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**PSYCHOSOCIAL ISSUES IN IMPLEMENTING  
MAMMOGRAPHY SCREENING IN AUSTRALIA**

**DEBORAH ANNE TURNBULL**

January 1992

This thesis is submitted in full satisfaction of the  
requirements for the Degree of Doctor of Philosophy,  
University of Sydney

## AUTHOR'S CONTRIBUTION

The work presented in this thesis has been carried out by the author under the supervision of, and consultation with, Associate Professor Les Irwig and Dr Judy Simpson of the Department of Public Health, University of Sydney. This includes: planning of the research, design of component studies, the collection, analysis and interpretation of data, and writing of the thesis, with the exception of the aspects of the research indicated below.

Coding of print and electronic media items for Chapter 3 was done by project staff using protocols developed by the author.

The study on women's knowledge and attitudes which forms the baseline survey in Chapter 4, including the original questionnaire, was designed and implemented by Associate Professor Les Irwig and Dr Jill Cockburn. Subsequent modifications to the protocol and questionnaire were done by the author.

Data for Chapters 4, 5 and 6 were collected by the field staff of the Public Policy Research Centre and project staff, under the supervision of the author. Protocols for field work were developed by the author. Data were entered by a commercial data entry company and project staff, but were cleaned and checked by the author.

Cross-tabulations were conducted by the author. Subsequent analyses were done by Mr Neil Donnelly, Mr Charles Algert and Mr Philip Mock under the supervision of the author.

Data on women who received false positive and normal mammogram results (Chapter 6) was provided by the Breast X-Ray Programme. The program from which women were randomly selected was written by Dr Paul Glasziou.

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## ABSTRACT

The subject of this thesis is mammography screening in the Australian community. The research was conducted in relation to the mobile Breast X-Ray Programme of the Central Sydney Health Service (CSHS) area. This program used generalised recruitment strategies aimed at the community level, supplemented by small-scale strategies aimed at individual women. The target population was 43000 women aged 45 to 70 living in the inner western suburbs of Sydney. The study examined a campaign period between February 1988 and December 1989. The objectives of this thesis are:

- 1) to examine the psychosocial impact, including both positive and negative effects, on the Australian community of implementing a mammographic screening program.
- 2) to evaluate a range of strategies to recruit women to screening.
- 3) to examine the psychological impact on women who receive a false positive result after attending for screening.

In order to examine the psychosocial impact of implementing a mammography screening program, telephone interviews were conducted with randomly selected women aged 45 to 70 living in the CSHS area and in the rest of Sydney. Interviews were done before the implementation of screening (N=628), and 2 years later (N=651). Later interviews included both longitudinal and cross-sectional components.



The campaign did not have an effect on knowledge of breast cancer risk, survival and lumpectomy as a treatment option. The majority of women (80 per cent) held favourable attitudes towards screening mammography and this did not change over the evaluation period. The proportion of women reporting ever having had a screening mammogram increased by 24 per cent in the CSHS area in 1990, compared to 15 per cent in the rest of Sydney. There was a decrease in the proportion of women in the CSHS area who reported concern about radiation, and generally there were no negative effects such as increased perceived personal susceptibility and morbid concern in relation to breast cancer.

The second objective of the study was to evaluate a range of strategies to recruit women to screening. The majority of these were implemented in the Drummoyne Local Government Area (LGA) which was identified as a 'mini-target area' within the wider screening area in which to concentrate recruitment efforts. First a generalised campaign aimed at the community as a whole was evaluated. Two years after the commencement of the campaign, 83 per cent of the target population were aware of the screening van's existence, 60 per cent of women reported 'seeing or hearing' any information about screening mammograms, and almost a third reported being exposed to 'quite a lot' of information.

Several specific strategies were also evaluated. The first was a randomised controlled trial of a generalised strategy which involved distributing leaflets in letterboxes within defined geographical areas. Overall the estimated increase in

attendance due to letterbox drops was 15 percent and not statistically significant. Other strategies were aimed at individual women. 'Invitation for Friends' involved asking women attending for screening to take invitations to encourage family and friends to also attend. Overall an attendance rate of 7 percent was achieved. Several randomised controlled trials were conducted with general practitioners (GPs). Written invitations from the GP with and without an appointment time resulted in attendance rates of 38 percent and 24 percent respectively. Other trials were conducted which involved the GP giving a verbal recommendation about the screening program during the consultation, and the practice receptionist distributing pamphlets to eligible patients. These resulted in attendance rates of 60 per cent and 43 per cent respectively. The final individualised strategy involved sending written invitations from the screening program to women listed on the electoral roll (33 percent attendance rate).

The results of these trials suggest that one potential model for recruitment is a 3-tiered approach which incorporates generalised strategies supplemented by those aimed at individual woman. The first stratum of the model is the generalised strategies which have been found to recruit approximately the first one-third of enthusiastic women. Strata 2 and 3 of the model are the individualised approaches.

While several potentially effective strategies have been identified, perhaps the most practical strategy to implement at a population level is written invitations from the program to eligible women listed on the via the electoral roll. This

approach in conjunction with generalised strategies would be expected to achieve an attendance rate of approximately 60 per cent.

Finally, this thesis considered the impact on those women who attend for screening and receive false positive results. Women who were recalled for further tests (12 months ago or more) and subsequently proved not to have a malignancy (i.e. a false positive group) (N=159), were compared with women who had not been recalled (N=179). Recalled women were more likely to have been concerned about the possibility of getting breast cancer and were concerned more often and to a greater degree.

These data suggest that promotional campaigns such as the one in the present study can reach a large proportion of the target population and inform them at a general level about screening mammography. However, there is a need to continue to improve specific areas of knowledge in order that women can make informed decisions about screening. Second, the research has identified a model for recruiting women to screening which has the potential for achieving the 70 per cent recruitment rate suggested as a target for Australia. Finally the research highlights the need for strategies to reduce psychological morbidity in women who receive false positive results.

## PUBLICATIONS

The following publications have arisen out of the research reported in Chapter 5 of this thesis :

Irwig L, Turnbull D, McMurchie M. A randomised trial of general practitioner written invitations to encourage attendance at screening mammography. *Community Health Stud* 1990;14:357-64.

Turnbull D, Irwig L, Adelson P. A randomised trial of invitations to attend for screening mammography. *Aust J Public Health* 1991;15:33-36.

Turnbull D, Irwig LM. Ineffective recruitment strategies for screening mammography: Letterbox Drops and invitations for friends (Letter) *Aust J Public Health*, 1991(in press).

Turnbull D, Adelson P, Irwig LM. Evaluating the impact of an intensive promotional campaign for screening mammography: Women's knowledge, attitudes and sources of awareness. *Aust J Public Health*, 1991 (in press).

## ABBREVIATIONS

Abbreviations used frequently in this thesis are listed below:

AHMAC	Australian Health Minister's Advisory Council
BSE	Breast self examination
CI	Confidence interval
CME	Continuing medical education
CSHS	Central Sydney Health Service
DF	Degrees of freedom
GHQ	General Health Questionnaire
GP	General practitioner
HIP	Health Insurance Plan
LGA	Local government area
NHMRC	National Health and Medical Research Council
NHS	National Health Service
NSW	New South Wales
OR	Odds ratio
RR	Relative risk
SES	Socioeconomic status
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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## CHAPTER 1

### INTRODUCTION

Breast cancer is a disease with a high burden of illness in the Australian community. It is the most common cancer in Australian women, accounting for 26 per cent of all female cancers in New South Wales (NSW).<sup>1</sup> It is also the most frequent cause of death in women aged 30 to 60 years.<sup>2</sup> In Australia, 5000 new cases are diagnosed each year, and the annual number of deaths exceeds 2000.<sup>3</sup> The lifetime risk of Australian women developing the disease is estimated to be one in 15<sup>4</sup> and one in 24 will die from it.<sup>3</sup>

Age-standardised breast cancer death rates have changed little in Australia over the past 25 years.<sup>3</sup> The percentage annual change between 1972 and 1982 in female breast cancer standardised incidence rates was negligible at -0.2 per cent.<sup>5</sup> In addition there does not appear to be any change in survival rates for breast cancer patients diagnosed in the period 1982-1986 compared with 1977-1981.<sup>6</sup> Data collected in 1988 in NSW shows the standardised incidence rate to be 68.2 per 100 000.<sup>7</sup>

There are several risk factors associated with breast cancer. First it is much more common in women. The age-standardised mortality from breast cancer in women is 20.2 per 100 000 person years compared with 0.2 for men.<sup>8</sup> Second the

incidence of breast cancer increases with age.<sup>8,9</sup> The age-specific incidence rates per 100 000 increase from 152.7 for women aged 45-49 to 200.6 in women aged 65-69 in NSW.<sup>7</sup> Third there are large geographical variations in breast cancer rates. Incidence rates are high in most industrialised countries (with the notable exception of Japan) and in southern Brazil and Argentina; they are intermediate elsewhere in South America and in eastern and southern Europe; and low in Central and tropical South America, Africa and Asia.<sup>9</sup>

The importance of environmental as compared with genetic factors has been demonstrated in several overseas studies examining the changes in risk in migrant populations.<sup>9</sup> In Australia, breast cancer risk in Italian-born women is much lower than that of Australian-born women, but increases progressively the longer they live in Australia.<sup>10</sup>

Several risk factors specific to the individual have been suggested. These include: reproductive variables (e.g. late age at first pregnancy); body build; oral and injectable contraceptive use; oestrogen replacement therapy; diethylstilboestrol use during pregnancy; dietary fat; alcohol consumption; other lifestyle variables (e.g. cigarette smoking); benign breast conditions; family history; previous history of cancer; radiation; endogenous hormones; mammographic parenchymal patterns; and oestrogen receptors<sup>11</sup>.

Neither the cause nor means of preventing the disease is known<sup>12</sup> and the importance of risk factors remains equivocal.<sup>13</sup> Most known risk factors generally

have modest relative risks, account for only a portion of breast cancer cases, and do not readily lead to preventive measures.<sup>11</sup> This issue is highlighted in the recent report to the Australian Health Ministers' Advisory Council. The report suggests that on present evidence, the only well-established and potentially modifiable risk factors are obesity, nulliparity and a first full-term pregnancy at a comparatively late age. It is estimated that if all women were to reduce their body weight to at or below their ideal weight and to have at least one full-term pregnancy before 25 years of age, about 35 per cent of breast cancers could be prevented completely. The report then notes that expectations of such significant modifications of these risk factors are unrealistic.<sup>14</sup>

The next means of reducing breast cancer mortality is secondary prevention. This refers to detecting breast cancer sufficiently early in its natural history when treatment has a more favourable impact on long-term survival from the disease. There are several screening or early detection methods which have been considered. These include mammography, breast self-examination, physical examination and a variety of other methods (ultrasound, transillumination light screening, thermography, computerised tomography, magnetic resonance imaging and immunological techniques).<sup>14</sup>

Of all these methods it is now generally accepted that mammography is the most effective in reducing mortality from breast cancer.<sup>12,14,15,16</sup> In mammography, a woman's breasts are individually x-rayed while compressed between 2 flat plastic surfaces. One or 2 views (using different orientations) of each breast are taken.

The procedure requires specific technology for taking and processing the x-ray film, and specially trained medical specialists for film reading and subsequent management of cancer cases.

There have been several studies examining the efficacy of mammographic screening in reducing mortality (Table 1.1). The studies are divided into 3 types: randomised trials, non-randomised studies of populations offered screening (population-based studies), and non-randomised studies of individuals accepting screening (usually analysed on a case-control basis).<sup>13</sup> Randomised controlled trials are generally considered the most scientifically rigorous method of hypothesis testing.<sup>17</sup> A major advantage of this design is that it controls for baseline characteristics that affect risk and differ between the treatment groups and which can potentially confound the relationship between exposure and disease. On average not only will all known confounding variables be equally distributed, but so will potential confounders that are unsuspected by the investigator because of limitations of biological knowledge when the trial starts.<sup>18</sup>

The first evidence for the efficacy of screening mammography was provided by the Health Insurance Plan (HIP) of New York randomised trial which used a combination of mammography and physical examination. Ten years after commencement, the breast cancer mortality in the study group was 29 per cent lower than that of the control group. Lower breast cancer mortality in the study group has persisted for 18 years, although the mortality reduction in the screened group relative to the control group has declined to about 21 per cent.<sup>19,20</sup>

Similar results were found in the Two Counties trial which used single-view mammography in a cluster randomised design. The most recent results at 8 years of follow-up show a statistically significant 32 per cent reduction in breast cancer mortality in the study group relative to the control group. There was no difference between the study and control groups in mortality from causes other than breast cancer, indicating that the apparently beneficial effect of mammography was not due to misclassification of cause of death.<sup>21,22</sup>

Results from the Malmö randomised trial were in the same direction as those in the HIP and Two Counties studies. In this trial 29 per cent more women in the study group aged less than 55 died of breast cancer. More women in the study group died from breast cancer in the first 7 years; after that the trend reversed, especially in women aged 55 or over at entry. Overall, women in the study group aged 55 or over had a 20 per cent reduction in mortality from breast cancer. It was concluded that invitation to mammographic screening may lead to reduced mortality from breast cancer, at least in women aged 55 or over.<sup>23</sup>

The Edinburgh study was a randomised controlled trial of screening with physical examination and mammography. At 7 years after entry into the study, the breast cancer mortality reduction in the study group was 17 per cent. This was not statistically significant, even when corrected for socioeconomic status (SES). However, the authors pointed out that the data lacked statistical power and the relatively low attendance rate (61 per cent) may have diluted any possible benefit of screening.<sup>24</sup>



Table 1.1: Studies of breast cancer screening updated to the end of 1990

Study	Screening interval yrs (rounds)	Method M:mammography P:palpation	Age (years)	No. of women in initial screen ( <sup>'000s</sup> ) (%)	Controls	Follow-up (years)	Relative risk (95% CI)	Relative risk in women aged 50 and over at entry (95% CI)
Randomised controlled trials								
HIP <sup>19,20</sup>	1 (4)	M+P	40-64	30 (67%)	31	18	0.79(0.62,0.99)	0.79(0.58,1.06)
Two Counties <sup>21,22</sup>	2-3 (3)	M	40-74	78(89%)	57	8	0.69(0.56,0.88)	0.61(0.44,0.84)
Malmö <sup>23</sup>	1-2 (5)	M	45-69	21(74%)	21	11	0.96(0.68,1.35)	0.79 <sup>a</sup> (0.51,1.24)
Edinburgh <sup>24</sup>	2 (4)	M+P	45-64	23 (61%)	22	7	0.83(0.58,1.18)	0.80(0.54,1.17)
Study with geographical controls								
UK <sup>25</sup>	2 (3)	M+P	45-64	23 (60% Edinburgh)	127	7	0.80(0.64,1.01)	Not published
Studies of screening acceptors								
BCDDP <sup>26</sup>	1 (5)	M+P	35-74	283000 enrolled	-	9	0.80 (0.72,0.87)	0.75(0.67,0.84)
Nijmegen <sup>27,28</sup>	2 (4)	M+P	35+	30 (85%)	-	7	0.48(0.23,1.00)	0.40(0.19,0.84)
Utrecht <sup>29</sup>	1-2 (4)	M+P	50-64	21(72%)	-	7	0.30(0.13,0.70)	0.30(0.13,0.70)
Florence <sup>30</sup>	2.5 (6)	M	40-70	25(60%)	-	8	0.53(0.29,0.95)	0.49(0.26,0.89) <sup>b</sup> 0.24(0.13,0.43) <sup>c</sup>

a) women aged  $\geq 55$

b) women attending a single examination

c) women attending 2 or more examinations

This study also included a non-randomised comparison. At 6 years after entry into the study, the breast cancer mortality rate in the screened group was 20 per cent lower than in the control group. While this fell short of statistical significance ( $P=0.06$ ), the results are compatible with those of the other trials which show that screening for breast cancer reduces mortality.<sup>25</sup>

Statistically significant reductions in breast cancer mortality as a result of mammographic screening were also observed in 4 case-control studies in Nijmegen,<sup>27,28</sup> Utrecht,<sup>29</sup> Florence<sup>30</sup> and the United States<sup>26</sup>. Due to possible biases in case-control studies of screening, the magnitude of the reduction in breast cancer mortality may be overestimated in these studies.<sup>13</sup>

The various studies give different estimates of the reduction in mortality due to breast cancer screening. However, they all show a reduced risk of dying from breast cancer resulting from screening in women over 50.<sup>13</sup> Evidence for the efficacy of screening for women under 50 years remains unclear.<sup>15,16</sup> A recent meta-analysis shows that when data from the randomised trials (HIP, Two Counties, Malmö and Edinburgh studies) are analysed as a whole, a 22 per cent reduction in breast cancer is found (95% CI: 0.10-0.33). If the analysis is restricted to more recent prospective trials in which mammography was the primary method of screening, (Two Counties, Malmö, Edinburgh and the rest of the UK trial), a 19 per cent reduction in breast cancer deaths is found (95% CI: 0.06-0.30).<sup>14</sup>

On the basis of these studies it has recently been re-stated in both Australia<sup>14</sup> and the United Kingdom (UK)<sup>13</sup> that mammography screening can reduce mortality from breast cancer. While the Forrest Report<sup>12</sup> concluded that one could expect mortality reduction in the UK to be at least 30 per cent (i.e. in screened women relative to unscreened women), more recent reviews<sup>13,31</sup> concluded that the mortality reduction may be somewhat less, about one quarter. In Australia, it is estimated that the annual reduction in the number of deaths from breast cancer may range from 13 per cent (with a 55 per cent participation rate) to 23 per cent (with a 100 per cent participation rate).<sup>14</sup>

There continues to be debate, however, about the potential benefits of screening mammography. Skrabanek presents an argument against screening mammography on several grounds. He maintains that the evidence for efficacy is equivocal and that the disadvantages of screening (e.g. false negative mammograms resulting in false reassurance and false positive mammograms resulting in anxiety) are not addressed.<sup>32,33</sup>

A similar argument is presented by Roberts who also points to the problem of lack of successful treatment.<sup>34</sup> An article published by Mitchell in 1987 before the implementation of the Australian program, argued strongly against screening tests becoming a rebate item and expressed concerns about financial costs and personal costs to the woman.<sup>35</sup>

On the basis of the results from overseas studies a national evaluation of breast

cancer screening was commenced in Australia in 1987. In February 1988 the Australian Health Ministers' Advisory Council (AHMAC) created the Steering Committee to oversee and direct the National Evaluation of Breast Cancer Screening Pilot Projects.<sup>14</sup>

The evaluation was conducted by the Screening Evaluation Coordination Unit (SECU) which was established at the Australian Institute of Health. Data were collected from 11 pilot projects, including 3 in NSW, one in Victoria, 3 in Queensland, 2 in Western Australia and 2 in South Australia. They included publicly and privately funded projects operating from fixed sites and mobile vans;<sup>14</sup> in total they served 15 per cent of the 1.4 million women in the 50-69 year age group.<sup>36</sup>

In June 1990 the Steering Committee's report was submitted for consideration. Independently of this in March 1990, the federal Labor Government announced its intention to implement the National Early Breast Cancer Detection Program.<sup>14</sup> Commonwealth funds totalling \$64 million over 3 years were set aside in the 1990-1991 budget for the purpose. The program is being phased in over 5 years. Screening will be available to all women aged 40 and over, although recruitment strategies will be targeted at the 50 to 69 year age group. Services will be provided at minimal or no cost to women and a doctor's referral will not be required.<sup>37</sup>

In June 1990 the NSW Minister for Health announced the NSW initiatives for

breast cancer screening. These included an allocation of \$1 million to be spent on a training centre for radiographers, radiologists and surgeons; the establishment of a planning group to administer service expansion; the establishment of a demonstration assessment centre in a rural area; and the establishment of a screening register within the Central Cancer Registry.<sup>38</sup> In October 1990 the Minister announced the establishment of the State Planning and Co-ordination Unit for Mammographic Screening under the administration of the Cancer Council of NSW.<sup>39</sup> Table 1.2 shows the mammography services which will be included in the NSW initiative. It is intended to introduce a total of 7 programs in the period up to 1992.

Table 1.2<sup>i</sup>

Mammography services due to be implemented up to 1992 in NSW

Location	Assessment Centres	Screening Units
Central Sydney Area Health Service	Rachel Forster Hospital, Redfern	1 fixed site 2 mobile units
Hunter Area Health Service	Mater Misericordiae Hospital, Newcastle	1 fixed site 2 mobile units
New England Health Region	Tamworth Base Hospital	1 fixed site 1 mobile unit at Glen Innes
Western Sydney Area Health Service <sup>ii</sup>	Westmead Hospital	1 fixed site 1 mobile unit
Northern Sydney Area Health Service <sup>ii</sup>	Royal North Shore Hospital	1 fixed site 1 mobile unit
North Coast Health Region <sup>ii</sup>	North Coast Mammography Assessment Centre, Lismore	1 fixed site 1 mobile unit
Eastern Sydney Area Health Service <sup>ii</sup>		1 fixed site at Royal Hospital for Women

<sup>i</sup> Based on Figure 3 Early detection of breast cancer. The New South Wales Mammography Screening Program May 1991.<sup>40</sup>

<sup>ii</sup> Services to commence operating in 1992.

There exist several other Australian policies and initiatives in relation to breast cancer and mammography screening. The Health Targets and Implementation (Health For All) Committee<sup>41</sup> sets out goals and targets based on those from the cancer prevention plan of the Australian Cancer Society (1987). These are in turn iterated by the National Women's Health Policy<sup>42</sup> and include:

reducing the death rate from breast cancer by 25 per cent or more by the year 2000; and increasing participation in breast cancer screening to 70 per cent or more of eligible women by the year 1995.

It should be noted however, that this policy statement does not include age limits. Therefore it is unclear whether the policy refers to all women or women in the eligible age group only.

In June 1990 the following policy of the Australian Cancer Society<sup>43</sup> was released:

The Committee supports the continuation of the pilot programs in Australia and is in favour of an expansion of mammography. We wish to emphasise however that any such expansion must be closely monitored and phased in so as to preserve the high quality which is essential for effective screening.

The policy of the NSW Cancer Council<sup>44</sup> is as follows:

Women over 35 years of age should practise monthly breast self-examination and have a regular clinical breast examination. As it becomes accessible/available, mammographic screening for asymptomatic women aged 50-69 years every two years.

The National Health and Medical Research Council (NHMRC) made the

following statement in June 1989<sup>36</sup> on the introduction of screening mammography in Australia:

Council endorses the current strategy of careful evaluation of pilot projects and staged introduction of mammographic screening in an integrated program of breast health which ensures reliable high quality services that are acceptable to Australian women.

In order for mammographic screening to be successfully implemented in Australia, several key issues must be addressed. These include: the optimum frequency for screening; quality control of all steps of screening and subsequent management; availability of skilled personnel and highly specialised multidisciplinary services and development of services which meet the needs of disadvantaged groups such as ethnic women and women living in rural areas.<sup>36</sup>

In particular, there are several behavioural research issues which need to be examined. These include effective strategies to recruit women to screening; factors which predict whether a woman attends for screening; women's reasons for attendance and non-attendance; and sources of awareness about screening among attenders. It is also necessary to examine the psychosocial impact of implementing screening on the community as a whole and on attenders in particular. It is specifically important to examine the impact on those women who receive false positive results. The following will provide a brief overview of these issues.

The impact of mammography screening on mortality is heavily dependent on the proportion of women who are recruited to screening.<sup>14</sup> A number of overseas

studies have achieved high participation rates. For example, in the Health Insurance Plan of New York study, 65 per cent of those invited appeared for an initial examination.<sup>45</sup> More recently, the Swedish Two Counties trial obtained a compliance rate of 89 per cent.<sup>21</sup>

These programs, however, make use of recruitment strategies which are not generalisable to an Australian setting. The Swedish programs identified women from central population registers and then sent individual letters of invitation.<sup>21,23</sup> The New York study individually invited women registered with the Health Insurance Plan of Greater New York.<sup>45</sup> It is clear that there is a need to develop and evaluate strategies which will encourage Australian women to attend for screening.

It is important to identify those factors which predict attendance for screening in order to develop effective recruitment strategies. Predictors can be divided into the following categories: demographic factors; family and personal history of breast disease; use of medical services; other health behaviours; and attitudes, knowledge and beliefs about breast cancer and mammography.

A recent review indicates several sociodemographic predictors of attendance. First there is an inverse association between age and attendance whereby younger women are more likely to attend. Second, most studies that include socioeconomic status variables have found a positive association with attendance. Results in relation to marital status have been inconsistent with some studies



finding no association between marital status and attendance and others reporting that married women are more likely to attend.<sup>46</sup> Recent studies have also found that women from non-English-speaking and minority groups are less likely to attend.<sup>47,48</sup>

Several studies examine whether women with a personal or family history of breast disease are more likely to attend for screening. Reviews of the research indicate that the evidence is equivocal.<sup>46,49</sup> For example, while several studies have found that women with a family history of breast cancer are more likely to attend for screening,<sup>50,51</sup> others have found no association.<sup>52</sup> In a recent Australian study intention to attend for screening was not significantly related to whether a woman had had breast cancer, had a breast lump, had a family history of breast cancer or knew someone with breast cancer.<sup>53</sup>

Several studies have identified a positive relationship between attendance and use of medical services and other health behaviours. In the HIP study attenders were more than twice as likely as non-attenders to have used an HIP physician during the year prior to screening.<sup>54</sup> A more recent study indicated that non-attenders tended not to participate in the health care system as readily as participants.<sup>55</sup> Similarly, another study found that those who had received gynaecological care in the previous year were 5 times more likely to attend for screening.<sup>56</sup>

Recent reviews indicate that attendance for mammography is associated with

other self-reported health behaviours such as Pap tests and dental checks.<sup>46,49</sup> A recent Australian study found that having had a Pap test within the last 2 years predicted whether a woman intended to attend for screening.<sup>53</sup> In comparison, another study concluded that there was a low probability of women who carry out one type of preventive health behaviour, including mammography screening, carrying out another.<sup>57</sup>

Two theories of health behaviour have been used in order to examine the relationship between knowledge and attitudes, and attendance. While these theories have been useful in identifying attitudes which predict attendance, they fail to explain a large proportion of the variance in participation.

The Health Belief Model predicts that a person's decision to undertake a health action is a function of the person's beliefs along 4 subjective dimensions: perceptions of the severity of the condition which the action will help prevent; the individual's perceived susceptibility to the condition; beliefs in the benefits (efficacy) of the action; and the perceived barriers to (costs of) performing the action.<sup>58</sup> The dimension of perceived self-efficacy or confidence in the ability to carry out the recommended health action has recently been added to the model.<sup>59</sup>

The Health Belief Model also asserts that a 'cue to action' must occur to trigger the appropriate health behaviour. This cue can be 'internal' (e.g. perceptions of bodily states) or 'external' (e.g. interpersonal interactions, mass media messages). While it is assumed that diverse demographic, personality, structural, and social

factors can affect an individual's health motivations and perceptions, these variables are not seen as directly causal of compliance.<sup>a</sup>

The model has been applied to address a wide range of self-protective behaviours including participation in genetic screening and immunisation, breast self-examination, and patient adherence to therapeutic regimens.<sup>b</sup> In particular, the various components of the model have been found to have explanatory and predictive value in relation to several preventive behaviours. For example, several studies have obtained positive correlations between relatively higher levels of perceived susceptibility and compliance with recommendations for: breast, cervical and other cancer screening; dental problems; and immunisation.<sup>a</sup> Similarly, other studies have found a positive relationship between perceived efficacy of the preventive health action and compliance with: immunisation, tuberculosis and cancer screening, and preventive dental visits.<sup>a</sup>

A study by Calnan applied the model in an attempt to explain attendance at mammographic screening. Results indicated that the overall variance explained by the model was only about 15 per cent. The best discriminators for attendance were intention to attend, use of the dentist for check-ups, previous use of mammography (negative relationship) and previous Pap smear. Several beliefs were identified as useful predictors after intention to attend was excluded from the analysis. These were perceived vulnerability to cancer and the perceived costs and benefits of screening.<sup>60</sup>

a) Becker MH, Malman LA. Sociobehavioral determinants of compliance with health and medical care recommendations. *Medical Care* 1975;13:10-24.

b) Mullen PD, Hersey JC, Iverson DC. Health behaviour models compared. *Soc Sci Med* 1987;24:973-981.

A more recent study also used the Health Belief Model to identify leading independent predictors of breast cancer screening. These included recommendation by a medical provider, gynaecological care in the previous year and having a regular source of gynaecological care, having ever had a diagnostic mammogram and perceiving mammography as safe enough to have annually.<sup>56</sup>

The Theory of Reasoned Action assumes that people make rational choices based on the available information when deciding whether or not to engage in behaviour. According to the theory the most important determinant of behaviour is the person's behavioural intention. This is determined by the person's attitude toward the behaviour and the social normative influence of people who are significant in his or her life. Attitude is determined by the person's specific beliefs about outcomes or characteristics of the action, weighted by the values the person places on those outcomes or characteristics. Social norm is determined by the person's perceptions of others' support for the behaviour, weighted by the person's motivation to comply.<sup>61,62</sup> Previous research indicates the applicability of this theory in explaining behaviour in relation to breast cancer screening.<sup>63</sup>

Generally speaking, this theory assumes that people intend to perform a behaviour when they view it positively and when they believe that important others think that they should perform it. The stronger people's intentions are to engage in a behaviour, the more successful they are expected to be. The relative importance of the attitudinal and normative factors may vary from one person to another.<sup>146</sup>

The theory was developed explicitly to deal with purely volitional behaviours. The Theory of Planned Action extends the earlier theory and was developed to account for those instances when a person has a strong intention but fails to attain the behavioural goal. An example is the smoker who intends to quit but is unable to do so. The Theory of Planned Action postulates that in addition to attitudes and subjective norm, the degree of success will also depend on perceived behavioural control. The more resources and opportunities individuals think they possess, the stronger the intention and the more likely they are to be successful.<sup>146</sup> The Theory of Reasoned Action has been applied to a variety of health related behaviours including family planning, substance abuse, weight loss, exercise, immunisation, and hypertension.<sup>c</sup>

A recent study applied an expanded Theory of Reasoned Action to predict mammography participation. This expanded theory included affect associated with having a mammogram, previous use of mammography and facilitating conditions such as transport and daily schedule. This model explained 39 per cent of the variance in women's intentions and 20 per cent of the variance in participation behaviour. Attitude, affect, subjective norm, and facilitating conditions were found to be all significantly associated with participation.<sup>62</sup>

Several other studies have examined the significance of knowledge and attitudes in determining whether a woman participates in screening. First, the importance of knowledge is equivocal. An early study found that similar proportions of attenders and non-attenders knew the chance of a breast lump being cancer and were aware of the benefits of early diagnosis and treatment.<sup>52</sup> More recently, Bastani, Marcus and Hollatz-Brown found that knowledge about guidelines significantly predicted whether a woman had a mammogram.<sup>51</sup> Similar results have been found in other studies.<sup>55,64</sup>

A recent Australian study suggests that some types of knowledge are more important than others. This study indicated that while knowledge about breast cancer risk was not associated with intention to attend, women who were knowledgeable about treatment had stronger intentions. However, knowledge was not included in the final regression model which predicted attendance.<sup>53</sup>

Several attitudes have been identified as important in predicting attendance.

These include: personal susceptibility,<sup>53,55</sup> belief in the possibility of curing cancer,<sup>65</sup> and concern with cancer.<sup>54</sup> Conversely non-attenders are more likely to believe that 'one shouldn't go looking for trouble', are more afraid of cancer being found and are more anxious about what would happen if cancer were found.<sup>52</sup>

Additional factors identified by Australian research as important include: the intensity of thought about getting breast cancer; a belief that early detection is extremely desirable; a belief that screening mammograms are accurate; a belief that health is controlled by chance; and a feeling of personal susceptibility to breast cancer.<sup>53</sup>

Related to the issue of the psychological predictors of attendance is that of the psychological profile of attenders in comparison with the general population. Results from a British study indicated that women attending for screening did not differ from women in the general population on measures of extroversion or neuroticism. From these results it was concluded that attendance at screening is prompted by legitimate concern about breast disease, rather than exceptional personality characteristics or neurotic anxiety.<sup>66</sup>

Several studies address the reasons that women provide when asked why they had decided to attend or not attend for screening. In an early study structured interviews were conducted with non-attenders. The main reasons for not attending included practical difficulties, a lack of interest or belief that screening

was irrelevant, fear and 'not feeling like it'.<sup>52</sup> Another study found that the major reasons for non-attendance were practical considerations, fears, worries and anxieties, and a belief that screening was unnecessary.<sup>67</sup>

A qualitative study by Leathar and Roberts indicated that many women claimed that day to day considerations prevented them from attending. Preventive behaviour such as attending for screening also appeared to offer nothing positive in any tangible sense but only the negative possibility of finding something wrong. Other issues included not seeing the issue as important and embarrassment.<sup>68</sup> Similar results have been reported by Calnan.<sup>69</sup>

A Canadian study examined why women were reluctant to participate in screening. This study was conducted after a series of problems such as physician reluctance and media attention on radiation hazards threatened the program. The main reason provided by women for not participating was 'regular check-ups with the family doctor'; surprisingly, only 13 per cent of the sample mentioned fear of x-rays.<sup>70</sup> In fact while some studies have found radiation concern to be a barrier to screening,<sup>51,71</sup> others have not found this to be the case.<sup>72</sup>

Several other studies have also addressed the issue of reasons for non-attendance.<sup>48,72,73,74,75,76</sup> These studies show consistently that there are 2 major reasons that women give for not participating. First, there is the perceived lack of need which covers responses like: mammogram is not necessary, never thought about it, no problem, and no one in the family has breast cancer. These

responses account for between 10 per cent<sup>73</sup> and 67 per cent<sup>72</sup> of reasons for non-attendance. The other major reason for non-attendance was lack of physician recommendation which accounted for between 12 per cent<sup>72</sup> and 56 per cent<sup>73</sup> of reasons.

Related to reasons for non-attendance is the issue of practical barriers to attendance. Recent reviews of the research indicate that while logistic barriers such as cost and transportation have been found to be important barriers in some studies, others have found no association with attendance.<sup>46,49</sup>

Australian research indicates the average out of pocket expenses per attendance at a government funded mammography screening program to be approximately \$20. It was concluded that further work to determine whether these personal costs are a deterrent to attendance would be useful.<sup>77</sup> Another recent Australian study found that intention to attend for screening was related to perceived ease of getting to the hospital and a subjective familiarity with the hospital.<sup>53</sup>

A British study examined women's reasons for attending for screening in response to an invitation from a general practitioner (GP). The reasons most frequently given for accepting the invitation were connected with the idea that it was a good opportunity. These were closely followed by issues such as the chance for reassurance or peace of mind, and concern for health.<sup>49</sup> Similar results have been found by another study.<sup>69</sup> Leather and Roberts identified 2 basic reasons for attending regularly, including the rational consideration that



early diagnosis minimises the consequences of serious illness and the need for reassurance.<sup>68</sup> Another study also identified the need for reassurance as the major reason for attending.<sup>52</sup>

The expression 'source of awareness' refers to how attenders report finding out about the existence of the screening service. Sources of awareness are generally regarded as prompts for attendance rather than reasons for attendance. A recent study conducted in conjunction with the research for this thesis indicated that the major sources of awareness about a mobile screening van were 'seeing the van' (34 per cent), GP (18 per cent), print media such as posters, pamphlets and letterbox drops (12 per cent) and newspaper (11 per cent).<sup>78</sup> Other Australian and overseas studies have found that radio and television, friends and newspapers are important sources of awareness.<sup>79,80</sup>

There are two major ways that the implementation of mammography screening may impact at the community level. First, campaigns aimed at increasing attendance may have other beneficial outcomes such as improving knowledge and attitudes about breast cancer and screening. Australian research indicates that while the majority of women have favourable attitudes to screening and intend to participate, there are several areas of knowledge which need addressing in order that women make informed decisions about screening. Major areas of concern are lack of knowledge about lumpectomy as a treatment option and increased breast cancer risk with age.<sup>81</sup>

Conversely, the promotion and implementation of mammography screening may have negative consequences such as engendering morbid concern about breast cancer. While several researchers have expressed reservations on these grounds,<sup>32,33,68,82</sup> there is a dearth of research examining this issue.

Related to the issue of community knowledge and attitudes are those of GPs. While a GP referral is not required for women participating in the national screening program, numerous studies have identified GPs as major motivators for women attending screening.<sup>56,83,84,85</sup> A random survey conducted in Sydney prior to the implementation of screening indicated that while GPs held favourable attitudes to screening, there were deficits in knowledge. For example only 25 per cent of the sample knew that breast cancer increases with age.<sup>86</sup> A follow-up study conducted 2 years later found that although there were some improvements, GPs continued to lack knowledge about important aspects of breast cancer and mammography.<sup>87</sup>

Studies examining the impact of screening on participants have found attendance to be a positive experience which does not lead to an increase in psychiatric morbidity. Recent research on attenders of the Canadian National Breast Screening Study indicated that only 5 per cent reported anxiety after screening. Participation in the program was a positive experience for 93 per cent.<sup>88</sup> Similar results have been found in other studies.<sup>85</sup>

Importantly, other studies have found that participation does not lead to

increased psychiatric morbidity.<sup>89,90</sup> One study compared women who had attended for screening (and received a normal result) with a matched random sample from the community. Only 8 per cent of attenders said that screening had made them more anxious about developing breast cancer. Thirty-eight per cent said they were more aware of the disease since screening, but they regarded this as advantageous. In addition there were no differences in the General Health Questionnaire case rates before or after screening. The study concluded that screening does not appear to increase the prevalence of psychiatric morbidity.<sup>89</sup>

Inviting women to screening however, has some negative impact. Several studies indicate that women who respond to an invitation to screening are made to feel anxious or worried after receiving the invitational letter. In one study, 30 per cent of women reported being made to feel anxious after receiving an invitational letter.<sup>89</sup> A study by Eardley and Elkind found 12 per cent of women responding to an invitation had some negative reaction such as shock, fear or nervousness, although almost half of this group also had some positive response.<sup>49</sup>

All of these studies were conducted with women who had responded to the invitational letter and attended for screening. It is also important to consider the impact on those women who receive an invitational letter and do not respond. The study by Maclean, Sinfield and Klein indicated that women who did not respond reported that the invitation caused them considerable anxiety.<sup>67</sup>

One group of attenders who warrant particular consideration are those who receive a false positive result. In the Australian pilot projects around 6-13 per cent of women screened were in the false positive category in the first round of screening.<sup>14</sup> Studies examining this issue indicate elevated anxiety in women with false positive results; however, there does not appear to be an effect on subsequent adherence for screening.<sup>90,91,92</sup>

This thesis addresses 3 of the issues in the preceding discussion. These are recruitment strategies to encourage women to attend, the psychological impact of implementing screening in an Australian community, and the impact on those attenders who receive a false positive mammogram. The research for the thesis was conducted in relation to one of the 3 pilot projects set up in NSW, the Breast X-Ray Programme of the Central Sydney Area Health Service (CSHS). The aims of this pilot project<sup>93</sup> are:

'to establish a free mammographic screening service for women over 45 years of age living in the CSHS, and to evaluate aspects of introducing a wider mammography screening service into Australia. The latter included methods of recruitment, costs of a screening service, ways to provide training for radiologists and radiographers, and strategies for assessment/work-up of screen-detected abnormalities.'

This program commenced screening in February 1988 and is the first population-based pilot mammography screening project in Australia. Funds for the program's service aspects are provided by the NSW Government. The research studies are supported by funds from the Commonwealth Government. The

target population is 43000 women aged 45 to 70 years living in the CSHS area. This area covers the inner western suburbs of Sydney.<sup>93</sup>

The program including its assessment centre, is based at Rachel Forster Hospital in Redfern, Sydney. Screening is conducted from a mobile van equipped with a dedicated mammography screening unit. Two mammographic views are taken per breast. Exposed films are transferred back to the assessment centre for development. Appointments for screening are not necessary and women do not require a referral for screening. The service is free of charge at point of delivery. The planned re-screening interval is 3 years<sup>93</sup>.

