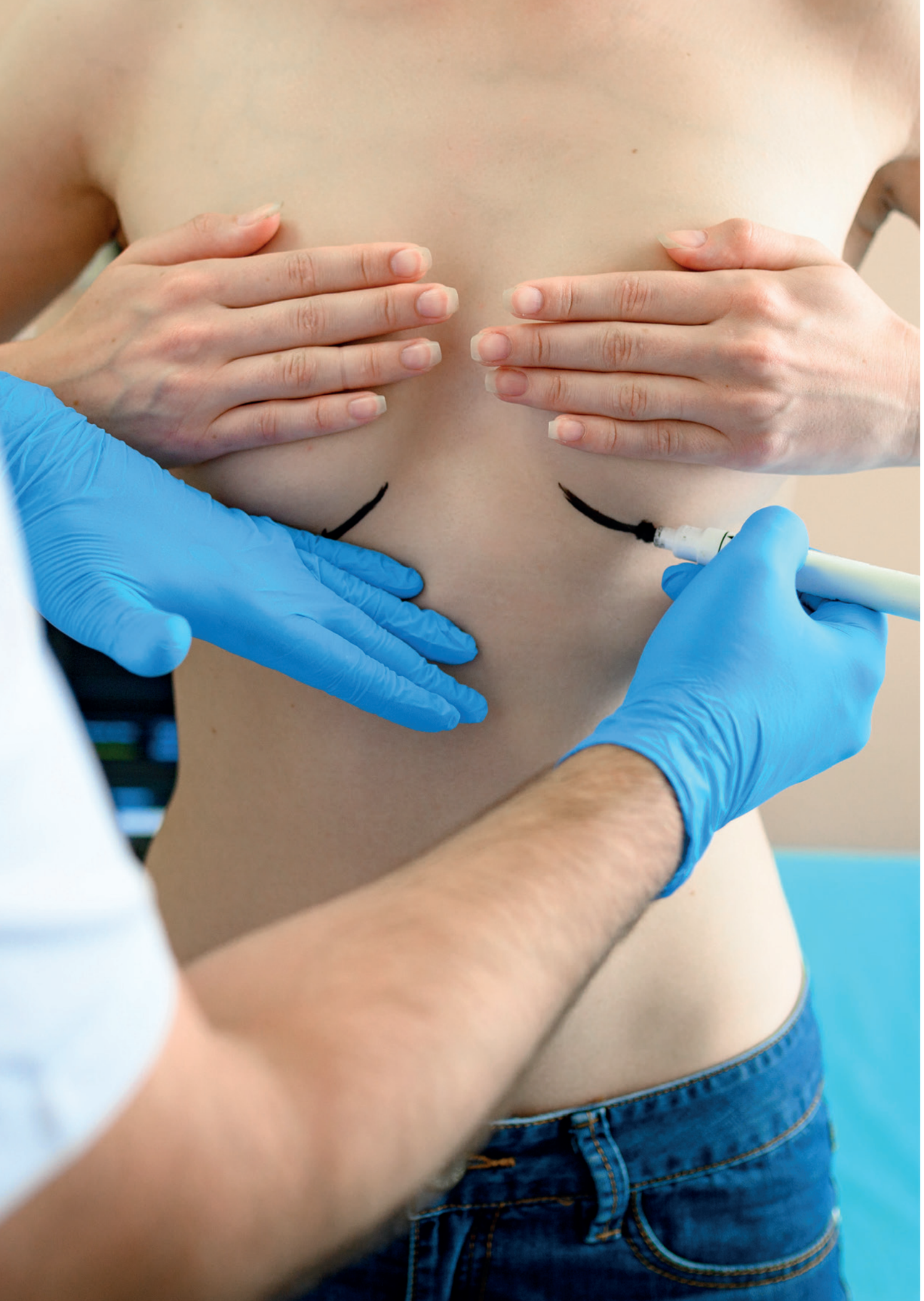
Breast Cancer Network Australia

BREAST RECONSTRUCTION IN AUSTRALIA 2021

August 2021



CONTENTS

ABOUT BREAST CANCER NETWORK AUSTRALIA

Breast Cancer Network Australia (BCNA) is the peak national consumer organisation for Australians personally affected by breast cancer and consists of a network of more than 150,000 individual members from across Australia.

BCNA works to ensure that all Australians affected by breast cancer receive the very best care, treatment and support.

bcna.org.au
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EXECUTIVE SUMMARY

BACKGROUND

Despite recognised benefits, breast reconstruction rates for Australian women with breast cancer managed by mastectomy are less than half those in found in comparable countries like England and the United States. Through the 2018 *State of the Nation* report, Breast Cancer Network Australia (BCNA) highlighted the need to 'Improve access to breast reconstruction surgery for all women who choose mastectomy'. As part of their work to meet this aim, BCNA undertook a members' survey to develop a better understanding of women's experiences regarding breast reconstruction, particularly waiting times, costs and the influence residential location has on these experiences. This report details findings from this survey.

RESULTS

Breast reconstruction status of participants

60% had decided to have reconstruction (41% completed; 10% having reconstruction; 9% planning to have), 28% had decided not to have reconstruction, and 13% were undecided.

Who has breast reconstruction

Breast reconstruction was more common for younger women (under 50), for those living in more socio-economically advantaged areas, and those living in metropolitan areas. Reconstruction was more common for women from Western Australia (WA: 66%), Victoria (VIC: 65%), and Tasmania (TAS: 64%) than for those from New South Wales (NSW: 58%) or South Australia (SA: 58%), Northern Territory (NT: 56%) the Australian Capital Territory (ACT: 54%) or Queensland (QLD: 53%).

Type of reconstruction

Of women who had completed, were having, or planning to have reconstruction, 44% had implants, 41% had autologous reconstruction, 7% had a combination of implants and autologous reconstruction, and the remaining 8% were not sure of the procedure. Socio-economic position based on postcode classification was not associated with having implants, but residential location was, with women from metropolitan and inner regional areas and women from Victoria more likely to report having autologous reconstruction. 45% had immediate reconstruction which was more common in Victoria (57%) and ACT (61%) and least common in Tasmania (26%) and Queensland (30%).

Immediate reconstruction was more common for women from least disadvantaged areas (52%) and those living in metropolitan areas (47%) than those living in most disadvantaged areas (36%), and remote/very remote areas (27%).

Mostly breast reconstruction happened in the private system with only 35% using the public system. Plastic surgeons (70%) mainly performed the reconstruction although this differed by state and was more common in Victoria (87%), and Tasmania (91%) than in NSW (56%), and the ACT (18%).

STUDY DETAILS

What we did:

Cross sectional online survey with participants indicating their reconstruction status (completed, having, planning to have, undecided, not having). Those deciding to have reconstruction provided information on the type, health system treated in, waiting times, costs, satisfaction with decisions and outcomes. Those undecided and those who had decided against reconstruction were asked to identify factors influencing this decision. All women were asked to provide suggestions for how the reconstruction process could be improved.

Who took part:

3,350 respondents provided information about their breast reconstruction experiences. Participants were from every state and territory across the country. and ranged in age between 18-80+ years, with 50% between 50-69 years.

Thirty-seven participants identified as being a First Nations person.

65% of respondents were from metropolitan areas, and 30% lived in more disadvantaged areas of Australia.

Most participants were diagnosed with early breast cancer (25% non-invasive; 63% invasive), and 82% had a mastectomy as part of their breast cancer care, reflecting the group of women for whom breast reconstruction is most relevant. The proportion of women having mastectomy in our study is greater than that found in the population of breast cancer survivors. While this reflects that breast reconstruction is most relevant to those having mastectomy, we note it means that study sample is not representative of all people affected by breast cancer.

Waiting

Of women having delayed reconstruction after mastectomy in the public health system who had either completed this surgery in the previous three years or were currently having it (n=66), 76% had to wait for this procedure with 27% of these waiting longer than 12 months. 61% of women waiting for their reconstruction surgery in the public system were informed about the wait. Only 3% of women having or completing their reconstruction in the previous 3 years in the private system indicated they had to wait for this procedure.

> *...The reason I am having my breast reconstruction [done privately as] I do not want to wait the 18+ months through the public and only to get there and have it reschedule on me. We did not choose to have breast cancer and then our breast taken of [us], we had to to save our lives, so reconstruction should be urgent surgery so we can get back to a happy mental and physical health.*

COVID-19 delayed reconstruction procedures of 13 of the 24 women having delayed reconstruction in the 12 months prior to the survey.

46% of women who were planning to have reconstruction, were on a waitlist and of these 26% had been waiting 1-2 years with another 17% waiting over 2 years. Of those waiting, 63% were told there would be a wait, however, 15 (20%) reported waiting longer than this advice.

> *When I first consulted my Plastic surgeon I was aware that I could be on a wait list from between 6-12 months. However, due to Covid this was blown out to 18 months.*

Out-of-pocket Costs

Of respondents who had completed their breast reconstruction in the private system, 16% had out-of-pocket costs less than $2000 and 23% had costs between $2,000-$5,000. However, 37.2% had costs between $5,000-$10,000 and 10-12% reported out-of-pocket costs of $15,000 or more.

> *Costs! It's unfair how expensive a reconstruction is. We didn't choose breast cancer.*

Distance travelled

While 50% of women having or who had completed breast reconstruction were able to access this procedure within 20 km of their home,15% travelled over 100 kms for this surgery, including 10% travelling over 200 kms. Between 23% (NSW) and 63% (SA) of those potentially eligible, accessed funding through their state's patient travel assistance scheme.

> *The PATS system needs to support country patients more as financially I am breaking with the cost of regular travel and taking time off work. The bills don't stop. Also some hospital staff are not sympathetic to the needs of country patients and not always willing to help with little things like appointments on a Friday so I can take less time off work and have the weekend to travel or early appointments so travel home in the afternoon can happen.*

Satisfaction with decision and outcomes

The majority (84%) of women who had completed or were still having reconstruction were satisfied with their decision to have reconstruction, and 77% of women who had completed reconstruction were satisfied with the outcome. Reasons for dissatisfaction with the outcome related to cosmetic appearance, complications, pain and time it took for the procedure to be completed.

Undecided or decided against breast reconstruction

In women who had had a mastectomy, the factors most commonly influencing those still deciding about breast reconstruction were: determining its importance to them (68%), insufficient information (32%), recovery time (31%) and costs (24%). For women deciding against breast reconstruction, the factors influencing their decisions were: recovery time (21%), importance of reconstruction to them (18%), costs (10%) and no one talking to them about it (10%). Few women mentioned type of cancer they had or other health factors as important factors in their reconstruction decisions.

> *Women should be given all the information they need to make an informed decision within a reasonable time frame, and not left to years later to hear that it could have been an option for them.*

What women would like to see improved

Approximately 60% of respondents providing suggestions for improvements. Responses were categorised into 10 major areas for improvement:

1. Information
2. Costs
3. Waiting times
4. Access
5. Support
6. Timing of decision
7. Having realistic expectations
8. Understanding impacts on/of treatment
9. Skill level of doctors
10. Legitimacy of not having a reconstruction.

> *More information about ALL the options including the option to go flat and be comfortable with that. I found the push/ encouragement for reconstruction quite surprising - only through my own research did I discover that going flat for aesthetics, as well as eliminating any potential risk of return, was a real option.*

Conclusion

Reflecting findings from previous Australian studies, results from this survey show disparities in access for breast reconstruction by residential location and socio-economic position. Our findings support calls for practice improvements in relation to information provision and access. Delays in ensuring women are provided with the information they need to make informed decisions about breast reconstruction and in identifying mechanisms for reducing costs associated with this procedure will likely entrench these disparities and must be addressed.

KEY RECOMMENDATIONS

- Transparency of State/Territory wait times for breast reconstruction procedures
- Patients having delayed breast reconstruction offered an operation within 365 days, with the development of an action plan where this has not occurred.
- Prioritised implementation of the Government's out-of-pocket costs portal to ensure greater transparency of fees
- Development of a range of reasonable out-of-pocket costs for breast reconstruction procedures in the private health system to address financial burden
- Provision of comprehensive information regarding breast reconstruction prior to breast cancer surgery to ensure women are empowered to make the most appropriate decision for them
- Discussion of the option not to have a breast reconstruction, with this presented as a viable option and the pros and cons discussed
- Ongoing commitment to telehealth to support those in rural and regional areas seeking breast cancer services which are not available in their local area.

For the full set of recommendations, see page 43.

INTRODUCTION

Despite advances in the medical management of breast cancer, surgical removal of the tumour remains a mainstay of treatment. While most breast cancer in Australia is diagnosed at an early stage and managed by breast-conserving surgery and radiotherapy,[1, 2] current estimates suggest around 40% of women with breast cancer (early and advanced disease) have mastectomy as part of their breast cancer care.[1] Breast reconstruction after mastectomy has been offered as an intervention than can improve women's wellbeing and body image.[2, 3] While recognising that many women decide to not have breast reconstruction after mastectomy, Australia's best practice recommendations for the care of women with breast cancer recommend that breast reconstruction is discussed with all women having mastectomy to allow them to make an informed choice about this procedure.[3] Australia's optimal care pathway for people with breast cancer also states that women should be fully informed of their options regarding reconstruction surgery, including being informed of the possibility of immediate reconstruction (performed at the time of their mastectomy), having reconstruction at some point after completion of treatment (delayed reconstruction) or not having reconstruction at all.[4]

> ***It was a hard decision, which took at least three years to decide on. But after having my reconstruction, it feels like a weight has been lifted and I no longer have the constant reminder. One of the best decisions that I have made.***

Current understanding of the rates of breast reconstruction after mastectomy in Australia is difficult due to limitations in the available data, including lack of information about delayed reconstructions, limited information about reconstructions performed by plastic surgeons, and recency of information. For instance, several studies have utilised the Quality Audit database of the Society of Breast Surgeons of Australian and New Zealand to assess rates of immediate reconstruction.[4, 5] However, data from this database is likely to underestimate the real rate of breast reconstruction as it captures only around 80% of breast cancer surgeries and does not account for delayed reconstruction procedures or reconstructions performed by plastic surgeons.[5]

Data from this dataset have suggested the rate for immediate reconstruction in women treated by mastectomy increased from 8% in 2006-2008[4] to 23% in 2018.[1] Population-based studies from NSW[6] and Queensland[7] have also tried to provide a picture of reconstruction experiences for Australian women; however, only the Queensland study[7] included delayed reconstruction, in its analyses. This study found that 11% of women diagnosed between 2008 and 2017 and treated by mastectomy had delayed reconstruction, providing an overall reconstruction rate in Queensland of 21% during this period.[7] While noting its limitations, the data from Australia suggests rates of breast reconstruction after mastectomy lag behind those found in other countries. For instance, data from England using the Hospital Episodes Statistics suggested an immediate reconstruction rate of 25% in 2013,[8] although rates for more recently diagnosed women in England have not been publicly reported.[9] In the United States (US), data from the American College of Surgeons national database for quality assurance found rates of breast reconstruction after mastectomy increased from 39% in 2010 to 47% in 2016, although whether this only includes immediate reconstructions is not clear.[10] A population-based study from the US state of Kentucky found that approximately 50% of women in urban areas who had a mastectomy for breast cancer in 2016 had breast reconstruction, although rates in rural areas were substantially less at 18%.[11] While quality of procedures also needs to be addressed when considering the increasing use of breast reconstruction, work from the United Kingdom (UK) has suggested that women receiving reconstruction are satisfied with outcomes and their care.[12]

