying meanings” (Downie et al., 1990, p. 56). A lot of theories abound that explain how people make choices that may affect their health. However, the influence, or lack of, such theories on planned interventions may be the result of flawed design or the interventions not being implemented correctly. In this case, the limitations of the influence of health promotion strategies may be a result of not recognising the underlying tenets of the model that is being applied.

## **AN EFFECTIVE FRAMEWORK FOR COMMUNICATION**

Theories that gain recognition do define the scope of practice, thus influence outcomes (Glanz, Lewis & Rimer, 1990b). Accordingly, it is essential that any attempt to provide communication about a health intervention should be firmly grounded in an appropriate theoretical framework. As stated at the beginning of

this thesis, a focus on communicating information requires that the form and content of the text itself be considered. However, of equal importance is the cognitive and emotional predisposition of those to whom the communication is directed. Information is critical to informed decision making in health care. How people process this information is equally critical. As Glanz, Lewis and Rimer (1990c) comment, “[Q]uestions of how people seek, use and process information” (p. 36) are central to any health research question. Accordingly, at all stages of the decision making process, communication must be framed within a context appropriate to those to whom it is directed.

## **Decisions about participation**

As discussed above, there are two distinct stages in communicating with women about both the presence of, and their ongoing participation in, the breast screening programme. This research has revealed the need for respondents to question a number of issues related to screening mammography and breast cancer. For many women, adequate levels of appropriate information are critical to providing an informed base for decision making, thus engendering a sense of control, thereby relieving anxiety (Marteau et al., 1996). However, any commitment to truly informed consent about participation in a breast screening programme requires the provision of balanced, informative resources to facilitate decision making in the community. A relevant example highlighted in this research was the recognition by staff that “the pilot breast screening programme [was] part of an epidemiological study” (I:S1). However, this information was not stated in any of the communication resources for the programme. As “research subjects”, further important issues of informed consent arise for women who participate in the programme.

In the past, women have stated that they want specific information related to their health care and the role of screening for breast cancer (Austoker & Ong, 1994; Ong, Austoker & Brouwer, 1996). They have also asked for “honest” information relevant to decision making about appropriate health behaviours (Austoker, 1991). This research confirms these assertions. It appears that the more worried women are about breast cancer, the less likely they are to feel in control (Calnan, 1984; Marteau, 1990) and are therefore less likely to accept an invitation for screening mammography. As Sutton et al. (1994) demonstrated, the highest screening attendance occurred by those women who were “a bit worried”, in contrast to those women who were “very worried” about the possibility of breast cancer. Gifford (1986) indicated that even by placing themselves in the position of receiving a potential diagnosis of breast cancer, women perceived of themselves as “losing control over the definition of [their] own health” (p. 234).

One thing that women are clear about is they do not want to be simply told “not to worry” (Kavanagh & Broom, 1997, p. 1389). However, information channels should be chosen with care. Leather and Roberts (1985) assert that using mass media channels alone to promote breast cancer screening programmes serves to increase anxiety to the point where women may refuse to even acknowledge the message. Similarly, defensive behaviour was illustrated in the media-focused study of Kitzinger, Philo, Henderson, Saywell and Beattie (2000), where women in the focus group interviews “described how they avoided any discussion of breast cancer in the media, because it just upset them or made them frightened” (p. 55).

Leather and Roberts (1985) identified that women find breast cancer to be a “highly emotive, deeply threatening topic” (p. 669). That contention is confirmed

by the response of women in this research to the booklet, *More about breast screening*. Although the booklet provided much needed information, the response of women in focus group interviews in this research underscores the need for recognition of their affective, as well as intellectual, response to information. This research confirms that any effective communication campaign about breast cancer and screening must include the input of the target audience, as differences in sociodemographics will influence women's responses to any message about screening mammography, as suggested by Collins, Davis, Rentz and Vannoy (1997). If information is to be presented within the right context, input from target publics is essential to formulating a message. As highlighted by Dignan et al. (1991), the need for a "thorough community analysis and developing an understanding of community functioning" (p. 265) prior to any media campaign was integral to a successful outcome.

### **Participating in mammography**

The need for information is equally imperative at the time when women choose to present for breast screening. Marteau (1990) contends that many women attend for their mammogram "without understanding precisely what the test is for" (p. 26) and inadequate counselling of this nature has been described as "ethically unjustifiable" (Rodgers, 1990, p. 201). As outlined in Chapter 7, Marteau (1990) argued that if women understand about the purpose of screening, the accuracy of testing and the implications of possible outcomes, they will be less anxious and thus more able to recall and act on advice offered. Marteau et al. (1996) further argued that the knowledge needs to "foster a sense of control over outcomes" (p. 187) before it will reduce the consistently high levels of anxiety that women appear to experience when undergoing screening mammography. A

combination of both information and control are required. Levanthal, Nerenz and Steele (1984) explain:

Interventions to reduce distress must provide a clear representation of both the abstract and concrete features of the stressor, appropriate coping skills for each, and criteria for evaluating outcomes and making attributions ... Both information on the nature of danger and information on coping were necessary for long term action. Both types of information are critical because knowing what to expect in a threat situation does not ensure knowing what to do, and knowing what to do is not useful if one does not know when to perform (p. 242).

The research in this thesis has supported the assertion of Roberts (1989) that the critical factor appears to be that women are not only given correct information, but are also encouraged to ask questions about the process they are undergoing in an environment of support. As Joos and Hickam (1990) contend, clients will respond positively to health professionals “whose affect is concerned and caring and information giving is enhanced by a positive emotional atmosphere” (p. 225).

### **Culturally diverse needs**

However, there is not one uniform communication approach that will suit all participants in a breast screening programme. Empowerment across all cultures requires acknowledgement that western medicine has undermined the lifestyle and social organisation of ethnic minority groups in this country (White, 1994). In recognition of this principle, in this research I have attempted to focus on the needs of ethnic minority groups rather than assimilate them into a “mainstream” perspective. As Thomas (1996) argues, there is a need to focus on the way in

which “policies and practices” (p. 207) of dominant groups affect minority ethnic groups. The premise that there is no place for stereotypical and ethnocentric values and assumptions is being upheld in this research as barriers have been revealed in the breast screening programme for ethnic minority groups. For example, the community health educator for Asian women explained that although Asian women experience difficulties with language, their “lack of confidence and reticence” (I:P19) precludes them stating their needs. Also, their cultural role is often one of caring for grandchildren while the parents are in the workplace. Accordingly, this role is not facilitated by appointments offered only in working hours as these women “need to attend with family support and at a time when those family members are available”, typically outside working hours (I:P19).

Similarly, Māori and Pacific Island women ask for a demonstrated willingness to welcome them when they arrive at the breast screening unit, enhanced access through flexible appointments, and recognition of their cultural diversity as welcome and agreeable. These reported needs reflect the “lack of acknowledgement, among Pakeha, of the importance of Māori language and culture to Māori people” (Thomas & Nikora, 1996, p. 248). Such needs also entail recognition of the variation in responses to the communication resources from the programme.

This research illustrates that Asian, Māori and Pacific Island women require culturally sensitive communication, both oral and written, if the breast screening programme is genuine about attaining their willing and informed consent to participate. Even more so, they require self-determination about how, whether, and on what basis they are prepared to participate in the breast screening programme. As “self-determination involves giving ethnic communities the

power to establish their own institutions in their own way” (Thomas, 1996, p. 224), there may be a requirement for devolution of the programme at government level if those in the current programme are unwilling or unable to mutually determine culturally-appropriate procedures. There are legitimate differences between cultures, the importance of which is reflected in clear evidence that a failure to recognise such differences has had a pernicious influence in underpinning the compromised health status of minority groups in this country, as illustrated by Triggs et al. (1995) and the Ministry of Health (1999).

### **Organisational influences**

Finally, to ensure that people can respond in a way that they regard as being in their self-interest at every stage of the decision making process, any effective health communication must be secured upon a foundation of trust and credibility. This requires a process that proceeds with respect and caution, and in this case, part of that caution must imply addressing conflicting communication from the different paradigms of health care within the breast screening organisation. The results of this research confirm the contention of Glanz et al. (1990d) that the balance between the science of biomedicine and the practice of health promotion demands compromise, creativity, appreciation of others’ skills and willingness to cooperate and learn when applying ideas and strategies. As Emerson (1977) demonstrated, any intervention designed to address problems is critically shaped by the intervening “authority”. The resulting reality of health professionals may not provide a fit with the reality of those whom an intervention is designed to assist.

## CONCLUSION

This discussion about the practice of the breast screening programme is an attempt to try to understand how to make communication more effective. On the presupposition that a critical analysis of the intended and unintended effects of health communication is necessary if the communication is to be effective, it has been argued that the process for communicating disease detection programmes needs to be embedded in the recognition of affective determinants of behaviour.

The preceding discussion has provided examples that reveal discrepancies between the communication offered from the breast screening programme, as perceived by unit staff, and that received and interpreted by the women who were undergoing screening mammography. The evidence illustrates how the expert focus of biomedicine failed to recognise crucial issues of importance to those participating in the programme. Similarly, although the tenets of health promotion offered a more community-focused approach relevant to the lifeworld of participants, the model also failed to recognise the affective elements of the decision making process, which undermined its effectiveness as a means of communicating screening mammography. Thus, the underlying tenets of health promotion models do not always facilitate an appropriate framework for communicating a programme predicated on the detection of disease.

Accordingly, I argued that the recognition of the affective influence on decision making about participation in a disease detection programme offers a more effective framework upon which to establish an appropriate means of communicating with women at all stages of the decision making process about whether they participate in screening mammography.

The research has also brought to the fore the need to enhance the current information strategies so that women can make truly informed choices about

participation. There is a further requirement for the right of autonomous choice for ethnic minority groups whose needs have been marginalised in the breast screening programme. The following, and final, chapter discusses the key findings from this research and identifies opportunities for further research.

## CHAPTER 9

### CONCLUSIONS

In this thesis, the use of a triangulated methodology has drawn together the multiple perspectives of those involved in the production and consumption of communication from the breast screening programme. The findings have emphasised the role of communication in providing an effective and acceptable experience for women who undergo screening mammography. Analysis of interview material using an interpretive approach with a critical turn brought to the fore the influences on the way in which staff communicate with participants during screening mammography. In turn, the use of a questionnaire survey, augmented with individual and focus group interviews, gave prominence to women's explanations of how they received and interpreted the same communication from the breast screening programme.

