Breast Cancer Network Australia
DXA bone mineral density survey
May 2012

“I won’t be having any more mineral density tests as I can’t afford the high cost.”

Introduction

Of the 14,200 women diagnosed with breast cancer every year, approximately 75% of women are diagnosed with a particular type of breast cancer known as ER+, and approximately 65% with PR+ breast cancer. These women are usually required to undergo hormone treatment with either tamoxifen or an aromatase inhibitor.

These treatments work to either reduce the amount of oestrogen in the body, or act to stop the oestrogen from being used by the body. While the aim of these hormone treatments is to stop breast cancer cells from growing, they can often result in loss of bone mineral density in women.

Pre-menopausal women with breast cancer who are taking the hormonal treatment tamoxifen can experience a decrease in their bone mineral density, which places them at an increased risk of osteoporosis and / or bone fracture. For post-menopausal women, aromatase inhibitors can have an adverse effect on bone mineral density.

As a result, women taking hormone treatment may need to undergo bone mineral density tests to determine whether their bone mineral density has been negatively affected. Bone mineral density tests used in Australia are the DXA (Dual-emission X-ray Absorptiometry) test, also known as bone densitometry.

There are a number of Medicare rebates available for bone mineral density tests; however, there is no rebate specifically available to women who require a test in conjunction with their breast cancer treatment. Women may be eligible for a rebate for reasons that do not directly relate to their breast cancer treatment, including:

- Being 70 years or older
- Having a presumed diagnosis of osteoporosis after experiencing one or more bone fractures after minimal trauma
- Experiencing menopause for more than 6 months before the age of 45
- For the diagnosis and monitoring of a variety of health conditions, including rheumatoid arthritis
- 12 months after a significant change in treatment for low bone mineral density

Women who are not eligible for any of the above existing Medicare rebates are required to pay the full cost of their tests. These out-of-pocket costs further contribute to the substantial financial costs associated with breast cancer treatment and care that many women experience.

BCNA has developed a background paper to help us to better understand the issue. We surveyed women with breast cancer, to try and determine whether this was an issue impacting a significant number of women. In particular, we wanted to understand how often women are having bone mineral density tests, and the out-of-pocket costs for these tests.
We are also aware that there is a variation in the costs incurred by women, depending on the test provider.

Emails were sent to all 1,171 members of BCNA’s Review & Survey Group inviting them to complete one of two surveys. Women who are currently taking, or who previously took an aromatase inhibitor were invited to complete the aromatase inhibitor survey. Women who are currently taking, or who previously took tamoxifen were invited to complete the tamoxifen survey. For women who had taken both types of hormone therapy, we asked them to complete the survey corresponding to their most recent treatment.

A total of 447 women participated in the survey. The response rates to different questions may vary slightly, as not all women were required to answer all questions.

The survey also included qualitative questions, so women were able to tell us about their personal experiences in their own words.

**Aromatase inhibitor survey results**

**Eligibility question**

Women were asked whether they previously or currently took an aromatase inhibitor, to assess their eligibility to complete the survey.

Of the total number of women who responded to the survey (n = 253) 249 women (98.4%) reported that they had taken an aromatase inhibitor. These women were eligible to continue the survey.

3 women reported never having taken an aromatase inhibitor, and one woman did not know or could not remember. These 4 women were ineligible to complete the survey and were therefore exited.

**Demographics**

Of the 249 women who were eligible to complete the aromatase inhibitor survey, 200 (80.3%) told us they had a diagnosis of early breast cancer as their most recent diagnosis, 19 women (7.6%) told us they were diagnosed with Ductal Carcinoma in Situ (DCIS), and 18 women (7.2%) were diagnosed with secondary breast cancer. Of the women who answered ‘other’:

- 3 women told us they were diagnosed with LCIS
- 3 women were diagnosed with inflammatory breast cancer
- 3 women were diagnosed with locally advanced breast cancer

While the year of women’s most recent diagnosis ranged from 1992 to 2012 (figure 1), the majority of women were diagnosed between 2004 and 2011 (87.9%).
Women responding to the survey ranged in age from 30 to 81 years (figure 2); however, the majority of women were aged 50 to 69 (79.8%).

All states and territories were represented, with the majority of respondents from Victoria and New South Wales (figure 3).
The majority of women who responded to the survey live in a metropolitan area (58.5%), followed by a regional area (29%), rural area (11.7%) and remote area (0.8%).

