‘Women seem to lack the initial knowledge about accessing the public system. Although there is a wait, they are usually surprised that there is no cost under Medicare and if they are not privately insured then they are usually ok about waiting. In the private sector paying “upfront” can be an issue. Gaps in cover can also come as a shock. I try to encourage ladies to do their homework about these issues prior to committing to surgery.’ – Survey participant

Introduction

This survey of breast care nurses was conducted as part of BCNA’s Breast Reconstruction Project.

For many years, we have heard anecdotal reports from women about long waiting times for breast reconstruction in some public hospitals (up to ten years), and high out-of-pocket costs in the private system. We decided to investigate issues surrounding breast reconstruction.

Previous work on this project has included:

- an online survey of BCNA Members about their personal experiences with breast reconstruction
- a hard-copy survey distributed to women who attended BCNA’s Sunshine Coast Forum in Nambour, Qld
- telephone conversations with breast cancer support group coordinators in selected areas of all states and territories (to learn if access to breast reconstruction surgery is an issue for women in their local area).

The results of these three approaches have been written up separately. All found that most women were having their surgery through the public system within twelve months of being placed on a waiting list. Very few women reported waiting longer than two years for breast reconstruction surgery.

As the next step in this project, we decided to survey breast care nurses (BCNs). We wanted to learn if their experiences of public hospital waiting times for breast reconstruction surgery were any different to those reported to us by women.

Our survey asked BCNs about waiting times for women in their local area, and whether they think the waiting times are too long. It also included questions about the cost of breast reconstruction surgery in the private system, and women’s satisfaction with the outcomes of their surgery.

We distributed an online survey, using SurveyMonkey, to 456 BCNs on our database. 115 BCNs started the survey, with 104 completing it. The response rates to different questions may vary slightly, as BCNs were not required to answer all questions and not all questions were relevant to all BCNs.
The survey included quantitative and qualitative questions, so BCNs were able to tell us their views in their own words.

Background information

BCNs from all states and territories undertook our survey, with the majority of respondents from Victoria (36) and New South Wales (34). (Figure 1)

![Figure 1](In which state or territory do you work?)

Fifty BCNs indicated they work in a metropolitan area, with 65 BCNs working in a regional or rural area.

The majority (53) work in the public health system, with 37 BCNs in the private health system and 26 working in both the public and private systems. Most work in a hospital, regardless of whether they are public or private. (Figure 2)

![Figure 2](In what sort of health facility do you work?)

Other = community nursing (5), Cancer Council (2), District Nursing Service (1), residential care (1), Integrated Cancer Care Centre (1)
We asked if breast reconstruction surgery is available in each BCN’s local area.

70 BCNs (63%) said breast reconstruction surgery is available through a public hospital in their local area, and 86 (77%) said it is available through a private hospital.

Thirty-one BCNs (28%) said breast reconstruction surgery is not available locally in a public hospital. Of these, 22 (20%) said it is also not available in a private hospital in their area, meaning that women who live in these areas and want reconstruction have no option but to travel to another centre for it.

“For rural women there are significant distances to travel, particularly if they have multiple procedures.”

For those women who have to travel for reconstruction in a public hospital, the majority travel between 50 and 400kms. (Figure 3)

![Figure 3](surveyresults.png)

Survey Results

Talking to women about breast reconstruction
We asked BCNs if, in their experience, breast surgeons talk to women about breast reconstruction and the options available to them. We also asked if BCNs themselves talk to women about reconstruction.

Thirty-six BCNs (32%) said they believe breast surgeons always talk to women about reconstruction, and 66 BCNs (59%) said they believe breast surgeons sometimes talk to women. Two BCNs said they believe surgeons never talk to women about reconstruction.

Of BCNs themselves, 80 (73%) said they always talk to women about options for breast reconstruction, and 27 (24%) said they sometimes talk to women about this. Three BCNs said they never talk to women about it.