Drawing together the complementary strands of the data in this research has revealed three key outcomes. First, the results emphasise the cogent role of communication in influencing the experience of women participating in the breast screening programme and their subsequent decision making about ongoing attendance. Second, an original contribution of this research has been, through the use of a random sample stratified by ethnicity, to highlight the cultural differences in the ways in which women respond to communication from the breast screening programme. Third, the data has clearly indicated how

organisational influences resulted in communication that contained the potential to create both deficient and ambiguous communication for some participants.

Overall, the results from the analysis in this research attest that although the breast screening programme has been provided as a community-based intervention, it remains firmly grounded in political and medical discourses that exclude the lifeworld experiences of some participants. Following a discussion of the key findings in this research, suggestions are made which are likely to enhance the process of screening mammography for those who wish to participate in the future. Finally, questions worthy of further study that have arisen from this research are also identified.

## **KEY FINDINGS**

### **The importance of the role of communication**

One of the key original contributions of this research has been to highlight the significance of the role of communication in encouraging women to both participate in, and return to, the breast screening programme. This study draws together various methodological perspectives to demonstrate how the experience of women throughout the breast screening process was directly related to the communication process they had encountered in their interface with the service.

This research identified a paucity of information resources to facilitate any process of informed decision making about participation in breast screening among eligible women in the community. As discussed in Chapter 5, a primary role of the breast screening programme as a community based health intervention, is to communicate its presence to eligible women and invite them to attend. However, if the underlying commitment is one of true empowerment through informed choice, information must be disclosed upon which decisions can be

made. Breast screening has a number of benefits and risks as discussed in this thesis. It is not an infallible process, nor is it without risk. Nevertheless, as discussed in Chapter 2, the lack of evidence for any preventive measures for breast cancer means that early detection currently offers the best alternative for women, as the chances of successful treatment are enhanced by early intervention. Thus, women are entitled to access an intervention with the potential to provide benefit in the form of longevity or reassurance. However, that access needs to be adequately and appropriately informed.

The outcomes from this research give precedence to the need to communicate the presence of screening mammography in a way that empowers women to take advantage of the benefits the programme may offer. As Maureen Roberts (1989), the clinical director of the Edinburgh programme since its inception in 1979, wrote just weeks before her death from breast cancer, women contemplating mammography must be offered communication that is “sympathetic, open and truthful” (p. 1155). Her plea was that the “air of evangelism” (p. 1154) from staff in breast screening programmes be replaced with research-based policy that will provide women with “a truthful account of the facts” (p. 1154) and “psychological back up” (p. 1155). To achieve this outcome, multiple evaluations of the procedure need to be offered to women to facilitate informed decision making. However, this research has further identified that the information needs to include both sides of the argument, both the risks and benefits, if it is to truly enhance the empowerment of women in undertaking a proactive stance towards the management of their own health care. Such evaluations must also make it clear, however, that women are entitled to choose whether they participate or not. That choice must be respected for whatever reason it has been made, whether it be personal, cultural or social. That is the

only way in which true ownership of the information can be devolved to participants.

## **Culturally diverse needs**

A further original contribution from this research was to reveal the diverse and contrasting responses of individual ethnic groups to the breast screening programme in a way that does not appear to have been effected in prior New Zealand research. As the research directly compared the experiences of members of each ethnic group as they participated in the breast screening programme, clear differences were apparent. In particular, both Māori and Pacific Island respondents reported higher levels of anxiety throughout the process and greater difficulty with the communication from the breast screening programme than any other ethnic groups in this study. When addressing the question in Chapter 1, of why it is desirable that women participate in screening mammography, the answer must incorporate a critical awareness of the socio-cultural needs of participants, not the conjecture of health providers - or even researchers. As Ma'ia'i (1992) argues, the participation of Pacific Island women depends on both recognition of, and respect for, their "racial and traditional sensitivities" (p. 68). However, the findings of this research indicate that the "discourse rights" (van Dijk, 1993, p. 263) of ethnic minority groups were controlled by the hegemony of a segregated discourse structure in the breast screening programme. The dominant discourse of the programme, derived from ethnocentric views, meant that "some 'voices' [were] censored, some opinions [were] not heard, some perspectives ignored" (van Dijk, 1993, p. 262) as traditional sensitivities were trivialised as unimportant. As van Dijk (1993) explains, even as participants, those who

belong to less powerful groups are usually marginalised through being “dominated in discourse” (p. 262).

For example, Devlin and Singsam (1994) report that there has been an ongoing desire for consultation about screening programmes among Pacific Island women, which is still prevalent. In one of the focus groups in this research, a participant stated, “It is my hope that we can meet to discuss the staff and facilities, and that they will hear and do something about it.” There is a need to do so. Newman et al. (1992), in their study of breast cancer among women in the Auckland region, found that many Pacific Island women presented with advanced disease. Furthermore, Lethaby et al. (1992) demonstrated that this group of women had significantly worse rates of mortality from breast cancer than other ethnic groups in the Auckland area. They noted the occurrence of a similar trend for Māori women.

It has also been suggested that some dialogue with Māori has been one-sided, and consequently, views have been imposed on Māori women who feel that they were “never integrated into the initial planning stages of the project” (Campbell & Bryant, 1996, p. 9). Māori women commented in this study that “there has been too much research” concerning their health status, and “very little outcome” to show for the commitment of time, effort and energy they had expended thus far. Their frustration with the lack of consultation is validated in the number of prior recommendations about issues relevant to Māori women’s needs for mammography in previous reports, such as Campbell and Bryant (1996), Lawson-Te Aho (1996) and Torrance and Sutherland (1996). Those same issues are highlighted once again in this study, thus demonstrating that they remain unresolved. It appears that van Dijk’s (1993) argument that “the

‘polarized’ models [which] are consistent with negative attitudes or ideologies” (p. 263) about the rights of ethnic minority groups are being used to sustain the status quo in a dominant western model.

The concept of partnership is entrenched in the Treaty of Waitangi. Effective communication is an essential part of developing partnerships. Māori representation is “vital to ensure that health planning, direction, delivery and policy development issues meet the stated needs of the community” (Rohipa, 1994, p. 53). Participation, as promised in the Treaty, will only occur if cultural relevance and safety are assured. As van Dijk (1993) contends, it is not either “ ‘just’, ‘necessary’ or ‘natural’ ” that one ethnic group has “privileged access to valuable social resources” (p. 263) through marginalising alternative voices.

Furthermore, although in this research Asian participants appeared to demonstrate lower levels of difficulty with assimilating into the breast screening programme than Māori and Pacific Island women, this outcome may have been a result of the small sample size (42) failing to demonstrate stastically significant differences. Alternatively, it may also reflect a cultural reluctance to complain or criticise the service, as suggested by the community health educator (I:P19). Nevertheless, this group of women are, in reality, well under-represented by over 70% on the breast screening database, as illustrated in Chapter 5. There is a clear deficit of attendance in the breast screening programme among this population. There is a further possible outcome, that of the absence of a dedicated health promoter for this population. Currently, an Asian community health educator is funded from the breast screening programme on a “fee-for-service” basis which means that an account is submitted to the manager of the breast screening programme for any time spent promoting the breast screening programme in the community. However, there are also incidental costs, such as transport and

planning meetings that are not reimbursed; therefore, “other priorities have to take first place” (I:P19). This arrangement contrasts with the direct government funding for promoting the programme to Māori and the funding for “a bunch of sessions” for health promotion to Pacific Island women through the breast screening programme (I:P17), although the latter funding is described as minimal and does not facilitate optimal promotion (I:P15).

The 73% shortfall in the desired 70% attendance rate for eligible Asian women in the Waikato region, illustrated in Chapter 5, suggests that the lack of a funded community health promoter may well impair the ability of Asian women to communicate their needs. This, in turn, impairs the ability of the breast screening programme to encourage appropriate levels of participation. The community health educator maintains that the outcome is that “those Asian women who can afford to, return home for their breast screen. That overcomes many of the communication and cultural barriers that they experience in the New Zealand programme” (I:P19). Accordingly, it may be that it is the views of the few who do manage to cope with the programme that are represented in this research.

## **Organisational influence on communication**

The third key outcome from the research in this thesis resulted from combining an interpretive and critical analysis of interview material to analyse the communication from staff in the breast screening programme. The significance of this analysis is that it drew together the relevant institutional, socio-cultural and political influences on the production of communication. In turn, this exposed the ideologies that underpinned the struggle for discursive positioning, thus providing

insight into the context of the source of the conflicting communication that some participants reported they received.

Thus, analysis brought to the fore the contested communication that informed the hegemonic struggle between professional groups in the breast screening programme as unit staff and health promoters discursively positioned themselves as presenting the most naturalised, or common-sense way of communicating screening mammography. The inherent values and social norms in each professional group means that solutions to differences within the organisation will require sensitivity and empathy to resolve the discursive struggle that results.

The commitment of all staff towards the programme was evident throughout this study. It was also apparent that many had not only coped with considerable change as the pilot programme developed, but were facing a major transition into the national programme. Nevertheless, it is essential that the different specialties in the screening programme be encouraged to share the debate about appropriate services. Flexibility and negotiation, combined with willingness to carry out even the smallest of modifications, will help to facilitate positive change. In the meantime, the result is a discursive struggle between opposing orders of discourse. The outcome is conflicting communication characterised by a diverging discourse that results in distress for some women who encounter mammography as a physical process for which they are largely unprepared. Respondents consequently reported perceptions of unease, discomfort and of feeling “lost in the system” in the unfamiliar health environment as they confronted the “systematically limited” (Habermas, 1971, p. 85) communication that resulted.

The thematic analysis with a critical turn also brought to the fore clear distinctions in the ideological perspectives of efficiency that discursively displaced the service ethic as the organisation adapted the imperative of the market. It appeared that government had successfully achieved the desired ideological shift towards the rationality of the marketisation of health care within the organisation, as the discourse of providing breast screening as a commodity was naturalised among staff members. The colonisation of the discourse of the breast screening programme as a service by one of a market discourse resulted in the blurring of the boundaries between the different orders of discourse. Thus, the breast screening programme was consistently and uncritically discursively presented as a commodity, rather than a service, by staff. However, in this research, neither the context of a market model nor a task-focused biomedical model sat comfortably in the common-sense world of the women who participated in screening mammography. The emphasis on an ideological investment of “efficiency” was not accepted as a “given” by them.

The combination of the questionnaire survey and individual and focus group interviews provided data that clearly indicated that the adoption of an economic paradigm further served to undermine communication from staff in the breast screening programme with the target audience. Women reported that they “didn’t want to feel processed” because of the “abrupt handling” they experienced because of the perceived “need [for staff] to stay on schedule” during the mammogram. Nevertheless, the “unequal encounters” (Fairclough, 1989, p. 44) that Fairclough describes in the health sector, as discussed in Chapter 3, were evident in this research as some respondents reported that they attempted to move the discourse towards their desired, acceptable outcomes of a “gentle”, “unhurried” and “careful” procedure.

