Breast Cancer Network Australia

The out-of-pocket cost of follow-up care: Mammogram, ultrasound and MRI

April 2009

‘It seems wrong that women who have had a diagnosis of breast cancer and have had to cope with all the associated costs, should then have to pay for their mammograms, while those blessed with not having the disease get theirs for free.’

‘I’m pleased this issue is being addressed. It is quite expensive to have the essential annual follow-up mammograms/ultrasounds – I worry that some patients may not have them for that reason.’

‘Add the costs of hormone therapy and other medication, blood tests, pelvic scans, follow up visits with surgeons, GPs, day charges in hospital etc. to mammograms and ultrasounds and you have a very high ongoing cost…’

Comments from women completing the BCNA 2008 Imaging Survey
**Introduction**

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. We work to ensure that Australians diagnosed with breast cancer and their families receive the very best information, treatment, care and support possible, no matter who they are or where they live.

In June 2008 BCNA surveyed women with breast cancer, to identify the out-of-pocket (OOP) cost of mammograms, ultrasounds and MRI following breast cancer treatment. This report summarises the findings of that survey.

**Process**

An online survey was emailed to 250 BCNA members\(^1\) from across Australia, who were randomly selected from our database.

There was a 64% response rate, with 160 women completing the survey. Thirty-five percent of respondents were under, or at the age of 50. In the general population, 24% of women diagnosed with breast cancer are under the age of 50\(^2\), making the sample younger than the general population of women with breast cancer.

![Age distribution of survey respondents](image)

**Table 1:**

**Age distribution of survey respondents**

All states and territories were represented in the survey, as indicated below\(^3\).

![Location distribution](image)

\(^1\) Survey respondents were women with breast cancer who were randomly selected from our BCNA membership, as well as the BCNA ‘Review and Survey’ group. These are women who have agreed to complete surveys sent to them from BCNA from time to time.


\(^3\) Australian figures cited in ‘Breast Cancer in Australia: an overview 2006 AIHW and NBCC: 2006.'
Table 2: Location distribution of survey respondents

Seventy-eight percent of respondents were diagnosed with breast cancer within the last five years. Sixty-six percent of women had early breast cancer. Twenty-six percent had DCIS at first diagnosis, which is higher than the general population of women diagnosed with breast cancer. Just over 5% of women had locally advanced cancer and 1.2% of women had secondary breast cancer.

Findings

Mammograms

Cost and frequency

Ninety percent of the women completing the survey had regular follow-up mammograms (144 out of 160). Eighty-three percent of women had mammograms annually (120 respondents), while 17% (24 respondents) had their follow-up mammograms at six-monthly intervals.

Of the 16 women that were not having mammograms, the most commonly cited reason was bilateral mastectomy (9 respondents), that they hadn’t yet completed active treatment (6 respondents), with one woman stating she was ‘not sure’.

Sixty-three percent of women having follow-up mammograms (91 out of 144 respondents) incurred OOP expenses for these. Forty-seven percent of the 144 women having follow-up mammograms (67 respondents) were OOP between $51 and $150 for each mammogram. Of the five women that payed $150 or more, the OOP cost ranged from $166 to $400.

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Table 3: Out-of-pocket costs of mammograms after Medicare/insurance rebates

Eighty-four percent of women were referred for their follow-up mammogram by their surgeon, 31% percent by an oncologist, and 19% by a general practitioner. Some women had been referred by different practitioners over time.

Forty-eight percent of women had mammograms at private imaging services, 29% at an imaging service at a private hospital, and 20% at imaging services in public hospitals. Eight percent of women had their mammogram at a BreastScreen service. Six percent of women chose more than one answer to this question, suggesting that they had attended different clinics for their mammograms over time.
Eighty-seven percent of women travelled less than one hour to their mammogram appointment. Of the seven women who took over three hours to get to their appointment, two had to stay at their destination overnight, incurring additional costs. Over half of the women who had follow up mammograms (77 women) chose to make additional comments. Thirty-eight women told us that mammograms should be available free of charge.

Many of their comments reflected concerns about the cost of mammograms in addition to the other costs associated with breast cancer:

‘I think once diagnosed and for further mammogram costs, that these should be bulk billed to government. Family and friends could not believe that I was further out of pocket after experiencing all expenses last year, and what with the ongoing cost of medication now.’

Many women stated that having to pay for mammograms was inequitable, especially when screening mammography was free of charge.