The existing Australian data show variations in the rates of breast reconstruction by rurality, socio-economic status and women's age.[5-7] Data from NSW found an inverse association between age and reconstruction with just under half (45%) of women under 45 years of age having reconstruction after mastectomy compared to 12% of women aged 60-69 years.[6] A similar inverse association with age was found in a study from Queensland where 38% of women under the age of 40 had reconstruction after mastectomy while only 6% of those aged 60-69 years had breast reconstruction.[13] This study also found significant differences in breast reconstruction by socio-economic status, with women from high socio-economic areas more likely to have reconstruction (22%) than those from low socio-economic areas (4%).[13] Access to major cancer treating centres in urban areas was also associated with reconstruction for women in Queensland.[13] In addition to these demographic factors, breast reconstruction in Australia has been associated with health service factors including: private/public health system; hospital volume and location; and large out-of-pocket costs for women.[5-7, 13]

While studies suggest breast reconstruction is associated with improved quality of life in women who have a mastectomy,[3, 12, 14] there is also is a growing appreciation that not all women will want to have breast reconstruction after mastectomy[15] and that factors including tumour type, treatment plan and comorbidities may influence both clinical and women's decisions regarding breast reconstruction.[12] As many Australian women report receiving limited information about breast reconstruction at the time of their mastectomy.[16, 17] Treatment recommendations are calling for women to be fully informed about their reconstruction options - including not to have reconstruction when they are considering their treatment plan - so women can be empowered to make reconstruction decisions that align with their values and preferences.[18, 19]

If a woman does decide to have breast reconstruction, ensuring equitable access to this procedure is paramount to reduce inequalities in the complete care women receive for their breast cancer. In the 2018 *State of the Nation* report,[20] Breast Cancer Network Australia (BCNA) highlighted the need for action to "Improve access to breast reconstruction surgery for all women who choose mastectomy". To assist BCNA in reviewing and developing policies and advocacy work to support women regarding breast reconstruction decisions, BCNA undertook a survey of its members regarding breast reconstruction. This report details the findings from this survey and aims to:

- Understand women's experiences in relation to the timing (immediate or delay) and type (implant or autologous) of their reconstruction, and explore whether these are influenced by residential location (state, rurality), socio-economic advantage/disadvantage and health system (public or private);
- Examine women's experiences of waiting times for reconstruction procedures and assess whether these differ by state, rurality and socio-economic advantage/disadvantage;
- Examine women's experiences of out-of-pocket costs for reconstruction procedures;
- Examine women's experiences of distance needed to travel for reconstruction procedures, and assess women's knowledge and use of patient travel assistance schemes in their state;
- Understand factors that might influence women's decisions to not have reconstruction.

As the report details findings from a survey of women, the focus is understanding experiences from the women's point of view. While recognising that reconstruction may not be appropriate for some women, assessing the appropriateness of breast reconstruction for women was not an area assessed in this survey.

> ***I think there needs to be more understanding of the psychological effect of losing your breasts. Even reconstructed, they are hard to deal with. Better than the possibility of dying of course but we still need to live.***

METHOD

Design

Cross sectional online survey of members of BCNA, a national breast cancer consumer organisation.

Eligible participants: The survey was open to all BCNA members with a diagnosis of non-invasive breast cancer (ductal carcinoma in situ (DCIS) or lobular carcinoma in situ (LCIS)), invasive breast cancer (early stage breast cancer or metastatic breast cancer), and people not diagnosed with breast cancer but at risk due to a strong family history of breast cancer, as prophylactic mastectomy may be recommended as part of their risk management. For those with breast cancer, no restrictions were placed on time since diagnosis. Women were informed the study aimed to assess experiences in having and deciding whether to have or not have breast reconstruction surgery.

Survey

An online survey developed by BCNA staff.

Survey items

A mix of closed and open-ended questions were utilised for this report. Respondents were initially asked to indicate the stage of breast cancer they were diagnosed with (or were most recently diagnosed with) and could choose an option from the following: DCIS or LCIS; early breast cancer (described as being contained within the breast and/or lymph nodes) or metastatic breast cancer (described as having spread to distant parts of the body; also called advanced, secondary or stage four). Respondents not diagnosed with breast cancer could indicate this with an option to indicate that they were at high breast cancer risk due to their family history. Time since diagnosis was assessed and treatment including type of surgery (lumpectomy, mastectomy, prophylactic mastectomy) and adjuvant therapies (radiotherapy, chemotherapy, hormone blocking therapy, targeted therapy) were indicated.

Respondents were then asked about their breast reconstruction status with options indicating their breast reconstruction was completed, was ongoing, they planned to have breast reconstruction, they were undecided about reconstruction, or they had decided against it. Respondents who had completed or were currently having breast reconstruction were asked questions relating to the type of reconstruction they had/were having:

- Nipple reconstruction;
- Timing of the reconstruction (e.g. immediate, delayed);
- Whether they were having their reconstruction in the private or public system;
- Experience of delays and communication from health services regarding any delays;
- Distance travelled for surgery;
- Access to state based travel assistance schemes;
- Out-of-pocket costs if treated in the private system; and
- The number of surgeries.

Satisfaction with the decision to have reconstruction, and for those that had completed this procedure, with the outcome, was assessed with a text box allowing women to comment on the reasons for their satisfaction or dissatisfaction in these areas provided.

Women planning to have breast reconstruction were asked if they were currently on a waiting list and, if so, the length of time they had been waiting, if they were told how long the wait may be, and how their waitlist experience has matched this expectation. Women also indicated whether they were planning to have their reconstruction in the private or public system, with those planning to have their surgery in the private system providing an estimate their expected out-of-pocket costs. Women were also asked about the type of reconstruction they were having and the timing of the surgery.

Women who were undecided about reconstruction and those who had decided not to have reconstruction were asked which of 10 items described their reasons for this, with women able to select as many items as relevant. The list of items included costs, distance, importance of breast reconstruction to the woman and her family, waiting times, time needed to recover, and lack of information about the procedure. Respondents indicating that distance, costs or waiting times influenced their decisions were asked to indicate what these items would have been for them if they were to have reconstruction.

At the end of the survey, an open-ended question allowed all respondents to provide comments regarding what could be changed to ensure women have a better experience with breast reconstruction in the future.

Demographic questions assessed age (in eight 10-year age groups with 80+ years the oldest group), state of residence, First Nations person status, language spoken at home, and postcode. Postcode was used to determine residential location (metropolitan city, inner regional, outer regional, remote and very remote) based on classifications developed by the Australian Bureau of Statistics (ABS). Postcode was also used to determine socio-economic position based on the relative disadvantage scale from the Socio-Economic Indexes for Areas (SEIFA) developed by the ABS. This area-based indicator of socio-economic disadvantage ranks each area in Australia using a number of indicators including unemployment, income, education, and home-ownership within the area. For this study, postcode level rankings were grouped into quintiles indicating most to least disadvantaged areas.

Procedure

An email was sent to BCNA members meeting the eligibility criteria, inviting them to take part in the survey. A reminder email was sent to members who had not opened the initial invitation.

The survey was administered online via SurveyMonkey and was open between April 10 and April 30, 2021. Completed surveys were downloaded and transferred to SPSS for data analysis via Excel.

Statistical analyses

Descriptive statistics were used to characterise participants in terms of their age, residential status, breast cancer stage, when diagnosed, treatment received, and breast reconstruction experiences or decision. Women who had completed, were having or were planning to have reconstruction surgery were classified as having decided to have breast reconstruction and associations with demographic, breast cancer and treatment characteristics were examined in univariate and multivariate (regression) analyses.

The association between women's various experiences of breast reconstruction and state, rurality, and socio-economic advantage/disadvantage are explored using chi-square analyses with proportions compared presented in tables. Sample size for each analysis varied between questions depending on relevance of the question to respondents, e.g. questions relating to waiting times were only relevant to those having delayed reconstruction. Sample size is reported for different groups in tables.

Satisfaction with reconstruction decisions is examined using means and multivariate regression analyses examined factors associated with higher satisfaction levels.

Respondents opting not to have reconstruction or still deciding on this procedure indicated the factors they considered important in these decisions. Multivariate logistic regression analyses examined the association between the different factors and the outcome, 'I'm still working out if having breast reconstruction is important for me,' for women who were still deciding about reconstruction with these analyses also including age, residential location, and socio-economic advantage/disadvantage.

Thematic analyses were undertaken on responses to open-ended questions.

Data cleaning

Questions asking women to provide information about their out-of-pocket expenses and the distance travelled to have breast reconstruction used an open-ended format with women writing in a response. While most respondents answering these questions provided an estimate in dollars for costs and kilometres for distance, some respondents provided an estimate with a comment indicating the price was approximate or an estimate, others provided a range, and others indicated it was a lot of money and mostly out-of-pocket. If women provided a range for their out-of-pocket costs, a midpoint was taken for their estimate. If women provided a written response that did not include an estimate of the dollars spent, the response was excluded from analyses. Some women indicated that their estimate included costs for mastectomy surgery, and other related costs, and some indicated that the estimate was for reconstruction of both breasts. These estimates were included in the data relating to costs, and while we note they may have increased the estimates slightly, only a handful of respondents provided this type of information. For open-ended responses relating to distance travelled, while most respondents providing this information gave an estimate in kilometres, some indicated the time taken to drive to the treatment centre, and some indicated the flight time. If a flight time was provided, the data was excluded from estimates. If the drive time was provided and the name of town the woman travelled from was provided, google maps was used to provide an estimate of the distance from the town to the capital city in the respondent's state. If a respondent indicated the distance was for a round trip, the estimate was divided in half to provide the one-way distance.

SAMPLE RECRUITED

Characteristics of respondents

The survey request was sent to approximately 43,122 members with 3,385 people responding to the survey request. Of these, 6 who did not have breast cancer and were not at high risk of breast cancer were excluded as were 29 who did not provide information about their breast reconstruction experiences. Thus a total of 3,350 were included in the study sample.

The age and state profile of participants in the study sample along with age and state profiles of incident cases of female breast cancer,[21, 22] are shown in Figures 1 and 2 respectively.

While the age and state distribution of participants in the study broadly reflects the incidence of breast cancer, there are some differences to be noted. Regarding age, there is an over-representation of women aged 50-59 and an under-representation of women aged over 70 in our sample compared to the broader sample of breast cancer survivors. While in general the distribution of respondents from the different Australian state and territories reflects the distribution of incident breast cancer cases, we note there is a slight under-representation of women from NSW and slight over-representation of women from WA in the sample compared to the broader population of breast cancer incidence. As previous studies using BCNA membership lists for participant recruitment have found a similar under-representation of women from NSW,[23] this finding may reflect differential membership in BCNA across Australian states.

Figure 1: Percentage of sample in the 7 age groups along with age profile of 2021 incidence cases of breast cancer across Australia projected by Australian Institute of Health and Welfare (AIHW).[21]

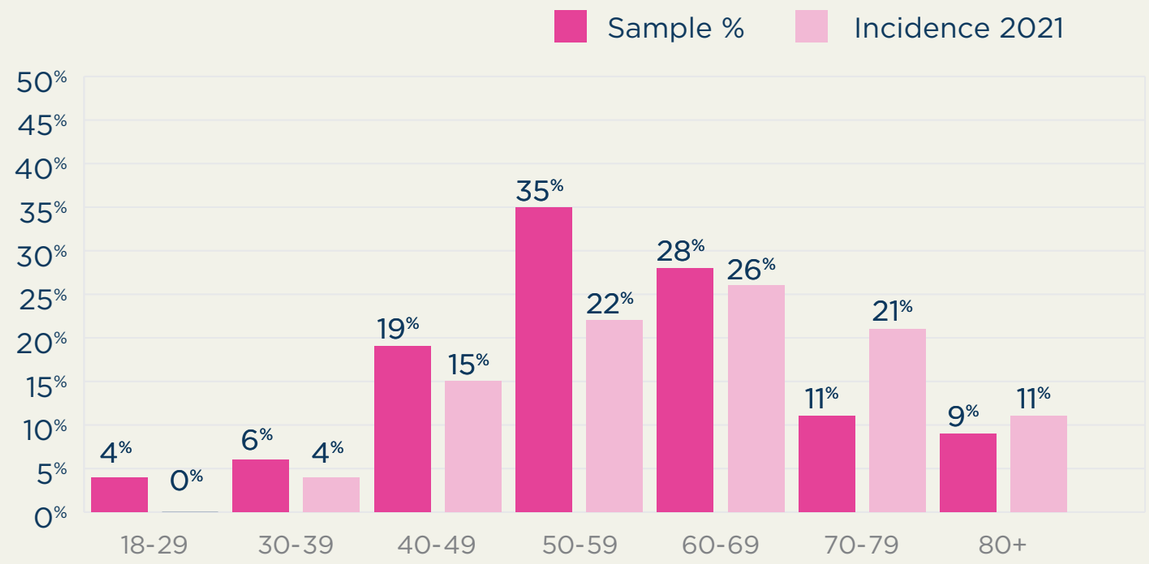


Figure 2: Percentage of sample from each Australian state and territory along with percentage of incidence female breast cancer case diagnosed in each state in 2017 as reported by Australian Institute of Health and Welfare (AIHW).[22]

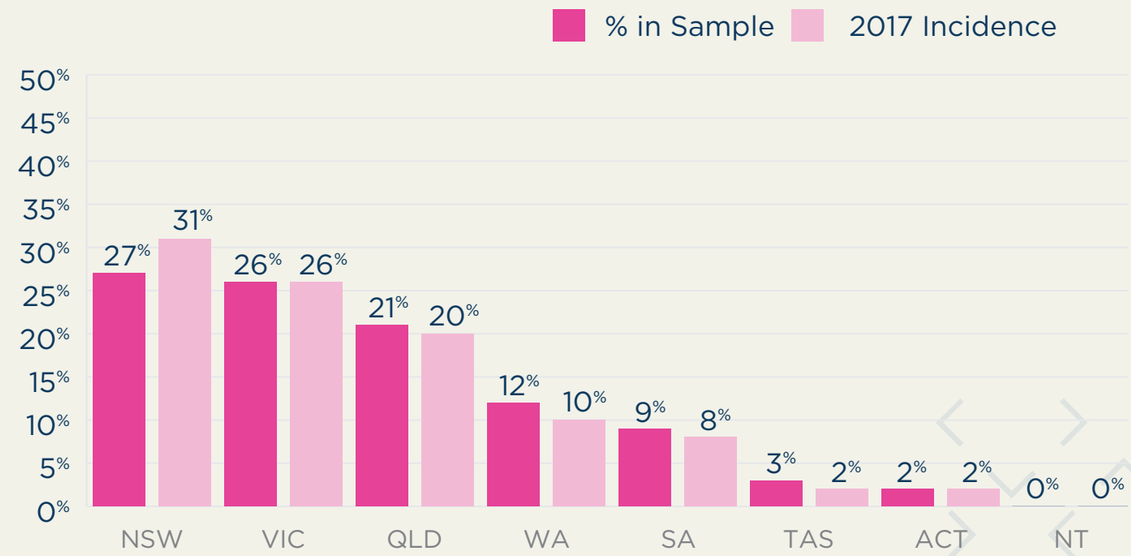


Table 1: Demographic characteristics of respondents and proportion of women deciding to have reconstruction (had, having or plan to have) within each characteristic^, (n=3350)