**Treatment with aromatase inhibitors**

177 respondents (71.4%) told us that they are currently taking an aromatase inhibitor, while 71 women (28.6%) said that they had, but were no longer taking an aromatase inhibitor.

Of the women who are currently taking an aromatase inhibitor (figure 4), the majority of women have been taking it for 5 years or less (91.5%). This is expected as aromatase inhibitors are usually prescribed for five years in women with early breast cancer\(^1\). However, for some women aromatase inhibitors can be prescribed for longer periods of time, which is also reflected in the survey data. A small number of women reported taking an aromatase inhibitor for 6 to 9 years.

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Of the women who no longer took an aromatase inhibitor (figure 5), the majority reported taking an aromatase inhibitor for 5 years or less (88.9%). Of this majority, 25 women (35.2%) took an aromatase inhibitor for five years.

We know that women are usually prescribed an aromatase inhibitor for 5 years by their oncologist, and we would therefore expect more women to have taken an aromatase inhibitor for a 5 year period. In fact, the data shows that many women (53.7%) took an aromatase inhibitor for less than five years. Some women may have taken the hormone treatment tamoxifen first, and were then switched to an aromatase inhibitor, which is a common treatment pathway.
These same women were asked why they stopped taking an aromatase inhibitor, and the majority of women (55.8%) told us that they finished the course of treatment recommended to them by their oncologist (figure 6).

![Figure 6](image)

**Figure 6, n=77**

Note: Women were able to select more than one option to this question

Women also reported experiencing unwanted side effects from taking an aromatase inhibitor (36.4%), or switching to a different treatment (5.2%), which often occurs in women on this treatment and noted in research findings². Of the 2 women who answered ‘Other’:

- 1 woman told us that she stopped because she was diagnosed with secondary breast cancer, and
- 1 women stopped treatment to begin in vitro fertilisation (IVF)

**Bone mineral density tests**

We asked women whether they had ever had a bone mineral density test in conjunction with their aromatase inhibitor treatment. The majority of women (207 women, 83.1%) told us that they had, and 30 women (12%) had not. The remaining women did not know, or could not remember, and were therefore exited from the survey.

Of the women who told us that they had had a bone mineral density test in conjunction with their aromatase inhibitor treatment, 63.8% of women had their first test before or within three months of starting treatment (figure 7).

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The women were also asked how many bone mineral density tests they have had in conjunction with their aromatase inhibitor treatment (figure 8). The majority of women (87.2%) had three or fewer tests.

We also asked women how frequently they were having bone mineral density tests (figure 9). 31.9% of women reported having a test every 12 months, and 27.6% of women every 2 years. 21.4% of women answered ‘This question doesn't apply to me’. As we know that these women have had a test in conjunction with their aromatase inhibitor treatment, we assume that they have had only one test.
Of the women who answered ‘other’, many reported having infrequent tests or only one test. The remaining women reported having tests at 1.5 year, 2 year, or 3 year intervals.

Of the women who told us that they had not had a bone mineral density test in conjunction with their aromatase inhibitor treatment, 58.1% said that their doctor had not talked to them about it (figure 10).

Of the women who answered ‘other’, most told us that they are due to have their first test soon.
Out-of-pocket costs

As outlined earlier, the purpose of this survey was to find out how often women are having bone mineral density tests in conjunction with their breast cancer treatment, and what their out-of-pocket costs are. The following section summarises the information relating to women’s out-of-pocket costs.

We asked them how much their last test cost (figure 11). 83 women (40.1%) women told us that they were bulk-billed for their last test. Of the 114 women who had to pay a cost for their last test, 63 women payed between $51 and $150. 3 women told us that they paid more than $300 for their last test.

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<th>% women</th>
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</tbody>
</table>

Figure 11, n = 207

123 women (59.4%) received a Medicare rebate. 83 of these women were bulk-billed.

As there is no rebate specifically available to women who require a test as a result of breast cancer treatment, we assume that women who received a rebate were eligible for a different reason. The Medicare rebate for a bone mineral density test is $75.40 for inpatients and $85.45 for outpatients. However, due to the wording of the survey question, it is unclear whether the cost these women reported paying for their last test was the cost incurred before or after receiving a Medicare rebate. 52 women (56.52%) who reported incurring a cost for their last test did not receive a Medicare rebate.
General comments

The final question of the survey allowed women to make open-ended comments, and a range of issues were raised.

