Privacy or life: how do women find out about screening mammography services?

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Abstract

Aim This study investigated how women found out about the Waikato pilot breast cancer screening programme and what influenced them to participate.

Methods A sample of 1085 women who had undergone screening mammography were sent survey questionnaires in 1999 to investigate how they had found out about the programme and what had influenced them to participate. Data from 599 completed questionnaires were analysed.

Results The most common external sources of information about the availability of screening mammography were: letters of invitation (42%), family doctors (42%), television (32%), and newspapers (27%). The most important external sources of influence for attending screening were: letter of invitation (28%), and knowing someone with breast cancer (27%).

Conclusions Letters of invitation from the programme provide an important source of influence for attending screening mammography clinics. Up-to-date databases are needed to ensure that women receive information from the screening programme. There was an inconsistency between the government policy to provide a population-based screening programme and the operation of the Privacy Act 1993, which prevents use of other sources of information to update addresses for population groups most likely to benefit from screening. The high ‘gone, no address’ rate reduced ongoing screening among women who depend on receiving regular recall notices.

The incidence of breast cancer has been increasing throughout the industrialised world, ‘even when earlier diagnosis and better cancer registration are discounted’. New Zealand is no exception, and past trends indicate that rates of breast cancer may continue to increase. Randomised controlled studies in other countries, such as that undertaken in 1963 by the New York Health Insurance Plan and the 1977 two-county trial in Sweden, have shown that screening mammography significantly reduces mortality from breast cancer in women aged 50 and older.

It has been estimated that at least 70% of the eligible population need to attend screening mammography programmes for the cost and mortality savings to be worthwhile. In order to attain the desired criteria of accessibility, acceptability and efficiency, women need to be made aware of, and participate in, the programme.

However, if women do not know about the screening programme they cannot present for screening, and thus breast cancer is unlikely to be detected early. The more effective and efficient means a programme has at its disposal to communicate its
presence to eligible women, the better. To determine how women found out about the breast screening programme and what influenced them to participate, women who had attended the third round of the Waikato pilot breast cancer screening programme were identified, and a stratified sample selected for a self-completion questionnaire survey.

**Methods**

Following approval from the Waikato Ethics Committee, the research commenced with a survey in Phase 1, designed to explore various influences on the communication process related to screening mammography. The questionnaire included both closed and open-ended questions to allow women to contribute feedback about their experience of the programme. Following pre-testing among 60 women, the survey questionnaire was distributed to 1085 women in October 1999. Completed questionnaires were received from 599 women. In Phase 2, the issues arising from the survey were explored in five focus groups (with 41 women in total) and with three women in individual interviews.

**Sample selection**

The sampling frame was the database of women who had participated in the third round of the Waikato pilot programme. As part of a national pilot, participants had given consent to participate in a survey evaluating the programme. However, this source also eliminated those eligible women who had not attended the pilot programme from the study. There were 14 392 women between 50 and 64 years old in the Waikato breast screening database in August 1999 who could have been selected to participate in this research. To protect the anonymity of the women on the database, the researcher was not given access to names and addresses of participants. Accordingly, the sample selection was obtained by request from the information technology staff of the breast screening programme.

To obtain data that included known groups within the population, a sample of 1100 women stratified by region, age and ethnic group, was selected from the database. Maori were oversampled to ensure adequate numbers, so specific ethnic samples were drawn to represent 35% of Maori and 4% of the NZ European groups respectively on the database. All women of ethnic groups other than NZ European and Maori were selected. Next, programme staff eliminated names without a current address, and a total of 1085 questionnaires were distributed in October 1999. A reminder letter was sent to those who did not respond within five weeks. The numbers of women sent questionnaires for each of the ethnic groups was: Maori 370, NZ European 505, Pacific 71, Asian 64, Indian 64 and Other 11. Due to the limited number of Pacific women on the programme database, questionnaires were hand delivered to them by the health workers where possible, and collected on completion.

In the initial mailing group of 1085, 13 people were found to be not available/suitable and were removed from the list (eight deceased, four living overseas, one male). Forty eight letters returned with the addressee listed as ‘gone, no address’ (GNA) and were replaced with 48 names randomly selected from the database. Subsequently, another 21 GNA letters were returned. Excluding the 21 GNA addressees and the 13 not available, the net number of questionnaires distributed was 1051. A total of 611 completed questionnaires were received (response rate 58%, 611/1051). Of these 611 women, 599 were in the sample frame, aged between 50 and 64 years. Twelve of the completed questionnaires were answered by telephone, as some women were not confident with written responses and requested assistance.