Furthermore, although many respondents expressed their gratitude for the screening service, they also believed it should be provided to all women in New Zealand. Women have been encouraged by government to attend screening as a “well” population. This population is targeted on the basis of age. Since the late nineteen-eighties, the economic discourse has overtly specified the need for “improved efficiency and operational effectiveness” in the health sector (Gibbs et al., 1988, p. 2) which dictates that resources must be “efficiently” applied. However, respondents resisted this discourse, questioning the dissonance of a primary message about “increasing age means increasing risk”, and another about the age-specific nature of the programme.

Although breast cancer is the leading cause of cancer deaths for women in New Zealand; 84% of the deaths from breast cancer occur in those aged over 54 years (Armstrong & Borman, 1996). With research demonstrating significant mortality savings from screening mammography in 65-74 year olds (H. Chen et al., 1995), in this study many participants questioned their future exclusion from the programme. Attempts to discursively shift away from an economic model predicated on the need for efficiency were illustrated in the consistent, and often vehement, level of concern expressed by women in this research, who reported they felt “past their use-by date” and “seen as obsolete” once they were over the age of 64 because of their eminent exclusion from the breast screening programme on no other basis than advancing age.

It does appear that Foucault’s “medical gaze” (1973, p. 51) of surveillance is no longer interested in those past the age of economic productivity, as the possibility of the stated “other health problems” (Breast Cancer Screening Policy Advisory Group, 1998, p. 140) precludes them from the programme. It could be argued that such discourse reflects victimisation of a group of women on the basis

of nothing other than growing old. In an aging society dominated by the demographic bulge of “baby-boomers”, many of whom are well on the way to 65, it appears that women who are past the “productive” age of being in the workplace are effectively being marginalised through the inequality inherent in the economic ideology of the state. As Battersby (2000) points out, social and moral issues of inequality prevail for this aging population, which, in this research, are not addressed by the current stance of the breast screening programme.

### **IMPLICATIONS OF FINDINGS**

The outcomes of this research reflect the dominance of the political and biomedical dialogues which served to ideologically invest the discourse about, and from within, the breast screening programme. As Wallack et al. (1993) state, “How we define the problem determines its solution. The crucial act of definition relies on a particular analytical perspective, yet that perspective remains invisible” (p. 10). In the case of screening mammography, the debate was ideologically invested by the discursive constructions of politicians and health professionals. The Ministry of Health sought submissions framed within the discourse of market and biomedical paradigms of treatment and communication. Positions outside the constraints of these models were eliminated by the criteria set for the breast screening programme.

Wallack (1990) contends that whoever frames the issue also determines the framework of the ensuing discussion. Community-based health interventions such as population-based breast screening programmes, are founded on a definition of a “problem” as it is constituted through a political and institutional discourse. Thus, solutions are chosen according to the resulting definition.

Rogers (1994) points out that because health-focused interventions are seen as advancing the public welfare, they are therefore justified. However, as Redman, Henrikus, Bownam and Sanson-Fisher (1988) clearly demonstrated, many problems identified by health planners are vastly different from those identified by women in the community. Nevertheless, it is the planners and managers who ultimately decide what is acted upon (Klein, 1990); thus they ultimately establish the criteria for “compliance”. This may explain why, in the end, causal connections between activities promoted by health intervention programmes may be perceived as having outcomes that deny any real proof of success for those involved (Hayry, 1998).

To ensure that the breast screening programme genuinely intends to provide a community-based service for women, there is a conspicuous need for consultation with those women. Issues of control come to the fore. Although participants are not altogether comfortable in their role as health “consumers” imposed by a market model, they are demonstrating an associated desire not to be treated as “patients” implying dependence and subordination to a clinical process. However, some ambivalence was detected in the responses of women to the rearticulation of a discourse that is produced in consumerist logic rather than a social service framework. One example of the ensuing contradictory discourse was from Māori women, who reported that they wanted “the staff to have the right attitude” of smiling and accepting their cultural differences. In contrast, however, they also subsequently stated that they were “reluctant to complain, as by identifying themselves publicly the free service could get taken away”. Therefore, on one hand, the “new” environment was established as “empowering”, but equally so, the hegemonic setting and practice of a service provided by “experts”

also appeared to constrain the perceived freedom of respondents to express their needs.

## **OPPORTUNITIES FOR NEW RESEARCH**

In providing a perspective on communication in the breast screening programme, this study has given rise to a number of further questions worthy of consideration. The complexity of the issues and the significance of the decisions made on the lives of many women make it imperative to welcome the interest and input of other disciplines and also of the community into the debate about screening mammography. For example, in this research the experiences of those women who have chosen to attend for screening mammography have been looked at. There is another population who have chosen not to attend, and their views are equally, if not more, relevant in establishing effective ways of communicating with eligible women about breast screening.

As McCormick (1996) points out, there are fundamental ethical differences between individuals seeking help from health professionals, and those same professionals going into the community to “offer” a service. It could be argued in this case that one of the dilemmas arises from introducing a biomedical model and its associated scientific discourse into the community, which subjugates participants to the associated scientific framework. In Foucault’s (1980) words, concern is with “the effects of the centralising powers which are linked to the institution and functioning of an organised scientific discourse within a society such as ours” (p. 84).

This analysis has demonstrated how the discourses from the breast screening programme and their reproduction privileged the “expert” accounts of health professionals. It also illustrated the discursive struggle of biomedicine to

gain ascendancy with that of the order of health promotion. Thus, in the process, both served to undermine alternative perspectives. The subsequent communication, which resulted from an imperfect and contested framework, has practical implications for the future of health communication. It is no longer enough simply to consider the consumption of health communication strategies. The influences on the production of health communication have been brought to the fore in this research to illustrate that the process does not occur in an institutional vacuum. Thus, the implications of the way in which political interventions and the socio-cultural context of organisations impact on the resulting communication highlight the need for further recognition in future research.

Nevertheless, such research also needs to recognise that the discourse on health reform has been a carefully constructed rhetoric designed to impose a new ideology. Although the Labour Government of 1999 has pledged to remove the market from health care, to date, the discourse persists. Within any discourse, subjects occupy positions. The economic discourse constituted staff as subjects who were required to function within an ascendant market model. The power effects of the discourse were thus reproduced through the organisation, not only to participants, but also to staff. In this thesis, in my attempts to compel the reader's attention towards the women who experienced screening mammography, at times, I may appear to have taken for granted the way in which organisational realities are constructed, reproduced and changed, thereby marginalising the difficulties that staff face as they cope within the resulting structure. Their view is equally valid and may have parallel implications for the way in which community health interventions are offered in the future. Further research with this focus in mind would help to provide another perspective about health communication.

The identified outcomes of how the target audience receives and interprets the communication about ongoing participation from the breast screening programme in this research have practical applications for recognising the need for the perspectives of participants to gain ascendancy. Simply providing information is not enough to assist women through the physical process of screening mammography, which some describe as “uncomfortable and undignified” (Brown, 1989, p. 2690). Prior literature has clearly revealed that participation in screening mammography is a painful and anxiety-provoking experience for some women which deters both them and other women from participating. As a disease detection intervention, the potential for screening mammography to induce anxiety as a result of both “procedural” (the process) and “outcome” (what may eventuate) stress identified in this study, is reflected in earlier research findings, including others in New Zealand, such as Elwood et al. (1998) and Richardson (1990). Similarly, Munn’s (1993) survey of New Zealand women identified 39% who expressed a “fear of a positive screen result” (p. 284) as a reason for refusing screening mammography.

Similar numbers (39%) were identified in the Edinburgh study of Maclean et al. (1984), and fear about outcomes was the primary reason for non-participation given in Leather and Roberts (1985) British study. Accordingly, even to be convinced that mammography is a potentially life-saving option may not be enough to convince some women to participate, even though they have previously experienced breast cancer, as Hugh (1991) illustrated. However, the role of health professionals using appropriate communication strategies to address this outcome appears previously to have either been unrecognised, or alternatively, treated as a secondary issue. This study has highlighted the role of communication. Further research is needed to explore related questions, such as

the need to encourage participants to question, that have thus far been largely disregarded.

Clear, culturally specific differences have been demonstrated in this research into the various ways in which communication is presented. Furthermore, it is readily apparent that ethnic minority groups of women do not experience the process of screening mammography in the same manner as European women. Cultural bias of the dominant European culture is creating barriers for those who hold alternative views, views which may even reject participation in a disease detection programme. Accepting that there were small sample sizes for the Pacific Island and Asian groups of women in this study because of their under-representation on the breast screening database, the findings do indicate that there are a number of issues of communication that do not facilitate attendance. As Littlejohn (1996) points out, when processing information, individuals “organise new information into systems of existing beliefs and attitudes” (p. 154), which in this case, clearly do not fit with those of the dominant culture. Alongside addressing physical barriers such as difficulties of access, further research is required to establish the ways in which these women would feel more comfortable. Clarification of communication processes that are culturally acceptable is required. However, research without a willingness to incorporate changes that meet culturally-appropriate requirements will prove to be of little value.

## **LOOKING TO THE FUTURE**

It has not been my intent in this thesis to deny the importance of the skilled technical practice of health professionals. It is necessary only to reflect on the now public case of Colleen Poutsma, as she struggles to survive for long enough

to testify against the health professional who failed to treat her developing cervical cancer appropriately (Commissioner apologises, 2000), to recognise how foolhardy it would be to adopt such a stance. Neither is this discussion about health promotion intended to be negative, nor to deny the integral role of health education. Nor is it an attempt to suggest that women are not responsible for their own health behaviour. This research has served to illustrate, however, that the breast screening service exists in a dynamic context which influences the way in which it communicates as a community-based health intervention. Thus, many assumptions that traditionally underpin health care communication need to be challenged if the progressive transition into a community setting is not to be fraught with unintended outcomes.

As community values will continue to change, ideas and expectations must continuously be exchanged to respect the autonomy and needs of those who are in the community. The basic assumptions of providing services for women are being questioned by many who want a greater share of the power to determine not only which problems should be addressed, but how and for whom. The pressures for change will continue to increase and will come from diverse groups.

The triangulated data collection and analysis methodology used in this research generated significant findings about the communication experiences of women who experience screening mammography. It is likely that a number of those findings may have broader applications for communication within the health sector. Meantime, as a community-based programme for “well” women, the breast screening programme relies on effective communication for its success. If communication strategies within the programme are adapted to enhance the power of participants through enlarging the range of choices, such as allowing them to both define problems and solutions, both the participants and staff will be likely to

benefit. The breast screening programme has been established for the women of New Zealand; they are entitled to have their feedback heard, so that one day, they all may believe that this service is truly their own. Perhaps then, the breast screening programme may attain its declared goal of the 70% participation rate required to achieve mortality savings in the population.