The need for a Medicare rebate

Of the women who chose to leave a comment (144), 41 women told us that they believe a Medicare rebate should be available for women diagnosed with breast cancer who require a bone mineral density test in conjunction with their breast cancer treatment. Many of these women emphasised that the tests should be provided at no cost (bulk-billed) because they are required as part of their breast cancer treatment.

3 women also commented that it would be cheaper overall to provide a Medicare rebate for women with breast cancer, which may result in the early detection of bone density issues which can be treated before bone fractures occur.

“If bone density is an issue as a result of my breast cancer treatment, surely testing should be standard and covered by Medicare.”

“The tests should definitely be covered by Medicare. Breast cancer is expensive enough without this complete out of pocket expense. When on Femara these tests are a must, as I have so far lost 10% of my bone density in 2 years.”

“A Medicare rebate should be in place for this test when on an aromatase inhibitor, as they are known to have an impact on bone density. Having regular tests will ensure that bone density is monitored and prompt action can be taken, if required, rather than more expensive intervention down the track.”

2 women also expressed concern at being ineligible for a Medicare rebate because they had not yet experienced a bone fracture.

“It seems crazy that the first test is not covered by any rebate, unless the patient has already broken a bone.”

6 women expressed confusion because they received a Medicare rebate for one or some of their tests but not others.

“I had to pay for my baseline (pre-treatment) test and also for the first test at 12 months, but was not asked to pay for the last test after 3 years on Arimidex. I'm not clear why.”

3 women understood that they were eligible for a Medicare rebate for only some of their tests; however, they were required to have additional tests that did not attract a Medicare rebate, and expressed concern about the additional out-of-pocket costs. One woman told us that she does not have the number of tests prescribed by her doctor because she is not eligible for a rebate each time.

“Even though I was not charged for this most recent scan, I had to pay for every other test, with no rebate. Apparently I get a free test every 5 years, but due to bone density loss I require them annually. This has been a complete out of pocket expense for me of approximately $150.00 per year.”

“I am supposed to have a bone mineral density test every year but the Government will only pay for one every 2 years, so I wait until I am in the allotted time span to save money.”
Finally, 2 women told us that they received a Medicare rebate because of a related medical condition. They stated that, had they instead declared that they required a test because of their aromatase inhibitor treatment, they would not have received a rebate.

“Mine were only at no cost to me as I have a malabsorption condition. Had I just said ‘aromatase inhibitor’ or breast cancer, it would not have been bulk-billed. I believe this is wrong.”

**Other issues**

20 women stated the importance of bone mineral density tests. Specifically, women mentioned that, in their view:

- Bone mineral density tests should be required as part of a woman’s treatment
- Women should be required to have a baseline test before beginning treatment, and regularly throughout treatment
- A woman’s vitamin D levels should be checked in conjunction with her aromatase inhibitor treatment
- Different doctors prescribed tests at different times

“What is the ‘best practice’ advice on frequency of these tests?”

“The policy on when bone density is checked varies from doctor to doctor.”

2 women told us that they were not informed of the possible side effects associated with aromatase inhibitor treatment, or did not know the possible extent of these side effects.

6 women also told us that they had to directly request a bone mineral density test from their doctor.

“It was at my request that the bone mineral density test was carried out, it was not suggested by my GP or oncologist.”

14 women chose to tell us about the unwanted side effects they experienced as a result of their aromatase inhibitor treatment. Women told us of reduced bone mineral density, reduced flexibility, stiffness, bone aches and pains, loss of height, osteopenia and osteoporosis.

“I lost 5 cm in height since beginning treatment, and now I have osteopenia at last testing.”

“I have lost approximately 11% of my bone density in the 2 tests undertaken.”

There were also a few women (3) who told us that they did not experience any issues with their bone mineral density, or other unwanted side effects as a result of their aromatase inhibitor treatment.

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3 Lower than normal bone mineral density which results in an increased risk of bone fracture.  
http://www.osteoporosis.org.au/about/about-osteoporosis/frequently-asked-questions/#faq1
**Tamoxifen survey results**

**Eligibility question**

Women were asked whether they previously or currently took tamoxifen, to assess their eligibility to complete the survey.

Of the total number of women who responded to the survey (n = 200) 198 women (99%) reported that they had taken, or are currently taking tamoxifen. These women were eligible to continue the survey.