The starting point for the thesis was a survey conducted prior to the implementation of the Breast X-Ray Programme in 1987. The aim of the study was to describe knowledge and attitudes towards breast cancer and screening mammography, and personal susceptibility and morbid concern about breast cancer. It also aimed to determine the predictors of attitudes to screening mammography and perceptions of personal susceptibility, which were considered to be the major determinants of future attendance. Telephone interviews were conducted with randomly selected Sydney women aged 45 to 70. A response rate of 56 per cent was obtained.<sup>81</sup> The conceptual format for the interview questionnaire was derived from the Health Belief Model<sup>59</sup> and the Theory of Reasoned Action.<sup>61</sup>

Results indicated that while the majority of women had some experience with

breast cancer, knowledge about which age groups were most at risk and treatment alternatives was limited. For example, only 6 per cent of women knew that the incidence of breast cancer increases with age and only 22 per cent were aware of lumpectomy as a treatment alternative. Only about half the sample had heard about screening mammography before the survey. However, when a simple explanation was given, 79 per cent expressed a favourable attitude toward it. Only 22 per cent thought of themselves as being personally susceptible to breast cancer; the proportion was lower in women over 60 than in those in their 40s. Morbid concern about breast cancer was rare. Overall 26 per cent of women said they were quite or very concerned about any exposure to radiation which was involved in having mammography.<sup>81</sup>

Attitudes and perceptions of personal susceptibility were not associated with knowledge about risks of breast cancer. However, having a favourable attitude and a lack of concern about radiation were associated with previously having heard about screening mammography. Women speaking a language other than English at home and from households where the main income earner was in an unskilled occupation were least likely to have heard of screening mammography.<sup>81</sup>

The thesis addresses the research questions in the following order. Chapter 2 describes the research methods. Chapter 3 describes the sociodemographic characteristics of the target group and the program's promotional campaign in the CSHS area between February 1988 and December 1989. The chapter also

describes the target group and campaign conducted in the Drummoyne Local Government Area (LGA) which was chosen as a 'mini-target area' within the CSHS area in which to concentrate recruitment efforts. In addition the messages being promoted about screening in the print and electronic media have been monitored in order to aid in the interpretation of study results.

Chapter 4 examines the impact of the campaign in the CSHS area in terms of positive outcomes such as increased knowledge, and negative consequences including increases in morbid concern about breast cancer. This chapter also deals with the question of whether there has been an additional impact or 'dose-response' in the Drummoyne LGA which was selected as a 'mini-target area' within the CSHS area in which to intensively recruit women to screening. Chapter 5 explores the issue of how to most effectively recruit women to screening. This question is addressed in the context of the Drummoyne mini-target area.

Chapter 6 considers the effect of being recalled for further tests following attendance for screening. This chapter compares women who are recalled and subsequently prove not to have a malignancy (i.e. the false positive group) with those who are not recalled. 'Concluding remarks' consider the implications of the research findings for the implementation of mammography screening in Australia, and suggest areas of research which the current study indicates as worthwhile.

## CHAPTER 2

### RESEARCH METHODS

Data about women's knowledge, attitudes and concerns were collected by telephone surveys. The following methodology is common to all the surveys described in this thesis. Details of the sampling strategies used for each study objective will be described in the appropriate chapter.

#### 2.1 DATA COLLECTION

Telephone interviewing was chosen as the most cost-effective method of data collection. An Australian study has shown that there is little difference in the validity and reliability of data obtained via telephone and face-to-face interviewing.<sup>94</sup> Other studies have also considered whether mode of survey (i.e. telephone interview, self-administered questionnaire, and face-to-face interviews) affects data quality. Hochstim<sup>d</sup> found that the 3 strategies were practically interchangeable in terms of response rates, comparability of findings and validity of responses. Locander, Sudman and Bradburn<sup>e</sup> found no differences in terms of response distortion (i.e. the proportion of responses known to be false from objective records).

d) Hochstim J. A critical comparison of three strategies of collecting data from households. *J Am Statist Assoc* 1967;62:976-89.

e) Locander W, Sudman S, Bradburn N. An investigation of interview method, threat and response distortion. *J Am Statist Assoc* 1976;71:269-75.



Similarly, Siemiatycki<sup>f</sup> found no differences between mail and telephone modes in terms of item omission (approximately 5 per cent each). However, so called sensitive questions (e.g. family income and Medicare number) were more readily answered in mail than in telephone or home interview (face-to-face) modes.

A recent Australian Bureau of Statistics survey indicates that 90.2 per cent of households in NSW have a telephone.<sup>95</sup> This suggests that the recruitment method obtains a reasonably representative sample of the target population.

## **2.2 PROCEDURE**

The procedure was based on that used in the original survey conducted prior to the implementation of the Breast X-Ray Programme.<sup>81</sup> Data were collected using the centralised telephone interviewing field team of the Public Policy Research Centre, a commercial market research organisation specialising in

f) Siemiatycki J. A comparison of mail, telephone, and home interview strategies for household health surveys. *Am J Public Health* 1979;69:238-45.

government and academic research. The only exception to this was for survey 2 data in Chapter 5 which were collected by a research assistant from the Department of Public Health, University of Sydney (Jane Hunt). All interviews were conducted by women. Interviewers were fully briefed by members of the research team. A manual giving general information on the survey procedures and detailed information on each question was provided for each interviewer and formed the basis of the briefing session (Appendix 1). Interviewing was monitored throughout the course of the study in order to ensure ongoing reliability.<sup>96</sup>

Interviewers identified themselves as being from the Public Policy Research Centre, conducting an interview on behalf of the Medical Faculty of the University of Sydney. (The research assistant introduced herself as being from the Medical Faculty at Sydney University). When gaining consent for interview, the study was described as being about women's health rather than about breast disease or cancer. Data for the studies in Chapters 4 to 6 were collected together and interviewers were blind as to the study group that women were in.

Up to 8 calls were made to each telephone number at different times of the day and night in an attempt to contact all eligible women. Calls were made on both weekends and weekdays with a minimum delay of 4 hours between attempts. If there was more than one eligible woman in a household, the woman with the most recent birthday was selected for interview.

Arrangements were made with the Royal Prince Alfred Hospital Interpreter Service and other qualified health care interpreters to recontact women identified as non-English-speaking from the initial contact. Again only women interpreters conducted interviews. Interpreters were given briefing sessions similar to those for the English-speaking interviewers. Interviews were then conducted in the appropriate language. They introduced themselves as being from either The Medical Faculty of the University of Sydney or the Interpreter Service at Royal Prince Alfred Hospital. The survey was advertised on ethnic radio in several community languages.

### **2.3 INTERVIEW SCHEDULE**

The interview schedule (Appendix 2) was devised by researchers at the Department of Public Health (Jill Cockburn, Les Irwig). It was formulated on the basis of a review of the literature on women's knowledge and attitudes about breast cancer and mammography screening, interviews with health professionals and colleagues, and women attending a Sydney breast clinic.

While, the overall conceptual format for the schedule was derived from the Health Belief Model<sup>59</sup> and the Theory of Reasoned Action,<sup>61</sup> it was not the intention of the questionnaire to include all components of these models. In addition, it was not the intention of the research to examine interrelationships between the different components of the models, as this had been done in previous research.<sup>81</sup> Rather, the overall aim of the research was to apply the questionnaire in order to address further research questions.

In particular, the following components of the Health Belief Model were addressed in the questionnaire: perceived susceptibility (questions 29 to 36), and beliefs about benefits and barriers (questions 28 a to g). Similarly, the main component of the Theory of Reasoned Action to be addressed by the questionnaire was that of attitudes towards screening mammography. Intention to attend for screening was excluded as it was considered inappropriate to ask women residing outside the central Sydney area about their intention to attend

a service which was not readily available to them during the study period.

The schedule took approximately 15 to 20 minutes to complete. Most of the items were asked as closed-ended questions with the interviewer reading out a series of possible responses. Where appropriate, the majority of questions had the order of response categories rotated in order to prevent response bias.

Measurements obtained and the variables that were subsequently derived are listed below. Appendix 2.1 shows all the scales that have been constructed. In order to aid analyses, ordinal variables (such as responses to the 5-point Likert attitudinal scale) were dichotomised.

### **Knowledge**

The schedule contained 9 questions which assessed women's knowledge. Three questions assessed knowledge of the risks of getting breast cancer. Women were asked what they thought the most common type of cancer was amongst women of their age group; about how many women will get breast cancer at some time in their lives; and which age group is at greatest risk of developing breast cancer. Answers to these questions were combined to give a score out of 3 for each woman. A woman was regarded as knowledgeable if she received a score of 2 or 3.

Knowledge about survival rates was addressed by asking women to reply true or false to the following question: 'With early treatment, most women with breast cancer live for 10 years or more after diagnosis.' In order to examine knowledge about treatment, women were asked the open-ended question: 'What other treatments do you know of for breast cancer?' Up to the first 4 responses were coded.

In order to determine if women had heard of screening mammography, they were asked if they knew of any ways which can be used to detect breast cancer in the early stages. If they replied that they did not, they were asked if they had

heard of a mammogram. All women were read a description of a mammogram and a screening mammogram and then asked if they had heard of screening mammograms.

### **Attitudes**

Six questions examined women's attitudes towards screening procedures. Items were given in the form of a complete statement and a 5-point Likert<sup>97</sup> response format ranging from 'strongly agree' (Point 1) to 'strongly disagree' (Point 5) was used to indicate extent of agreement. Some items were negatively worded and the scores were reversed before data analysis. Examples of the items include: 'It is very important for women of your age to have screening mammograms' and 'A person with breast cancer is better off if she doesn't know it'. The scale had a Cronbach's alpha of 0.71 indicating adequate internal consistency. The average score for each woman over all 6 questions was calculated. These were subsequently dichotomised into favourable (an average score less than or equal to 2.5) and unfavourable attitudes (an average score of greater than 2.5). Women were also asked if they believed that when a woman is called back for further tests after a screening mammogram, it means that she has breast cancer. In addition they were asked if they were concerned about any exposure to radiation.

### **Prior experience**

Women were asked whether they had ever had breast cancer; had ever had a lump in the breast; had a mother, sister or daughter with breast cancer; or knew someone else with the condition. Women were also asked if they had ever had a mammogram; whether it was for screening or symptoms or both; and where they had had it done. The remainder of women were asked if they knew anyone who had had a screening mammogram.

### **Amount of information 'seen or heard' about screening mammograms**

Two questions asked women if they had 'seen or heard' any information about screening mammograms in the last 6 months and the amount of information to which they had been exposed. Response categories were 'quite a lot', 'a moderate amount', 'only a little', and 'none'.

### **Perceived susceptibility to breast cancer**

One question asked women to estimate their chances of getting breast cancer in the future, compared to other Australian women of their age. Women were also asked if they had been concerned over the past 12 months about the possibility that they may get breast cancer, about the degree and frequency of their concern and whether they had spoken to anyone about it, including a doctor or other

health professional. A combined variable called 'perceived personal susceptibility' was subsequently created; this variable labelled as susceptible all those who expressed concern and/or regarded their risk as greater than average. This was done for two reasons. First, there was a highly significant association between the 2 variables ( $P$  for trend  $<0.0001$ ); and second, the 2 variables related similarly to other variables. Therefore it appeared that they were measuring the same underlying construct. Women were also asked if they had spent any time in the last 12 months thinking about breast cancer and the frequency with which they had thought about it.

#### **Morbid concern about breast cancer**

A scale was used to measure any psychological morbidity which might be associated with concern about breast cancer. Women who responded that they had been concerned about the possibility of getting breast cancer were read a list of 11 symptoms. They were asked to indicate on a three-point scale how much concern about breast cancer may have contributed to them experiencing these symptoms over the previous 12-month period. The possible responses were as follows: 'Not at All' (1); 'A Little' (2); and 'A Lot' (3). Examples of the types of symptoms are 'having sleep disturbances', 'feeling anxious', 'being unable to concentrate' and 'feeling less hopeful about the future'. These 11 symptoms came from 3 sources: relevant items from the 30-item General Health Questionnaire (GHQ),<sup>98</sup> concerns expressed by women interviewed at the breast clinic and the clinical experience of the research team. The scale had a

Cronbach's alpha of 0.94, indicating very high internal consistency. A mean score was obtained and dichotomised into not morbidly concerned (i.e. those who said they were not concerned plus those with a mean score of 1) and morbidly concerned (mean score > 1).

### **Sociodemographic information**

**Age:** Women were asked their age; if they refused to answer this they were read age categories from which to choose (45-49, 50-54, 55-59, 60-64, 65-70 years). While these include one 6-year age group (65-70), for ease of explanation, the data are referred to as 5-year age groups. Although women aged 45 to 70 years were targeted by the screening program, Australian Bureau of Statistics data used for comparison purposes, were frequently more readily available for women aged 45 to 69. It is stated where the data refers to women aged 45 to 69 (as opposed to 70 years).

**Education:** Women were asked for the highest level of education they had completed. Their responses were allocated to the following categories: No Schooling; Some Schooling; Finished Primary; 1-4 Years Secondary; 5-6 Years Secondary; Some Tertiary; Certificate/Diploma; Degree. Women who were interviewed by interpreters were asked 'How many years of schooling have you had?' The interpreter then allocated the response to one of the above categories based on her knowledge of her country's school system.

**Occupation:** Women were asked to name the occupation of the main income earner in their household and to give a position or job title for that person. If the main income earner was retired, unemployed or a student, the respondent was asked for the last occupation. Both the occupation and the position or job title were recorded verbatim. Responses were later coded on the Daniel scale of occupational prestige.<sup>99</sup>

Those occupations or descriptions which were not included on the scale



were assigned the score of the nearest appropriate occupation. The scale was treated in a categorical format as only the integer part was used and not the decimal part. Examples of occupations which fall into each of these categories are presented in Table 2.3.1. Those responses which were not included on the occupational prestige scale, such as 'housewife' or 'unemployed', were excluded from the analyses.

Table 2.3.1: Examples of occupations from the Daniel scale of occupational prestige<sup>99</sup>

Category	Examples of occupations (prestige score)
Highest prestige category 1	Judge (1.2) Orthopaedic specialist (1.5) Church leader (1.8)
2	Orthodontist (2.1) Airline pilot, domestic (2.4) Accountant (2.9)
3	Author (3.5) Art dealer (3.7) Columnist, media (3.6)
4	Teacher, infant school (4.0) Piano tuner (4.8) Payroll clerk (4.9)
5	Picture framer (5.0) Panel beater (5.5) Clerical assistant (5.9)
Lowest prestige category 6	Removalist, furniture (6.0) Metal polisher (6.4) Road sweeper (6.7)

### **Language**

Women who were interviewed in English were asked 'Do you speak a language other than English at home?' Possible responses were either 'yes' or 'no'. This is the same question as used in the 1986 Australian census.

Three additional questions were asked of women at the repeat survey conducted in 1990:

#### **Knowledge of the screening van's existence**

Women who had not attended the screening van were asked a series of 3 questions to determine if they were aware of its existence. The questions were structured so as to become more general; the woman was asked if she knew where she could have a screening mammogram, if she knew whether there was a screening van in her area, and if she knew of any areas of Sydney where women of her age are eligible to have free screening mammograms.

#### **Practice of Breast Self-Examination (BSE)**

Women were read a description of breast self-examination. They were then asked if they had examined their breasts in the last 12 months and if so how often.

## **Time of Most Recent Mammogram**

Women were asked when they had their most recent mammogram.

### **2.4 RESPONSE RATES**

The following formula was used to calculate response rates. The total number of interviews were calculated as a proportion of those eligible women who were contacted plus 30 per cent of those households where it could not be established if an eligible woman was present. This figure was based on the Australian Bureau of Statistics estimate of the number of households in the Sydney area containing a woman aged 45 to 70 years.

$$\frac{I}{(I) + (RW) + (RP) + (A) + (N) + (FW) + (30\% O + AM + E + RH + F)}$$

The codes listed below refer to the results obtained for each telephone number after the final call was made.

#### **Major codes used to obtain response rates**

I (Interview): Interview with an eligible woman.

RW (Refusal by woman): Eligible woman refused to be interviewed.

RP(Refusal by Proxy): Telephone respondent refused on behalf of an eligible

woman.

A (Call back): Household had an eligible woman and requested to be called at another time.

N (No callback possible): Household had an eligible woman but no callback was possible because the woman was incapacitated or not available during the study period.

FW (Foreign woman): eligible woman was not able to be interviewed in English.

O (Out): No response.

AM (Answering machine).

E (Engaged).

RH (Refusal by Household): Telephone respondent refused before it could be ascertained if there was an eligible woman in the household.

F (Foreign household): telephone respondent did not speak English and it was not possible to ascertain if there was an eligible woman in the household.

As indicated in Chapters 4, 5 and 6, response rates ranged from 46 per cent to 68 per cent, which is not as high as desired. Inevitably this will produce bias. However, as noted previously, an attempt was made to minimise bias by introducing the survey to respondents as being concerned with women's health generally, rather than breast cancer specifically.

## **CHAPTER 3**

### **DESCRIPTION OF THE PROMOTIONAL CAMPAIGN**

This chapter will report on the following:

1. The sociodemographic characteristics of women in the Central Sydney Health Service (CSHS) Area and the Drummoyne Local Government Area (LGA);
2. The promotional campaign of the Breast X-Ray Programme and attendance rates;
3. Print and electronic media coverage of breast cancer and mammography.

#### **3.1 SOCIODEMOGRAPHIC CHARACTERISTICS OF THE CSHS AREA AND THE DRUMMOYNE LGA**

The CSHS area is located in the inner western suburbs of Sydney. It covers approximately 75 square kilometres and comprises 8 Local Government Areas. The eligible population aged 45 to 69 years comprises 43345 women. From September 1988, the Drummoyne LGA comprising postcodes 2046 (Five Dock) and 2047 (Drummoyne), was chosen as a mini-target area within the wider screening area in which to concentrate recruitment efforts. This LGA was chosen because it consists of only 2 postcode areas allowing for easier

enumeration of attenders. In addition it has the advantage of being well-defined geographically in that it is located on a peninsula overlooking the Parramatta River and has a major arterial road as its southern boundary. The LGA covers an area of approximately 3.5 square kilometres; 59 per cent of eligible women reside in the Five Dock postcode area and 41 per cent live in Drummoyne. The eligible population aged 45 to 69 years comprises 4322 women.

Data in the following tables were obtained from the 1986 Australian Bureau of Statistics. The data refer to women aged 45 to 69 for whom information is readily available. As shown, the sociodemographic characteristics of the Drummoyne LGA are very similar to those of the CSHS area as a whole.

### Age

Each 5-year age category comprises about 20 per cent of the overall sample (Table 3.1.1).

Table 3.1.1: Distribution of age in women in the CSHS area and Drummoyne LGA

Age group (Years)	CSHS (n = 43345) %	Drummoyne LGA (n = 4322) %
45 to 49	22.0	20.3
50 to 54	19.8	19.3
55 to 59	20.5	20.9
60 to 64	20.2	21.4
65 to 69	17.5	18.0
TOTAL:	100.0	100.0

## Language spoken at home

About one-third of women speak a language other than English at home. The main non-English language is Italian (Table 3.1.2).

Table 3.1.2: Distribution of language spoken at home by women aged 45 to 69 in the CSHS area and Drummoyne LGA

Language spoken at home	CSHS (n = 43347) %	Drummoyne LGA (n = 4319) %
English only	63.1	69.1
Italian	9.8	19.4
Greek	7.4	4.4
Chinese	2.6	1.0
Spanish	1.4	0.5
Russian	1.0	0.1
Maltese	0.7	0.6
Macedonian	0.2	0.05
Other	13.0	4.2
Not stated	0.8	0.7
TOTAL:	100.0	100.0

## Aboriginal and Torres Strait Islander origin

Overall, 0.4 per cent of the target population in the CSHS area, and 0.05 per cent in the Drummoyne LGA, are of Aboriginal or Torres Strait Islander origin.

## Proficiency in English

In the CSHS area, 18 per cent of the target population speak English 'not well' or 'not at all'; in the Drummoyne LGA the figure is 13 per cent. Overall, of those who speak a language other than English at home, about 40 per cent speak it 'not well' and 10 per cent speak it 'not at all' (Table 3.1.3).

Table 3.1.3: Distribution of proficiency in English in women aged 45 to 69 in the CSHS area and Drummoyne LGA

Proficiency in English	CSHS (n = 43347) %	Drummoyne LGA (n = 4319) %
Speaks English only	60.8	67.7
Uses other language:		
Speaks English very well	6.9	6.2
Speaks English well	12.1	12.0
Speaks English not well	14.1	11.2
Speaks English not at all	3.6	1.3
Not stated	2.6	1.6
TOTAL:	100.0	100.0

## Trade or other qualifications since leaving school

About 70 per cent of women in the CSHS area and Drummoyne LGA have no qualifications since leaving school (Table 3.1.4).



Table 3.1.4: Distribution of trade or other qualifications since leaving school in women aged 45 to 69 in the CSHS area and Drummoyne LGA

Level of qualification	CSHS (n = 43318) %	Drummoyne LGA (n = 4325) %
Degree or higher	2.5	2.2
Diploma	2.4	2.5
Trade	2.0	2.7
Other	10.6	13.9
Not qualified	71.0	68.9
Not stated	11.5	9.7
TOTAL:	100.0	100.0

### Age left school

About 60 per cent of women left school at ages 14 to 16 (Table 3.1.5).

Table 3.1.5: Distribution of age left school in women aged 45 to 69 in the CSHS area and Drummoyne LGA

Age left school	CSHS (n = 43318) %	Drummoyne LGA (n = 4325) %
Less than 13 years	10.9	11.1
13 years	3.8	3.7
14 years	21.9	21.9
15 years	25.0	29.3
16 years	13.3	15.3
17 years	6.1	6.9
18 years	4.3	2.9
19+ years	2.6	1.7
Still at school	0.04	0.05
Did not go to school	4.4	2.3
Not stated	7.7	4.8
TOTAL:	100.0	100.0

### Hours worked in the main job held last week

Overall, 32 per cent (13969/43345) of women in the CSHS area and 37 per cent (1616/4322) of those in the Drummoyne LGA are in paid employment. In both areas, about two-thirds of those in the workforce worked 35 hours or more (Table 3.1.6).

Table 3.1.6: Distribution of hours worked by women aged 45 to 69 in the CSHS area and Drummoyne LGA

Hours worked in last week	CSHS (n = 13969) %	Drummoyne LGA (n = 1616) %
None	3.3	3.2
1-24	20.0	21.0
25-34	11.2	12.1
35-39	31.8	30.9
40	19.1	18.8
41+	11.4	11.3
Not stated	3.2	2.7
<b>TOTAL:</b>	<b>100.0</b>	<b>100.0</b>

## Occupation of the main job held last week

Of those who provided an occupation, the majority are employed as clerks and labourers or related workers (Table 3.1.7).

Table 3.1.7: Distribution of occupation in women aged 45 to 69 in the CSHS area and Drummoyne LGA

Occupation	CSHS (n = 13969) %	Drummoyne LGA (n = 1616) %
Managers and administrators	5.0	6.1
Professionals	9.1	8.7
Para-professionals	5.5	5.7
Tradespersons	4.0	4.4
Clerks	29.3	35.1
Personal service and sales	12.2	14.1
Plant and machine operators	8.2	7.3
Labourers/related workers	23.9	15.7
Not stated	2.8	2.8
Total	100.0	100.0

### **3.2 PROMOTIONAL CAMPAIGN OF THE BREAST X-RAY PROGRAMME**

The campaign aimed to inform women of the van's existence and to provide information on which to make informed decisions about attendance. It specifically targeted women aged 45 to 70 years. Within this group, it aimed at all sectors of the community including those from non-English speaking backgrounds and lower socioeconomic groups.

In order to describe the strategies implemented as part of the promotional campaign, the screening program's health education officer kept ongoing logs listing the recruitment strategies. These were later collated by the author.

#### **Attendance rates and the promotional campaign in the CSHS Area**

In the first 18-month period between February 1988 and August 1989 (for which data is readily available), 15 per cent of the target population aged 45 to 70 years were screened.<sup>93</sup>

The promotional campaign consisted mainly of generalised recruitment strategies aimed at the community as a whole. These strategies were planned by the program's health education officer, in consultation with the researcher. A major strategy comprised placing the mobile screening van (Figure 3.2.1) in highly visible locations (Table 3.2.1). These included main shopping areas and

thoroughfares. In the period February 1988 to December 1989, the van moved 24 times between 16 different major sites. The van was open for screening in each location for a period ranging from 5 to 46 days. Screening was conducted during week days and Saturday mornings. For a limited period the van was open until about 7pm on Thursday and Fridays.

Table 3.2.1: Screening van operation from February 1988 to December 1989

Major Locations	Time period	Approx number of screening days
<b>1988</b>		
Rachel Forster Hospital, Redfern	29 Feb - 5 June	28
Royal Prince Alfred Hospital, Camperdown		5
Leichhardt Marketplace		15
Strathfield Mall		20
Main road, Marrickville	6 June - 25 Dec	41.5
Leichhardt Marketplace <sup>i</sup>		26.5
Main road, Five Dock <sup>A</sup>		45.5
Drummoyne Civic Centre <sup>A</sup>		6.5
<b>1989</b>		
Drummoyne Civic Centre <sup>B</sup>	9 Jan - 5 March	9
Main road, Abbotsford <sup>B</sup>		7.5
Balmain Hospital		4.5
Main road, Balmain		15
Glebe shops	6 March - 4 June	19
Main road, Annandale		11
Drummoyne Civic Centre <sup>C</sup>		12.5
Main road, Five Dock <sup>C</sup>		6.5
Main road, Burwood	5 June - 1 Oct	24
Ashfield Mall		25.5
Concord Hospital		5.5
Strathfield Mall		19.5
Main road, Burwood	2 Oct - 24 Dec	19.5
Drummoyne Civic Centre <sup>iiD</sup>		12
Main road, Five Dock <sup>D</sup>		12
Birkenhead Point Shopping Centre <sup>D</sup>		6

i) Commenced screening Saturday mornings.

ii) Including 2 days per week with extended week day hours.

A) Visit 1 to the Drummoyne LGA.

B) Visit 2 to the Drummoyne LGA.

C) Visit 3 to the Drummoyne LGA.

D) Visit 4 to the Drummoyne LGA.

Figure 3.2.1 Breast X-Ray Programme Screening Van



The van spent a median of 40.5 days in each LGA in the central Sydney area, ranging from 6 days in Concord to 118 days in Drummoyne (Table 3.2.2). In total the screening van spent 26 screening days per 1000 women in the Drummoyne LGA.

Table 3.2.2: Number of van screening days in each LGA in the CSHS area

LGA	Number of screening days	Number of screening days per 1000 women
Ashfield	25.5	5
Burwood	43.5	12
Concord	5.5	2
Drummoyne	117.5	26
Leichhardt	91.0	15
Marrickville	41.5	5
Strathfield	39.5	10
Sydney City (Western Sector)	33.0	4

The majority of strategies in the CSHS area were aimed at the community as a whole (Table 3.2.3). As screening was only available to women in the CSHS area, promotion did not extend to wide-scale electronic and print mass media. Advertisements (Figure 3.2.2) and articles (Figure 3.2.3) were placed in local newspapers, magazines and community newsletters. Posters and pamphlets (Figure 3.2.4) were distributed to a wide range of locations including shops, libraries, clubs and worksites (particularly in pay packets). They were mainly in English, but where possible Greek and Italian inserts (the main non-English languages) were included. Letters and information packages were also sent to several places including clubs, community groups, and parish priests. Ongoing

information was sent to GPs including information packages containing posters, pamphlets, van locations and maps. Other strategies included local radio broadcasts, including ethnic radio announcements; visits and personal contacts with local groups; the use of volunteers to network among the community; shopping centre promotions and announcements at local meetings.


Table 3.2.3: Promotional strategies of the Breast X-Ray Programme in the CSHS Area

Strategy	Number (where applicable)		
	February 1988- December 1988	January 1989- December 1989	Total
<b>Advertisements and Articles</b>			
Local newspapers and magazines	23	47	70
Newsletters	1680	8600	10280
<b>Other Written Material</b>			
Information packages	232	110	342
Additional posters	115	415	530
Additional pamphlets	5205	4755	9960
Letters, memos	570	1120	1690
Letterbox drops	5370	38450	43820
<b>General Practitioners</b>			
Visits**	15	45	60
Letters	1040	1645	2685
Information packages	1630	35	1665
Additional posters	5	25	30
Additional pamphlets	2015	195	2210
<b>Other Strategies</b>			
Local radio broadcasts	2	12	14
Health education talks (including conferences and talks to health professionals)	40	27	67
Visits, contacts to shops, clubs, community groups and media representatives	35	45	80
Volunteer training sessions and community meetings	Nil	4	4
Shopping centre and other promotions	5	7	12
Video, loudspeaker announcements	1	30	31

\* Numbers are approximate. \*\* Excludes GP visits made for individualised strategies.



Figure 3.2.2 Examples of newspaper advertisements for the Breast X-Ray Programme




**BREAST X-RAY  
PROGRAMME**

## HAVE A FREE BREAST X-RAY

The Breast X-Ray Programme is a State Government-funded programme which offers free breast x-rays to women from 45 to 70 years who live in the Central Sydney Area Health Service suburbs (inner western suburbs). Changes which may suggest early breast cancer can be seen on a breast x-ray when still too small to feel or notice.

Our mobile van has moved from Marrickville and is now located on the upper level of the carpark at Marketplace shopping complex in Marion St., Leichhardt.

Please ring 699-5441 for more details



**BREAST X-RAY  
PROGRAMME**

## Esame gratuito al seno

Il Breast X-Ray Programme è un programma sovvenzionato dal governo statale, che offre un esame radiologico al seno gratuito per le donne di età compresa tra i 45 ed i 70 anni, che vivono nei sobborghi del Central Sydney Area Health Service (Inner western suburbs). Attraverso i raggi X si possono rilevare cambiamenti al seno, che altrimenti non potrebbero essere né visti né sentiti al tatto e che in futuro potrebbero portare al cancro.

Il nostro furgone da Marrickville si è trasferito a Leichhardt ed è ora situato al piano superiore del parcheggio nel complesso commerciale Marketplace, di Marion Street.

Per ulteriori informazioni, telefonare  
al 699 5441

## Best bet to beat breast cancer

Until medicine comes up with a way of preventing breast cancer in women, the next best thing is detecting it early with a breast X-ray called a mammogram.

This can identify tiny cancers when they are still too small to be felt by a woman or her doctor. Breast cancer — which affects one in 15 women and is more common in the over-45s — is much easier to treat at an early stage.

In fact the death rate in Sweden has been reduced by an impressive 60 per cent, thanks to a regular screening programme available to women over 40. Mobile X-ray vans go from area to area and the women are sent a personal invitation to visit the van.

The programme is so familiar to Swedish women that 90 per cent of over-40s turn up for a check at regular intervals (every one to two years, depending on their age), as routinely as they visit their dentist.

Now some Sydney women have the same chance to "visit the van" just as the Swedes do.

The Mammography Screening programme based at Rachel Forster Hospital in Redfern, has a mobile unit visiting the following areas from 8.30am to 4pm on weekdays: Leichhardt (outside Market Town) until May 9 and Strathfield (outside Strathfield Plaza) from May 11-30.

The van will also visit Marrickville, Ashfield, Drummoynes and Burwood at dates to be fixed.

To be eligible for a free mammography, women must be over 45 and live in the area covered by the Royal Prince Alfred Hospital and the Area Health Service.

### Privacy

The X-ray takes about 15 minutes and is done in complete privacy by a team of caring female radiographers. Appointments are not necessary.

But if you live outside the area and would still like a mammogram, it will cost you \$66 to have both breasts X-rayed. A medicare rebate of \$56.10 is only available if you have a referral from your doctor.

An interesting thing about mammograms is that X-rays show a delicate pattern of breast tissue and fine blood vessels unique to each person.

This is why the National Health and Medical Research Council and the Australian Cancer Society recommend all women have a routinely baseline mammogram done at the age of 40.

This can then be used for comparison with future mammograms, making it easier to pick up any suspicious changes.

If you would like more information on the location of the mobile van, ring the NSW Cancer Council, 264 8888.

Results of the test are posted directly to you and, if you wish, to your doctor.

Figure 3.2.4 Breast X-Ray Programme pamphlet

# **BREAST CARE**

## **Have a free Breast X-ray**

**For Women 45 to 70 years  
and living in the  
Inner Western Suburbs.**



## Attendance rates and the promotional campaign in the Drummoyne LGA

In total 48 per cent of the target population aged 45 to 70 had been screened after the van's final visit during the campaign. The overall attendance rates by the end of each visit (including women who had attended the van when it was outside the Drummoyne LGA) were: 26 per cent for the first visit; 10 per cent for the second visit, 7 per cent for the third visit and 5 per cent for the last visit. Women from non-English speaking-backgrounds were just as likely to attend as women from English speaking-backgrounds. Older women from English speaking-backgrounds were less likely to attend, whereas no age trend existed for women of non-English speaking-backgrounds. Sampled attendance data of women from English speaking-backgrounds showed that women with higher levels of education and additional qualifications since leaving school were more likely to attend screening. Women who were employed were just as likely to attend as those who were not in the workforce.<sup>100</sup>

The promotional campaign in the Drummoyne LGA was more intensive than that in the CSHS area. As shown in Table 3.2.2 the time spent in this LGA was more than double the median time spent in each of the other LGAs. The screening van visited the LGA on 4 separate occasions over the campaign period. On each occasion, the van was parked at 2 or 3 locations (Table 3.2.1: visits are noted by A, B, C, D). On the first occasion the van was in the LGA for a period of about 4 months. The 3 subsequent visits lasted a period of about a month each.

In order to compare the intensity of this campaign with that in the CSHS area, the relative exposure of each strategy being implemented in the LGA compared with the rest of central Sydney was calculated (Column 7 Table 3.2.4). The denominators for these calculations were the number of eligible women in each area. As can be seen the majority of strategies were much more likely to have been implemented in Drummoyne. For example, local newspaper and magazine articles were 2.5 times more likely to have been implemented in Drummoyne; shopping centre and other promotions were 7 times more common in Drummoyne. In addition to the strategies aimed at the community as a whole, several strategies were aimed at individual women. These were intended to have an incremental effect on attendance over the generalised interventions. The main interventions were: written invitations and verbal recommendation by the GP; invitations for friends; and invitations from the service using the electoral roll. These strategies were evaluated separately by several small scale trials which are reported in detail in Chapter 5. In total 14 per cent (615/4322) of women aged 45 to 69 were targeted with these strategies.

Table 3.2.4: Generalised promotional strategies of the Breast X-Ray Programme in the Drummoyne LGA

Strategy	Number <sup>i</sup> (where applicable)					
	Visit 1	Visit 2	Visit 3	Visit 4	Total	Relative Exposure <sup>ii</sup>
<b>Advertisements and Articles</b>						
Local newspaper	3	3	2	5	13	2.5
Local magazines	-	1	-	-	1	""
Newsletters	505	100	-	-	605	0.6
<b>Other Written Material</b>						
Information packages	150	-	103	6	259	31.2
Additional posters	77	25	50	100	252	9.1
Additional pamphlets	400	305	150	1530	2385	3.2
Letters	160	210	-	13	383	2.9
Letterbox drops	1900	12000	-	12000	25900	14.4
<b>General Practitioners</b>						
Visits <sup>iii</sup>	5	5	1	15	26	7.7
Letters	50	50	-	-	100	3.9
Information packages	25	16	-	-	41	0.2
Additional posters	-	-	20	-	20	20.0
Additional pamphlets	-	100	120	500	720	4.8
<b>Other Strategies</b>						
Local radio broadcasts	-	8	-	1	9	18.0
Health education talks	3	1	2	4	10	1.8
Visits, contacts to shops, clubs, community groups and representatives	-	1	-	70	71	78.9
Volunteer training sessions and community meetings	-	-	2	2	4	00
Shopping centre and other promotions	-	-	1	4	5	7.1

i) All numbers are approximate.

ii) Relative exposure Drummoyne versus CSHS area excluding Drummoyne.

iii) Excludes GP visits made to discuss individualised strategies.

### **3.3 MEDIA COVERAGE OF BREAST CANCER AND MAMMOGRAPHY**

In addition to the strategies initiated by the Breast X-Ray Programme, women were also informed by messages from the print and electronic mass media. In order to observe these messages, a media monitoring firm monitored the Australian print and electronic media for the campaign period.

#### **Print media coverage**

Articles on breast cancer, breast screening and mammography were collected on a monthly basis. Monitoring covered: metropolitan newspapers in all Australian states (e.g. the Sydney Morning Herald in NSW and the Age in Victoria), AAP Wire Service, Sydney suburban newspapers (eg: the Liverpool Leader), trade and technical journals (e.g. Australian Family Physician), news magazines (e.g. Time Australia), women's magazines (e.g. Australian Women's Weekly) and special interest magazines (e.g. Australian Society).

Each article was coded for the tone of the message being given about mammographic screening and the degree to which the Breast X-Ray Programme was mentioned. The tone of the messages were coded as positive, negative or neutral from the perspective of woman who would be eligible for screening in Australia, i.e. aged over about 45 years. Included in the neutral category were those articles which discussed aspects of breast cancer other than the issue of screening, or merely mentioned breast cancer in narratives which focused on

other issues.

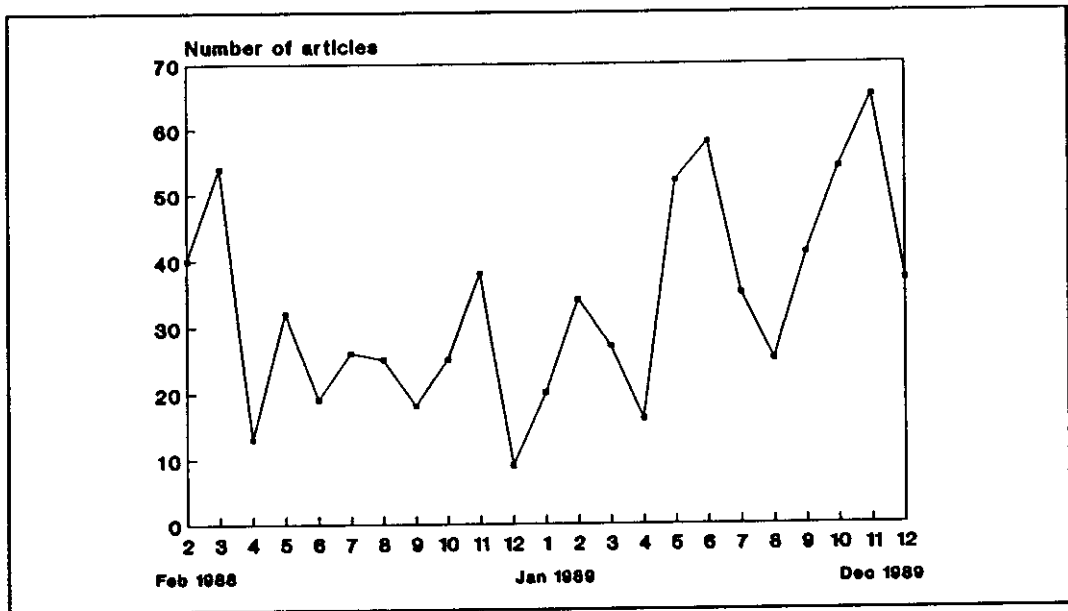
The articles were coded by 3 independent coders. Training sessions were held for groups of coders in order to attain acceptable levels of inter-coder reliability. At each training session, approximately 20 articles were randomly selected to check that inter-rater agreement was at least 90 per cent.

In the period from February 1988 to December 1989, 770 articles were published on breast cancer and mammographic screening. Figure 3.3.1 shows the distribution of these articles by month. Only 8.6 per cent (N=66) mentioned the Breast X-Ray Programme. This small proportion is partly accounted for by the fact that the program's promotional activities were confined to the inner western suburbs of Sydney. Screening was limited to women in a specific target area, promotion did not extend to wide-scale electronic and print mass media.

The majority of articles were positive or neutral in their discussion of mammographic screening. About half of the articles (48.2 per cent) were coded as neutral because they principally discussed aspects of breast cancer other than the issues of mammography and screening; for example, risk factors, incidence, treatments, or merely mentioned breast cancer in narratives which focused on other issues. The rest of the articles were principally positive (47.3 per cent) and only 4.5 per cent were coded as negative. In only 2 months throughout the campaign period were more than 5 negative reports published.



Figure 3.3.1: Breast Cancer and mammography screening in the print media February 1988 to December 1989



### Electronic media coverage

Media monitoring data were obtained from the New South Wales State Cancer Council on television and radio reporting about breast cancer and mammographic screening. Monitoring was restricted to news and current affairs programs and other selected telecasts. Coverage included Sydney and national radio and television stations. There were a total of 71 radio segments and 29 television segments during the campaign period. Overall a third of the segments dealt with screening.

## CHAPTER 4

# THE PSYCHOSOCIAL IMPACT OF MAMMOGRAPHY SCREENING ON AN AUSTRALIAN COMMUNITY

### 4.1 INTRODUCTION

While previous research has carefully considered the effects of mammographic screening on population mortality and morbidity,<sup>15,16</sup> there has been little examination of the impact of mass mammography on community knowledge, attitudes and psychological morbidity. There have been several investigations of the effect of attendance at screening on the psychological status of participants.<sup>88,85,89,90</sup> In addition several studies have compared the psychological profiles of attenders and non-attenders.<sup>46,49</sup> However, there have been few studies examining the impact of mammography programs on the psychological health of all women in the target population, including non-participants.