Demographic Characteristic		N	%	Disease characteristics		N	%
Total		3,350	100				
Age	18-39	200	6.2	**Type of breast cancer***	DCIS/LCIS	860	25.4
	40-49	613	19.1		Early breast cancer	2,121	62.7
	50-59	1,121	34.8		Metastatic	164	4.8
	60-69	904	28.1		Not sure	54	1.6
	70-79	345	10.7		High risk	15	0.4
	80+	30	0.9		Other	163	4.8
First nation person	Yes	37	1.1	**Surgery experience***	Lumpectomy only	527	15.6
					Lumpectomy then mastectomy	337	10.0
Language at home	English	3,147	93.9		Mastectomy (any including prophylactic)	2,423	71.9
	Other language	202	6.0				
					No surgery yet	86	2.5
State	NSW	873	26.1	**Treatment**	Chemotherapy	1,914	56.6
	Victoria	831	24.8		Radiotherapy*	1,614	47.7
	WA	383	11.4		Hormone therapy	1,936	57.2
	Queensland	682	20.4				
	SA	274	8.2				
	Tasmania	80	2.4				
	ACT	76	2.3				
	NT	18	.5				
Residential location	Major city	2,200	65.7	**How long ago diagnosed?**	< 12 months	833	24.9
	Inner regional	620	18.5		1-<2 years	661	19.8
	Outer regional	256	7.6		2-<3 years	394	11.8
	Remote	24	0.7		3-<4 years	214	6.4
	Very remote	10	0.3		4-<5 years	243	7.3
					5-<10 years	591	17.7
					10+ years	393	11.8
Socio-economic position (quintiles)	Most disadvantage (lowest 20%)	525	15.7		High risk	12	0.4
	21-40%	505	15.1				
	41-60%	553	16.5				
	61-80%	744	22.2				
	Least disadvantage (81-100%)	1,022	30.5				

^Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Information provided for completeness only.

Other demographic characteristics of the sample are shown in Table 1. Thirty-seven participants identified as being a First Nations person and while most (n=17) lived in NSW, First Nations respondents came from all states except SA and the NT. Similar to the broader Australian population, most participants lived in metropolitan cities and spoke English at home. Of those speaking a language other than English at home, a broad range of other languages were spoken including: Mandarin (n=7), French (n=5), Spanish (n=5) Greek (n=4), Cantonese (n=4), languages of the Philippines (n=6), Dutch (n=3), and Afrikaans (n=3).

Women from areas that were the least socio-economically disadvantaged were over-represented in the sample while those in the three lowest economic disadvantaged quintiles were under-represented. While the over-representation may reflect the BCNA membership or the greater use of breast reconstruction by women from higher socio-economic groups, we note it is in line with greater incidence of breast cancer among women from higher socio-economic groups and the slight survival advantages for women from higher socio-economic groups compared to women with more social disadvantage.[24]

Table 1 also shows breast cancer characteristics of survey participants. Most women were diagnosed with early breast cancer (63%) and had had a mastectomy (77%) as part of their breast cancer treatment. As the proportion of women treated for breast cancer by mastectomy in Australia has been between 40-50% for the past 10 years,[1, 4] there is an over-representation of women having mastectomy in the sample compared to what might be expected among the population of breast cancer survivors. The high proportion of women treated by mastectomy in the study reflects that breast reconstruction is most commonly an issue for this group of women.

Time since diagnosis ranged from less than 12 months to over 10 years. While the majority were diagnosed within the past 3 years (57%), 18% were between 5-10 years post diagnosis and 12% were more than 10 years post diagnosis. The analyses reported here includes experiences of all women regardless of when they were diagnosed. This decision recognises that delayed reconstruction can occur several years after diagnosis[8] and may be delayed by women needing time to recover from breast cancer treatment, needing time to decide to have reconstruction, and long waiting times for the procedure in some public hospitals. However, we note that time since diagnosis and the procedure may influence recall of the events, and that procedures, costs, and waiting times may change over time. The impact of time since diagnoses on some experiences is examined in Appendix 1.

RESULTS

Table 2 shows the breast reconstruction stage of participants according to their residential state. Of all 3,350 participants, 59% had decided to have reconstruction with 41% (N=1364) having completed their breast reconstruction, 10% (n=326) in the process of having their breast/s reconstructed, and 9% (N=295) planning to have reconstruction. While 28% (n=936) of participants had decided not to have reconstruction, 13% (n=428) were currently undecided. Of the 28% of participants deciding against breast reconstruction, 66% were women reporting having a mastectomy.

Information about residential state was missing for 133 participants. Among those with information about their residential state, there were some differences in whether women decided to have reconstruction surgery, with a greater proportion of women from Victoria, WA and Tasmania having or planning to have reconstruction than found in other states and territories ($p<.01$). While the finding that breast reconstruction was more common in survey participants from Victoria, Tasmania and WA reflects the top three states for immediate breast reconstruction following mastectomy as reported in the 2018 ANZ quality audit[1], as there is no data currently available relating to the prevalence of breast reconstruction in Australian women with breast cancer, further comparison to confirm representativeness or otherwise is not possible.

> *"Excellent result and 10 years later have not had any issues. Breasts are relatively scar free, are symmetrical and apart from not having nipple reconstruction, look pretty good.*

Table 2: Breast reconstruction decision stage (percent by state/territory)^

Reconstruction stage	NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
(n)	**(873)**	**(831)**	**(383)**	**(682)**	**(274)**	**(80)**	**(76)**	**(18)**	**(3,217)**
	%	%	%	%	%	%	%	%	%
Plan to have and on waiting list	3.4	4.8	5.5	7.8	6.2	7.5	3.9	11.1	5.3
Plan to have and waiting for treatment to finish	3.2	3.2	3.4	4.4	4.0	2.5	2.6	5.6	3.5
In the process of having breast reconstruction	8.1	12.5	9.7	8.7	10.2	11.3	3.9	0.0	9.7
Have completed breast reconstruction	43.0	43.9	47.0	32.3	37.6	42.5	43.4	38.9	40.9
Decided to have reconstruction	**57.7**	**64.5**	**65.5**	**53.1**	**58.0**	**63.7**	**53.9**	**55.6**	**59.5**
Still deciding	12.5	10.3	8.6	17.3	17.5	13.8	7.9	22.2	12.9
Decided not to have reconstruction	29.8	25.2	25.8	29.6	24.5	22.5	38.2	22.2	27.6

^Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Information provided for completeness only.

The proportions having completed, in the process of, or planning to have breast reconstruction were combined to indicate a group of women who had decided to have breast reconstruction. Table 3 shows this proportion deciding to have breast reconstruction in each of the demographic and breast cancer groups reported in Table 1.

Similar to previous studies,[6, 7] there was an inverse association between age and reconstruction, with older respondents less likely to indicate they had decided to have a reconstruction (p<.01). Those living in outer/remote/very remote areas were also less likely to indicate they had decided to have a reconstruction than those from metropolitan areas (p<.01). Those residing in more disadvantaged areas were also less likely to report deciding to have breast reconstruction than those residing in the more socio-economically advantaged areas (p<.01). As indicated above, there were some state differences with those living in Queensland and the ACT less likely to report deciding to have reconstruction (p<.01).

With regards to breast cancer characteristics, deciding to have a breast reconstruction was associated with type of breast cancer and was less likely for those with metastatic disease (p<.01), and for those diagnosed in the past 12 months (p<.01).

There was also an association with type of surgery, with breast reconstruction most common for those having mastectomy (p<.01). Table 3 also shows that 23% of women having only a lumpectomy reported having breast reconstruction. Exploration of responses from these women indicated they had had oncoplastic therapeutic mammoplasty to reshape their breast. Following others,[10] oncoplastic surgery has been classified as a type of breast reconstruction surgery for this report.

In multivariate analyses that included demographic and breast cancer characteristics, breast reconstruction was statistically significantly associated with age (p<.01), socio-economic position (p<.01), residential location (p<.01), state (p<.01), and type of surgery (p<.01).

> *I was lucky to be able to finance my reconstruction and am very grateful for that. For women who are not in this position I am dismayed that they have to wait so long in public system particularly those in rural and remote areas as I know that is was a momentous step forward for me in the holistic recovery from breast cancer.*

Approximately 35% of women who had completed their breast reconstruction had this surgery 6 or more years earlier. Impact of time since reconstruction on type of reconstruction, timing of reconstruction, speciality of surgeon in charge of reconstruction, and health system for reconstruction is shown in Appendix 1. While type of reconstruction did not change over time, having reconstruction immediately, having a breast surgeon undertake this surgery, and having this surgery in the public system were more common for more recently treated women. However, it is not clear if these changes reflect practice change, sample selection biases or recall biases.

Influence of health system on type and timing of reconstruction surgery

Given differences in the type and timing of reconstruction surgery between states, we looked to see if this was due to differences in practices between public and private health systems. As shown in Table 5, following the pattern seen in Table 4, autologous reconstruction procedures were more likely to be used in Victoria in both the private and public system (p<.01), while in most other states/territories, implants were more likely to be used in both the private and public systems. The exceptions to this were in SA (P<.05) and WA (p<.05) where women in the public system were more likely to have autologous procedures than women in the private system.

BREAST RECONSTRUCTION EXPERIENCES

Type of Reconstruction

Women who had completed their breast reconstruction, were in the process of having reconstruction, or planned to have reconstruction were asked similar questions relating to type of reconstruction, timing of reconstruction, and health sector for the procedure (i.e., public or private). Those having or having completed their procedure were asked further questions about waiting periods, delays, out-of-pocket costs, distance travelled, and the doctor undertaking the procedure. The following section presents information relating to the breast reconstruction experiences of these women, with data combined across groups when questions were similar. Women having a lumpectomy reporting having breast reconstruction are included in these analyses. Data are presented by state to allow identification of any differences.

Table 3: Proportion of women had, having, or planning to have breast reconstruction within each demographic and breast cancer characteristic

Demographic characteristic		Decided to have BR %	Disease characteristic		Decided to have BR %
Total		59.3			
Age	18-39	77.0	**Type of breast cancer***	DCIS/LCIS	66.3
	40-49	71.9		Early breast cancer	57.0
	50-59	64.1		Metastatic	47.0
	60-69	53.4		Not sure	56.5
	70-79	32.2		High risk	80.0
	80+	16.7		Other	54.0
First Nation person	Yes	59.5	**Surgery experience***	Lumpectomy only	22.6
				Lumpectomy then mastectomy	71.2
Language at home	English	59.4		Mastectomy (any including prophylactic)	66.4
	Other language	56.9		No surgery yet	-
State	NSW	57.7	**Treatment**	Chemotherapy	59.8
	Victoria	64.5		Radiotherapy*	50.0
	WA	65.5		Hormone therapy	59.4
	Queensland	53.1			
	SA	58.0			
	Tasmania	63.7			
	ACT	53.9			
	NT	55.6			
Residential location	Major city	63.0	**How long ago diagnosed?**	< 12 months	53.5
	Inner regional	52.1		1-<2 years	60.5
	Outer regional	55.5		2-<3 years	61.2
	Remote/very remote	32.4		3-<4 years	62.1
				4-<5 years	65.4
				5-<10 years	60.6
Socio-economic position (quintiles)	Most disadvantage (lowest 20%)	49.7		10+ years	59.0
	21-40%	52.3			
	41-60%	55.0			
	61-80%	63.4			
	Least disadvantage (81-100%)	65.3			

* Variable statistically significantly related to deciding to have breast reconstruction

Table 4 shows the type of reconstruction and timing of the reconstruction surgery by residential state for women who had had, were having, or were planning to have reconstruction.

Roughly similar proportions of women indicated they were having/had had implants (44%) or an autologous (own tissue) reconstruction (41%), with 7% indicating they had had or were having a combination of implants and own tissue. Nipple reconstruction was undertaken for 33% of women. Residential state was associated with type of reconstruction (p<.01) and with nipple reconstruction (p<.01), with women from Victoria more likely to report having autologous reconstruction and nipple reconstruction than women from other states.

While socio-economic position was not statistically associated with having implants, residential location was associated with having implants (p<.05), with women from outer regional, remote and very remote locations more likely to have implants (52%) than those from metropolitan or inner regional areas (43%). Nipple reconstruction was not associated with socio-economic position or residential location.

> *...I live in an area where there is only one plastic surgeon who will perform a DIEP flap which gave me no opportunity to `shop around' for the best surgeon.*

Table 4: Type of breast reconstruction by state/territory^

Reconstruction stage	NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
(n)	**(504)**	**(536)**	**(251)**	**(362)**	**(159)**	**(51)**	**(41)**	**(10)**	**(1,914)**
	%	%	%	%	%	%	%	%	%
Type of reconstruction									
Implant	52.2	31.0	43.4	48.6	43.4	66.7	63.4	30.0	44.2
Own tissue	34.7	57.8	37.1	37.6	27.7	13.7	17.1	70.0	40.7
Combination of implant and tissue	5.6	3.9	13.5	3.0	17.6	11.8	9.8	0.0	6.9
Nipple reconstruction^	28.8	41.4	33.5	24.5	38.3	34.0	18.9	20.0	32.8
Timing of reconstruction procedure									
Immediate	45.8	57.3	47.4	32.3	29.6	25.5	61.0	20.0	45.0
Delayed	27.8	20.7	27.9	41.4	50.3	49.0	17.1	70.0	30.8
Staged	22.8	19.2	22.3	22.1	16.4	25.5	14.6	10.0	20.9
Health care system reconstruction conducted in									
Private	64.9	57.3	62.2	60.5	67.3	70.6	63.4	70.0	61.9
Public	31.3	40.9	34.7	36.5	32.1	29.4	34.1	20.0	35.4
Doctor reported as performing reconstruction^^									
(n)	**(419)**	**(442)**	**(215)**	**(266)**	**(126)**	**(43)**	**(34)#**	**(7)**	**(1,552)**
Breast surgeon	40.3	11.3	28.8	27.4	27.8	4.7	55.9	0.0	26.4
Plastic surgeon	56.3	87.3	68.4	70.3	65.9	90.7	17.6	100.0	70.3
General	1.4	0.0	0.9	1.1	1.6	0.0	17.6	0.0	1.2

^ Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Percentages when sample size is less than 10 are in light blue to indicate additional caution is needed. Information provided for completeness only. If the sample size is ≤ 4, percentages are not reported.
^^Only those having a mastectomy and have completed or in process of having breast reconstruction. # 9% listed as other not shown here.

