



# Evaluation of the National External Breast Prostheses Reimbursement Programme

Impact Evaluation Report

June 2016

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# Executive Summary

## BACKGROUND

The National External Breast Prostheses Reimbursement Programme (the Programme) commenced on 1 December 2008 and is administered by the Department of Human Services (DHS) on behalf of the Department of Health (DoH).

The objectives of the Programme are to:

- provide financial support towards the costs of external breast prostheses for women who have undergone a mastectomy as a result of breast cancer;
- ensure national consistency in the provision of support towards the cost of breast prostheses; and
- improve the quality of life of women who have undergone a mastectomy as a result of breast cancer.

In July 2015, DoH commissioned Urbis to evaluate the administration and outcomes of the Programme. The evaluation is being undertaken to identify whether the Programme remains appropriate, effective, and efficient, with a particular focus on the identification of efficiencies or improvements to the Programme and/or the Programme's administrative systems.

This report summarises the results of the outcome evaluation. It expands upon a formative evaluation provided to DoH in February 2016.

## METHODOLOGY

Data collection for the outcome evaluation of the Programme comprised the following research activities:

### Secondary research

- Analysis of Programme data

### Qualitative research activities

- In-depth interviews with Programme stakeholders (n=19)
- In-depth interviews with Programme participants and eligible women (n=20)

### Quantitative research activities

- Online survey of Programme participants and eligible women (n=295 respondents).

## PROGRAMME AWARENESS AND IMPACT

### PROGRAMME AWARENESS

- Over 90% of survey respondents indicated that they had heard of the Programme.
- This result is consistent with findings from the qualitative research, with Programme participants and stakeholders consistently suggesting that there is mostly high awareness of the Programme amongst eligible women and relevant support organisations.
- Programme participants mostly reported becoming aware of the Programme via face-to-face communication with a breast care nurse in the period immediately post-surgery, or through interaction with a breast prosthesis supplier.
- Programme participants consistently expressed a preference for face-to-face and written communication.

## PROGRAMME IMPACT

- Programme participants typically reported that the Programme had impacted them directly by allowing or enhancing their ability to access breast prostheses and indirectly by improving their overall quality of life.
  - For example, just over nine in ten survey respondents who had accessed the Programme in the past two years (93%) agreed or strongly agreed that the Programme had made it easier to afford a breast prosthesis and 86% agreed or strongly agreed that the Programme had a positive impact on their quality of life.
  - Programme participants indicated, via in-depth interviews, that the Programme had made it easier to afford breast prostheses and a minority of women reported that they would have been unable to afford a prosthesis – and would have made alternative, less favourable arrangements – without access to the Programme.
  - All stakeholders commented positively regarding the existence and effectiveness of the Programme in providing financial assistance to women who have undergone mastectomy as a result of breast cancer.
  - Upon prompting, the majority of interviewed Programme participants acknowledged that access to the Programme, and consequently an ability to obtain very affordable breast prosthesis as required, had positively impacted their quality of life, including through improved physical and psychological health.
- Programme impact could be enhanced through allowances for bras and swimming prostheses, and an improved discretionary claims process.

## PROGRAMME ACCESS

- Over six years, from financial year 2009-10 to 2014-15, a total of 96,514 breast prostheses have been provided to women across Australia. The sum of the value of the reimbursement over this time is \$34,111,819.
- Evidence of Programme access is further supported by survey results: almost two thirds (62 per cent) of respondents indicated that they had made a claim for reimbursement from the programme in the last two years.
- Stakeholders reported that the consistent national approach to administering the Programme has helped to ensure that most women across Australia have the ability to access the reimbursement scheme. Key factors reported to have boosted the accessibility of the Programme included the integration into the Medicare service provision system and the streamlined set of eligibility criteria which has ensured the information burden on claimants remains low.
- Stakeholders suggested that the ability of eligible women to access the Programme may be influenced by lack of awareness, financial hardship, remoteness, and surgery timing. Aboriginal and Torres Strait Islander women and women from diverse cultural and language backgrounds are underrepresented; however there is limited evidence to identify the reasons for this underrepresentation.
- Programme participants expressed concern about the reimbursement model, with most either agreeing that it had been difficult to afford the up-front payment or suggesting that it may be tough (and sometimes impossible) for women on a fixed income to afford the payment.
- Specific suggestions for alternative Programme arrangements (including arrangements that cover only select Programme participants) included:
  - vouchers that could be exchanged for a prosthesis at select or all suppliers



- a capacity for women to apply for up-front funding in special circumstances (i.e. when they are unable to make the payment)
- a system similar to Medicare, in which women are only required to pay the gap between the cost of the prosthesis and the reimbursement.
- Under DHS regulations, women who have received an income support payment (including age pension) for more than three months may be eligible for an advance up-front payment of a proportion of their benefit, which could (subject to approval of application) be used to cover the cost of purchasing a prosthesis. Awareness of this option was non-existent amongst interview participants, and direct promotion could assist in alleviating concerns about the reimbursement model.

## PROGRAMME EXPERIENCE

- The survey results suggest that eligible women, on the whole, have had a positive Programme experience:
  - just over three quarters (76%) of survey respondents rated their overall Programme experience as either four (27%) or five (49%) on a 5-point scale.
  - only four survey respondents (2%) gave their overall Programme experience a rating of one out of five on a 5-point scale.
- This result is consistent with the qualitative research findings: Programme participants consistently reported, via in-depth interviews, a very positive overall Programme experience, with most suggesting, unprompted, that the process for claim submission was simple and that they had received their reimbursement in a timely fashion.
- The claim submission process was typically viewed as simple and minimally burdensome by Programme participants.
- The reimbursement amount (i.e. \$400) and frequency (i.e. every two years) was considered to be appropriate by most participants, and the ease and efficiency of the reimbursement process was typically held in high-regard.
- Programme data shows that while the average total cost per prosthesis (i.e. purchase price) has increased steadily over the life of the Programme, it remains below the specified reimbursement amount (n.b. \$389.96 compared to \$400 in 2014-15).

## CONCLUSIONS

The National External Breast Prosthesis Reimbursement Programme is continuing to positively impact the lives of Australian women who undergo breast surgery as a result of breast cancer. Programme participants experience substantial physical and, especially, psychological benefits as a result of being able to access to affordable prostheses on an ongoing basis. Service engagement (i.e. claim submission) is minimally burdensome, especially given the substantial Programme impacts, and Programme participants consistently reported a very high level of satisfaction with the Programme experience. The simplicity of the Programme is key to its success: more complicated Programme guidelines (including coverage of bras and additional discretionary claims criteria) should only be implemented after careful consideration, and only in ways that maintain the simplicity of the Programme.

