

# **A REVIEW OF THE CONSISTENCY OF PAMPHLETS PROMOTING MAMMOGRAPHIC SCREENING IN AUSTRALIA**

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## **Abstract**

Breast cancer is the most common cancer diagnosed in women in Australia and the most common cause of cancer death in Australian women. Early detection of breast cancers with mammography has the potential to dramatically reduce mortality rates. Thus, there is an obvious need for clear, accurate information about breast cancer screening to be disseminated to Australian women. A 1997 review of breast cancer screening pamphlets in Australia noted some inconsistencies in the nature and content of the information provided, and recommended that these be addressed. The current study, conducted in January 2001, examined whether consistency has improved since the 1997 review. A total of 35 items were identified which met the inclusion criteria. These were reviewed for consistency across five specific content areas. The materials were largely consistent in their coverage of causes, risk factors, and screening information. However, considerable inconsistencies were identified for the estimated lifetime risk of developing breast cancer and for symptoms of breast cancer. These inconsistencies are disturbing because they appear in the two areas where accurate information is most likely to contribute to increased screening, detection and treatment of breast cancer.

## **Introduction**

Breast cancer is the most common cancer diagnosed in women in Australia (apart from non-melanocytic skin cancers) with an average annual incidence rate of over 9,000; and the most common cause of cancer death in Australian women, with an average mortality rate of over 2,500 women per year (NHMRC National Breast Cancer Centre 1999).

Early detection of breast cancers with mammography has the potential to dramatically reduce mortality rates. In 1996-1997, over 50% of the target population (women aged 50-69) were screened by BreastScreen Australia (Australian Institute of Health and Welfare 1998). Cancer screening behaviours for breast cancer have been shown to be associated with knowledge of the risk factors and perceptions of survivability (Pearlman, Clark, Rakowski and Ehrich 1999).

Numerous studies have demonstrated that women have many misperceptions about breast cancer, particularly in relation to their estimated likelihood of developing breast cancer (Skinner, Kreuter, Kobrin and Strecher 1998); (Paul, Barratt, Redman, Cockburn and Lowe 1999); the relevant risk factors (Johnson, Bottorff, Balneaves, Grewal, Bhagat, Hilton and Clarke 1999); and the recommended target group and interval for screening (Barratt, Cockburn, Redman, Paul and Perkins 1998). Additionally, the 1997 Australian Breast Health Survey found that many women in Australia want more information about breast cancer screening (Barratt, Cockburn, Lowe, Paul, Perkins and Redman 1997). There is an obvious need for clear, accurate information about breast cancer and breast cancer screening to be disseminated to Australian women (NHMRC National Breast Cancer Centre 1997).

In 1997 a review was undertaken of breast cancer screening pamphlets in Australia. Some inconsistencies were observed in the nature and content of the information provided (Slaytor and Ward 1998). However, this study was limited in scope, in that it reported only the proportion of these pamphlets that included information on 10 specific “risks and benefits of mammographic screening” (p. 263).

The aim of the current study was to review the consistency of information in materials promoting mammographic screening produced by health professionals for distribution to Australian women (this is part of a large-scale study reviewing all breast cancer screening messages disseminated in Australia, including those in the media). The current review included all pamphlets, posters, stickers and bookmarks currently distributed by these sources which aim to promote mammographic screening.

## Methodology

The materials reviewed in this paper were obtained from organisations that produce and distribute written information on breast cancer. An extensive list of these organisations was developed in consultation with experienced cancer education officers, and by searching electronic telephone directories and the Internet. The organisations contacted include all BreastScreen centres (National and State), major cancer councils and foundations, and relevant government departments. Finally, a number of health care providers, such as women’s hospitals and health information centres, were contacted to ensure that no major information sources had been overlooked.