Number of women having breast reconstruction
We asked BCNs to estimate how many of their patients undergo breast reconstruction surgery.
The majority of BCNs (61, 55%) reported that less than 10% of their patients have an immediate reconstruction (Figure 4). More women appear to have delayed reconstructions. (Figure 5)

We also asked how many women decide not to have a reconstruction. The majority of BCNs (38, 35%) said between one quarter and one half of their patients decide not to have reconstruction surgery. (Figure 6)
Reasons for not having breast reconstruction surgery
The table below shows reasons women give BCNs for not having reconstruction surgery.

Note: BCNs could select more than one response to this question, so the total number of responses equals more than 115.

<table>
<thead>
<tr>
<th>Reasons women give their BCN for not having reconstruction surgery</th>
<th>Number of BCNs</th>
<th>Percentage of BCNs</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s not a priority for me right now</td>
<td>102</td>
<td>92%</td>
</tr>
<tr>
<td>I don’t want breast reconstruction surgery</td>
<td>81</td>
<td>73%</td>
</tr>
<tr>
<td>I am still considering my options for breast reconstruction</td>
<td>69</td>
<td>62%</td>
</tr>
<tr>
<td>I can’t afford the cost of a breast reconstruction</td>
<td>49</td>
<td>44%</td>
</tr>
<tr>
<td>Breast reconstruction isn’t offered in my area and I don’t want to travel for it</td>
<td>24</td>
<td>22%</td>
</tr>
<tr>
<td>The public hospital waiting lists are too long</td>
<td>19</td>
<td>17%</td>
</tr>
<tr>
<td>My partner and/or family do not want me to have it</td>
<td>8</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>22%</td>
</tr>
</tbody>
</table>

‘The processes associated with (breast cancer) treatment leaves them just wanting to get on with life and feel well again.’

Other reasons reported by BCNs in the open-ended comments to this question included a woman’s age and co-morbidities, and her own preference not to have any further surgery.

‘I am too old to think about reconstruction. I don’t need to worry about it at my age.’

‘Don’t want further hospital admission, recovery, time off work, loss of income.’

‘I don’t want to have any more surgery, I’ve already had enough.’

These findings are similar to those reported by women in our initial survey of BCNA Members. The top four reasons given by women for not having breast reconstruction surgery are the same as the top four given by the BCNs, although in a different order:
- I have decided not to have breast reconstruction surgery (36%)
- I can’t afford the cost of breast reconstruction surgery (28%)
- I am still considering my options for breast reconstruction surgery (26%)
- It’s not a priority for me right now (24%)

Less than 6% of women reported long waiting lists in public hospitals as a reason not to have a reconstruction, compared with 17% of BCNs.

**Public hospital waiting times**
Seventy-one BCNs answered a question about public hospital waiting times, with the remainder reporting that they do not have information about waiting times. The majority of these work only in the private health system.

Fifty-nine (83%) of the BCNs who provided an answer said women in their local area can access breast reconstruction surgery through a public hospital within 2 years. (Figure 7)

Ten BCNs (14%) said women have to wait between 2 and 4 years. Of these, 4 BCNs work in Queensland, 4 in Victoria, one in Western Australia and one in New South Wales. They work across metropolitan, regional and rural areas.

The longest waiting time was reported by a Victorian regional BCN who indicated the waiting time in her area is 6-7 years. In a follow-up conversation with this BCN, she advised she knew of one woman who is currently on a waiting list and who has been waiting for more than six years. She believed this woman had been placed on the wrong waiting list (a cosmetic surgery list instead of the cancer surgery list). The BCN advised she was currently advocating on behalf of this woman to ensure her surgery happened quickly. In general, however, the waiting time for reconstruction surgery in that area is 18 months – 2 years.

One Queensland regional BCN said the waiting time for women in her area is 5-6 years. In a follow-up discussion with her, she advised that women from her area who want a reconstruction through the public system have to travel to Brisbane, and that only one Brisbane hospital accepts her patients. She has been advised by that hospital that the current waiting time is more than five years. There is a private plastic surgeon who works in her regional centre and provides surgery privately for women who are able and prepared to meet the costs.