**Sample profile**

The sample of 599 included women across three specific age groups (50–54 = 38%, 55–59 = 35%, 60–64 = 27%) and area of residence (city = 32%, rural town = 53%, country = 15%). Many of the women attended the Waikato Hospital clinic (52%); the mobile van was used by 48%. Most had attended secondary school (62%) and a smaller proportion had attended university (12%) or a polytechnic (7%). Ethnic groups represented were: NZ European 348 (57%), Maori 155 (25%), Pacific 51 (8.5%), Asian 42 (7%) and Other 15 (2.5%). The Maori group included those who identified themselves as both Maori and another ethnic group.

**Analysis**

The data were analysed using SPSS (Release 8, 1997). Chi square was used to test the significance of associations between demographic characteristics and other variables. The 15 women categorised as ‘Other’ were not included in the analyses examining differences among ethnic groups because of their small number.
Results

Sources of information

To provide some indication of the ‘visibility’ of the various approaches used to communicate screening mammography to the eligible population, the questionnaire asked respondents how they obtained information about the screening programme. Their responses are shown in Figure 1. Most women reported multiple sources of information, so the frequencies for the categories shown in Figure 1 are not mutually exclusive.

Figure 1. How respondents obtained information about the programme.
(Numbers exceed 599 as respondents could nominate more than one category)

Letters of invitation from the programme and family doctors were the most common sources of information. When women registered on the Waikato database, they were sent a letter of invitation to participate in the screening programme. Ideally, this invitation was coordinated with a letter from their family doctors. Forty two per cent of women (251) heard about the programme through letters of invitation and 42% (249) from their doctors. The next most common sources of information were television (33%, 198) and newspapers (27%, 165). A higher proportion of older women (52% of women aged between 60 and 64 years) obtained information about the programme from the letter of invitation, than younger women (36% of those aged 50–54 years). The differences in sources of information by age (shown in Table 1) were significant (p = 0.003).
Table 1. Sources of information and influence by age

<table>
<thead>
<tr>
<th>Age</th>
<th>50–54 years</th>
<th>55–59 years</th>
<th>60–64 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>231</td>
<td>208</td>
<td>160</td>
</tr>
<tr>
<td>% receiving information from letter of invitation</td>
<td>36%</td>
<td>38%</td>
<td>52%</td>
</tr>
<tr>
<td>% influenced to participate by letter of invitation</td>
<td>21%</td>
<td>30%</td>
<td>36%</td>
</tr>
<tr>
<td>% receiving information from health workers</td>
<td>16%</td>
<td>12%</td>
<td>10%</td>
</tr>
<tr>
<td>% influenced to participate by health workers</td>
<td>17%</td>
<td>11%</td>
<td>8%</td>
</tr>
</tbody>
</table>

Influence of ethnicity

All groups reported receiving information about screening mammography from their doctors (Maori = 41%, NZ European = 39%, Pacific = 45%, Asian = 27%). Pacific women (59%) and Maori women (21%) were more likely to find out about screening from health workers (those people involved in health promotion other than doctors) than Asian women (9%) or NZ European women (3%) (p < 0.0005, see Table 2). Pacific women were more likely to report personal contact sources of information, such as family (35%), friends (22%), church (20%) and health days (16%), compared with other ethnic groups. Pacific women were also more likely to have obtained information from the radio (33%).

Table 2. Sources of information and influence by ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>NZ Maori</th>
<th>NZ European</th>
<th>Pacific</th>
<th>Asian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of respondents</td>
<td>155</td>
<td>348</td>
<td>51</td>
<td>42</td>
</tr>
<tr>
<td>% receiving information from letter of invitation</td>
<td>38%</td>
<td>44%</td>
<td>31%</td>
<td>40%</td>
</tr>
<tr>
<td>% influenced by letter of invitation</td>
<td>28%</td>
<td>32%</td>
<td>6%</td>
<td>29%</td>
</tr>
<tr>
<td>% receiving information from health workers</td>
<td>21%</td>
<td>3%</td>
<td>59%</td>
<td>10%</td>
</tr>
<tr>
<td>% influenced to participate by health workers</td>
<td>22%</td>
<td>2%</td>
<td>61%</td>
<td>7%</td>
</tr>
<tr>
<td>% who made own decision about participation</td>
<td>28%</td>
<td>38%</td>
<td>18%</td>
<td>31%</td>
</tr>
</tbody>
</table>