2 women who reported never having taken tamoxifen were ineligible to complete the survey and were therefore exited.

**Demographics**

151 women (76.3%) told us they had a diagnosis of early breast cancer as their most recent diagnosis, 31 women (15.6%) told us they were diagnosed with Ductal Carcinoma in Situ (DCIS), and 8 women (4%) were diagnosed with secondary breast cancer. Of the women who answered ‘other’:

- 2 women were diagnosed with locally advanced breast cancer
- One woman told us she was diagnosed with colloid cancer (a rare type of early breast cancer sometimes called Mucinous carcinoma)
- One woman was diagnosed with ‘lobular’ in her left breast and DCIS in her right breast. It is unclear whether ‘lobular’ refers to LCIS or invasive lobular carcinoma.

While the year of women’s most recent diagnosis ranged from 1989 to 2012 (figure 12), the majority of women were diagnosed between 2004 and 2011 (85.6%).

![In what year was your most recent diagnosis of breast cancer?](image)

Figure 12, n=194

Women responding to the survey ranged in age from 25 to 76 years (figure 13). The majority of women were aged 50 to 69 (58.3%); however, there was a high representation of younger women aged 25 to 49 (38.2%). This is expected, as tamoxifen is suitable for pre-
menopausal women (as well as post-menopausal women) whereas aromatase inhibitors are only suitable for post-menopausal women.

Figure 13, n=194

All states and territories were represented, with the majority of respondents from Victoria and New South Wales (figure 14).

Figure 14, n=194

The majority of women who responded to the survey live in a metropolitan area (56.7%), followed by a regional area (26.3%), rural area (14.4%) and remote area (2.6%).
Treatment with tamoxifen

117 respondents (60.3%) told us that they are currently taking tamoxifen, while 77 women (39.7%) said that they were, but were no longer taking tamoxifen.

Of the women who are currently taking tamoxifen (figure 15), the majority of women have been taking it for 5 years or less (98.3%). This is expected as tamoxifen is usually prescribed for five years in women with early breast cancer⁴. However, for some women tamoxifen may be prescribed for longer periods of time, which is also reflected in the survey data.

![Graph showing the duration of tamoxifen usage](image)

**How long have you been taking tamoxifen?**

Of the women who no longer took tamoxifen, the majority reported taking tamoxifen for 5 years or less (figure 16). 38 women (49.4%) took tamoxifen for five years - the number of years that women are usually prescribed tamoxifen. 33 women (42.9%) took tamoxifen for less than 5 years.

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These women were asked why they stopped taking tamoxifen, and 45 women (51.7%) told us that they finished the course of treatment recommended to them by their oncologist (figure 17).

Note: Women were able to select more than one option to this question.
(27.6% of women reported experiencing unwanted side effects from taking tamoxifen, or switching to a different treatment (11.5%), which is common and noted in research findings\(^5\). Of the 7 women who answered ‘Other’:

- One woman decided to stop taking tamoxifen
- One woman was taking a break from treatment before beginning treatment with an aromatase inhibitor
- One woman told us that she stopped because she was diagnosed with secondary breast cancer
- One woman told us that she stopped because she was diagnosed with early breast cancer in her other breast
- One woman reported that tamoxifen failed to control the disease (unsure if this resulted in another diagnosis of early breast cancer or a diagnosis of secondary breast cancer)
- One woman’s doctor did not think it was necessary to continue treatment
- One woman stopped treatment to begin in vitro fertilisation (IVF)

**Bone mineral density tests**

We asked women whether they had ever had a bone mineral density test in conjunction with their tamoxifen treatment. 85 women (43.8%) told us that they had, and 103 women (53.1%) had not. The remaining women did not know, or could not remember, and were therefore exited from the survey.

Of the women who told us that they had a bone mineral density test in conjunction with their tamoxifen treatment, 20 women (24.1%) had their first test before starting tamoxifen, and 25 women (30.1%) had their first test between one and two years after starting treatment (figure 18).

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Of the women who reported ‘Other’:
- 2 women had their first test before starting treatment with an aromatase inhibitor (which they were treated with before tamoxifen)
- 2 women had their first test between 3 and 4 years after starting treatment
- 1 woman had her first test at the completion of her treatment
- 7 women did not specify, or could not remember, when they had their first test in relation to beginning tamoxifen treatment
- 1 woman reported that she is yet to be prescribed a test by her doctor. It is possible that this woman, when asked whether she has had a bone mineral density test in conjunction with her tamoxifen treatment, selected ‘yes’ instead of ‘no’, and was therefore routed to this section of the survey.