![Figure 7: How long do women in your area wait for reconstruction after being placed on a public hospital waiting list?](image)
These results are again similar to those of our survey with women, which found that 94% of women received their surgery within 2 years. The longest waiting time was 3-4 years, which was reported by just one woman. No women reported waiting more than 4 years. Of women on a waiting list at the time of the survey, the longest waiting time was 18-24 months.

We asked BCNs if they think public hospital waiting lists are an issue for women in their local area. Almost half of BCNs (53, 49%) said public hospital waiting times are an issue for women. (Figure 8)

We note that there is no national standard for desirable treatment time for this type of surgery (Category 3 elective surgery), but that 365 days is used as a guide. Some BCNs commented that a waiting time of more than 365 days (one year) was considered too long by some women.

‘A lot of patients feel that 12-24 months for a delayed reconstruction is too long.’

‘Rural women find being told the waiting list is up to two years extremely difficult. They are unable to plan their life and move on from their breast cancer experience.’

‘Most women are ok with the wait of one year but often these cases are the ones that are put off, so they actually end up getting a few different (surgery) dates. This aspect is the hard part.’

A number of BCNs reported that while waiting lists may have been an issue in the past, improvements have been made.

‘(Waiting times have) recently been addressed and (delayed breast reconstruction surgery) is much more accessible than before.’

‘We have previously had long waiting times until we had a dedicated plastic surgeon employed to oversee this surgery.’

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1 Category 3 surgery is classified as ‘non-urgent surgery, where the patient’s medical condition causes minimal or no pain, dysfunction or disability; is unlikely to deteriorate quickly; and is unlikely to become an emergency.’ – Parliament of Australia Parliamentary Library, Amanda Biggs: Background Note – Hospital Waiting Lists Explained. 14 March 2008
Some BCNs raised the need for good communication with women about expected waiting times.

‘It’s very frustrating for women who get told the waiting list is 6-12 months by the surgeon when the reality is 2-3 years.’

‘When women have made their decision they often want it now. I aim to set up the expectation from the first discussion that the wait may be a year.’

Other BCNs indicated they did not think waiting times are an issue for women in their area.

‘The ladies I’ve spoken with have been happy with the waiting time as it gave them time to get over their initial treatments.’

‘I think that, due to media coverage of extended waiting times for non-urgent surgery, women are more accepting of a 12-18 month wait. Also, the costs of private health insurance or paying ‘up-front’ are both relevant reasons for ladies to accept the waiting times.’

**Cost of private surgery**

We asked BCNs what the average out-of-pocket cost is for women in their area who have a reconstruction through the private system. More than half of respondents either did not answer this question, or said they didn’t know. Of those who did answer this question (52), the responses were spread from less than $500 to more than $15,000. (Figure 9)

‘The cost of reconstruction for women with private health insurance is an issue. Comments such as “we didn’t choose to have breast cancer requiring mastectomy so why do we have to pay so much for reconstruction” and “public patients have no costs involved with their surgery so why are we paying so much” are often made by women.’

![Figure 9](image-url)
Other issues affecting access to breast reconstruction

In an open-ended (qualitative) question, we asked BCNs if there were any other issues that make it difficult for women in their local area to access breast reconstruction. The key themes in the responses were:

- Traveling for treatment, including
  - The cost of travel and accommodation not only for the women, but for their families if they wish to have them close by
  - Patient Assisted Travel Schemes are inadequate
  - Having to leave home and families for more treatment
  - The frequency of travel for reconstruction procedures
- Timeliness of surgery in the public system
- Tissue flap reconstructions are not available in some areas, restricting women’s choices or forcing them to travel for reconstruction
- The cost of reconstruction in the private sector.

‘(Breast reconstruction is) not available locally, so women need to travel away from family for the initial consults and workup assessments, surgery and tissue expansion, if this form of reconstruction is used. There are multiple trips to metro and extended time in the metro area, so the cost of travel and being away from home and unable to work during this surgery and recovery period can result in a huge financial burden even in the public system.’