It is important that studies examining the impact of mammographic screening include non-participants because it is feasible that those who choose not to attend are at most risk of developing psychological morbidity. There is evidence that women who accept an invitation to screening but do not attend are more likely to report health problems, particularly sleep problems and social isolation.<sup>101</sup> Other research indicates that women who decline an invitation to attend a breast screening clinic report that the invitation caused them

considerable anxiety.<sup>67</sup>

### **Major ways that the implementation of mammographic screening can impact on the community**

The major way in which a mammography screening program might influence community perceptions is as a consequence of the process by which the service is advertised and promoted in the community. As the effect of mammography screening is critically dependent on attendance rates, Australian screening programs have been developing promotional campaigns to inform and encourage women to attend. These include community based promotions such as displays and lectures in shopping centres, schools, local councils and women's groups; print and electronic mass media; involvement of GPs; posters, pamphlets and letterbox drops; personal letters to women; and promotion in other health facilities such as Family Planning Clinics and health centres.<sup>14</sup>

As described in Chapter 3 the Breast X-Ray Programme has mainly used generalised strategies supplemented by small-scale strategies aimed at individual women. The Drummoyne Local Government Area (LGA) has been targeted as a mini-target area in which to concentrate recruitment efforts. Promotional campaigns implemented by overseas programs range from the individualised approaches used in Sweden and the United Kingdom to mass media campaigns favoured in the USA. These are described in more detail in Chapter 5.

In addition to influencing behaviour with regard to screening, such campaigns might also be expected to have other measurable effects. These may include beneficial outcomes such as increased knowledge about breast cancer, and more favourable attitudes towards mammographic screening and early detection. A recent study examined the impact of a mass media campaign designed to increase Pap smear usage among NSW women. While there were no detectable improvements in attitude, small improvements in several areas of knowledge were evident.<sup>102</sup>

Perhaps more importantly, the promotion and implementation of a mammography screening program may have negative consequences. It is possible that in some individuals, the campaign may create morbid concern about health and unrealistic and inaccurate perceptions about personal susceptibility to the development of breast cancer. This is an undesirable outcome in itself, in that it may have a detrimental effect on the quality of life for the individual involved. It may also have more far-reaching consequences for community health. Undetected psychological morbidity has been associated with over-utilisation of health services<sup>103</sup> and the ordering of unnecessary medical tests.<sup>104</sup>

The issue of anxiety caused by screening has been discussed in the literature and even mentioned as a reason why screening mammography should not be universally implemented.<sup>67</sup> For example, Skrabanek<sup>105</sup> has warned that screening may increase the levels of 'cancerophobia' and anxiety in women. This fear has

also been expressed by Maguire<sup>82</sup> and Leather and Roberts.<sup>68</sup> It is particularly important to monitor levels of concern and personal susceptibility as they are predictors of participation,<sup>53,54,55</sup> and consequently some screening programs may highlight these factors in their promotional campaigns in order to increase attendance.

### **Research examining the psychosocial impact of mammographic screening**

There are 2 broad categories of research which should be addressed when considering the psychosocial impact of mammographic screening on the community. First, there is the issue of community knowledge, attitudes and concerns prior to the implementation of screening programs. These are useful to review as they give an insight into baseline perceptions before the implementation of promotional activities and identify those areas which may be amenable to change. Second, there is the issue of how these are in turn modified by the implementation of screening.

Several Australian studies address baseline knowledge and attitudes before the implementation of screening. While studies use different question formats and are not directly comparable, some conclusions can be drawn from the AHMAC report.<sup>14</sup> Data from community samples indicate that 68 per cent to 81 per cent believe that breast cancer screening is worthwhile. In addition 47 per cent to 64 per cent report an intention to have a mammogram. A quarter to a third of women identify 'not knowing enough about mammograms' as a

perceived barrier to attendance.

The investigation which forms the starting point for this chapter is the first published Australian study to examine baseline knowledge and attitudes in relation to screening mammography.<sup>81</sup> Data have also been collected in the South West Statistical Division<sup>106</sup> and Cannington in Western Australia,<sup>107</sup> Victoria<sup>53</sup> and the Hunter Valley in New South Wales.<sup>108</sup> All studies used random community samples, except the Hunter Valley study which used a randomly selected sample of participants in previous research. The age range for the studies was 45 to 70 years. In addition a recent national survey of cancer related beliefs among a random sample of women aged 16 years and over included mammography among its outcome variables.<sup>109</sup>

The following broad observations can be made. First, knowledge of mammography ranges from 56 per cent in the South West area<sup>106</sup> to 70 per cent in Cannington.<sup>107</sup> In the Australia wide survey 77 per cent of women had ever heard of a mammogram<sup>109</sup> compared with 78 per cent in the Sydney study.<sup>81</sup> Second, the majority of women reported an intention to attend; this ranged from 55 per cent in the Hunter<sup>108</sup> to 86 per cent in Cannington.<sup>107</sup> While the Sydney study did not measure intention to attend, 79 per cent of women expressed a favourable attitude to screening after a brief description was read to them.<sup>81</sup>

An area of concern identified by several studies was lack of knowledge about increased risk with age. For example, in the South West area,<sup>106</sup> Cannington<sup>107</sup>

and Sydney<sup>81</sup> studies, the majority of women (63 per cent, 65 per cent and 94 per cent respectively) identified the main age at risk to be less than 60 years. Knowledge about lumpectomy has also been shown to be low. In the Sydney study 22 per cent of women mentioned lumpectomy as a treatment<sup>81</sup>; in the Western Australian studies about a third of women mentioned lumpectomy or mastectomy and about 15 per cent specifically mentioned lumpectomy.<sup>106,107</sup>

Baseline knowledge and attitudes have also been addressed in several overseas studies.<sup>47,64,68,72,73,76,110,111,112,113,114,115,116,117,118,119,120</sup> All of these studies, except those by Leathar and Roberts<sup>68</sup> and Schechter, Vanchieri and Crofton<sup>76</sup> which used focus groups, applied quantitative methods such as telephone and personal interviews and self-report questionnaires. Two major shortcomings of this research are the use of convenience and patient and client samples which limit generalisability,<sup>64,72,110,111,112,113,116,117,119</sup> and the inclusion of women as young as 18 years who are at low risk.<sup>112,114,115,116,117,118</sup>

The following broad generalisations can be made from studies which include random community samples.<sup>73,114,115,118</sup> First between 30 to 40 per cent of women are aware that breast cancer increases with age.<sup>72,118</sup> Knowledge about lumpectomy ranges from a very low 1 per cent<sup>115</sup> to 13 per cent.<sup>118</sup> The proportion of women who have heard about mammography ranges from about 50 per cent<sup>114</sup> to a very high 96 per cent.<sup>73</sup>

There have been no published studies examining the impact of mammographic

screening in Australia on community perceptions in relation to mammographic screening and breast cancer. One study has examined the effectiveness of a health education campaign about breast cancer and breast self-examination (BSE) conducted by the Anti-Cancer Council of Victoria. During a 12-month public education campaign, a population of over one million women was encouraged by television advertising and local doctors to practice regular BSE. Results showed several improvements in knowledge and attitudes, including awareness of BSE, confidence in ability to do BSE and the belief that only 'one in 10 breast lumps is cancer'.<sup>121</sup>

Several overseas studies have examined the impact of promotional campaigns and particular shortcomings of these can be noted. First, some studies have been limited to participants only. For example, one descriptive study surveyed women following attendance at the 1988 Connecticut Breast Cancer Detection Awareness Campaign. Women were recruited via a brief mass media campaign. Having an enhanced awareness that a baseline examination was due was cited as a reason for obtaining a screening mammogram.<sup>75</sup> Another Danish study compared patients' attitudes toward mammography in 1981 and 1984 following news coverage of a 1983 conference on screening. Shortcomings of this study include ill-defined sample selection and lack of statistical testing.<sup>122</sup>

Other studies have used before and after designs. However, some of these have small sample sizes (e.g. N=49 to N=156) and are restricted to small scale interventions not comparable to the intervention implemented by the Breast X-



Ray Programme.<sup>123,124</sup> Other studies are aimed at patient groups as opposed to being community based.<sup>125</sup> A relatively early study by Waters and Nichols examined women's knowledge about breast cancer and their attitudes to the disease before and after a public education campaign which encouraged the early reporting of breast symptoms. While the campaign had no significant effect on levels of knowledge, there were significant increases in the proportion of women who disagreed that it is pointless to think about breast cancer.<sup>120</sup>

More recently, surveys before and after a pilot program in the Chicago area showed a decrease in the proportion of women reporting fear of radiation (from 49 per cent to 25 per cent) and a similar decrease in the proportion of women who believed that BSE was sufficient for the early detection of breast cancer.<sup>126</sup>

Two community based studies currently in progress in the USA warrant attention. The first is that of Morisky, Fox, Murata and Stein.<sup>46</sup> This study uses a quasi-experimental design to test the impact of the Community Mammography Project on women in the Greater Los Angeles Area. Baseline levels of knowledge, awareness, attitudes and beliefs about breast cancer and breast cancer screening behaviour have been collected via a telephone survey in Spanish and English. Intervention activities are being driven by baseline results and include community presentations, networking with influential others, newspaper advertisements and programs for primary care physicians. The follow-up survey was due to be conducted in 1990.

Criticisms of the study include the fact that interviews were conducted on women who were 35 years and older, and consequently includes those at lower risk. Second, it is unclear whether the study will be able to examine possible negative impacts on the community including increased psychological morbidity in relation to breast cancer and screening.

The second investigation in progress is being conducted in 10 community areas in Chicago. Data on knowledge, attitudes and behaviour were collected at baseline in 1989 and subjects were due to be followed-up in 1991. The intervention is aimed at a population which is almost all black and among the poorest in the city. It includes education and outreach in the community and education and recruitment in publicly funded clinics. Again it is unclear whether the study will be able to examine possible negative effects on the community.<sup>127</sup>

Although there have been investigations of the negative impact of screening, these studies have been limited to participants and particularly the false positive group.<sup>89,90,91,92</sup> While no systematic attempt was made to measure anxiety in the evaluation of the Victorian breast self-examination campaign, anecdotal evidence indicated that no hypochondria or undue anxiety was induced. Only one case of unreasonable fearfulness was reported among the 4296 patients seen after the campaign began. However, this observation was limited to women who responded to the campaign by presenting to GPs.<sup>121</sup> The study by Waters and Nichols<sup>120</sup> also examined the issue of possible negative consequences in a minor way. They reported that the campaign did not 'overdo' the subject of breast

cancer since there was no increase in the percentage of women who thought that the amount of health education about the disease was 'too much and should be reduced'.

### **Role of the mass media**

In addition to the promotional strategies under the control of the screening programs, the community is also informed about breast cancer and screening by the mass media. It is commonly acknowledged that the mass media have significant powers to shape the public's knowledge, attitudes and behaviours.<sup>128,129</sup>

The extent of electronic and print media coverage of breast cancer and mammographic screening in Sydney during the study period has been described in Chapter 3. It is noted that the majority of print media items gave either positive or neutral messages and only 5 per cent of articles were negative. About 9 per cent of articles (N=66) mentioned the Breast X-Ray Programme.

The issue of the portrayal of media messages has been discussed by Baines.<sup>130</sup> She reports that many academic articles find their way into newspapers, television and radio and are not always reliably reported. The overall result may be to induce a belief that much is being done about breast cancer which is therefore encouraging and reassuring. Alternatively the result, in women in particular, may be the promotion of fear and uncertainty. This was particularly the case in the Canadian National Breast Screening Study where adverse publicity on the hazards of radiation was considered partly responsible for falls

in recruitment levels.<sup>70</sup> In contrast, several positive outcomes were noted as a consequence of media coverage of Nancy Reagan's experience with breast cancer screening, including increases in knowledge of risk, attendance for screening mammography,<sup>131</sup> and intention to attend for screening.<sup>132</sup>

### **Study rationale**

There is clearly a need to examine the psychosocial impact of the implementation of mammographic screening on the Australian community. The aim of this study is to examine changes in knowledge, attitudes, experience, perceived personal susceptibility, morbid concern, and the amount of information 'seen or heard' about screening.

The study utilises cross-sectional and longitudinal designs. While the longitudinal design is preferable because it allows for a comparison of the same individuals over time, it may be subject to the 'Hawthorne Effect'. This refers to an 'effect (usually positive or beneficial) of being under study upon the persons being studied'.<sup>17</sup> Because of the experimental conditions (in this case the telephone interview), their performance may be different than it would if they were not subjects.<sup>133</sup> The Hawthorne effect is analogous to the 'reactivity' effect whereby the behaviour of interest is altered by the presence of an observer or recording equipment.<sup>134,135</sup> This effect has been noted in studies of doctor-patient consultations.<sup>136</sup>

Thus the Hawthorne Effect may impinge on the internal validity of the longitudinal study because the action of interviewing women may make them more sensitive to the issue of mammography screening and breast cancer. This may subsequently lead them to modify either their behaviour or self-reporting during the follow-up interview. Because of the Hawthorne Effect a repeat cross-sectional comparison is added whereby the 1987 baseline sample (also used for the longitudinal study) is compared with a new random sample in 1990.

The study also examines whether there has been a 'dose-response relationship' in knowledge, attitudes and concerns in the Drummoyne LGA which has been exposed to additional promotional activities. As noted in Chapter 3 the screening van was in this area for over twice the median amount of time spent in other Local Government Areas in the CSHS area. In addition the recruitment strategies implemented in Drummoyne were more intensive than those conducted throughout the CSHS area. The 'dose-response relationship' refers to 'a relationship in which a change in amount, intensity or duration of exposure is associated with change either an increase or a decrease in risk of a specified outcome'.<sup>17</sup> In order to investigate this effect the following data are compared: the baseline survey conducted in central Sydney; the follow-up longitudinal survey conducted in central Sydney; and a follow-up survey conducted in Drummoyne.

## **4.2 METHODS**

### **4.2.1 Study design and sample**

Two study designs were used, involving a repeat cross-sectional and a longitudinal sample. The first survey was conducted between November 1987 and February 1988 before the implementation of the Breast X-Ray Programme. This survey provided the baseline sample for follow-up in both the cross-sectional and longitudinal studies. It also served as a baseline comparison for a follow-up study from the Drummoyne LGA. It was aimed to survey approximately 600 randomly selected women, 300 in the CSHS area and 300 from the rest of Sydney. A sample of 300 in each area has 80 per cent power to detect as statistically significant at the 0.05 level, a 10 per cent difference between areas if the characteristic occurs in at most 25 per cent of the women overall. For this sample non-business telephone numbers were randomly selected from the most recent Sydney telephone directory (02 area code). Residents of the CSHS area were selected by the first 3 digits of telephone numbers from the area and a subsequent check on whether their address fell within the area boundary. Other telephone numbers were chosen from numbers with prefixes indicating that they were from elsewhere in Sydney.

The second survey was conducted between February and May 1990, 2 years after the program commenced and after 17 per cent of the eligible CSHS population had attended. This survey comprised a repeat survey of the original longitudinal sample and a new cross-sectional sample. In the longitudinal survey it was aimed to re-survey women who originally consented to be followed-up, and who were English speakers or were in one of the 5 main non-English-speaking

groups. These were Greek, Italian, Maltese, Chinese and Russian, and comprised 75 per cent of non-English-speakers.

For the cross-sectional sample it was again aimed to contact 300 women from the CSHS area and 300 from the rest of Sydney. In addition it was aimed to survey 150 women specifically from the Drummoyne LGA. Women from the CSHS area were randomly selected via a more efficient computerised search of the 1986 Australian Bureau of Statistics Census which provided telephone numbers corresponding to the postcodes of the CSHS area. The Drummoyne sample was obtained from a similar computerised search of telephone numbers corresponding to the postcodes of the Drummoyne LGA. For the other metropolitan sample, non-business telephone numbers were randomly selected from the most recent Sydney telephone directory. Telephone numbers were chosen according to the prefix in a manner similar to that for the longitudinal sample. A check of the telephone directories used for surveys 1 and 2 showed that there were no changes in the allocation of number prefixes in the Central Sydney and other metropolitan areas, indicating that this sampling method was similar for both surveys.

#### **4.2.2 Method of data collection**

The method of data collection was as described in Chapter 2. Telephone interviews were sought with women aged 45 to 70 years. In the repeat longitudinal sample, those women who moved residence in the period between

survey 1 and 2, were classified as living in the CSHS area if they had resided in the area at either survey. Thus they were classified as living in central Sydney if they had been exposed to the Breast X-Ray Programme promotional campaign some time between the 2 surveys.

Data were collected using the centralised telephone interviewing field team of the Public Policy Research Centre. Women identified as non-English-speaking from the initial contact were subsequently interviewed by interpreters in the appropriate language. Interviewers were blind as to which study group the respondent was in.

#### **4.2.3 Measurements obtained**

The measurements obtained have been described in detail in Chapter 2. In summary, the following variables were used in this study.

**Knowledge:** risks (knowledge about breast cancer as the most common cancer, incidence and age of greatest risk, overall knowledge of risk); survival rates; early detection procedures, including screening mammography; and treatment.

**Attitudes:** scale measuring benefits and barriers associated with screening procedures; belief that callback for further tests means you have breast cancer; and concern about exposure to radiation.



**Prior experience:** questions about any experience a woman had had with breast cancer, including personal experience, having a relative with the condition or knowing someone else with the condition; and questions about previous experience with mammography, particularly screening mammography.

Amount of information 'seen or heard' about screening mammograms in the last 6 months.

Awareness of the screening van's existence.

**Perceived susceptibility to breast cancer:** these variables included 'perceived personal susceptibility' and whether the women had spoken to anyone about her concern, including a doctor or other health professional.

**Morbid concern about breast cancer:** women who expressed concern were subsequently asked a series of 11 questions about how this concern had affected their daily life.

**Sociodemographic information:** age, educational level, occupation of the main income earner in the household and language spoken at home.

#### **4.2.4 Analyses**

The repeat cross-sectional and longitudinal data were analysed separately.

The cross-sectional data were analysed as follows. The proportions for 1987 and 1990 were compared within each area using chi-square tests for independent proportions; 95 per cent confidence intervals (CI) were calculated for the change in proportions. For the comparison between areas it was necessary to control for possible sociodemographic confounders which had been identified by previous research.<sup>81</sup> A 2-stage modelling procedure was adopted whereby primary model building was undertaken using logistic regression to identify potential confounders, and then additive risk difference models were used to obtain an estimate of change in the outcome variables adjusted for these co-variates.

Logistic regression is frequently employed for the analysis of data where there is a dichotomous outcome variable.<sup>137</sup> The regression coefficients can simply be exponentiated to give an odds ratio (OR). These odds ratios can, under certain circumstances, be considered to be good estimates of relative risk or rate ratios, and interpreted as such.

The principal strategy used for model development was backward elimination. In this process the initial model contains all predictor variables. The least significant is then eliminated and the regression is conducted on the remaining significant variables. The model building process is terminated once the model contains only statistically significant terms (in this case  $P \leq 0.1$ ).<sup>138</sup>

Each outcome variable was modelled as a function of time (survey 1 vs survey

2), area (CSHS vs other metropolitan), time-area interaction and sociodemographic variables. The time-area interaction allows for one area to change at a greater rate than the other.

The computing system GLIM<sup>139</sup> was then used to fit additive risk difference models.<sup>140</sup> This method has the advantage of producing estimates which are absolute differences in risk between 2 groups, rather than the relative differences provided by odds ratios. Absolute differences are useful for public health planning as they can indicate the number of additional occurrences (or the deficit) of the outcome that occur in the group of interest<sup>141</sup>.

However, additive risk models may behave unstably<sup>140</sup>, with potential for making model building difficult and unreliable. For this reason logistic regression was used to identify significant co-variates. Outcome variables were modelled as a function of time, area, time-area interaction and the possible sociodemographic confounders identified by the logistic regression models. These variables were subsequently tested in the risk-difference model and only retained if they met the stricter criterion of  $P < 0.05$ .

The longitudinal data were analysed using the software package SPSS PC<sup>142</sup> to examine both within area change (i.e. CSHS and other Sydney metropolitan) and between area change. For within area change, McNemar's chi-square test for paired proportions<sup>138</sup> was used for dichotomised variables. Categorical variables were dichotomised without knowledge of the frequency distributions within the

two areas. Cut-points were selected by examining the marginal totals of the response categories of each question for the whole sample. For each question the middle category/categories were examined in order to determine if they were closer conceptually to one or the other end of the range of responses. Differences in proportions (with 95% CI)<sup>143</sup> were then calculated as the change in the proportion of women in one category from 1987 to 1990.

In order to examine between area change, 2x2 contingency tables were constructed for only those women who changed categories. The proportions changing in a favourable direction were compared between the 2 areas. The odds ratio was calculated for the change in CSHS area relative to that for the other metropolitan area.

Logistic regression models were performed in order to determine whether it was necessary to adjust for confounders. A model was constructed for each outcome variable which included the co-variates retained for that variable in the cross-sectional analysis. Thus outcome variables were modelled as a function of time, area, time-area interaction and the relevant sociodemographic confounders. Each model was fitted to the sample of women who changed response categories from 1987 to 1990.

It was consequently decided for 3 reasons not to adjust for the co-variates. First, none of the co-variates were significant at the 10 per cent level. Second, when the co-variates were examined for confounding, the odds ratio did not change by

more than 10 per cent. The only exceptions to this were for the following variables: 'Knows survival for breast cancer' (OR changed from 0.65 to 0.51); 'Has heard of mammography screening' (OR changed from 1.08 to 1.89); 'Has a favourable attitude towards screening mammography' (OR changed from 0.57 to 0.49); and 'Knows someone with breast cancer' (OR changed from 0.90 to 1.02). Third, overall it was considered that in no case did it change the estimate of effect. Therefore estimates are presented as unadjusted.

In order to determine if those followed-up for interview for survey 2 were different in any way from those not followed-up, chi-square tests were conducted on each sociodemographic and outcome variable.

## **4.3 RESULTS**

### **4.3.1 Response rates and sample characteristics**

#### **Baseline survey**

In the first survey 628 interviews were conducted, with 285 women in the CSHS area (response rate: 50 per cent) and 343 women from the rest of Sydney (response rate: 55 per cent). Differences in the sociodemographic characteristics of the CSHS area and the rest of Sydney are presented in the following tables (4.3.1.1 to 4.3.1.4) and are adjusted for in the regression models. The only statistically significant non-demographic difference between the 2 areas was in the proportion of women who had heard of mammography ( $X^2=7.15$ ,  $df=2$ ,  $P=0.03$ ). In the CSHS area 72 per cent of women had heard of mammography, including 53 per cent who had heard of screening mammography. In the rest of Sydney, 81 per cent of women had heard of mammography including 58 per cent who had heard of screening mammography.

#### **Repeat cross-sectional survey**

For the second cross-sectional survey, 651 interviews were conducted with 336 with women from the CSHS area (response rate: 46 per cent) and 315 from the other metropolitan area (response rate 47 per cent). The demographic characteristics of the 1987 and 1990 cross-sectional samples are shown in the following tables (4.3.1.1 to 4.3.1.4).

The women were fairly evenly distributed between the 5 age groups, with each age category comprising about one-fifth of the overall sample. The 1990 sample was very similar to that for 1987 (Table 4.3.1.1).

Table 4.3.1.1: Age distribution of women in the 1987 baseline and 1990 repeat cross-sectional samples

Age group (years)	CSHS		Other Metropolitan	
	1987 (n=280) %	1990 (n=326) %	1987 (n=337) %	1990 (n=311) %
45-49	24.6	23.0	22.0	24.8
50-54	19.6	23.3	19.6	23.5
55-59	15.4	19.0	22.6	17.4
60-64	21.8	17.5	17.5	18.0
65-70	18.6	17.2	18.4	16.4
Total	100.0	100.0	100.0	100.0

In the CSHS area the proportion of women who spoke a language other than English at home increased from 30 per cent in 1987 to 39 per cent in 1990. The corresponding proportion for the other metropolitan area was 22 per cent in both time periods (Table 4.3.1.2).

Table 4.3.1.2 : Distribution of language spoken at home in the 1987 baseline and 1990 repeat cross-sectional samples

Language spoken at home	CSHS		Other Metropolitan	
	1987 (n=283) %	1990 (n=334) %	1987 (n=341) %	1990 (n=315) %
English only	69.6	60.8	78.3	78.7
Language other than English <sup>i</sup>	14.1	16.2	11.4	12.4
Interviewed by interpreter <sup>ii</sup>	16.3	23.1	10.3	8.9
Total	100.0	100.0	100.0	100.0

<sup>i</sup> Women who speak a language other than English at home but were interviewed in English.

<sup>ii</sup> Interviewing was done in 14 languages, the most common being Greek and Italian.

The majority of respondents in both time periods and both areas (about 60 per cent) were in occupational prestige categories 3 and 4 (Table 4.3.1.3).

Table 4.3.1.3: Distribution of occupational prestige of main income earner in household in the 1987 baseline and 1990 repeat cross-sectional samples

Occupational prestige of the main income earner	CSHS		Other Metropolitan	
	1987 (n=253) %	1990 (n=317) %	1987 (n=319) %	1990 (n=299) %
Highest prestige categories				
1 & 2	8.7	11.0	15.4	15.1
3	20.2	24.0	25.4	25.1
4	34.4	33.8	36.4	32.4
5	17.8	16.1	11.9	15.4
Lowest prestige category 6	19.0	15.1	11.0	12.0
Total	100.0	100.0	100.0	100.0

About half of the respondents from the other metropolitan area had completed 1 to 4 years schooling, compared with about 40 per cent in the CSHS area. The CSHS sample had a higher proportion of women with only primary level schooling (18 per cent in 1987 and 24 per cent in 1990 compared with 12 per cent in the other metropolitan area) (Table 4.3.1.4).



Table 4.3.1.4: Highest level of education completed by women in the 1987 baseline and 1990 repeat cross-sectional samples

Educational level	CSHS		Other Metropolitan	
	1987 (n=281) %	1990 (n=324) %	1987 (n=336) %	1990 (n=307) %
Primary	18.1	23.8	11.9	11.7
1-4 years secondary	44.5	36.7	56.0	50.2
5-6 years secondary	21.4	16.0	14.6	19.2
Tertiary	16.0	23.5	17.6	18.9
Total	100.0	100.0	100.0	100.0

### Follow-up longitudinal survey

Of the English speakers and those in the 5 main non-English groups (N=607), 504 (83 per cent) originally consented to be re-surveyed. Of these women, 344 were re-interviewed for the longitudinal study. This comprised 68 per cent of those who consented to follow-up and 55 per cent of the original sample. These included 153 women from the CSHS (54 per cent of the original CSHS sample) and 191 women from the other metropolitan area (56 per cent of the original sample from the other metropolitan area).

In order to determine if those followed-up for interview for survey 2 were different in any way from those not followed-up, chi-square tests were conducted on each sociodemographic and outcome variable. Those who were followed-up were more likely to have higher levels of education; 41 per cent of those with primary level education were followed-up compared with 59 per cent of those with tertiary education ( $X^2 = 10.78$ ,  $df=3$ ,  $P=0.01$ ). In addition they were more likely to speak only English at home; 60 per cent of English speakers were re-interviewed compared with 38 per cent of those who required an interpreter for

the survey ( $X^2$  trend = 18.03, df = 1,  $P < 0.0001$ ).

The re-surveyed women were different in terms of several outcome variables. Fifty-nine per cent of those who had heard of screening were followed-up compared with 50 per cent of those who had not heard ( $X^2 = 5.35$ , df = 1,  $P = 0.02$ ). They were also more likely to know someone with cancer; 58 per cent of those who knew someone with cancer were followed-up compared with 42 per cent of those who knew no-one ( $X^2 = 9.47$ , df = 1,  $P = 0.002$ ). In addition 57 per cent of those who did not believe that callback for further tests means cancer were followed-up compared with 39 per cent of those who believed that further tests did mean cancer ( $X^2 = 8.91$ , df = 1,  $P = 0.003$ ).

#### Drummoyne survey

The following tables show the sociodemographic characteristics of the Drummoyne survey. Similar to the other samples, each 5-year age group comprised about one-fifth of the overall sample (Table 4.3.1.5).

Table 4.3.1.5 Age distribution of women in the Drummoyne sample

Age group (years)	No.	%
45-49	38	22.6
50-54	21	12.5
55-59	32	19.0
60-64	35	20.8
65-70	42	25.0
Total	168	100.0

Overall 36 per cent of women spoke a language other than English at home (Table 4.3.1.6). The corresponding proportions for the CSHS area were 30 per cent in 1987 and 39 per cent in 1990; these were higher than those for the other metropolitan area (about 20 per cent).

Table 4.3.1.6: Distribution of language spoken at home in the Drummoyne sample

Language spoken at home	No.	%
English only	107	63.7
Language other than English <sup>1</sup>	19	11.3
Interviewed by interpreter	42	25.0
Total	168	100.0

<sup>1</sup>Women who speak a language other than English at home but were interviewed in English

In total 46 per cent of the Drummoyne sample were in occupational prestige categories 3 and 4 (Table 4.3.1.7). Overall about 60 per cent of respondents from the CSHS and other metropolitan areas were in these categories.

Table 4.3.1.7: Distribution of occupational prestige of the main income earner in each household in the Drummoyne sample

Occupational prestige of the main income earner	Number	%
Highest prestige categories 1 & 2	29	17.9
3	28	17.3
4	46	28.4
5	22	13.6
Lowest prestige category 6	37	22.8
Total	162	100.0

In the Drummoyne sample 45 per cent of women had completed 1 to 4 years of secondary school (Table 4.3.1.8). This compared with 45 per cent and 37 per cent respectively in the 1987 and 1990 CSHS samples. These proportions are lower than those for the other metropolitan area where about half the sample had completed 1 to 4 years secondary school.

Table 4.3.1.8: Highest level of education completed by woman in the Drummoyne sample

Educational level	Number	%
Primary	45	26.9
1-4 years secondary	75	44.9
5-6 years secondary	14	8.4
Tertiary	33	19.8
Total	167	100.0

#### 4.3.2 Outcome measures

The following tables show the change from 1987 to 1990 within the CSHS and other metropolitan areas. For the longitudinal survey this is expressed as a difference in proportions with 95% CI. In addition, in order to show if one group has changed at a greater rate than the other, the OR and P value for the change between the 2 areas is shown. For the cross-sectional survey the results are expressed in terms of crude differences between 1987 and 1990. These are then shown after adjustment for the co-variables found to be significant in the logistic regression model and confirmed in the risk-difference model.

The following example will describe the results for the question examining women's knowledge of breast cancer as the most common cancer. In the longitudinal sample (Table 4.3.2.1), the proportion of knowledgeable women in

the CSHS area increased from 71 per cent in 1987 (column 1) to 78 per cent in 1990 (column 2). This represents a 7 per cent change in proportions (column 3). The 95% CI for this difference is shown in column 4; as it includes 0% this interval also indicates that the difference is not statistically significant. The comparable results for the other metropolitan area are indicated directly below those for the CSHS area. The test of the difference in change between the 2 areas is demonstrated by the odds ratio in column 5 and the P value in column 6. This is non-significant indicating that both areas have changed at the same rate.

Results for the cross-sectional sample are indicated in Table 4.3.2.2. The proportion of knowledgeable women in the CSHS area decreased from 74 per cent in 1987 (column 1) to 71 per cent in 1990 (column 2). This represents a crude change of -2.6 per cent (column 3). The change adjusted for the co-variates is shown in column 4, with the 95% CI in column 5. The corresponding co-variates are shown in column 6. The comparable results for the other metropolitan area are indicated directly below those for the CSHS area. Column 7 gives the P value for the test of whether one area has changed at a rate greater than the other.

The proportions for 1987 (column 1) for the tables showing longitudinal and cross-sectional results are different because they pertain to different samples. In the longitudinal comparison, only those women who had baseline and follow-up data, i.e. matched pairs, were included in the analyses. In contrast, the cross-sectional comparison consisted of the total baseline sample, of which the

longitudinal sample was a subset.

### Knowledge

Results for the knowledge items are summarised in Tables 4.3.2.1 and 4.3.2.2. The cross-sectional and longitudinal samples show similar results. About 70 per cent of women were aware that breast cancer is the most common cancer before the implementation of the program . There were no significant changes either within or between the groups. Knowledge about the incidence of breast cancer was low with only about a third of women correctly identifying that 1 in 15 women will get breast cancer at some time in their lives. Again the change was not significant for the within or between group comparisons. Knowledge about age of risk was very low before the implementation of the program with only 7 per cent of women knowing that the risk increases with age. This did not increase significantly in either area. Responses to these items were combined to give an overall score out of 3 for knowledge of risk. Scores of 2 or 3 were regarded as knowledgeable; about a third of women were coded as knowledgeable and this did not improve.

Other questions addressed knowledge about survival, treatment, and screening mammography as an early detection method. Over 80 per cent of women were aware that with early treatment most women live for 10 years or more after diagnosis, and this did not improve in either group over time. There were significant increases in both areas of approximately 10 per cent to 20 per cent in the proportion of women who had heard of screening mammography. Only

about a quarter of women were aware of lumpectomy as a treatment and this did not change statistically significantly over time in the CSHS area. The increase in knowledge of lumpectomy was larger and statistically significant in the other metropolitan area. However, the difference between the areas was not significantly different.

Table 4.3.2.1: Changes in community knowledge between 1987 and 1990 in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas:	
					OR <sup>1</sup>	P value
<b>Knows that breast cancer is the most common cancer</b>						
CSHS	71	78	+7	-1% to 17%	1.4	0.4
Other Met	73	76	+3	-6% to 11%		
<b>Knows incidence of breast cancer</b>						
CSHS	28	32	+4	-6% to 13%	1.5	0.3
Other Met	29	26	-3	-11% to 5%		
<b>Knows age at greatest risk for breast cancer</b>						
CSHS	7	7	+0.7	-4% to 6%	0.8	0.7
Other Met	6	8	+2	-2% to 7%		
<b>Regarded knowledgeable about risk of breast cancer</b>						
CSHS	24	29	+5	-4% to 13%	1.3	0.5
Other Met	26	25	-1	-8% to 9%		
<b>Knows survival for breast cancer</b>						
CSHS	82	86	+4	-3% to 11%	1.5	0.4
Other Met	86	85	-1	-7% to 6%		
<b>Has heard of mammography screening</b>						
CSHS	54	75	+21	11% to 31%	0.9	0.9
Other Met	64	81	+17	9% to 25%		
<b>Knows about lumpectomy</b>						
CSHS	20	22	+2	-6% to 10%	0.7	0.4
Other Met	27	34	+7	0.05% to 15%		

<sup>1</sup> (Odds of change in knowledge variable in CSHS area)/(odds of change in knowledge variable in other metropolitan area).

Table 4.3.2.2: Changes in community knowledge between 1987 and 1990 in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI for adjusted change <sup>i</sup>	Co- variates	Test of diff in change between areas: P value
Knows that breast cancer is the most common cancer							
CSHS	74	71	-2.6	-1.4	-9% to 6%	Lang Age	0.7
Other Met	73	70	-3.5	-3.4	-10% to 3%		
Knows incidence of breast cancer							
CSHS	30	35	+5.3	+6.7	-1% to 14%	Lang	0.3
Other Met	33	34	+1.1	+0.7	-7% to 8%		
Knows age at greatest risk for breast cancer							
CSHS	8	7	-0.6	-0.6	-5% to 4%	None	0.8
Other Met	5	5	+0.2	+0.1	-3% to 4%		
Regarded as knowledgeable about risk of breast cancer							
CSHS	30	33	+3.2	+4.5	-3% to 12%	Lang	0.4
Other Met	28	29	+0.1	-0.2	-7% to 7%		
Knows survival for breast cancer							
CSHS	81	81	-0.6	+0.5	-6% to 7%	Lang Occ	0.6
Other Met	84	83	-0.4	-1.6	-7% to 4%		
Has heard of mammography screening							
CSHS	53	73	+19.7	+17.7	10% to 25%	Educ Occ Lang	0.2
Other Met	58	68	+9.8	+10.0	3% to 17%		
Knows about lumpectomy							
CSHS	19	25	+6.4		0% to 13%	None	0.5
Other Met	24	34	+9.5		3% to 16%		

<sup>i</sup> For those variables which do not have any co-variates, the unadjusted CIs are reported.



## Attitudes

The following tables (4.3.2.3 and 4.3.2.4) summarise the changes in community attitudes between 1987 and 1990. Prior to the implementation of screening, the majority of women held favourable attitudes towards screening mammography. In the longitudinal sample the proportion with positive attitudes did not change over time; in the cross-sectional sample there were significant increases in both areas of about 7 per cent. About 80 per cent of women believed that callback for further tests after screening mammography did not necessarily mean breast cancer; there were no significant changes for either sample. In the longitudinal sample the proportion of women who expressed concern about radiation decreased significantly by 15 per cent from 65 to 50 per cent in the CSHS area. This change was significantly greater than that for the other metropolitan area ( $P=0.005$ ). In comparison in the cross-sectional sample, both areas experienced significant decreases of about 10 per cent.

Table 4.3.2.3: Changes in community attitudes between 1987 and 1990 in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas:	
					OR	P value
<b>Has a favourable attitude towards screening mammography</b>						
CSHS	80	82	+2	-4% to 11%	1.7	0.3
Other Met	85	84	-1	-4% to 7%		
<b>Believes that callback for further tests does not mean cancer</b>						
CSHS	80	81	+1	-1% to 9%	1.0	1.0
Other Met	88	89	+1	-5% to 6%		
<b>Concerned about radiation</b>						
CSHS	65	50	-15	-7% to -24%	3.3	0.005
Other Met	58	60	+2	-7% to 9%		

Table 4.3.2.4: Changes in community attitudes between 1987 and 1990 in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI for adjusted change	Co- variates	Test of diff in change between areas: P value
<b>Has a favourable attitude towards screening mammography</b>							
CSHS	77	84	+6.5	+9.9	4% to 16%	Lang Educ	0.3
Other Met	81	88	+6.5	+5.4	0.003% to 11%	Occ	
<b>Believes that callback for further tests does not mean cancer</b>							
CSHS	76	74	-2.3	+0.9	-5% to 7%	Lang	0.6
Other Met	79	84	+4.3	+2.8	-2% to 8%	Educ	
<b>Concerned about radiation</b>							
CSHS	65	53	-12.1	-12.1	-20% to -4%	Lang	0.6
Other Met	62	53	-8.9	-9.1	-17% to -2%		

## Community experience with breast cancer and screening mammography

Changes in community experience with breast cancer and screening mammography are shown in Tables 4.3.2.5 and 4.3.2.6. The proportion of women reporting that they have had a screening mammogram has significantly increased in both the study areas. While the difference between the areas is significant for the cross-sectional survey, both the longitudinal and cross-sectional samples show the same magnitude of effect. In 1987, over 80 per cent of women reported knowing someone with breast cancer and this has not increased significantly.

Table 4.3.2.5: Changes in community experience with breast cancer and screening mammography between 1987 and 1990 in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas:	
					OR	P value
Has had a screening mammogram						
CSHS	16	39	+23	+14% to 29%	2.4	0.2
Other Met	8	19	+11	+6% to 17%		
Knows someone with breast cancer						
CSHS	88	90	+2	-4% to 8%	1.2	0.8
Other Met	86	87	+1	-4% to 6%		

Table 4.3.2.6: Changes in community experience with breast cancer and screening mammography between 1987 and 1990 in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI for adjusted change	Co- variates	Test of diff in change between areas: P value
Has had a screening mammogram							
CSHS	14	38	+24.1	+24.1	18% to 31%	Nil	0.04
Other Met	9	24	+14.8	+14.8	9% to 20%		
Knows someone with breast cancer							
CSHS	82	83	+0.6	+1.5	-4% to 7%	Lang	0.9
Other Met	83	85	+2.3	+0.8	-5% to 6%		

Table 4.3.2.7 examines where women had their screening mammogram in the last year. This analysis excludes women who have had both a screening and symptomatic mammogram. While this under-represents the number who have had screening mammograms, it gives a more accurate indication of where screening is being conducted as location of each mammogram was not recorded separately.

Table 4.3.2.7: Locations where women had screening mammograms in previous 12 months in the CSHS and Other Metropolitan areas

Locations	CSHS Area		Other Metropolitan Area	
	No.	%	No.	%
Medicheck, breast clinic	5	6.9	11	30.6
Hospital	2	2.8	5	13.9
Private radiologist	12	16.7	11	30.6
Other	4	5.6	9	25.0
Screening van	49	68.1	0	0.0
Total	72	100.0	36	100.0

As expected there were differences between the 2 areas in where women attended for screening. In the CSHS area, 68 per cent of women who had a screening mammogram in the last 12 months, had it done at the Breast X-Ray Programme van. Other major locations were private radiologists (17 per cent) and Medicheck or breast clinics (7 per cent). In the other metropolitan area, screening was conducted mainly from Medicheck and other breast clinics (31 per cent) and private radiologists (31 per cent).

## The amount of information 'seen or heard' about screening mammography

The following tables (4.3.2.8 and 4.3.2.9) show the changes in the amount of information 'seen or heard' about screening mammography in the last 6 months. Prior to the implementation of screening, about 20 per cent of women reported 'seeing or hearing' 'quite a lot' or 'a moderate amount' of information. This increased by over 20 per cent in the CSHS area compared with 5 per cent in the rest of Sydney. Results for both longitudinal and cross-sectional samples showed that the improvement in the CSHS area was significantly greater than that for the other area.