These same women were asked how many bone mineral density tests they have had in conjunction with their tamoxifen treatment (figure 19). The majority of women (78.3%) had two or fewer tests.

These women were also asked how frequently they were having bone mineral density tests (figure 20). 15.7% of women reported having a test every 12 months, and 20.5% of women every 2 years. 41% of women answered ‘This question doesn’t apply to me’. As we know that these women have had a test in conjunction with their tamoxifen treatment, we assume that they have had only one test.

Of the women who answered ‘other’, many told us that they only had one test. Two women told us they had tests every 3 years and one woman every 5 years.
Of the women who told us that they had not had a bone mineral density test in conjunction with their tamoxifen treatment, 80.8% said that their doctor had not talked to them about it (figure 21).

Of the women who answered ‘other’ most told us that they are due to have their first test soon, or they had had a test previously, in conjunction with their aromatase inhibitor treatment.
Out-of-pocket costs

As outlined earlier, the purpose of this survey was to find out how often women are having bone mineral density tests in conjunction with their breast cancer treatment, and what their out-of-pocket costs are. The following section summarises the information relating to women’s out-of-pocket costs.

Of the women who told us that they had a bone mineral density test in conjunction with their tamoxifen treatment, we asked them how much their last test cost (figure 22).

31 women (37.35%) told us that they were bulk-billed for their last test. Of the 36 women who had to pay a cost for their last test, 20 women payed between $51 and $150.

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<tr>
<th>How much did your last bone mineral density test cost?</th>
<th>If you paid an upfront cost, did you receive a Medicare rebate for your bone mineral density test?</th>
<th>No of women</th>
<th>% women</th>
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<tr>
<td>No cost - bulk-billed</td>
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<td>31</td>
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Figure 22, n=83

A total of 44 (53.01%) of women received a Medicare rebate (31 of these women were bulk-billed). As there is no rebate specifically available to women who require a test in conjunction with their breast cancer treatment, we assume that women who received a rebate were eligible for a different reason. The Medicare rebate for a bone mineral density test is $75.40 for inpatients and $85.45 for outpatients. Due to the wording of the survey question, we are unsure whether the cost these women reported paying for their last test was the cost
incurred before or after receiving a Medicare rebate. 23 women (27.71%) did not receive a Medicare rebate.

**General comments**

The final question of the survey allowed women to make open-ended comments, and a range of issues were raised.

**The need for a Medicare rebate**

Of the women who chose to leave a comment (89), 7 women commented on the out-of-pocket cost associated with bone mineral density tests, or told us that they believe a Medicare rebate should be available for women diagnosed with breast cancer. One woman commented that she needed more frequent tests than what the rebate allowed. Another woman told us that she stopped having bone mineral density tests because she cannot afford the out-of-pocket cost.

“I was shocked that bone density tests do not attract any Medicare rebate when they are taken as a preventative measure, so that osteoporosis can be picked up early while it is treatable.”

“As I have yearly tests, only every second bone density test is bulk-billed.”

“I won't be having any more mineral density tests as I can't afford the high cost.”

**Other issues**

16 women told us that they were unsure if they needed a bone mineral density test, or their doctor or oncologist had never mentioned it. One woman told us that she requested the test herself, and as a result is now taking Actonel (an osteoporosis treatment). 2 women told us that they thought bone mineral density tests were not required in conjunction with tamoxifen.

“While I was taking tamoxifen I was never advised to have a bone mineral density test. It was only when I requested that I have one that my doctor sent me for one. Following the test I am now taking Actonel, so just as well that I myself followed up. There is not enough information around about this.”

3 women told us that their bone mineral density tests were in conjunction with their aromatase inhibitor treatment, not their tamoxifen treatment.

“Yes, my bone mineral density tests where done whilst I was taking Arimidex. My oncologist has not recommended these whilst I've been on tamoxifen.”

One woman commented about the long waiting times in her local area. We assume this woman is referring to waiting times for a bone mineral density test.

“Up to 2 months wait for appointment in Geelong.”