While 45% of all women having reconstruction indicated this process started immediately (that is at the time of their breast cancer surgery), for 31% reconstruction started after treatment completion, while 21% indicated reconstruction was staged. Timing of reconstruction surgery was related to state/territory, with more women from Victoria and the ACT indicating the process started immediately (p<.01). Women having immediate reconstruction were less likely to have chemotherapy (p<.01) or radiotherapy (p<.01). However we note that 30% of women having immediate reconstruction reported having radiotherapy and 46% reported chemotherapy. Having immediate reconstruction was associated with socio-economic position (p<.01) and residential location (p<.01). Women from the least disadvantaged areas were more likely to report immediate reconstruction (52%) than those from the most disadvantaged areas (36%), while women residing in metropolitan areas (47%) were more likely to report immediate reconstruction than those living in remote/very remote areas (27%).

> *I think it should be discussed at diagnosis. I read about immediate reconstruction but it was never something that was even discussed or offered as an option, if everything could have been done together I may have been more inclined to do it.*

Most commonly, women had their reconstruction surgery or planned to have this surgery in the private system, with only 35% using the public system. The proportion having reconstruction surgery in the private system was similar for those having immediate (68%) or delayed (72%) reconstruction. While there were some differences between states in the proportion of women having the surgery in the public system, these were not statistically significant. Residential location was statistically related to having reconstruction in the public system, with this more likely for women residing in outer regional, remote or very remote areas (44%) than for women in metropolitan areas (33%) (p<.001). Socio-economic position was also statistically related to reconstruction in the public system, with this more likely for women residing in the most disadvantaged areas (42%) than for those in the least disadvantaged areas (24%) (p<.001).

> *...I elected to have the surgery as a private patient as otherwise I was told I could be waiting for 18 months with the expander in for the implant surgery.*

Table 5: Type of reconstruction procedure by state by private and public health system^

		NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
		%	%	%	%	%	%	%	%	%
(n)	Private	(327)	(307)	(156)	(219)	(107)	(36)	(26)	(7)	(1,185)
	Public	(158)	(219)	(87)	(132)	(51)	(15)	(14)	(2)	(678)
Type of reconstruction										
Implant	Private	54.4	41.0	48.7	57.1	52.3	66.7	65.4	42.9	51.1
	Public	51.3	17.4	35.6	37.1	25.5	66.7	64.3	-	34.1
Own Tissue	Private	35.8	51.5	29.5	36.5	22.4	11.1	23.1	57.1	37.0
	Public	32.3	67.1	51.7	40.9	39.2	20.0	7.1	-	47.6
Timing of reconstruction										
(n)	Private	(320)	(303)	(154)	(216)	(105)	(36)	(26)	(7)	(1167)
	Public	(149)	(210)	(85)	(123)	(47)	(15)	(12)	(2)	(643)
Immediate	Private	48.6	59.0	51.3	36.1	35.5	27.8	65.4	14.3	47.7
	Public	44.3	56.2	44.8	28.0	15.7	20.0	57.1	-	42.6

^Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Proportions calculated when sample size is under 10 are shown in light blue to indicate the low sample size. Information provided for completeness only. Proportions not reported when n ≤ 4

Women who had had a mastectomy and had either completed their reconstruction surgery or were still in the process were asked to indicate the type of doctor performing their reconstruction. Overall, reconstruction surgery was mainly performed by plastic surgeons (70%). However, reporting the involvement of plastic surgeons differed by state (p<.01), with women in Victoria (87%) and Tasmania (91%) more likely to report a plastic surgeon performed their reconstruction. There was an association between type of reconstruction (e.g. implant or autologous) and type of doctor performing the procedure, with plastic surgeons more likely to be involved when an autologous reconstruction was being performed and breast surgeons predominantly involved when implants were used for breast reconstruction. As breast surgeons can work along with plastic surgeons to undertake mastectomy and reconstruction procedures, the differential reporting of plastic surgeon involvement in reconstruction across the states may reflect differential awareness of doctors involved in this surgery by women in the study. Data from an audit of medical records that record the doctors involved in a woman's breast reconstruction procedures is needed to confirm the state differences in plastic surgeon involvement suggested here.

> *Access to qualified and experienced surgeons is very important. Even though I live in a rural area, I was fortunate to have access to a wonderful surgeon who supported me through the two operations that I needed.*

Approximately 35% of women who had completed their breast reconstruction had this surgery 6 or more years previously. Impact of time since reconstruction on type of reconstruction, timing of reconstruction, speciality of surgeon in charge of reconstruction, and health system for reconstruction is shown in Appendix 1. While type of reconstruction did not change over time, having reconstruction immediately, having a breast surgeon undertake this surgery, and having this surgery in the public system were more common in for more recently treated women. However, it is not clear if these changes reflect practice change, sample selection biases or recall biases.

Influence of health system on type and timing of reconstruction surgery

Given differences in the type and timing of reconstruction surgery between states we looked to see if this was due to differences in practices between public and private health systems. As shown in Table 5, following the pattern seen in Table 4, autologous reconstruction procedures were more likely to be used in Victoria in both the private and public system (p<.01), while in most other states/territories, implants were more likely to be used in both the private and public systems. The exceptions to this were in SA (P<.05) and WA (p<.05), where women in the public system were more likely to have autologous procedures than women in the private system.

> *Publicly, the wait times between each stage is ridiculous. The process should be regarded as a whole by hospitals/surgeons, not as individual operations.*

While the proportion of women having an immediate reconstruction in the private and public systems differed between states, except for SA, within each state having an immediate reconstruction did not differ between the public and private sector. In SA, women were less likely to have immediate reconstruction in the public sector (16%) compared to the private sector (36%) (p<.01).

Waiting times for surgery

Of all women having delayed reconstruction (completed or ongoing) after mastectomy (n=619), 20% indicated they had been placed on a waiting list for the procedure. While state was not associated with being on a waiting list for this group of respondents, health system was, with the majority of respondents on a waiting list managed in the public system (90%) (p<.05).

All women having delayed reconstruction who waited for this procedure were provided with the opportunity to provide comments about their delay. Forty-seven respondents provided some comments regarding waiting times, with most comments explaining that the respondent moved from the public to the private system to reduce the time they had to wait for their reconstruction:

> *Waited on the public waiting list, after my original implant surgery date was cancelled, despite there being a clear problem with the tissue expander. Went privately to have the implant inserted.*

> *Went private, as I was not due to be seen in the public system for the first consult for another 12 months, which would mean almost four years wait, just for first consult.*

However, several respondents indicated that they managed to have their reconstruction surgery in the public system quite quickly due to cancellations or other factors.

A small number of respondents provided a comment about the negative emotional impact long waits for the procedure had on them.

For women having delayed reconstruction (completed or ongoing) after mastectomy in the public system (n=150) regardless of time since their procedure, 72% reported they had to wait for this procedure.

Table 6 shows the length of time women who were currently having or had completed delayed reconstruction after mastectomy in the public system, waited for this procedure. To ensure experiences were relatively recent, data in Table 6 are from women who completed their reconstruction within the previous 3 years (n=66). Of these women, around 76% indicated they went onto a waitlist. Due to the small number of respondents in this set of analyses, results are not reported by state.

Only 3% of women having had or completing their delayed reconstruction after mastectomy in the previous 3 years in the private system indicated they had to wait for this procedure.

Just over one quarter of the women having delayed reconstruction after mastectomy in the public system indicated they waited for more than 12 months for this procedure. Sixty-one percent of women waiting for the procedure indicated they had some contact about their waiting times from the health service.

> *I have been waiting for my breast reconstruction now since March last year and called my breast nurse at RAH a few weeks ago and was told that I need to wait 500 days since I spoke to the surgeon. Then I was told that the surgery could go ahead at the end of this year or early next year. I was so disappointed as I have been anxiously waiting every day for the mail hoping that THE LETTER may be in my letter box.*

Table 6: Experiences of waiting for breast reconstruction surgery for women having delayed reconstruction after mastectomy in the public system still undergoing of completing reconstruction in the previous 3 years

	Total
	%
(n)	(66)
Yes	
Did you go onto a waiting list: Yes	75.8
Number of respondents reporting they had to wait	(50)
How long did you have to wait?	
<6 months	37.4
7-12 months	35.3
1+ years	27.4
Did you receive communication about the wait?	
Yes	60.8

Of women still undergoing their delayed reconstruction or who had completed reconstruction in the previous 12 months (n=24), 13 (54%) indicated that COVID-19 delayed their procedure.

> *I was diagnosed with breast cancer when I was 78 years of age, I am now 80. My breast reconstruction was to be performed at the same time as my mastectomy. Due to the Co-vid virus it did not happen. I am still waiting and this has been an extremely stressful and disappointing time of my life. Every time I have an appointment at the hospital it amounts to nothing positive being done in the reconstructive area. This results in me coming home filled with major disappointment my hopes shattered, as usual.*

Influence of COVID-19 pandemic on experience of delays

A total of 68 women indicated that the COVID-19 pandemic caused some delay to their reconstruction, with 28% having delayed reconstruction procedures, 29% having a staged reconstruction and 43% reporting that they had immediate reconstruction. Of those having immediate reconstruction, most reported the delays were associated with subsequent surgeries relating to replacement of implants, or subsequent surgeries needed to complete reconstruction satisfactorily. All respondents whose surgery was delayed due to the COVID-19 pandemic were asked to indicate what impact this delay had, with 61 providing an open text response. The most common impact was an increase in negative emotions including anxiety, depression and stress (n=20) associated with living with uncertainty regarding when their surgery may happen, dissatisfaction with the impact to their body, and having to live with the reminder of their cancer for longer. The next most common impact was women reporting that the delay prevented them from moving on from their cancer (n=15). Seven respondents mentioned disappointment with the delay and four indicated that the delay meant they needed to change their arrangements relating to work, and other aspects of their day-to-day lives. Five respondents indicated that the delay meant they needed to continue with painful/unformattable tissue expanders.

> *Tissue expanders are such an uncomfortable experience, and the healing process was much more traumatic than I'd expected. I was always scared that something had gone wrong and it was deeply uncomfortable. I was worried about the asymmetry and had no real idea what they were meant to look and feel like. The scar tissue felt strange and no one explained what was scar tissue and what was implant.*

Number of surgeries and time between surgeries

Of all women having a mastectomy and who had completed their breast reconstruction, 31% indicated they only needed 1 surgery for this procedure. Of the 850 women (68%) indicating they had more than 1 surgery, 162 women (19%) indicated there was delay for their subsequent surgery. While there was some variation in the proportions reporting delays across state and territories (from 14% in Tasmania to 23% in Victoria), these differences were not statistically significant.

> *Just frustration really. I feel like my cancer journey was extended by this huge wait time.*

Costs of reconstruction

Women who had their reconstruction surgery in the private system, were currently having reconstruction or planning on having reconstruction in the private system, were asked to provide an estimate of their actual or quoted out-of-pocket costs for the procedure. Across these 3 groups, 301 women provided information about their out-of-pocket costs (23% of those treated privately). Noting the caveats around this data discussed in the Methods, Table 7 shows the average out-of-pockets costs reported, and the median (the amount that captures the costs for 50% of respondents) and interquartile range (IQR: the values that captures 25% and 75% of respondents) for women in each state and territory. On average, across the country, the estimated out-of-pocket costs for having reconstruction in the private sector was $8,285. Median values for out-of-pocket costs were generally less than the average estimates. While for most states, around 25% of respondents providing costs information were captured at around $4,000-$4,625 out-of-pocket, we note this value was less in Victoria with 25% of respondents from this state captured at around $2500 out-of-pocket.

> *It is very expensive. If this had occured a few years earlier, I could not have afforded it. I know it is big surgery but does make a difference to your overall recovery.*

Table 7: Average and median estimated out-of-pocket costs for having reconstruction surgery in the private system by state for those treated in the private system^.

	NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
(n)	(91)	(71)	(37)	(56)	(21)	(9)	(8)	(3)	(301)
For those treated in the private system									
Mean	$8,166	$7905	$8,638	$8,260	$6,859	$12,500	$11,338	-	$8,285
Median (IQR)	$6,593 ($4,000, $10,000)	$6200 ($2,500, $11,000)	$8,000 ($4,250, $12,500)	$7,500 ($4,625, $10,000)	$7,000 ($4,000, $10,000)	$10000 ($4,500, $19,000)	$8,600 ($5,375, $13,750)	-	$7,000. ($4,000, $10,000)

^Note small n sizes for some cells in this table. Means reported when the sample is under 10 should be treated with caution and are shown in light blue in Table. Information provided for completeness only. IQR interquartile range represents the value capturing 25% and 75% of the sample. If the sample size is ≤ 4, data not reported.

Table 8 shows the proportion of respondents with different levels of out-of-pocket costs for those receiving treatment in the private system. The table shows that more than 50% of respondents estimated they were more than $5,000 out-of-pocket, with 10% indicating they would be more than $15,000 out-of-pocket.

Table 8: For those indicating their out-of-pocket costs for reconstruction in the private health care system, proportion of respondents indicating different levels of costs

	Those treated in the private system %
(n)	(301)
≤$1,000	8.3
$1,001-$2,000	8.0
$2,001-$5,000	23.3
$5,001-$10,000	37.2
$10,001-$15,000	13.0
More than $15,000	10.3

Distance travelled

Women who had completed their breast reconstruction or were still having breast reconstruction indicated the approximate number of kilometres travelled one way for these procedures. Across the country, the average number of kilometres travelled one way was 89.5 km with a median of 20 km (Table 9).

There was a statistically significant effect of state on distance travelled, with higher average distances travelled in Tasmania and Queensland compared to Victoria (p<.01).

The median number of kilometres travelled one way was substantially less than the average, with 50% of women in each state and the ACT travelling less than 20 kilometres for their reconstruction procedures. The lower median compared to the average for distance travelled suggests that some women need to travel substantial distances to have their reconstruction procedures.

All states and territories in Australia provide a scheme to assist with the costs of travel to specialist medical treatments for people living in rural/remote areas. While details of the schemes can differ between states and territories, they all provide at least some funding to assist with costs associated with public or private transportation to a treatment centre. Criteria for eligibility can include type of treatment accessed, treatment centre, and distance travelled, with most jurisdictions having a distance threshold for people to be eligible for these schemes (Table 10).

All respondents were asked if they accessed their jurisdiction's travel subsidy program to assist with the costs associated with travelling for their reconstruction surgery. Of all respondents, only 6% accessed the scheme with 2% reporting that the subsidy covered only part of their costs. As access to the scheme is based on distance travelled in many states, we examined whether access was greater for those living further away from their treatment centre. Of respondents living between 101 and 200 km (meets distance criteria in all states except NT), 22% received some money from the travel subsidy scheme in their state, with 44% of those living more than 200 km away accessing some money through this scheme. The proportion reporting that they had to travel the eligibility distance for treatment accessing the scheme in each state/territory is shown in Table 10. Access was greatest for SA residents and lowest for NT (0%) and NSW residents (23%).