‘Cost - the gap fee if using private health insurance can be enormous and some women don’t have reconstruction because of this.’

Three BCNs advised that sometimes hospitals decline referrals of new patients from outside their area.

‘We have to send our patients to the city for reconstruction. Today I had two referrals denied because those particular hospitals had long waiting lists and the patients would not be done in a timely manner. These two patients are eligible for immediate reconstruction as category 1 surgery following mastectomy for DCIS.’

Women’s satisfaction with their reconstruction surgery

The majority of BCNs who answered a question on women’s satisfaction with the outcome of their surgery reported that the women they care for are satisfied with their results. (Figure 10)

‘Most are very happy, whether they’ve had their surgery public or private. Approximately 50% need ‘tweaking’ and minor repairs prior to nipple reconstruction.’
Some BCNs gave reasons why women are sometimes unhappy with the outcome, including ongoing pain and unhappiness with the shape and/or feel of the reconstructed breast.

‘There are cases where patients are not happy due to uneven shape, (or the breast feels) hard when touched.’

Two BCNs commented that sometimes women’s expectations of the outcome of the surgery may not be realistic.

‘It’s difficult to assess as the women vary. Some women’s expectations do not mirror that of reality. … Most though are satisfied if there have been no complications post op.’

**General comments**

The final survey question asked BCNs if they had any other comments about breast reconstruction surgery.

A small number of BCNs commented on the need for more and better information to be available to women about options for reconstruction.

‘I would like to see information about breast reconstruction surgery made available to women in public hospitals, and women given the opportunity to find out about reconstruction surgery before their original breast surgery. I would also like to see breast reconstruction surgery made available to women in regional areas at the time of their breast surgery.’

‘More information and face-to-face meetings for women undergoing reconstruction with women who have already had the procedure, so that women are fully informed about what to expect.’

‘The literature they (women) read leads them to believe there will be a cost, so they come to us believing it won't be possible to have reconstruction.’

‘I think women find it hard to access information on the different types of reconstruction, so a decision aid would be really helpful.’
BCNs also commented on the need for more plastic surgeons to undertake this surgery, especially in regional areas.

‘In this rural area, only one out of six surgeons offers reconstruction (implants after tissue expanders). Clients need to travel interstate to see a plastic surgeon for flaps/grafts.’

‘More breast reconstruction surgeons. More money for reconstruction. Think outside the square, have surgeons come to the regional areas to provide the service, e.g. once a month a breast reconstruction surgeon could go to regional areas. Utilise the private reconstruction surgeons in the area. It’s all possible - it just has to be made a priority by the health administrations.’

‘Access is the issue - the increased interest in reconstruction as an option for women undergoing breast cancer treatment places an immense burden on the health system and the overall services required for this surgery. There are too few surgeons trained in this area also.’

Conclusion

This survey was designed primarily to learn from breast care nurses how long women in their local area are waiting for delayed breast reconstruction surgery in a public hospital, and whether BCNs think waiting lists are an issue for women. We also asked questions about the cost of breast reconstruction in the private system, and women’s satisfaction with the results of their reconstruction surgery.

115 BCNs started the survey, with 104 completing it. They work in metropolitan, regional and rural areas across all states and territories of Australia.

The survey results appear to support the findings of our previous work on waiting times for delayed breast reconstruction surgery in public hospitals. Those findings were that most women receive the first stage of their surgery within two years of being placed on a waiting list.

Twelve BCNs (11%) said women in their area had to wait more than 2 years for breast reconstruction in a public hospital. However, almost half of BCNs (49%) said they believe that waiting times are an issue for women. This may suggest that they consider two years to be too long for women to wait.

While there is no national standard waiting time for Category 3 surgery, which includes breast reconstruction surgery, 365 days is used as a guide. Of the 71 BCNs who provided an answer about waiting times in their area, 29 (41%) reported that women receive their surgery within that time frame. This is a significantly lower number than we found in our women’s survey, where 82% of women said they received their surgery within one year of being placed on a waiting list.