Table 4.3.2.8: Changes between 1987 and 1990 in the amount of information 'seen or heard' about screening mammography in the last 6 months in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas:	
					OR	P value
Has 'seen or heard' 'a moderate amount' or 'quite a lot' of information about screening mammography in last 6 months						
CSHS	18	40	+22	13% to 31%	3.5	0.006
Other Met	20	25	+5	-7% to 8%		

Table 4.3.2.9: Changes between 1987 and 1990 in the amount of information 'seen or heard' about screening mammography in the last 6 months in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI adjusted change	Co- variates	Test of diff in change between areas: P value
Has 'seen or heard' 'a moderate amount' or 'quite a lot' of information about screening mammography in the last 6 months							
CSHS	15	34	+19.1	+17.5	12% to 23%	Lang	0.01
Other Met	8	24	+6.2	+7.9	2% to 13%	Educ	

## Perceived personal susceptibility

Tables 4.3.2.10 and 4.3.2.11 show results for the 2 variables examining perceived personal susceptibility. A woman was categorised as personally susceptible if she expressed concern about the possibility of getting breast cancer, and/or regarded her risk of breast cancer as greater than average. About 20 per cent of women regarded themselves as personally susceptible prior to the implementation of screening and this did not change significantly over time. About 8 per cent of women had discussed their concern with a doctor or other health professional prior to the implementation of the program and this did not increase over time.

Table 4.3.2.10: Changes in community perceived personal susceptibility between 1987 and 1990 in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas:	
					OR	P Value
Feels personally susceptible						
CSHS	18	16	-2	-10% to 6%	1.0	0.9
Other Met	23	20	-3	-9% to 4%		
Has spoken to a doctor or other health professional about concern						
CSHS	10	7	-3	-3% to 9%	0.7	0.5
Other Met	7	6	-1	-0.3% to 4%		

Table 4.3.2.11 Changes in community perceived personal susceptibility between 1987 and 1990 in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI adjusted change	Co- variates	Test of diff in change between areas: P value
Feels personally susceptible							
CSHS	19	21	+2.5	+3.0	-3% to 9%	Age	0.7
Other Met	24	25	+1.8	+1.0	-6% to 8%		
Has spoken to a doctor or other health professional about concern							
CSHS	8	7	-1.0	-0.6	-5% to 4%	Age	0.4
Other Met	8	11	+2.9	+1.8	-2% to 6%		

## Morbid concern

Prior to the implementation of screening, morbid concern about breast cancer was rare with only about 7 per cent in the CSHS area and about 12 per cent in the other area being classified as concerned. This did not change significantly in either area (4.3.2.12 and 4.3.2.13).

Table 4.3.2.12 : Changes in community morbid concern about breast cancer between 1987 and 1990 in the longitudinal sample

	1987 %	1990 %	Diff %	95% CI	Test of diff in change between areas	
					OR	P value
Feels morbidly concerned about breast cancer						
CSHS	7	9	+2	-4% to 7%	1.7	0.4
Other Met	12	10	-2	-7% to 3%		

Table 4.3.2.13: Changes in community morbid concern about breast cancer between 1987 and 1990 in the cross-sectional sample

	1987 %	1990 %	Crude change	Adjusted change	95% CI for adjusted change	Co- variates	Test of diff in change between areas: P value
Feels morbidly concerned about breast cancer							
CSHS	8	8	-0.4	-0.9	-5% to 3%	Age	0.3
Other Met	11	13	+2.2	+2.3	-3% to 7%		

### 4.3.3 The impact of the promotional campaign in the Drummoyne LGA

The 1990 data for the CSHS area (excluding women from the Drummoyne LGA) (N= 299) were compared with the 1990 data for Drummoyne (N=207). Table 4.3.3.1 shows those variables for which there was a significant difference between the 2 groups. Except for concern about radiation there was an additional effect in the Drummoyne LGA for those variables which changed significantly in the CSHS area as a whole.

Table 4.3.3.1: Variables with significance when the CSHS 1990 (excluding Drummoyne) was compared with Drummoyne LGA 1990

CSHS 1987 %	CSHS 1990 %	Crude difference between CSHS 1987 and 1990	Drummoyne LGA 1990 %	Crude diff. between CSHS (excl. Drummoyne) and Drummoyne 1990	P value CSHS (excl. Drummoyne) and Drummoyne 1990
53	70	+17.6	81	+10.3	0.009
14	36	+21.7	53	+17.9	0.00006
15	31	+16.3	42	+10.4	0.02

In order to compare knowledge in Drummoyne of the screening van's existence with that in Central Sydney, 1990 cross-sectional data for the CSHS area were cross-tabulated with those for the LGA (Table 4.3.3.2).



Table 4.3.3.2: Comparison of knowledge of the screening van's existence in the Drummoyne LGA with that in the CSHS area

Knowledge of screening van	CSHS Area		Drummoyne LGA	
	No.	%	No.	%
Not aware of the van's existence	100	29.8	28	16.6
Aware of the van's existence	164	48.8	67	39.6
Had a mammogram at the van	72	21.4	74	43.8
Total	336	100.0	169	100.0

In Drummoyne 83 per cent of women were aware of the van's existence and 44 per cent overall had attended. In comparison 70 per cent of women in the CSHS area knew about the van and 21 per cent had attended ( $X^2$  trend = 26.26 df = 1,  $P < 0.00001$ ).

## **4.4 DISCUSSION**

The aim of this study was to examine the impact of the implementation of a mammography screening program on an Australian community. The study assessed both positive consequences, such as improvements in knowledge and attitudes, and negative outcomes including increased community psychological morbidity in relation to breast cancer.

### **4.4.1 Methodological considerations**

Before discussing the results, some comments on the methodology should be noted. First, response rates were not as high as desired which may inevitably introduce bias. For example, response rates for the baseline survey were 50 per cent for the CSHS area and 55 per cent for the other metropolitan area. Of this sample, 55 per cent were followed-up for the repeat survey.

Those who were followed-up were different on several sociodemographic and outcome variables compared with the group who were not re-surveyed. Those who were followed-up were more likely to: have higher levels of education; speak only English at home; have heard of screening; know someone with breast cancer; and not believe that call-back for further tests means breast cancer.

The follow-up cross-sectional sample had response rates of 46 per cent and 47 per cent. These lower rates were due to the fact that for the most part only 4 follow-up calls were made compared with 8 for the baseline survey.

Thus while some differences were found, this may be due to selection bias. While it is not possible to predict in which way the results are biased, some speculation is warranted.

For example, previous research with this sample indicates that non-English-speaking women are more concerned about radiation.<sup>81</sup> Given that fewer of these women were followed-up than English speakers, the reduction in concern about radiation may be due to an exclusion of this more concerned (and hence potentially more difficult to convince) group. Alternatively, it might be argued that the non-English-speakers have a greater chance to reduce their concern. In this case, excluding this group would potentially mask greater improvement.

Another consideration is the method of interviewing. The interview schedule was designed for English speakers. Thus non-English-speakers' responses may have been less valid due to poorer understanding of the questions. In addition, the questionnaire may have addressed attitudes and beliefs that were less culturally appropriate for this group. This should

be taken into account when considering the effect of language spoken at home.

#### 4.4.2 Outcome measures

##### **Knowledge**

First the results indicate that there was no change in knowledge of breast cancer risk and survival. While knowledge of lumpectomy increased significantly by about 9 per cent in the other metropolitan area, this increase was not significantly greater than that for the CSHS area. Knowledge of screening mammography increased significantly in both areas by approximately 10 per cent to 20 per cent. It appears then, that while knowledge about specific issues has not changed, the community as a whole has experienced increases in knowledge about screening mammography.

It could be argued that the general increase is due to the messages promoted through electronic and print media. As outlined in Chapter 3 there was a total of 770 print media items, 71 radio segments and 29 television segments about breast cancer and mammography which women living in Sydney were potentially exposed to during the campaign period. Of the print media items, 8 per cent mentioned the Breast X-Ray Programme. This is quite a high proportion given that promotional activities were restricted to the CSHS area.

An alternative explanation is that there has been a 'spill-over' effect from the

promotional activities of the Breast X-Ray Programme to the rest of Sydney. While the campaign was restricted to the CSHS area it was impossible to completely isolate activities from the rest of Sydney. In addition, other research indicates that 'word of mouth' is an important source of awareness about the service.<sup>78</sup> It is possible that women spread information about screening mammograms through their personal and work networks which are not necessarily confined to central Sydney.

There are two ways of assessing these results. First, one can consider the proposition that knowledge is a worthwhile outcome in its own right for a campaign of this kind<sup>144,145</sup>; indeed there is a view that knowledge is all that campaigns can change.<sup>145</sup> On these grounds it would appear that for the most part, the promotional campaign has been unsuccessful. Second, the implications of the results for screening attendance can be taken into account. The acquisition of 'appropriate' knowledge is a necessary, although not sufficient, prerequisite to the performance of the desired behaviour in most well-accepted health behaviour models.<sup>58,59,61,146</sup> However, the consequences of these results for actual attendance for mammography screening is unclear. The results from overseas studies are equivocal with some indicating that attenders have higher levels of knowledge<sup>51,55,64</sup> and others showing no differences between attenders and non-attenders.<sup>52</sup>

There are 2 major reasons for the program to continue to attempt to improve knowledge as part of its generalised promotional campaign. First, as recently

highlighted by Maureen Roberts<sup>34</sup>, women require information in order to make informed decisions about screening. Both the letter by Roberts and the reply by Chamberlain<sup>147</sup> stressed the importance of being open and honest with women in the target population. This has been supported by others including Cribb and Haran<sup>148</sup> who argue that in order to make programs 'ethically defensible' we must aim to 'maximise both informed choice and overall utility'.

Secondly the role of the promotional campaign in 'agenda-setting' should not be underestimated. This refers to the campaign's function in increasing the level of information about screening and thereby indirectly improving its acceptability.<sup>149,150,151</sup> This is important in providing the back-drop against which strategies aimed at the individual can be implemented. This approach is discussed in more detail in Chapter 5.

The lack of a substantial improvement in the CSHS area in knowledge about lumpectomy as a treatment option is particularly concerning. Recent Australian data indicate that only 22 per cent of Australian breast cancer patients have breast-conserving operations. The rest undergo mastectomy, most commonly radical mastectomy.<sup>152</sup> While there are many reasons for this, women who get breast cancer in the future may not be equipped to discuss treatment options with their doctor or seek a second opinion if they are unaware of possible alternatives. More importantly in terms of recruitment to screening, lack of knowledge that some breast cancers may be treatable by breast-conserving surgery may act as a barrier to attendance.<sup>81</sup>

## Attitudes

Prior to the implementation of the campaign, approximately 80 per cent of women held favourable attitudes towards screening mammography; therefore there was little room for improvement. While the longitudinal sample indicated no changes, the cross-sectional sample suggested increases of about 7 per cent in both the areas. It appears then that change if any, has been small.

The majority of women also believed that recall for further tests does not mean cancer and this did not increase over time. This is reassuring given that the program's recall rate was 16.5 per cent<sup>93</sup> and consequently had the potential to affect community perceptions.

Another pleasing result is the significant decrease in concern about radiation. Both samples suggest that the change is greater in the CSHS area. Similar results have been noted for a recent study of a television-promoted mammography screening pilot project in the Chicago metropolitan area. In this study a pre-post survey of women living in the viewing area indicated a 24 per cent reduction in the proportion of women expressing fears about radiation.<sup>126</sup>

The results of the present study may be interpreted in two ways. First it might be argued that the campaign was successful in promoting the message about minimal radiation hazards. This was addressed specifically in both the

pamphlets and health promotion talks. Alternatively and perhaps more realistically, women may come to see the service as safe as it is promoted as a free state government funded project. This perception of the service as non-threatening or harmless may be reinforced as friends and others visit the van.

### **Experience with breast cancer and screening mammography**

As would be hoped, the proportion of women reporting ever having had a screening mammogram increased significantly. In the CSHS area in 1990 almost 40 per cent of women reported that they had been screened at some time, an increase of about 24 per cent. While the longitudinal survey showed significant increases in both areas, the cross-sectional sample showed that the increase in the CSHS area was greater than that for the rest of Sydney. The increase in the other metropolitan area, however, should not be underestimated. This was indicated to be about 11 to 15 per cent. It would appear that as with favourable attitudes and knowledge of screening mammography, there has either been a 'spill-over' effect from the CSHS campaign or a change due to media messages aimed at the general community.

Of those who had been screened in the last 12 months in the CSHS area, 68 per cent had attended the van. It would appear then, that the campaign may have encouraged women to attend for screening in other locations. There are several likely scenarios. One possibility is that some women were encouraged by the campaign to be screened but missed the van when it was in their area and



subsequently went to another service. Other women may have preferred to go a fixed-site. Indeed anecdotal evidence shows that some women find the van 'too public' as it is parked in highly visible locations. Other women may have been referred to services known by their medical practitioner.

In assessing these results the validity of self-report of mammography should be considered. A recent study by King et al compared mammography reports in medical records to self-reports obtained during a telephone interview.<sup>153</sup> This study concluded that self-report can be used to accurately monitor mammography utilisation. In contrast a recent investigation conducted with the data from this study (Appendix 3), indicated that a small proportion of women (7 per cent) reported that they had not had a mammogram when program records indicated that they had attended. It would appear then that the screening rate of almost 40 per cent for 1990 may be a slight underestimate.

The present campaign achieved an estimated 21 per cent attendance rate (based on self-reported attendance at the screening van) in an eligible population of 43000 over a period of 22 months. This rate compares very favourably with that obtained for 2 similar campaigns conducted from mobile screening vans in the United Kingdom. Two recent studies examined the uptake for screening at a project in Scotland with an eligible population of about 23000 women. When local publicity alone was used over a period of about 9 months an attendance rate of 24 per cent was obtained.<sup>154,155</sup> A similar study examined compliance with breast cancer screening in the Aylesbury Vale district with an eligible population

of about 10000 women. Access to the service was by self-referral for the first 23 months of operation; the estimated uptake during this period was 28 per cent.<sup>156</sup>

Prior to the campaign over 80 per cent of women knew someone with breast cancer and this did not increase over time. These results are to be expected; the cancer detection rate of the Breast X-Ray Programme during this period was 0.7 per cent<sup>93</sup> and consequently one would not anticipate an increase in the number of women knowing someone with breast cancer.

#### **Amount of information 'seen or heard' about screening mammography**

For a campaign to be successful it must first reach its target audience. In this study, campaign reach was measured by a question asking women how much information they had 'seen or heard' about screening mammograms in the last 6 months. Both the longitudinal and cross-sectional surveys indicated that the increase in the amount of information 'seen or heard' about screening mammograms was significantly greater in the CSHS area. At the follow-up survey 40 per cent of women in the longitudinal survey and 34 per cent in the cross-sectional survey reported that they had 'seen or heard' 'a moderate amount' or 'quite a lot' of information. This represented an increase of about 20 per cent in Central Sydney compared with an increase of about 7 per cent in the rest of Sydney. Thus while both areas experienced increases in awareness about screening mammography, women in Central Sydney reported greater increases

in the amount heard; it appears then that the campaign has been successful in this regard in targeting the Central Sydney area.

After 2 years of the campaign about 60 per cent of the target population reported being exposed to 'only a little' or no information at all. There are several considerations in assessing these results. First, as screening was restricted to the CSHS area, the campaign comprised regionally based initiatives and did not extend to metropolitan print and electronic media. As the National Early Breast Cancer Detection Program is implemented it will become possible to make use of strategies such as television which has been indicated to be an important source of information about mammography screening.<sup>47,126</sup>

The capacity for television to promote mammographic screening has not been evaluated in Australia; however, it has been shown in NSW and Queensland to be successful in reaching a high proportion of the target community. After a national mass media campaign for cervical screening, 40 per cent of NSW women aged 18 to 70 recalled materials which were produced as part of the campaign.<sup>102</sup> Following a similar statewide media campaign aimed at rural and urban women in Queensland, 89 to 97 per cent of the target population recalled the campaign.<sup>157</sup>

Second, one of the original aims of the pilot program was to examine the most effective methods of recruiting women to screening.<sup>93</sup> Consequently, to a large extent the campaign period was of an experimental nature. As such only limited

use was made of strategies aimed at the individual which have been found to be more effective than generalised approaches (Chapter 5). Such strategies include letters from the GP or the screening service, recommendation by the GP or pharmacist and invitation from friends.

### **Perceived personal susceptibility and morbid concern**

A major aim of this study was to assess possible negative outcomes as a consequence of implementing a mammography screening program. The results show that there have been no changes in perceived personal susceptibility or morbid concern in relation to breast cancer. In addition the proportion of women having spoken to a doctor or other health professional about their concern has not increased. These results indicate that there has been no negative impact at a general community level as a result of implementing screening. In addition they help to answer concerns of those such as Skrabanek<sup>22,23,105</sup>, Maguire<sup>82</sup> and Leather and Roberts<sup>68</sup> who have warned of the potential negative outcomes of screening.

This is not to say that screening programs should not remain vigilant about possible negative consequences. A quality assurance initiative designed to minimise anxiety and dissatisfaction has recently been implemented in the United Kingdom by the National Health Service (NHS) Breast Screening Programme. This report gives guidelines for addressing issues related not only to attenders but to the community as a whole. As screening progresses in

Australia it will be necessary to consider similar initiatives.<sup>158</sup>

Australian screening programs should also be cognisant of the messages that the media present about screening. While the analysis presented in Chapter 3 indicates that the majority of messages were positive, overseas studies have indicated that the media can potentially alarm the community, for example in relation to radiation hazards.<sup>70</sup> It is necessary for screening programs to monitor the media in order to counteract messages designed to frighten or provoke the public.

#### **4.4.3 The impact of the promotional campaign in the Drummoyne LGA**

One of the aims of this study was to examine whether the campaign had an added effect or 'dose-response' in the Drummoyne LGA which was identified as a mini-target area in which to intensively recruit women to screening. With the exception of concern about radiation, there was an additional effect in Drummoyne for those variables which changed in the CSHS area as a whole. These included added increases in the proportion of women who: had heard of screening mammography (an additional effect of 10 per cent); had a screening mammogram (an additional effect of 18 per cent); and had 'seen or heard' 'a moderate amount' or 'quite a lot' of information about screening mammography (an additional effect of 10 per cent). In addition women from Drummoyne were more likely to be aware of the screening van's existence (83 per cent) compared with those from the CSHS area (70 per cent) and were more likely to attend (44

per cent and 21 per cent respectively).

It is clear that the additional effort in the Drummoyne campaign was successful in encouraging greater awareness of the van and greater attendance. However, it is questionable whether the campaign achieved extra impact in terms of improving knowledge and attitudes. In order to achieve the increases, the mobile van was open for operation in the LGA for approximately 118 days. As shown in Table 3.2.2 this was more than double the median time spent in each of the other LGAs. It should be noted, however, that one would not expect an effect directly proportional to the time spent operating in the area because over time the campaign is aimed at more reluctant women. Thus over time there is an effect of diminishing returns.

The lack of a large additional effect on knowledge and attitudes can in part be explained by the nature of the campaign in Drummoyne. This campaign placed greater emphasis on individualised strategies. These included written invitations and recommendation by the GP, invitations for friends, and invitations from the service using the electoral roll. Approximately 615 women were approached through these strategies. This comprises 14 per cent of the eligible population. While these strategies have been found to be more effective than generalised strategies in encouraging women to attend (Chapter 5) they clearly do not add to improving community knowledge and attitudes to a large extent. Indeed evidence from Pap smear programs indicates that the success of individualised approaches appears to be independent of attitudes.<sup>159</sup>

#### 4.4.4 Comparison of longitudinal and cross-sectional designs

In order to control for the 'Hawthorne effect' this study employed both cross-sectional and longitudinal samples. Results for these two samples were very similar. The following differences were found for attitudes, concern about radiation and the proportion of women who have had a screening mammogram. First, the cross-sectional sample showed increases in favourable attitudes in both areas compared with no improvements in the longitudinal sample. Second, the cross-sectional sample showed decreases in concern about radiation in both areas, while the longitudinal sample showed a decrease only in the CSHS area. Third, the cross-sectional sample showed a greater increase in the CSHS area in the proportion of women having had a screening mammogram. In comparison the difference was not significant in the longitudinal sample.

It is not possible to explain these results in terms of a 'Hawthorne effect'. If such an effect had occurred one might expect the baseline interview of the longitudinal sample would prompt greater improvements in knowledge and attitudes compared with the cross-sectional survey. Clearly there was no evidence of this occurring in a systematic manner across the variables.

Two other factors must be taken into account when comparing the results of the two surveys. First, they have different sample sizes and therefore do not have the same statistical power in order to detect differences between the CSHS and other metropolitan areas over time. Due to loss to follow-up, the longitudinal

sample had a much smaller sample size than the cross-sectional sample. In addition, it should be noted that in the longitudinal sample, it is not just the number of women surveyed that matters, but the number who changed in each outcome variable between baseline and follow-up. Second, the comparability of the 2 surveys may be affected by the bias in the longitudinal study due to the differences between the women who were followed-up and not followed-up.

Given that it is not always practical to use both sampling methods, it is possible to use the results of this study to debate which method is preferable. It is clear that both methods have advantages and disadvantages. The advantage of the longitudinal study is that it allows for comparisons of the same individuals making it a potentially more powerful design compared with the cross-sectional study. In addition, the results showed no indication of a Hawthorne effect. The main disadvantage is the potential bias introduced as a consequence of loss to follow-up.

In comparison, while the cross-sectional design is less powerful, it is not subject to loss to follow-up. Weighing this evidence, it would appear that the cross-sectional design is preferable in that it provides similar results to the more powerful longitudinal design while avoiding the possible bias due to loss to follow-up.



#### 4.4.5 Conclusions

It is apparent that the impact of the Breast X-Ray Programme in the CSHS area was at a fairly general level. The major changes included: increases in the number of women being aware of and having screening mammograms; increases in favourable attitudes; and decreases in concern about radiation. There was no evidence for negative outcomes such as increases in perceived personal susceptibility and morbid concern. The next chapter will examine the impact of specific recruitment strategies on attendance rates. It will focus on a specific area within Central Sydney, that of the Drummoyne LGA, which was designated as an area to test recruitment strategies.

## CHAPTER 5

### RECRUITMENT STRATEGIES FOR SCREENING MAMMOGRAPHY IN AN AUSTRALIAN COMMUNITY

#### 5.1 INTRODUCTION

The impact of mammographic screening on breast cancer mortality rates in Australia will be heavily dependent on the proportion of women who are recruited for screening. The Australian Health Ministers' Advisory Council (AHMAC) report examines the effect of participation on total breast cancer mortality using a computer model incorporating data from the Health Insurance Plan (HIP) and Two Counties studies. As participation by women aged 40 to 69 years increases from 55 per cent to an ideal level of 100 per cent, the estimated reduction in breast cancer mortality increases from 13 per cent to 23 per cent.<sup>14</sup>

In addition to the impact on breast cancer mortality, high participation rates need to be obtained across all groups of eligible women in order to achieve equity. One of the recommendations of the AHMAC report is that all eligible women should have similar opportunities to attend for screening. It is noted that emphasis needs to be given to the recruitment of groups likely to be under-screened, particularly older women, women of low socioeconomic status, rural women, Aboriginal women, and women from non-English speaking backgrounds.<sup>14</sup> As noted in Chapter 1, while breast cancer incidence is approximately 25 per cent lower in migrants from Italy and Greece, it increases

progressively with increasing duration of residence in Australia.<sup>8</sup> In addition, equity of service delivery and access among all population groups is a fundamental principle of the World Health Organisation (WHO) and Health for All by Year 2000 program.<sup>160</sup>

It is vital to determine a satisfactory level of participation in Australian women. The AHMAC report recommends that a rate between 50 and 70 per cent of the target population is acceptable. This figure was adapted from the recommendations developed for the UK national screening mammography program.<sup>14</sup> The Health for All Australians report suggests a target participation rate of 70 per cent or more of eligible women by the year 1995.<sup>41</sup>

The following section considers 3 issues in relation to participation for mammography screening. These include overall community attendance rates, the sociodemographic profile of attenders, and attendance in response to particular strategies to recruit women. Several sources provide information on these, including: the original trials examining the efficacy of screening (Table 1.1, Chapter 1); national and regional surveys; and recent evaluations of interventions to increase attendance.

### **5.1.1 Overall community attendance rates**

Several regional and national surveys examining attendance for mammography have been conducted in Australia (Table 5.1.1.1). These were conducted prior

to the commencement of the National Early Breast Cancer Detection Program in 1990, when screening occurred primarily on 'on demand' from women who knew of and believed in its value. Screening was initiated by either the woman or service provider, as part of a consultation for some other health matter. In those studies differentiating screening from symptomatic mammograms, around 10 per cent of women had had a screening mammogram prior to the implementation of the national screening program.

Several national studies have also been conducted in the USA examining participation rates.<sup>48,161,162,163</sup> Recent national surveys of women 40 years and over indicate that the percentage of women ever having had a mammogram has increased from 37 per cent in 1987 to 64 per cent in February 1990.<sup>48</sup>

Table 5.1.1.1: Australian participation rates in mammography screening prior to the National Early Breast Cancer Detection Program in 1990

Survey	Method	Time period of data collection	Age	% Had screening mammogram	% Had mammogram for symptoms
Irwig, Cockburn, Turnbull, Simpson, Mock, Tattersall (1991) <sup>81</sup>	Random survey of women living in the CSHS area (NSW)	late 1987-early 1988	45-69	11	10
Hill, White, Borland, Cockburn (1991) <sup>109</sup>	Random national Australian survey	June-August 1988	40-49	5	13
			50-59	9	10
			60-69	7	13
			70+	4	2
Clover, Redman, Sanson-Fisher, Knight (1989) <sup>108</sup>	Randomly selected women from previous research in Hunter Valley (NSW)	November 1988	50-70	25% of women had ever had a mammogram	
Fitzgerald Diggins, Moore (1990) <sup>106</sup>	Randomly selected women living in the South West Statistical Division (WA)	May 1989	45-69	26% of women had ever had a mammogram	
Diamond, Fitzgerald, Moore (1990) <sup>107</sup>	Randomly selected women living in the Cannington Area (WA)	February 1989	45-69	28% of women had ever had a mammogram	
Cockburn, Murphy, Schofield, Hill, Borland (1989) <sup>164</sup>	Randomly selected English speaking women living in Essendon and Broadmeadows (Victoria)		50-69	7.5%	10%

### 5.1.2 Sociodemographic profile of attenders

The sociodemographic profile of women attending the original trials indicates that some women are more likely to participate in initial screening than others. First, the majority of studies reported decreased attendance with increasing age.<sup>21,23,24,28,45,165</sup> For example in the Malmö trial, 64 per cent of women aged 65-69 attended for screening compared with 79 per cent of women aged 45-49;<sup>23</sup> in the Two Counties trial, attendance ranged from 79 per cent in women aged 70-74 to 93 per cent in women aged 40-49.<sup>21</sup>

The HIP study<sup>45</sup> found that women with higher levels of education were more likely to attend and the UK trial found that attendance was higher with increasing socioeconomic status of the practice at which women were listed.<sup>24</sup> In this trial 67 per cent of those in the highest socioeconomic status group attended, compared with 54 per cent in the lowest status group. In the Breast Cancer Detection Demonstration Project (BCDDP), there was a slight trend for increased attendance with increasing education and household income.<sup>166</sup> In comparison the Utrecht study found no correlation between occupational grading of participants' residential area and response rates.<sup>165</sup>

The HIP<sup>54</sup> and BCDDP<sup>166</sup> studies also found that about 80 per cent of attenders were married women. In the Utrecht study<sup>165</sup> unmarried women had a slightly higher response rate. Almost 90 per cent of BCDDP participants were white.<sup>166</sup>

Surveys in the United States also indicate the characteristics of women who are

less likely to be screened. A national random survey conducted in February 1990<sup>48</sup> indicated the following patterns for those reporting ever having had a mammogram. First, screening ranged from 56 per cent in women aged 70 and over to 64 per cent in women aged 40 to 49. In terms of education, screening ranged from 58 per cent in those with less than high school level education to 74 per cent in those who had a college degree or more. Overall 58 per cent of black women had ever had a mammogram compared with 65 per cent of white women. In addition, screening rates ranged from 60 per cent in those with an annual income of less than \$25000 to 71 per cent in those with an annual income of \$25000 or more. Another random survey conducted in the Greater Los Angeles Area indicated that Hispanic women were also half as likely as white women to ever have had a mammogram.<sup>47</sup>

### **5.1.3 Attendance in response to particular recruitment strategies**

The strategies used to recruit women to screening can be described as individualised or generalised. Individualised strategies are those aimed at individual women and include personalised letters of invitation and personal interactions with health practitioners. Personalised letters may be sent to women identified from national population registers as is done in Scandinavia and Europe,<sup>21,23,30,165</sup> or to women whose names are on the patient lists of participating GPs as is done in the UK.<sup>167</sup> The letters are personalised in that they address each woman by name.

Generalised strategies are those which operate at the population or community level. They include: electronic and print media, legislation and health education. Health education may be defined as ‘any combination of learning experiences designed to facilitate voluntary actions conducive to health’. Thus health education incorporates multiple interventions aimed at facilitating learning as a systematic planned activity. Action can occur at either an individual, group or community level and is voluntary. Forms and methods of health education that define its scope are: community organisation, in-service training, consultation, group work, audiovisual methods, patient teaching, health fairs, exhibits and conferences, and poster and pamphlet distribution.<sup>168</sup>

A recent report<sup>169</sup> provides an update of the recruitment methods being used in overseas screening programs (Table 5.1.3.1). Individualised recruitment is used in all programs except Canada where it is proposed to use generalised strategies alone.

Table 5.1.3.1: Recruitment strategies used by overseas screening programs

Program	Strategies
United Kingdom	Personalised mailed invitations; variable level of generalised strategies; GP information
Canada	Media including newspaper articles and advertisements; volunteers
Sweden	Individualised letters with appointment date
Netherlands	Individualised letters; mass media
Finland	Individualised letters; public education



### Individualised strategies

There are several advantages to individualised approaches. First, they minimise the effort required by individual women, such as organisation of appointments. This may be especially important for older women and women from lower socioeconomic strata and non-English speaking-backgrounds.<sup>170</sup> Second, evidence from Pap smear programs indicates that the success of such systems is independent of attitudes such as those about vulnerability to cancer and efficacy of treatment, which are often very difficult to address.<sup>159</sup> In addition there is evidence that Australian general practitioners support the use of recall systems for some types of screening.<sup>171</sup>

A potential disadvantage of individualised strategies is that they rely on population registers which may be unreliable. While the Swedish national register is updated weekly,<sup>169</sup> several researchers have highlighted the inadequacies of the family practitioner lists being used in the United Kingdom.<sup>172,173,174</sup> In a recent study of GP invitational letters, 35 per cent of the women did not receive their invitations because of inaccuracies in the family practitioner committee's database.<sup>175</sup> In other reviews, inaccuracy rates as high as two-thirds have been reported. The inaccuracy rate appears to be higher for older patients, women in lower socioeconomic classes and those in inner city areas. Major sources of inaccuracy include changes of address and death of women on the list.<sup>173</sup>

The original trials examining the efficacy of screening mammography discussed in Chapter 1 have achieved high participation rates using individualised approaches. In the Health Insurance Plan of New York study, 65 per cent of those invited appeared for the initial examination.<sup>45</sup> In the Two Counties trial, compliance at first screening was 89 per cent.<sup>21</sup> The attendance rate in the Malmö randomised trial was 74 per cent.<sup>23</sup> In the UK trial, the response was 60 per cent in Edinburgh and 72 per cent in Guildford.<sup>25</sup> An 85 per cent attendance rate was obtained in the Nijmegen project,<sup>28</sup> and in the Utrecht case-control study 72 per cent of eligible women attended for screening.<sup>29</sup> In the Florence case-control study, the average compliance on first invitation was 60 per cent.<sup>30</sup>

These projects used written invitations aimed at women identified from a range of population lists. The New York study implemented an elaborate recruitment strategy. Letters were sent to women registered with the Health Insurance Plan of Greater New York. Women were asked to make an appointment through use of an enclosed postcard giving a choice of appointment hours. Most of the women who did not respond to the first letter were contacted through a second letter with an appointment postcard. Further attempts were made to reach women through telephone calls. Women who failed to keep appointments were subsequently followed up by telephone.<sup>45</sup>

The Swedish programs identified women from central population registers and then sent letters of invitation.<sup>21,23</sup> Similarly in the Nijmegen,<sup>27</sup> Utrecht<sup>29</sup> and Florence<sup>30</sup> case-control studies, women in the eligible age group were identified from population registers and invited by mail. In the Utrecht study, a second

letter was sent to those who failed to respond to the first.<sup>165</sup>

In the UK trial a computerised register of women listed with eligible GPs in Edinburgh was compiled. These women were then sent a letter of invitation offering an appointment for screening.<sup>167</sup> Several more recent investigations have evaluated individualised interventions to increase attendance. Strategies have included GP written invitations; written invitations using population registers; and recommendation by a GP during the consultation (Table 5.1.3.2). Evaluation of these trials was generally poor. None of the studies included a control group and only one,<sup>176</sup> which compared 2 different interventions, used a randomised trial design.

Table 5.1.3.2: Recent individualised strategies aimed at increasing attendance at screening mammography

Study	Intervention	Method of evaluation and results (attendance for screening)
<b>GP WRITTEN INVITATIONS</b>		
Hobbs, Kay, Friedman et al. (1990) <sup>177</sup>	Responses of 2 groups of women sent personalised letters (with appointment) were compared.	No control group 50-64 year olds: 77% 65-79 year olds: 61%
McEwan, King, Bickler (1989) <sup>175</sup>	Personalised letters (with appointment) sent to women registered with several general practices. Non-respondents were sent a second letter.	No control group 46%
Dowell & Gosling (1991) <sup>178</sup>	Personalised letters sent to women registered with one general practice. Reminder letter sent.	No control group 52%
Williams & Vessey (1989) <sup>176</sup>	Randomised trial of 2 interventions: i) letter with an appointment; ii) Open ended letter inviting women to return a form indicating convenient times. An appointment was then sent. Non-respondents were sent a reminder. Non-attenders from both groups were sent another appointment.	No control group Appointment letter: 86% Open-ended invitation: 76%
Royle, Rubin, Guyer (1989) <sup>179</sup>	Invited 13111 women in first 10 months of screening program.	No control group 75%
<b>WRITTEN INVITATIONS USING POPULATION REGISTERS</b>		
Donato, Bollani, Spiazzi et al. (1991) <sup>180</sup>	Personal letter with appointment time. Second letter sent to non-attenders.	No control group 57% Participation did not change substantially with age. Participation decreased significantly with increased level of education. Married and widowed women attended more than single and separated/divorced women.
<b>GP VERBAL RECOMMENDATION DURING THE CONSULTATION</b>		
Cockburn, DeLuise, Hill, Hurley, Reading, Russell (1990) <sup>181</sup>	GP verbal recommendation and pamphlet during the consultation.	No control group 41% of those given the verbal recommendation. Older women were more likely to attend.

Responses to written invitations have ranged from 46 per cent to 86 per cent. It appears that including an appointment increases attendance.<sup>176</sup> Out of the 6 studies examining the effect of a written invitation, 4 state that a second follow-up letter was sent to those women who failed to respond to the first letter.<sup>175,176,178,180</sup> In addition, one study<sup>176</sup> which obtained a 76 per cent response rate, included 2 follow-up letters.

A recent study conducted at a mobile screening van in the United Kingdom has examined the impact of personal invitations from GPs following a period of generalised recruitment strategies. Generalised strategies included poster displays and local newspaper advertisements and articles. Response to the generalised strategies was 24 per cent with a marked reduction in attendance with increasing age. Personal invitations produced a response rate of 75 per cent among women who had not attended previously.<sup>155</sup> In a similar study, the estimated uptake was 28 per cent following an opportunistic self-referral recruitment strategy. After an intervention of GP letters was introduced, a 68 per cent response rate was achieved for those who had not responded to the opportunistic recruitment strategy.<sup>156</sup>

A pilot randomised trial of GP written invitations to the central Sydney Breast X-Ray Programme has also had promising results. This trial was run on 156 women in two general practices who had indicated support for the program. An attendance rate of 51 per cent was obtained in women sent an invitation with an appointment time compared with 14 per cent for the control group ( $X^2=25$ ,  $df=1$ ,  $P<0.001$ ).

Another Australian study examined the effect of a verbal recommendation from the GP. The study used a small sample of volunteer doctors. Results indicated that there are few difficulties incorporating such a recommendation into consultations as 96 per cent of those eligible were given the recommendation. Of those given the recommendation, 41 per cent subsequently attended for screening.<sup>181</sup>

### **Generalised recruitment strategies**

A major advantage of generalised strategies is their ability to reach a large audience at one time with correct information about health behaviour set in a persuasive format. It appears that such approaches have an indirect rather than a direct effect in that they may encourage discussion and inform people who are ready to respond about how to do so. It appears that the primary effect of generalised approaches is to raise the level of awareness, which can 'set the stage' for other interventions. A disadvantage is the lack of specificity concerning the content of the message. That is, it is often difficult to determine what aspect of the communication was effective.<sup>159</sup>

Mass media have a number of additional advantages over more traditional generalised strategies. First, mass media are able to reach groups who are difficult to access through traditional medical delivery. Second, they are a relatively inexpensive method of exposing the population to health information. Third, the message itself can be sophisticated and potentially powerful in a

manner not available to other types of intervention. Finally, mass media have the potential to modify the knowledge or attitudes of a large proportion of the community simultaneously, thereby providing support for behaviour change not available with individualised approaches.<sup>182</sup>

Several of the original trials applied generalised recruitment strategies aimed at the community as a whole. The BCDDP study included strategies such as radio and television announcements and health education presentations. Lists of women to be contacted were also compiled, but it is unclear as to how these women were approached.<sup>166</sup> The computerised register used in the UK was supplemented by an extensive health education campaign providing information about breast disease, treatment and BSE to the community as a whole.<sup>167</sup> The Utrecht study also applied 'extensive publicity' prior to sending invitational letters.<sup>165</sup>

The generalised strategies applied in 9 interventions implemented in the United States are summarised in Table 5.1.3.3. These have usually been sponsored by major cancer organisations such as various state divisions of the American Cancer Society. Several have involved inviting high-quality mammography screening providers to participate in a low-cost screening program. Women are then recruited through generalised recruitment strategies and asked to telephone a phone-bank or hotline in order to obtain a coupon or information on screening at participating centres. A recent paper<sup>183</sup> provides a description of the Breast Cancer Detection Awareness Program (BCDA) which employed this approach on a statewide basis in the USA between 1986 and 1988.

Evaluations of these interventions have generally been poor. Only 3 of the 9 studies<sup>47,73,127</sup> include a control group. Most of the other studies do not incorporate a denominator or target group of eligible women in the community from which to determine attendance rates.<sup>75,126,184,185,186</sup> Of those women who contact the programs to seek information about screening, between about half and 60 per cent actually attend.



Table 5.1.3.3: Generalised recruitment strategies aimed at increasing attendance at screening mammography

Study	Recruitment method used	Method of evaluation and results
Wilkes, Schoenfeld, Ruesch, Mettlin (1988) (Breast Cancer Detection Awareness Program, Western New York) <sup>184</sup>	GP information, TV, telephone hot line to receive a coupon for low-cost mammography.	No control group. 6355 women requested a coupon. 50% of callers to the hotline had a mammogram.
Pratt Lacey, Phillips, Ansell, Whitman, Ebie, Chen (1989) (10 towns in Chicago) <sup>127</sup>	Education and outreach activities.	Experimental communities compared with matched control group before and after. Results not available yet.
Lane, Polednak, Burg (1989) (Long Island New York) <sup>73</sup>	Media campaigns, mailings of brochures using motor vehicle records, physician education, community outreach.	Three intervention towns compared with a control town at baseline and post-baseline. Results not available yet.
Morisky, Fox, Murata, Stein (1989) (Three communities in the Greater Los Angeles Area) <sup>47</sup>	Community presentations, networking with influential others, GP information, newspaper ads, informational materials.	Quasi-experimental design, comparing 2 intervention communities with one control community. Results not available yet.
Winchester, Lasky, Sylvester, Maher (1988) (Illinois) <sup>126</sup>	TV news segments.	No control group. 16118 eligible women called a phone-bank to make an appointment; 9307 (58%) were screened. Low income women less likely to be screened.