Satisfaction with reconstruction decision

Women who had completed their reconstruction or were still having reconstruction were asked how satisfied they were with this decision using a 5-point rating scale ranging from (1) very unsatisfied to (5) very satisfied. While most women were satisfied with their decision, women who had completed their reconstruction were more likely to be satisfied (86%) than those still undergoing reconstruction (76%) (p<.01) (Table 11). In univariate analyses, satisfaction was related to type of reconstruction with those having implants slightly less likely to be satisfied (mean=4.2) than those not having implants (mean=4.4) (p<.01). Whether the procedure started immediately or not was not related to satisfaction. Satisfaction was inversely associated with socio-economic position and age but was not related to residential location or whether the reconstruction happened in the public or private setting. In multivariate analyses that included type of reconstruction (implant or not), timing of reconstruction (immediate or delayed), age, socio-economic disadvantage, residential location, and whether the surgery was in the public or private system, satisfaction was only related to type of reconstruction and was lower for those having implants.

Most women who had completed their reconstruction surgery were very satisfied (44%) or satisfied (34%) with the result. The key factor associated with satisfaction in multivariate analyses was whether an implant had been used, with lower levels of satisfaction found for women having an implant (3.9) compared to 4.3 for those not having an implant (p<.01).

Table 9: For women who had completed or were having breast reconstruction, the average and median distance travelled one way for these procedures (in kilometres) and the proportions accessing their state's patient travel subsidy schemes, by state

	NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
(n)	(424)	(441)	(200)	(254)	(125)	(40)	(32)	(7)	(1523)
How far did you travel?									
Km (mean)	72.3	46.3	68.3	133.3	88.9	138.8	82.2	2,640.0	89.5
Km (median) (IQR^)	18.9 (10,50)	15.0 (10,35)	20.0 (10,50)	20.0 (10,50)	20 (10,38.5)	17.5 (10, 187.5)	20.0 (9.2,178.0)	3,000.0 (1500, 3,000)	20.0 (10,45)
Distance travelled in kilometres (km) to hospital categories.									
	%	%	%	%	%	%	%	%	%
≤10 km	36.1	39.0	26.5	26.4	35.2	42.5	34.4	0.0	33.9
11-20 km	21.9	23.4	25.0	28.7	25.6	12.5	34.4	14.3	24.2
21-50 km	17.5	20.6	28.0	24.4	22.4	12.5	6.3	0.0	20.9
51-100 km	8.0	6.3	5.0	4.7	4.0	5.0	0.0	0.0	6.0
101-200 km	7.5	4.3	5.0	4.3	2.4	5.0	0.0	0.0	5.1
201+ km	9.0	6.3	10.5	11.4	10.4	22.5	25.0	85.7	10.0
Accessed state-based patient travel subsidy scheme.									
(n)	(446)	(469)	(217)	(279)	(131)	(43)	(36)	(7)	(1628)
	%	%	%	%	%	%	%	%	%
Didn't know about it	33.2	31.1	21.2	37.6	15.3	34.9	27.8	14.3	30.2
Didn't need it	56.7	60.3	65.9	50.5	72.5	48.8	63.9	28.6	59.0
Yes but not successful	0.0	0.0	0.0	0.0	0.0	0.0	0.0	14.3	0.1
Yes covered all/most costs	2.9	2.1	5.5	3.9	4.6	2.3	0.0	0.0	3.3
Yes but still had gaps	1.3	2.3	1.8	3.2	3.1	7.0	0.0	0.0	2.3
Didn't think scheme existed in state	0.0	0.0	0.0	0.0	0.0	2.3	2.8	28.6	0.2

^ IQR interquartile range represents the value capturing 25% and 75% of the sample.
Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Percentages when sample size is less than 10 are in light blue to indicate additional caution is needed. Information provided for completeness only. If the sample size is ≤ 4, percentages are not reported.

Table 10: Distance needed to travel (one way) to specialist medical care as part of the eligibility criteria for accessing transport subsidy schemes in different states and territories

State	Distance (one way, one trip) to specialist cancer treatment	Percentage of sample having breast reconstruction that travelled further than eligibility distance %	Percentage meeting travelling eligibility distance for each state/territory accessing travel assistance scheme %
ACT	Not specified. Need to travel outside ACT for treatment	-	-
NSW	100 km	17 (n=70)	23
Victoria	100 km	11 (n=47)	43
WA	100 km (70 km for oncology and renal treatment centre)	16 (n=31)	48
Queensland	50 km	20 (n=52)	36
SA	100 km	13 (n=16)	63
Tasmania	75km (50 km for oncology or dialysis treatment centre)	35 (n=13) (for 50km)	31
Northern Territory	200 km	85 (n=6)	0

^Note small n sizes for some cells in this table. Means reported when the sample is under 10 should be treated with caution and are shown in light blue in Table. Information provided for completeness only. IQR interquartile range represents the value capturing 25% and 75% of the sample. If the sample size is ≤ 4, data not reported.

An open-ended question asked those women dissatisfied with the outcome of surgery why this was, with 115 women providing a response. The main reason for dissatisfaction related to cosmetic appearance, with women indicating there was asymmetry in their breasts due to different size, height, and nipple placement, with scar tissue, rippling, and implant movement also contributing to these concerns. Some women commented how the different look and feel of their breasts made them feel self-conscious and prevented them from wearing certain clothes and engaging if some activities (e.g., bathers). Some women experienced ongoing pain or tightness associated with their implants and this caused them dissatisfaction. The experience of complications, including multiple surgeries, replacement of implants, length of time it took for the procedure, and experience with infection, contributed to some women's dissatisfaction.

> *My right breast is twice as large as my left breast. I feel very self-conscious about this and have lost a lot of confidence.*

> *The Plastic Surgeon set too high expectations for me by saying that my new breasts would be better than what I had. The world was my oyster!*

> *I am physically uncomfortable with the reconstruction and was very disappointed by the appearance which was not properly communicated to me. The doctor corrected the surgery after I lodged a complaint. … Breasts are also a significantly different shape to those available in the catalogue. I am ashamed of the appearance when I have never had any sense of body dissatisfaction previously. So basically, they look stupid and they hurt.*

Key comments from women who were very satisfied with the outcomes from their reconstruction reflected regaining confidence and self-esteem and that it, "changed my life", or, "It has made me feel whole again and able to wear clothes /swimwear/ lingerie without worry. Given back my body image confidence". Satisfaction with the decision was often related to satisfaction with the outcome. Comments related to outcome satisfaction frequently mentioned the look of the breast and psychological benefits obtained.

> *I don't have to be reminded that I have lost a breast every day after shower prior to having a reconstruction.*

Table 11: Satisfaction with decision to have breast reconstruction for those having breast reconstruction or who had completed their reconstruction, and satisfaction with outcome of reconstruction surgery for those who had completed surgery

State		Having reconstruction %	Completed reconstruction %	Total %
Decision	Very unsatisfied	1.8	2.0	2.0
	Unsatisfied	4.0	4.0	4.0
	Not sure	18.4	7.8	9.9
	Satisfied	34.0	29.8	30.7
	Very satisfied	41.7	56.3	53.5
	Mean	Mean=4.1	Mean=4.3	Mean=4.3
Outcome^			36	
	Very unsatisfied	-	3.0	
	Unsatisfied	-	7.1	
	Not sure	-	11.9	
	Satisfied	-	33.9	
	Very satisfied	-	44.1	
	Mean	-	Mean=4.1	

^ Satisfaction with outcome was only asked of those women who had finished their reconstruction surgery.

> *Physically and psychologically, it helped me move forward with my life and feel more normal. Prosthetics are very hot and uncomfortable in summer and I was very self-conscious wearing summer clothes or a bathing costume.*

Planning to have reconstruction

A total of 258 women who had had a mastectomy indicated they were planning to have breast reconstruction (on a waiting list: n=161; waiting for treatment to end: n=97). Women who had had a mastectomy and were planning to have reconstruction were more likely to be within 1 year of their diagnosis (43%) compared to other women who had had a mastectomy in the study (20%) ($p<.01$). As Table 12 shows, most women planning to have reconstruction after their mastectomy were having this surgery in the public system (57%). The waiting experiences of women planning to have reconstruction are also shown in Table 12. Forty-six percent of women planning to have a reconstruction indicated they were on a waiting list, which was more commonly reported for those intending to have reconstruction in the public system (66%) than for those intending to be treated in the private system (14%). Of those on a waiting list, 11% had been waiting less than 1 month, 11% 1-3 months, and 16% 4-6 months. However, 26% indicated they had been waiting for between 1-2 years, with another 17% waiting for over 2 years.

Of those indicating they were waiting for their reconstruction surgery, 63% were told there would be a wait, with 3% told the wait would be less than 1 month, 10% told 1-3 months, 10% told 4-6 months, 30% told 7-12 months, 37% told 1-2 years, and 12% were told the wait would be more than 2 years. Of these women, 15 (20%) indicated they had been waiting longer than what they had been told.

Thirty women who were waiting for their reconstruction provided some comments about their wait. While eight women indicated their wait times or when they were scheduled for the procedure, two indicated that due to the waiting times at public hospitals they have elected to go privately for the procedure, and two indicated that they needed to lose weight before they could have the procedure. The remaining women provided comments that reflected frustration with the system and the reasons for their delays and/or the impact on their emotional state that waiting has caused.

Table 12: Proportion of women who were planning to have reconstruction indicating they were having reconstruction in the public or private system#, and percent on a wait list regardless of health system by state^

	NSW	VIC	WA	QLD	SA	TAS	ACT	NT	Total
	%	%	%	%	%	%	%	%	%
(n)	(47)	(55)	(33)	(76)	(23)	(7)	(5)	(2)	(248)
Private	25.5	20.0	30.3	30.3	47.8	14.3	40.0	-	28.6
Public	48.9	70.9	51.5	56.6	47.8	85.7	40.0	-	56.9
% on waiting list	29.8	54.5	50.0	52.6	39.1	42.9	20.0	-	45.8

36 respondents were not sure what health system they would have their breast reconstruction in. They are included in the N for each state but this proportion is not shown in the table. Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Percentages when sample size is less than 10 are in light blue to indicate additional caution is needed. Information provided for completeness only. If the sample size is ≤ 4, percentages are not reported.

> *I feel that I have been kept waiting far too long, I am very self-conscious of my body.*

> *The waiting is the hard part. The not knowing when. My life seems to be on hold.*

Forty-six women, including nine indicating they would be having their reconstruction surgery in the public system and 10 who were unsure where they would be having their surgery, indicated they had been provided with an estimate of the out-of-pocket costs they might have if they had the procedure privately. Quotes ranged from $900 to $40,000, with 21 (50% of those reporting out-of-pocket costs) indicating their out-of-pocket costs would be over $15,000.

Women who decided not to have breast reconstruction or were still undecided

Nine-hundred and fourteen women who had had a mastectomy indicated they had either decided not to have reconstruction surgery (n=612) or were still undecided about this option (n=302). Table 13 shows that the demographic characteristics of these women were generally similar to those for the total sample.

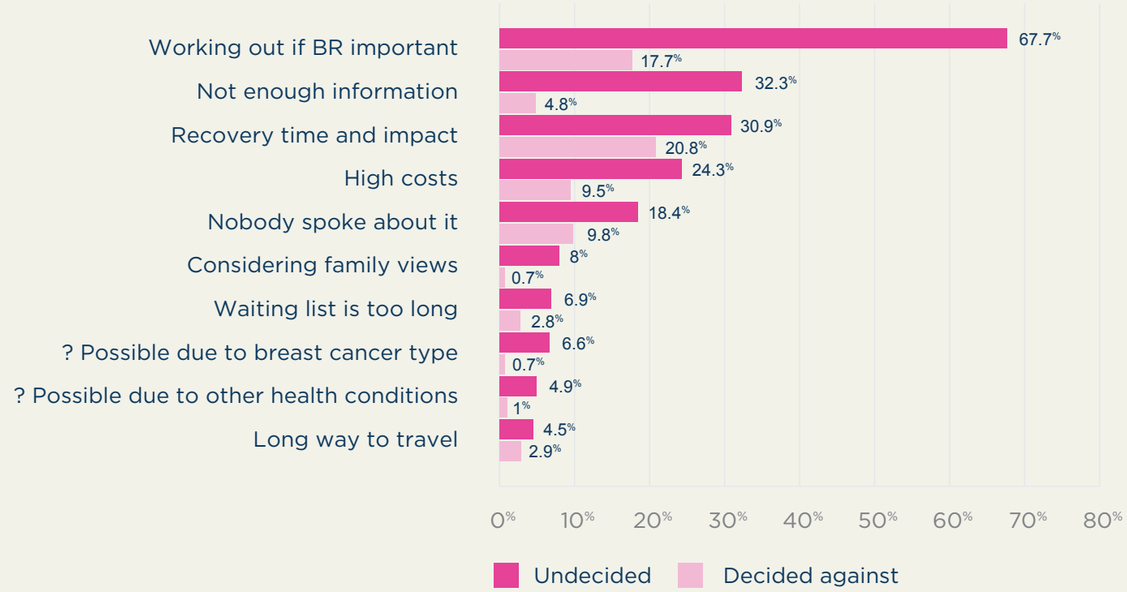
The type of breast cancer was generally similar across the groups. A greater proportion of women who were still deciding about breast reconstruction were within 12 months of their diagnosis compared to the whole sample and women who had decided against breast reconstruction.

Respondents were asked to indicate whether a number of different factors influenced their decisions regarding breast reconstruction. The proportion of women who had had a mastectomy indicating each response was important is shown in Figure 3 for those who had decided against reconstruction and those who were undecided.

Issues were more likely to be endorsed by women still deciding about breast reconstruction with fewer women who had made their decision indicating that the different issues were important to them. The factors most commonly endorsed as influencing women still deciding about breast reconstruction were: determining its importance for them (68%), insufficient information (32%), recovery time (31%), and costs (24%). For women who had decided not to have breast reconstruction the most common factors influencing their decisions were: recovery time (21%), importance (18%), costs (10%), and no one speaking to them about it (10%). While the type of breast cancer women may have and the presence of other chronic health conditions including obesity can have a strong influence on clinical assessment regarding suitability of women for breast reconstruction,[12] few women mentioned these factors as influencing their decisions. While work is needed to understand how clinical factors influence women's decision making, the low reporting of these factors here may suggest women are not aware of the potential importance of these factors in reconstruction decisions.