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(Please note: Original documents have been reformatted for this thesis).

## APPENDIX 1

### INVITATION TO PARTICIPATE IN RESEARCH

#### **BreastScreen Midland**

As a woman participating in the Breast Screening Programme and registered with BreastScreen Midland your experience and opinions are very valuable. Your opinions will help the ongoing development of Programme and screening services in the Health Waikato area.

Margaret Brunton is undertaking research to explore your experiences and knowledge about breast screening. I would appreciate you taking time to answer the questionnaire and return it to the researcher in the post paid envelope.

You are free to withdraw from this research at any time, or decline to answer any particular questions. There is no method to identify whether you participated in this study or not. The answers you give will not jeopardise your relationship with the breast screening programme. All information provided by you will be treated with the utmost confidentiality.

Thank you for your participation in the future development of the BreastScreen Midland Programme.

If you have any queries about the research or your involvement in it, please feel free to contact the programme – Hamilton 0800 270 200.

Yours sincerely

Cheryl Billett  
Team Leader Health Promotion  
Breast/Cervical Screening

Susan Bramley  
Manager  
Breast Care Centre/Screening Services

## APPENDIX 2

### INFORMATION SHEET

#### **An exploration of the changing dialogue of health communication in New Zealand: a case study of the BreastScreen Midland Programme.**

You are invited to take part in a research project to help us to understand your opinions about the information recently provided by BreastScreen Midland to promote the breast screening programme for women aged between 50 and 64 years. The aim of the study is to identify which parts of the message were the most helpful. This will help to design future messages so that they will be useful to as many people as possible.

Your name was randomly selected as one of a sample of 1,100 women who are currently enrolled on the breast screening register. The process of selection was fully confidential and nobody has access to your name apart from those who normally handle this information. The questions that we are asking you relate to what parts of the messages you found useful and those parts you may not have thought were relevant to you. The information will be used by BreastScreen Midland to help meet the future information needs of people in the area. It is also being used to complete an analysis of community health messages for a doctoral study in the Waikato Management School. The study has received ethical approval from the University of Waikato Management School Ethics Committee and the Waikato Ethics Committee.

The questionnaire will be returned directly to the University of Waikato when you have completed it. You will notice that there is a number in the corner. This number has been put on to identify those people who may require a reminder about completing the questionnaire at a later date. The numbers will be collated when the mail is received at the university. The list of numbers will be sent to the BreastScreen Midland staff who will send out reminder letters to those who have not replied within a two-week period.

The researcher carrying out the study is Margaret Brunton, who can be contacted on telephone (07) 854-0622, should you have any queries. Her supervisor is Dr Kay Weaver, who may be contacted at the University of Waikato, telephone (07) 838-4466, extension 6222, and can provide information related to the study. The local BreastScreen contact for your area is:

Cheryl Billett	BreastScreen Midland	telephone(07)834-3632.
Elaine Preston	Raukura Hauora O Tainui	824-5585
Ramari Maipi	Raukura Hauora O Tainui	025 712-327
Grace Mitchell	Te Rapakau Health	847-7529
Elizabeth Mather	Asian community educator	855-5262

Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will continue to be offered invitations to breast screening. If you do agree to take part you are free to

withdraw from the study at any time, without having to give a reason and this will in no way affect your future opportunities to be a part of the screening programme. Should you be willing to complete the enclosed questionnaire, (or participate in an interview or discussion group), all of the information supplied will be treated with absolute confidentiality. No material which could personally identify you will be used in any reports on this study.

Should there be any questions that are unclear, please do not hesitate to ask for information. Should you prefer not to provide answers to any of the questions, please disregard these questions. All individual questionnaires (interview notes) will be destroyed by shredding or burning once the data has been taken from them. We anticipate that the study will be finished by March of 2000 and a copy of the results is available by telephoning the above contact numbers or by asking the researcher.

## APPENDIX 3

### CONSENT FORM

**An exploration of the changing dialogue of health communication in New Zealand: a case study of the BreastScreen Midland Programme.**

I have read and I understand the information sheet for volunteers taking part in the study designed to provide information about how women understand the information provided by the breast screening programme. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future participation in the breast screening programme.

I have read the information sheet for this study and have had the details of the study explained to me. I have had the opportunity to discuss this study and I am satisfied with the answers I have been given. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the study. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study. I wish to participate in this study under the conditions set out on the information sheet.

English	I wish to have an interpreter.	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero.	Ae	Kao
Samoaan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX 4

### QUESTIONNAIRE SURVEY

We would like to try and understand whether the information you are receiving about breast screening X-rays is meeting your needs. This questionnaire will take only 10-20 minutes to complete, and is strictly confidential.

1. How did you **find out** about the breast x-ray screening programme?  
(please tick as many as apply).

Doctor	[ ]	Radio	[ ]
Meeting	[ ]	Poster	[ ]
Newspaper	[ ]	Pamphlet	[ ]
Family/ Whanau	[ ]	Church	[ ]
Friend	[ ]	Community group	[ ]
Workplace	[ ]	Health day/expo	[ ]
Magazine	[ ]	Television	[ ]
Letter of invitation	[ ]	Health worker	[ ]

Other (please specify) \_\_\_\_\_

2. Did your doctor encourage you to take part in the breast screening programme? (please tick one box).

Yes [ ] No [ ]

3. What helped you to decide to **take part** in the breast-screening programme? (please tick as many as apply).

Know someone with breast cancer	[ ]	Have family history of breast cancer	[ ]
Letter from family doctor	[ ]	Newspaper	[ ]
Poster	[ ]	Television	[ ]
Pamphlet	[ ]	Family / Whanau	[ ]
Church	[ ]	Community group	[ ]
Friend	[ ]	Workplace	[ ]
Health day/expo	[ ]	Letter of invitation from programme	[ ]
Magazine	[ ]	Own decision	[ ]
Radio	[ ]	Health worker	[ ]

Other (please specify) \_\_\_\_\_

4. Please indicate how satisfied you were with the following aspects when you contacted the breast screening service? (*please tick one box for each question*).

	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied	Not applicable
If telephoning, the time it took to get through	[ ]	[ ]	[ ]	[ ]	[ ]
The welcome you received	[ ]	[ ]	[ ]	[ ]	[ ]
How understood you felt	[ ]	[ ]	[ ]	[ ]	[ ]
The answers given to your questions	[ ]	[ ]	[ ]	[ ]	[ ]
The amount of information you were offered	[ ]	[ ]	[ ]	[ ]	[ ]
The way the information was explained	[ ]	[ ]	[ ]	[ ]	[ ]
The choice of appointment times offered	[ ]	[ ]	[ ]	[ ]	[ ]
Choice of appointment days	[ ]	[ ]	[ ]	[ ]	[ ]

5. Describe how worried you felt while you were waiting for your appointment to have your breast screen? (*please tick one box*).

- Not at all worried [ ]
- A little bit worried [ ]
- Quite worried [ ]
- Very worried [ ]
- I don't remember [ ]

6. Describe how worried you were while you were waiting for the results of your breast screen? (*please tick one box*).

- Not at all worried [ ]
- A little bit worried [ ]
- Quite worried [ ]
- Very worried [ ]
- I don't remember [ ]

7. How long did you wait for the results of your breast X-ray? (*please tick one box*).
- Didn't wait at all [ ]  
Up to one week [ ]  
Up to two weeks [ ]  
Up to one month [ ]  
More than one month [ ]  
Never received them [ ]  
I don't remember [ ]
8. Comments – is there anything in the above questions that you would like to comment on? We especially value any comments you wish to make – (please write on the back of the page if you run out of space).
- 
- 

**The next part of the questionnaire asks you about your experience of having a breast screening X-ray taken.**

9. How many times have you had a breast screening X-ray taken? (*please tick one box*).
- Never [ ]  
Once [ ]  
Twice [ ]  
Three or more times [ ]
10. How did you feel during the last time you were having your breast X-ray carried out? (*please tick one box*).
- Relaxed [ ]  
Quite relaxed [ ]  
Stressed [ ]  
Very stressed [ ]
11. How physically uncomfortable or painful did you find having the breast screening X-ray taken? (*please tick one box*).
- Very painful [ ]  
Moderately painful [ ]  
Slightly painful [ ]  
Very uncomfortable [ ]  
Moderately uncomfortable [ ]  
Slightly uncomfortable [ ]  
No pain or discomfort at all [ ]

12. Did the staff explain to you the procedures involved in having the breast X-rays taken as they happened? *(please tick one box)*.
- Always [ ]  
 Usually [ ]  
 Sometimes [ ]  
 Never [ ]
13. Did you feel comfortable about asking the staff questions about anything? *(please tick one box)*.
- Always [ ]  
 Usually [ ]  
 Sometimes [ ]  
 Never [ ]
14. Did you ever have any concerns about the way staff treated you at the breast screening centre? *(please tick one box)*.
- Yes [ ] No [ ]

If yes, would you please comment. Also, is there anything about having a breast screen X-ray that you would like to comment on? We especially value any comments you wish to make– (please write on the back of the page if you run out of space).