## RECOMMENDATIONS

Financial hardship is not a significant enough Programme access barrier to prompt a substantial Programme redesign. A number of stakeholders and Programme participants argued that women may have trouble affording the up-front payment; however there was limited evidence to suggest this phenomenon is widespread. Programme data indicates that the average total cost per prosthesis (i.e. purchase amount) has steadily increased over the life of the Programme; however, this average is still below the specified limit of \$400. Despite this, evidence from the qualitative research suggests that at

least some women are being required to cover out-of-pocket costs. As such, we recommend that the amount of reimbursement allowed under the National External Breast Prosthesis Reimbursement be reviewed on an annual basis (i.e. comparison of annual average amount claimed to specified limit) to ensure that the reimbursement amount remains in line with current market rates.

**Recommendation one:** *The amount of reimbursement allowed under the National External Breast Prosthesis Reimbursement Programme should be reviewed on an annual basis, including a comparison of average annual amount claimed to specified limit.*

While financial hardship is not a significant barrier to Programme access, it appears that some women on limited means (including Aboriginal and Torres Strait Islander women) are not accessing the Programme because they are unable to afford the up-front payment. As noted above, there is insufficient evidence to suggest that a substantial Programme redesign is required (i.e. implementation of a Medicare-style approach in which women, or select women, are only required to pay a 'gap'); however, promotion of mechanisms for obtaining the required funds up-front could positively impact Programme access for women on limited means and women who do not have access to a credit card. As such, we recommend that the advance payment options that may be available to women receiving an income support payment be explicitly promoted as a possible option for obtaining the required funds for an external breast prosthesis prior to reimbursement. This promotion should include, but not be limited to, information on the DHS website.

**Recommendation two:** *The advance payment options available to women receiving income support payments should be explicitly promoted as an option for obtaining the funds for an external breast prosthesis prior to reimbursement.*

As noted above, most Programme participants were highly satisfied with the process of claim submission and processing; however, there was a general consensus the process could be even more streamlined through the introduction of an online claim submission portal. This would be in line with a large number of government services, and would assist in ensuring equity in Programme access (i.e. the claim submission process would not be easier for Programme participants located close to Medicare office or Post Office). It should, however, be noted that the demographic profile of Programme participants is skewed to an older age group, some of whom may be less tech-savvy. Despite this, we recommend that the claim submission process for the National External Breast Prosthesis Reimbursement Programme be expanded to include an online submission portal.

**Recommendation three:** *The claim submission process for the National External Breast Prosthesis Reimbursement Programme should be expanded to include an online submission portal.*



# 1 Introduction

## 1.1 BACKGROUND

### 1.1.1 PROGRAMME CONTEXT

After a mastectomy, restoration of the breast form and body symmetry can be achieved through either a surgical breast reconstruction or external breast prosthesis. It has been widely assumed that breast reconstruction offers superior psychological benefits to mastectomy patients. However, quality-of-life comparisons between women who undergo immediate breast reconstructions and those who have the mastectomy alone have failed to support this hypothesis, with similar outcomes consistently observed for both groups of women (Reaby, 1998). In addition, the differential outcomes observed for each approach (i.e. reconstruction or no reconstruction) do not clearly point to one approach being superior to the other: while reconstruction is associated with improved body image and greater feelings of attractiveness, evidence suggests that it is also associated with lower sexual responsiveness and sexual activity in the immediate postoperative period, and greater mood disturbance and poorer well-being over time (Nissen, 2001).

When a woman opts for a prosthesis (or prostheses), she is typically fitted with a temporary, lightweight external breast prosthesis constructed from fibrefill or foam in the immediate postoperative period. Six to eight weeks later, after the mastectomy wound has healed, she is subsequently fitted with a more permanent prosthesis (Glaus, 2009). Noteworthy improvements in breast prostheses over the past 25 years have increased the choices available to women, with prostheses now constructed in a variety of sizes, shapes, colours, materials, and with or without a nipple and areola. Studies that have evaluated the satisfaction of women with an external prosthesis have generally shown that the majority of wearers are satisfied with their prosthesis (Livingston, et al., 2005). If a woman elects to undergo breast reconstruction surgery, an external breast prosthesis will often be used whilst awaiting surgery, unless the reconstruction takes place directly after the mastectomy procedure (Fitch, 2012). As such, a good quality breast prosthesis and prosthesis fitting service is typically considered to be a crucial part of the recovery process following most mastectomies (Fitch, 2012).

### 1.1.2 THE NATIONAL EXTERNAL BREAST PROSTHESES REIMBURSEMENT PROGRAMME

The National External Breast Prostheses Reimbursement Programme (the Programme) commenced on 1 December 2008 and is administered by the Department of Human Services (DHS) on behalf of the Department of Health (DoH).

The objectives of the Programme are to:

- provide financial support towards the costs of external breast prostheses for women who have undergone a mastectomy as a result of breast cancer;
- ensure national consistency in the provision of support towards the cost of breast prostheses; and
- improve the quality of life of women who have undergone a mastectomy as a result of breast cancer.

In July 2015, DoH commissioned Urbis to evaluate the administration and outcomes of the Programme. The evaluation is being undertaken to identify whether the Programme remains appropriate, effective, and efficient, with a particular focus on the identification of efficiencies or improvements to the Programme and/or the Programme's administrative systems.

This report summarises the results of the outcome evaluation. It expands upon a formative evaluation provided to DoH in February 2016.

### 1.1.3 EVALUATION OBJECTIVES

The outcome evaluation is being undertaken to explore Programme effectiveness. This includes identifying any issues that may need to be addressed, and any modifications or opportunities for future improvements in order to strengthen the Programme's effectiveness, and maximise its potential for success.

## 1.2 METHODOLOGY

### 1.2.1 OVERVIEW

Data collection for the outcome evaluation of the Programme comprised the following research activities:

Secondary research

- Analysis of Programme data

Qualitative research activities

- In-depth interviews with Programme stakeholders (n=19)
- In-depth interviews with Programme participants and eligible women (n=20)

Quantitative research activities

- Online survey of Programme participants and eligible women (n=295 respondents)

### 1.2.2 ANALYSIS OF PROGRAMME DATA

Raw data provided by the Department of Human Services (DHS) for a period of six years from 2009 to 2015 reported on:

- state and postcode of claimants
- the number prostheses claimed
- the value of the claim
- the age group claiming (from 0 to greater than 90 years, in 5 year brackets)
- whether it was a left or right breast prosthesis
- the number of claims rejected
- aggregate process times.

With regard to postcode, Urbis was able to infer the rate of uptake for postcodes according to Socio-Economic Indexes for Areas (SEIFA) values, as well as identify uptake in regional versus metropolitan postcodes. These additional datasets were generated using the 2011 Census TableBuilder. Aggregate data on purchase amount (i.e. total cost of prosthesis) was also provided by DHS, and drawn upon in the analysis.

### 1.2.3 STAKEHOLDER CONSULTATION

Urbis conducted in-depth telephone interviews with a total of 19 Programme stakeholders between 23 September and 14 December 2015. Each interview lasted for between 15 minutes and one hour. Participants for this phase of the study were identified by the Department and selected for their ability to comment on the Programme.