6 women chose to tell us about the unwanted side effects they experienced as a result of tamoxifen treatment. Women told us of reduced bone mineral density, osteopenia⁶ and a bone fracture. One woman told us that she stopped taking tamoxifen because she

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⁶ Lower than normal bone mineral density which results in an increased risk of bone fracture. [http://www.osteoporosis.org.au/about/about-osteoporosis/frequently-asked-questions/#faq1](http://www.osteoporosis.org.au/about/about-osteoporosis/frequently-asked-questions/#faq1)
experienced depression. However, it is unclear whether depression was a side-effect of tamoxifen, or whether this woman had to stop taking tamoxifen because she began taking an anti-depressant that interferes with tamoxifen.

“I was under the impression that tamoxifen strengthened bone density, however, within two years of completing tamoxifen and having normal bone density I was diagnosed with osteopenia.”

However, there were a few women (5) who told us that their bone mineral density improved, or remained the same, as a result of their tamoxifen treatment.

Further out-of-pocket cost analysis

Out-of-pocket costs for all women who had a bone mineral density test

This section outlines the out-of-pocket costs of all women who told us that they had a bone mineral density test in conjunction with either tamoxifen or an aromatase inhibitor (figure 23).

56 women (19.31%) women were charged $1–$100 for their last test, 55 women (18.96%) $101–$200, and 17 women (5.86%) were charged more than $201. 167 women (57.58%) told us they received a Medicare rebate. Most of the women who received a rebate were bulk-billed (114 of 167 women; 68.26%) and did not incur an out-of-pocket cost. The remaining women did not know or could not remember what the cost of their last bone mineral density test was.

<table>
<thead>
<tr>
<th>How much did your last bone mineral density test cost?</th>
<th>If you paid an upfront cost, did you receive a Medicare rebate for your bone mineral density test?</th>
<th>No of women</th>
<th>% women</th>
</tr>
</thead>
<tbody>
<tr>
<td>No cost - bulk-billed</td>
<td>NA</td>
<td>114</td>
<td>39.31%</td>
</tr>
<tr>
<td>No cost - tests provided in clinical trial</td>
<td>NA</td>
<td>13</td>
<td>4.48%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>127</td>
<td>43.79%</td>
</tr>
<tr>
<td>Less than $50</td>
<td>Yes</td>
<td>5</td>
<td>1.72%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>5</td>
<td>1.72%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>10</td>
<td>3.45%</td>
</tr>
<tr>
<td>Between $51 and $100</td>
<td>Yes</td>
<td>14</td>
<td>4.83%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>32</td>
<td>11.03%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>46</td>
<td>15.86%</td>
</tr>
<tr>
<td>Between $101 and $150</td>
<td>Yes</td>
<td>17</td>
<td>5.86%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>20</td>
<td>6.90%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>37</td>
<td>12.76%</td>
</tr>
<tr>
<td>Between $151 and $200</td>
<td>Yes</td>
<td>7</td>
<td>2.41%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>11</td>
<td>3.79%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>18</td>
<td>6.21%</td>
</tr>
<tr>
<td>Between $201 and $250</td>
<td>Yes</td>
<td>4</td>
<td>1.38%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>5</td>
<td>1.72%</td>
</tr>
</tbody>
</table>
Discussion

The purpose of surveying women in our Review & Survey Group was to determine how often women are having bone mineral density tests in conjunction with their breast cancer hormone treatment, and what women’s out-of-pocket costs for these tests are.

Of the 1,171 Review & Survey Group members invited to participate in this survey, a total of 447 participated in the survey. Our demographic data suggests that the women who participated represented the general population of women diagnosed with breast cancer in Australia, in terms of age, location, and diagnosis type.

When asked whether they had ever had a bone mineral density test in conjunction with their hormone therapy, half the women who completed the tamoxifen survey answered yes (43.8%) compared with the majority of women in the aromatase inhibitor survey (83.1%). We know that all aromatase inhibitors can reduce a woman’s bone mineral density, whereas tamoxifen usually has a detrimental effect on bone mineral density only in women who are pre-menopausal (tamoxifen has been shown to protect bone mineral density in post-menopausal women). Given this, we would expect a greater proportion of women being treated with an aromatase inhibitor to be prescribed bone mineral density tests compared with women on tamoxifen.

It is also interesting to note that, of the women who had a bone mineral density test, almost double the number of women treated with an aromatase inhibitor had their first test before treatment (44.3%), compared with the number of women treated with tamoxifen (24.1%). More women treated with tamoxifen had their first test between 1 and 2 years after starting treatment (30.1%) compared with women treated with an aromatase inhibitor (14.8%).