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**The next part of the questionnaire asks what you think about breast screening X-rays.**

15. How important do you think it is to have a breast screening X-ray every two years? *(please tick one box)*.
- Very important [ ]  
 Important [ ]  
 Not important [ ]  
 Not at all important [ ]
16. How worried do you normally feel about getting breast cancer? *(please tick one box)*.
- Not at all worried [ ]  
 A little bit worried [ ]  
 Quite worried [ ]  
 Very worried [ ]

17. Did having a breast X-ray change how worried you normally feel about getting breast cancer?  
 Following your last breast X-ray, how did you feel? *(please tick one box).*
- |                               |                          |
|-------------------------------|--------------------------|
| Felt reassured (less worried) | <input type="checkbox"/> |
| Felt much the same            | <input type="checkbox"/> |
| Felt more worried             | <input type="checkbox"/> |

18. Do you plan to have a breast X-ray when you are next called from the breast screening register? *(please tick one box).*
- |     |                          |    |                          |           |                          |
|-----|--------------------------|----|--------------------------|-----------|--------------------------|
| Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Undecided | <input type="checkbox"/> |
|-----|--------------------------|----|--------------------------|-----------|--------------------------|

19. If not, or feeling undecided, would you be able to tell us the reasons why? *(please tick as many as apply).*
- |                               |                          |
|-------------------------------|--------------------------|
| Too busy                      | <input type="checkbox"/> |
| Too scared                    | <input type="checkbox"/> |
| It's painful                  | <input type="checkbox"/> |
| It's too stressful            | <input type="checkbox"/> |
| Lack of transport             | <input type="checkbox"/> |
| I'd sooner not know           | <input type="checkbox"/> |
| Don't like exposure to X-rays | <input type="checkbox"/> |
| I don't think it's important  | <input type="checkbox"/> |

Other, or comments on the above questions - we especially value your comments - *(please write on the back of the page if you run out of space).*

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**The next part of the questionnaire asks you about the information you have received.**

20. Can you please tell us whether you have received the following information from any source in the BreastScreen programme? *(please tick yes or no as applicable).*

	<b>Yes</b>	<b>No</b>
A clear explanation of what breast screening is looking for	<input type="checkbox"/>	<input type="checkbox"/>
A clear explanation of the breast screening procedure	<input type="checkbox"/>	<input type="checkbox"/>
A clear explanation of when and how test results will be made available	<input type="checkbox"/>	<input type="checkbox"/>
A clear explanation of the test results	<input type="checkbox"/>	<input type="checkbox"/>
A clear explanation of any further action required	<input type="checkbox"/>	<input type="checkbox"/>

21. The BreastScreen programme uses different sources of information. Can you please comment on the following? (*please tick one box for each column*).

	Written Information	Spoken or verbal Information	Video or TV
Very easy to understand	[ ]	[ ]	[ ]
Quite easy to understand	[ ]	[ ]	[ ]
Confusing	[ ]	[ ]	[ ]
Very confusing	[ ]	[ ]	[ ]
Too much at once	[ ]	[ ]	[ ]
Not enough	[ ]	[ ]	[ ]
Language was too technical	[ ]	[ ]	[ ]
Haven't seen or heard any	[ ]	[ ]	[ ]

22. The breast screening programme has various information pamphlets. Have you seen any? (*please tick one box*).

Yes [ ]                      No [ ]

If yes, could you please tell us which ones you have seen and how helpful you found them?

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23. Have you seen the recent breast screening advertisements on television? (*please tick one box*).

Yes [ ]                      No [ ]

If yes, what was your response to these advertisements? - (please write on the back of the page if you run out of space).

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24. Do you recall seeing or hearing other information about breast screening in the media? (for example, radio, books, magazines, newspapers). (*please tick one box*).

Yes [ ]                      No [ ]

If yes, what were they, and what was your response to these? - (please write on the back of the page if you run out of space).

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25. Was there any information about **anything** that you wanted to know but has not been offered to you? We especially value your comments - (please write on the back of the page if you run out of space).
- 
- 

**Just before we finish, there are a few general questions we would like to ask.**

26. Please read the following two statements carefully. Which one do you think would most encourage women to have a screening X-ray? (*please tick one box*).

Statement 1:

When you avoid having a mammogram, you are failing to take advantage of the best method for detecting breast cancer early.

Statement 2:

When you have a mammogram, you are taking advantage of the best method for detecting breast cancer early.

27. Could you please answer the following questions (please tick either true or false for each question).

	True	False
1. Most women who have breast X-rays will be reassured they don't have breast cancer	<input type="checkbox"/>	<input type="checkbox"/>
2. Most women who develop breast cancer have no relatives with the disease	<input type="checkbox"/>	<input type="checkbox"/>
3. The risk of breast cancer increases with age	<input type="checkbox"/>	<input type="checkbox"/>
4. Breast cancer is common in young women	<input type="checkbox"/>	<input type="checkbox"/>

28. Please tick the option which most closely reflects your attitude (*please tick one box*).

1. I like to be responsible for my own health care decisions
2. I like to be involved in my own health care decisions but still want to check with my doctor
3. I prefer to leave health care decisions entirely to health professionals such as my family doctor

**Finally, to help us understand how different people experience the information provided by the programme, we need to ask you for a few personal details.**

29. What age group do you fit into? *(please tick one box).*

- |         |                          |
|---------|--------------------------|
| 50 – 54 | <input type="checkbox"/> |
| 55 – 59 | <input type="checkbox"/> |
| 60 – 64 | <input type="checkbox"/> |
| 65+     | <input type="checkbox"/> |

30. What ethnic group do you identify with? *(please tick as many as apply).*

- |                |                          |
|----------------|--------------------------|
| NZ Maori       | <input type="checkbox"/> |
| NZ European    | <input type="checkbox"/> |
| Pacific Island | <input type="checkbox"/> |
| Asian          | <input type="checkbox"/> |

Other (please specify) \_\_\_\_\_

31. Where did you have your breast screening X-ray? *(please tick one box).*

- |                        |                          |
|------------------------|--------------------------|
| At the hospital        | <input type="checkbox"/> |
| In the mobile van      | <input type="checkbox"/> |
| Other (please specify) | _____                    |

32. When did you last have a breast screening X-ray?

(Month) \_\_\_\_\_ (Year) \_\_\_\_\_

33. Do you live *(please tick one box).*

- |                 |                          |
|-----------------|--------------------------|
| In a city       | <input type="checkbox"/> |
| In a rural town | <input type="checkbox"/> |
| In the country  | <input type="checkbox"/> |

34. Which of the following best describes your current work? *(please tick one box).*

- |                             |                          |
|-----------------------------|--------------------------|
| Working for wages or salary | <input type="checkbox"/> |
| Unpaid work in the home     | <input type="checkbox"/> |
| Self employed               | <input type="checkbox"/> |
| Retired                     | <input type="checkbox"/> |

35. What is your annual household income? *(please tick one box).*

- |                      |                          |
|----------------------|--------------------------|
| Less than \$15,000   | <input type="checkbox"/> |
| \$15,000 - \$30,000  | <input type="checkbox"/> |
| \$30,001 - \$50,000  | <input type="checkbox"/> |
| \$50,000 and over    | <input type="checkbox"/> |
| Don't wish to answer | <input type="checkbox"/> |

36. Where did your education finish? *(please tick one box).*

- Primary school [ ]
- Secondary school [ ]
- University [ ]
- Trade or polytech [ ]
- Other sources [ ]
- Don't wish to answer [ ]

Finally, can you give us any information about ways in which we can improve the things we have asked you about? Also, if there is anything that is important to you that we haven't asked about, we would welcome your comments (please write on the back of the page if you run out of space).

**We especially value your comments, which can be most revealing and can often lead to improved service.**

---

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---

---

---

Thank you for taking the time to answer these questions. We value your support in helping us to understand how to make things better. Again, we assure you that your responses are **strictly confidential**.

## APPENDIX 5

### INVITATION TO PARTICIPATE IN A FOCUS GROUP OR INDIVIDUAL INTERVIEW

We would welcome the opportunity to talk with you about your thoughts and ideas about breast screening. You may even prefer to talk about your experience rather than completing the questionnaire. If you would like to talk to Margaret, either on your own, or as a member of a discussion group, would you please fill in your contact details below and return it so that she can telephone you to make arrangements that would suit you. Just like the information from this questionnaire, any discussion would also be treated on the basis that it is **strictly confidential**.

Name (first name only if preferred):

-----

Contact address or telephone number:

-----

I would prefer a: Personal interview

Group discussion

## APPENDIX 6

### PRE-TEST FOR QUESTIONNAIRE

**Questions:**

1. Would you please time how long it takes you to complete the questionnaire

Time taken: \_\_\_\_\_

2. Were there any questions that you could not answer?

Yes [ ] No [ ]

If yes, which questions were they, and why?

---

---

How could they be improved?

---

---

3. Were there any questions that you had trouble understanding?

Yes [ ] No [ ]

If yes, which questions were they, and why?

---

---

How could they be improved?

---

---

4. Were there any questions that you felt limited your responses?

Yes [ ] No [ ]

If yes, which questions were they, and why?

---

---

How could they be improved?

---

---

5. Did you think any of the questions were 'leading', that is, you felt you had to answer in a specific way?

Yes [ ] No [ ]

If yes, which questions were they, and why?

---

---

How could they be improved?

---

---

6. Was there any part of the questionnaire that felt 'uncomfortable' for you?

Yes [ ] No [ ]

If yes, which part of the questionnaire?

---

---

Do you have any ideas about how we could improve this?

---

---

7. Do you have any other suggestions about questions we need to include in the questionnaire or the questionnaire in general?

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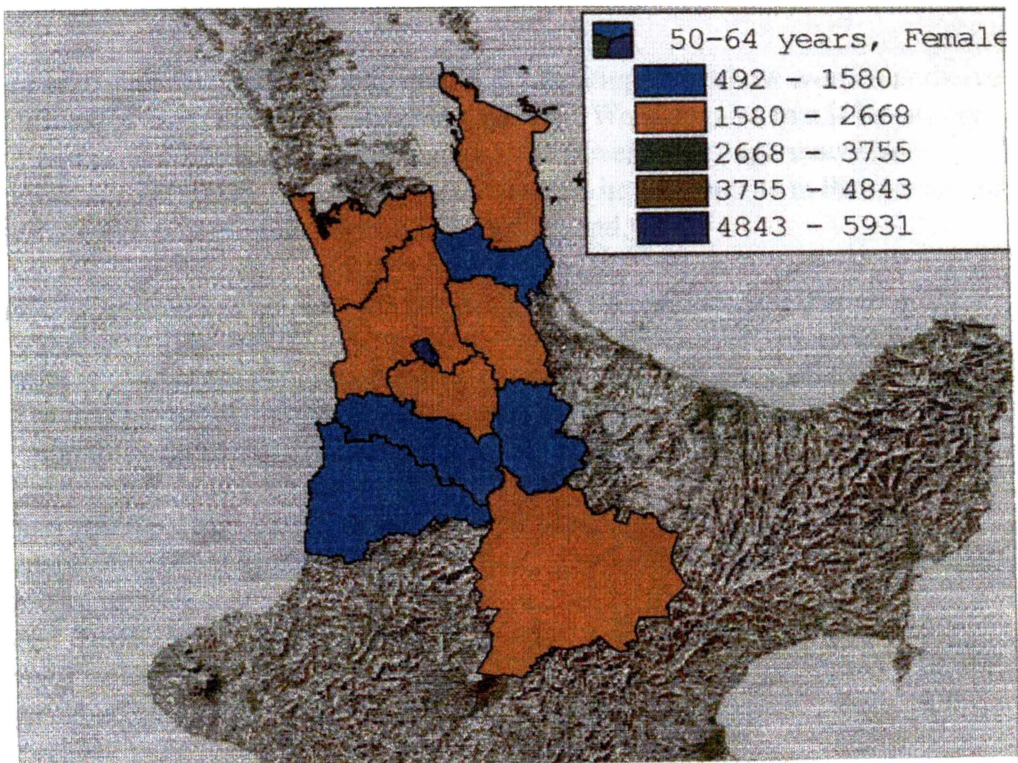
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Thank you for your help in improving the questionnaire. Your support is very much appreciated.