Participants included representatives from:

- Australian Government agencies and funded organisation (n=5 stakeholders)<sup>1</sup>
- State and Territory Cancer Councils (n=5 stakeholders)
- Medical professionals treating breast cancer (n=2 stakeholders)
- National and local support groups and charities (n=5 stakeholders)
- NGOs and professional organisations (n=1 stakeholder).

#### 1.2.4 IN-DEPTH INTERVIEWS WITH PROGRAMME PARTICIPANTS AND ELIGIBLE WOMEN

Urbis conducted in-depth interview with a total of 19 Programme participants and one eligible woman who had chosen not to access the Programme between 2 March and 23 March 2016. Each interview lasted for between 15 minutes and 45 minutes. Participants for this phase of the study were randomly selected from survey respondents who indicated that they were willing to participate in an in-depth interview, and had provided adequate contact details. Efforts were made to ensure that the sample included:

- women from all Australian States and Territories
- women located in metropolitan and regional locations
- women of various ages
- women who had undergone their most recent surgery 1-23 months ago, 2-5 years ago, and more than five years ago.

However, no firm quotas were placed on these characteristics.

#### 1.2.5 SURVEY OF PROGRAMME PARTICIPANTS AND ELIGIBLE WOMEN

Urbis designed and programmed a 10-minute online survey for women eligible for Programme participation (i.e. women who had undergone a full mastectomy, partial mastectomy, or lumpectomy as a result of breast cancer).

This survey was advertised and distributed by:

- Cancer Councils
- Breast Cancer Network Australia (BCNA) (including BCNA's Review & Survey Group)
- BreaCan
- National Breast Cancer Foundation
- Aussie Knockers
- Cancer Voices NSW
- McGrath Foundation
- Health Consumers NSW
- Bras 2 U Mobile Mastectomy Prosthesis Fitting

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<sup>1</sup> These stakeholders are collectively referred to as 'internal stakeholders' throughout the report. The remainder of stakeholders are collectively referred to as 'external stakeholders'.

- Transitions (Breast Cancer) Support
- Cancer Australia.

BCNA's Review & Survey Group consists of BCNA members who are interested in receiving invitations to participate in various research projects. Approximately 90% of BCNA's members have had a diagnosis of early or late stage breast cancer and have completed active treatment. The remaining 10% of members are relatives or loved ones of someone who has been affected by breast cancer.

The survey, which was in-field between 14 December 2015 and 14 March 2016, was completed by a total of n=295 respondents. Sixty two per cent of respondents (n=183) indicated that they had made a claim for reimbursement from the programme in the last two years.

## 1.3 PRESENTATION OF FINDINGS

### 1.3.1 QUALITATIVE RESEARCH

Qualitative findings from the in-depth interviews with stakeholders and Programme participants (including eligible women) are presented in a qualitative manner. This research approach does not allow for the exact number of participants holding a particular view on individual issues to be measured. This approach therefore provides an indication of themes and reactions among research participants rather than exact proportions of participants who felt a certain way.

In this report, *qualitative research* refers collectively to data collected during in-depth interviews with Programme stakeholders and Programme participants. When data has been collected through a single data collection method, this approach will be stated.

Quotes have been provided throughout the report to support the main results or findings under discussion.

### 1.3.2 QUANTITATIVE RESEARCH

Percentages presented in the report are based on the total number of valid responses made to the question being reported on. In most cases, results reflect those respondents who had a view and for whom the questions were applicable. 'Don't know' and 'Unsure' responses have only been presented where this aids in the interpretation of the results.

Overall percentage results for questions in the Programme participants' survey (answered by 295 respondents) have a degree of sampling error (i.e. confidence interval) at the 95% level of statistical confidence of +/- 6 percentage points (pp). That is, there is a 95% probability (abstracting from non-sampling error) that the percentage results will be within +/- 6pp of the results that would have been obtained if the entire population (i.e. all Programme participants) had responded. Higher degrees of sampling error apply to questions answered by fewer respondents.

Percentage results throughout the report may not sum to 100% due to rounding or due to the acceptance of multiple responses for some questions.

## 1.4 METHODOLOGICAL LIMITATIONS

Urbis had intended to undertake qualitative research with Aboriginal and Torres Strait Islander women and women from culturally and linguistically diverse backgrounds, as women from these populations were under-represented in the previous 2010 evaluation. To do so, we worked with Aboriginal researchers who sought to reach Aboriginal women through breast care nurses, hospital-based Aboriginal Liaison Officers, and informal women's networks. We were, however, unable to locate eligible Aboriginal women who had used the Programme and who wished to participate in the research. This may be due to the sensitivities in discussing such intimate matters with a stranger. It may also be that women who are eligible for the Programme are not aware of the Programme, or choose not to access the Programme for other reasons.

Similarly, although we provided information about the evaluation in several languages (Arabic, Chinese and Vietnamese) to GPs and other health practitioners within areas of Sydney with highly diverse populations, and sought to engage health practitioners working with specific cultural groups, there was no response from women from different cultural or language groups, perhaps also for the same reasons of sensitivities regarding the discussion of breast cancer, mastectomy, and prostheses.

In lieu of the qualitative research, Urbis undertook a brief literature review to explore barriers to health programme access for Aboriginal and Torres Strait Islander women and women from diverse cultural and language backgrounds, with a particular focus on programmes that cover sensitive topics. As noted later in the report, there is little information regarding the reasons why women may (or may not) be accessing reimbursements for breast prostheses through the Programme, and to avoid speculation further research is required to understand some of the particular needs of these diverse groups.

## 1.5 PROFILE OF SURVEY RESPONDENTS

Key characteristics of survey respondents are presented below

TABLE 1 – PROFILE OF RESPONDENTS BY AGE

AGE	RESPONDENTS
30-39	10
40-49	37
50-59	84
60-69	89
70-79	40
80 or over	3
Prefer not to say	32
<b>Total</b>	<b>295</b>

TABLE 2 – PROFILE OF RESPONDENTS BY MINORITY GROUP STATUS

IDENTITY	RESPONDENTS
I identify as Aboriginal or Torres Strait Islander	2
I speak English as a second language	6
I identify as having a disability	11

TABLE 3 – PROFILE OF RESPONDENTS BY STATE

STATE/TERRITORY	RESPONDENTS
NSW	89
VIC	53
QLD	43
SA	36
WA	19
TAS	13
ACT	11
NT	2
Prefer not to say	29
<b>Total</b>	<b>295</b>

TABLE 4 – PROFILE OF RESPONDENTS BY LOCATION

AREA	RESPONDENTS
Major/capital city	136
Regional city/large country town	67
Small town	41
Remote village/area away from a town	18
Prefer not to say	33
<b>Total</b>	<b>295</b>