Table 5.1.3.3 continued

Study	Recruitment method used	Method of evaluation and results
Vogel, Graves, Coody, Winn, Peters (1990) (Texas) <sup>185</sup>	News release, newspaper and TV.	No control group. 64000 mammograms done in 306 centres.
Gregorio, Kegeles, Parker, Benn (1990) (Connecticut) <sup>75</sup>	Brief mass media campaign.	No control group. 2150 telephone calls from eligible women. 58% had a screening mammogram. Those less likely to be screened: non-white women, women with lower levels of education, widowed and never married women.
McClatchey, Calonge, Furmanski, Barbour, Hager, Rich (1989) (Lifescreeen, Metro Denver Area) <sup>186</sup>	TV, newspaper, radio, direct mailing. Women phoned a telephone bank to obtain information packets.	No control group. 4054 packets were sent. 3829 respondents were eligible. 1796 eligible callers (47%) had a mammogram. Participants tended to be highly educated and be employed in higher status occupations.
Sobel, Gordon, Kristal, Eklund, Curtin, Kennedy (1989) (Oregon Breast Cancer Detection Awareness Project) <sup>74</sup>	Newspapers, TV, radio, volunteers.	No control group. 2.6% of the eligible population of Oregon participated. The majority of participants were white and had graduated from high school or had some college education.

One strategy receiving increased attention in the USA is the use of legislation. Unlike Europe, the United Kingdom and Australia, the United States has no national screening program whereby mammography is free of charge at point of delivery. As of 1989, 21 states had legislation requiring third-party insurers to pay for screening mammograms or establish breast cancer screening programs. The legislation varies markedly with regard to periodicity of examinations, ages covered, type and extent of coverage, dose regulation and radiographic equipment standards.<sup>187</sup>

There has been little published Australian research into the impact of mass media. Intensive electronic mass media campaigns were not conducted in the pilot projects because they were limited to specific target groups and there was concern that such campaigns would create a level of demand that could not be met. One study in 2 country towns in the Hunter Valley, New South Wales found a 30 per cent attendance rate in response to a minimal mass campaign comprising newspaper advertisements, pamphlets for women and information to general practitioners.<sup>14</sup>

### **The role of the general practitioner**

As noted previously, there are 2 major ways that GPs can recruit women to screening. These are through written invitations to patients and by recommending screening during the usual consultation. The use of general practitioners in these ways has several specific advantages. First, this health care delivery system is readily accessible to a wide section of the community;

Australian data indicate that over 85 per cent of 45 to 69 year old women visit a general practitioner at least once a year, over half of them attending more than 5 times a year.<sup>188</sup> Second, there is evidence that both patients and medical practitioners view the practitioner as an appropriate person to deliver preventive care.<sup>189</sup> Finally, research indicates that medical practitioners are effective in persuading patients to modify health behaviour.<sup>189</sup>

Data collected at the Breast X-Ray Programme in the CSHS area indicates that GPs are an important source of awareness about the service. GP advice during the consultation was the second most commonly reported source of awareness, with 14 per cent of attenders mentioning this response.<sup>190</sup>

Several overseas studies have also highlighted the importance of GPs in recruiting women to mammography screening. The Health Insurance Plan study found that those who had used an HIP physician during the previous year were more likely to participate.<sup>45</sup> More recently, quantitative and qualitative studies have indicated that physician advice or referral is a major reason or motivational factor in encouraging attendance.<sup>72,75,76,83,85,119,192</sup>

Recent Australian data indicates that a potential disadvantage of using GPs is their lack of knowledge about breast cancer and mammography screening. A random survey of GPs conducted before the implementation of the Breast X-Ray Programme indicated that only 25 per cent of the sample knew that the risk of breast cancer increases with age and only 30 per cent knew that the evidence for a reduction in mortality as a result of mammographic screening is weakest for

women of less than 50 years of age. However, the study also found only a small association between levels of knowledge and the willingness to recommend screening.<sup>86</sup>

A follow-up study conducted 2 years later found that although there were some improvements, GPs continued to have low levels of knowledge on important aspects of breast cancer and mammography screening.<sup>87</sup> This is concerning in that it may lead to GPs giving inappropriate advice and recommending ineligible women to screening.

While there are distinct advantages in using GPs to recruit women, many report low referral rates for screening mammography.<sup>191,193</sup> A US random national survey of primary care physicians in 1989 indicated that only 37 per cent reported referring asymptomatic women for mammography.<sup>194</sup>

While there are no comparable national Australian studies, data collected in the CSHS area indicates increases in the proportion of GPs advising screening mammograms following the introduction of a GP educational campaign. In 1990, 51 per cent of GPs reported advising asymptomatic women to have screening mammograms compared with 24 per cent in 1988. In addition GPs reported advising more women than prior to the campaign.<sup>87</sup>

Several US studies have investigated barriers to GPs recommending screening mammography. These include perceived ineffectiveness or unreliability of the procedure, concern about radiation and cost, an anticipated lack of patient

compliance or outright patient rejection,<sup>195,196,197</sup> concerns about causing unnecessary worry to patients,<sup>195,197</sup> being unfamiliar with recommended guidelines,<sup>195,196</sup> and non-accessibility of the service.<sup>195</sup>

Several US studies have examined strategies to increase physicians' referrals for screening mammography (Table 5.1.3.4). The evaluation of these strategies have been of a high standard; the evaluations include 3 randomised controlled trials, and the other 4 studies include control groups. Response to seminars has been low with only about 10 per cent of physicians subsequently ordering mammography.<sup>198</sup> The most effective strategies applied intensive approaches such as monthly feedback and peer comparison on the percentage of patients who met the guidelines of an annual mammogram.<sup>199</sup>

Table 5.1.3.4: Individualised strategies aimed at increasing GP recommendation for screening mammography

Study	Intervention	Method of evaluation and results (attendance for screening)
Cohen, Littenberg, Wetzel, Nauhauser (1982) <sup>200</sup>	Checklists of recommended preventive procedures (including mammograms for women aged 45 to 64) were attached to patient charts. Provision of weekly seminars on screening.	Randomised controlled trial. After the intervention, mammography was performed on 32% of the eligible women in the experimental group compared with 4% in the control group.
Fox, Tsou, Klos (1985) <sup>198</sup>	Seminar and 2 behavioural cues to increase referral for screening mammography.	Control group used. Compared with a control group, there was a significant increase in the mean mammography referral rate of the experimental group from 4% to 11%.
Fox, Tsou, Klos (1985) <sup>201</sup>	Continuing medical education (CME) session.	Control group used. Post-intervention referral rates for mammography were significantly higher in the CME group compared with a control (12% compared with 5%).
Chambers, Balaban, Carlson et al. (1989) <sup>202</sup>	Computer reminders.	Randomised controlled trial. Women in the experimental group were more likely to have a mammogram ordered than those in the control group (19% compared with 12%).
Nattinger, Panzer, Janus (1989) <sup>199</sup>	1. Monthly feedback and peer comparison. 2. Patient handout which acted as a cue. Simplified mammography ordering system. 3. Control group.	Prospective controlled trial. Not randomised. 1. 62% 2. 54% 3. 36%
Ornstein, Garr, Jenkins, Rust, Arnon (1991) <sup>203</sup>	1. Physician computer reminders alone. 2. Patient computer reminders alone. 3. Computer reminders to patients and physicians. 4. Control group.	Randomised controlled trial. The largest increase in referral for mammography was in the group receiving physician and patient reminders: 11% to 27%.
Harris, O'Malley, Fletcher, Knight (1990) <sup>204</sup>	1. Computer prompt 2. Manual prompt from registered nurse. 3. Control period	Retrospective cross-sectional data with a control period. 1. 41% 2. 13% 3. 4%

#### 5.1.4 Implications for Australia

There are clearly a range of potential strategies available for recruiting Australian women to mammography screening. In considering the degree to which these interventions can be generalised to the Australian community, social and organisational considerations need to be taken into account.

The social context in which Australian women will be recruited is probably more like that of the USA and the United Kingdom, than the Scandinavian countries. For example, Swedish women tend to be ethnically homogeneous and there is a high level of formal education. An illustration of this is Falun where the Two Counties trial was conducted, where apart from a small Finnish community, the vast majority of women are Swedish. In comparison, in the CSHS area, 37 per cent of eligible women are from non-English speaking-backgrounds and 71 per cent have no qualifications since leaving school (Chapter 3). In addition the Swedes have a strong tradition of a centralised health system and population registers, and consequently women are familiar with receiving unsolicited mail requesting them to attend for screening.

The major organisational consideration in recruiting Australian women to screening is the lack of a population register comparable to those used in Scandinavia and Europe. An ideal population list would contain the following information for all female residents: name, address, telephone number, date of birth, spoken language, past screening history and information on past diagnosis of breast cancer. A model population list would be updated, probably at



monthly intervals, as changes of address and deaths occurred.<sup>205</sup>

There are three lists of subsets of the Australian population: the Medicare database, GP patient lists and the electoral listing. While the Medicare database has complete population coverage, its accuracy is unknown as updating of addresses and deletion of persons who have died is totally dependent on volunteered information.<sup>205</sup> In addition there is considerable political and community resistance against using Government records for such purposes.<sup>206</sup> This database is currently not available to identify and recruit women to screening.

Two lists which are available are GP patient files and the electoral roll. As previously discussed, GP lists have been used extensively to recruit women to screening in the United Kingdom. It remains to be seen if this form of recruitment can be applied to Australia. Compared with the United Kingdom, Australian women are not registered with a specific GP and indeed it has been found that 48 per cent of Australian women change GPs over a 3-year period.<sup>206</sup> This may reduce the efficacy of the GP intervention, be it either letter or verbal recommendation, as Australian women may be less likely to identify with the source of the invitation.

The electoral roll is a register of those who are enrolled to vote. Australian citizens aged 17 years and over and certain British subjects are eligible to enrol to vote, and in June 1989 an estimated 85 per cent of the Victorian population in this age group was on the roll. The Australian Electoral Commission updates

the roll on the basis of deaths and changes of address. The roll contains name, address, date of birth, and occupation data. Although persons enrolling are required to state their telephone number and country of birth on the application form, this information is not stored on the roll. Names and addresses are publicly available. Special permission is required for the provision of age details. The electoral roll has a less complete population coverage than the Medicare database which covers an estimated 102 per cent of the resident population; a higher percentage of women who are not on the roll speak a language other than English at home. A recent Victorian study estimates that 6 per cent to 7 per cent of addresses are incorrect.<sup>205</sup>

Several other strategies are available in Australia which have not been explored in depth elsewhere. One individualised strategy available to Australian screening projects is the use of personal networks such as family and friends. Such networks have been found to be important in several Australian studies. A recent study at the Breast X-Ray Programme found that 10 per cent of women found out about the van's existence this way.<sup>190</sup> A recent Victorian study found that 79 per cent of women believed that their friends would be favourably disposed to them having a mammogram.<sup>164</sup> In addition in a Western Australian study, 18 per cent of women stated their reason for attending for screening was related to family and friends.<sup>79</sup> While these networks appear to be potentially useful for recruiting women to screening, there have been few attempts to formally utilise them.

The use of incentives in association with personal networks is another potentially

useful strategy. Apart from the promotion of low-cost mammograms in the US campaigns, the use of incentives to encourage women to participate in screening has also not been examined in detail. Incentives may be particularly pertinent for this purpose as it appears that they act to facilitate initial participation in activities that are not of immediate interest. Incentives to increase early participation include giveaways and lottery tickets.<sup>207</sup> Incentives such as amounts of \$25, 'secret gifts' and prize drawings for holidays have been used in health promotion campaigns such as smoking cessation programs.<sup>208,209</sup>

For such an approach to be effective, both the incentive itself and the context in which it is applied is important. The incentive should be valued and salient and perceived in a positive way; it is important that it is not perceived as demeaning or coercive. It should be applied in a supportive context where appropriate beliefs and values are in place, and be delivered through public and interpersonal channels, thus optimising the vicarious reinforcement of others. In addition, the incentive should be delivered with interrelated strategies as part of a comprehensive approach.<sup>207</sup>

The use of letterbox drops or direct mail is also a potentially useful generalised strategy. While letterbox drops are currently being used to advertise Australian screening programs, they have not previously been evaluated in an Australian community. A major advantage of this strategy is that it can reach all socioeconomic and age groups. A major disadvantage is the high cost per person exposed.<sup>210</sup>

### 5.1.5 Study objectives

1. To examine the extent of coverage or 'reach' of a generalised campaign to recruit women to screening. Both the overall coverage and the reach across different sociodemographic groups is examined. Reach is determined by examining ongoing changes in knowledge about screening and the Breast X-Ray Programme itself. Examining campaign reach helps to determine if non-attendance is due to inadequate knowledge about the service and the need for screening, or barriers between knowledge and actual attendance. In comparison with Chapter 4 which deals with the issue in the CSHS area before and after a less intensive campaign, the present chapter examines reach across three successive time periods. These include prior to screening, and 10 months and 2 years after the commencement of screening.
2. To evaluate a specific generalised strategy; that is letterbox drops or direct mail.
3. To evaluate several individualised strategies. 'Invitation for friends' involves giving program attenders, invitations to attract their family and friends to screening. An additional strategy is conducted whereby the incentive of a scratch lottery ticket is given to those attenders who successfully recruit another woman to the program. GP interventions include written invitations and verbal recommendations during the consultation. The final individualised strategy to be implemented involves inviting women to the program via the electoral roll.

## **5.2 METHODS AND RESULTS**

### **5.2.1 Setting**

The majority of the strategies described in this chapter were conducted in the Drummoyne LGA which was identified as a 'mini-target area' in which to intensively recruit women to screening. The campaign which was conducted in this area and the overall community attendance rates have been reported in Chapter 3. In total, 48 per cent of the target population of 4480 had been screened after the van's final visit during the 1988-1989 campaign period.

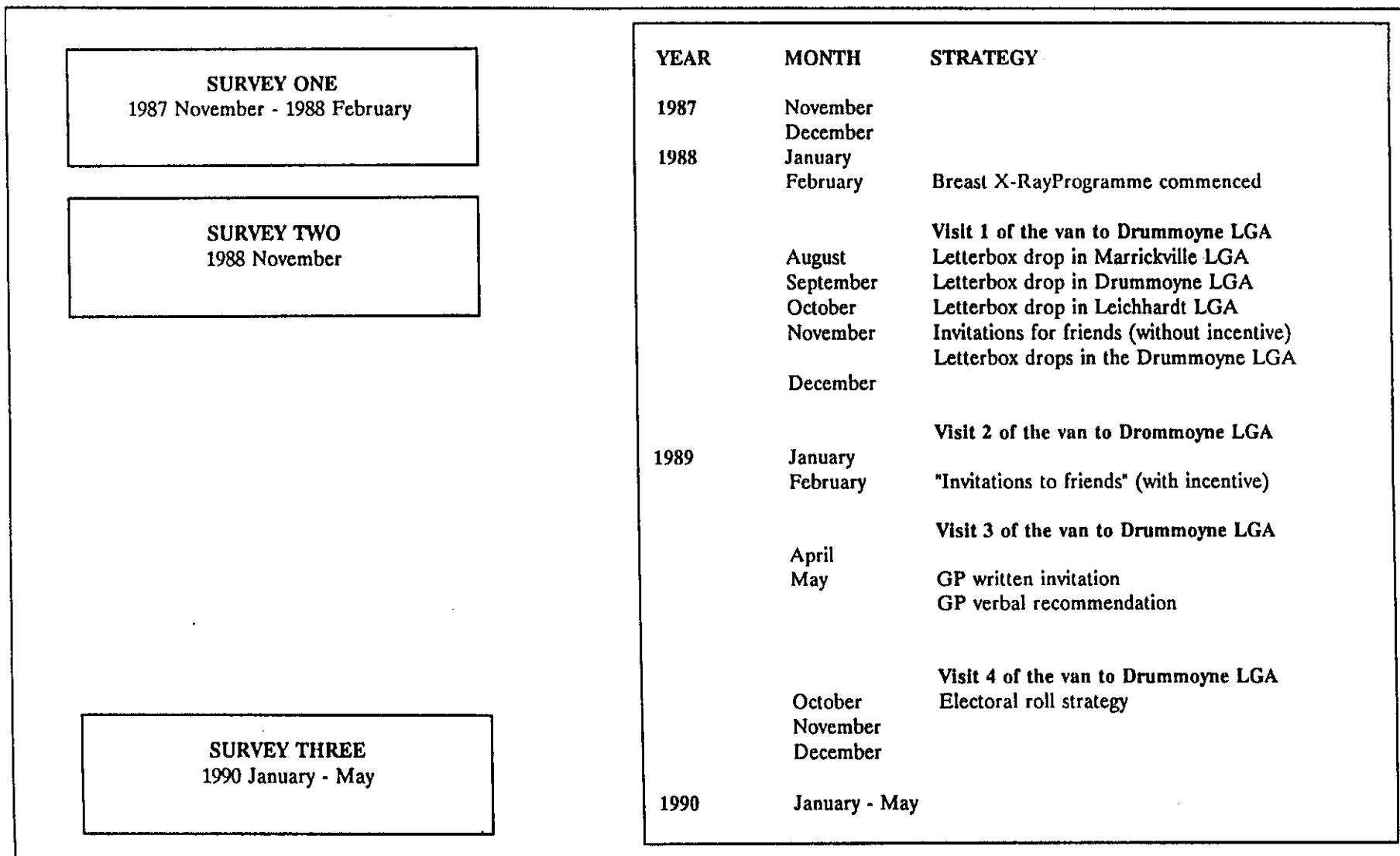
The time frame for this study is shown in Figure (5.2.1.1).

### **5.2.2 Objective 1. To examine the reach of a generalised campaign to recruit women to mammography screening**

#### **Method**

Data about women's knowledge were collected by telephone interviewing. Details of the methods used have been described in Chapter 2. The sample comprised randomly selected women aged 45 to 70. Arrangements were made to interview non-English-speaking women in their own language in Survey 1 (13 per cent) and 3 (25 per cent). Surveys were conducted on 3 separate occasions using a cross-sectional design.

Figure 5.2.1.1: Time frame for implementation of community surveys and recruitment strategies



### Survey 1

The baseline sample comprised 628 Sydney women (285 from the CSHS area and 343 from the rest of Sydney) who were interviewed as part of the baseline longitudinal survey. Details of how the sample was obtained are outlined in Chapter 4. Within this sample, 44 women were from the Drummoyne LGA. The distribution was compared between Drummoyne and the rest of the sample for each of the variables of interest including: knowledge of breast cancer as the most common cancer and increased risk with age, knowledge of mammography and screening mammography and the amount of information 'seen or heard' about screening mammograms. The distributions were similar for these variables and there were no statistically significant differences on chi-square testing. Thus it was considered that the total sample was representative of Drummoyne.

### Survey 2

The second survey was conducted in the Drummoyne LGA. Women were randomly selected from the most recent Sydney telephone directory. At the time of interviewing, the van had been operating for a total of about 10 months and during this time had been in the Drummoyne LGA for about 2 months. It was aimed to interview 100 women.

### Survey 3

This survey comprised 2 separate samples: women from Drummoyne interviewed

as part of the repeat cross-sectional sample in the CSHS area; plus a separate sample specifically of women from Drummoyne. Details of how the sample was derived are outlined in Chapter 4. Interviewing was conducted after the fourth visit to Drummoyne by the van. Thus the van had been operating for about 2 years and had been in the Drummoyne LGA for a total of 9 months.

### **Measurements obtained**

All surveys included the following information:

**Knowledge of risk:** respondents were read a list of cancers and asked which is the most common type amongst women in their age group in Australia. In addition they were asked at what age a woman is most at risk of breast cancer.

**Knowledge of mammography and screening mammography:** women were asked a series of questions about whether they had heard of mammography and screening mammography. They were also asked if they had 'seen or heard' any information about screening mammograms in the last 6 months and if so how much. Response categories were 'none', 'only a little', 'a moderate amount', and 'quite a lot'.

**Knowledge of mobile screening van:** respondents (in surveys 2 and 3 only) were asked a series of questions to determine if they knew of the existence of the mobile screening van.



**Sociodemographic data:** these included age, language spoken at home, occupation of the main income earner and highest level of education completed by the woman.

### **Analysis**

Data were analysed using chi-square tests on cross-tabulated data including chi-square tests for linear trend on ordered data. In order to determine the impact of the campaign across various sociodemographic groups, the computing system GLIM was used to fit additive risk difference models.<sup>139</sup> (The rationale for risk difference models has been discussed in Chapter 4). The following variables were modelled as a function of time (survey 1 vs survey 3), sociodemographic variables, and the interaction of these 2 effects: knowledge of mammography, knowledge of screening mammography, and the amount of information 'seen or heard' about screening mammography.

### **Results**

#### **Response rates and sample characteristics**

Response rates were as follows- survey 1: 56 per cent (N=628); survey 2: 56 per cent (N=93); survey 3: 51 per cent (N=206). Sample characteristics are shown in the following tables.

Age distribution was generally similar for the 3 surveys with each of the 5 age

categories comprising about a fifth of the total (5.2.2.1).

Table 5.2.2.1: Distribution of age of women in surveys 1, 2 and 3

Age group (years)	Survey 1 (N=617) %	Survey 2 (N=93) %	Survey 3 (N=206) %
45-49	23.2	18.3	22.8
50-54	19.6	17.2	12.6
55-59	19.3	18.3	20.9
60-64	19.4	27.9	19.4
65-70	18.5	18.3	24.3
Total	100.0	100.0	100.0

In surveys 1 and 2, about 75 per cent of women spoke only English at home, compared with about two-thirds in survey 3 (Table 5.2.2.2).

Table 5.2.2.2: Distribution of language spoken at home of women in surveys 1, 2 and 3

Language spoken at home	Survey 1 (N=624) %	Survey 2 (N=93) %	Survey 3 (N=206) %
English only	74.4	74.2	63.1
Language other than English <sup>1</sup>	12.7	25.8	12.1
Interviewed by interpreter	13.0	Did not attempt to interview these women	24.8
Total	100.0	100.0	100.0

1. Women who speak a language other than English at home but were interviewed in English.

Occupational prestige of the main income earner was collected for surveys 1 and

3. The 2 surveys were roughly similar with the exception that survey 1 had 8 per

cent more women in occupational level 4 and survey 3 had 7 per cent more women in category 6 (Table 5.2.2.3).

Table 5.2.2.3: Distribution of occupational prestige of main income earner in the household for surveys 1, 2 and 3

Occupational prestige of the main income earner	Survey 1 (N=572) %	Survey 2	Survey 3 (N=199) %
Highest prestige categories 1 & 2	12.4	Not Collected	17.1
3	23.1		20.6
4	35.5		27.6
5	14.5		13.1
Lowest prestige category 6	14.5		21.6
Total	100.0		100.0

Surveys 1 and 2 had approximately 15 per cent of women with primary level education compared with 27 per cent of women in survey three. The last survey also had a lower proportion of women with secondary schooling (68 per cent in survey 1, 63 per cent in survey 2 and 53 per cent in survey 3) (Table 5.2.2.4).

Table 5.2.2.4: Distribution of highest level of education completed by women in surveys 1, 2 and 3

Educational Level	Survey 1 (N=617) %	Survey 2 (N=92) %	Survey 3 (N=204) %
Primary	14.7	14.1	27.0
1-4 years secondary	50.7	50.1	44.6
5-6 years secondary	17.7	13.0	8.8
Tertiary	16.9	22.8	19.6
Total	100.0	100.0	100.0

### Outcome measures

Prior to the campaign 71 per cent of women were aware that breast cancer is the most common cancer among Australian women; this did not change significantly over time ( $X^2=2.02$ ,  $df=2$ ,  $P=0.4$ ). In the pre-campaign period, only 6 per cent of women were aware that breast cancer risk increased with age and this did not change over time ( $X^2=0.75$ ,  $df=2$ ,  $P=0.7$ ).

There was a significant increase in the proportion of women who had heard of mammography from 71 per cent in the pre-campaign period to 88 per cent at 10 months and 90 per cent at 2 years ( $X^2$  Trend=37.73,  $df=1$ ,  $P<0.001$ ). Similar results were found for knowledge about mammography specifically used for screening. Fifty-six per cent of women had heard about it before the campaign and this increased to 66 per cent at 10 months and 81 per cent at 2 years ( $X^2$  Trend=42.96,  $df=1$ ,  $P<0.001$ ). The amount of information 'seen or heard' about

screening mammography in the last 6 months is summarised in Table 5.2.2.5.

Table 5.2.2.5: Amount of information 'seen or heard' about screening mammography in last 6 months

Amount	Pre-screening (N=623)	10 months after commencement of screening (N=93)	2 years after commencement of screening (N=206)
None	68%	57%	40%
Only a little	15%	19%	18%
Moderate amount	9%	16%	15%
Quite a lot	8%	8%	27%

There were significant increases in the proportion of women reporting exposure to any information about screening mammography. During the pre-campaign period 32 per cent of women had 'seen or heard' any information; this increased to 43 per cent at 10 months and 60 per cent at 2 years ( $X^2$  Trend=50.59, df=1,  $P<0.001$ ).

The proportion of women aware of the van (including those who had attended) increased significantly from 56 per cent at second interview to 83 per cent ( $X^2=24.19$ , df=1,  $P<0.001$ ) (Table 5.2.2.6). After 2 years, 17 per cent of the target population were still unaware of the van's existence.

Table 5.2.2.6: Knowledge of screening van

Knowledge of the screening van	10 months after commencement of screening (N=93)	2 years after commencement of screening (N=206)
Unaware of van's existence	44%	17%
Aware of van's existence	42%	39%
Had mammogram at the van	14%	44%

In order to determine whether non-attenders were aware of screening mammography and the van itself, the relationship between attendance and the amount of information 'seen or heard' about screening and awareness of the van was examined for survey 3 data. Thirty-four per cent of non-attenders reported 'seeing or hearing' 'a moderate amount' or 'quite a lot' of information and 73 per cent were aware of the van's existence.

Only 2 risk difference models showed a significant interaction effect, indicating that the campaign had a differential effect on different sociodemographic groups. The first was for knowledge of mammography and language spoken at home. Prior to the campaign 79 per cent of English speakers were aware compared with 48 per cent of women from non-English speaking-backgrounds (NESB). At 2-year follow-up this increased to 96 per cent for English speakers (a 17 per cent increase) and 80 per cent for NESB women (a 32 per cent increase), a statistically significant difference ( $X^2=4.92$ ,  $df=1$ ,  $P=0.03$ ).

Similarly for the amount of information 'seen or heard' about screening mammography: prior to the campaign 42 per cent of women from occupational

groups 1,2,3 (i.e. the highest occupational status groups) reported that they had 'seen or heard' 'a moderate amount' or 'quite a lot' of information about screening mammography. This compared with 15 per cent for women in occupational groups 4,5,6. At 2-year follow-up this remained the same for occupational groups 1,2,3 and increased to 41% for occupational groups 4,5,6 (a 26 per cent increase), a statistically significant difference ( $X^2=8.00$ ,  $df=1$ ,  $P=0.005$ ).

### **5.2.3 Objective 2. To evaluate a specific generalised strategy, letterbox drops**

#### **Time Period**

A series of 4 randomised trials of letterbox drops were conducted, 2 during the van's first visit to the Drummoyne LGA, and the other 2 outside the Drummoyne LGA.

#### **Method**

Leaflets were distributed in letterboxes within defined geographical areas. First an area near or around the mobile screening van was identified as the study area. The areas ranged in size from 0.5 by 2 kilometres to 4 by 4.5 kilometres. Streets were then randomly allocated to an intervention group which received pamphlets and a control group which received no pamphlets.

The pamphlets were developed by the education officer at the screening service

in conjunction with the researchers. Information was based on local research findings about women's knowledge and attitudes about breast cancer and screening mammography.<sup>81</sup> The leaflets were photocopied usually on coloured paper with the program logo on the top. They varied from a one page explanation about the service and general information about breast cancer and mammography to a 2 page leaflet with more detailed information in question and answer format (Appendix 4). They were in English only.

Time intervals for the drops included the commencement of screening in the targeted LGA (one drop), about a week after (one drop), and the two months after (2 drops). They were timed in order to allow women between 6 and 46 operational screening days to attend before the van moved to the next location which was usually noted on the pamphlet. In three of the drops, the van subsequently moved to the adjacent suburb for a period of 23 operational days, so most women did not have far to travel to have a mammogram.

### **Analysis**

The central data base of van attenders was accessed in order to evaluate the number of women attending from each street. Data analysis would conventionally be done by comparing the attendance rates in intervention and control streets. However, the denominator for estimating attendance rates, i.e. the number of eligible women in these streets, is unknown. As a proxy the number of attendances from intervention and control streets in the time period prior to the intervention (7 to 10 months) can be determined. This has the



advantage of incorporating into the 'denominator' any differences in probability of attendance between intervention and control streets due to unmeasured confounders. Therefore, the relative risk of attendance as a ratio of post/pre intervention attendance in intervention streets to post/pre intervention attendance in control streets was estimated. This is equivalent to estimating relative risks and confidence intervals using odds ratios for each study. A Mantel-Haenszel summary estimate was obtained over all studies.<sup>138,211</sup> Sixteen experimental streets (17 per cent) in which no drop was made (due to time constraints) were excluded from the analysis.

## Results

Overall 3984 pamphlets were placed in letterboxes. The following tables (5.2.3.1 to 5.2.3.4) show the number of women who attended in the period up to the drop, i.e. the pre-intervention period, and the post-intervention period approximately 3 months after the drop. For example in trial 1 (Table 5.2.3.1), 36 women from the intervention streets had attended up to the period of the drop. In the 3 month period after the drop, 13 women attended. Similarly in the control streets, 9 women attended in the pre-intervention period and 3 women attended in the 3 months after the drop. Attendance in response to the letterbox drop in trial 1 was only 8 per cent higher than in the control streets and not statistically significant (RR = 1.08, 95% CI: 0.22 to 7.16).

The ratio of pre to post intervention attendance varies between the 4 trials depending on the time intervals before and after intervention. The pre-

intervention attendance also varies between experimental and control streets depending presumably on the population density in them. Nevertheless, each trial had a similar result, with relative risks (RR) ranging from 1.06 to 1.49. Overall the estimated increase in attendance due to the letterbox drops was 15 per cent and not statistically significant (RR=1.15, 95% CI: 0.61 to 2.19).

Table 5.2.3.1: Randomised trial 1, Marrickville LGA (1608 pamphlets)

No. of women attending	Intervention streets (N=35)	Control streets (N=32)
Pre-intervention	36	9
Post-intervention	13	3

RR = 1.08; 95% CI: 0.22 to 7.16

Table 5.2.3.2: Randomised trial 2, Leichhardt LGA (776 pamphlets)

No. of women attending	Intervention streets (N=9)	Control streets (N=11)
Pre-intervention	35	11
Post-intervention	11	3

RR = 1.15; 95% CI: 0.24 to 7.56

Table 5.2.3.3: Randomised trial 3, Drummoyne LGA (600 pamphlets)

No. of women attending	Intervention streets (N=7)	Control streets (N=10)
Pre-intervention	4	7
Post-intervention	23	27

RR = 1.49; 95% CI: 0.33 to 7.80

Table 5.2.3.4: Randomised trial 4, Drummoyne LGA (1000 pamphlets)

No. of women attending	Intervention streets (N=28)	Control streets (N=25)
Pre-intervention	82	58
Post-intervention	15	10

RR = 1.06; 95% CI: 0.41 to 2.84

### 5.2.4 Objective 3. To evaluate a strategy entitled 'Invitations for Friends'

#### Time Period

This strategy was conducted in November 1988 during the screening van's first visit to the Drummoyne LGA and in February 1989 during the screening van's second visit.

#### Sample and method

A research assistant approached 69 consecutive attenders at the mobile screening

van. Two women were not approached because of illness and language barriers. Women were asked to take invitations for 2 friends. Invitations included explanatory letters to the original attender and the woman being invited for screening (with an appointment time), and a pamphlet (Appendix 5).

The trial was repeated where an incentive of an instant scratch lottery ticket was offered to 21 consecutive attenders for each friend they successfully recruited to screening. As the van was screening about 30 women per day, it was decided to collect data over 2 days in order to approach about 60 women. This would provide information to decide whether the effect of the strategy was large enough to warrant a randomised controlled trial.

### **Results**

Sixteen of the 69 women approached (23 per cent) refused the invitations. The main reason was that they felt that their eligible friends had already attended. A total of 106 invitations were distributed (i.e. two invitations to each of 53 women). This resulted in 8 attendances (7 per cent (8/106), 95% CI: 3.6% to 14.8%).

The following results were obtained for the trial which included an incentive of an instant scratch lottery ticket. Out of 21 consecutive attenders, 15 (71 per cent) accepted 2 invitations each. This resulted in 2 attendances (7 per cent (2/30), 95% CRI: 1.2% to 23.5%). Interestingly, one woman was recruited through an attender who specifically asked not to be sent a lottery ticket.

#### **5.2.5 Objective 4. To evaluate 2 interventions involving GPs: written invitations and verbal recommendation during the consultation**

##### **Time period**

These interventions were conducted in May 1989 during the screening van's third visit to the Drummoyne LGA. Twenty-seven per cent of the eligible population had already attended the screening van.

##### **Sample**

A stratified random sample of general practices was obtained as follows. All GPs who practice in the Drummoyne LGA were selected from a list maintained by the Breast X-Ray Programme. The program's list was based on one supplied by the Department of Community Medicine at Royal Prince Alfred Hospital supplemented by names of GPs given by women who attended for mammography. The 1989 Sydney Telephone Yellow and White Pages Directory was also examined to identify other Drummoyne GPs and to exclude GPs no longer in practice and specialists. Two general practices were excluded from the trial, one where the majority of patients had already attended and one which had participated in pilot trials. This left 21 practices, out of which 11 were randomly selected to receive an intervention.

Practices were ranked from 1 to 4 according to the number of women from the Drummoyne LGA who had already attended the Breast X-Ray Programme.

Each practice within the first rank was randomly allocated to one of 2 intervention groups. The procedure was repeated for the remaining ranks producing two intervention groups representative of the range of previous involvement with the Breast X-Ray Programme. Out of the 11 practices, 6 (9 GPs) were approached to send written invitations. The other 5 practices (5 GPs) were approached to recommend mammography screening in the consultation.

### **Procedure**

Each practice was visited by a GP researcher on behalf of the Breast X-Ray Programme. Each GP received an information package including material on the incidence, mortality and risk groups for breast cancer, overseas evidence for the effectiveness of screening, radiation, costs, and information about the Breast X-Ray Programme. S/he was given an invitation to attend a promotional function being organised in conjunction with the local council and asked to participate in a randomised trial of the relevant intervention.

### **GP written invitations**

#### *Method*

For those GPs who agreed to participate in this intervention, all eligible women in the appropriate age range were identified from practice files by receptionists. If it was not possible to use all eligible women in a practice, files were randomly

selected using a random sampling frame supplied by the research team. The following details were recorded: name and title, address, date of birth and date of last visit. The list was surveyed by the GP to exclude any women who should not receive an invitation because they had another serious medical condition or because they had had a recent mammogram. Twelve women were excluded on this basis. This list was then compared with the Breast X-Ray Programme's computer list to exclude any woman who had already attended, unbeknown to the GP.

Within each practice, women on the final list were individually randomised to a control group (who did not receive invitations) and an intervention group (who received letters). Randomisation was done in such a way that a third of the sample were controls and two-thirds received the invitation letter. This split was done in order to maximise throughput at the screening van.

The letter was developed by Jill Cockburn and modified by the researcher (Appendix 6). It invited the woman by name to attend and contained basic information on screening mammography and the Breast X-Ray Programme. A pamphlet was included, plus an appointment time and a contact number for more information or to change the appointment. For those practices which preferred a more general invitation, the letter was sent without an appointment time.

The time frame for examining attendance in the control and intervention groups extended from the day the invitation letter was posted (between 6 and 21 days

before the pre-arranged appointment time) to the last day of screening in Drummoyne, at most 25 days later. Data were analysed using chi-square tests on cross-tabulated data and a risk difference model.<sup>140</sup> An intervention/letter type interaction was included in order to determine if the attendance rate in women sent a letter with an appointment time exceeded the attendance in women sent a letter without an appointment time.

After attendance data had been collected, GPs were asked if they could suggest the names of non-respondents whom they thought would be able to comment on the intervention. To aid in designing other strategies, it was of interest to examine women's attitudes to receiving the letter and the barriers which had prevented them from attending. Out of the 5 practices, 3 agreed either to contact women by telephone themselves or to write and ask permission to be interviewed by a research assistant. Those women who were approached by letter were asked to contact the GP by a certain date if they did not wish to be interviewed.

Each consenting practice was provided with a list of those non-respondents who had attended the practice in the last 6 months. A total of 15 names were suggested by the GPs. Semi-structured telephone interviews were conducted with 9 of these women.

There were several reasons for not attending including having had a recent mammogram. Only one woman had negative reactions to the letter. Common responses of the other women included being away when the letter arrived, being



busy and procrastinating. On the basis of this qualitative feedback it was decided that a potentially useful intervention would be to send a second invitation as a reminder as has been done in several overseas studies.<sup>45,165,175,178,180</sup>

Consequently GPs were approached approximately 6 months after the first invitation was sent to ask permission to send a second invitation to women who had failed to respond to the first letter. This was done to coincide with the screening van's next visit (Visit 4) to the Drummoyne LGA. These follow-up invitations were restricted to women who had attended the practice in the last 12 months. Within each practice, women on the final list were individually randomised to a control group (who did not receive invitations) and an intervention group (who received letters). Invitations (Appendix 7) included a letter from the GP which emphasised the van's new extended opening hours, plus the original pamphlet (with translations in Italian and Greek) and an information sheet about the progress of the service to date. The time frame for examining attendance in response to the second invitation extended from the day the letter was posted (10 days before the pre-arranged appointment time) to the last day of screening in Drummoyne, at most 38 days later.

### *Results*

Five of the 6 practices selected agreed to participate. Every GP within each of the 5 practices agreed to participate (N=7). Four of the participating practices sent letters with an appointment time as requested and one large practice decided to send invitations without an appointment time. Three practices

included all of their eligible patients, of whom 92 per cent lived in the Drummoyne LGA. One included all those women living within 2 postcode areas in the immediate vicinity of the screening van's location. In addition, one practice randomly sampled a portion of their files.

A total of 604 names of eligible women were provided. Of these, 164 (27 per cent), had already been screened. Four names were listed on more than one GP list; these were randomly excluded from one of the lists. After the invitations had been posted it was found that 15 women had had recent mammograms elsewhere, 4 women had moved out of the area, two were away at the time and one had already been screened at the program. Analyses were performed in the original groups of allocation.

There were no important differences in response to invitation between the 4 practices which sent invitations with appointment times ( $X^2=1.43$ ,  $df=3$ ,  $P=0.3$  for an intervention/GP interaction), so these practices will be considered collectively in analysis.

Overall 32 per cent of women (91/288) who were invited attended for screening compared to 7 per cent of those not invited (11/152) ( $X^2=33$ ,  $df=1$ ,  $P<0.001$ ). The attendance rate of 38 per cent among women sent a letter with an appointment exceeded the 24 per cent attendance in women sent a letter without an appointment (Table 5.2.5.1) ( $X^2=7.54$ ,  $df=1$ ,  $P=0.006$ , for an intervention/letter type interaction).

Table 5.2.5.1: Response rates of intervention and control groups

	Letters with appointment		Letters without appointment	
	Control	Intervention	Control	Intervention
Total number	82	162	70	126
Number attended	4	61	7	30
Percentage attended	5	38	10	24
95% CI	(1,12)	(30,46)	(4,20)	(17,32)
Difference	33		14	
95% CI	(24,42)		(14,24)	

Of the 61 attenders who received an invitation with an appointment time, 33 (54 per cent) came at the designated appointment time. Of the 28 women who attended at another time, only 8 (29 per cent) contacted the program to change their appointment.

Age and time since last consultation with the GP were examined as predictors of attendance using chi-square analyses. The relationship between these 2 variables and attendance was similar for the appointment and no-appointment intervention groups and the data were therefore combined.

As shown in Table 5.2.5.2 for the combined data, women who had consulted their GP within the previous 6 months were more likely to attend in response to the invitation (38 per cent, 95% CI: 30% to 46%) than women whose last consultation was over 2 years ago (15 per cent). The attendance rate among women whose last consultation was within the previous 6 months and who were sent a letter with an appointment was 43 per cent (95% CI: 32% to 54%). By

contrast, attendance by women who had recently attended their GP did not increase among those in the control group ( $X^2=7.25$ ,  $df=3$ ,  $P=0.06$ , for an intervention/time since last consultation interaction).

Table 5.2.5.2: Attendance by time since last consultation with general practitioner

Attendance	Time since last consultation				Total
	$\leq 6$ months	$> 6$ months $\leq 1$ year	$> 1$ year $\leq 2$ years	$> 2$ years	
Attended	59 (38%)	10 (24%)	12 (25%)	5 (15%)	86 (31%)
Did not Attend	97 (62%)	31 (76%)	36 (75%)	28 (85%)	192 (69%)
Total	156	41	48	33	278 <sup>a</sup>

$X^2$  Trend=8.18,  $df=1$ ,  $P=0.004$ .

(a) 10 women are omitted from the table because of missing data.

The relationship between age and response to the GP invitation is shown in Table 5.2.5.3. While there was a suggestion that older women responded more than younger women, this was not statistically significant ( $X^2=2.19$ ,  $df=2$ ,  $P=0.3$ , for an intervention/age interaction). The results for both age and time since last consultation did not alter appreciably if they were simultaneously entered in a risk difference model.