## APPENDIX 7

### MAP OF GEOGRAPHICAL AREA COVERED BY THE WAIKATO PILOT BREAST SCREENING PROGRAMME



Source: New Zealand Census of Population and Dwelling 1996, Supermap 3.

## APPENDIX 8

### REMINDER LETTER

Recently we sent you a questionnaire asking about your experiences of the messages that BreastScreen Midland uses to communicate with you about breast screening, or mammography.

The purpose of this research is to obtain information about how women perceive the messages from the breast screening service. We recognise that it is entirely your choice to complete the questionnaire. However, your experiences and opinions are very valuable in helping us to make improvements in the service that is being offered to eligible women in New Zealand.

If you are willing to complete the questionnaire we reassure you that all of the information will be treated with absolute confidentiality. We would be most grateful if you would participate in this research study. We realise that the only way to make things better is to discover what women are finding both helpful and not so helpful about the messages that we are using.

Should you have any questions, the researcher who is carrying out the study is Margaret Brunton (telephone (07)854-0622). The local BreastScreen contact for your area is:

Cheryl Billett,	BreastScreen Midland	telephone(07)834-3632
Elaine Preston	Raukura Hauora O Tainui	824-5585
Grace Mitchell	Te Rapakau Health	847-7529
Ramari Maipi	Raukura Hauora O Tainui	025 712-327
Elizabeth Mather	Asian community	855-5262

Please do not hesitate to contact us if you need another copy of the questionnaire or if you should you have any queries about the research, either on the above numbers or on the BreastScreen programme programme contact number of 0800 270 200.

Yours truly

Manager Screening Programmes

## **APPENDIX 9**

### **INTERVIEW SCHEDULE (STAFF)**

#### **Interview Schedule**

Introduction to research.  
Invitation to participate  
Explanation of process and confidentiality  
Invitation for questions  
Explanation and signing of consent form

#### **Question Guide**

Would you please explain to me your current role in the organisation?

What do you perceive the purpose of the breast screening programme to be?

What role do you think communication plays in this process?

What role do you play in this communication process?

Do you perceive that the overall approach is consistent with the needs of the women who have participated in the programme?

Are there any issues related to communication processes that you would like to discuss further?

(Note to participants: This is a very 'loose' guide to try and illustrate the direction of the discussion. However, I would like you to feel as free as possible to express your own feelings and ideas).



# APPENDIX 11

## WAIKATO BREAST SCREENING PILOT PROGRAMME PAMPHLET

---

### WHERE DO I GO FOR MY BREAST X-RAY (MAMMOGRAM)?

---

The Hamilton Centre is located in the Hospital grounds.

For your convenience a Mobile Unit will visit outlying centres and rural areas.

You will be advised by letter of the x-ray unit closest to you.



---

### THINGS TO REMEMBER?

---

For your convenience, wear a two piece outfit, a skirt or slacks and a top.

Do not wear talcum powder as it may show on the films.

If you have any questions please do not hesitate to call us on the telephone help line.

Telephone: (07) 834 3665

---

Breast X-Ray Programme, Waikato Area Health Board  
Pembroke Street, PO Box 485, Hamilton.

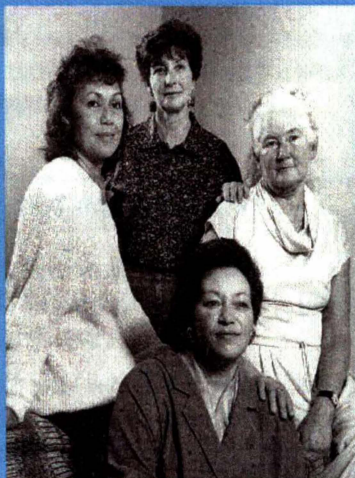


Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆

## A BREAST X-RAY

◆ ◆ ◆  
*is a positive personal statement that  
you care about your health*



*Take Part in the  
Waikato Free Pilot  
Breast X-Ray Programme for  
Waikato Women  
aged from 50 to 64 years.*



Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆

# A BREAST X-RAY (MAMMOGRAM) IS A SAFE, EASY WAY



---

## WHY SHOULD I HAVE A BREAST X-RAY?

---

A breast x-ray is able to detect early changes to the breast, long before you may feel or notice anything unusual.

These changes may indicate the early stages of breast cancer.

Early detection means that small lumps can be removed before they spread.

*Most changes detected in breast tissue are not cancer.*

---

## WHO IS ELIGIBLE FOR THIS PROGRAMME?

---

All women aged between 50 and 64 years, living in the Waikato Area Health Board region (Waiora Waikato). The benefits of screening have so far been demonstrated only for women in this age group.

---

## WHEN CAN I TAKE PART?

---

You will receive, in the mail, a written invitation with an appointment day and place, but please telephone to confirm a time for your breast x-ray. Should your breasts be particularly tender at the time, please tell our receptionist who will change your appointment day.



Waikato Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆

---

## WHAT WILL IT COST ME?

---

Only a little of your time. It is absolutely free.

---

## WHAT HAPPENS WHEN I HAVE A BREAST X-RAY (MAMMOGRAM)?

---

You will be welcomed by our friendly staff and asked to fill in a form.

Then you will be asked to prepare for the x-ray by undressing from the waist up. The breast x-ray programme is staffed solely by women.

---

## HOW IS THE X-RAY TAKEN?

---

When you are ready, a radiographer will take you into the x-ray room where you will be helped into the right x-ray position.

Each breast in turn will be placed between two plates on the x-ray machine and the pictures will be taken. This will allow all the breast tissue to be seen in the picture.

---

## HOW DOES IT FEEL?

---

You may find it uncomfortable because the breast is held quite firmly for a few seconds while the x-ray is taken.



Waikato Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆

# TO CARE FOR YOURSELF

---

## IS THE X-RAY SAFE?

---

Yes it is. With our modern machinery the amount of radiation to the breast is very low.

The benefits of having a breast x-ray every two years far outweigh any risks from being exposed to very small amounts of radiation.

---

## HOW LONG WILL I BE AT THE CLINIC?

---

The actual x-ray takes only a few minutes. Your whole visit should only take half an hour.

---

## WHEN WILL I GET MY RESULTS?

---

You will receive a letter within 10 days or less, regardless of results. It will probably confirm all is well.

You may be called back for a second check. This could be because of the quality of the x-ray or because something needs following up.

**REMEMBER** — MOST WOMEN CALLED BACK DO NOT HAVE BREAST CANCER.



Waiora Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆

---

## WILL MY DOCTOR BE INVOLVED?

---

Yes. If you consent we will send a copy of results to the doctor of your choice.

We do like to involve your regular doctor. Please bring their name and address with you.

If any treatment should be necessary, you will be free to see the specialist of your choice.

---

## DOES IT MATTER IF I HAVE ALREADY HAD A MAMMOGRAM?

---

No, you may be still eligible for the programme. On receiving your invitation please contact the breast x-ray unit to discuss whether you need a further mammogram.

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## WHAT IF I HAVE ALREADY HAD A MASTECTOMY?

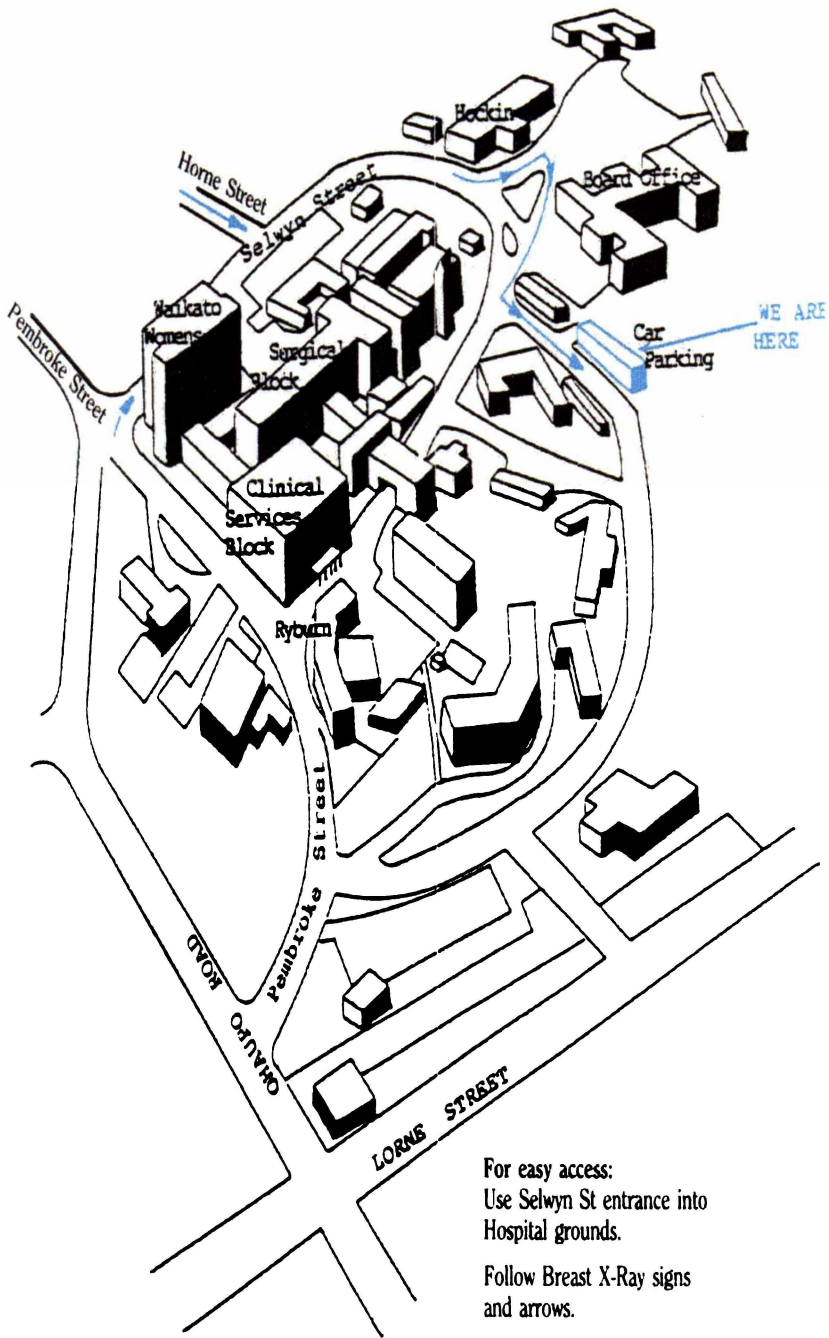
---

If you have already had surgery for breast cancer this programme is not for you. You will already be receiving regular care.