> *After 3 operations in 8 weeks I didn't have the energy for 2 more surgeries and recovery.*

Figure 3: Proportion of women who had decided against reconstruction and those undecided about reconstructing indicating that the different issues were important in their decision making



State of residence was not associated with factors influencing breast reconstruction decisions for either women who had decided not to have reconstruction or those that were still undecided. In the main, socio-economic position did not influence the importance of the different factors to both women deciding not to have breast reconstruction and those still undecided. An exception to this for those that had decided against reconstruction was working out if breast reconstruction was important to them, with more women in the most disadvantaged groups indicating this (see Appendix 2 for details on associations with socio-economic position).

Residential location seemed to play more of a role in influencing the importance of some factors in those deciding not to have reconstruction. For those that had decided against reconstruction, women from outer regional/remote/very remote areas were more likely to indicate that they did not receive enough information, waiting lists were too long, and the distance travelled were important in their decisions compared to women living in metropolitan areas (see Appendix 2 for more details). Women from outer regional/remote areas were also more likely to indicate that they were still working out the importance of reconstruction to them.

As around two thirds of women who were undecided about reconstruction indicated they were still determining whether reconstruction was important to them, we examined whether the other factors shown in Figure 3 were influencing considerations of importance. Regression analyses found that concerns regarding the time needed for recovery and views of family members were key considerations in determining the importance of reconstruction for this group of women.

Women undecided about breast reconstruction who indicated costs, distance, or waiting times were influencing this position, were asked to specify the sort of costs, distance, and waiting times they were experiencing. Of the 23 women indicating waiting times, 35% (n=8) were not sure what the waiting times were but thought they could be substantial, with 6 (26%) indicating waits of less than 12 months, and 6 indicating waits of more than 2 years. In relation to distance, of the 17 women answering this question, 8 (47%) indicated they would have to travel over 500 km, including 3 indicating they would have to travel more than 1,000 km. Two women indicated they would have to travel less than 100km. Of the 66 undecided women indicating costs were influencing their decisions, 27 (41%) were not sure of the costs, 14 (21%) thought out-of-pockets costs would be under $10,000, 12 (18%) thought their costs would be between $10,000 and $20,000 while 13 indicated costs would be over $20,000.

Of the women deciding not to have breast reconstruction, 4 thought the wait would be up to 3 years, and 6 thought it would be more than 3 years,

Table 13: Demographic characteristics of women who decided not to have breast reconstruction or are still undecided compared to the demographic characteristics of the total sample

		Not having reconstruction			Total sample
Characteristic		Undecided %	Decided Against %	Total %	%
	(n)	(302)	(612)	(914)	23
Age	18-29	0.3	0.0	0.1	0.4
	30-39	6.0	2.0	3.3	5.6
	40-49	16.8	10.1	12.3	18.1
	50-59	35.9	27.4	30.2	33.1
	60-69	31.5	31.7	31.7	26.7
	70-79	8.1	25.6	19.8	10.2
	80+	1.3	3.0	2.4	0.9
State^	NSW	23.8	30.0	28.0	27.1
	Victoria	18.8	21.4	20.5	25.8
	WA	8.4	11.6	10.5	11.9
	Queensland	31.5	23.2	26.0	21.2
	SA	12.8	7.5	9.2	8.5
	Tasmania	2.3	2.2	2.2	2.5
	ACT	1.3	3.8	3.0	2.4
	NT	1.0	0.3	0.6	0.6
Residential location^^	Metropolitan city	64.1	62.7	63.1	65.0
	Inner regional	26.8	26.0	26.3	18.3
	Outer regional	7.7	9.6	9.0	7.6
	Remote/very remote	1.4	1.7	1.6	1.0
Socio-economic position (quintiles)	Most disadvantage (lowest 20%)	14.9	15.8	15.5	16.5
	21-40%	18.9	18.3	18.5	14.9
	41-60%	19.2	19.4	19.4	16.3
	61-80&	24.8	18.0	20.2	22.0
	Least disadvantage (81-100%)	22.2	28.4	26.4	30.2
Type of breast cancer	DCIS/LCIS	22.8	21.6	22.0	25.4
	Early breast cancer	65.2	63.2	63.9	62.7
	Metastatic	5.0	7.2	6.5	4.8
Treatment	Lumpectomy then Mastectomy	11.6	10.1	10.6	10.0
	Mastectomy only	88.4	89.9	89.4	71.9
When diagnosed	< 12 months	28.9	22.3	24.5	24.9
	1-2 years	20.6	17.1	18.2	19.8
	2-3 years	12.6	9.7	10.7	11.8
	3-4 years	7.0	6.1	6.4	6.4
	4-5 years	9.0	5.7	6.8	7.3
	5-10 years	15.0	22.5	20.0	17.7
	11+ years	7.0	16.6	13.4	11.8

^ 13 respondents had missing data for state and are excluded from analyses.
^^ 46 respondents had missing data for rurality/urban and are excluded from analyses.

with 3 women not knowing how long the wait would be. Regarding costs, of the 53 women providing information about the costs they expected to pay, 17 indicated that they didn't have a quote but had heard it would be expensive, and 14 indicated they were not sure of the costs or didn't investigate it. Seven women reported that the costs would be less than $10,000, 10 indicated a cost of between $10,000-$20,000 and 4 women indicated that their health insurer or Medicare had told them that the procedure was not covered so they didn't investigate further.

For those indicating distance was a factor in their decision, 81% indicated they would have had to travel over 200 km one way, with 6 (29%) travelling between 500-1,000 km and another six travelling over 1,000 km.

Comments from respondents indicating that other factors influenced their decision to not have a reconstruction could be grouped into 4 key factors: not wanting to put their body through further surgery; not wanting to introduce a foreign implant into their body; feeling that at their age it was not needed; and not able to have the surgery due to previous treatment, body size, metastatic disease, or other health conditions.

> *I am not a fan of having the prosthetics in my body, as I have known others who have had their implants recalled.*

> *My age at the time 77 and wasn't interested.*

Several women also reacted to a societal focus on breasts and body image noting that they as they were not defined by their breasts, they did not see the need for reconstruction.

> *I do not feel the need to have a breast shape on my chest. I am looking forward to going flat.*

Recommendations for improving the process of breast reconstruction

At the end of the survey, participants were asked: "Thinking about women who may experience a breast reconstruction in the future, is there anything you think needs to change so that they have a better experience?" with approximately 60% of respondents providing a response to this question. Written responses were analysed and 10 major themes were identified: information; costs; waiting times; access; support; timing of decision; realistic expectations; impacts on/ of treatment; skill level of doctors; and legitimacy of not having a reconstruction. These major themes often included several sub-themes. A number of additional themes were also identified, although these were less commonly mentioned by respondents. Women's comments often covered a range of ideas and and so could be classified into multiple themes.

Information provision

The most commonly identified area for change related to information provision, with approximately 31% of respondents providing a comment indicating this needed to improve. While many women noted the need for women to be informed that breast reconstruction was an option for them, others were more specific in the type of information they wanted improved. Many commenting that information on the different implants, the pros and cons of the different implants and types of procedures, access to the procedure through public hospitals, possible risks and complications, better descriptions of what the process of reconstruction involves, and realistic estimates of recovery time. Comments classified in this theme suggested that many women often felt ill-informed about the nature of the surgery involved in reconstruction, and that they had little awareness of the different types of implants and surgical techniques that could be used. In addition, women thought more information was needed regarding the look and feel of implants, the possibility of infection, and the potential need to replace implants at some point needed to be mentioned.

> *Yes, more information is needed then is given in the hospital brochures. Doctors need to explain more clearly the reality of reconstruction and show examples of women with a natural breast and a reconstructed breast. They need to make it clear that only by doing surgery to the natural breast can they make your reconstructed breast match. They need to discuss the loss of feeling that will occur in any surgery. There needs to be support offered for the changes to women's lives.*

> *More information and guidance through the process, procedures and timelines.*

Costs

Around 16% of respondents commenting made suggestions relating to the costs of the procedures and the need to reduce the costs to ensure greater access to the procedures. Respondents noted the large out-of-pocket costs if having the surgery done in the private sector and the need to reduce these costs to ensure it was affordable to more people. Comments in this theme also included calls for the procedure to be subsidised more through Medicare, with many commenting that the whole procedure should be free. Some women indicated that they felt that breast reconstruction surgery was seen as cosmetic in some areas of the health system. These women were annoyed by this as they saw reconstruction surgery as a continuation of their breast cancer treatment.

> *I think it is outrageous that there is such a huge gap for private patients. You're already hurting from a dent in your career - one that set me back financially, to have to spend more money on something you never wanted to go through is salt in the wound.*

Waiting times

Improvements to waiting times for the surgery in public hospitals was raised by approximately 9% of respondents providing a comment. While many respondents noted the need for shorter waiting times, others noted that the potential for negative impacts on people's mental health through long waiting times.

> *We did not choose this, so having to pay exorbitant amounts, or wait for years, is completely unnecessary, even cruel. We are already dealing with enough.*

Some noted that when their reconstruction was delayed until after their treatment had been completed, they felt this procedure was treated differently from their breast cancer care and there was a perception that the health system did not see it as part of their breast cancer treatment. This perception was often highlighted when women indicated they were placed on general plastic surgery waiting lists. This perception regarding how the health system viewed breast reconstruction surgery contrasted with many women's expressed view that they did not feel their breast cancer treatment was complete or finished until their reconstruction had been completed.

> *Absolutely no delays as reconstruction should be considered an essential part of the treatment for those women who want reconstruction.*

Access

While comments relating to the costs of reconstruction and waiting times for this procedure often touched on issues of access to this procedure, 3% of respondents mentioned access explicitly in their comments. Most commonly, access was mentioned in relation to the need for more local services in regional areas, reducing the need to travel for this procedure. Comments relating to access also reflected a need for better access to a greater range of procedures in the public system, as well as in regional areas. Access was seen as an equity issue and there were comments relating to the need to ensure this procedure was available to all women who needed it, not just to those who could afford it.

> *Better access to reconstruction in the public sector, lower out-of-pocket expenses. And it should be offered to all women who undergo breast surgery (mastectomy).*

Access to rehabilitation services, including physiotherapy, was also mentioned as needing improvement.

Support

Around 6% of comments related to the need for women to be able to access support services, including peer support and counselling services, to help both when making the decision to have or not have reconstruction but also to help women during the procedure. Access to women who have gone through the procedure was seen as a strategy to help women understand the likely outcomes from reconstruction, as well as gaining a better sense of what living through the process would be like. The emotional toll of the reconstruction process and living with a mastectomy while waiting for the reconstruction was recognised in many comments, with women suggesting that access to counselling and support services would help to improve the experience for many.

> *I feel like there needs to be more support for women to be able to access specialised physiotherapy services to help achieve functional skills to whatever level they had prior to surgery. I paid for specialist support because I had the financial means but I recognise this is not possible for everyone.*

> *Being able to speak to peers about their experience really helped. Being informed is the best way to feel like you have autonomy over what happens to your body.*

> *Access to emotional support before, during and after procedures.*

Timing of the decision

Around 6% of respondents made comments relating to the timing of decisions regarding reconstruction. Some women suggested that reconstruction should be seen as part of the mastectomy procedure and should be discussed with women having a mastectomy at this time. However, others noted that this was not an ideal time for these conversations, commenting that the shock of the diagnosis and the need for a mastectomy made it hard for women to consider all their options appropriately. While some women commented that they felt rushed into making the decision, others wanted people to know that they "shouldn't be rushed into making this decision".

> *I felt rushed in my decision making to have mastectomy and reconstruction at the same time. When breast cancer diagnosis is given all the tests etc are brutal and exhausting.*

Those suggesting that reconstruction should be seen as part of the mastectomy commented that this reduced the need for multiple surgeries, and could make it more likely for women to have this surgery especially if it meant they did not go on a waiting list. Others noted a psychological benefit of waking up after surgery and seeing a breast.

> *Better and more clear advice on options for immediate reconstruction. In hindsight I would have preferred that option to avoid a 2 plus year wait.*

Realistic expectations

Approximately 4% of respondents mentioned a need to have realistic expectations relating to both the experience of the procedure and the final outcome of the reconstruction process, including the possibility of asymmetry between the breasts if only one breast was reconstructed. There was a feeling that some surgeons didn't provide women with sufficient information regarding what they could expect in terms of the outcome, and women were often disappointed or shocked when their reconstructed breast did not meet their expectations. Strategies to encourage greater understanding of the likely outcomes after surgery were needed.

> *I think having a realistic picture of what you will look like would have made my decision easier. Also the realisation it couldn't happen in 1 operation was upsetting so having the expectation that this is unlikely would have helped with my anxiety.*

> *It's not as bad as you think it will be but adjust your expectations. It's about making the best of a bad lot. Acceptance is hard but you'll get there.*

Impact on/of treatment

About 1% of respondents noted that there needed to be better information or discussion about the impact of treatment - especially radiotherapy on implants if they were inserted prior to this treatment - and the potential of radiotherapy prohibiting reconstruction at a later timepoint.

> *From my personal experience radiotherapy had changed the treated breast so much that I am not sure I will get what I want even with few follow up surgery. May be having the reconstruction after radiotherapy can be better for the look/feel? Not sure about other impacts.*

Skill levels of doctors

Approximately 2% of respondents made comments relating to the need for doctors to have strong communication and technical skills, the importance of women accessing skilled clinicians, and the difficulty in identifying skill levels of clinicians they may be referred to. While many women commented positively about the skills of their clinicians, others wondered how women should go about identifying appropriately skilled clinicians, suggesting the possibility of a register, a navigator, or other mechanism to assist with this.

> *Better communication skills of the surgeon when it came to explaining options for reconstruction. I was basically handed the Cancer Council booklet at the end of the consultation and at the next consultation asked what option I wanted to go for. Zero discussion of the suitability of the different options, relative advantages etc. I had to ask the surgeon to talk me through the various options. It was like pulling teeth.*

Not having reconstruction

About 2% of respondents noted that there needed to be greater acceptance and promotion of the option to not have reconstruction and that living 'flat chested' was an acceptable alternative for women who have had a double mastectomy and wanted to avoid further surgery. Women making these comments indicated they tended to feel a pressure (both at a societal and medical professional level) to have reconstruction and that their decision was being judged negatively. Women thought that the option to not have reconstruction should be promoted as an acceptable alternative for women.

> *Going flat should be discussed as a viable, reasonable alternative to long, invasive, expensive reconstruction. Women are not, or shouldn't be, defined by their breasts.*

> *I think that for those who have had bilateral mastectomy there should be more advice about the advantages of being flat. I felt judged particularly by the breast cancer nurse because I did not want further surgery or to wear protheses and this did not help my recovery.*

Other issues

A number of other issues arose from the comments, including greater access to double mastectomies when this was called for due to risk of breast cancer or difficulties with getting breast size to match, better follow-up care with women, and changes that can occur to women's bodies with age that can impact on the reconstruction. Better access to nipple reconstruction and tattooing was also highlighted as an area that needed improvement. Some women mentioned that they were told they needed to lose weight before they could have a reconstruction, with several noting that there should be more clinicians able to perform breast reconstruction surgery on women who were overweight.