Finally, the survey data shows that women on aromatase inhibitors are having more bone mineral density tests (66.7% of women had more than one test) compared with women treated with tamoxifen (43.3% of women had more than one test).

When asked about the cost of their last bone mineral density test, we noted that just over 19% of women were charged $1–$100 for their last test, just under 19% were charged $101–$200, and just under 6% were charged more than $201. Almost 40% of women were bulk-billed and did not incur an out-of-pocket cost (just over 58% of women received a Medicare rebate, including those who were bulk-billed). The costs of bone mineral density tests vary greatly and are determined by each radiology clinic. When phoning a sample of radiology clinics, we noted that some bulk-billed patients who had a healthcare, concession or pension card.

<table>
<thead>
<tr>
<th>Total</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between $251 and $300</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>More than $300</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>I don’t know / remember</td>
<td>NA</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 23, n=290**
As there is no Medicare rebate specifically available to women who require a test in conjunction with their breast cancer treatment, we assume that the women who received a rebate were eligible for a different reason.

When asked whether they had any general comments, many women told us that a Medicare rebate should be available for women diagnosed with breast cancer who require a bone mineral density test in conjunction with their breast cancer treatment. One woman even told us that she stopped having bone mineral density tests because she cannot afford the out-of-pocket cost.

“I won't be having any more mineral density tests as I can't afford the high cost.”

We also noted that some women were unsure why they received a rebate for some of their tests but not others, while others understood that they were only eligible for a rebate if they had a test at certain times. One woman told us that she does not have the number of tests prescribed by her doctor because she is not eligible for a rebate each time.

“I am supposed to have a bone mineral density test every year but the Government will only pay for one every 2 years, so I wait till I am in the allotted time span to save money.”

Finally, of concern to BCNA is the lack of Australian clinical guidance in prescribing bone mineral density tests in women diagnosed with breast cancer. This makes it difficult for us to determine whether the number of women who reported having bone mineral density tests in this survey, and the frequency of tests, is expected.

**Recommendations**

Considering the results presented in this survey report, BCNA has identified a number of recommendations for further work in this area.

BCNA believes that a Medicare rebate should be available for women diagnosed with breast cancer who require a bone mineral density test(s) in conjunction with their diagnosis and treatment. Our survey results tell us that many women diagnosed with breast cancer are having bone mineral density tests, and for many women, the cost can be quite high.

“A huge cost. A long time after cancer, the financial burden continues.”

BCNA often hears from women about the financial hardship from both the direct and indirect expenses associated with breast cancer, which can sometimes total tens of thousands of dollars. The cost of a bone mineral density test may further contribute to this financial burden and in particular, if women are required to have multiple tests in conjunction with their treatment. The availability of a Medicare rebate specifically for women diagnosed with breast cancer will reduce this cost to women, and in some instances eliminate the cost entirely if women are bulk-billed for their test. BCNA will meet with the Medical Oncology Group of Australia (MOGA) to discuss approaching the federal government for a Medicare rebate, for women who need a bone mineral density test in conjunction with their breast cancer treatment.

In addition to a Medicare rebate being introduced, BCNA would like to see evidence-based clinical guidance for health professionals, in regards to prescribing bone mineral density tests in women being treated for breast cancer. BCNA will encourage MOGA to take this matter up with Cancer Australia.
Finally, BCNA believes that women should be aware of the costs associated with bone mineral density tests, and in particular the variability in cost from clinic to clinic. BCNA will encourage women diagnosed with breast cancer who require a bone mineral density test to ask about their out-of-pocket costs before making an appointment, and to shop around for a better price if required.

In summary, BCNA will:

- Encourage MOGA to approach the federal government for a Medicare rebate, for women who need a bone mineral density test in conjunction with their breast cancer treatment.
- Encourage MOGA to raise with Cancer Australia the gap in clinical guidance for health professionals, in regards to prescribing bone mineral density tests in women being treated for breast cancer.
- Encourage women who require bone mineral density tests to ask about their out-of-pocket costs and shop around for a better price if required.

The main findings of this report will be published in the Spring 2012 (issue 60) edition of The Beacon magazine. These results will be shared with relevant health professionals, breast cancer and cancer organisations, and women with breast cancer.

Last updated: 29 April 2014