‘It’s not fair that women who have had breast cancer have to pay for their mammograms and women who are cancer free can access BreastScreen with no cost for their mammograms. Those of us who have had, or in my case recently diagnosed with secondary breast cancer, have enormous out of pocket expenses.’

Some groups such as rural women, and those with a strong family history of breast cancer, noted particular challenges:

The cost of a mammogram for the under 50s in some cases is prohibitive, especially in the country where you have to travel 100kms – so a day off work, organising the children for after school care, then the cost of petrol and the procedure. It should be free…

I was having mammograms and ultrasounds performed annually from the age of 30 until diagnosed at 35 as I have BRCA1 gene, and this was used as a screening program for me. I am lucky that I was able to afford the high out of pocket costs, as otherwise my cancer would not have been detected so early. I do feel that as a high risk woman, my costs should have been covered by Medicare.

Some women stated the reasons they did not have to pay:

‘I am a now a pensioner and this year there was no cost for my mammogram and ultrasound…’

‘It was very helpful not to have to pay for the service as there were many other costs in follow up checks and treatment.’

Importantly only two women stated that they were not concerned about the costs:

I am happy to be alive! I don’t worry about the costs, however, I have been travelling around Australia and am appalled at outback health services.
Breast ultrasound

Cost and frequency

Ultrasound is often a more effective imaging option for younger women, as they tend to have dense breast tissue. Sixty-seven percent of women (108 out of 160 respondents) reported having had at least one follow-up ultrasound. Of these women, fifteen percent of women had six monthly ultrasounds, 59% yearly ultrasounds, and 9% every two years. Seventeen percent of women stated that they had only had one ultrasound or had them only occasionally. A number of women chose more than one response to this question.

Breakdown by age

In this way, 100% of women in the 21 to 30 year-old age group (1 woman), 70% of women in the 31 to 40 year age group, 65% of women in the 41 to 50 year-old age group, 56% of women in the 51-60 year-old age group, and 52% of women in the 61 to 70 year-old age group were having ultrasounds.

As with mammograms, the costs for women having ultrasounds as part of their follow-up care varied widely. Sixty-four percent of women (69 respondents) incurred OOP expenses, with 51% (55 women) paying between $51 to $200.

Table 4: Out-of-pocket costs of ultrasounds after Medicare/insurance rebates

Various reasons were given for why women had ultrasounds. These included the ultrasound:
• providing a better overall picture, especially where the mammogram was not clear
• investigating a suspicious lump or cyst
• being part of their follow-up routine
• being used when mammography was not possible, as in cases of pregnancy or lymphoedema in the breast
• being performed at their request.

Eighty-percent of women were referred for their ultrasound by a surgeon, 27% by an oncologist and 20% by a general practitioner. As with mammograms, in some instances women provided more than one answer to this question, suggesting that they were referred for ultrasound at different times by different doctors.

Fifty-three percent of women had their ultrasound at private imaging services, 30% at imaging services at private hospitals, and 16% at imaging services in public hospitals.

Eighty-six percent of women took less than one hour to travel to their ultrasound appointment. Of the three women who took over three hours to get to their appointment, this ranged from just over three hours, to nine hours. One woman had to stay overnight.

As with mammograms, some women clearly expressed that follow-up ultrasound should be free to women, or that it was too expensive.

‘I believe costs for follow up ultrasound should be free of charge to the patient.’

In some instances the ultrasound was seen as ‘optional’ and the cost as prohibitive.

‘…if a woman has had breast cancer then this extra need for care should be free as a lot of women don’t go ahead with optional ultrasounds because of the cost factor.’

Magnetic Resonance Imaging (MRI)

Cost and frequency

The use of MRI is not part of the regular regime of follow-up care after breast cancer treatment. Only thirteen percent of women (21 out of 160 respondents) stated that they had an MRI as part of their follow-up care. Twelve women had had a single MRI, seven women had had two MRIs and two women had had three or four MRIs.

The cost of each MRI varied from no OOP cost, to $700 per MRI, with most falling within these ranges.
Table 5: Out-of-pocket costs of MRI after Medicare/insurance rebates

Various reasons were given for having an MRI. These included:

- a suspected spread of cancer, with symptoms including bone or hip pain
- a diagnosis of secondary breast cancer
- a high risk of recurrence because of bilateral cancer
- it being undertaken as a precautionary measure
- it being more sensitive than a mammogram.