Some women mentioned the emotional impact of both having breast reconstruction and not having breast reconstruction. While the need for additional support during the process of deciding and then having breast reconstruction, some women mentioned the distress women can experience during this process as something others should be aware of.

> *Surgeons need to be more prepared to operate on women who are overweight. I am overweight and had a very successful outcome. I have heard many stories of women in the public system being denied reconstructive surgery because of their weight.*

DISCUSSION

This study examined the experiences of breast reconstruction in Australian women treated for breast cancer and those at high risk of breast cancer. Enlisting participants through the member list of the national breast cancer consumer organisation Breast Cancer Network Australia, over 3,300 women completed the survey, and 59% had decided to have breast reconstruction. The proportion of women in our study having mastectomy and reconstruction is much higher than that reported in population studies,[6, 7] reflecting the source of participants and the focus of the survey. However, despite the higher rates of breast reconstruction found in our study, our study's finding that reconstruction was more common in younger participants, in participants from metropolitan areas, in those from the least disadvantaged areas in Australia, and in some states and territories, reflects the associations between these socio-economic characteristics and reconstruction rates reported in other studies of Australian women having mastectomy.[4, 6, 7, 25] The survey highlighted differences in the type of reconstruction procedure and the timing of the reconstruction surgery between Australian states/territories, with women from Victoria most likely to report an immediate, autologous reconstruction, while women from other jurisdictions most commonly had delayed or staged implants. While having reconstruction surgery in the public health system was similar across states, time waiting for the procedure in the public system differed, with women from Queensland most likely to report waiting over 12 months compared to women from other states. Reducing the cost of reconstruction, reducing waiting times in public hospitals, and improving the provision and type of information about the different types of procedures were key areas women would like to see improved.

> ***The waiting time for public patients is ridiculous it needs to be a much quicker process as it can affect your mental health.***

Similar to other studies,[5, 6, 25] having breast reconstruction was associated with location of residence and socio-economic status. We found that women in outer regional and remote areas of Australia were less likely to have or plan to have breast reconstruction. Data from our study in relation to women who were undecided about breast reconstruction suggests that clinicians are less likely to raise the topic of breast reconstruction with women from these areas. Women from these areas also indicated that distance was a reason for them not to have breast reconstruction. Others have highlighted the lack of access to quality local expertise, disruptions to family, work and access to emotional support by the need to travel long distances from home to have reconstruction. These, in addition to inadequate financial support for travel, are barriers to women in remote areas of Australia in accessing breast reconstruction.[17, 26]

> ***There is no reconstruction surgery opportunity through the public system where I live...If I remember correctly, I would have to travel to Brisbane if I wanted to have a reconstruction. About 2,000 kms.***

We found that older women were less likely to have breast reconstruction than women under 50. This negative association with age is consistent with previous findings.[4, 6, 7] A systematic review suggested that rates of complications from breast reconstruction did not differ for older (over 60 years) and younger women, and quality of life outcomes post reconstruction are as good or better for older compared to younger women.[27] Responses in open-ended questions in the current study suggested that many older women indicated age as a reason for their decision not to have reconstruction. This reflects findings from other work.[17] Some have suggested that older women are reluctant to undergo this procedure due to fear of complications and desire to avoid more surgery.[17] Comments from our study also suggest that many older women simply do not see a need for reconstruction, especially from the point of view of needing the surgery to maintain their physical or sexual attractiveness. It is important that women of all ages are informed about breast reconstruction options to ensure all women are empowered to make the decision that is most appropriate for them, whether that is to have or not have breast reconstruction.

The majority of women who had decided to have breast reconstruction surgery and those who had had reconstruction were satisfied with this decision and the outcome of the surgery. Implants were associated with less satisfaction with the outcome of the surgery, with comments indicating that factors relating to the cosmetic appearance, implant movement, ongoing pain, and complications from surgery leading to dissatisfaction. Systematic reviews of studies assessing quality of life and patient reported outcomes for women having autologous or implant reconstruction have also found greater breast satisfaction in those

having autologous reconstruction,[28, 29] with satisfaction with the outcome also higher in those having autologous reconstruction procedure.[28] Women in our study who were satisfied with their decision and their outcome noted their increased confidence, regained self-esteem, and that they felt whole again.

Out-of-pocket costs associated with having the procedure in the private system were key concerns for women in our study, with estimates arising from the information provided here that 50% of women had out-of-pocket costs of $7,000 or more. Women noted that costs associated with the procedure threatened equity of access, with many indicating the out-of-pocket costs made them opt for treatment in the public system. Comments made by women in relation to areas that can be improved indicated substantial out-of-pockets costs for procedures were seen negatively by many women who felt 'insulted' about the amounts they were charged given the surgery was needed as a consequence of their cancer treatment.

Women in the current study called for out-of-pocket costs to be reduced. Currently in Australia, there can be substantial out-of-pocket costs for reconstruction surgery for women with breast cancer if procedures are undertaken in the private system, with costs differing by whether a woman has private insurance or not, the type of private insurance, fees charged by doctors, and amounts rebated. In 2008 in the United States the Women's Health Care and Cancer Rights Act mandated that all insurers that cover the costs of mastectomy also cover costs associated with breast reconstruction following mastectomy, with surgery to the contralateral breast to achieve symmetry covered in this Act as well.[11, 30] Currently, delayed breast reconstruction is considered category 3 elective surgery and women requiring this surgery are placed on the elective surgery list of public hospitals. There was also a call by respondents in the survey to reconsider the classification of delayed breast reconstruction in public hospitals. Our study found that about one third of women on public hospital waiting lists waited for over 12 months for breast reconstruction, although small numbers and limitations of our sample suggest this finding needs to be treated cautiously. As reducing the waiting periods for surgery was a key suggestion for improving the experience of breast reconstruction, for women, further work is needed to fully understand the waiting periods for breast reconstruction surgery in public hospitals and how these lists are currently managed.

> ***Consider it a priority for the successful recovery of breast cancer. It shouldn't be a year(s) long waiting list. It is NOT vanity.***

A key finding from this study was that women needed more information about reconstruction to allow them to make informed decisions regarding whether or not have this procedure. There was a strong sense from comments provided in the survey that there was an absence of information about the possibility of having reconstruction, the types of reconstruction available, and the availability of reconstruction in the public system. Others have also found that women report a lack of information about reconstruction when they are discussing treatment options with their clinician.[15] While many resources regarding breast reconstruction exist, the call for more information about this procedure may reflect inadequate awareness of this information for many women. The recently formed Australian Access to Breast Reconstruction Collaborative Group (AABRCG) has recommended that "all patients requiring mastectomy have the opportunity to discuss breast reconstruction with a specialist who has an interest, appropriate training and experience in breast reconstruction, whether this be in-person or via telehealth, prior to mastectomy." [31] Reflecting the information needs of women identified in this study, the AABRCG recommend that through this discussion women receive information that breast reconstruction: does not have a negative impact on survival; can usually be performed safely after post-mastectomy radiotherapy, and is available through both the public and the private health systems.[31] The *Optimal Care Pathway for people with breast cancer* in Australia also recommend that women be informed about breast reconstruction before having a mastectomy.[19] Findings from our study suggest that efforts are needed to ensure implementation of this recommendation.

> ***I had to make my decision very quickly, at the same time as the mastectomy. It's worked out well, but I felt rushed at the time and not sure I had all the information to make the best decision.***

In addition to information about the type of reconstruction procedures available and where reconstruction can be undertaken, women in our study indicated that more information about the process of having a reconstruction was needed, with this information including the time taken for the procedure and the recovery, complications, and realistic information about possible outcomes of the surgery. To assist with finding this information, women were keen to have access to, and connect with, women who had been through the process, both to learn about the realities of having a breast reconstruction and to hear about their outcomes. Women reported that they often felt the images they were presented with regarding outcomes from the procedure were more related to breast augmentation procedures than reconstruction, with women suggesting that more realistic before and after photos were needed, with photos demonstrating results using different reconstruction procedures and for different groups of women (e.g. large breasted, small breasted) also requested.

> ***I feel there needs to be more detailed discussions of what may occur during surgery, like removal of ribs etc & more visual examples of what things will look like like. At the time there are so many different rushed discussions it is hard to take it all in, I believe with images, it would make things more clear.***

Greater access to services that can assist and support women when they are making decisions regarding breast reconstruction are needed, with many women commenting in the survey on the difficulties they had in reaching a decision. Breast reconstruction is major surgery involving potential for risks and complications regardless of whether an implant or autologous procedure is used[32] that can involve substantial costs and/or wait times for Australian women and their families.[17, 33]

> ***I think I would have benefitted from a discussion with a woman who had experienced breast reconstruction (both positive and negative) to ask some first-hand questions. I also think that it would be important to have access to a psychologist or someone similar to discuss the challenges that might be associated with a negative breast reconstruction. I no longer have any implants in due to the restriction of skin along my scar lines due to radiation therapy - I was never offered any counselling prior to or post implant removal.***

Studies have reported on the factors women consider when making decisions regarding breast reconstruction, with several reporting many experience decisional conflict due to the surgery being associated with positive and negative potential outcomes.[32] To assist women in their decisions regarding breast reconstruction, decision aids including BRECONDA have been developed, with findings from a randomised trial testing the potential impact of BRECONDA demonstrating that it reduces decisional conflict and increases satisfaction with information regarding breast reconstruction in women treated by mastectomy for breast cancer.[18] Ensuring women who are considering mastectomy for their breast cancer care are provided with this decision aid may provide a strategy to support women with reconstruction decisions.

Many women also noted the stress and distress they experienced while waiting for their reconstruction surgery. While this was often related to body image concerns and dissatisfaction, living with these concerns and the uncertainty regarding when surgery may happen also contributed to women's stress in this area.

> ***It has had a major impact on me, I don't feel fully a person as all I see is one breast and a big scar which I get severely depressed over.***

Women noted that access to hospital-based support services became difficult once they had finished their breast cancer treatment. While access to peers who had been through reconstruction through a peer support program was mentioned as one mechanism for women to access support at this time, reducing waiting times and increasing awareness that reconstruction surgery can be a key part of breast cancer care may also assist with this. Further work is needed to understand the influence of factors within the private and public health systems in each state that may impact women's access to breast reconstruction.

This study looked at breast reconstruction from the woman's perspective and as such it does not comment on factors in the health system that make breast reconstruction more or less difficult for women to access. For instance, this study suggests there may be differences between states regarding the involvement of plastic surgeons in reconstruction procedures. While this finding needs to be confirmed by service use data (e.g. audits of medical records), if confirmed, possible reasons for the difference may need to be understood. It is possible, for instance, that differences

in the number of oncoplastic surgeons between states and the numbers operating in the public health system may contribute to these types of differences. As it is likely that access to plastic surgeons may influence the type of reconstruction procedure used - especially for autologous procedures, differences between states in the type of reconstructions women reported may be influenced by the number of oncoplastic surgeons practising in each state. A qualitative study by Flintoff and colleagues has started to explore some of the system level barriers that influence access to breast reconstruction for women in regional and remote areas in Australia.[26] They reported the barriers including access to skilled surgeons and specialised equipment made it difficult for women from remote areas to access reconstruction surgery. Further work exploring the system level factors that make access to breast reconstruction more or less likely is needed.

Limitations and strengths

A number of limitations to the study need to be noted. A key limitation is recruiting women for the survey through BCNA's member database. While the number of women participating in the survey was, at over 3,300, large, we cannot determine how representative respondents are of women on the database that had mastectomy. It may be that women who spent longer waiting for the procedure, had more negative experiences - or even had more positive experiences - were motivated to complete the survey. However, we note that the characteristics of women reporting having or planning to have breast reconstruction, including being younger, being more likely to reside in metropolitan areas, and being less likely to reside in outer regional or remote areas of Australia reflect demographic characteristics of women having reconstruction found in population-based surveys.[5-7] Despite our large sample size, few women from the NT participated and there were few women from remote and very remote areas. Findings in relation to the experiences of women from these areas of Australia are more difficult to ascertain from our study. The low numbers in these areas reflect the distribution of Australia's population. Qualitative studies that focus on exploring the breast reconstruction experiences of women from remote areas of Australia may be useful. As there were no time limits on when women may have had their reconstruction surgery, some women participating in the survey were more than 10 years post reconstruction. While in general, time since reconstruction did not influence findings, we note that recall - especially in relation to out-of-pocket costs, waiting time, and information received - may affect the information provided by women further out from their reconstruction surgery. In addition, women provided estimates of their out-of-pockets costs for breast reconstruction. While some women commented that they could not remember and left this blank, others indicated that they provided a best guess. Components of the costs reported may differ between women, with some women noting costs associated with anaesthesia and post-surgery care were included in their costs, while others noted they were excluded. While caution is needed in interpreting this data, we note that the median out-of-pocket costs found in the current study is within the range reported by other work.[23] In addition, the sample included a small number of respondents who did not have breast cancer, but were at high risk for breast cancer, with responses from this group not distinguished from the larger group of people with breast cancer in the report. While the small number of high risk women is unlikely to influence the findings for the larger group, our results should not be taken as examining the reconstruction experiences of this group of women. Further work is needed to explore how women at high risk of breast cancer opting for prophylactic mastectomy experience breast reconstruction.

Despite these limitations some strengths need to be noted. The large sample size is a key strength of the report, with few studies of the reconstruction experiences of women in Australia involving such a large sample. The large sample gives confidence that the overall experiences reported here reflect those of women across Australia. Participants came from all Australian states and territories, again indicating that the study captured the experiences of women across the country. Open-ended questions contained throughout the survey provided women with the opportunity to provide further insight into their breast reconstruction experiences. Experiences documented in the responses to questions reflect findings from other studies involving qualitative data.[17, 26]

Conclusion

Findings reported here reflect previous studies showing disparities in access and waiting times for breast reconstruction for women in different parts of the country and different economic positions. Our findings suggest that improvements in relation to information provision and access to breast reconstruction are needed. Delays in ensuring women are provided with the information they need about breast reconstruction and in identifying mechanisms for reducing the out-of-pocket costs associated with this procedure will further entrench these disparities.

The findings from this study lead to the following recommendations:

RECOMMENDATIONS

Call to Government (Federal)

1. Require State and Territory Departments of Health to collect and publicise health service wait times for breast reconstruction to enable greater transparency for consumers, and call on hospitals/health services to ensure category 3 procedures are being undertaken within 365 days.
2. Implement recommendations from the MBS review contained in the Plastic and Reconstructive Surgery Clinical Committee's report.
3. Regarding the out-of-pocket costs portal:
    - 3.1 Prioritise the implementation of the Government's out-of-pocket costs portal to ensure greater transparency of fees charged for breast reconstruction.
    - 3.2 Endorse and publicise via the Government's out-of-pocket costs portal an established range of costs, to be developed in partnership with BCNA, breast cancer consumers and the clinical community, to ensure transparency of reasonable out-of-pocket costs for private breast reconstruction procedures related to breast cancer.
4. Telehealth:
    - 4.1 Ensure continuation of telehealth MBS item numbers
    - 4.2 Support improvements to telehealth guidelines to ensure an optimal consumer care experience.