Table 5.2.5.3: Attendance by age

Attendance	Age (years)			Total
	45-54	55-64	65-70	
Attended	34 (29%)	30 (28%)	27 (42%)	91 (32%)
Did not attend	82 (71%)	77 (72%)	38 (58%)	197 (68%)
Total	116	107	65	288

$X^2=3.88$ ,  $df=2$ ,  $P=0.14$ .

Three of the 5 practices agreed to send a second invitation to women who had not responded to the initial invitation. Two practices sent letters with appointment times and one sent invitations without appointments. A total of 111 names were provided of women who failed to respond to the first invitation and who had attended the practice in the previous 12 months. Eighteen of these were excluded because they had had a recent mammogram or breast surgery, or had moved to an address outside the screening area. Of the remaining 93 women, 45 were randomly allocated to the intervention group and 48 were allocated to the control group. The attendance rate in the intervention group was 18 per cent (8/45), and in the control group was 2 per cent (1/48), ( $X^2=6.5$ ,  $df=1$ ,  $P=0.01$ ).

## Recommendation during the consultation

### *Method*

In this intervention each woman who entered the practice during a 6-week period (i.e. when the screening van was in the Drummoyne LGA) was screened for eligibility by the receptionist. The receptionist checked that the woman was aged 45 to 70, lived in the CSHS area and had not already attended the program. This was done by either asking the patient or checking the patient card.

If the woman fulfilled all of the criteria, the receptionist opened a sealed envelope provided by the research team. The envelopes were numbered and receptionists were instructed to open them in numerical order. Each envelope gave instructions to give the woman either a pamphlet about the Breast X-Ray Programme (Figure 3.2.4) or a questionnaire (Appendix 8). As with the other GP intervention, one-third of the women were randomised to receive a pamphlet and two-thirds to receive a questionnaire. Women who were given questionnaires were asked to complete them and hand them to the doctor. Receptionists were also asked to record the age and reason for excluding any woman, plus women who refused the questionnaire.

The questionnaire was printed with either the Breast X-Ray Programme logo or the practice letterhead on the top. It consisted of a brief introduction about the program, demographic information (name, address, age, language spoken at

home), plus 5 questions on knowledge and attitudes.

The GP conducted the consultation as usual then gave brief advice on mammography and the program. Advice-giving involved discussing the patient's responses to the questionnaire using information outlined on a GP prompt sheet (Appendix 9). The questionnaire and prompt sheet were designed so that the GP could tailor advice appropriate to the individual woman.

First, in order to introduce the topic, a general question about whether the woman knew anyone with breast cancer was asked. Second, a question about age and risk addressed the fact that the patient was at greater risk than younger women. Next, information was provided about mammography and the fact that it can detect cancers too small to be felt. The fourth point for discussion addressed the woman's concerns about having a mammogram. Finally the GP provided information about the screening van and reinforced his/her support for the program. The GP then gave the woman a pamphlet and offered her an appointment time. This was recorded on an appointment slip for the patient. GPs recorded the appointment time given to each woman, plus the reason for not conducting the advice session with any woman. In addition, reasons for refusing an appointment were noted.

### *Results*

All of the 5 practices (5 GPs) approached agreed to participate. A total of 49 women were entered in the trial during the 6-week study period. Receptionists

offered a pamphlet to 14 women and one woman refused. Of the 13 women who accepted a pamphlet, 6 attended. This gives a total attendance rate of 43 per cent.

A total of 35 women were offered questionnaires and 33 (94 per cent) accepted. Of these, 32 women were given brief advice and offered appointments. Another woman was given brief advice but not offered an appointment. Of the women who were offered appointments, 22 (69 per cent) accepted. Of these, 17 (77 per cent) attended, including 7 (41 per cent) on a day other than their appointment time. The woman who received brief advice only and 3 of the 10 women who refused appointments also attended. This gives an overall attendance rate of 60 per cent (21/35). The difference between the attendance rate for the 2 arms of the trial was 17 per cent (95% CI: -13% to 48%).

The majority of women who refused were not opposed to the idea of screening, but expressed a preference to make their own appointment or to 'drop in' at a time of their convenience. Other reasons for refusal included a fear of radiation exposure, work commitments, a dislike of women doctors (the screening van is staffed by all female staff) and not wanting to know anything about breast cancer and screening.



### **5.2.6 Objective 5: To evaluate a strategy using the electoral listing to recruit women to mammography screening**

#### **Time period**

This intervention was conducted in October 1989 during the van's fourth visit to the LGA. Prior to implementing this strategy, 37 per cent of the eligible population had already attended.

#### **Sample**

A random sample of 385 women aged 45 to 69 resident in the State Electoral District of Drummoyne was selected from the 1989 NSW electoral listing. The names were cross-referenced with a list of Breast X-Ray Programme attenders and women who had already attended were excluded (142/385, i.e. 37 per cent of eligible women). Women on the final list (N=243) were randomly allocated to a control group (who did not receive invitations) or an intervention group (who received invitations). In order to maximise throughput at the screening van, randomisation was done so that a third of the sample would be controls (N=80) and two-thirds (N=163) would receive the invitation letter.

### **Written invitation**

The letter invited each woman by name to attend and was signed by the Director of the Breast X-Ray Programme (Appendix 10). It contained basic information on screening mammography and the program. An appointment was provided plus a contact number for more information or to change the appointment. A pamphlet was enclosed with translations in Greek and Italian (the two major non-English languages in the area).

### **Data collection and analyses**

Response to the invitations was monitored using the program's computerised list of attenders. Language spoken at home was recorded for all women who attended. The time frame for examining the responses to the personalised invitation extended from the day it was posted (between 8 and 12 days before the pre-arranged appointment time) to the last day of screening in the mini-target area. Thus the total time frame extended from 24 October to 9 December 1989. Analyses were performed in the original groups of allocation, even if information became available that women could not be reached at the address given on the electoral roll. Thus data were analysed according to the 'intention to treat' principle; this method of data analysis minimises potential bias.<sup>18</sup>

To determine whether response to the invitations was different by language group, attendance data were compared with 1986 census data. Attendance data comprised of census compatible questions. Overall, census data showed that 30

per cent of the eligible women were from non-English speaking-backgrounds. Prior to this intervention, the screening van had been in Drummoyne LGA at 2 different time periods and had screened 36 per cent (1570/4319) of the eligible population. Of this screened population, 75% (1172/1570) were English speakers and 25 per cent (398/1570) spoke a language other than English at home (Table 5.2.6.2, Col 2). These women previously screened in Drummoyne were subtracted from the census data (Table 5.2.6.2, Column 1) to show the remaining proportion of women in language-groups eligible for screening prior to the electoral listing intervention (Table 5.2.6.2, Col 3).

### Results

Three letters were returned marked 'not at this address'. Overall 33 per cent of women (53/163) (95% CI: 25% to 40%) who were sent invitations attended for screening compared to 9 per cent of those not invited (7/80) (95% CI: 4% to 17%) ( $X^2 = 16.3$ ,  $df = 1$ ,  $P < 0.001$ ).

Of the 53 women who attended, 32 per cent (17/53) attended at the appointment time and 68 per cent (36/53) attended at another time. Forty-four per cent (16/36) of the women who attended at a time other than their original appointment, contacted the program to change their appointment.

Age was examined as a predictor of attendance. There were no significant differences in attendance across the age groups (Table 5.2.6.1:  $X^2 = 2.8$ ,  $df = 2$ ,  $P = 0.3$ ).

Table 5.2.6.1: Attendance by age in intervention group

Age	Attendees		Non-attendees		Total	
	Number	(%)	Number	(%)	Number	(%)
45-54	17	(26)	49	(74)	66	(100)
55-64	23	(35)	43	(65)	66	(100)
65-69	13	(42)	18	(58)	31	(100)
Total	53	(33)	110	(67)	163	(100)

Table 5.2.6.2 compares the proportion of eligible women screened from English (34/1815) and non-English speaking-backgrounds (19/905). There was no significant difference between English and non-English speakers in response to the invitations ( $X^2=0.16$ ,  $df=1$ ,  $P=0.7$ ).

Table 5.2.6.2: Attendance in intervention group by language(s) spoken at home

Language(s) spoken at home	Eligible women in Drummoyne <sup>a</sup>		Women screened prior to intervention		Remaining eligible women		Women responding to intervention	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
English only	2987	(70)	1172	(75)	1815	(67)	34	(64)
Other	1303	(30)	398	(25)	905	(33)	19	(36)
Total	4290	(100)	1570	(100)	2720	(100)	53	(100)

(a) 1986 census data for Drummoyne, postcodes 2046 and 2047. Language spoken was not stated for 29 women (< 1%) and they were excluded from the total.

## **5.3 DISCUSSION**

The aim of this study was to evaluate a promotional campaign to recruit Australian women to mammographic screening. The campaign was conducted in the Drummoyne LGA which has a target population of 4480 women aged 45 to 70. First the study examined the reach or coverage of a generalised strategy aimed at the community as a whole. Second the study evaluated attendance at screening in response to a range of strategies including letterbox drops, invitations for friends, GP written invitations, GP recommendation during the consultation and invitations using the electoral roll.

### **5.3.1 The generalised campaign**

The campaign was unique in that it was conducted in 4 intensive time periods over 2 years, and focussed on general community strategies supplemented by those aimed at individual women. These individualised strategies were designed to have an incremental effect on attendance. In addition it was implemented without the aid of mass media strategies such as TV and advertisements in major newspapers. Consequently it is difficult to find similar Australian programs with which to compare these results.

There is a dearth of comparative information on the reach achieved by other generalised strategies to recruit Australian women to mammography screening. Nevertheless, it would appear that the reach achieved in this study compares

favourably with that achieved by those for cervical screening. For example, after a national mass media campaign for Pap smear screening, 40 per cent of NSW women aged 18 to 70 recalled materials which were produced as part of the campaign.<sup>102</sup> After a statewide media campaign aimed at rural and urban women in Queensland, 89 per cent to 97 per cent of the target population recalled the campaign.<sup>157</sup> A recent study examined the reach of a 4-week regionally-based campaign in rural Victoria which included community education, media coverage and service provision activities. Awareness of Pap test information in those overdue for a Pap test increased from 27 per cent to 62 per cent.<sup>212</sup>

Two years after the commencement of the CSHS generalised strategy, 90 per cent of women had heard of mammography and 81 per cent had heard of screening mammography. Sixty per cent reported 'seeing or hearing' any information about screening mammography in the last 6 months, and 83 per cent were aware of the van's existence. Of note however, is the lack of improvement in knowledge of risk. Only 6 per cent of women were aware of increased risk with age and this did not improve over time. While knowledge alone is not sufficient to ensure attendance,<sup>52</sup> it could be argued that the program should keep highlighting these issues in order for women to make informed decisions about attendance.

The results indicate that non-attendance is not necessarily related to lack of information about screening and the van. Thirty-four per cent of non-attenders reported 'seeing or hearing' 'a moderate amount' or 'quite a lot' of information

and 73 per cent were aware of the van's existence. Thus it appears that for a proportion of women there is a barrier between knowledge and actual attendance. As screening progresses it will be necessary to identify strategies to attract these women.

Forty per cent of women still report no exposure to information about screening mammography. This is quite high when one considers the intensity of the campaign. Again as screening progresses it will be necessary to investigate why these women have not been reached. For example it would be useful to conduct qualitative studies to identify their social networks; that is, where they shop and work, club membership, newspapers and magazines read.

It would appear that for the most part the generalised strategy had an equal effect on different sociodemographic groups. There were 2 exceptions to this and they are in the direction one would hope for. While women from non-English speaking-backgrounds were initially less knowledgeable about mammography than English speakers, they experienced significantly greater improvements as a result of the campaign (32 per cent change for NESB women compared with 17 per cent change in English speakers). This may be one explanation for the results discussed in the introduction to this chapter indicating negligible differences in attendance for the 2 groups.

Similarly, while women from lower occupational status backgrounds were initially exposed to less information about screening mammography they showed greater

increases as a result of the campaign. Thus those from higher occupational status groups showed no change compared with a 26 per cent change in those from lower status groups. At the 2-year follow-up, the 2 groups were reporting being exposed to similar amounts of information.

Some evidence for the costs associated with implementing a similar generalised campaign is provided by the AHMAC report which provides cost per screen estimates based on the cost data for the first 12 to 18 months of operation from the Australian pilot projects. It is not clear how closely one can compare the present campaign with those in the report. However, data from the AHMAC report suggests that it costs between \$8 to \$28 to recruit a woman to screening at a fixed site using generalised strategies supplemented by personal letters to women.<sup>14</sup> The comparative cost for the mobile Breast X-Ray Programme is estimated at \$22.<sup>213</sup>

A recent study conducted at a fixed site in Melbourne examined the efficiency of three public recruitment strategies-local newspaper articles, community promotion and promotion to physicians. Community promotion consisted of localised publicity through displays of motivational material, appointment stalls at shopping centres, and personal contact with community, health and workplace groups. Physician promotion involved the education officer visiting doctors' surgeries. The estimated costs per woman recruited through local newspaper articles and community promotion were \$22 and \$106 respectively. No effect of physician promotion on attendance could be detected.<sup>214</sup>



### 5.3.2 Specific recruitment strategies

In addition to measuring the reach of the generalised campaign, the study examined attendance in response to specific recruitment strategies. The first intervention to be evaluated was a generalised strategy aimed at the community as a whole, i.e. letterbox drops. The randomised trials carried out in this study indicate that this strategy is ineffective regardless of location and the time period of the drop in relation to the screening van's visit to the area. Even if it were considered a real effect rather than due to chance, the overall response was small in relation to the number of pamphlets dropped. An overall relative risk of 1.15 implies that 8 women attended in response to the letterbox drop. To explain in more detail, a total of 62 women attended from intervention streets. A relative risk of  $1.15 = 62/x$  where  $x$  is the number of women who would have attended in the absence of an intervention. From this equation,  $x = 54$ , suggesting only 8 (62-54) extra attendances because of the letterbox drops. These 8 attendances arise from distributing 3984 pamphlets (0.2 per cent); that is about 500 pamphlets need to be distributed to elicit one attendance.

This response is disappointing when the high costs of letterbox dropping are taken into consideration.<sup>210</sup> Although the confidence intervals around the estimate are wide, the results are similar to those found elsewhere, for example in the Lothian Mobile Mammography Project in Edinburgh.<sup>155</sup>

The trials did not test however, the effect of the overall quality of the pamphlet in terms of content and presentation. It may be worthwhile if other programs are using types of material which they believe will have greater affect, to test that hypothesis using a randomised trial with a large sample size. It may also be worthwhile to test whether pamphlets incorporating information in languages other than English are more effective.

In addition the study did not include a process evaluation to address the number of women who actually read the pamphlet and whether the letterbox drop had a flow-on effect outside the intervention streets. This would have occurred if women receiving the letterbox drop discussed the pamphlet with neighbours in the control streets.

Several individualised strategies were also evaluated. The first of these was an intervention entitled 'Invitation for Friends'. This intervention involved asking women attending for screening to take invitations to encourage family and friends to also attend. Other research conducted at the Breast X-Ray Programme indicates that personal networks are important sources of awareness for mammography screening;<sup>190</sup> however, it appears that attempts to make formal use of these networks at an individual level are unsuccessful.

There are several levels at which this intervention may have failed. First a high proportion of attenders refused to take the invitation in the first place (23 per cent in the trial with no incentive and 29 per cent in the trial with an incentive).

Those who accepted the invitations may have subsequently not distributed them to friends, or alternatively the friends may have declined the invitation or accepted it and then failed to respond.

When the intervention was piloted, respondents stated that they had regular contact with family and friends and therefore would have opportunities to distribute invitations before the van left the area. However, this intervention may be more appropriate for a fixed service which provides women with a longer time period in which to distribute invitations. In addition it may be worthwhile to trial the strategy in a simpler, less formal format. Instead of asking attenders to hand friends a bulging envelope with an explanatory letter with appointment time, contact phone number and pamphlet, it may be more acceptable to ask them to simply distribute pamphlets to friends.

The use of an incentive did not improve the response to this intervention. The reaction of attenders to being offered a scratch lottery ticket was that they felt somewhat embarrassed. Attenders stated that the lottery ticket was not necessary and it somehow undermined their motivation for encouraging friends to attend. The nature of the incentive itself may have been inappropriate or alternatively this approach may not be effective given the relatively intimate nature of screening mammography attendance for the individual woman.

It is possible that the number of attenders responding to the intervention was underestimated as some women may have attended at a time other than their

appointment time and did not inform the program about their original appointment and how they found out about the service.

The second individualised strategy to be evaluated was a written invitation from the GP. The results show a 38 per cent response rate from women receiving a written invitation with appointment from the GP and a 24 per cent response from women receiving a general GP invitation. These figures are low compared to those achieved in overseas evaluations of this strategy which have ranged from 46 per cent<sup>175</sup> to 86 per cent.<sup>176</sup> However, it should be noted that it was obtained after a large proportion of women had already been recruited through more general strategies. The fact that the invitations were aimed at the more reluctant participant is confirmed by the result that 27 per cent of the women on the GP files had already attended. This is the same as the percentage of women estimated to have attended from Drummoyne using the address given by attenders as the numerator and census data on women aged 45 to 69 in Drummoyne as the denominator.

Including a second letter for non-respondents appears to be a useful practice. In this study, 18 per cent of non-respondents who had attended the practice in the last 12 months subsequently responded to a reminder letter. The HIP study<sup>45</sup> found that a second contact increased the response rate from 47 per cent to 54 per cent and repeated contacts increased attendance to 65 per cent. In the Utrecht study the response rate after one letter was 66 per cent and a second letter brought a further 6 per cent attendance.<sup>165</sup> Similarly in a recent study at

a mobile screening van, response to the first contact (with an appointment time) was 70 per cent; this increased to 84 per cent for a second contact and 86 per cent for a third contact.<sup>176</sup>

The response to the invitations can also be interpreted in relation to background levels of community knowledge prior to the implementation of the strategy. While knowledge alone is not sufficient motivation for attendance,<sup>52</sup> it is obvious that a woman will be more reluctant to attend a service which she has not heard about before. Levels of background community knowledge were obtained in the second survey of campaign reach which was conducted about four months before this study. It indicated that while the majority of women in Drummoyne were aware of mammography (88 per cent) and screening mammography (66 per cent), 44 per cent were unaware of the existence of the Breast X-Ray Programme. Thus it may be possible to improve the response rates by supplementing the strategy with more background information.

Despite the fact that almost half of the women who attended did so at a time other than their appointment time, the invitations with an appointment produced higher participation. In addition, many women who attended at a time other than their appointment time did so without contacting the program, suggesting that screening services need to have a flexible approach to appointment times. Thus while women may prefer to 'drop in' to the screening van at a time of their convenience, a definite appointment makes it more likely that women will attend. While allocation to appointment and no-appointment letters was not

random, these results are compatible with prior evidence from other studies for breast<sup>176</sup> and cervical cancer screening.<sup>215</sup> For example a randomised study by Williams and Vessey<sup>176</sup> compared the response rate to invitations including a definite appointment with those with an open-ended request to make an appointment. The results indicated an 86 per cent response rate from the appointment group compared with a 76 per cent response rate from the open-ended invitation group.

The response to the invitations was higher in women who had consulted the GP more recently, a similar result to that found in the HIP study.<sup>45</sup> This may be because recent GP attenders are more likely to use health services in general, or because they identify more with the source of the invitation. At the other extreme, women who have not seen that GP for over a year may indeed be using another practitioner and may not see the GP who has sent the invitation as their source of health care.

These results suggest that in Australia, invitations by GP letter are able to improve screening rates for older women at least as much as for younger women. This is encouraging given that both the demonstration projects indicate that older women have generally lower attendance rates.<sup>21,23,28,45,165,167</sup> Indeed, older women in Australia perceive themselves as less susceptible to breast cancer,<sup>81</sup> although in reality they are more at risk.<sup>8</sup>

While the sample is small, the study evaluating GP recommendation during the

consultation also showed promising results. A 60 per cent (21/35) attendance rate was obtained for those women who were offered advice, and a 43 per cent (6/14) response rate was found for those women who received a pamphlet from the receptionist. This compares with a recent study in Victoria which found a 41 per cent response rate in those given verbal advice.<sup>181</sup>

The higher response rate in the current study may be due to the more intensive nature of the intervention which required the GP to discuss the woman's response to questionnaire items and also offer her a pamphlet and appointment. In comparison in the Victorian study the GP simply recommended the service and offered a pamphlet. It should be noted however, that the actual process of the intervention is unclear as the interaction between GP and woman was not recorded. Consequently it is not possible to obtain reliable estimates of, for example, the proportion of times the GP actually offered the pamphlet.

The 43 per cent response rate for the minimal intervention whereby the receptionist simply offered a pamphlet is very encouraging. The main advantage of this intervention is that it is less intensive than the GP advice strategy. These results confirm those of another study examining women's sources of awareness about the program.<sup>190</sup> The second most reported source was GPs and 25 per cent of this response was attributed to posters and pamphlets in the GP's surgery. Thus this intervention may be an important action in recruiting women to screening especially where the GP may not have time to discuss mammographic screening or may forget to mention the service. Again, it would

be worthwhile to evaluate this intervention using a randomised trial design.

A major disadvantage of these interventions is that they require constant vigilance by both the receptionist and GP to identify and deal appropriately with eligible women. Increased ongoing vigilance to detect a smaller number of unscreened women will occur as screening becomes more common. Interviews conducted with GPs after the intervention indicated that, while they were positive about the strategy, time constraints had placed them under pressure. In addition, the number of eligible women is small in the few weeks when the mobile van is visiting the area. During the 6-week period of the study only 49 eligible women were reported for the 5 practices. This was found to be a reliable estimate when checked against Medicare records of the average number of GP consultations per year for women aged 40 to 69.<sup>188</sup> In comparison, the Victorian study collected 135 eligible women over a 2-week period from one practice. However, this study had a larger pool of eligible women from which to recruit as the program had only been operating for 3 months compared with approximately 14 months in the current study.

The final strategy to be evaluated was the use of the electoral listing to recruit Australian women for mammography screening. The results indicate that 33 per cent of women sent invitations for screening attended. This figure was achieved after 36 per cent of the population had already attended for screening and therefore the invitations were aimed at the more reluctant participant.



This attendance rate compares favourably with that obtained by general practitioner invitations. These results indicate that it is possible to achieve a similar response with an approach by a health professional unknown to the woman. Similar to the results for the GP invitations, about half of the women who attended at a time other than their designated appointment time did not inform the program. This supports the previous suggestion that screening services may need to develop a flexible approach to booking these type of appointments.

As with the results for the GP invitations, there is a suggestion that older women respond more than younger women. In addition, the distribution of language spoken at home is similar for electoral invitation attenders and the community as a whole (Table 5.2.6.2). In comparison, prior to the intervention, the program had screened a slightly disproportionately high number of English speakers (75 per cent of attenders spoke only English at home compared with 70 per cent in the general population). Thus the electoral listing may be an equally effective intervention for attracting older women and women of non-English speaking-backgrounds who are traditionally more reluctant to attend for screening.<sup>46,47,48,216</sup>

### **5.3.3 A potential model for recruitment**

In addition to evaluating the response rates to the different trials it is important to discuss how the strategies can be incorporated into a model for recruitment. The ultimate decision as to which interventions should be put in place will

depend not only on the efficacy of the strategies but also on the relative costs and potential for implementing the results at a broad community level. The results of this study suggest that one potential model for recruitment is a 3-tiered approach which incorporates both generalised strategies supplemented by those aimed at individual women; this approach might be anticipated to achieve an attendance rate of about 60 per cent.

### **Stratum 1**

The first stratum of the model is the generalised strategies which the current study indicates can recruit about the first one-third of women who are enthusiastic. Other Australian and overseas mobile mammography screening programs have had similar experiences. In the Hunter Valley NSW, about a third of women were recruited via minimal mass media.<sup>14</sup> Two studies in the UK found that generalised strategies produced attendance rates of 24 per cent<sup>155</sup> and 28 per cent.<sup>156</sup> While this study has not attempted to examine which components of these strategies are most effective, other research on sources of awareness about the service provides some indication. This research indicates that 'seeing the van' is the most important source followed by GPs, print media such as posters, pamphlets and newspapers. Together these strategies account for 75 per cent of sources of awareness.<sup>190</sup>

## **Stratum 2**

Stratum 2 includes the individualised approaches which are designed to have an incremental effect on attendance over that achieved by the generalised strategies. It is important that the individualised and generalised strategies are implemented in a combined manner so that they complement each other. The generalised strategies not only recruit the more enthusiastic attender but are intended to provide a backdrop or 'set the stage' for the individualised approaches.

It is also important for screening programs to be cognisant of possible 'flow-on' effects if several different individualised strategies are implemented together. If such an approach is applied, it is possible for a woman to receive multiple invitations from different sources to attend for screening. This may have a positive effect in that the invitations may reinforce each other. Alternatively women may feel inundated with the different invitations which may actually deter them from attending.

This research has evaluated a range of strategies and found the following to be the more effective in terms of attendance rates: GP written invitations and invitations using the electoral roll, GP advice during the consultation and a pamphlet about the screening program from the receptionist. The GP approaches are potentially generalisable to a broad community level as they appear to be acceptable to GPs. Out of the 11 randomly selected practices approached, 10 (91 per cent) agreed to participate. The intervention involving

the GP receptionist giving pamphlets to eligible patients may be a more sustainable long-term approach compared with the GP giving advice during the consultation as it requires less intensive input.

Written invitations are perhaps the most practical strategy to implement at the population level. This study has found invitations from the screening program using the electoral roll and GP written invitations have similar results. When these are applied after about one-third of the more enthusiastic women have attended, they have the potential to produce attendance rates of about 30 per cent (33 and 38 per cent respectively). This amounts to approximately an additional 25 per cent. For example in the case of the GP written invitations, it was demonstrated that 38 per cent of the remaining 73 per cent (i.e. an additional 28 per cent) may be recruited by this approach.

Screening services can encourage GPs to send invitations by providing support for accessing files and organising invitations. An approach similar to that used in the Edinburgh unit may be considered where a register of eligible women was constructed and computerised for each consenting practice. The register is updated by the screening program and all names on the register are flagged through the National Health Service Central Registry so that subsequent events (both cancer incidence and mortality) can be monitored.<sup>167</sup> Perhaps the most generalisable strategy is the electoral roll invitations in that they require liaising with one central organisation (the electoral commission) as opposed to many GPs.

Several issues are important when considering implementation of the GP and electoral roll invitations. First, it may be necessary to implement both interventions if it is found that they attract different sociodemographic groups. While the current study shows that there are no age differences in response to both interventions, it would be ideal to examine the sociodemographic profile of attenders in more detail. This would help to determine whether one intervention is more likely to attract certain women than the other intervention.

Second, it is essential for both interventions that records of attenders are accurate and searched thoroughly, as a letter sent to someone already screened may be interpreted as a need for further investigation rather than an administrative error. Invitations could also ask women to contact the program if they have already attended. This will become more important as screening rates in the community increase.

Third, the effectiveness of both interventions will rely heavily on the accuracy of the electoral roll and GP lists. In the electoral roll intervention only 3 letters were returned as not known at this address; however there is other recent evidence that 6 per cent to 7 per cent of addresses are incorrect.<sup>205</sup> In the trial of GP written invitations, GPs were asked to exclude those women who should not receive an invitation because they had a serious medical condition or because they had had a recent mammogram. Twelve women were excluded on this basis before the women were randomly allocated to experimental and control groups. However, after the invitations were posted it was found that 15

women had had recent mammograms elsewhere, four had moved out of the area, 2 were away at the time and one had already been screened by the program. This highlights the need for screening programs to assist GPs to check their lists in order to eliminate women for whom it is inappropriate to invite to screening.

Fourth, the relative cost of the 2 interventions needs to be considered. An approximate costing of the GP written invitations was conducted by identifying and measuring the various expenses involved such as staff and consumables. The marginal cost per woman attending (excluding the evaluation component) in response to the first letter (with and without appointment time combined) was \$44.50. The cost for the follow-up letter to non-respondents was \$35.48.<sup>217</sup>

A recent Australian study also examined the costs of sending personalised letters from the program to women listed on the electoral roll.<sup>214</sup> The results are not directly comparable as average costs were used as opposed to marginal costs as in the present study; however, it is appropriate to also describe these other results. Five individualised strategies were examined including invitation letters (with and without specific appointment times) alone and with a follow-up letter or telephone call to non-attenders. These were implemented in the sixth month of the program and were sent to women who had not previously attended.

The most efficient personal recruitment strategy was an invitation without a specific appointment time plus a follow-up letter to non-attenders. This cost \$10.52 per attender and recruited 35.6 per cent of women in the sample who

received it. In comparison, a letter with a specific appointment time plus a second letter to non-attenders recruited 44.1 per cent of women, at an average cost of \$19.99 per woman recruited.<sup>214</sup>

### **Stratum 3**

Stratum 3 of the model is the repeat written invitations aimed at women who do not respond to the first written invitation. Although reminder letters were not tested for electoral roll invitations, the trial of GP written invitations shows that a second letter increases attendance by approximately another 5 per cent. To explain in more detail, the trial of GP written invitations suggested that the first 55 per cent of women may be recruited via the generalised strategies (27 per cent) followed by the first GP written invitation (an additional 28 per cent). The study then found that 18 per cent of the remaining 45 per cent (i.e. an additional 8 per cent) may be recruited by second invitations. This gives a total attendance rate of 63 per cent.

In comparison, to overview the results from the electoral roll trial: results showed that thirty-six per cent of attenders may be recruited mainly through generalised strategies, supplemented with some individualised approaches such as GP written invitations. Thirty three per cent of the remaining 64 per cent may be obtained with invitations from the program (i.e. an additional 21 per cent). These strategies achieve an overall attendance rate of 57 per cent.

Two considerations should be taken into account when using follow-up letters to recruit Australian women to screening. First the issue of privacy and acceptability is important. There was no negative feedback from women receiving a second GP letter; however, it is not clear how acceptable women would find further reminders as used in the HIP<sup>45</sup> and other studies.<sup>175,178</sup> In addition it is unclear as to how acceptable women would find a second letter from the service. This may prove to be less acceptable than a second letter from the GP, as the source of the letter (i.e. the screening program) is less familiar to the woman. However, this was not found to be the case in a recent qualitative study in Victoria which assessed women's responses to receiving a second letter from the Essendon Breast X-Ray Program.<sup>218</sup> Although the numbers were small (N=11), it was concluded that women were not offended by the second letter and about half were positive. It was suggested however, that using a certified mail procedure to send the invitations may affront and induce concern in a small number of women.

The issue of cost of the follow-up letter also needs to be considered. Screening programs may find that putting effort into the generalised strategies to attract higher numbers of enthusiastic women is more cost-effective than repeated efforts in a smaller pool of reluctant women. Screening programs will need to decide after what point they regard a woman as no longer potentially recruitable.



### 5.3.4 Conclusions

It would appear from this research that the 70 per cent attendance rate proposed by the Health For All Australians<sup>41</sup> and AHMAC<sup>14</sup> reports may be achievable. As demonstrated, by applying a combination of generalised strategies supplemented by individual invitations from the GP or screening program (via the electoral roll), an attendance rate of about 60 per cent can be achieved. This might be improved by the incorporation of mass media strategies such as TV, magazines and metropolitan newspapers which overseas programs have found to be important sources of awareness about mammography screening.<sup>80,219</sup>

The ideal way to confirm which combination of strategies produce the greater attendance rate would be to conduct a randomised trial using a sample of women who were listed on both the electoral roll and participating GP lists. First a generalised strategy would be conducted. Women who did not attend in response to this intervention would then be randomised to receive either a GP written invitation or an invitation from the service. Next, non-attenders from both interventions would be randomly allocated to receive a follow-up letter from either the GP or the screening service.

In conclusion it should be stated that these results need to be considered in view of the sociodemographic context of Drummoyne and the Central Sydney Health Service area. This is a community near the centre of a large city where about a third of eligible women speak a language other than English at home (Chapter

3). The strategies trialled in this area need to be further tested in order to examine generalisability to other localities. For example it may be worthwhile repeating the invitation for friends and letterbox strategies in other communities. This would help to determine for example, whether the letterbox drop is more effective in communities with a higher proportion of English speakers, and whether the invitations for friends are more effective in communities which have different social networks. In addition the model for recruitment put forward in this chapter is based on a mobile screening van. Clearly other approaches will need to be considered for fixed site services.

## CHAPTER 6

### THE PSYCHOSOCIAL IMPACT OF BEING RECALLED FOR FURTHER TESTS FOLLOWING ATTENDANCE FOR MAMMOGRAPHY SCREENING

#### 6.1 INTRODUCTION

Since screening tests are not always accurate indicators of whether a woman has cancer, screened women fall into 4 groups. These are categorised according to whether they have cancer and whether the screening test is positive or negative.<sup>14</sup>

These 4 groups are as follows:

1. true positives: women who the screen correctly indicates to have breast cancer;
2. false positives: women who do not have breast cancer but who have a positive screening test;
3. true negatives: women who do not have the disease and have a negative screen; and
4. false negatives: women who prove to have breast cancer but are mistakenly cleared by the screen.<sup>14</sup>

Table 6.1.1 summarises the benefits and adverse effects for each of these 4 groups and the likely proportions of screened women who will fall into each group. The false positives form the second largest group of screened women. While these women may be eventually reassured that they do not have cancer,

in the meantime they face anxiety and further investigations.

In the Australian pilot projects around 6-13 per cent of women screened were in the false positive category in the first round of screening. While this is high compared with the rates of 2-5 per cent achieved overseas, it is argued that this should decline to between 5-10 per cent as clinical experience increases. In addition it should drop below 5 per cent of all women screened as the screening program approaches 'steady-state' operation by round 3 or 4.<sup>14</sup>

**Table 6.1.1: Benefits and adverse effects anticipated among a group of 10000 women attending for their first screen**

Group	Expected number	Benefit	Adverse effects
True positive	50-80 (<1%)	Mortality reduction, less invasive treatment	Anxiety
False positive	420-950 (4-10%)	Reassurance after investigation	Anxiety, negative investigations
True negative	9000-9500 (90-95%)	Reassurance	Inconvenience of screening, transient anxiety after screening
False negative	Up to 4 (<0.04%)	Nil	False reassurance, possible delay in treatment

Based on Table 7.1. Breast cancer screening in Australia: future directions.<sup>14</sup>

In the first 18 months of operation of the Breast X-Ray Programme the recall rate was 16.5 per cent. Recall fell into 3 groups. First, 3.8 per cent were recalled for technical faults including poor positioning of the breast or poor film

quality. Second, 12.6 per cent were recalled for radiological reasons following recommendation by one or both reporting radiologists. Third, 0.1 per cent were recalled for clinical reasons; that is, they gave a history of breast lump even though both radiologists reported the screening films as normal.<sup>93</sup>

After attending the screening van all women were given a pamphlet explaining that a proportion will be recalled for further tests and this does not necessarily mean cancer. Recalled women were either sent a letter with an appointment to attend the assessment centre or telephoned. Some women were approached both by telephone and letter. GPs were also notified if the woman had requested.

At the assessment centre an appropriate work-up for each recalled woman was selected by the program director. The work-up included extra mammographic views, special mammographic techniques and ultrasound. If the results of the assessment were not suspicious of malignancy, the director informed the woman in a brief consultation. Both the woman and her GP were then notified by mail of these findings.<sup>93</sup>

Those women in need of further evaluation were referred for surgical assessment and planning of management either to one of 7 surgeons attached to the service or to a surgeon of their own or their GP's choice. Assessment included physical and surgical examination (i.e. biopsy) by the surgeon. A small number of women were given clinical follow-up only. Of all recalled women, 9.9 per cent

proceeded to surgical consultation.<sup>93</sup>

Overall of those recalled, 95.5 per cent subsequently proved not to have a malignancy, i.e. were false positives. While the detection rate of the program compares favourably with those from overseas,<sup>93</sup> it is clear that there is great potential for anxiety generated by false positive results.

Anxiety is a negative outcome in itself as it affects a woman's quality of life. In addition a false positive result might affect what a woman tells her friends about screening. The latter is important as both Australian<sup>190</sup> and overseas research<sup>88</sup> indicates that information from friends is a major source of awareness about screening.

Previous research indicates that about 80 per cent of women do not equate callback for further tests with a diagnosis of cancer.<sup>81</sup> However, this research was conducted on a random community sample and may not reflect the perceptions of those who are recalled. Indeed, research examining women's responses to an abnormal Pap smear result indicate that the majority fear that they have cancer.<sup>220</sup> It is likely that a woman who is recalled for further tests following attendance for mammography is faced with similar concerns about breast cancer and all that it means. A US study conducted using focus groups with women drawn from the general community found that breast cancer was associated with mastectomy and death.<sup>76</sup>

When considering the impact of a false-positive result it is necessary to consider the context in which women attend for mammography. In comparison with the clinical consultation where the patient seeks out the clinician, mammography requires well women to volunteer for screening. The implied promise is that women will derive health benefit. At best this includes reassurance and peace of mind and at least an increased chance of longer survival and less radical surgery.<sup>221</sup> Indeed a recent study indicated that over a third of women attended for screening because they believed that it was a good opportunity or that it was for their own benefit. These ideas were closely followed by issues such as the chance for reassurance or peace of mind.<sup>49</sup> Clearly when a woman is recalled the implied promise of benefit is immediately brought into question at least until she is cleared by further tests.

The impact of a false positive result on the psychological well-being of women has been the issue of some debate. It has even been argued that the anxiety induced in women with false positive results outweighs the benefit of prolongation of life for some cancer patients.<sup>222</sup> The problem is highlighted by the fact that a delay of 8 weeks is common between detection of an abnormality and a hospital appointment in some UK centres.<sup>223</sup>

Roberts<sup>34</sup> has identified the false positive rate of 10 per cent in the UK program to be a major problem. She maintains that while it does not cause all women psychological harm, it is traumatic for many. The need for counselling services and more research into the psychological aspects of screening was noted in

responses to Roberts' article.<sup>224,225</sup> The consensus statement from an earlier King's Fund report also concluded that a screening program requires the services of a trained nurse counsellor.<sup>226</sup> The anxiety and delays in assessment faced by some women is well illustrated in a case history reported by Fentiman<sup>227</sup> and a subsequent response.<sup>228</sup> Concern about the effect of false positive results has also been expressed in the Australian research.<sup>229</sup>

The literature highlights several specific issues in relation to the false positive result. First, Marteau<sup>230</sup> argues that many people undergo screening without understanding exactly what the test is for, the accuracy of the test, and the implications of possible test results. She maintains that these are the bases of many potentially avoidable adverse psychological consequences of screening. Second, while the subsequent normal test results may be of relief to some women, for others it is difficult to remove the 'seeds of doubt'.<sup>231</sup> Third, the process involves labelling well women as unhealthy, for a short period of time at least. The negative outcomes of such labelling have been indicated in research into hypertension screening.<sup>232</sup>

In addition the very process of confirming that a woman does not have an abnormality is anxiety provoking. The woman faces more invasive investigations and delays as other opinions are obtained and the clinician confirms the diagnosis. She may face further delays and anxiety if the clinician wants to reassess her later.<sup>233</sup> The extreme case is the woman who has one or more biopsies in order to confirm a normal result. It is speculated that this woman



may lose confidence in the efficacy of screening and may potentially suffer from life-long body image distortion.<sup>130</sup>

A search of the literature in the last 15 years revealed only 3 empirical studies into the effect of false positive results in relation to mammography screening. There have been no published Australian studies. A study by Ellman, Angeli, Christians, Moss Chamberlain and Maguire<sup>90</sup> compared psychiatric morbidity in 287 attenders at screening in whom no abnormality was found (routinely screened women) and 266 review clinic attenders whose further investigation showed no cancer (false positives). Women completed the 28-item General Health Questionnaire (GHQ) before seeing the doctor or undergoing screening and 3 months later. The prevalence of probable psychiatric morbidity among women in the false positive group was slightly but not significantly higher than in those attending for routine screening. Anxiety symptoms were significantly more common in the false positive group and a few women admitted to experiencing panic while waiting for their review clinic appointment. Three months after clinic attendance, the prevalence of psychiatric morbidity had fallen significantly to the same level in both the routinely screened and false positive group.

A study by Lerman, Trock, Rimer, Boyce, Jepson and Engstrom<sup>92</sup> compared women with normal mammograms (N=121), women with low-suspicion mammograms (N=119), and women with high-suspicion mammograms (N=68). The study excluded women with breast cancer. Psychological responses 3 months

after mammography and adherence to subsequent mammography were assessed. Women with high-suspicion mammograms had substantial mammography-related anxiety (47 per cent) and worries about breast cancer (41 per cent). Such worries affected the moods (26 per cent) and daily functioning (17 per cent) of these women, despite diagnostic evaluation excluding malignancy. For each variable, a consistent but non-significant trend was seen with degree of mammogram abnormality. Sixty-eight per cent of women with normal results, 78 per cent with low suspicion results and 74 per cent of women with high-suspicion results obtained their subsequent annual mammograms ( $P > 0.05$ ). The study concluded that a substantial proportion of women with suspicious mammograms have psychological difficulties, even after learning that they do not have cancer; however, such sequelae do not appear to interfere with subsequent adherence.

Another recent study by Gram, Lund and Slenker<sup>91</sup> compared 126 women who had a false positive mammogram with 152 women randomly selected among screenees with a negative exam. Eighteen months after the screening the reported prevalence of anxiety about breast cancer was 29 per cent among women with a false positive and 13 per cent among women with a negative screening mammogram ( $P = 0.001$ ). A false positive mammogram was described by 5 per cent of the women as the worst thing they had ever experienced. However, most women with a false positive result regarded this experience, in retrospect, as but one of many minor stressful experiences creating a temporary decrease in quality of life. They reported the same quality of life today as

women with negative screening results and 98 per cent would attend another screening.

Further evidence comes from several studies into Pap smear screening. While these are not confined to women with false positive results, they suggest that an abnormal result produces a range of negative outcomes. These include fear of cancer and possible death and fear of the medical procedure.<sup>234,235</sup>

Other studies into neonatal screening programs also provide evidence of the negative impact of false positive results. These include adverse effects on the parent-child relationship;<sup>236,237</sup> persistent insecurity regarding the baby's health;<sup>238</sup> heightened anxiety until normal results are obtained;<sup>239</sup> and concern about the health of the infant.<sup>240</sup>

It is clear that there is great potential for adverse psychological effects as a consequence of a false positive result after attending mammography screening. Given the high proportion of screened women receiving false positive results and the dearth of Australian research it is important that this issue be addressed. The aim of this study is to compare women with normal results with those who are recalled for further tests and subsequently prove not to have a malignancy, i.e. a false positive group. As the study is concerned with long-term effects, the sample is restricted to women who were screened 12 months ago or more. The study concentrates on women's concerns and feelings of personal susceptibility. In addition it includes other variables which might reasonably be affected by the

recall process including attitudes towards screening and knowledge about treatment and survival.

## **6.2 METHODS**

### **6.2.1 Study design and sample**

This study was carried out between February and May 1990, 2 years after the Breast X-Ray Programme had commenced. The sample was drawn from women who had attended the Breast X-Ray Programme 12 months ago or more. The false positive group comprised randomly selected women who had been recalled for further tests and had subsequently been shown not to have a malignancy. Women who had gone on to biopsy were excluded. The normal screenee group were randomly selected women who had not been recalled for further tests. It was aimed to survey 200 recalled women and 200 women who had not been recalled.

### **6.2.2 Method of data collection**

#### **Procedure**

This has been described in detail in Chapter 2. Data were collected as part of a wider community survey and interviewers were blind as to the study groups. Telephone interviews were sought with women aged 45 to 70 years using a centralised telephone interviewing field team. Women identified as non-English-speaking from the initial contact were subsequently interviewed by interpreters in the appropriate language.

## **Measurements obtained**

These have been described in detail in Chapter 2. In summary the following variables were used in this study.

**Knowledge:** including knowledge of survival and treatment, plus overall knowledge of risk.

**Attitudes:** including the scale measuring benefits and barriers associated with screening procedures; belief that callback for further tests means you have breast cancer; and concern about radiation.

**Prior experience:** a series of questions asked women if they had ever had breast cancer; ever had a lump in the breast; had a mother, sister or daughter with breast cancer; or knew anyone with breast cancer. Women were also asked when they had their most recent mammogram.

**Breast Self-Examination (BSE):** 2 questions asked women if they had examined their breasts in the last 12 months to check for lumps, and if so how often.

**Perceptions of chance of getting breast cancer:** women were asked to estimate their chances of getting breast cancer compared to other women of their age.

**Concern in the last 12 months about the possibility of getting breast cancer:** women were also asked if they had been concerned over the past 12 months about the possibility that they may get breast cancer, and about the amount and frequency of their concern.

**Spoken to a doctor or other health professional about concern:** women were asked whether they had spoken to a doctor or other health professional about

their concern.

**Morbid concern about breast cancer:** women who expressed concern were subsequently asked a series of 11 questions about how this concern had affected their daily life.

**Sociodemographic information:** including age, educational level, occupational prestige level of the main income earner in the household, and language spoken at home.

### **6.2.3 Analyses**

Differences between the recalled and non-recalled groups were tested for significance by the chi-square test. Ordered variables were tested for significance by the chi-square test for linear trend. Adjacent categories were combined where more than 20 per cent of cells had an expected frequency of less than 5.

## 6.3 RESULTS

### 6.3.1 Response rates and sample characteristics

Interviews were conducted with 159 women who had been recalled (response rate: 68 per cent) and 179 non-recalled women (response rate 57 per cent). The difference between the response rates of the 2 groups was not statistically significant ( $X^2=3.42$ ,  $df=1$ ,  $P=0.06$ ). The sample characteristics are shown in Tables 6.3.1.1 to 6.3.1.4.<sup>i</sup>

#### Age

There was no significant difference in age between the 2 groups ( $X^2=3.6$ ,  $df=4$ ,  $P=0.5$ ). Except for the 45-49 year age group, each category comprised about 20 per cent of the sample (Table 6.3.1.1).

Table 6.3.1.1: Age of recalled and non-recalled women

Age group (years)	Recalled women		Non-recalled women		Total	
	No.	%	No.	%	No.	%
45-49	20	12.8	29	16.2	49	14.6
50-54	37	23.7	29	16.2	66	19.7
55-59	31	19.9	42	23.5	73	21.8
60-64	35	22.4	42	23.5	77	23.0
65-70	33	21.2	37	20.7	70	20.9
Total	156	100.0	179	100.0	335	100.0

i. Totals do not always add up to the full number due to missing data. Up to 16 responses were missing from each group for any particular question.



### Language spoken at home

There was no difference in the language spoken at home for the 2 groups (Table 6.3.1.2) ( $X^2=1.96$ ,  $df=2$ ,  $P=0.4$ ). Almost a third of women were from non-English speaking-backgrounds.

Table 6.3.1.2: Language spoken at home of recalled and non-recalled women

Language spoken at home	Recalled women		Non-recalled women		Total	
	No.	%	No.	%	No.	%
English only	114	71.7	138	77.1	252	74.6
Language other than English <sup>i</sup>	18	11.3	20	11.2	38	11.2
Interviewed by interpreter	27	17.0	21	11.7	48	14.2
Total	159	100.0	179	100.0	338	100.0

i. Women who speak a language other than English at home but were interviewed in English.

### Occupational prestige of the main income earner in the household

Occupational prestige is shown in Table 6.3.1.3. There was no significant difference between the 2 groups ( $X^2=2.61$ ,  $df=4$ ,  $P=0.6$ ). Overall, 57 per cent of women were classified in occupational prestige categories 3 and 4.

Table 6.3.1.3: Occupational prestige of the main income earner in household of recalled and non-recalled women

Occupational prestige of the main income earner <sup>1</sup>	Recalled women		Non-recalled women		Total	
	No.	%	No.	%	No.	%
Highest prestige categories 1 & 2	18	12.5	25	14.6	43	13.7
3	30	20.8	38	22.2	68	21.6
4	49	34.0	62	36.3	111	35.2
5	19	13.2	24	14.0	43	13.7
Lowest prestige category 6	28	19.4	22	12.9	50	15.9
Total	144	100.0	171	100.0	315	100.0

i. Daniel's scale of occupational prestige<sup>99</sup>

#### Educational level of the woman

There was no significant difference between the 2 groups in educational level (Table 6.3.1.4) ( $X^2=1.45$ ,  $df=3$ ,  $P=0.7$ ). About 40 per cent of women had completed 1 to 4 years secondary schooling.

Table 6.3.1.4: Educational level completed by recalled and non-recalled women

Educational level	Recalled women		Non-recalled women		Total	
	No.	%	No.	%	No.	%
Primary	32	20.4	28	16.2	60	18.2
1-4 years secondary	65	41.4	77	44.5	142	43.0
5-6 years secondary	23	14.6	30	17.3	53	16.1
Tertiary	37	23.6	38	22.0	75	22.7
Total	157	100.0	173	100.0	330	100.0

### 6.3.2 Outcome Measures

#### Knowledge

As shown in Table 6.3.2.1 there were no differences between the recalled and non-recalled groups for any of the knowledge variables. Almost 90 per cent were aware that with early treatment most women live for 10 years or more after diagnosis. About one-third were aware of lumpectomy as a treatment for breast cancer and about one-third were regarded as knowledgeable about breast cancer risk.

Table 6.3.2.1: Knowledge of recalled and non-recalled women

	Recalled women (N=159)	Non-recalled women (N=179)	X <sup>2</sup>	df	P value
Knows survival for breast cancer	87%	87%	0.00	1	1.0
Knows about lumpectomy	32%	38%	1.29	1	0.3
Regarded as knowledgeable about risk of breast cancer	36%	35%	0.06	1	0.8

## Attitudes

As indicated in Table 6.3.2.2 the majority of women had favourable attitudes towards screening mammography. There was no significant difference between the 2 groups. About 10 per cent believed that callback for further tests means breast cancer. There was no significant difference between the 2 groups.

Table 6.3.2.2: Attitudes of recalled and non-recalled women

	Recalled women (N=159)	Non-recalled women (N=179)	X <sup>2</sup>	df	P value
Has a favourable attitude towards screening mammography	91%	94%	0.93	1	0.3
Believes that callback for further tests means cancer	9%	10%	0.1	2	1.0

Similarly, there was no difference in concern about radiation with about half the group being not at all concerned and about a third being a little concerned ( $X^2=2.16$ ,  $df=3$ ,  $P=0.5$ ) (Table 6.3.2.3).

Table 6.3.2.3: Concern about radiation among recalled and non-recalled women

Concern about radiation	Recalled women		Non-recalled women	
	No.	%	No.	%
Not at all concerned	81	50.9	98	55.7
A little concerned	48	30.2	55	31.3
Quite concerned	16	10.1	12	6.8
Very concerned	14	8.8	11	6.3
Total	159	100.0	176	100.0

### Prior experience

Overall 20 per cent of the recalled women and 12 per cent of the non-recalled women reported that they had ever had a lump in the breast ( $X^2=3.85$ ,  $df=1$ ,  $P=0.05$ ). The recalled women were more likely to have had a lump in the breast or breast cancer when these 2 categories were combined ( $X^2$  Trend=4.38,  $df=1$ ,  $P=0.04$ ) (Table 6.3.2.4).

Table 6.3.2.4: Experience with breast cancer among recalled and non-recalled women

Experience with breast cancer	Recalled women		Non-recalled women	
	No.	%	No.	%
Knows no-one with breast cancer	14	8.8	14	7.8
Knows someone with breast cancer	95	59.7	130	72.6
Has a relative with breast cancer	16	10.1	12	6.7
Has had a lump in the breast or has had breast cancer	34	21.4	23	12.9
Total	159	100.0	179	100.0

Self-report of recency of last mammogram is shown in Table 6.3.2.5. About 40 per cent of women reported that their last mammogram was within the last year. There was no difference between the 2 groups ( $X^2$  Trend=0.56,  $df=1$ ,  $P=0.5$ ).

Table 6.3.2.5: Self-report of recency of last mammogram of recalled and non-recalled women

Self-report of recency of last mammogram	Recalled women		Non-recalled women	
	No.	%	No.	%
Up to 6 months ago	16	11.2	20	12.0
6 months to 1 year	50	35.0	46	27.5
> 1 year	77	53.8	101	60.5
Total	143	100.0	167	100.0

Of those who reported that their mammogram was within the last 12 months, 20 per cent of the recalled women and 14 per cent of the non-recalled women said that it was at a location other than the screening van (Table 6.3.2.6) ( $X^2=0.87$ ,  $df=1$ ,  $P=0.4$ ).

Table 6.3.2.6: Location of most recent mammogram among recalled and non-recalled women (restricted to women who reported their most recent mammogram as within the last 12 months)

Location of most recent mammogram	Recalled women		Non-recalled women	
	No.	%	No.	%
Medicheck; breast clinic	1	1.4	4	6.1
Private hospital	2	2.8	2	3.0
Public hospital	6	8.6	1	1.5
Private radiologist	2	5.7	1	1.5
Van	53 <sup>i</sup>	78.6	57	86.4
Other	2	2.9	1	1.5
Total	66	100.0	66	100.0

i. Includes 2 women who were screened at the Rachel Forster Hospital screening clinic.

## Breast self-examination

The practice of breast self-examination was not significantly different between the 2 groups ( $X^2$  Trend=0.05, df=1, P=0.8). About 80 per cent of women reported that they had examined their breasts in the last 12 months. About a quarter reported doing BSE more than once a month and about 15 per cent reported a frequency of at least once a week (Table 6.3.2.7).

Table 6.3.2.7: Frequency of breast self-examination in the last 12 months among recalled and non-recalled women

Frequency of BSE	Recalled women		Non-recalled women	
	No.	%	No.	%
Not at all	29	18.4	32	18.0
Not as often as once a month	49	31.0	63	35.4
About once a month	40	25.3	39	21.9
About 2 or 3 times a month	16	10.1	15	8.4
At least once a week	24	15.2	29	16.3
Total	158	100.0	178	100.0

## Perceptions of chance of getting breast cancer

Women were asked to estimate their chances of getting breast cancer compared

with other women of their age. As indicated in Table 6.3.2.8 there were significant differences between the 2 groups ( $X^2=11.56$ ,  $df=3$ ,  $P=0.009$ ;  $X^2$  Trend= $3.25$ ,  $df=1$ ,  $P=0.07$ ). Recalled women were more likely to rate their chances as 'about the same' whereas non-recalled women were more likely to rate their chances as 'less than average'.

Table 6.3.2.8

Perceptions of chance of getting breast cancer among recalled and non-recalled women

Perceptions of chance of getting breast cancer	Recalled women		Non-recalled women	
	No.	%	No.	%
Much less than average	15	10.1	13	8.2
Less than average	30	20.3	60	38.0
About the same	90	60.8	74	46.8
Greater than or much greater than average	13	8.8	11	7.0
Total	148	100.0	158	100.0



**Concern in the last 12 months about the possibility of getting  
breast cancer**

Women were asked if they had been at all concerned in the last 12 months about the possibility of getting breast cancer. Twenty-two per cent of recalled women responded that they had been concerned compared with 12 per cent of the non-recalled group ( $X^2=6.58$ ,  $df=1$ ,  $P=0.01$ ).

Those who expressed concern were asked how often and how much they were concerned. Recalled women were more likely to report that they were concerned 'some of the time' or 'a lot of the time' ( $X^2$  Trend=4.67,  $df=1$ ,  $P=0.03$ ) (Table 6.3.2.9).

Table 6.3.2.9: Frequency of concern about breast cancer among recalled and non-recalled women

Frequency of concern about breast cancer	Recalled women		Non-recalled women	
	No.	%	No.	%
Rarely concerned	3	9	6	29
Occasionally concerned	12	34	8	38
Concerned some of the time or a lot of the time	20	57	7	33
Total	35	100	21	100

Recalled women also expressed greater amounts of concern. Forty-four per cent of recalled women reported feeling 'very' or 'extremely' concerned compared with 14 per cent of women from the non-recalled group (Table 6.3.2.10) ( $X^2$

Trend = 6.6, df = 1, P = 0.01).

Table 6.3.2.10: Amount of concern about breast cancer among recalled and non-recalled women

Amount of Concern	Recalled women		Non-recalled women	
	No.	%	No.	%
Slightly concerned	5	15	8	38
Moderately concerned	14	41	10	48
Very or extremely concerned	15	44	3	14
Total	34	100	21	100

**Spoken to a doctor or other health professional about concern**

The groups did not differ on whether they had spoken to a doctor or other health professional about their concern (Table 6.3.2.11) ( $X^2 = 0.25$ , df = 1, P = 0.6).

Table 6.3.2.11: 'Spoken to a doctor or other health professional about concern' among concerned recalled and non-recalled women

Spoken to a Dr or other health professional	Recalled women		Non-recalled women	
	No.	%	No.	%
Concerned, but not spoken to a doctor	14	40	7	33
Spoken to a doctor or other health professional about concern	21	60	14	66
Total	35	100	21	100

## Morbid concern

Women who reported that they were concerned were asked how this concern had affected their life in the last 12 months. There were no differences between the 2 groups ( $X^2$  Trend=0.04, df=1, P=0.8) (Table 6.3.2.12).

Table 6.3.2.12: Morbid concern about breast cancer among recalled and non-recalled women

Morbid concern in those women who were concerned	Recalled women		Non-recalled women	
	No.	%	No.	%
CONCERNED				
Not at all	15	44	9	43
A little	12	35	7	33
A lot	7	21	5	24
Total	34	100	21	100

### 6.3.3 Analyses excluding women who reported having had a breast lump or breast cancer

As indicated, recalled women were more likely to have had a breast lump or breast cancer, and expressed greater levels of concern on several variables. In order to determine if the cause of increased concern was due to previous experience with breast cancer rather than recall, the analyses were conducted again excluding the 57 women who reported breast cancer or a breast lump.

Out of the 4 variables examining concern which showed significant differences between the 2 groups overall, the following remained statistically significant when those with previous personal experience were excluded: perceived susceptibility to breast cancer, frequency of concern, and amount of concern. The variable which no longer showed statistically significant differences between the 2 groups was that which addressed whether a woman had been concerned in the last 12 months about getting breast cancer.

#### **6.3.4 Personal susceptibility to breast cancer and concern over time**

In order to examine if personal susceptibility and concern decreased over time in the recalled women, those who had been screened 12 to 18 months prior to interview were compared with those who had been screened over 18 months up to 24 months previously. Breast X-Ray Programme records were used to obtain dates of attendance.

### Perceptions of chance of getting breast cancer

As shown in Table 6.3.4.1 there were no differences in terms of perceptions of chance of getting breast cancer. The majority of women in both groups rated their chances as 'about the same' as other women of their age ( $X^2$  Trend=0.03, df=1, P=0.9).

Table 6.3.4.1: Perceptions of chance of getting breast cancer in recalled women (those screened 12 to 18 months and >18 to 24 months prior to interview)

Perceptions of chance of getting breast cancer	Women screened 12 to 18 months previously		Women screened >18 to 24 months previously	
	No.	%	No.	%
Much less than average	4	6	10	13
Less than average	15	22	12	16
About the same	44	66	44	59
Greater than or much greater than average	4	6	9	12
Total	67	100	75	100

### Concern in the last 12 months about the possibility of getting breast cancer

The 2 groups were also similar as to whether they were concerned or not about the possibility of getting breast cancer. Twenty-six per cent of the

women screened 12-18 months ago expressed concern, compared with 21 per cent of those screened over 18 up to 24 months before being interviewed ( $X^2=0.53$ ,  $df=1$ ,  $P=0.5$ ).

There were no differences between the 2 groups in terms of frequency of concern about breast cancer (Table 6.3.4.2). The majority of women responded that they were concerned 'some of the time' or 'a lot of the time' ( $X^2=0.24$ ,  $df=1$ ,  $P=0.6$ ).

**Table 6.3.4.2: Frequency of concern about breast cancer in recalled women (those screened 12 to 18 months and >18 to 24 months prior to interview)**

Frequency of concern about breast cancer	Women screened 12 to 18 months previously		Women screened > 18 to 24 months previously	
	No.	%	No.	%
Rarely or occasionally concerned	7	39	8	47
Concerned some of the time or a lot of the time	11	61	9	53
Total	18	100	17	100

There were differences between the 2 groups in terms of the amount of concern about breast cancer (Table 6.3.4.3) ( $X^2=5.85$ ,  $df=1$ ,  $P=0.02$ ). Women who were screened 12 to 18 months prior to interview were more likely to report that they were 'very' or 'extremely' concerned compared with those who were screened over 18 up to 24 months previously.

Table 6.3.4.3: Amount of concern about breast cancer in recalled women (those screened 12 to 18 months and >18 to 24 months prior to interview)

Amount of concern	Women screened 12 to 18 months previously		Women screened >18 to 24 months previously	
	No.	%	No.	%
Slightly or moderately concerned	6	35	13	76
Very or extremely concerned	11	65	4	24
Total	17	100	17	100

**Spoken to a doctor or other health professional about concern**

There was no significant difference between the 2 groups on this variable

( $X^2=0.69$ ,  $df=1$ ,  $P=0.4$ ) (Table 6.3.4.4).

Table 6.3.4.4: 'Spoken to a doctor or other health professional about concern' in recalled women (those screened 12 to 18 months and >18 up to 24 months prior to interview)

Spoken to a Dr or other health professional	Women screened 12 to 18 months previously		Women screened >18 to 24 months previously	
	No.	%	No.	%
Concerned, but not spoken to a doctor	6	33	8	47
Spoken to a doctor or other health professional about concern	12	67	9	53
Total	18	100	17	100

### Morbid concern about breast cancer

There was no difference between the 2 groups for this variable ( $X^2=1.07$ ,  $df=1$ ,  $P=0.3$ ) (Table 6.3.4.5).

Table 6.3.4.5: Morbid concern about breast cancer in recalled women, restricted to those who expressed concern (those screened 12 to 18 months and > 18 up to 24 months prior to interview)

Morbid concern in those women who were concerned	Women screened 12 to 18 months previously		Women screened > 18 up to 24 months previously	
	No.	%	No.	%
<b>CONCERNED</b>				
Not at all	6	35	9	53
A little or a lot	11	65	8	47
Total	17	100	17	100

### Concern about radiation

The difference between the 2 groups in concern about radiation was not significant ( $X^2$  Trend=3.68,  $df=1$ ,  $P=0.06$ ) (Table 6.3.4.6).

Table 6.3.4.6: Concern about radiation in recalled women (those screened 12 to 18 months and > 18 up to 24 months prior to interview)

Concern about radiation	Women screened 12 to 18 months previously		Women screened > 18 up to 24 months previously	
	No.	%	No.	%
Not concerned	38	54.3	38	45.8
A little concerned	23	32.9	24	28.9
Quite concerned	6	8.6	10	12.0
Very concerned	3	4.3	11	13.3
Total	70	100.0	83	100.0



### Breast self-examination

Frequency of BSE did not decrease over time ( $X^2$  Trend=0.75, df=1, P=0.4)

(Table 6.3.4.7).

Table 6.3.4.7: Frequency of BSE in last 12 Months in recalled women (those screened 12 to 18 months and > 18 up to 24 months prior to interview)

Frequency of BSE	Women screened 12 to 18 months previously		Women screened > 18 up to 24 months previously	
	No.	%	No.	%
Not at all	11	15.9	16	19.3
Not as often as once a month	26	37.7	22	26.5
About once a month	16	23.2	22	26.5
About 2 or 3 times a month	9	13.0	7	8.4
At least once a week	7	10.1	16	19.3
Total	69	100.0	83	100.0

Therefore the only variable which showed a decrease in concern over time in the recalled group was that which measured amount of concern. A comparable analysis for non-recalled women indicated no change over time ( $X^2$  Trend=0.01, df=1, P=0.9).

## 6.4 DISCUSSION

A major goal of a successful screening program is to maximise the benefits of screening and minimise the adverse effects to women.<sup>14</sup> This study has examined a major adverse effect, that of the psychological distress associated with having a false positive result.

The results indicate that there were no differences between the recalled and non-recalled women in knowledge of lumpectomy, risk, and survival for breast cancer. It appears then that the recall process has not made an impact on informing women about these 3 issues. It can be argued that it is not the responsibility of the recall clinic to deal with these matters and that the process of informing women should be left to the general promotional campaign. However, as shown in Chapter 4, the campaign has not been successful in this regard. In particular it is probably inappropriate to discuss the issue of lumpectomy with recalled women who do not need treatment because it may increase anxiety unnecessarily.

Alternatively, it could be asserted that the recall system should aim to provide information such as that about the risk of breast cancer so women understand the importance of attending for subsequent screening. It is clear that as screening progresses it will become important for programs to develop policy about the role of the recall clinic in provision of information.

There were no differences between the 2 groups in attitudes towards screening,

and the belief that recall usually does not mean cancer. Over 90 per cent of women had favourable attitudes and only about 10 per cent equated recall with cancer. These results are very reassuring and suggest an explanation for the results of overseas research indicating that recalled women are equally likely to adhere to subsequent mammography.<sup>92,93</sup> Similarly there were no differences between the 2 groups in concern about radiation. About half of both groups reported no concern and about a third were only 'a little' concerned. This indicates that the recall process, which for some women involves additional breast x-rays, does not produce additional concern about radiation.

Prior experience with breast cancer and self-report of recency of last mammogram was also examined. Overall 20 per cent of the recalled women and 12 per cent of the non-recalled women reported that they had ever had a lump in the breast. These proportions are much higher than expected; Breast X-Ray Programme figures report that only 0.1 per cent of those screened gave a history of a breast lump.<sup>93</sup> While the recalled women were more likely to report a breast lump ( $P=0.05$ ), the proportions were elevated for both groups. Therefore, while it is difficult to account for this excess in reporting about breast lumps, it is unlikely that it is occurring as a consequence of the recall process.

Although the recalled women were more likely to have had a breast lump or breast cancer, this did not appear to be the cause of the excess concern in this group. When women with this previous experience were excluded, the majority of variables still showed elevated concern among the recalled women.

The sample was obtained from those women who had attended the Breast X-Ray Programme 12 months ago or more; however, about 40 per cent of both groups reported their most recent mammogram as within the last year.

There are 2 possible explanations for this. First a 'telescoping' process may have occurred. This results when, because of the salience of the event, women recall having their mammogram more recently than they actually did.<sup>241</sup>

An alternative explanation is that these women may in fact have had another mammogram in the last year. Overall, 46 per cent of the recalled and 40 per cent of the non-recalled women reported their most recent mammogram within the last 12 months. Of these, 21 per cent of the recalled women and 14 per cent of the non-recalled women said that it was at a location other than the screening van. In the case of the recalled women, it could be that they attended for additional, more recent screening at another location as follow-up to their false positive result from the van. A similar process may have occurred in the non-recalled women who, after attending the van, subsequently attended for another mammogram at another location. This may have occurred because of lack of knowledge about the correct screening interval or need for reassurance from another mammogram result.

There were no differences between the 2 groups in terms of breast self-examination. This is reassuring in that it might be expected that any increased anxiety in recalled women might lead to examining the breasts at inappropriately frequent intervals. It is of concern however, that about a quarter of women

reported doing BSE more than once a month and about 15 per cent reported a frequency of at least once a week. Given that the recommended interval is once a month,<sup>242</sup> it is clear that a high proportion of women who attend for screening are checking their breasts too frequently. This may be associated with either lack of information about the appropriate interval for BSE or an elevated anxiety about breast cancer. Alternatively it could be explained by 'social desirability response set',<sup>243</sup> whereby because BSE is salient as a community norm, respondents report it whether true or not. These results are similar to those obtained for a random sample of screening attenders in Edinburgh. In that study 29 per cent of women were performing BSE more than once a month and 21 per cent reported a frequency of once or more weekly.<sup>89</sup>

There was a significant difference in the way women rated their chance of getting breast cancer compared with other women of their age. There was a shift between 2 adjacent response categories whereby recalled women were more likely to rate their chance as 'about the same', whereas non-recalled women rated their chance as 'less than average'. Thus while the recalled women rated their chance as higher, they still did not perceive it to be greater than average.

Recalled women were almost twice as likely to report that they had been concerned in the last 12 months about the possibility of getting breast cancer; they were also concerned more frequently and to a greater degree.

The study also examined whether personal susceptibility to breast cancer and

concern decreased over time. Women screened 12 to 18 months ago were compared with those screened over 18 months up to 24 months previously. While the sample size for these analyses was small, the only variable which indicated a decrease over time was that which examined amount of concern about breast cancer. There was no comparable decrease for the non-recalled group, indicating there was no general shift for this variable.

It is clear that there is a negative psychological impact on women who are recalled for further tests. While they have positive attitudes to screening, they obviously are affected in terms of concern about breast cancer. The sample comprised women who had been screened up to 2 years prior to interview. Consequently, it is obvious that for some women at least, there are long-term concerns about breast cancer following recall. These results are comparable with those of Gram et al.<sup>91</sup> who found that 18 months after screening, levels of anxiety about breast cancer were over twice as high among women with a false positive result as among those with a negative screening mammogram. In contrast Ellman et al.<sup>90</sup> and Lerman et al.<sup>92</sup> found no statistically significant differences between routinely screened and false positive groups at three months post screening.

There are several ways to deal with this issue. First, the decision threshold for recalling women could be addressed so that women are only recalled for more likely abnormalities. The AHMAC report sets the acceptable proportion of screened women referred for assessment at 10 per cent or less in the first round

of screening and 5 per cent or less in subsequent rounds.<sup>14</sup> Recent guidelines from the NHS Breast Screening Programme also recognise that an effective way of reducing anxiety is by reducing the recall rate below 10 per cent. It is estimated that each 1 per cent decline will mean 10000 fewer women recalled when the program is fully operational.<sup>244</sup>

Second, it is clear that both appropriate counselling services and intervention strategies need to be developed. While this has not yet been considered in detail at either a state or federal level, it is expected that these will be linked to assessment and treatment centres accredited with the National Early Breast Cancer Detection Program. In the overseas programs there is little separate provision for the counselling of women with false positive results. In Scandinavia they rely on the surgeon, nurses and radiographers for support. In Canada, volunteers are used in the screening clinics to provide reassurance. At the King's College Hospital in London, a nurse counsellor does not attend until the cancer diagnosis is confirmed.<sup>169</sup>

Associated with this is the issue of information provision. Ideally this should be given before the mammogram is taken. Information should include: how the test will be carried out, when and how the results will be available, the likelihood of being recalled, and the meaning of the results.<sup>230</sup>

Accurate and comprehensive information is needed since some of the anxiety arises from the fact that the woman is not sure what is going to happen to her

when she attends the assessment clinic.<sup>244</sup> There is evidence from cervical screening indicating that women who receive information when they are informed of their abnormal result have significantly lower levels of anxiety.<sup>245</sup>

It is worth emphasising to women that being recalled is not unusual. It may help to tell women that screening is a 2 phase procedure. This means that women may be expected to be called back. Those who are not called back will experience relief whereas those who are recalled are more likely to see it as a routine part of screening.<sup>230</sup> It is important to emphasise to women that the main objective of the review stage is to confirm normality as the great majority of recalled women will be normal.<sup>244</sup> There is also need for data indicating what information women should be given in order to minimise adverse effects.<sup>231</sup>

The way results are relayed is also important. Staff need to be trained in how to give the test results.<sup>230</sup> Both verbal and non-verbal communication skills need to be considered; it is important for program workers to observe one another and give feedback about communication.<sup>244</sup> In the study by Ellman et al.<sup>90</sup> 7 per cent of women with false positive results and 14 per cent of women with symptomatic benign abnormalities criticised some form of communication at the clinic.

An important way of reducing anxiety is by keeping the time delay between notification of the results and assessment to a minimum.<sup>244</sup> The study by Ellman et al.<sup>90</sup> indicated that the main way in which women felt that anxiety could be



alleviated was by shortening all periods of waiting. It is not acceptable to inform a patient of a positive result by telephone on a Friday afternoon without offering a consultation before the Monday.<sup>230</sup>

An effective means of helping women cope with anxiety is to encourage them to phone or make contact if they are anxious. It appears that some of the anxiety arises from the uncertainty as to whether or not they should consult a professional. Many women are concerned about worrying busy professionals with small questions which are major sources of anxiety to them. As women may wish to see their general practitioner, it is essential that GPs are provided with accurate information about the recall process. Women should also be provided with information on how to seek further information about their test or about breast cancer in general.<sup>244</sup>

Women with symptomatic benign abnormalities have been identified as potentially at risk of long lasting elevated anxiety. The study by Ellman et al.<sup>90</sup> indicated that these women showed a prevalence of probable psychiatric morbidity higher than those with false positive results. Moreover this persisted for 3 months, even after the diagnosis of breast cancer had been ruled out. In the current study 20 per cent of the recalled women reported that they had ever had a lump in their breast. While the numbers are too small to examine the effect in this group, it is clear from the results of Ellman et al.<sup>90</sup> that clinicians should be aware of the fact that these women may need additional attention in alleviating anxiety.

This research indicates that there are adverse effects on women who receive false positive results following attendance for mammography screening. This chapter has explored the extent of these effects and suggested strategies for overcoming them. It is important that such strategies be evaluated before they are implemented in Australian screening programs.

## CONCLUDING REMARKS

This thesis has considered 3 aspects of mammography screening in Australia. These are the psychosocial impact on the community of implementing mammography screening, strategies to encourage women to attend, and the psychological impact on women who receive a false positive result.

The research findings have implications for the implementation of the National Early Breast Cancer Detection Program, and suggest several areas of investigation which require further research. First, the research provides data to allow us to examine the impact of promoting mammographic screening in the community. Importantly, it indicates that we are not inducing psychological morbidity in relation to breast cancer. In addition it appears that promotional campaigns such as the one in the present study can reach a large proportion of women and inform them at a general level about screening mammography. However, we need to continue to improve specific areas of knowledge in order that women can make informed decisions about screening.

Second, the research has identified a model for recruiting women to screening which has the potential for achieving the 70 per cent recruitment rate suggested as a target for Australia.<sup>14</sup> The final decision as to which approach to apply will depend not only on the effectiveness of the different strategies, but also the relative costs of the approaches and the ability to apply the strategies at a population level. It should be reiterated that the proposed model was developed

for a mobile van servicing an inner city urban population with a heterogeneous population. Consequently it needs to be examined whether the approach can be generalised to fixed site services (with potentially different access) and other settings such as rural communities.

Several recruitment strategies have been suggested as worthy of additional trials. These include letterbox dropping pamphlets with a variety of content messages and styles of presentation; asking attenders to distribute pamphlets rather than formal invitations to friends, and simple non-time-intensive interventions with GPs such as displaying posters and pamphlets in waiting rooms and asking receptionists to give pamphlets to eligible patients.

As screening progresses in Australia, there will be a need to examine whether the strategies identified in this thesis are also effective in encouraging women to re-attend. This is particularly important as overseas studies indicate a marked decline in subsequent re-attendance.<sup>45</sup> It is also important that Australian studies examine predictors of attendance for screening. This type of research is vital for designing recruitment campaigns as it identifies those items of knowledge and attitudes most conducive to attendance. While there has been some Australian research conducted in relation to fixed sites,<sup>53</sup> there is a need for research into mobile services.

Finally the research highlights the need for strategies to reduce anxiety in women who receive false positive results. The current investigation should go towards

encouraging state and federal mammographic screening coordination units to commission research into these strategies.

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## **APPENDICES**

**APPENDIX 1: INTERVIEWERS' MANUAL**

**UNIVERSITY OF SYDNEY - DEPARTMENT OF PUBLIC HEALTH**

**MAMMOGRAPHY SURVEY - 1990**

**INTERVIEWERS' MANUAL**

### OVERALL COMMENTS

Questionnaire and ID numbers: Remember ALWAYS to put the Questionnaire Number on the log sheet. Put the ID Number and the Call Sheet Number on the questionnaire. When you sign your name at the end, also note your Interviewer Number.

Establishing Identity: If respondents require that your identity and credentials be confirmed, tell them that they can contact either Ms Deborah Turnbull at the University of Sydney on 692-4368, or Professor Les Irwig (University of Sydney) on 692 4370 between 9am and 5pm.

Uncodable Responses: It is important to attempt to gain a valid answer, i.e., an answer which fits into specified response categories, for every question in the interview. However, there will be times when respondents' answers don't seem to fit.

Respondents not understanding questions: In this case, repeat the question and the response categories. DO NOT PARAPHRASE THE QUESTION in an attempt to enhance understanding. If after repetition the respondent still does not understand, write this next to the question, with any comments the respondent makes. DO NOT CIRCLE A RESPONSE CATEGORY.

Respondents feeling response categories do not cover the response they want to give: Repeat the categories, stressing that these are the only ones given. If respondents still feel their response is not covered, write their response next to the question. DO NOT CIRCLE A RESPONSE CATEGORY.

So, as a general rule of thumb: make every attempt to gain an appropriate answer by repeating questions and response categories; but if respondent really can't answer, write reasons and comments beside the question. DO NOT CIRCLE A RESPONSE CATEGORY.

Value judgements: Do not give your own value judgements on the worth of any of the questions i.e., if the respondent says questions are silly or hard to understand, do not agree with them.

Knowledge questions: If respondent asks you for the correct answer to any questions, say you are really not sure of what they are.

Acknowledgment of respondents' answers: Be non-committal when acknowledging respondents' answers. Do not use phrases like "good", "great", "that's right".

Respondents want more information on breast cancer and mammography: If, at the conclusion of the interview, respondents express an interest in finding out more about breast cancer and mammography, tell them they can contact the NSW State Cancer Council on 264-8888.

#### SPECIFIC QUESTIONS

Q 1. Column 1. "START" - code for rotation.

- . circle the number of the response from which you start reading the list.

Column 2. "MOST COMMON"

- . circle the number corresponding to the condition which respondent gives as the most common.

Column 3. "2ND COMMON"

- . circle the number of the condition which the respondent gives as the second most common.

Q 2. Circle the number corresponding to respondent's answer

If respondent says she doesn't know the answer circle 5 for "don't know."

Q 3-4 As for Q 2.

- Q 5. As for Q 2. If respondent says True or Don't Know go to Q 7. If respondent says False go to Q 6.
- Q 6. Ask question. Write down respondent's responses, verbatim. When respondent appears finished. Ask "do you know of any others?" Write down any further responses obtained. If respondent asks you if there are any other treatments, say you are not sure.
- Q 7. From woman's response, code whether a mammogram or breast X-ray is mentioned. DO NOT PROBE. If mammogram (or breast X-ray) mentioned go to Q 9.  
If mammogram (or breast X-ray) not mentioned to Q 8.
- Q 8. Code response.  
If respondent doesn't know or is unsure whether she has heard of a mammogram code 3.
- Q 9. Read the description regardless of whether the respondent has indicated that she has heard of a mammogram (or breast X-ray).  
  
If after reading description, the respondent has not heard of mammogram being used for screening, GO TO Q 12.
- Q 10. Code response. If NO GO TO Q 12.
- Q 11. Code response.
- Q 12. Code response. If NO GO TO Q17.
- Q 13. IF ONLY ONE MAMMOGRAM HAS BEEN HAD IN PAST: code whether this was for screening only or whether the person had symptoms at the time. A person who has had only one mammogram cannot receive CODE 3 "both". It must be for either screening or symptoms not both. Probe to distinguish.

Possible Responses: "I had a lump/discharge/pain" - code 1 symptoms present.  
"The doctor sent me" - probe whether or not the person had symptoms at the time.

N.B. "Family history" is NOT a symptom so if respondent mentions this as the only reason for having a mammogram, than this should be coded 2 - screening.

IF RESPONDENT HAS HAD MORE THAN ONE MAMMOGRAM IN THE PAST: Code BOTH only if at least one previous mammogram has been for symptoms and at least one for screening. This situation will arise, for example, if a woman had a mammogram for a lump which was not cancer. The lump was removed, and after this she has been having mammograms as a check-up.

- Q 14. Rotate responses-code whether list read from top to bottom or bottom to top. This will be the same rotation to be used for Q22, 30, 33, 34, 39 and 40.
- Q 15. Code response. If the answer is coded 1 to 6, go to Q16. If respondent mentions the name of a hospital ask whether it is public or private. If respondent mentions the name of a doctor - ask whether this is a private radiologist, a breast clinic doctor or public hospital doctor. If respondent has had more than one mammogram at different places - code where the most recent one was taken. If the response still does not clearly fall in one of the specified codes, mark "other" (6) and note what the respondent says on the form.
- The Breast X-Ray Van is a mobile van which conducts free mammography screening in the inner western suburbs of Sydney (Central Sydney Area Health Service, formerly Royal Prince Alfred Hospital Area). It is State government funded and administered out of Rachel Forster Hospital. Code Breast X-Ray Van for responses such as mobile van, mobile caravan, van like the TB van, screening van, Rachel Forster Van, Breast Care, Breast Concern, Breast X-Ray Programme.
- N.B. There is only one mobile mammography screening van and it is the only free screening service in Sydney. Probe as necessary.
- Q 16. Code first 2 responses. If first response is not "Breast X-Ray Van", probe once with "anywhere else". Stop if Breast X-Ray Programme mentioned first. If Breast X-Ray Van is mentioned on either the first or second response, go to Q 20.
- Q 17. As for Q16. Emphasise the word "screening".
- Q 18. Code response. If respondent replies no, go to Q 19. If the respondent asks you if such a van exists, tell her you don't know. If the respondent says that there is a van, but it's not in her area, code no and go to Q 19.
- Q 19. Code response. If NO or DON'T KNOW, go to Q 21.
- Q 20. Code response.
- Q 21. Code response.
- Q 22. Rotate responses in same way as for Q14. Code whether rotation is top to bottom or bottom to top. Code response.
- Q 23. If the respondent has indicated prior to this point that she has had breast cancer, DO NOT ASK this question, circle 1 and go to Q 27. Otherwise, ask question, code response. If YES, go to Q 27.
- Q 24. If respondent has indicated prior to this point that she has had a lump in her breast DO NOT ASK this question. CIRCLE 1. Otherwise, code response.