The items were then reviewed for relevance by two independent coders to determine whether they fell within the focus of the project, which was “mammographic screening messages aimed at asymptomatic women in Australia”. Thus, the review excluded items written: for the information of medical practitioners, students, or researchers; in languages other than English (note that all of these items were translations of items that were also available in English, and the English versions were included); targeting symptomatic women – that is, items written for women who had already found a breast lump; for women referred for further tests following an abnormal mammogram; for women who have been diagnosed with breast cancer or had treatment for breast cancer; and for specific groups of women which, by their nature, contain different information (such as those written for women with implants, for women under 40 to explain why they are ineligible for a free mammogram, for women with a family or personal history of breast cancer) and are designed to be read in conjunction with the standard materials. These items were not included due to the necessarily different information contained in them, but were found to be consistent in relation to the overlapping information provided.

A total of 35 items fitted the criteria, and were included in the review:

- 25 pamphlets or booklets
- 5 posters
- 3 fact sheets
- 2 bookmarks.

Five specific content areas were included in the analysis:

1. estimated lifetime risk of developing breast cancer
2. causes of breast cancer
3. risk factors for developing breast cancer
4. symptoms of breast cancer

5. screening information (breast self-examination, clinical breast examination, and mammography).

## **Results**

Five of the posters were reviewed separately as, by their nature, they did not contain comprehensive information. All of these items referred to women aged over 50, all stated that free mammograms are available, and all included a contact telephone number. Only one advised that women aged 40-49 can also attend.

The remaining 23 items (17 pamphlets, two bookmarks, one poster, 2 fact sheets and one card) provided more details about breast cancer and mammography, and are the basis for the results discussed below.

### **1. Lifetime risk**

Fourteen of the 23 items contained no information on the lifetime risk of breast cancer. Of those that did, two stated that the incidence was 1 in 11, one 1 in 12, one 1 in 13, and five 1 in 14. Additionally, three items made reference to breast cancer being one of the most common cancers that can kill women.

There is a lack of consensus in terms of the stated lifetime risk of breast cancer, with the figures quoted ranging between 1 in 11 and 1 in 14. This result is similar to a 1997 review of breast cancer pamphlets in Australia which reported that lifetime risk was estimated at between one in 11 and one in 16 (Slaytor and Ward 1998). Whereas the author acknowledges that there is some variation across time periods, it is important to note that all the materials included in this study were written in Australia between 1995 and 2001 and, more importantly, were provided to the author in January 2001 by the organisations as materials that are currently distributed to Australian women. It has been suggested that one reason for the variation is differences in incidence rates between states (Slevin 2001). However a comparison of the stated incidence rates shows agreement across states in some instances and disagreement within states in others.

### **2. Causes**

One item stated that the causes of breast cancer are not known, and the other 22 did not discuss causation.

### **3. Risk factors**

Nine of the 23 items did not discuss risk factors for breast cancer. Among those that did, the most commonly mentioned risk factor was age; either generally that breast cancer risk increases with age, or that it is more common in older women, or specifically that breast cancer is more common in women over 50; and four items stated that 70% of breast cancer cases occur in women aged over 50. One item also mentioned a number of other risk factors (including reproductive history, previous cancer, diet, etc.), but also added that only a small fraction of cases is explained by these risk factors. Finally, one item also mentioned strong family history is a risk factor, and another reported that nine out of ten women with breast cancer have no close relatives who have had the disease.

#### 4. Symptoms

Seventeen of the items addressed symptoms of breast cancer. All 17 instructed women to see their doctor if they noticed any changes, problems, and/or symptoms. The symptoms most frequently mentioned were:

- Breast lumps – 14 items mentioned lumps, and three thickening.
- Discharge – 14 items mentioned discharge from the nipple.
- Changes – two items mentioned a change in breast shape,
- Skin – one item mentioned dimpling, one puckering or dimpling, and one change in the skin
- Nipple – one mentioned a change in nipple shape, and one a new inverted nipple
- Pain – two items referred to pain, two unusual pain, and two new and persistent breast pain
- Armpit – none of the brochures referred to changes in the arm or armpit
- Finally, three items included all-inclusive statements such as “any other changes,” and two referred to “unusual appearance”.