TABLE 5 – PROFILE OF RESPONDENTS BY EDUCATION

EDUCATION	RESPONDENTS
Year 10 (school certificate) or equivalent	39
Year 12 or equivalent	45
Apprenticeship or cadetship	1
TAFE or technical college	57
University	136
Prefer not to say	17
<b>Total</b>	<b>295</b>

TABLE 6 – PROFILE OF RESPONDENTS BY TYPE OF BREAST SURGERY

SURGERY	RESPONDENTS
Full mastectomy	186
Double or bilateral mastectomy	69
Lumpectomy	16
Other (please specify)	11
Partial mastectomy	9
<b>Total</b>	<b>295</b>

TABLE 7 – PROFILE OF RESPONDENTS BY DATE OF BREAST SURGERY

TIME	RESPONDENTS
1-23 months ago	48
2-5 years ago	99
More than 5 years ago	119
Prefer not to say	29
<b>Total</b>	<b>295</b>

Note: respondents who have undergone more than one episode of breast cancer were asked to report the time since their most recent procedure



## 2 Programme awareness and impact

### 2.1 PROGRAMME AWARENESS

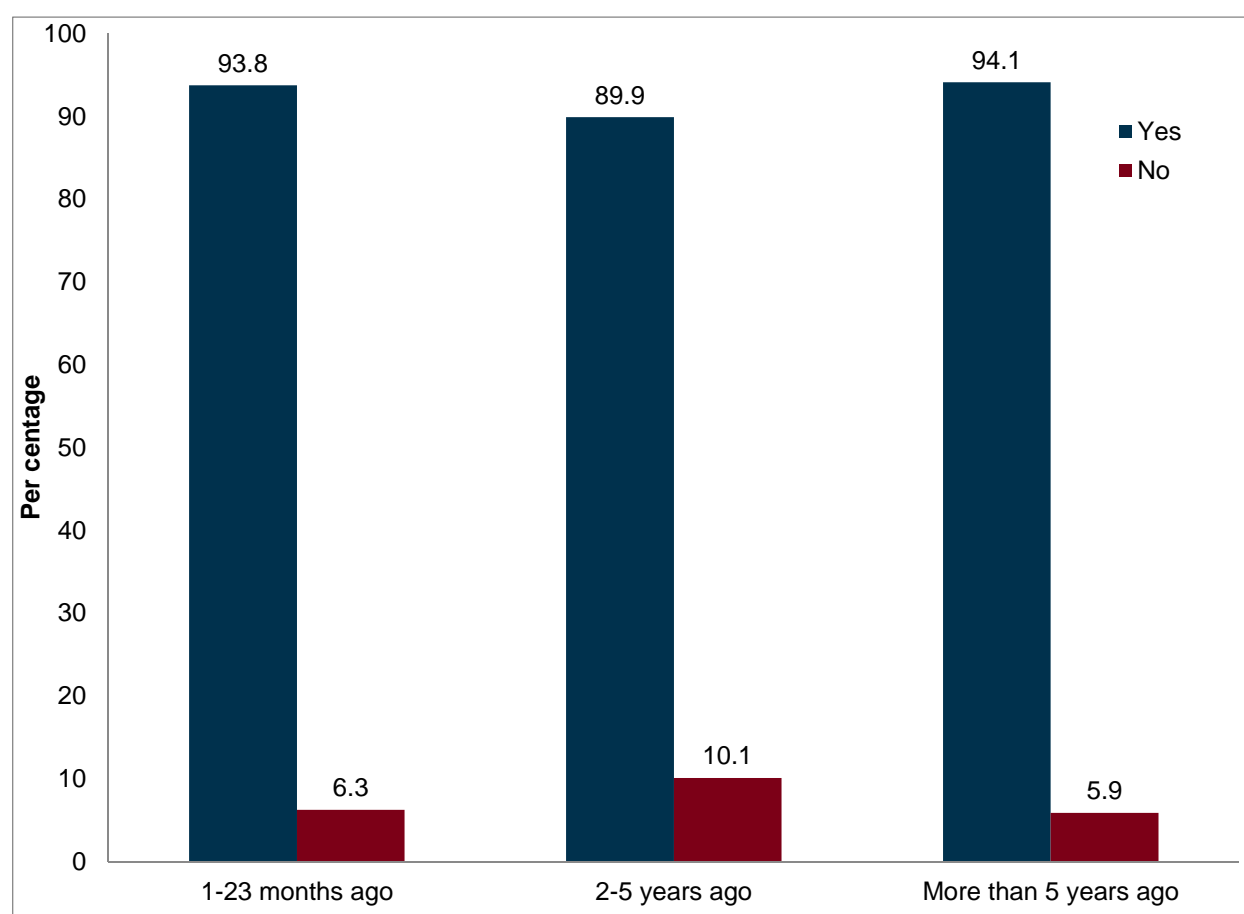
This section of the report covers Programme awareness, including:

- overall awareness
- information channels and
- information availability and usefulness.

#### 2.1.1 OVERALL AWARENESS

Survey results suggest that there is high Programme awareness amongst eligible women, including women who underwent their most recent breast surgery some time ago (see Figure 1): around 95% of survey respondents who had their most recent breast surgery more than five years ago indicated that they were aware of the Programme.

FIGURE 1 – PROGRAMME AWARENESS BY DATE OF BREAST SURGERY



Question: Have you heard of the National External Breast Prostheses Reimbursement Programme?