Call to Governments (State/Territory)

1. Ensure the data for breast reconstruction wait times collected by State and Territory Departments of Health is publicly available to enable greater transparency for consumers.
2. Ensure all patients having delayed breast reconstruction are offered an operation within 365 days. Where this has not occurred, an action plan should be developed and communicated to patients.

Call to professional associations

1. Work with BCNA in partnership with breast cancer consumers to develop a range of reasonable out-of-pocket costs for breast reconstruction procedures related to breast cancer undertaken in the private health system.

Call to health services/health professionals

1. All hospitals/health services notify patients that they are on a waiting list for breast reconstruction and what the category is.
2. General practitioners, breast cancer surgeons and breast care nurses to:
    - 2.1 Ensure all women having a mastectomy are provided with comprehensive information about their breast reconstruction options to empower women to make the most appropriate decision for them. This information should be provided prior to breast cancer surgery.
    - 2.2 Ensure not having a reconstruction is discussed as a viable option with women, with the pros and cons of this presented.
    - 2.3 Ensure women affected by breast cancer are provided with information about the Patient Assisted Travel Schemes and other services/supports in their area which may be of assistance and may help to reduce the financial impact of breast reconstruction.

Call to BCNA

1. Work with the Australian Commission on Safety and Quality Healthcare to develop an advisory statement/quality standard around breast reconstruction procedures, which sets out the information requirements for patients, requirements regarding wait times, and requirements regarding quality and safety.
2. Increase awareness of the information regarding breast reconstruction, which is available to enable people affected by breast cancer to make decisions that are most appropriate for them.
3. Advocate for an ongoing commitment to telehealth to support those in rural and regional areas seeking breast reconstruction services which are not available in their local area.
4. Continue to understand those jurisdictions where there are high wait times by working with consumers, government, and health services. Work with these services to find solutions for improved access for all women.
5. Continue to support the implementation of projects and initiatives aimed at increasing financial transparency for people affected by cancer, including Cancer Council Australia's Standard for Informed Financial Consent.

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APPENDIX 1

Influence of time since reconstruction on type of reconstruction

Women who had completed their breast reconstruction were asked how long ago the reconstruction was. While the majority of participants had completed their reconstruction within the last 5 years (65%, including 26% 0-1 year ago, 24% 2-3 years ago, and 15% 4-5 years ago), 11% reported their reconstruction was more than 10 years ago. We examined the influence of time on type of reconstruction surgery, when reconstruction started, and who performed the reconstruction surgery for women who had completed their breast reconstruction (Table A2.1).

There was no significant change over time in use of implant or autologous tissue graft.

However, immediate reconstruction became more common over time, with 66% having their breast reconstruction immediately compared to 42% of those having this procedure 11 or more years ago.

There was a change in who was performing the breast reconstruction over time, with a decrease in the proportion of women having this procedure done by a plastic surgeon and an increase in the involvement of breast surgeons. While having the procedure in the private system was most common across the years, there was a notable decrease in the proportion of women having reconstruction in the private system over time, decreasing from 78% to 64% more recently.

Table A2.1: For women who had completed breast reconstruction, influence of time on type of procedure, when started and who did the breast reconstruction

	0-1 year ago	2-3 years ago	4-5 years ago	6-10 years ago	11 or more years	Total
(n)	(346)	(316)	(204)	(320)	(148)	(1,334)
Type of reconstruction						
Implant %	52.9	49.7	54.4	51.6	46.6	51.3
Own tissue %	37.3	40.2	33.8	38.1	41.9	38.2
Timing of reconstruction						
Immediate %	65.6	54.6	49.0	41.3	41.5	51.9
Type of surgeon						
Breast %	39.6	31.0	28.4	23.4	19.6	29.8
Plastic %	51.2	66.8	65.7	70.6	76.4	64.5
General %	2.6	0.9	1.5	1.6	0.0	1.5
Health system for surgery						
Private %	63.9	71.4	70.4	74.0	78.2	70.7
Public %	36.1	28.6	29.6	26.0	21.8	29.3

APPENDIX 2

Factors influencing decisions for respondents indicating they had decided against reconstruction or were still undecided

In this section, the influence of socio-economic position and rurality on factors influencing the decision to not have breast reconstruction and their influence on women who are still undecided about reconstruction are explored. For the analyses, due to the small number of respondents, socio-economic disadvantage quintiles were combined to form 3 groups with the 2 most disadvantage groups combined, the 2 mid groups combined, and the least disadvantaged 20% forming the third group. For residential location, again due to smaller numbers, respondents from remote/very remote areas were combined with the outer regional respondents.

Women who had had a mastectomy

Responses for women who had a mastectomy are shown in Table A3.1 by socio-economic disadvantage and in Table A3.2 by residential location. Table A3.4 and Table A3.4 shows responses to these items for all respondents who were still deciding about breast reconstruction or had decided again reconstruction regardless of type of surgery for breast cancer, by socio-economic position and residential location.

In the main, socio-economic position did not influence the importance of the different factors to both women deciding not to have breast reconstruction and those still undecided. An exception to this for those that had decided against reconstruction was working out if breast reconstruction was important to them, with more women in the most disadvantaged groups indicating this.

Residential location seemed to play more of a role in influencing some factors that women indicated were important in deciding not to have reconstruction. For those who had decided against reconstruction, women from outer regional/remote and very remote areas were more likely to indicate that they did not receive enough information, waiting lists were too long, and the need for long distance travel were important in their decisions compared to women living in metropolitan areas (Table A3.2). Women from outer regional/remote areas were also more likely to indicate that they were still working out the importance of reconstruction to them.

There was less difference in responses by residential location for women who were undecided. The only significant difference was found for distance needed to travel, with more women from outer regional/remote areas thinking this important than women from metropolitan areas (Table A3.2).

Multivariate analyses examined the relative influence of socio-economic position and residential location on each item after adjusting for age and time since diagnosis.

For those undecided, socio-economic position was not related to any of the items. However, residential location was still significantly associated, with reporting that the distance needed to travel to access breast reconstruction was important in their decisions in multivariate analyses controlling for age, time since diagnosis, and socio-economic position.

In those who had decided against breast reconstruction, socio-economic position was not associated with any factor in the multivariate analyses. Residential location was associated with concerns about travel for those who had decided against reconstruction. Women from outer regional and remote areas were more likely to report this factor importance, after adjusting for socio-economic position, age, and time since diagnosis.

All women deciding or deciding against regardless of surgery

Questions assessing factors influencing reconstruction decisions were asked of all respondents who had decided against reconstruction or were still undecided regardless of their surgery. Table A3.3 shows the responses to these questions for all respondents answering them by economic disadvantage, and Table A3.4 shows response by residential location.

For all respondents, regardless of type of breast cancer surgery, the key factors influencing women still deciding about breast reconstruction were: determining its importance for them (59%), recovery time (25%), and costs (24%). For women who had decided not to have breast reconstruction, the most common factors influencing their decisions were: importance (16%), recovery time (15%), and no one speaking to them about it (14%). State of residence was not associated with factors influencing breast reconstruction decisions for either women who had decided not to have reconstruction or those who were still undecided.

Table A3.3 shows the proportion of those undecided about breast reconstruction and those who had decided against reconstruction selecting each of the 10 items as being important by socio-economic position. This information, also shown by residential location in Table A3.4.

Table A3.2: For women who have had a mastectomy and who were undecided or who had decided against breast reconstruction, factors reported as important in their decision regarding breast reconstruction by residential location^

		Socio-economic disadvantage index			
Factor		Most (0-41)	41-80	81-100 (least)	Total
		%	%	%	%
	Decided against (n)	(178)	(229)	(174)	(581)
	Undecided (n)	(88)	(133)	(67)	(288)
Nobody spoke to me about it	Decided against	10.7	12.2	5.7	9.8
	Undecided	20.5	16.5	19.4	18.4
Doctors still working out if I can have breast reconstruction due to type of breast cancer I have	Decided against	1.1	0.9	0.0	0.7
	Undecided	8.0	6.0	6.0	6.6
Don't have enough information about breast reconstruction and option	Decided against	7.3	4.8	2.3	4.8
	Undecided	35.2	33.1	26.9	32.3
Still working out if I can have breast reconstruction due to other health conditions	Decided against	1.1	1.3	0.6	1.0
	Undecided	1.1	6.8	6.0	4.9
Recovery time would mean a lot of time from work or other impact	Decided against	15.2	22.3	24.7	20.8
	Undecided	23.9	31.6	38.8	30.9
Waiting list sounds too long	Decided against	4.5	3.1	0.6	2.8
	Undecided	6.8	5.3	10.4	6.9
Long way to travel to have it	Decided against	3.4	3.9	1.1	2.9
	Undecided	4.5	5.3	3.0	4.5
Cost is high unsure about affordability	Decided against	7.9	12.2	7.5	9.5
	Undecided	20.5	28.6	20.9	24.3
Working out if reconstruction is important to me	Decided against	21.9	18.8	12.1	17.7*
	Undecided	60.2	69.2	74.6	67.7
Considering my partner's or family's views	Decided against	1.1	0.4	0.6	0.7
	Undecided	4.5	9.8	9.0	8.0

* p<.05
** p<.01

Table A3.3: For women who were undecided or who had decided against breast reconstruction, factors reported as important in their decision regarding breast reconstruction by socio-economic disadvantage quintiles

		Disadvantage index					
Factor		Most (0-41)	21-40	41-60	61-80	Least (81-1000)	Total
		%	%	%	%	%	%
	Decided against (n)	171	163	175	163	264	936
	Undecided (n)	76	78	74	109	91	428
Nobody spoke to me about it	Decided against	12.9	14.7	14.9	20.2	9.1	13.8 *
	Undecided	7.3	6.6	2.8	9.6	4.5	6.1
Doctors still working out if I can have breast reconstruction	Decided against	1.2	0.6	0.0	1.2	0.0	0.5
	Undecided	2.6	7.7	6.8	5.5	7.7	2.6
Don't have enough information about breast reconstruction and option	Decided against	4.7	6.7	5.7	4.9	2.3	4.6
	Undecided	8.5	10.4	8.8	12.5	7.6	9.5
Still working out if I can have breast reconstruction due to other health conditions	Decided against	1.8	0.6	1.7	0.0	0.8	1.0
	Undecided	2.6	2.6	6.8	5.5	4.4	4.4
Recovery time would mean a lot of time from work or other impact	Decided against	10.5	9.8	16.6	16.6	18.6	14.9 *
	Undecided	13.2	19.2	31.1	24.8	33.0	24.5 *
Waiting list sounds too long	Decided against	1.2	4.3	1.1	3.7	1.1	2.1
	Undecided	2.6	6.4	2.7	10.1	8.8	6.5
Long way to travel to have it	Decided against	2.3	3.7	2.9	2.5	1.1	2.4
	Undecided	6.6	5.1	4.1	5.5	2.2	4.7
Cost is high unsure about affordability	Decided against	6.4	5.5	9.7	9.2	5.3	7.1
	Undecided	17.1	24.4	31.1	23.9	22.0	23.6
Working out if reconstruction is important to me	Decided against	14.6	17.8	18.3	20.2	12.5	16.2
	Undecided	38.2	66.7	64.9	60.6	63.7	59.1 **
Considering my partner's or family's views	Decided against	1.8	0.6	0.6	0.0	0.4	0.6
	Undecided	5.3	6.4	6.8	9.2	6.6	7.0

* p<.05
** p<.01

Table A3.4: For women who were undecided or who had decided against breast reconstruction, factors reported as important in their decision regarding breast reconstruction by residential location^

		Residential location				
Factor		**Metropolitan**	**Inner regional**	**Outer regional**	**Remote/ very remote**	**Total**
	Decided against (n)	(555)	(200)	(77)	(16)	(848)
	Undecided (n)	(259)	(97)	(37)	(7)	(400)
Nobody spoke to me about it	Decided against	14.2	15.5	16.9	6.3	14.6
	Undecided	17.8	17.5	35.1	42.9	19.8 *
Doctors still working out if I can have breast reconstruction	Decided against	0.7	0.0	0.0	0.0	0.5
	Undecided	6.9	5.2	8.1	0.0	6.5
Didn't/don't have enough information about breast reconstruction and options	Decided against	3.1	7.0	13.0	0.0	4.8 **
	Undecided	32.0	30.9	29.7	14.3	31.3
Still working out if I can have breast reconstruction due to other health conditions	Decided against	1.1	0.5	1.3	0.0	0.9
	Undecided	4.6	6.2	2.7	0.0	4.8
Recovery time would mean a lot of time from work or other impact	Decided against	15.3	17.5	13.0	18.8	15.7
	Undecided	27.4	23.7	18.9	28.6	25.8
Waiting list sounds too long	Decided against	2.0	1.5	6.5	0.0	2.2
	Undecided	7.3	5.2	8.1	0.0	6.8
Long way to travel to have it	Decided against	0.4	2.5	11.7	31.3	2.5 **
	Undecided	0.4	7.2	21.6	42.9	4.8 **
Cost is high unsure about affordability	Decided against	7.2	6.0	9.1	6.3	7.1
	Undecided	25.1	24.7	16.2	28.6	24.3
Working out if reconstruction is important to me	Decided against	16.6	14.5	26.0	12.5	16.9
	Undecided	61.0	60.8	62.2	57.1	61.0
Considering my partner's or family's views	Decided against	0.4	0.5	2.6	0.0	0.6
	Undecided	7.7	7.2	2.7	0.0	7.0

Note small n sizes for some cells in this table. Percentages reported when the sample is under 30 should be treated with caution as confidence interval for estimate is large. Percentages when sample size is less than 10 are in light blue to indicate additional caution is needed. Information provided for completeness only. If the sample size is ≤ 4, percentages are not reported.

In the main, socio-economic position did not influence the importance of the different factors to both women deciding not to have breast reconstruction and those still undecided. An exception to this for both groups was found with recovery time, which was of greater importance for women from the least disadvantaged group compared to women in the more disadvantaged group. In addition, in women who had decided against breast reconstruction, a greater proportion of women in the lower socio-economic positions reported that nobody spoke to them about breast reconstruction compared to the proportion found in the least disadvantaged group. For undecided women, those from the least disadvantaged group were more likely to report that they were still working out if breast reconstruction was important to them compared to women from the more disadvantaged groups.

Similar to findings for socio-economic position, mostly residential location did not influence women's responses. The exception to this for both groups related to the importance of travel distance, with a greater proportion of women from remote/very remote areas indicating this was a consideration for them compared to women in metropolitan areas (Ps <.05). For women who were undecided, those from outer regional and remote areas were more likely to report that nobody spoke to them about breast reconstruction compared to women from metropolitan or inner regional areas (p<.05). There was a significant association between residential location and information for women who had decided against breast reconstruction (P<.01), with more women from outer regional areas reporting that they did not feel they had enough information about breast reconstruction compared to women from metropolitan areas.

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