Waiora Waikato  
Waikato Area Health Board

◆ BREAST X-RAY PROGRAMME ◆



For easy access:  
 Use Selwyn St entrance into  
 Hospital grounds.  
 Follow Breast X-Ray signs  
 and arrows.  
 Carpark at rear of building.

## APPENDIX 12

### LETTER OF INVITATION

7 July 1999

**Our Reference:**

**IF YOU ARE OVER THE AGE OF 65, PLEASE DISREGARD THIS LETTER**

**The Waikato Breast Cancer Screening Programme invites you to have a free breast X-Ray at our Central Screening Unit situated in the Waikato Hospital grounds.**

THIS IS A FREE SERVICE TO ALL WOMEN 50-64 YEARS OF AGE. Finding breast cancer early offers the best chance of cure. Women who have regular two yearly mammograms halve their risk of dying from breast cancer.

We suggest an appointment for:

**Please telephone us on (07) 858 0980**

**8.30 – 4.30pm Monday to Friday to arrange a convenient time.**

**You may change the day if this is not convenient and early evening clinics are available.**

Please phone or write to cancel this appointment if you do not wish to have a breast X-ray or if you have had a breast X-ray within the last 12 months, so that we may offer it to someone else.

If you have specific concerns about your current breast health, please see your general practitioner to discuss whether breast screening is appropriate for you.

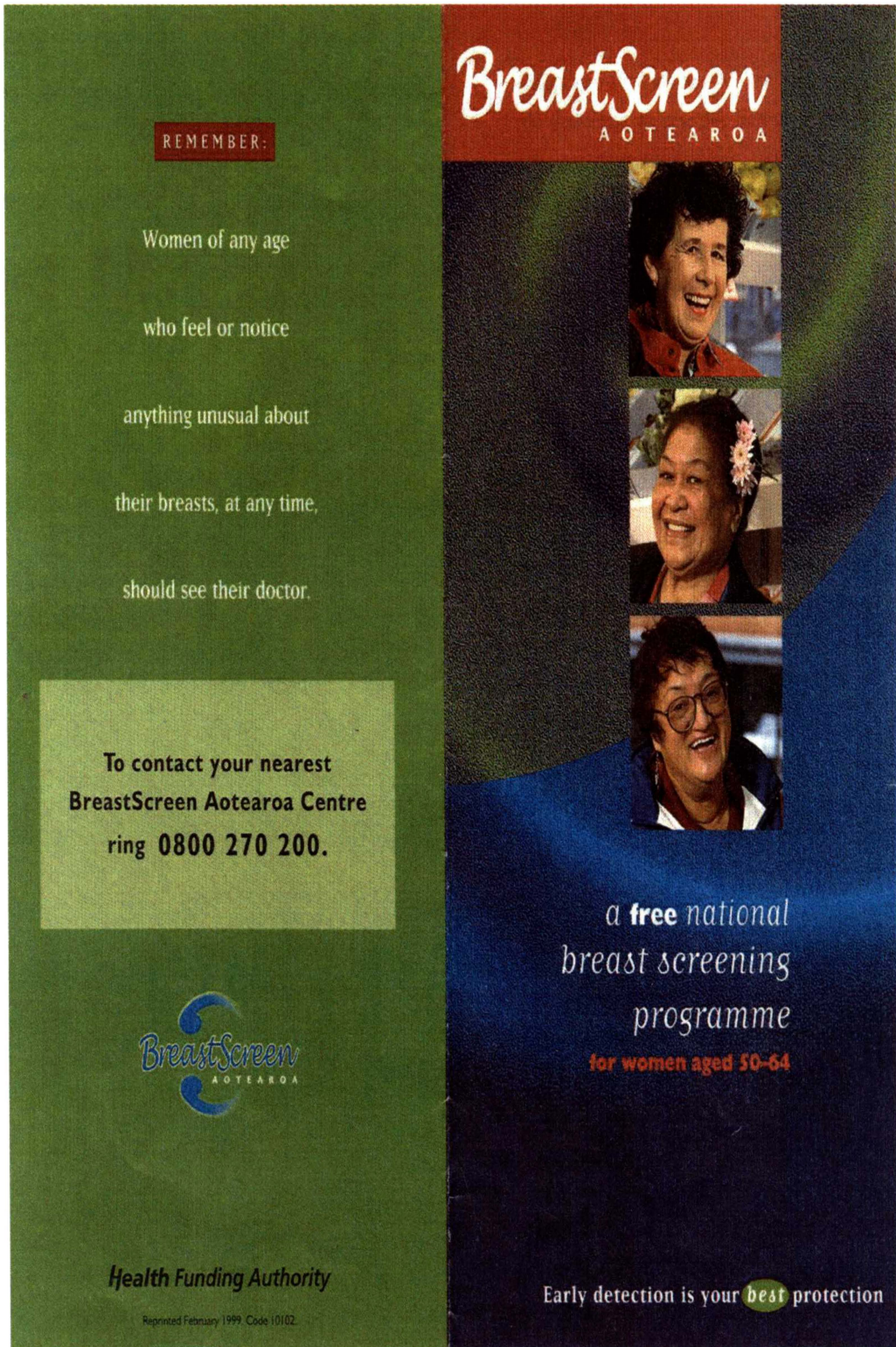
We look forward to hearing from you soon.

**MANAGER**

**BREAST CANCER SCREENING PROGRAMME.**

## APPENDIX 13

### BREASTSCREEN AOTEAROA PAMPHLET



The pamphlet cover features a green background on the left and a dark blue background on the right. At the top right, the text 'BreastScreen AOTEAROA' is written in white, with 'BreastScreen' in a script font and 'AOTEAROA' in a sans-serif font. Below this, three small photographs of smiling women are stacked vertically. The text 'REMEMBER:' is in a red box on the green background. The main text on the green background reads: 'Women of any age who feel or notice anything unusual about their breasts, at any time, should see their doctor.' A white box contains the contact information: 'To contact your nearest BreastScreen Aotearoa Centre ring 0800 270 200.' At the bottom left is the 'BreastScreen AOTEAROA' logo and the 'Health Funding Authority' name. At the bottom right, it says 'a free national breast screening programme for women aged 50-64' and 'Early detection is your best protection'.

**REMEMBER:**

Women of any age  
who feel or notice  
anything unusual about  
their breasts, at any time,  
should see their doctor.

To contact your nearest  
BreastScreen Aotearoa Centre  
ring **0800 270 200.**

**BreastScreen**  
AOTEAROA

*a free national  
breast screening  
programme*  
**for women aged 50-64**

**Health Funding Authority**

Early detection is your **best** protection

Reprinted February 1999. Code 10102.

# BreastScreen

A O T E A R O A

is a **free** national breast x-ray (mammography) service that helps check for early breast cancer.

This programme is offered to all women in New Zealand aged 50 to 64 years who have no symptoms. It aims to reduce the number of women who die from breast cancer.

The following information about breast cancer and mammograms (breast x-rays) may help you make a decision about joining the national breast screening programme.

## WHAT ARE THE CHANCES OF GETTING BREAST CANCER?

- About one in 10 women in New Zealand will develop breast cancer in their lifetime.
- The risk of breast cancer increases with age. Of those women who get breast cancer, three-quarters are over 50 years of age.
- Most women who develop breast cancer have no close relatives with the disease. Even among women with a family history of breast cancer, only a very small number will be at high risk.

## WHAT SHOULD I KNOW ABOUT MAMMOGRAMS?

Mammograms are breast x-rays. When you have a mammogram, the radiographer who takes the x-ray will place each breast in turn between two plates on the x-ray machine. The plates hold the breast firmly for a few seconds while the pictures are taken. Many women find this uncomfortable; a few find it painful. It does not harm the breasts.

## MAMMOGRAMS . . .

- can detect tissue changes in the breast before anything can be seen or felt. In most cases, any changes detected will not be cancer.
- are particularly effective in women over 50 years of age who have mammograms every two years.
- can detect about 90% of all unsuspected cancers. However, in some cases an x-ray may indicate that something is not quite right when in fact all is well (false positive result). Or an x-ray may fail to pick up a cancer (false negative result).

- cannot prevent breast cancer, and cannot always prevent death from breast cancer. They can only detect breast cancer – but early detection means early treatment and a better chance of a successful outcome.
- are relatively safe because only very small amounts of radiation are used.

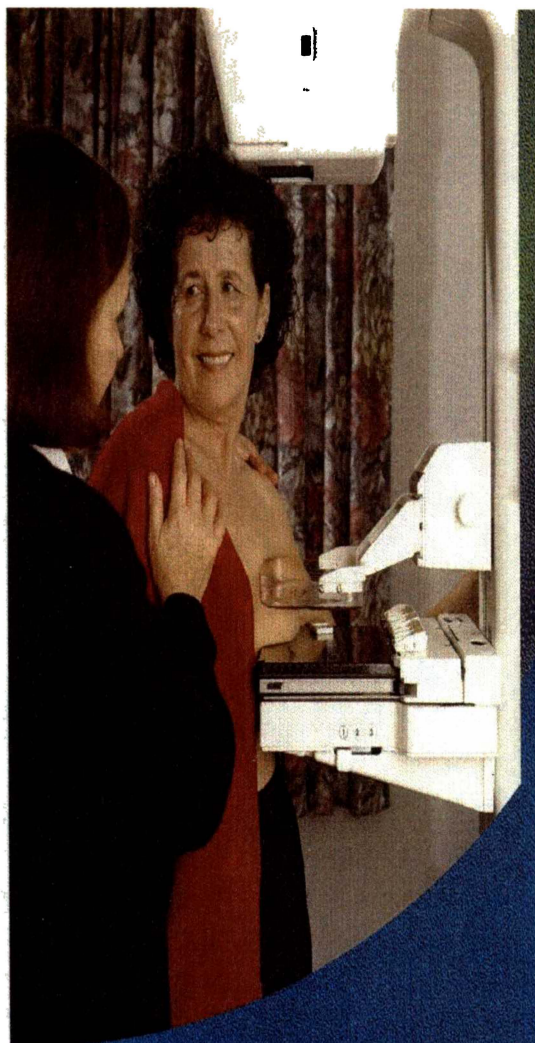
#### WHAT DOES BREASTSCREEN AOTEAROA OFFER?