The representation of symptoms was one of the areas of greatest inconsistency. Each “symptom” was described in several different ways across the set of items, with the variation sufficient in many cases that the same occurrence could be interpreted as a symptom or a non-symptom depending on the specific brochure read. While many of the other differences between the items included in this study (such as estimated incidence rates) could be argued to be of minor consequence as individual women are likely to only read one or two items and thus be unaware of the inconsistencies, this very fact argues for the importance of these findings. The rationale for providing women with information on the symptoms of breast cancer is to (a) enable them to recognise potential symptoms of breast cancer and seek appropriate medical advice, and (b) minimise the distress caused to women who mistakenly interpret ‘non-symptoms’ as evidence of breast cancer. As most women will read only one, or a few, of these items, there is the potential for women with detectable symptoms of breast cancer to delay seeking medical advice as their symptoms do not fit the descriptions in the literature to which they have been exposed.

#### 5. Screening

Breast self-examination (BSE): Sixteen of the 23 items referred to breast self examination, with 13 of them explicitly stating that this should be done monthly. Additionally, one item targeting indigenous women urged women not to feel shame about doing BSE.

Clinical Breast Exam: Fifteen of the 23 items discussed clinical breast examinations; eight describing this as a check by your doctor and seven as by your doctor, nurse or health worker. Nine stated that this check should be conducted annually, and six “regularly”.

Mammography: The majority of items recommended mammographic screening from the age of 50 onwards (11 items) or, more specifically, between 50 and 69 (nine items). Two items simply stated that mammographic screening was available to women aged over 40. The remaining two items did not include an age recommendation, but these were ‘call back’ items designed for women who had been screened previously). Twelve items mentioned that free screening was also available to women aged forty to forty-nine, but that the evidence of effectiveness in this age group was ‘not clear’ or ‘not strong’. Six items also made a similar

statement in relation to women aged over seventy.<sup>1</sup> Five items also referred specifically to women with a strong family history of breast cancer, recommending screening from the age of 40, 10 years before the relative's age at diagnosis, or on a doctor's recommendation.

Twenty one of the 24 items recommended two-yearly screening; one just stated 'regularly' and the other did not give a frequency. Only nine of the items stated that screening was for asymptomatic women.

Most stated that mammography is 'not 100%' accurate or 'will not detect all' breast cancers; with three of the items stating an accuracy rate of around ninety percent. Seven of the 23 items did not include a statement along these lines, and four of these were items with very limited text (such as bookmarks or posters).

All but five of the items stated that mammograms are provided free of charge, although one stated that mammograms were free from the age of fifty, rather than forty (the latter being the correct age).

Ten of the items addressed the mammogram experience itself, and all of these mentioned that having a mammogram was 'uncomfortable' or caused temporary "discomfort," but should not be painful.

Finally, seven discussed the timing of a mammogram – and these recommendations were somewhat inconsistent: two suggested having a mammogram "during or just after your period," one "soon after," one "one-two weeks after," one simply "after," and one "avoiding times when your breasts are more tender".

## **Conclusions and Recommendations**

This review of breast cancer screening messages in materials available to Australian women found a high level of consistency in information about screening, such as recommended age and interval of screening, but many serious inconsistencies in the information about breast cancer itself, and particularly about the incidence and symptoms of breast cancer. Early detection of breast cancer (by mammography) dramatically increases survival rates, and reduces the extent of surgery required to remove the cancer. Conveying *accurate* information to Australian women in order to persuade them to undergo regular mammography is an important activity for social marketers.

As noted in the introduction, women in Australia are exposed to an array of messages about breast cancer through the media and other sources, and it is recognised that health authorities have little direct control over the content of this information. However, material produced by health authorities, which is ideally seen by consumers as 'expert' opinion, has as one of its functions correcting inaccurate perceptions generated by exposure to these other sources.

It is recommended that an appropriate body – such as the Cancer Council or the NHMRC – oversee a process of consultation between those working in the field of breast cancer screening to agree on consistent quantifications and definitions of, particularly, incidence and symptoms. Further, once this consensus has been reached, there is a need for an extensive social marketing campaign to both develop and disseminate appropriate messages to convey this information in such a way as to provide Australian women with an accurate understanding of breast cancer and breast cancer screening, and thus increase screening rates.

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<sup>1</sup> Two items used the phrase "may have other health priorities" to explain why women in this age group may choose not to be screened.

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