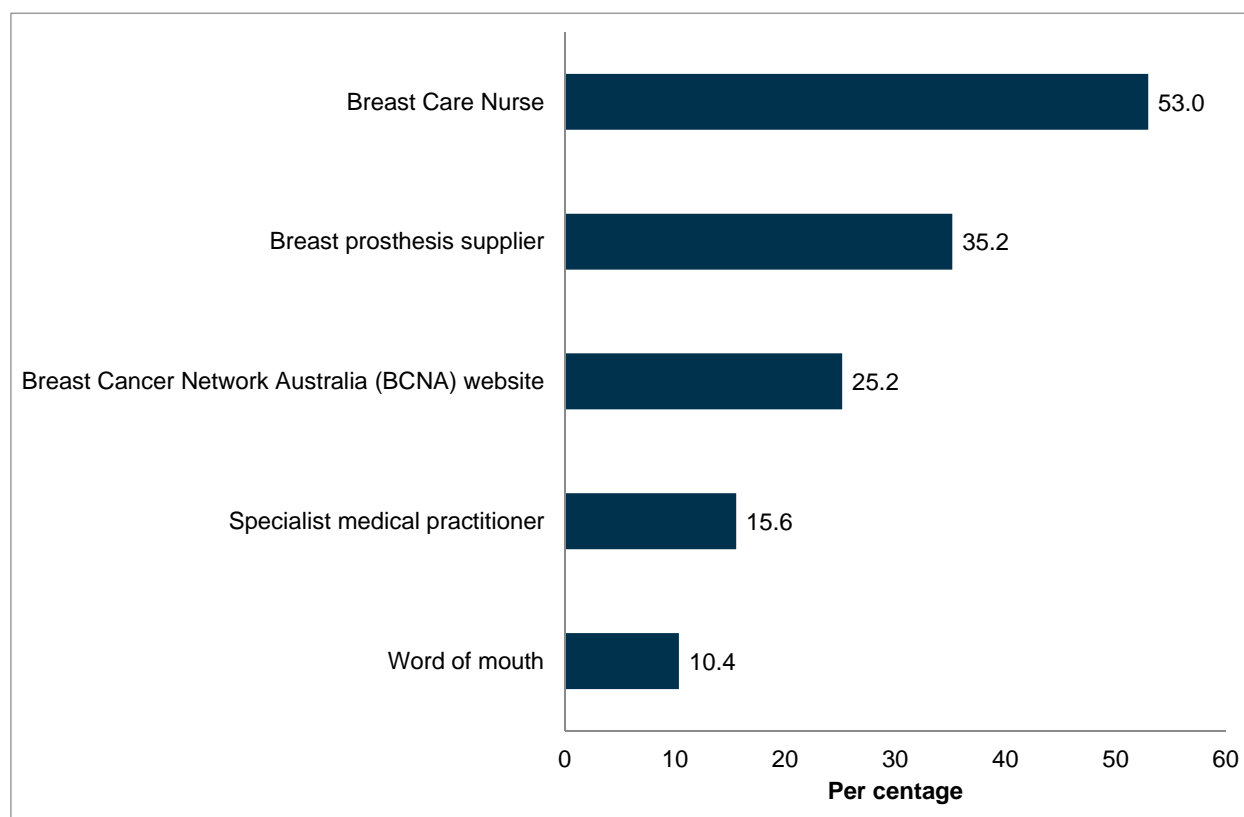
Base: n=266

This result is consistent with findings from the qualitative research, with programme participants and stakeholders consistently suggesting that there is high awareness of the Programme amongst eligible women and relevant support organisations. That said, some Programme participants suggested, unprompted, that Programme awareness continues to be one of only two significant barriers to access – the other barrier being inability to make upfront payment – for eligible women, especially women located in regional areas, women from culturally and linguistically diverse backgrounds, and women with disability.

## 2.1.2 INFORMATION CHANNELS

As shown in Figure 2, survey respondents most commonly indicated that they found out about the Programme through a breast care nurse (53%), breast prosthesis supplier (35%), or via the BCNA website (25%).

FIGURE 2 – INFORMATION SOURCES



Question: How did you hear about the National External Breast Prostheses Reimbursement Programme?

Base: n=270

This result is consistent with findings from the qualitative research, with Programme participants generally recalling that they were given written information (e.g. a flyer or pack of information about treatment or next steps) in the period immediately post-surgery, but that the meaningful discovery of the Programme came through discussion with a nurse or support group. Women who did not have access to a breast care nurse, or felt that they had been inadequately served by a breast care nurse, were more likely to report that they had first been informed about the Programme via a prosthesis supplier. These women, while typically pleased with other aspects of Programme delivery, expressed disappointment that they had not been informed about the Programme through a more formal mechanism. Women who had heard about the Programme via word of mouth expressed a similar disappointment at the lack of formal (and timely) information provision, especially if they had missed an opportunity to obtain a prosthesis or claim for a reimbursement.

*We have a cancer support group and we're a wing of it. I think had I been... where I previously lived I would have been lost in the system. I wouldn't have heard about it unless I read about it in the media.*

Programme participant

Few Programme participants reported – either through the survey or interview – that they had found out about the Programme from a health practitioner other than a breast care nurse. For example, only 16% of survey respondents indicated that they had heard about the Programme from a specialist medical practitioner, and interview participants typically stated that *doctors really aren't that involved* (or similar). A few women noted that discussing prostheses might be difficult for certain health professionals, such as male doctors and overseas trained doctors, because prostheses and accompanying equipment are viewed as underwear, not medical equipment, and therefore culturally difficult to talk about.

Some Programme participants reflected that Programme awareness amongst eligible women could potentially be improved by ensuring that breast surgeons possess a basic understanding of the Programme, and are able to sensitively provide relevant information (especially related to Programme access) to women when discussing post-surgery options. One interview participant further argued that improvements in surgical training (i.e. greater emphasis on patient welfare) may mean that surgeons are better equipped to undertake Programme-related discussions than they were in the past, stating: *Breast surgeons nowadays are perhaps more likely to listen and perhaps convey information whereas some time ago they weren't necessarily inclined to do that.* Other women, however, felt that breast care nurses were an effective conduit for clinical and support information (i.e. from other medical staff and support organisations), and that DoH's efforts should primarily be focussed on ensuring consistent awareness of, and engagement with, the Programme amongst these nurses.

### 2.1.3 INFORMATION AVAILABILITY AND USEFULNESS

Survey respondents were asked to rate aspects of the Programme out of five (with five being the highest, and one the lowest). Fifty-four per cent of respondents rated **information availability** as a four or five and 66% of rated **information usefulness** as a four or five (see Table 8). This suggests that while information provision and content is commonly held in high-regard by eligible women, there is potential for improvement. This assertion is supported by the results of the qualitative research, with most interview participants (including stakeholders and Programme participants) stating that they are, on the whole, satisfied with information provision and content, and making some, mostly unprompted, suggestions for communication enhancement. The following quote is typical of the responses made by interview participants (including stakeholders and Programme participants) when they were asked to rate the availability of information about the Programme:

*Now I know about it there's not a problem [with information availability]. And I'm actually coordinator of the local breast cancer support group and everyone that comes in I make sure they are aware and where we are we're lucky, we have a McGrath nurse so again that helps tell people.*

Programme participant

TABLE 8 – INFORMATION AVAILABILITY AND USEFULNESS

	ONE	TWO	THREE	FOUR	FIVE
<b>Availability</b>	6%	12%	28%	30%	24%
<b>Usefulness</b>	2%	8%	24%	31%	36%

Question: On a scale of 1 to 5, where 5 is the best score, how would you rate to following aspects of the Programme?  
The availability of information about the Programme; The usefulness of information about the Programme  
Base: Availability-n=173; Usefulness-n=170

Programme participants, via in-depth interviews, consistently expressed a preference for face-to-face and written communication. Women also suggested that the timing of communication activities is important (i.e. Programme information should be provided to women as close to their operation as possible), while stakeholders (and occasionally Programme participants) argued that more targeted communication activities are required to ensure equity in Programme information access. Each of the suggestions made by Programme participants and stakeholders is discussed in turn below.