* Excluding ‘Other’ ethnic group (15 respondents)

Maori women reported that, in addition to the letter of invitation (38%) and health workers (21%), they also relied on family (20%) and friends (17%) as sources of information. For Asian and NZ European women, common sources of information besides the letter of invitation were newspapers (Asian = 33%, NZ European = 30%) and magazines (Asian 14%).
Sources of influence

Although the above methods demonstrated levels of programme visibility to women in the community, it was also important to identify the sources of communication women perceived to be influential in helping them to make a decision about participating in screening mammography. The most common influences reported are shown in Figure 2. During the pre-test phase of the questionnaire development, most women wished to nominate more than one source of influence. Accordingly, in the main survey they were invited to nominate more than one source of influence.

Figure 2. Sources of influence that encouraged participation in programme.
(Numbers exceed 599 as respondents could nominate more than one category)

Two hundred women (33%) believed they had made their own decision to attend screening irrespective of external influences. Of these, 115 reported this as a sole category of influence on their decision to participate in the breast screening programme. A further 85 respondents nominated between one and seven other influences as well as making their “own decision”. The most commonly nominated other category of influence was “know someone with breast cancer” (6%, 37). NZ European women (38%) were more likely (p = 0.009) to report making their own decision about having a mammogram than other ethnic groups (see Table 2). Letters of invitation (29%, 174) were the most common external source of influence in the programme. These letters were more than twice as influential as letters from family
doctors (12%) and information on television (7%). There was significant variation between age groups, with women between 60 and 64 years of age more likely to respond to letters (36%) than women aged 50–54 years (21%, p = 0.006, see Table 1). Responses to the letter of invitation also varied among ethnic groups, with 32% of NZ European women responding to the letter, compared with 6% of Pacific women (p = 0.002, see Table 2). Twenty eight per cent of respondents reported that knowing someone with breast cancer had encouraged them to undergo screening mammography.

Although health workers influenced only 12% of all women to participate in screening mammography, health workers were significantly more influential (p < 0.0005) for Pacific (61%) and Maori women (22%), compared with Asian (7%) and NZ European women (2%). The pilot programme employed two Maori health workers through Tainui to promote the breast and cervical screening programmes. Mammography staff were responsible for promoting breast cancer screening to NZ European, Pacific and Asian women during this period. Twenty two per cent of Maori and Pacific women commented in the survey about their reliance on the input of health workers for decision making as well as for support through the process. The influence of health workers was also higher among younger women (17% among those aged 50–54 years) compared with older women (8% among those aged 60–64 years, p = 0.019).

Discussion

Women must participate in regular screening mammography if they are to benefit. Given that 70% of the eligible population need to participate to ensure benefits in both cost and mortality are achieved, the programme must be able to communicate its presence to the target audience in the most efficient and effective way possible. This study provides information about the women who have chosen to participate in the pilot programme only. Obtaining a random sample of women who had participated in the third round of screening (between 1 November 1995 and 23 April 1998) from the breast screening database provided a sample of women who had been exposed to the communication from the breast screening programme. It did not include those who had not attended. As only those women registered on the database were included, the results may not be generalisable to Waikato women in general. However, a comparative analysis of ‘early’ and ‘late’ responders (pre- and post-reminder letter) in this study indicated a lack of significant differences. There are a number of eligible women in the Waikato who have not been identified, who have been identified but not invited to the programme, or who have been identified and have declined screening. Currently, BreastScreen Aotearoa has 54% coverage in the first round of screening. Of the 46% of eligible women who have not attended, there is no way of knowing whether they have not been identified, have been identified and not invited, or have declined screening or decided to undergo mammography in the private sector. One of the key criteria for the success of any population-based screening mammography programme is its ability to communicate its presence to eligible women. If a significant number of the target audience are not aware of a screening programme, they are unlikely to participate.

The health reforms introduced in 1991 encouraged primary health care services such as screening mammography. The breast screening programme presents the option of
regular screening mammography to eligible women in the community, and encourages them to register in addition to those women being directed towards the services by their doctors. In the present study, 64% of all women indicated that they wished to confer with their doctors about future health care decisions, and 50% consulted with their family doctor about the programme. However, the willingness of the remaining 50% to make that decision independently of their family doctors emphasised the importance of effectively communicating the presence of the programme.