- Q 25. Code response. If YES, go to Q 27.  
**N.B.** grandmothers, aunts, etc. don't count as a positive response.
- Q 26. Code response.
- Q 27. Ask this question only if respondent has not indicated that she has had a screening mammogram (Q13).
- Q 28. It is very important to gain answers to all questions A-G in the response categories specified.

EXCEPTIONS:

- 1) if a person really doesn't understand a particular question. Write this reason beside question and DO NOT CIRCLE A NUMBER.
  - 2) A person may feel that they cannot give an answer to a particular question. (e.g. respondents may say they don't have enough information to answer questions about screening mammograms). Ask firstly if they cannot answer because they neither agree or disagree with the statement. If they say no, it's because they really can't answer, write this reason and any comments beside answer and DO NOT CIRCLE A NUMBER.
  - 3) For all questions, if respondent says only "agree" or "disagree", probe whether this is "strongly agree" or "agree", or, "Strongly disagree" or "disagree". Do not insert the word 'just' before "agree" or "disagree". If people have trouble with any of the questions, ask if they would like the question read again. Do not paraphrase any of the questions.
- Q 29. Code response  
 If no go to Q 31.
- Q 30. Rotate responses in the same way as in Q 22. Code whether rotation is top to bottom or bottom to top.  
 Code response.
- Q 31. Code response.
- Q 32. Code response.  
 If respondent answers "I've thought about it", repeat the second sentence.
- Q 33. Rotate responses - Use same rotation as previously. Code response.  
 If respondent wants to use a response category which isn't there tell her that these are the only categories which can be used.
- Q 34. Rotate responses - Use same rotation as previously. Code response.  
 If respondents want to use a response category which isn't there, tell them that these are the only categories which can be used.
- Q 35. Code response. If no go to Q 37.



- Q 36. Code response. Health professional includes nurses or any therapists, including alternative therapists, such as naturopaths.
- Q 37. Read through the symptoms as written in the schedule. If respondents say "no, not really" to any of the symptoms prompt for "not at all" or "a little". Prompt respondents with categories where necessary. Be sure to repeat the statement "How much has concern about breast cancer contributed to you ..." as shown before A, between C and D, and between G and H on the questionnaire.
- Q 38. Read the statement slowly. If No ask Q 40.
- Q 39. Rotate responses as previously. Code responses.
- Q 40. Read the question slowly. Read out 1-5 or 5-1 as previously. If the respondent replies don't know, probe to determine if this is doesn't know when she had the Pap Smear (CIRCLE 6), doesn't know if she ever had one (CIRCLE 7), or doesn't know what a Pap Smear is (CIRCLE 8).
- Q 41. Record date of birth as a 6 digit number, eg: 01 03 37 for the first of March, 1937. If respondent is unwilling to give date of birth, ask what category their age falls into. Read out categories. If still unwilling write refused.
- Q 42. Code responses. If person says intermediate certificate, school certificate or years 1-4 secondary, code 4. If person says 5-6 years secondary, leaving certificate, matric, HSC, completed high school - Code 5. Some tertiary will include a person still studying at Uni, college, Institute or TAFE. Certificate/Diploma includes most nursing courses, secretarial courses. If unsure of code for a given response - write in space provided.
- Q 43. Code response. If the other language and English are spoken by the respondent, code YES.
- Q 44. We want to avoid as far as possible the responses "retired" "unemployed" "student" or "home duties" so if a person give those responses probe with "What was the last occupation of the main income earner of the household". We also need as full a description as possible of the occupation, so if it is not clear ask for more details of the position or job title and the business or industry people are working in. If a person says only "self employed" or "runs own business", write this down, but also determine what sort of business it is.

**NB.** OCCUPATION REFERS TO THE MAIN INCOME EARNER OF THE HOUSEHOLD, NOT NECESSARILY THE RESPONDENT. WHEN READING THE QUESTION, PLEASE STRESS THE WORDS "MAIN INCOME EARNER". FOR THOSE WHO ARE RETIRED OR UNEMPLOYED, OR HOME DUTIES, STRESS AGAIN THAT WE WANT THE LAST OCCUPATION OF THE MAIN INCOME EARNER.

- Q 45. Code response. If respondent doesn't know postcode, ask what suburb they live in.
- Q 46. If person refuses to give name don't push. Just write refused. For follow-up study, record Yes if woman gives permission for us to recontact, record No if woman does not want to be recontacted.

Completing Yellow Log Sheet: New Sample

- I - Interview completed with woman aged 45-70.
- NS - There is no woman aged between 45-70 living in the household.
- RW - Woman in the 45-70 year old age group refuses to participate - record reason in the "notes" column.
- RP - This code to be used when there is a woman in the appropriate age group living in the household - but someone else refuses on behalf of this woman.
- RH - This code to be used when someone else in the household refuses before you can find out whether there is a woman in the 45-70 year age group in the household.
- F - This code to be used when the person you speak to doesn't speak English and its not possible to determine whether there is a woman in the appropriate age group in the household. Record the language spoken by the household. (Not applicable for ethnic interviewers).
- FW - This code to be used if the person you speak to indicated that there is a women in the appropriate age group in the household, but that woman does not speak English. Record the language spoken by the woman. DO NOT ATTEMPT TO GAIN PERMISSION TO INTERVIEW THE WOMAN. (Not applicable for ethnic interviewers).

## Languages to be Coded

Italian  
 Greek  
 Maltese  
 Russian  
 Chinese languages: Cantonese and Mandarin  
 Other

- A - To be used when there is a woman in the appropriate age group temporarily not at home.
- N - To be used when there is a woman in the appropriate age group in the household who will not be available during the study period, ie end Feb 1990. Record the reason in the 'notes' column.
- AM - Answering machine.
- E - Engaged.
- O - No answer.
- TM - Disconnected signal, telecom message.  
 (Call backs no less than four hours apart.)

Completing the White Log Sheet: Follow-up Sample

I - as above

NS - The woman originally interviewed is no longer resident at that address (ie, she has moved or died).

RW - as above

RH - as above

RP - as above

F - this code to be used when the person you speak to doesn't speak English and it's not possible to determine whether the original woman is in the household. Record language spoken by household (not applicable for ethnic interviewers).

**Languages to be Coded**

Italian

Greek

Maltese

Russian

Chinese languages: Cantonese and Mandarin

Other

N - as above

AM - as above

E - as above

O - as above

TM - as above

A - as above

Call backs no less than 4 hours apart.

**APPENDIX 2: QUESTIONNAIRE USED IN 1990 CROSS-SECTIONAL SURVEY.**

**NB:**The questionnaire for the 1987 survey was identical, with the exception that it did not cover questions Q14, Q16-20, Q38, Q39, Q40.



UNIVERSITY OF SYDNEY - DEPARTMENT OF PUBLIC HEALTH

QUES NO  
1562

MAMMOGRAPHY SURVEY

ID NO

CALL SHEET NO

COLS

1-4

5-6

7-9

Preamble

Hello, I'm ..... from the Public Policy Research Centre. Your telephone number has been selected at random for a survey the Medical Faculty at Sydney University is conducting on an important community health issue. Would you please tell me how many women aged between 45 and 70 are in your household?

IF NONE: THANK PERSON. STOP.  
IF ONE ONLY. SEEK INTERVIEW WITH HER.

IF MORE THAN ONE ASK: Who out of the women aged between 45-70 in the household had their birthday last? SEEK INTERVIEW WITH THIS WOMAN.

IF ONLY WOMAN DOES NOT SPEAK ENGLISH: ASK LANGUAGE SPOKEN. THANK PERSON. STOP. RECORD LANGUAGE ON CALL SHEET.

WHEN SPEAKING TO PERSON IN APPROPRIATE AGE GROUP:- REPEAT INTRODUCTION.

ADD - "The interview will take about 15 minutes - perhaps a little less, and all the information obtained in the study will be confidential. Just before we start, can I just check that the number I dialled was (READ OUT NUMBER). IF INCORRECT, TERMINATE.

Q 1. First, I'd like to talk to you about cancer, as this is often mentioned as a major health concern of women in your age group. I'm going to read you a list of cancers. Could you tell me which you think is the most common type of cancer amongst women of your age in Australia. (READ DOWN LIST AND ROTATE START POINT: REPEAT LIST IF NECESSARY)

	START	MOST COMMON	2ND COMMON
BOWEL	1	1	1
BREAST	2	2	2
LUNG	3	3	3
CERVIX	④	4	4

10-12

ASK: What is the second most common (READ LIST AGAIN)

Now, I'd like to ask some questions specifically about breast cancer because a lot of women mention this as a common health concern. We're trying to find out how much women know about this condition. Please tell me what you think the answers are even if you are not sure.

Q 2. About how many women will get breast cancer at some time in their lives? Do you think it is about (READ OUT 1- 4 AND ROTATE START POINT IN THE SAME ORDER AS FOR Q1)

13

1	in	15	1
1	in	5	2
1	in	35	3
1	in	60	4
		DK	5

Q 3. Who do you think is at greatest risk of developing breast cancer? (READ OUT 1 - 3)

14

A WOMAN IN HER 40'S	1
A WOMAN IN HER 50'S	2
A WOMAN IN HER 60'S	3
DK	4

Q 4. The following two questions are to be answered true or false. With early treatment, most women with breast cancer live for 10 years or more after diagnosis. Is this true or false?

15

TRUE	1
FALSE	2
DK	3

Q 5. Even if cancer is found early, removal of the breast is the only treatment for breast cancer. Is this true or false?

16

TRUE	1	<u>GO TO Q7</u>
FALSE	2	<u>ASK Q6</u>
DK	3	<u>GO TO Q7</u>

Q 6. What other treatments do you know of for breast cancer? (PROBE AND SPECIFY BELOW)

17-24

.....  
 .....  
 .....

Q 7. Do you know of any ways which can be used to detect breast cancer in the early stages? (INDICATE WHETHER MAMMOGRAM OR BREAST X-RAY MENTIONED)

25

MENTIONED	1	<u>GO TO Q9</u>
NOT MENTIONED	2	<u>ASK Q8</u>

Q 8. Have you heard of a mammogram?

	YES	1
	NO	2
	NOT SURE	3

26

Q 9. I would like to ask a few more questions about mammograms. Before I go on I'll read you a standard description.

A mammogram is a special X-Ray which can detect cancer of the breasts. Mammograms can also be used for screening purposes, that is to detect cancer even when there are no apparent symptoms. Have you heard of mammograms being used for screening?

	YES	1	ASK	Q10
	NO	2	GO TO	Q12
	NOT SURE	3	ASK	Q10

27

Q 10. In the last 6 months, have you seen or heard any information about screening mammograms?

	YES	1	ASK	Q11
	NO	2	GO TO	Q12

28

Q 11. How much information would you say you have seen or heard? (READ 1 - 3).

	QUITE A LOT	1
	A MODERATE AMOUNT	2
	ONLY A LITTLE	3

29

Q 12. Have you ever had a mammogram, screening or otherwise?

	YES	1	ASK	Q13
	NO	2	GO TO	Q17

30

Q 13. Why did you have it, because you had symptoms or for screening purposes? (PROBE TO DISTINGUISH)

	SYMPTOMS PRESENT	1	ASK Q14 THEN GO TO	Q17
	SCREENING	2	ASK	Q14
	BOTH	3	ASK	Q14

31

Q 14. When did you have your most recent mammogram?  
 (READ OUT 1-4 OR 4-1 CODE ROTATION)

(CODE ROTATION)      Top    1  
    Bottom 4

   WITHIN THE LAST MONTH    1  
 OVER A MONTH BUT LESS THAN 6 MONTHS AGO    2  
 OVER 6 MONTHS BUT LESS THAN A YEAR AGO    3  
    OVER A YEAR AGO    4

32

33

Q 15. Where did you have it done?

	MEDICHECK	1	
	BREAST CLINIC	2	
	PRIVATE HOSPITAL	3	<u>ASK Q16</u>
	PUBLIC HOSPITAL	4	
	PRIVATE RADIOLOGIST	5	
.....	OTHER (PLEASE SPECIFY)	6	
	BREAST X-RAY VAN	7	<u>GO TO Q21</u>
	(Central Sydney, Breast Care, Breast Concern)		

34

Q 16. Do you know anywhere else it is possible to have a screening mammogram? And anywhere else?

(CODE UP TO 2 IN ORDER REPORTED. STOP AS SOON AS BREAST X-RAY VAN MENTIONED.)

		Mentioned		
		1st	2nd	
YES	MEDICHECK	1	1	
	BREAST CLINIC	2	2	
	PRIVATE HOSPITAL	3	3	<u>GO TO Q18</u>
	PUBLIC HOSPITAL	4	4	
	PRIVATE RADIOLOGIST	5	5	
.....	OTHER (PLEASE SPECIFY)	6	6	
	BREAST X-RAY VAN	7	7	<u>GO TO Q20</u>
	(Central Sydney, Breast Care, Breast Concern)			
	NO	8		<u>GO TO Q18</u>
	NOT SURE	9		<u>GO TO Q18</u>

35-36



Q 17. Do you know where it is possible to have a screening mammogram? And where else?

(CODE UP TO 2 IN ORDER REPORTED. STOP AS SOON AS BREAST X-RAY VAN MENTIONED).

		Mentioned		
		1st	2nd	
YES	MEDICHECK	1	1	
	BREAST CLINIC	2	2	
	PRIVATE HOSPITAL	3	3	ASK Q18
	PUBLIC HOSPITAL	4	4	
	PRIVATE RADIOLOGIST	5	5	
.....	OTHER (PLEASE SPECIFY)	6	6	
	BREAST X-RAY VAN (Central Sydney, Breast Care, Breast Concern)	7	7	GO TO Q20
	NO	8		ASK Q18
	NOT SURE	9		ASK Q18

37-38

Q 18. Do you know if there is a mammography screening van in your area?

YES 1 GO TO Q20  
NO 2 ASK Q19

39

Q 19. Are there any areas of Sydney where women of your age are eligible to have free screening mammograms?

YES 1 ASK Q20  
NO 2 GO TO Q21  
DK 3 GO TO Q21

40

Q 20. Are you eligible to have a free screening mammogram?

YES 1  
NO 2  
DK 3

41

Q 21. In any group of women who have screening mammograms, i.e. mammograms when there are no symptoms, a certain number are asked to come back for further tests. Do you think this necessarily means they have breast cancer?

YES 1  
NO 2  
DK 3

42

Q 22. How concerned would you be about any exposure to radiation which is involved in having screening mammograms?  
(READ OUT 1-4 OR 4-1 CODE ROTATION)

Top	1	43
Bottom	4	

VERY CONCERNED	1	
QUITE CONCERNED	2	
A LITTLE CONCERNED	3	44
NOT AT ALL CONCERNED	4	

Q 23. Have you ever had breast cancer? (CODE YES WITHOUT ASKING IF THIS HAS BEEN PREVIOUSLY MENTIONED, THEN GO TO Q 27).

YES	1	<u>GO TO Q27</u>	45
NO	2	ASK Q24	

Q 24. Have you ever had a lump in your breast? (CODE YES WITHOUT ASKING IF THIS HAS BEEN PREVIOUSLY MENTIONED, THEN ASK Q 25).

YES	1		46
NO	2		

Q 25. Has your mother or any sisters or daughters ever had breast cancer?

YES	1	<u>GO TO Q27</u>	47
NO	2	ASK Q26	
DK	3	ASK Q26	

Q 26. Do you know anyone who has had breast cancer?

YES	1	48
NO	2	

Q 27. Do you know anyone who has had a screening mammogram i.e. a mammogram when they haven't had any symptoms? (CODE SELF WITHOUT ASKING IF PERSON HAS PREVIOUSLY MENTIONED HAVING SCREENING MAMMOGRAM - CODE 2 OR 3 Q13)

YES	1	49
NO	2	
SELF	3	



Q 31. Compared to other women of your age, do you think the chances that you may get breast cancer at some time in the future are less than average, about the same as average, or greater than average.

If LESS THAN AVERAGE, ASK: Is that less than average or much less than average?

If GREATER THAN AVERAGE ASK: Is that greater than average or much greater than average?

MUCH LESS THAN AVERAGE	1	
LESS THAN AVERAGE	2	
ABOUT THE SAME	3	
GREATER THAN AVERAGE	4	
MUCH GREATER THAN AVERAGE	5	
DON'T KNOW	6	

60

Q 32. This question is a little bit different. In the last 12 months have you been at all concerned about the possibility that you may get breast cancer?

YES	1	<u>ASK Q33</u>
NO	2	GO TO Q38

61

Q 33. How often would you say you have been concerned?  
Would you say ... (READ LIST 1-4 OR 4-1, REPEAT IF NECESSARY)

( <u>CODE ROTATION</u> )	Top	1
	Bottom	4

62

RARELY	1
OCCASIONALLY	2
SOME OF THE TIME	3
A LOT OF THE TIME	4

63

Q 34. And at the times you have been concerned, would you say you were ... (READ LIST 1-4 OR 4-1, REPEAT IF NECESSARY)

( <u>CODE ROTATION</u> )	Top	1
	Bottom	4

64

SLIGHTLY CONCERNED	1
MODERATELY CONCERNED	2
VERY CONCERNED	3
EXTREMELY CONCERNED	4

65

Q 35. Have you spoken to anyone about this concern?

YES	1	<u>ASK Q36</u>
NO	2	GO TO Q37

66

Q 36. Have you spoken to a doctor or other health professional about this concern?

YES 1  
NO 2

67

Q 37. I would like to ask you a bit more about how this concern about breast cancer may have affected your life in the last 12 months. I'm going to read you a list of symptoms. Could you tell me how much any concern about breast cancer has contributed to you experiencing these things. The choices are: not at all, a little, or a lot.

How much has this concern about breast cancer contributed to you:-

	NOT AT ALL	A LITTLE	A LOT	
A) HAVING SLEEP DISTURBANCES	1	2	3	68
B) FEELING UNDER STRAIN	1	2	3	69
C) FEELING NERVOUS OR STRUNG UP	1	2	3	70
How much has concern about breast cancer contributed to you:-				
D) LOSING CONFIDENCE IN YOURSELF	1	2	3	71
E) FEELING UNABLE TO FACE UP TO YOUR PROBLEMS	1	2	3	72
F) BEING UNABLE TO CONCENTRATE	1	2	3	73
G) FEELING UNABLE TO PLAY A USEFUL PART IN THINGS	1	2	3	74
How much has concern about breast cancer contributed to you:-				
H) FEELING UNABLE TO ENJOY NORMAL DAY TO DAY ACTIVITIES	1	2	3	75
I) FEELING ANXIOUS	1	2	3	76
J) FEELING LESS HOPEFUL ABOUT THE FUTURE	1	2	3	77
K) FEELING UNHAPPY OR DEPRESSED	1	2	3	78

Q 38. Now I'd like to talk to you about breast self-examination or BSE. This is when a woman examines her own breasts to check for lumps. In the last 12 months, have you examined your own breasts to check for lumps?

YES 1 ASK Q39  
NO 2 GO TO Q40

79

Q 39. In the last 12 months, about how often did you do breast self-examination?

(READ OUT 1-4 OR 4-1, CODE ROTATION)

(CODE ROTATION)	Top	1
	Bottom	4
	AT LEAST ONCE A WEEK	1
	ABOUT 2 OR 3 TIMES A MONTH	2
	ABOUT ONCE A MONTH	3
	NOT AS OFTEN AS ONCE A MONTH	4

80

81

Q 40. We've been talking so far about screening for breast cancer. Another type of screening which is often done is the Pap Smear test. If you have ever had a Pap Smear test, could you please tell me roughly when you had your most recent test?

(CODE 1-8; IF UNSURE READ OUT 1-5 OR 5-1.  
IF ANSWERS DON'T KNOW, PROBE).

(CODE ROTATION)	Top	1
	Bottom	5
	WITHIN THE LAST 12 MONTHS	1
	MORE THAN 1 BUT LESS THAN 2 YEARS AGO	2
	MORE THAN 2 BUT LESS THAN 3 YEARS AGO	3
	MORE THAN 3 YEARS AGO	4
	NEVER	5
	(DON'T KNOW WHEN)	6
	(DON'T KNOW IF EVER)	7
	(DON'T KNOW WHAT A PAP SMEAR IS)	8

82

83

Q 41. Finally, I'd like to get some background information to be sure we have spoken to a representative cross-section of women.

Could you tell me your date of birth, please?.....

(IF RESPONDENT IS UNWILLING ASK AGE IN FOLLOWING CATEGORIES 45-49; 50-54; 55-59; 60-64; 65-70)

84-89

.....

90-91

Q 42. What was the highest level of education you completed?

- |                                   |                            |   |
|-----------------------------------|----------------------------|---|
|                                   | NO SCHOOLING               | 1 |
|                                   | SOME SCHOOLING             | 2 |
|                                   | FINISHED PRIMARY           | 3 |
|                                   | 1-4 YEARS SECONDARY        | 4 |
|                                   | (includes intermediate)    |   |
| IF UNSURE OF CODE RECORD RESPONSE | 5-6 YEARS SECONDARY        | 5 |
| .....                             | (includes leaving, matric) |   |
|                                   | SOME TERTIARY              | 6 |
|                                   | CERTIFICATE/DIPLOMA        | 7 |
|                                   | DEGREE                     | 8 |
|                                   | REFUSED                    | 9 |

92

Q 43. Do you speak a language other than English at home?

- |     |   |
|-----|---|
| YES | 1 |
| NO  | 2 |

93

Q 44. Please tell me the occupation of the main income earner in your household? (IF RETIRED OR UNEMPLOYED OR STUDENT ASK FOR LAST OCCUPATION OF MAIN INCOME EARNER - PROBE ON HOME DUTIES).

.....

94-95

Could I also have the position or job title of the main income earner in your household?

.....

Q 45. Finally, what is your postcode? (IF DON'T KNOW ASK:)  
What suburb do you live in?

.....

96-99

Q 46. We would like to follow-up some people in the future.  
Could I have your name please, in case we need to recontact you?

.....

THANK RESPONDENT FOR HER CO-OPERATION

I certify that this is a true, accurate and complete record of interview carried out strictly in accordance with the survey instructions.

SIGNATURE: .....

DATE .....

100-101

## **APPENDIX 2.1: SCALES DEVELOPED FROM THE QUESTIONNAIRE**

**Scale 1: Knowledge of breast cancer risk (Q1,2,3).**

**Q1**

Correct answer: breast

**Q2**

Correct answer: 1 in 15

**Q3**

Correct answer: A woman in her 60's.

Regarded as knowledgeable: 2 or 3 responses correctly answered out of 3.

Not regarded as knowledgeable: 0 or 1 responses correctly answered out of 3.

**Scale 2: Attitudes towards screening procedures (Q28 A,B,C,E,F,G). Note: QD is excluded.**

Scoring for the following questions is reversed: QB,E,F,G.

Regarded as having a favourable attitude: average score of less than or equal to 2.5 out of 6.

Regarded as having an unfavourable attitude: average score of greater than 2.5 out of 6.

**Scale 3: Perceived susceptibility to breast cancer (Q31,32).**

Regarded as susceptible: response category 4 or 5 (Q31); and/or response category 1 (Q32).

Otherwise, the respondent is regarded as not susceptible.

**Scale 4: Morbid concern about breast cancer (Q32, Q37 A to K).**

Regarded as not morbidly concerned: response category 2 (Q32) or mean score of 1 (Q37 A to K).

Regarded as morbidly concerned: mean score of greater than 1.



### **APPENDIX 3 : SELF-REPORT OF MAMMOGRAPHY**

A survey was conducted with 362 randomly selected women aged 45 to 70 who had been screened at the Breast X-Ray Programme 1 to 2 years previously. Women were asked the following questions in a telephone survey: Have you ever had a mammogram, screening or otherwise? Why did you have it, because you had symptoms or for screening purposes? When did you have your most recent mammogram? Where did you have it done?

Twenty-six women (7 per cent) reported that they had NOT had a mammogram. A total of 332 of the remaining 336 women reported that they had their most recent mammogram at the Breast X-Ray Programme. Forty-three per cent (143 of 332) of women incorrectly recalled having their mammogram more recently than they actually did. Almost one-third of these reported that their mammogram was less than 6 months ago.



# A Breast X-Ray is a safe, easy way to look after yourself

## Can I have a free breast x-ray with Breast Care?

Breast Care is funded to give you a free breast x-ray if you are between 45 and 70 years and live in the inner western suburbs (the suburbs are listed on the back of this leaflet).

## Why is it a free service?

Breast Care is funded by the New South Wales State Government.

## Why is having a breast x-ray a good idea?

Peace of mind.

A breast x-ray (or mammogram) can pick up cancer before you or your doctor can notice anything wrong.

If a small cancer is detected early, then it can be removed and cured.

The whole breast may not need to be removed.

## Am I at risk?

Yes. About 1 in 15 women develop breast cancer.

The older every woman gets, the more likely she is to have breast cancer.

## What happens when I have a breast x-ray?

You will be welcomed by our receptionist and asked to fill in a form.

She will show you into the change room where you undress to the waist in strict privacy. Then, our female radiographer will take your breast x-ray.

Each breast is positioned carefully on the x-ray machine. To get the best pictures, the machine flattens the breast on the film.

## How does it feel?

Some women find it uncomfortable. However any discomfort lasts for only a few seconds while the x-ray is taken.

## How long does it take?

Your whole visit takes about 15 minutes.

## Is the x-ray safe?

Yes it is. With our modern machinery the amount of radiation to the breast is very low and does no harm.

## When will I get my results?

You will receive a letter with your results in a week or so. If you want, we will also send the results to your doctor.

Most women are reassured to hear that their x-ray is clear.

You may be called back to our clinic for a second check. Most women called back do not have breast cancer. We may simply need to take more films before we can definitely reassure you that everything is O.K.

## Where is the breast care van?

Our van moves from suburb to suburb, like the TB vans.

For the van's location, ring **Breast Care on 699 5441**.

## Do I need an appointment to go to the breast care van?

No. Just drop into the van. However, if you find it more convenient, ring **Breast Care on 699 5441** for an appointment.

You are enjoying perfect health now.

Make sure you stay that way.

Visit the Breast Care Van — Today!

APPENDIX 5: SAMPLE OF PROMOTIONAL MATERIAL USED IN  
'INVITATIONS FOR FRIENDS'



**BREAST  
X-RAY  
PROGRAMME**

We need your help to encourage other women to come to the BREAST CARE van. We would like you to offer the enclosed invitations to our free service to two of your friends.

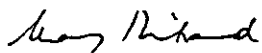
To thank you for taking the time to help us we will send you a free SCRATCH LOTTERY TICKET for each appointment kept.

You might want to offer these invitations to neighbours or relatives, or to women with whom you work or play sport. However, please remember that to be eligible, women must be aged 45 to 70 years and live in one of the suburbs listed on the back of this letter.

The appointment times for your friends and location of the van are enclosed inside the pamphlets. If your friends wish to change their appointment times or obtain more information they can phone Breast Care on 699 5441. Please ask them to mention that they are phoning in response to this invitation.

Thank you for attending the Breast Care van and for helping us to encourage other women to attend.

Yours sincerely



Dr Mary Rickard  
Director



**BREAST  
X-RAY  
PROGRAMME**

The attached pamphlet describes the BREAST CARE van which your friend recently attended. We are now inviting you to attend this free service.

To be eligible you must be aged 45 to 70 and live in one of the suburbs listed on the back of this letter.

Below are details of an appointment we have made for you. If you wish to change your appointment or obtain more information, please phone Breast Care on 699 5441. Please mention that you are phoning in response to this invitation and let us know your appointment details.

We hope you can attend.

Yours sincerely

Dr Mary Rickard  
Director

---

**YOUR APPOINTMENT:**

**VAN LOCATION(map overleaf):391 Great North Road, Abbotsford,  
opp Wareemba Post Office.**

**PLEASE BRING THIS LETTER WITH YOU TO THE BREAST CARE VAN**

Mammography Screening Programme - (Royal Prince Alfred Hospital and Area Health Service).  
Rachel Forster Hospital, Pitt Street, Redfern, N.S.W. P.O. Box 178, Redfern, N.S.W. 2016. Telephone (02) 699 5441.

SUBURBS OF:

Abbotsford  
Alexandria  
Annandale  
Ashfield  
Balmain  
Belfield  
Birchgrove  
Burwood  
Cabarita  
Camperdown  
Canada Bay  
Chippendale  
Chiswick  
Concord  
Concord North  
Concord West  
Croydon  
Croydon Park  
Darlington

Dobroyd Point  
Drummoyne  
Dulwich Hill  
Enfield South  
Enfield  
Enmore  
Erskineville  
Five Dock  
Flemington  
Forest Lodge  
Glebe  
Greenacre  
Haberfield  
Homebush  
Leichhardt  
Lewisham  
Lilyfield  
Marrickville

Mortlake  
Newtown  
North Strathfield  
Petersham  
Pymont  
Redfern  
Rhodes  
Rozelle  
Russell Lea  
St Peters  
Stanmore  
Strathfield  
Strathfield West  
Strathfield South  
Summer Hill  
Sydenham  
Tempe  
Ultimo  
Waterloo





**BREAST  
X-RAY  
PROGRAMME**

A BREAST X-RAY IS A SAFE, EASY WAY  
TO LOOK AFTER YOURSELF

CAN I HAVE A FREE BREAST X-RAY WITH BREAST CARE ?

BREAST CARE is funded to give you a free breast x-ray if :  
you are between 45 and 70 years

AND

live in the inner western suburbs  
(the suburbs are listed on the back of this leaflet).

WHY IS IT A FREE SERVICE ?

BREAST CARE is funded by the New South Wales State  
Government.

WHY IS HAVING A BREAST X-RAY A GOOD IDEA ?

Peace of mind.

A breast x-ray (or mammogram) can pick up breast cancer  
before you or your doctor can notice anything wrong.

If a small cancer is detected early, then it can be removed  
and cured.

AM I AT RISK ?

YES. About 1 in 15 women develop breast cancer.

The older every woman gets, the more likely she is to have  
breast cancer.

## WHAT HAPPENS WHEN I HAVE A BREAST X-RAY ?

You will be welcomed by our receptionist and asked to fill in a form.

She will show you into a change room where you undress to the waist in strict privacy. Then, our female radiographer will take your breast x-ray.

Each breast is positioned carefully on the x-ray machine. To get the best pictures possible, the machine flattens the breast on the film.

## HOW DOES IT FEEL ?

Some women find it uncomfortable. However any discomfort lasts for only a few seconds while the x-ray is taken.

## HOW LONG DOES IT TAKE ?

Your whole visit takes about 15 minutes.

## IS THE X-RAY SAFE ?

YES it is. With our modern machinery the amount of radiation to the breast is very low and does no harm.

## WHEN WILL I GET MY RESULTS ?

You will receive a letter with your results in a week or so. If you want, we will also send the results to your doctor.

Most women are reassured to hear that their x-ray is clear.

You may be called back to our clinic for a second check. Most women called back do not have breast cancer. We may simply need to take more films before we can definitely reassure you that everything is O.K.



## APPENDIX 6: GP LETTER OF INVITATION

Dear

I am writing to women in my practice over the ages of 45 to tell them of a new service which is currently operating in the area.

The Breast X-Ray Programme operates out of a mobile van and offers a free breast X-Ray - a mammogram. The X-Ray is used to detect breast cancer in the early stages, before other signs and symptoms (such as lumps) become apparent. It is recommended by many authorities as a general screening procedure for well women in your age group. I am urging women in my practice to take advantage of this free service. Most women will be reassured to find nothing is wrong, but for those few who do need further treatment, early detection greatly increases the chances of a complete cure.

Please find enclosed a pamphlet about the service. At the bottom of this letter are details of the Van's location and an appointment time arranged for you.

If you have any queries, or would like to change the appointment, please phone the Programme on 699-5441. Mention that you are phoning in response to my invitation.

Yours sincerely,

### APPOINTMENT TIME

YOUR APPOINTMENT TIME IS:

LOCATION OF VAN: DRUMMOYNE CIVIC CENTRE, CORNER OF LYONS ROAD AND  
MARLBOROUGH STREET, DRUMMOYNE.

**APPENDIX 7: DOCTOR'S REMINDER LETTER**

Date

Dear

I am writing to follow up my letter from May about the Breast X-Ray Programme. Because (as far as I know), you were not able to attend earlier, I thought you may like to know that the mobile screening van is returning to this area.

I have enclosed an information sheet about the progress of the programme to date. For a limited period, the van will be open for extended hours to make it easier for some women to attend. (Please see back of information sheet).

**AN APPOINTMENT HAS BEEN MADE FOR YOU AT**

.....ON.....

**LOCATION OF THE VAN FROM .... TO....**

.....

If you would like to change the appointment or have any queries, please contact the Programme on 699 5441. Mention that you are calling about my invitation. I hope that you will be able to take advantage of this FREE service.

Yours faithfully,

.....

## **APPENDIX 8: PROTOCOL FOR RECEPTIONIST**

1. Receptionist checks all female patients who attend practice between now and Friday 26 May (the last day the Van will be in Drummoyne local Government Area is Monday 29 May). Can check age and address either by asking or by getting details from patient card.

\* Woman must be aged 45 to 70.

\* Must live in CSHS Area (list suburbs over).

\* Must not already have been to Breast Care. Please ask "Have you been to the Breast Care Van?"

2. If a woman is eligible (ie fills all the above criteria), receptionist should go to the next envelope. Please use the envelopes in numerical order.

(i) Write the woman's name, address, age and today's date on the envelope.

(ii) Open the envelope to see what to do.

The envelopes will say either "Pamphlet" or "Doctor". For "Pamphlet", give the woman a pamphlet. For "Doctor", hand the questionnaire to woman. Ask her to complete and hand in to doctor.

3. Place all the opened envelopes in the big brown envelope provided for collection.

### **Inappropriate Women**

There may be a small number of women whom it is inappropriate to include in a study of this type. Please record age and reason for exclusion below:

AGE REASON FOR EXCLUSION

Women Who Refuse Questionnaire

There may also be a few women who are not prepared to complete a questionnaire. If a women refuses to complete a questionnaire, then put questionnaire back in white envelope with her name etc. on it and write "refused" on it.

List of suburbs in the Central Sydney Area Health Service

Local Government Areas of

Ashfield	Drummoyne	Strathfield
Burwood	Leichhardt	Sydney City
Concord	Marrickville	(Western Sector)

Suburbs of

Abbotsford	Dobroyd Point	Newtown
Alexandria	Drummoyne	North Strathfield
Annandale	Dulwich Hill	Petersham
Ashfield	Enfield	Pymont
Balmain	Enfield South	Redfern

Belfield	Enmore	Rhodes
Birchgrove	Erskineville	Rozelle
Burwood	Five Dock	Russell Lea
Cabarita	Flemington	St Peters
Camperdown	Forest Lodge	Stanmore
Canada Bay	Glebe	Strathfield
Chippendale	Greenacre	Strathfield South
Chiswick	Haberfield	Strathfield West
Concord	Homebush	Summer Hill
Concord North	Leichhardt	Sydenham
Concord West	Lewisham	Tempe
Croydon	Lilyfield	Ultimo
Croydon Park	Marrickville	Waterloo
Darlington	Mortlake	

## **APPENDIX 9 : PROTOCOL FOR DOCTOR**

1. Conduct consultation as usual.
2. Go through questionnaire with woman using ideas outlined on prompt sheet.
3. Give pamphlet and offer appointment. Write appointment time on slip inside pamphlet.
4. Complete "Doctors Use Only".
5. Please hand all completed questionnaires to receptionist so she can put in big brown envelope provided for collection.

### **GENERAL PRACTITIONERS PROMPT SHEET**

This is a guide to how you can deal with the questionnaire. Introduce your advice with an explanation like "Before you go I'd like to go over the questionnaire which you've filled out". How you word your response will depend on the woman's answers.

Q1. Do you know anyone who has breast cancer?

This is meant as a general introduction to the topic. If a woman does know someone with breast cancer, you could say something like "Yes, I can see from your first answer that you know that breast cancer is a very common disease".

Alternatively, if she doesn't know someone, you can point out that it affects 1 in

15 Australian women at some time in their life.

Q2. Who do you think is at the greatest risk of developing breast cancer?

Our research shows that the majority of women don't feel themselves to be at personal risk. Consequently, they may feel that they don't need a breast X-Ray. Emphasis that all women in their age group are at risk. Even though she may feel perfectly well, you think that she still needs to be checked. In addition, explain that breast cancer increases with age. So women in her age group (ie 45 plus) are at greater risk than younger women.

Q3. Have you heard of a mammogram or breast X-Ray to check well women for cancers which are too small to be felt by the women or her doctor?

Reinforce that information that a mammogram is a special breast X-Ray that can pick up cancers very early, even before a woman or her doctor can feel a lump.

Q4. Do you have any concerns about having a breast X-Ray?

For women who answered that they have concerns - ask them to explain what they are worried about. Common concerns women express include fear of radiation and a belief that they will have to have their whole breast if a cancer is found.

Radiation: Explain that with modern machinery, the amount of radiation to the breast is very low and does no harm. The risk is equivalent to smoking 3/4 of a cigarette or 60 miles travelled by car.

Removal of the whole breast: Explain that if a cancer is found early

enough, than it can be removed and cured. Some women with breast cancer have a part of the breast removed rather than the whole breast. This is called a partial mastectomy or lumpectomy.

Q5. Have you heard of the Breast Care Van operating in this area?

For all women, explain that Breast Care is a State Government funded project which offers free breast X-Rays to women over 45 years who live in the inner West.

End your advice by reinforcing your support for the program and suggest you make an appointment for her.

"Well you can see that I think it's a good idea for you to attend this program, I'll give you a pamphlet which will give you more details and I'd like to make you an appointment.

Please complete "Doctors Use Only" by ticking the appropriate box.

ACC - women accepted appointment. Record appointment date.

REF - women refused appointment. Record reason for refusal.

NOTOFF - women was not offered an appointment. Please give a reason.

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VAN LOCATION

Date

Location and address

OPEN 8.30am to 4.30pm Except Tuesday and Sunday

YOUR APPOINTMENT



**BREAST  
CARE**



**BREAST X-RAY  
PROGRAMME**

*This practice is currently encouraging women to attend the Breast Care Programme. We are inviting you to participate in this important health programme. You can do this by doing the following:*

*Complete the details below on this page. Next, turn over and read the information carefully and answer the questions. Take this in with you when you see the doctor.*

i. Name.....

ii. Address.....

iii. Age.....

**EXAMPLE**

Out of the following cancers, which do you think is the most common type of cancer amongst women of your age group?

Bowel 1  
Breast 2  
Lung 3  
Cervix 4

By circling the number 2, this woman thinks that breast cancer is the most common type of cancer.

iv. Do you speak a language other than English at home?  
**CIRCLE ONE NUMBER ONLY**

YES 1  
NO 2

v. If yes, please state which language.....

**PLEASE TURN OVER AND CONTINUE**

CIRCLE ONE NUMBER ONLY

1. Do you know anyone who has had breast cancer?  
YES 1  
NO 2

2. Who do you think is at the greatest risk of developing breast cancer?

A WOMAN IN HER 40'S 1  
A WOMAN IN HER 50'S 2  
A WOMAN IN HER 60'S 3  
DON'T KNOW 4

3. Have you heard of a mammogram or breast x-ray to check well women for cancers which are too small to be felt by the woman or her doctor?

YES 1  
NO 2

4. Do you have any concerns about having a breast x-ray?

YES 1  
NO 2

5. Have you heard of the Breast Care Van operating in this area?

YES 1  
NO 2

.....  
DOCTOR'S USE ONLY

PLEASE TICK A BOX

ACC  (DATE).....

REF  (REAS).....

NOTOF  (REAS).....

# APPENDIX 10: ELECTORAL ROLL INVITATION

**BREAST  
CARE**



**BREAST X-RAY  
PROGRAMME**

Mrs

16th October 1989

Dear Mrs

We are writing to women in your area to tell them about a free breast x-ray service.

The Breast X-Ray Programme is funded by the NSW State Government. It has a mobile van where you can have a free breast x-ray - a mammogram. The x-ray is used to detect breast cancer in its early stages when it is curable and before you can feel or notice anything unusual. It is recommended by many authorities as a screening procedure for all women aged between 45 and 70 years. We are urging women to take advantage of this FREE service. Most women will be reassured to find nothing is wrong. For those few who are found to have cancer, early detection greatly increases the chance that there is a complete cure. Please find enclosed a pamphlet about the service.

AN APPOINTMENT HAS BEEN MADE FOR YOU AT:  
11.00 am on Friday 17th November 1989

LOCATION OF THE VAN FROM THURSDAY 16th NOVEMBER TO THURSDAY 30th NOVEMBER 1989: 151 Great North Road, Five Dock, (opposite library).

Please attend.

If you would like to change the appointment or make one for a later location, please phone the Programme on 699 5441. Mention that you have received our invitation.

Yours sincerely

Dr Mary Rickard  
Programme Director

08 SEP 1992

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