**Written information:** Programme participants typically noted the importance of receiving written information about the Programme, especially if the information is received shortly before or after a breast surgery (i.e. while in hospital). When discussing their time in hospital, women typically noted that it was an extremely emotional and stressful period, during which they were 'bombarded' with information, especially information related to 'next-steps'. With regard to written material, many women noted that they were give a 'pack' of flyers, pamphlets, and information sheets shortly after surgery, much of which they were not interested in or able to read and understand at the time, but that it was helpful to have a physical resource they could read at an appropriate time.

*I had flyers of all kinds of things so I'm sure this was part of it because [finding out about prostheses] wouldn't have even occurred to me at that time.*

Programme participant

A small number of Programme participants also suggested that cancer treatment (e.g. radiotherapy and chemotherapy) had negatively impacted their ability to process and retain information – women referred to this mental cloudiness as *chemobrain* – making it especially important to have clear written material to guide decision-making, and to facilitate discussions with clinicians and support staff, as necessary.

*I think if I had to go looking for it myself, well I wouldn't have known the questions to ask.*

Programme participant

**Face-to-face communication:** Reflecting again on their time in hospital, some Programme participants reported being so overwhelmed and emotional during this period that they were not in a position to process written information, even after returning home post-surgery. Some of these women had found out about the Programme via a conversation with a breast care nurse (or less commonly another clinician), and spoke favourably of this experience.

*I think face to face is better in that it's all very confronting and you have all these decisions to make and, for me, I found there was a lot of written information but you go into overload and you go 'oh yes, here's something else'.*

Programme participant

It was, however, generally acknowledged that breast care nurses, especially in large territory institutions, are typically very busy, and sometimes only have time to respond to direct questions. For example, one interview participant stated: *I mean you've got the breast care nurses but you don't always see them and they're so busy that unless you're specifically asking something a lot of the time you won't see them.* As noted above, women suggested that the likelihood of successful face-to-face communication (at least of very basic Programme information) could be enhanced by ensuring that surgeons (and to a less extent other clinicians) are in a position to convey Programme information to eligible women during their pre- or post-surgery consultation. Oncologists, it was suggested, are also in a position to draw women's attention to the Programme when discussing treatment options.

*Well I think it probably wouldn't hurt to have the surgeons actually have the information there. After you have your operation then [the surgeon] comes into your room and that information is available to you.*

Programme participant

Women who had undergone their breast surgery in the period since Programme inception but had not learned about the Programme from a health professional reported a significantly reduced experience of finding out about the Programme. These women were disappointed that they had been required to seek out information – rather than having information provided to them in a timely and sensitive manner – during a stressful and vulnerable period. It should be noted that while these women typically requested face-to-face contact, Programme access experience would also be improved by ensuring more targeted provision of written material (i.e. contained within a pack given post-surgery rather than available in surgery waiting rooms).

*For me [finding out about the program was] disgusting... the information was just anywhere arbitrarily in the surgery, to just help yourself.*

Programme participant

**Timing of communication:** Programme participants consistently suggested that the provision of clear Programme information – including via written material and face-to-face contact – during the post-operative period would assist in ensuring ongoing opportunity for Programme access by all eligible women. Although it was generally acknowledged that women may feel overwhelmed during this period, it was considered to be the only time that contact could be made with *all women* who may wish to access (or at minimum consider accessing) the Programme. Stakeholders and Programme participants alike cautioned that written information provided during this period should be clear, concise, and provide contact details so that women can ask follow-up questions immediately or at a later date. Eligible women also suggested that face-to-face communication needs to be sensitive in conveying information, and ensure that patients are aware of all their options (i.e. claiming for a reimbursement does not preclude women from having a reconstructive surgery at a later date).

*[After surgery] you get a lot of information in like a little bag and things like that, like after you've had a baby, you get a bag of information. I think there might have been something*

*about it in that. And that is probably the best way because that's point of sale basically... If it isn't in the information that's given to post-operative breast patients then it should be, because that's where people take the most notice.*

Programme participant

**Targeted communication:** Stakeholders, and to a lesser extent Programme participants, suggested that the Programme could be more effective if it increased its marketing activity to women entitled to claim, particularly those women who may have had surgery pre-2008 and may not be aware of the Programme and entitlements. This could be achieved by ensuring campaigns are reaching women that may be eligible via targeted media planning and relevant collateral in media and places relevant to older women.

*We find some women sit with these deteriorating prostheses for years and years, because they can't afford prostheses, and don't know about this programme.*

Stakeholder

Stakeholders also thought that current communication could be more responsive to women who are newly eligible or have claimed under the current Programme. Ideas provided by stakeholders included responsive mechanisms such as distributing reminder notices at or approaching the two year renewal mark which may act as a reinforcement of key eligibility messaging. A few stakeholders provided the suggestion that in-language and targeted communication strategies directed at culturally and linguistically diverse women and Aboriginal and Torres Strait Islander women may improve access and participation in the Programme.

## 2.2 PROGRAMME IMPACT

Programme participants typically reported that the Programme had impacted them directly by allowing or enhancing their ability to access breast prostheses and indirectly by improving their overall quality of life. For example, just over nine in ten survey respondents who had accessed the Programme in the past two years (93%) agreed or strongly agreed that the Programme had made it **easier to afford a breast prosthesis**, and 86% agreed or strongly agreed that the Programme had a positive impact on their **quality of life** (see Table 9).

TABLE 9 – PROGRAMME IMPACT

STATEMENT	AGREE	DISAGREE
The programme made it easier to afford a breast prosthesis (n=171)	93%	2% (n=4)
The programme had a positive impact on my quality of life (n=170)	86%	2% (n=3)

*Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme.*

*Base: Contained in table.*

This result is consistent with the qualitative research findings:

- All Programme participants indicated that the Programme had made it easier to afford breast prostheses and a minority of women reported that they would have been unable to afford a prosthesis – and would have made alternative, less favourable arrangements – without access to the Programme.
- All stakeholders commented positively regarding the existence and effectiveness of the Programme in providing financial assistance to women who have undergone mastectomy as a result of breast cancer. The following stakeholder comment was typical of the positive response to the Programme:

*With breast cancer... there are such a huge number of costs ongoing and things like follow up screening, annual mammogram and out of pocket costs – to be able to buy your prosthesis and get it reimbursed is a huge benefit.*

Stakeholder

- Upon prompting, the majority of Programme participants acknowledged that access to the Programme, and consequently an ability to obtain very affordable breast prostheses as required, had positively impacted their quality of life, including through improved physical and psychological health.

*It is such a difficult time, I can't tell you what it meant to me having this support as you try to reclaim your life. It just feels like someone cares.*

Programme participant

Programme impact will be explored further in this section of the report, including:

- access to prostheses
- quality of life, including physical and psychological well-being
- suggestions for improved impact.

## 2.2.1 ACCESS TO PROSTHESES

As noted above, the Programme impacts most commonly reported by Programme participants are as follows:

- The majority of Programme participants reported that the Programme had made it easier to afford breast prostheses. These women typically reflected that while it would have been possible to 'scrape together' the funds to cover the cost of the prosthesis, it was comforting not to have to worry about covering the cost, especially during the period immediately post-surgery, when women are, reportedly, required to cover numerous other costs.