The high and prohibitive cost of MRI was noted, with some choosing not to pursue it for this reason:

‘I think most people realise there will be some cost involved when you have a serious illness, however the cost of MRI is prohibitive for some people. I have top private cover and I still had to pay upfront and there was no rebate. $600 is a lot of money to pay when you are already paying so many other medical expenses. I wonder how many women miss out on this due to the high costs. It seems very unfair.’

‘My surgeon did discuss the possibility of MRI instead of mammogram/ultrasound but advised that the cost is prohibitive and not yet Medicare funded – he did state that he’d refer me if I was prepared to pay approximately $500 for the pleasure!’

Discussion

Some 50 women stated strongly at the end of the survey that imaging tests (with a focus on mammograms and ultrasounds), should be available free of charge to women. As there were 91 women paying for mammograms in the sample, this represents 54% of these women. Many of these comments were echoed and reiterated throughout the survey. It was noted time and time again that these tests add to the significant financial burden of having breast cancer.

It seems that particular groups of women, including rural women, younger women and those with high familial risk of breast cancer, are particularly disadvantaged by the costs associated with having mammograms and ultrasounds.
It is concerning that some women may forfeit necessary tests because of the cost, as indicated by the following comments:

‘Because of the costs of these scans, as time goes by, I feel less inclined to continue.’

‘The costs of what should be regarded as a necessary part of ongoing surveillance for women who have been diagnosed with breast cancer can be prohibitive, and consideration must be given to making these services totally rebatable or free of charge.’

Mammograms
There is great variation in the costs that women paid for mammograms. The majority of women surveyed (90%) were having regular follow-up mammograms, with most (83%) having these annually. Whilst some women incur no extra costs (37%), most women (47%) were paying between $50 and $150.

Whilst many of the women surveyed (84%) were referred by their surgeon for their mammogram, some women indicated more than one response for this question, suggesting that they were referred for mammograms by more than one health care professional. A similar trend was noted for ultrasounds. It is not clear if this occurred in the same twelve month period, thereby potentially adding to the cost to women, or if different health care professionals referred women at different times.

Eight percent of women had their mammograms at a BreastScreen service. It is not clear why this is happening. It may be that some women have been able to re-enter the program following a period of remission. This draws attention to a potential inconsistency amongst BreastScreen services in allowing women to re-enter the program after a breast cancer diagnosis.

Many women felt that it was unfair that as they had been diagnosed with breast cancer, they must pay for follow-up mammograms, whereas before their diagnosis mammograms were free through the BreastScreen Australia program. Whilst the purpose and type of mammogram that is undertaken with the BreastScreen program is different, women understandably stated the inequity of this.

Many women felt that the costs of mammograms (and other imaging such as ultrasounds) cannot be considered in isolation. Women noted that there are costs for specialist consultations, medication such as hormonal treatments, travel and lost days off work in addition to their breast cancer treatment costs. Over time, these costs can be substantial.

‘I am so glad you are doing this survey. My checkups are way too expensive and that’s on top of the ‘actual’ treatment I’ve had! My surgeon asked me why I only see him once a year and I was too embarrassed to say that it’s due to how much each consult costs…having an ultrasound and mammogram post breast cancer is much much scarier than having one when you have a lump in your breast and to pay significant $$$ after that is a bit of a slap in the face…’

Ultrasounds
Once again, there is great variation in what women pay for ultrasound. Whilst some women (36%) incur no costs, around half of women (51%) are paying between $50
and $200. Most of these women reported having annual ultrasounds (59%), with some (15%) having them at six-monthly intervals.

In the sample, a high percentage of women (67%) reported having ultrasounds. This may be in part explained by the slightly younger age group of the sample (35% of women under 50 years of age). This high number was significant, posing yet another cost for women to bear in the follow-up after breast cancer.

This is an issue that impacts particularly on younger women.

**MRI**

Thirteen percent of women in the sample had had an MRI, with most women having had one (57%). This is a very specialised area that impacts on a smaller number of women. The cost however is substantial for those women, with most (52%) paying between $100 and $500. It is clear from women’s comments that the cost may prohibit some from having it. While the Federal Government has developed a subsidy for screening MRI for young women at high risk of breast cancer, this does not include women who have already been diagnosed with breast cancer.

The cost of MRI is an issue that impacts particularly on younger women.