If you are aged 50 to 64 years, the programme offers you free mammograms (with free follow-up, if necessary) every two years. Your mammograms will be checked by at least two radiologists (doctors who specialise in reading x-rays). They will check for small cancers and will compare your mammograms with any previous ones taken by the programme to see if there are any changes in your breasts.

#### WHAT ABOUT MY RESULTS?

The programme will send your results to you within two weeks of having your mammogram.

- For most women the result will be normal and they will be asked to return for their next mammogram in two years.
- However, a small number of women will be phoned for a second appointment because something needs further checking. This may involve further x-rays, an ultrasound and/or taking a small sample of tissue for examination under a microscope. Most women recalled will not have breast cancer.
- The few women who do have breast cancer will be referred to a specialist for treatment. Most women with breast cancer will have surgery to remove the cancer.



#### CONFIDENTIALITY

We are aware that this is very important to women.

The programme has a legal obligation to adhere to the terms of the Health Information Privacy Code. You will receive more information about confidentiality when you are invited to, or attend, a BreastScreen Aotearoa Centre.

Once you have had your mammogram, the results will be sent directly to you. They will also be sent to your doctor if you have agreed to this.

### HOW DO I JOIN BREASTSCREEN AOTEAROA?

If you are aged 50 to 64 years, you may get a letter inviting you to join the breast screening programme, or you may decide to make an appointment for yourself by contacting the BreastScreen Aotearoa centre nearest you. Or speak with your doctor.

### HOW DO I MAKE CONTACT WITH BREASTSCREEN AOTEAROA?

Contact details of your nearest centre may be in the box at the end of this leaflet. If not, look in your phone book under BreastScreen Aotearoa, or ring **0800 270 200** and your call will be put through to the nearest centre.



### HAVING A MAMMOGRAM WITH BREASTSCREEN AOTEAROA

- On the day of your mammogram avoid using talcum powder, creams or deodorants as these can make the x-ray film difficult to read.
- Wear a blouse or jersey as you will need to undress from the waist up.
- Every care will be taken to ensure privacy when you have your mammogram.
- The radiographer (X-ray taker) will want you to be as comfortable as possible. Discuss any concerns with her.
- Bring your reading glasses - you may need to fill in a form or read something.
- Bring your doctor's name if you want them to get your results.
- You may bring a support person with you if you wish.
- The whole visit should only take about 30 minutes.

### FOR FURTHER INFORMATION

For more information on mammograms and the national programme read the booklet "**BreastScreen Aotearoa: More about Breast Screening and the National Breast Screening Programme**" available from your nearest BreastScreen Aotearoa centre; or talk with a staff member from the centre.

The *choice* to  
have mammograms  
is *yours*

## APPENDIX 14

### BREASTSCREEN AOTEAROA PAMPHLET FOR MAORI WOMEN

**Kia maumahara tātou**

Women of any age  
who feel or notice  
anything unusual about  
their breasts, at any time,  
should see their doctor.

*Whāia te ara tika,  
Kia noho ora ai koe,  
Kia noho ora ai  
tō whānau*

To contact your nearest  
BreastScreen Aotearoa Centre  
ring **0800 270 200**.

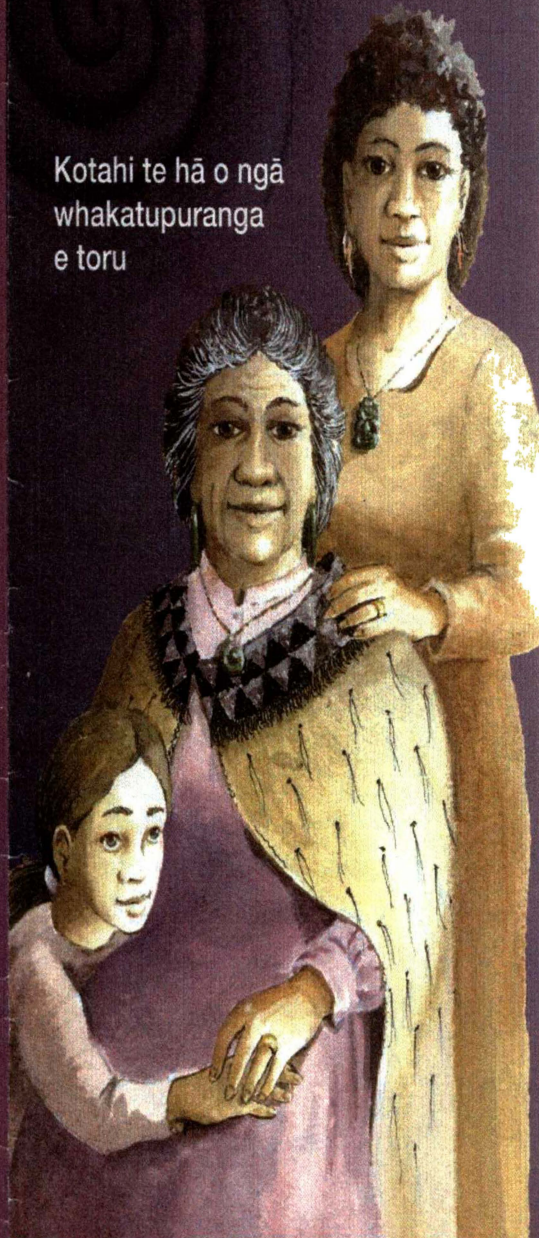


**Health Funding Authority**

February 1998, Code 10123

*Tiakina ō Ū*

Kotahi te hā o ngā  
whakatupuranga  
e toru

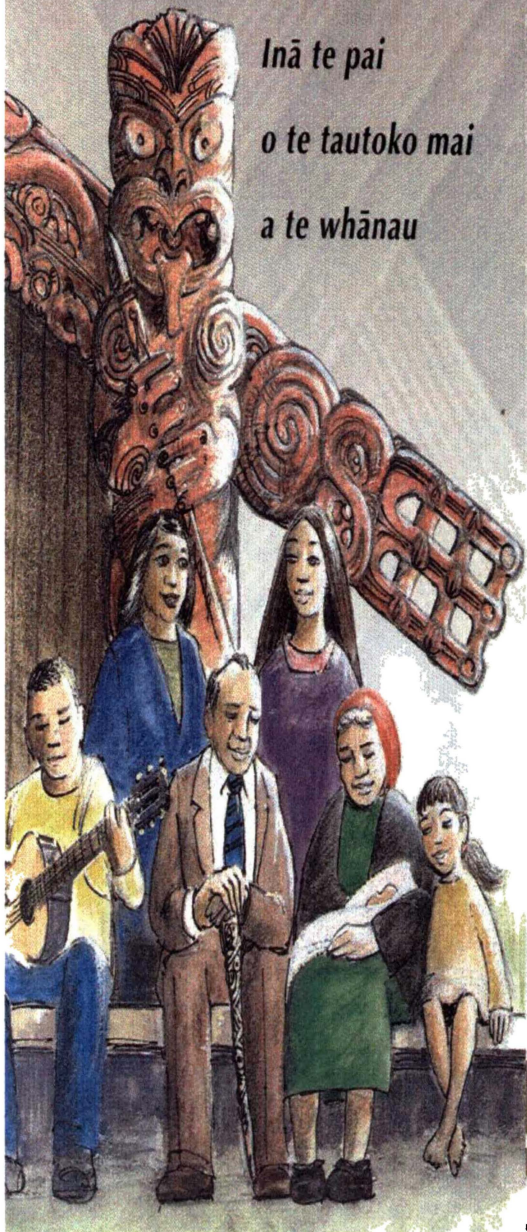


**BreastScreen**  
AOTEAROA

A free national breast screening service for women aged 50-64

## BreastScreen Aotearoa is:

- A free national breast screening service for women aged 50-64.
- It offers free mammograms (breast x-rays) every two years.



*Inā te pai  
o te tautoko mai  
a te whānau*

## Kia mōhio noa mai koe

- About one in ten women will get breast cancer in their lifetime.
- The risk of breast cancer increases with age. Most women who get breast cancer are over 50 years of age.
- Most women who get breast cancer have no close relatives with the disease.

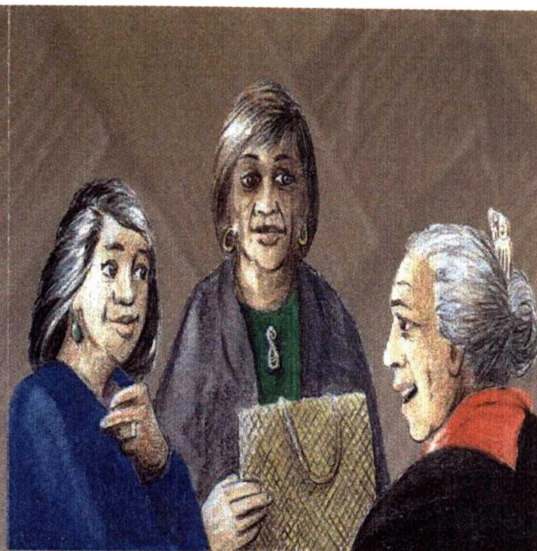
## Te āta tirotiro i ngā ū

- Mammograms are breast x-rays.
- Mammograms can detect tissue changes in the breast before anything can be seen or felt.
- Mammograms can detect about 90% of all unsuspected cancers.
- Early detection means early treatment and a better chance of a successful outcome.
- Mammograms may be uncomfortable. A few women find them painful.

*Otirā, kia kaha wāhine mā*

## Ngā hua o te tirohanga

- You will get your results within two weeks.
- Most women will have normal results.
- A small number of women will be asked to return for further assessment.



## He mea nui tonu te kōrero ki tētahi atu

- Most women who return for assessment will not have breast cancer.
- The few women who do have breast cancer will be referred to a specialist for treatment.

*“Tērā te rā  
kei tua o tāwauwau  
e whiti-mai ana”*

## Ka noho tapu ngā kōrero mōu

- BreastScreen Aotearoa will adhere to the terms of the Health Information Privacy Code.

Once you have had a mammogram the results:

- will be sent to you
- will be sent to your doctor if you wish.

*Nau mai, piki mai*

*ki runga i tēnei*

*kaupapa nui*

You may receive an invitation  
to join BreastScreen Aotearoa

or

phone **0800 270 200**

or

look in your telephone book  
under BreastScreen Aotearoa for  
your nearest Centre.

## Ina haere koe kia tirohia ō ū

- Your privacy will be respected at all times.
- Bring a support person with you if you wish.
- Don't use talcum powder, creams or deodorant - they make the x-ray hard to read.
- Wear a skirt or trousers so that you can undress your top half easily.
- Bring your doctor's name with you if you want your results sent to them.

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