*I am grateful for this programme, as the costs involved with dealing with the other issues that breast cancer presents (compression garments for lymphedema, medications, special mastectomy bras etc) can be ongoing and very expensive.*

Programme participant

- A minority of women stated outright that they would not have been able to afford breast prostheses (especially on an ongoing basis) without access to the Programme, or a comparable state-based programme. One woman noted that she had continued to use the soft prosthesis provided by the hospital prior to hearing about, and consequently accessing, the Programme, while another woman recalled that some women, prior to project inception, had used rolled-up socks in lieu of a prosthesis.

*I know some people were saying that they use rolled up socks and things in their bras which they might feel comfortable with but it's not quite the same as having a nicely made prosthesis that gives you that natural look again.*

Programme participant

When discussing key Programme impacts (i.e. ongoing access to prostheses), Programme participants sometimes reflected on the importance of personal choice in cancer treatment, including during follow-up and ongoing care. These women were of the view that a key benefit, if not the key benefit, of the Programme was that it allowed breast surgery patients to consider their post-operative options without having to factor in additional costs (n.b. there is no charge to a woman if she has her breast reconstruction through the public health system). On a related note, some women explicitly stated that the existence of the Programme, and ongoing access, made them feel supported by the health system in their choice to not undergo reconstructive surgery. One woman was also pleased that the government was aiding access to a product that likely has more psychological (e.g. due to improved physical appearance) than physical (e.g. restored balance) benefits.

*I'm just very grateful that it's there and I really hope it continues because it does give women who don't want to go down the path of more surgery, an option of regaining their feminine looks.*

Programme participant

Programme participants with experience of other schemes (including state-based schemes) reflected that while Australian women had access to a reimbursement for a breast prosthesis prior to Programme



inception, it was much more difficult to obtain this reimbursement. A number of stakeholders with knowledge of past state-based schemes similarly noted that the consistent national approach to delivering an external breast prosthesis program reflected an overall improvement on previous schemes that were much more difficult for claimants to navigate.

*The fact that I've been able to even go through the public health system and have the reimbursement has been fantastic. Without that, it wouldn't have been simple. It would have been difficult. So it's been wonderful.*

Programme participant

On a related note, women who had lived in other jurisdictions, or had knowledge of approaches taken in other jurisdictions (or lack thereof), suggested that the Programme is quite unique, and tended to reiterate their contentment in not having to cover the cost.

*Well it's fantastic it's even offered. It's interesting Googling just seeing in other countries like in America or whatever where it doesn't sound like you necessarily have this reimbursement program and just the cost.*

Programme participant

## 2.2.2 IMPROVED QUALITY OF LIFE

Findings related to improved quality of life primarily came from information gleaned via in-depth interviews with Programme participants. Nevertheless, a number of stakeholders commented on the *vital* role that the Programme plays in improving well-being at a time when claimants may be experiencing significant stress and mental health issues.

*The mental things they go through, you can't begin to understand. Everyone goes through something, doesn't matter how strong you are – everyone goes through it*

Programme participant

As noted above, women typically suggested that the timely and ongoing access to breast prostheses afforded by the Programme had positively impacted their quality of life through improved physical or psychological health. Each of these aspects of health is discussed in turn below.

### PHYSICAL HEALTH

A small number of women noted the physical benefits of wearing a prosthesis (as opposed to a less formal breast-replacement structure), including:

- reduced sweating
- improved posture
- improved capacity to exercise
- protection of scars.

### PSYCHOLOGICAL HEALTH

Programme participants were far more likely to mention the psychological than the physical benefits of Programme access, including:

- **Reduced financial stress:** As noted above, women commonly suggested that they had borne, and sometimes continued to bear, substantial out-of-pocket costs as a result of their cancer diagnosis. This assertion is supported by the literature: for example, the 2006 Cost of Cancer in NSW report estimated that the total out-of-pocket costs (excluding productivity and medical costs) for adult cancer patients in NSW were \$2,648 per year for males and \$2,120 for females diagnosed with cancer. Women were typically pleased that they were not required to cover the cost of prostheses, and that this reduction in out-of-pocket costs, while admittedly minor, had reduced their level of financial stress (or at least not added to their financial stress).

*It's made it better not to have to worry about really spending extra money on something like this. It's probably made it better, the whole process better, if it can be.*

Programme participant

- **Improved body-image:** Improved body-image was mentioned by a large number of Programme participants. These women typically recounted that access to prostheses, especially affordable prostheses, had either increased their confidence or enhanced feelings of femininity. In both cases, the ultimate outcome was improved quality of life.

*I think it's given me a fantastic opportunity to restore my femininity. For some people surgery is a pathway you don't really want to go through yet again after having a mastectomy.*

Programme participant

*Obviously it was the best day that I'd had, honestly, getting that bra and how they put the t-shirt over the bra with the prosthesis in it and for the first time, you look sideways and go 'oh wow! I don't look like I've just had surgery,' and it was an emotional thing.*

Programme participant

Some women noted that they had chosen not to undergo a reconstructive surgery as they were passed the 'vanity of physical appearance'; these women typically noted that the prosthesis allowed their clothing (including pre-surgery clothing) to fit correctly, and had also meant that they were not required to disclose or discuss their medical condition unless desired.

*So having a prosthesis just means that my clothes hang really nicely on me and I feel quite normal. In fact no one, when I run into people, no one even knows what I've been through because I look very normal still with my prosthesis.*

Programme participant

- One woman suggested the purchasing of prosthesis could contribute to a sense of closure after a, sometimes long, cancer diagnosis and treatment journey, stating: *It's part of recovery because you've gone through a long journey of surgery, chemo, radiation, you need to have some sort of closure and feeling normal again, so it helps.*

## 2.3 SUGGESTIONS FOR IMPROVED IMPACT

### 2.3.1 BRAS AND OTHER UPKEEP COSTS

A large proportion of Programme participants requested, via in-depth interviews and open-ended survey responses, that specialist undergarments (i.e. bras) and swimwear, required to wear most external breast prostheses, be covered as part of the Programme. While mostly acknowledging that all women are required to purchase lingerie, interview participants noted that mastectomy bras are typically more expensive than non-mastectomy bras. These women also tended to argue that it was not possible to wear the large majority of external breast prostheses without a specialist mastectomy bra. A number of stakeholders from the NGO sector also commented that the Programme could be more effective in providing financial support to women by allowing for a number of prosthesis-related support equipment to be claimed, such as specialised external prosthesis bras and specialised swimwear.

*And that's my biggest gripe about it because the bras are just so expensive and you know, she fitted me and then she brought out a bra and I said well how much is that and she said \$80 and I said that's ridiculous haven't you got anything cheaper and she did bring me out a \$60 one.*

Programme participant

Women with experience shopping for mastectomy bras in other jurisdictions also suggested the price of these bras in Australia compared unfavourable to the price in other jurisdictions.