Fifty-nine BCNs (83%) reported that women receive their surgery within two years. This finding is similar to that of our survey with women, which found that 94% of women surveyed had their surgery within two years.

We note that much has been done by governments across Australia to reduce public hospital waiting lists in recent years. Additional government money has been provided to reduce elective surgery waiting lists, the Australian Government has introduced new elective surgery targets as part of national health reform, and more public hospitals appear to be employing plastic surgeons to undertake breast reconstruction surgery.
BCNA is concerned that women are waiting up to two years for the first stage of their surgery, especially as there may be further waiting times between each stage of surgery.

‘One woman I recently spoke with had 6-12 month delays for each phase of her surgery, i.e. the breast reconstruction, the insertion of prosthesis, the nipple reconstruction. She found this too long.’

We hope that the Australian Government’s National Access Guarantee will help to further reduce waiting times. Under the Guarantee, from 1 July 2012 any patient who has not received their surgery within the clinically recommended times will be prioritised and have their surgery fast-tracked. For Category 3 surgery, which includes breast reconstruction, this will mean that, from 1 July 2012, women who have already waited 365 days must have their surgery within the next 45 days. This could be by having their surgery performed at another hospital – public or private – in the same or neighbouring Local Hospital Network, at no cost to the patient.

These reforms should ensure that, by mid-2012, no woman will wait more than 410 days (approximately 13 months) for breast reconstruction surgery in the public system.

We are also concerned that some women are incurring high out-of-pocket costs for reconstruction surgery in the private system, even with private health insurance. BCNs reported that some women are paying significant out-of-pocket costs for reconstruction surgery.

‘There should be less out-of-pocket costs for women with private health insurance.’

This is consistent with the findings in our survey of women, where 40% of the women who had their surgery through the private system told us they had an out-of-pocket cost of more than $5,000.

We were interested to find that BCNs reported that between 25% and 50% of the women they see elect not to have a breast reconstruction. The reasons given to BCNs by women reflect that this is largely their personal choice (based on age, co-morbidities and desire not to have further surgery) rather than as a result of waiting times, although 44% of BCNs said cost was a contributing factor.

‘Cost is an issue for most patients.’

In the qualitative comments, some BCNs referred to the cost of having to travel to another centre for surgery as a potential disincentive to surgery, even for those women having surgery in a public hospital at no cost to themselves.

‘The cost of traveling to a city to seek breast reconstruction.’

BCNs views that women should be provided with more and better information about breast reconstruction reflect some of the qualitative answers provided by women in our survey with them. Women commented on the difficulty they had in obtaining information about breast reconstruction, especially in the early weeks following their breast cancer diagnosis, and talked about the need for women considering reconstruction to do their homework before committing to surgery and to consider all their options.

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A review of currently available Australian resources has found some useful information resources for women, including Cancer Council Victoria’s booklet *Breast Reconstruction: Your Choice* and Cancer Council NSW’s publication *Understanding Breast Prostheses and Reconstruction*. BCNA is a collaborative partner in the development of new resources for Australian women, including a comprehensive booklet on breast reconstruction (and an online breast reconstruction decision aid to help women through the decision-making process. We hope these resources will be valuable additions to those currently available.

The results of this survey will be published on BCNA’s website and will be used to inform our Breast Reconstruction Project. This survey is one part of this project, which also included:

- an online survey of BCNA Members about their personal experiences with breast reconstruction
- a hard-copy survey distributed to women who attended BCNA’s Sunshine Coast Forum in Nambour, Qld
- telephone conversations with breast cancer support group coordinators in selected areas of all states and territories (to learn if access to breast reconstruction surgery is an issue for women in their area).

For further information about this survey or about BCNA’s Breast Reconstruction Project, please contact Kathy Wells, Senior Policy Officer, Breast Cancer Network Australia at kwells@bcna.org.au or on 1800 500 258 (Freecall).