Research in several countries (such as New Zealand, Britain, Australia, Israel and America) has identified general practitioners as an important source of information for women who participate in screening mammography. The fact that half of the women who responded to this survey entered the screening programme without encouragement from their general practitioner, gave rise to the question of whether non attenders either did not receive information or encouragement from their family doctor, or received information, encouragement, or both, and chose not to respond. In New Zealand, GPs’ letters ideally coordinate with those of the breast cancer screening programme. In this research, a review of coded registration forms distributed to GPs in the South Waikato towns of Mangakino, Tokoroa and Rotorua by the breast screening programme in late 1999 revealed a 7% response rate, assuming that all were distributed. However, due to the inadequacies of the information support system, it is not possible to identify how many women in the designated areas chose to respond by telephone. Because of this, the outcomes were inconclusive. In previous research, letters from a screening mammography programme were just as effective as letters from doctors in encouraging women to take part. In the present study, 42% of respondents received letters about breast screening from their doctor. However, letters of recommendation from doctors were less influential (12%) than letters of invitation from the programme (29%), which is consistent with the results of an earlier Australian study.

With the increasing visibility of the national programme in the media, it could be argued that women can obtain information from sources such as television or magazines and do not require direct targeting. In this study, although 64% of respondents reported they had seen breast screening advertisements on television recently, only 33% nominated television as a source of information, and only 7% of respondents had been influenced by television promotion to participate. Although exposure to sources of information may provide information about breast screening, it does not necessarily encourage participation. Furthermore, a British study argued that breast cancer is such a ‘highly emotive, deeply threatening topic’ that using mass media channels to promote screening mammography may heighten anxiety in some women unless it is combined with other more personal methods of communication. Another recent British study has revealed that this anxiety can be so acute that some women avoid media information altogether. While sources of information such as television have some influence, letters of invitation from screening programmes have been consistently demonstrated as an efficient means of recruitment. An Australian study found that, in contrast to community promotional strategies, letters of invitation from the programme provided the most effective and efficient means of recruitment to screening mammography programmes.
Regular, ongoing screening is required if mammography is to be an effective means of lowering mortality from breast cancer. Thus reminders are an important part of the programme. Over half of the study participants were working. It was commonly reported that they were “busy and relied on prompting” for health checks, especially as they occurred only once every two years. Reliance on an effective system of recall was shown in one study, which demonstrated that reminder letters from a screening programme can double the likelihood of participation. It has also been reported that reminder telephone calls, or a combination of both letters and telephone calls, are likely to encourage participation.

Women in this study relied on the programme to let them know when they were due for re-screening. Without access to current contact details, staff were frequently unable to provide timely, appropriate information for women. Respondents often wrote of their reliance on local papers (27%) and radio (18%) as a source of information about the timing of the mobile van visits to their areas. They expressed their “disappointment” that they did not receive reminders, and perceived that the reminder service was “unreliable”, and sometimes reported feeling “lost in the system”. The difficulty in achieving ongoing participation through lack of current, accurate records was shown by 69 (12%) letters returned as ‘gone, no address’ during this survey. This indicates that at least 12% of women sent recall notices are not likely to receive them. Access to a current, population-based database to ensure that contact details for women are as accurate as possible is necessary if the national screening mammography programme is to achieve cost and mortality savings. Currently, the BreastScreen Aotearoa programme has no population database from which to send invitations. The three potential databases of the electoral roll, GP records and NHI figures, are inaccessible because of privacy issues. Only some of the GP databases are available. Thus, there is no way of knowing how many eligible women were not reached, not asked, declined, and for what reasons.

The effectiveness of a national database has been demonstrated in other countries. In Sweden, where a national population register is used to identify eligible women, a participation rate of between 83% and 89% has been reported. Although identification of the eligible population for the Waikato pilot was achieved primarily through access to electoral rolls, the Privacy Act of 1993 precluded this source of identification for the national BreastScreen Aotearoa programme. The result is an anomaly in a government policy that provides a population-based screening programme designed to be as barrier-free as possible for women, but then creates a barrier for that programme (through the 1993 Privacy Act), preventing use of the most effective means of identifying the target population. Government has a responsibility to ensure that legislation does not directly contravene the successful attainment of goals it has put in place for population-based screening programmes.

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References: