Breast Reconstruction Project Report
November 2011

This project was undertaken with the support of Cancer Australia through the *Building Cancer Support Networks Initiative: Better Cancer Support through Consumers* program.

Introduction

> *'Breast reconstruction should be considered part of the treatment program for breast cancer patients, not as an optional extra for those who can afford it.' – Women's survey participant*

In 2010–2011, BCNA undertook a project to investigate issues relating to breast reconstruction after mastectomy for breast cancer. In particular, we wanted to learn about:

- Barriers which reduce women's access to breast reconstruction surgery
- Women's satisfaction with the outcome of their breast reconstruction surgery.

BCNA's Breast Reconstruction Project was prompted by anecdotal reports we had received from women over a number of years about long waiting times for breast reconstruction in the public health system (up to 10 years was reported in some states), and high out-of-pocket costs for surgery in the private system.

The project comprised the following pieces of work, which are discussed in more detail below:

- Development of a background paper
- An online survey of women who have been diagnosed with breast cancer
- A telephone survey of selected breast cancer support group coordinators
- A hard-copy survey of women attending BCNA's 2011 Sunshine Coast Forum
- An online survey of breast care nurses enrolled in BCNA's *My Care Kit* program[1]

This paper reports on the findings of these pieces of work, what action BCNA has undertaken as a result, and what further work can be done to assist women who are considering breast reconstruction surgery. The individual reports from each of the pieces of work listed above complement this report, and provide additional detailed information on those individual activities. They can be found on BCNA's website at www.bcna.org.au > About BCNA > Advocacy> Research reports.

Background paper

The background paper was developed to provide an understanding of the issues around breast reconstruction, women's access to breast reconstruction surgery and women's satisfaction with breast reconstruction outcomes.

It includes general information about the purpose of breast reconstruction, the types of surgeons who perform it and the various types of procedures available in Australia. It also explains the terms 'immediate' and 'delayed' with regards to breast reconstruction.

The paper investigates statistics around the numbers of women having breast reconstruction surgery, both here in Australia and overseas. We found no definitive figures, as there is no systematic collection of data about breast reconstruction in Australia and little research has been done in this area.

[1] The *My Care Kit* is a free kit provided by BCNA, with the support of Berlei, to women who have recently had breast cancer surgery. The kit contains a specially designed Berlei bra and soft form prostheses (if required), designed to be used by women in the first months following their breast cancer surgery. Kits are ordered for women by their breast care nurse or another related health professional who is registered with BCNA's *My Care Kit* program.

An audited review published in 1999 indicated that only 6% of Australian women who had mastectomies for breast cancer were receiving breast reconstructions at that time.[2] National Breast Cancer Centre[3] statistics published in 2003 showed that only 8% of Australian women who had mastectomies had breast reconstructions, compared with up to 40% in some other countries.[4] Figures quoted more recently are that between 6% and 12% of Australian women who have mastectomies have reconstructions.[5]

The background paper also discusses issues around breast reconstruction in the public and private health systems.

We looked at the way in which elective surgery is categorised in the public system, and reviewed the current published statistics for hospital waiting times for Category 3 elective surgery[6]. We also discussed some successful initiatives in Australian public hospitals which have improved women's access to breast reconstruction surgery.

A section on breast reconstruction in the private health system looks particularly at out-of-pocket costs for women having surgery privately. It discusses the Medicare Benefits Schedule fees and benefits payable, and the 'gap' payments that many women incur, despite having private health insurance.

The background paper also discusses the current Australian clinical guidelines for breast reconstruction surgery, which we found to be very limited and unclear. We also looked at consumer resources currently available to women to inform them about breast reconstruction options. We found some useful resources, and noted that there are others are currently in development.

Our background paper also considered issues around women's satisfaction with the outcome of their breast reconstruction surgery. We conducted a literature review of research conducted in Australia and overseas.

In addition to literature review, other methods used in developing this paper included an internet search of relevant websites, such as other cancer organisations and government health departments, and telephone discussions with key stakeholders, including state and territory health department officials, plastic surgeons, breast care nurses, and women diagnosed with breast cancer.

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[2] D Hill D, K Jamrozik, V White, J Collins, J Boyages, D Shugg, M Pruden, G Giles, M Byrne: *Surgical management of breast cancer in Australia in 1995*. Sydney: NHMRC National Breast Cancer Centre; 1999

[3] National Breast Cancer Centre subsequently became National Breast and Ovarian Cancer Centre and, in July 2011, merged with Cancer Australia to become Cancer Australia

[4] J Robotham *Why breast surgery is a rarity*, The Age 20 October 2003

[5] D Nesbitt, *The Health Report*, ABC Radio National, 5 January 2009

[6] Category 3 elective surgery is defined as non-urgent surgery, where the patient's condition causes minimal or no pain, dysfunction or disability; is unlikely to deteriorate quickly; and is unlikely to become an emergency. Many surgeons categorise breast reconstruction surgery as Category 3, although some categorise it as Category 2. See page 5 of this report for further explanation on elective surgery categories.

Online survey of women

Using our learnings from the background paper, the first phase of this project was an online survey of women who have had a breast cancer diagnosis about their personal experiences with breast reconstruction. The survey comprised quantitative and qualitative questions. Women did not need to have had a reconstruction to participate, but did need to have considered it.

In October 2010, the survey was sent to 1,089 women on BCNA's database. These women were members of BCNA's Review & Survey Group[7] (799 women) and women who had responded to an article promoting the survey in Issue 52 of BCNA's *The Beacon* magazine (290 women). Of these, 482 women self-selected as eligible to participate and 462 completed all questions.

The majority of respondents (71%, 341 women) told us they had received breast reconstruction surgery. Of these, 20% (67) had their reconstruction in the public system and 80% (274) in the private system. Some of the key findings for women who had had reconstruction surgery included:

- Of the 67 women who had their surgery in the public system:
    - 82% (55) reported having their breast reconstruction surgery within twelve months of being placed on a public hospital waiting list
    - 94% (63) reported having their breast reconstruction surgery within two years of being placed on a public hospital waiting list
    - No woman reported waiting longer than four years for breast reconstruction surgery
- Of the 274 women who had their surgery in the private system:
    - 40% (94) reported an out-of-pocket cost of more than $5,000, with 9 of these women paying more than $15,000
- 74% (210) of all women who had received breast reconstruction surgery rated their satisfaction with the outcome at 8 or more out of 10
- Eight per cent (23) of all women who had received breast reconstruction surgery reported being unhappy with the outcome, rating their level of satisfaction at less than 5 out of 10.

These findings did not reflect the anecdotal advice we had received from women about very long waiting times (up to ten years) for surgery through the public system. They did more accurately reflect, however, figures published on departmental websites which showed median waiting list times[8] for Category 3 surgery ranging from 99 days (Western Australia) to 192 days (ACT). (See table below)

[7] BCNA's Review & Survey Group comprises BCNA members who have a personal history of breast cancer and who have volunteered to participated in breast cancer research

[8] The median waiting time is the time at which half of the patients have had their surgery and half have not.

State/ Terr.	Median waiting list time for Category 3 surgery, all types unless specified	Source of information
Vic	100 days for plastic surgery 93% of all patients treated within 365 days	Department of Health – *Your Hospitals: a report on Victoria's public hospitals, July – December 2009*[9]
WA	99 days 89% of patients treated within 365 days	Department of Health – *Elective Surgery Wait List Report, June 2010 Quarter*[10]
NT	Median wait times not available but the current waiting time is quoted at 6 -12 months	NT Department of Health and Families[11]
Qld	122 days 90% of patients treated within 438 days	Queensland Health – *Quarterly public hospitals performance report, June Quarter 2010*[12]
NSW	175 days 88% of patients treated within 365 days	*Department of Health Quarterly Report, January-March 2010*[13]
ACT	192 days	*ACT Public Health Services Quarterly Performance Report, March 2010*[14]

Note: No data available for SA or Tasmania

We were interested to note that 29% of respondents (140) had not had a breast reconstruction. Of these, 26% (36) were still considering their options for reconstruction and 13% (18) were currently on a waiting list. The most common reason given by women for not having breast reconstruction surgery was that the woman had decided not to have it (36%, 51). Only eight women said they had not had a reconstruction because waiting lists were too long.

In open-ended responses, women gave their advice and tips for other women considering or undertaking breast reconstruction surgery.

The results of our survey were written up in a comprehensive report which is available on the BCNA website.[15] A list of the tips provided by women through the survey is also available on the website.[16]

The survey findings were reported in the Summer 2010 edition of *The Beacon* magazine.[17] We received no feedback from women to that article that the survey findings did not reflect their personal experience. Had there been women who had experienced very long waits, we might have expected them to contact us after reading the article to let us know that.

[9] http://www.health.vic.gov.au/yourhospitals/yourhospsjuly-dec09.pdf
[10] http://www.health.wa.gov.au/ElectiveSurgery/docs/2010_apr-june_qtr.pdf
[11] Information provided by Kylie Rose, NT Department of Health and Families, 24 October 2010
[12] http://www.health.qld.gov.au/performance/docs/QHQPHPR.pdf
[13] http://www.health.nsw.gov.au/resources/reports/2010/pdf/201003_QHPR_0910_q3.pdf
[14] http://www.health.act.gov.au/c/health?a=sendfile&ft=p&fid=1277958667&sid=
[15] www.bcna.org.au > About BCNA > Advocacy > Research reports
[16] www.bcna.org.au > New diagnosis > Treatment > Breast reconstruction
[17] www.bcna.org.au > News > The Beacon magazine > The Beacon archive

We were somewhat surprised at the findings regarding public hospital waiting times, given this project had been prompted by women telling us of waiting times of up to 10 years. In particular, we wondered if our survey may have failed to reach low-income women. We decided to undertake some further work to determine if the survey findings accurately represented public hospital waiting times around Australia. These included an informal telephone survey of breast cancer support group coordinators, and a questionnaire distributed to women attending a BCNA information forum in Queensland.

Informal telephone survey of selected breast cancer support group coordinators

In March 2011, we telephoned approximately 25 women who coordinate support groups in lower socio-economic areas in major cities and regional areas across all states and territories. After several attempts, we were able to make contact with 16 of them.

We asked the coordinators if they believed access to breast reconstruction through a public hospital is an issue for women in their local area. While almost all reported that in the past they had heard of long waiting times, they said this had changed in recent years. Most reported that the waiting time in their area was now less than two years. All of the coordinators we spoke to said they were unaware of any woman in their support group having difficulty accessing breast reconstruction surgery. Some of the coordinators went back to their support groups to ask this specific question before providing us with this response.

Survey of women attending BCNA's Sunshine Coast Forum (Nambour, Qld)

In April 2011, BCNA held an information forum for women and their partners/support people living on Queensland's Sunshine Coast. We thought this was a good opportunity to raise the issue of breast reconstruction directly with some of our members. The Sunshine Coast has only limited breast cancer services and women must travel to another centre (usually Brisbane) for breast reconstruction surgery. We thought, therefore, that access to breast reconstruction may be an issue for some women living in that area.

A hard copy questionnaire was distributed to approximately 125 women who attended the forum. This was a shortened version of the original online survey. Women were asked to complete the survey and return it to us either at the forum or by post.

Thirteen surveys were returned to us. This in itself was an indication that access to breast reconstruction surgery is not an issue in that catchment area. Only one of the 13 women who returned a survey reported having a reconstruction through the public system and she waited less than 6 months for her surgery.

A brief report on these two activities is available on the BCNA website.[18]

Survey of breast care nurses

As further follow-up to this project, in August 2011 we surveyed breast care nurses (BCNs) who are subscribed to BCNA's *My Care Kit* program about their experiences with women accessing breast reconstruction surgery.

The breast care nurses (456) were sent an email inviting them to participate in an online survey. 115 BCNs started the survey, with 104 completing all questions.

[18] www.bcna.org.au > About BCNA > Advocacy > Research reports

The findings of this survey were, in the main, consistent with the findings of our survey of women with breast cancer.

Eighty-three per cent of BCNs told us that women in their local area can access breast reconstruction surgery in a public hospital within two years of being placed on a waiting list. This compares with 94% of women.

One BCN in regional Queensland reported that women in her area wait 6-7 years for a reconstruction at a particular hospital in Brisbane. The longest wait reported by a woman was 3-4 years (one woman in Tasmania).

Of the 52 BCNs in the private system who answered our question about out-of-pocket costs of breast reconstruction, 67% (35) said that women in their area have an out-of-pocket cost of more than $5,000. This compares with 40% of women.

The majority of BCNs (93%) who answered a question about women's satisfaction with the outcome of their surgery said women were 'very satisfied' or 'satisfied'. No BCN said women were 'unsatisfied' or 'very unsatisfied'. In our women's survey, 74% of women rated their satisfaction level at eight or more (out of 10), with 8% reporting a satisfaction level of less than five.

A report on the findings of this survey is available on the BCNA website.[19] An article on the findings will be published in Issue 57 of *The Beacon* magazine (Summer 2011).

Discussion

As stated in the Introduction to this paper, this project was developed to assess women's access to breast reconstruction surgery in Australia. It was prompted by anecdotal reports we had received from women over a number of years about long waiting times for breast reconstruction in the public health system (up to 10 years was reported in some states), and high out-of-pocket costs for surgery in the private system. We also investigated women's levels of satisfaction with the outcome of their reconstruction surgery.

Women who do not have reconstruction surgery

Statistics show that only a small proportion of Australian women who have a mastectomy for breast cancer also have breast reconstruction surgery. National Breast Cancer Centre[20] statistics published in 2003 indicated that only 8% of Australian women who had mastectomies had breast reconstructions.[21] Figures quoted more recently vary from 6% to 12% of women who have mastectomies.[22]

In our women's survey, 71% of women (341) told us they had received a breast reconstruction, with 29% (140) reporting they had not had a reconstruction. Some of these 140 women were on a waiting list (18) or still considering their options for reconstruction (36). We do not think these figures have any implication for national reconstruction rates, as our survey was targeted very specifically at women who had had breast reconstruction surgery or considered it.

[19] www.bcna.org.au > About BCNA > Advocacy > Research reports
[20] National Breast Cancer Centre subsequently became National Breast and Ovarian Cancer Centre and, in July 2011, merged with Cancer Australia to become Cancer Australia
[21] J Robotham: *Why breast surgery is a rarity*, The Age 20 October 2003
[22] D Nesbitt: *The Health Report*, ABC Radio National, 5 January 2009

Given the low national reconstruction rates however, we wondered if sometimes women decide not to have reconstruction surgery because they believe waiting lists are too long and the cost of private surgery too high. We put these questions to women and BCNs in our surveys.

Only 5% of women (8) and 17% of BCNs (19) reported long waiting lists as a reason for not having reconstruction surgery. A greater proportion of women (28%, 39) and BCNs (44%, 49) said the high out-of-pocket cost of private surgery was a deterrent, however.

The most common reasons given for not having reconstruction surgery were:

Reason	**Percentage (number) of women providing this response**	**Percentage (number) of BCNs who reported this response from women**
I have decided not to have breast reconstruction	36% (51)	73% (81)
I can't afford the cost of private surgery	28% (39)	44% (49)
I'm still considering my options	26% (36)	62% (69)
It's not a priority for me right now	24% (34)	92% (102)

Note: these figures total more than 100% because women and BCNs could select as many responses as applied to them

Waiting times for reconstruction in the public system

The research undertaken during our project did not support anecdotal reports of extremely long waiting times in the public sector, i.e. up to ten years. While some breast care nurses reported that there had been extremely long waiting times for women in their area in the past, the majority (83%) reported that women are now able to access breast reconstruction through a public hospital within two years of being placed on a waiting list. Ninety-four per cent of the women who completed our survey and who had breast reconstruction through a public hospital had their surgery within two years.

While we recognise that two years is still a long time for women to wait for this surgery, it is more acceptable than the previously reported very long waits. In addition, we are aware that new initiatives are being introduced to further reduce waiting times.

Breast reconstruction following a mastectomy for breast cancer is considered a medical procedure – it is not cosmetic surgery. In all states and territories it is elective surgery, which is defined as surgery that a doctor believes to be necessary but that can be delayed for at least 24 hours.[23] Elective surgery is categorised into three urgency types:[24]

- Category 1 – urgent
    - Has the potential to deteriorate quickly to the point it may become an emergency
    - National standard desirable waiting time for treatment is 30 days

[23] Parliament of Australia Parliamentary Library, A Biggs: *Background note – Hospital Waiting Lists Explained* http://www.aph.gov.au/library/pubs/bn/2007-08/Hospital_waiting_lists.htm
[24] ibid

- Category 2 – semi-urgent
    - Causes some pain, dysfunction or disability; unlikely to deteriorate quickly; unlikely to become an emergency
    - National standard desirable waiting time for treatment is 90 days

- Category 3 – non-urgent
    - Causes minimal or no pain, dysfunction or disability; unlikely to deteriorate quickly; unlikely to become an emergency
    - There is no national standard for desirable treatment time, but 365 days is used as a guide.

Which category a woman's breast reconstruction surgery is placed into is at the discretion of her surgeon. Often, breast reconstruction surgery is classified as Category 3 surgery; although we are aware that some surgeons categorise it as Category 2. While there is no nationally agreed desirable waiting time for Category 3 surgery, 365 days is used as a guide.[25]

Our surveys found that many women undergo their surgery within one year – 82% of women (55 women) in our women's survey said they had their public hospital surgery within 12 months, and 41% of BCNs (29) said women in their area receive surgery in a public hospital within this time frame. We are unsure why there is this discrepancy in the figures – 82% of women versus 41% of BCNs. (The results were more closely aligned for women who have surgery within two years of being placed on a waiting list – 94% of women and 83% of BCNs.)

We are aware that, in recent years, a number of initiatives have been undertaken by some hospitals and governments, state and federal, to reduce Category 3 waiting lists. These include the establishment of specialised breast reconstruction units (such as the Flinders Medical Centre breast reconstruction unit in Adelaide); the employment of additional plastic surgeons in some public hospitals; and additional government funding for elective surgery (such as the Queensland Government's *Surgery-Connect* program, under which the Queensland Government paid for 'long-wait' Category 2 and 3 patients to have their surgery done in the private system). It seems these initiatives may have helped to reduce waiting list times, however we cannot say for certain that this is the case.

We are also aware that, as part of national health reform, the Australian Government is introducing new elective surgery targets and a National Access Guarantee for public hospitals.[26]

Under the new targets, state and territory governments are required to improve their elective surgery waiting times so that, from 31 December 2015, 95% of patients waiting for surgery are seen within the clinically recommended times. For Category 3 surgery, this will be 365 days.

The Government is also introducing a National Access Guarantee 'to ensure that no Australian experiences extremely long waits for elective surgery'.[27] Under the Guarantee, from 1 July 2012, anyone who has not received their surgery within the clinically recommended time will be prioritised and have their surgery fast-tracked. For Category 3 surgery this will mean that, from 1 July 2012, women who have already waited 365 days

[25] Parliament of Australia Parliamentary Library, A Biggs: *Background note – Hospital Waiting Lists Explained* http://www.aph.gov.au/library/pubs/bn/2007-08/Hospital_waiting_lists.htm
[26] Prime Minister of Australia media release: *A better deal for patients*, 13 February 2011 http://www.pm.gov.au/press-office/better-deal-patients-0
[27] ibid

must have their surgery within the next 60 days. From 1 July 2014, this will be reduced to 45 days.

It is hoped that these initiatives will help to ensure that, in the future, all women wishing to access delayed breast reconstruction surgery through a public hospital will be able to do so in a timely manner. We acknowledge, however, that these reforms may be difficult for state governments to implement. We are unsure how they will meet these targets, particularly given the current economic difficulties. We note, for instance, that the Tasmanian Government has recently announced a cut in funding for elective surgery in that state to obtain savings of $21.5 million in the health budget.

BCNA will write to surgeons and breast care nurses on our database informing them of these reforms and the potential benefits for women requiring delayed breast reconstruction surgery. We will also write to Health Ministers (federal, state and territory) to advise them of our support for this initiative. BCNA will continue to monitor the issue of public hospital waiting times over the period of this initiative.

Cost of surgery in the private health system

In our survey of women, 270 women answered a question about the out-of-pocket costs of their breast reconstruction surgery. They reported out-of-pocket costs ranging from less than $500 (25 women, 9%) to more than $15,000 (9, 3%). Forty per cent of respondents (108) paid more than $5,000 in out-of-pocket costs.

Fifty-two BCNs answered a similar question in the BCN survey. Of these, 67% (35) said women in their area had an out-of-pocket cost of more than $5,000. Some BCNs also commented on the unfairness of women with private health insurance having to pay for reconstruction surgery.

> *'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.' – Breast care nurse*

The issue of out-of-pocket costs for breast reconstruction surgery is a complex and difficult one. The Government sets a fee (the *Schedule Fee*) under the Medicare Benefits Schedule (MBS), and Medicare pays a rebate of 75% of this fee. If a woman has a private health insurance policy that covers breast reconstruction surgery, she can claim the remaining 25% from her health fund.

However, surgeons are free to set their own fees and many charge significantly more than the Schedule Fee. The reasons for the discrepancy between MBS fees and surgeons' fees are not clear. Perhaps MBS fees are set too low to reflect the true cost of providing this surgery, given the time and expertise required. Perhaps some surgeons are charging too much.

Some private health insurance funds have agreements with individual health practitioners to pay them more than the Schedule Fee, thereby reducing or eliminating the 'gap' for patients. We are unsure how many specialist reconstructive surgeons, and anaesthetists, have entered into gap agreements with private health insurance funds, and whether women are aware of these agreements. It can certainly be recommended to women with private health insurance that they ask their fund for a list of surgeons who participate in the fund's gap scheme, as using specialists from the list may reduce or eliminate out-of-pocket costs for their services.

We note that the issue of out-of-pocket costs is not restricted to breast reconstruction surgery, but is an issue right across the Australian health system.

Some women provided advice on financial aspects of breast reconstruction in the private system, and these have been included in the information sheet of tips and advice developed as a result of our original survey. This sheet is available on our website.[28] BCNA will develop further information on this issue for our website.

Some women also told us they were unaware they could have breast reconstruction surgery through the public health system, at no cost to themselves. It is important that women are aware that this is an option for them.

Satisfaction with breast reconstruction surgery outcomes

Our questions to women and breast care nurses about satisfaction levels with the results of breast reconstruction surgery found that the majority of women were satisfied. Seventy-four per cent of women who had received breast reconstruction surgery rated their satisfaction with the outcome at eight or more out of ten, with only 8% rating their level of satisfaction at less than five out of ten.

Most BCNs (93%, 90) said they believed women were 'very satisfied' or 'satisfied' with the results. No BCN said women were 'unsatisfied' or 'very unsatisfied', although a small number of BCNs (7%, 7) said women were 'neutral'.

These results are in line with the findings of research conducted at the Royal Adelaide Hospital Breast Unit in 2005.[29] Their survey of 123 women who had reconstructions at the hospital between 1990 and 2002 found that 77% were highly satisfied with the outcome.

Two BCNs noted that sometimes women's expectations of the outcome of the surgery may not be realistic and that this can have an impact on their satisfaction with the results.

> *'It (women's satisfaction) is 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.' – Breast care nurse*

This was reflected in another piece of Australian research undertaken in 2008.[30] The researchers found that 47% of women in their study experienced regret at their decision to have a reconstruction. The researchers recommended 'optimal input from surgeons and therapists in order to promote realistic expectations regarding the outcome of breast reconstruction and to reduce the likelihood of women experiencing decision regret'.

It is very important that women contemplating breast reconstruction surgery have a realistic understanding of what the outcome of any surgery may be and how their reconstructed breast may look and feel. BCNA believes it is incumbent on surgeons to provide women with this information prior to any decision being made about reconstructive surgery. It is also important that women feel comfortable asking questions of their surgeons. This issue is addressed further in the next section, *Women's information needs*.

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[28] www.bcna.org.au > New diagnosis > Treatment > Breast reconstruction

[29] M Nano et al, *Qualitative assessment of breast reconstruction in a specialist breast unit*, Australia and New Zealand Journal of Surgery, 2005, Vol 75 (6)

[30] J Sheehan, KA Sherman, T Lam, J Boyages: *Regret associated with the decision for breast reconstruction: The association of negative body image, distress and surgery characteristics with decision regret*, Psychology and Health, February 2008, 23 (2): p 207-219

Women's information needs

In both the women's survey and the BCNs' survey, comments were made on the need for more comprehensive information to be available to women about their options for reconstruction.

> *'I found it (reconstruction) was something I had to ask about myself. … You are kind of on your own when you go this path.' – Women's survey participant*

> *'Finding information is near impossible. I have been researching this for years.' – Women's survey participant*

Our review of current resources available for women found some useful material, including Cancer Council Victoria's breast reconstruction booklet, although it is currently unavailable due to a re-write. This booklet has recently been adapted and released by Cancer Council NSW under the title *Understanding Breast Prostheses and Reconstruction*.

BCNA is participating in the development of new breast reconstruction resources, including a comprehensive information resource being developed by researchers at the University of Sydney. This resource is currently being piloted with women and will be available online and in hard copy. An online decision aid to help women reach decisions about breast reconstruction surgery is being developed by a Sydney Health Psychology Lecturer.

> *'I think women find it hard to access information on the different types of reconstruction, so a decision aid would be really helpful.' – Breast care nurse*

BCNA considers it should not be up to women alone to gather information about reconstruction surgery. We know that many surgeons talk to women about breast reconstruction, however some of the comments made in our women's survey would indicate that this is not always the case. BCNA believes that all surgeons should provide women with good quality information about reconstruction options, and that this information should be provided early so that women for whom immediate reconstruction is clinically appropriate can consider it. Surgeons should explain to each woman the reconstruction options that best suit her, and the reasons behind these recommendations. This helps women make informed decisions about their best option/s.

> *'I think that there is not enough effort made to educate us about reconstruction prior to mastectomy.' – Women's survey participant*

Breast care nurses also commented on the need for information to be provided to women. More than half of those who responded to our survey (59%, 66) said that, in their experience, surgeons only 'sometimes' talk to women about breast reconstruction options.

> *'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.' – Breast care nurse*

Project outcomes

There have been a number of outcomes as a result of this project.

Reports have been developed for each of the separate activities that comprise the project. These are available on our website at www.bcna.org.au > About BCNA > Advocacy > Research reports > BCNA's Breast Reconstruction Project 2010-11.

We have reported on the results of our breast reconstruction surveys through our free quarterly magazine, *The Beacon*, which has a readership of more than 65,000 individuals. Issue 53 (Summer 2010) included a summary of the women's survey and Issue 57 (Summer 2011) a summary of the breast care nurses' survey.

One of the key findings of both surveys was the need for comprehensive information about breast reconstruction to be available for women who are undergoing breast cancer surgery. In response to this, BCNA dedicated Issue 52 of *The Beacon* to the topic of breast reconstruction. The issue included personal stories from women about their experiences with reconstruction and articles prepared by BCNA staff on topics relating directly to the work undertaken for this project, including:

- The different types of breast reconstruction
- Breast reconstruction in the public health system
- The psychological benefits of breast reconstruction.

In conjunction with that issue of *The Beacon*, we developed a resource sheet for women considering breast reconstruction. It lists organisations, websites, books and other resources which provide helpful information for women about breast reconstruction issues. The resource sheet is available via our website.

An information sheet listing the advice and tips we received from women who have had, or considered, breast reconstruction was developed and published on the breast reconstruction page of our website.

A copy of this report will be sent to key surgeons (105) and breast care nurses (573) on our database to inform them of the project and our findings. In particular, we will raise with surgeons the need to provide women with information about options available to them for breast reconstruction, including that they may be able to have this surgery in the public sector if they cannot afford private surgery.

As discussed in the *Waiting times for reconstruction in the public system* section of this report, we will also advise surgeons and breast care nurses of the government reforms to elective surgery targets and the potential benefits these reforms may have for women requiring delayed breast reconstruction surgery. We will also write to federal, state and territory Health Ministers to congratulate them on this initiative and advise them of our support. We will continue to monitor this issue and how the health reforms impact waiting times for women over the course of the initiative.

Next steps

The next steps will include the development of a position statement on breast reconstruction, outlining BCNA's view that women should be able to access affordable, timely, quality breast reconstruction and that they should receive sufficient information about breast reconstruction options to enable them to make informed decisions.

We will also further develop the breast reconstruction page of our website to include information and advice on accessing breast reconstruction through the public and private health systems. This may include the development of a fact sheet on breast reconstruction options.

Acknowledgements

Breast Cancer Network Australia thanks all those who participated in this project. In particular, we thank the women and breast care nurses who shared their experiences with us, completed our surveys and provided feedback and information about breast reconstruction services in their area.

We also thank Cancer Australia for providing funding to undertake this work.