*Alright, well some of the big supermarkets, so Marks and Spencers in England, they sell mastectomy bras and they cost 8 pound, \$16 compared to our \$60 cheapest. Anyway*

*when I got home I wrote to K-Mart and I said how disappointed I was that they didn't cater for people who are looking for mastectomy bras and of course they don't do anything.*  
Programme participant

Other specialist products and upkeep costs noted by Programme participants included:

- swimming costumes
- specialist activewear
- adhesive tape/backing:

*I wear adhesive prosthesis [and] the adhesive can wear out before the 2 years - I can replace just the backing but cannot claim this even though it is much less than the whole prosthesis*

Programme participant

- specialist washing detergent for bras: *I had to buy a special wash for it and all this sort of caper.*

### 2.3.2 SWIMMING PROSTHESES

A significant number of women requested the Programme be expanded to cover specialist swimming prostheses, and less commonly, sport prostheses. It was envisaged that eligible women would either claim for one of these specialist prostheses in lieu of, or ideally in addition to, an everyday prosthesis. Some interview participants specifically suggested the Programme should reimburse women for an everyday prosthesis every two years and a specialist prosthesis every four years. It should, however be noted that women are in fact able to claim for a swimming prosthesis (in lieu of an everyday prosthesis) under the Programme, and further promotion of this option may help to alleviate women's concerns.

Women who expressed a desire for a swimming or sport prosthesis tended to point out the importance of exercise for breast cancer survivors, especially in the period immediately post-cancer treatment. Some women also noted that their everyday prostheses tended wear out more quickly when worn during regular, vigorous exercise (e.g. weekly netball games). In addition, some women felt that by not being able to wear a swimsuit, they were missing out on an opportunity to express their femininity.

*I think to do anything that encourages women to feel good about themselves and be active, got to be a good thing.*

Programme participant

### 2.3.3 IMPROVING DISCRETIONARY CLAIMS PROCESSES

Since the launch of the Programme, a number of discretionary business rules have been introduced to ensure that entitlement can be maintained under a number of special circumstances. The medical discretion policy allows for a replacement prosthesis to be reimbursed within two years of a previous reimbursement for medical and/or cancer treatment reasons (i.e. due to a medical condition). This could, for example, include weight loss/gain due to breast cancer treatment.

A small number of eligible women suggested that the discretionary claims eligibility criteria should specifically cover instances of weight gain or weight loss (i.e. changed breast shape or size) that are unrelated to a medical condition of cancer treatment; however, this was not a widely held view.

*It is only 10 months since my purchase - and since that time I have lost a considerable amount of weight - which means that my remaining natural breast is considerably smaller than the prosthesis - meaning that I continue to appear and feel lopsided as I cannot afford to purchase another prosthetic breast until eligible under [the] Programme.*

Programme participant

The need for discretionary claims to be evidenced by further information often delays the reimbursement process. DHS however do not provide information about the specific information needed to process a

discretionary claim, which stakeholders suggest can lead to inefficiencies. This process could be made more effective and efficient by DHS informing discretionary claimants up-front of the requirements to process a claim successfully. For example, provision of specific guidance on seeking reimbursement for an additional prosthesis due to weight gain or weight loss would assist in ensuring that women do not go through the process of applying for a discretionary claim, only to have the claim rejected.

## 3 Programme access

### 3.1 PROGRAMME ACCESS

#### 3.1.1 OVERALL ACCESS

Stakeholders reported that the consistent national approach to administering the Programme has helped to ensure that most women across Australia have the ability to access the reimbursement scheme. Key factors reported to have boosted the accessibility of the Programme include the integration into the Medicare service provision system and the streamlined set of eligibility criteria which has ensured the information burden on claimants remains low. This approach, it was reported, has ensured that all women with access to Medicare who have undergone breast surgery as a result of breast cancer can claim for reimbursement under the scheme. Eligible women too stressed that, in their experience, awareness and understanding of the Programme, and ultimately access, had improved over time. These women recalled that there was limited promotion of the Programme during the phase of implementation, and that promotion material was sometimes confusing, but that approaches to communication had improved in recent years.

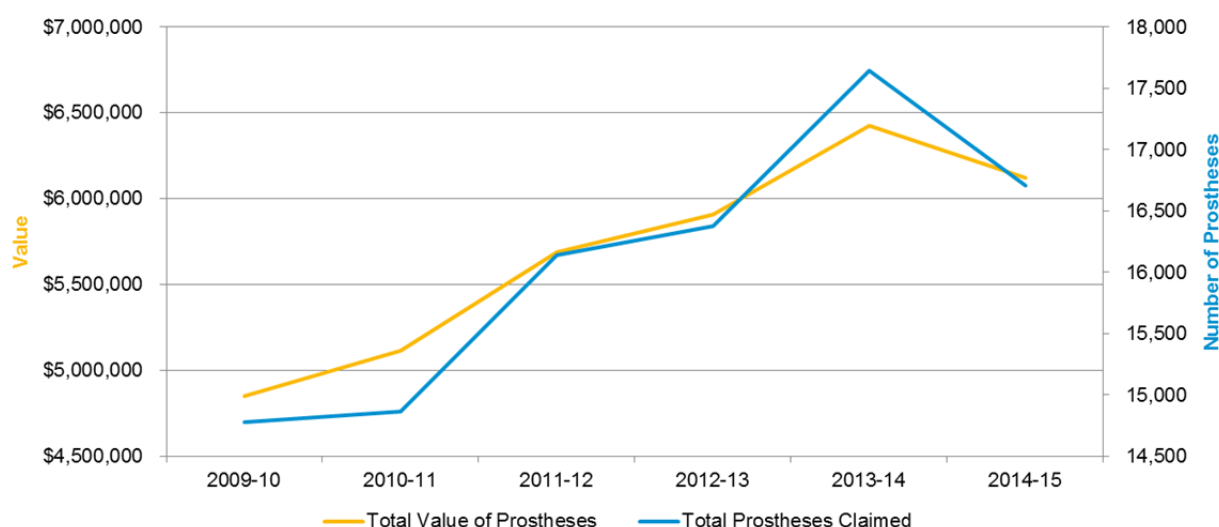
According to stakeholders, improved awareness and understanding of the Programme amongst healthcare providers and support organisations was also thought to have improved Programme access by assisting to ensure that all newly diagnosed, eligible women are aware of the Programme. In addition, the introduction of discretionary rules has meant that women are able to access the Programme more than once over a two-year period, with a certificate from a medical practitioner.

*Our role has been really to inform women about the program through the 13 11 20 line. So we'll have women ring, with questions around, they've had a mastectomy, what do they do and we'll tell them about the programme. And we'll give them the right information and point them in the right direction and where they need to go to access that programme if they haven't heard of it before.*

Stakeholder

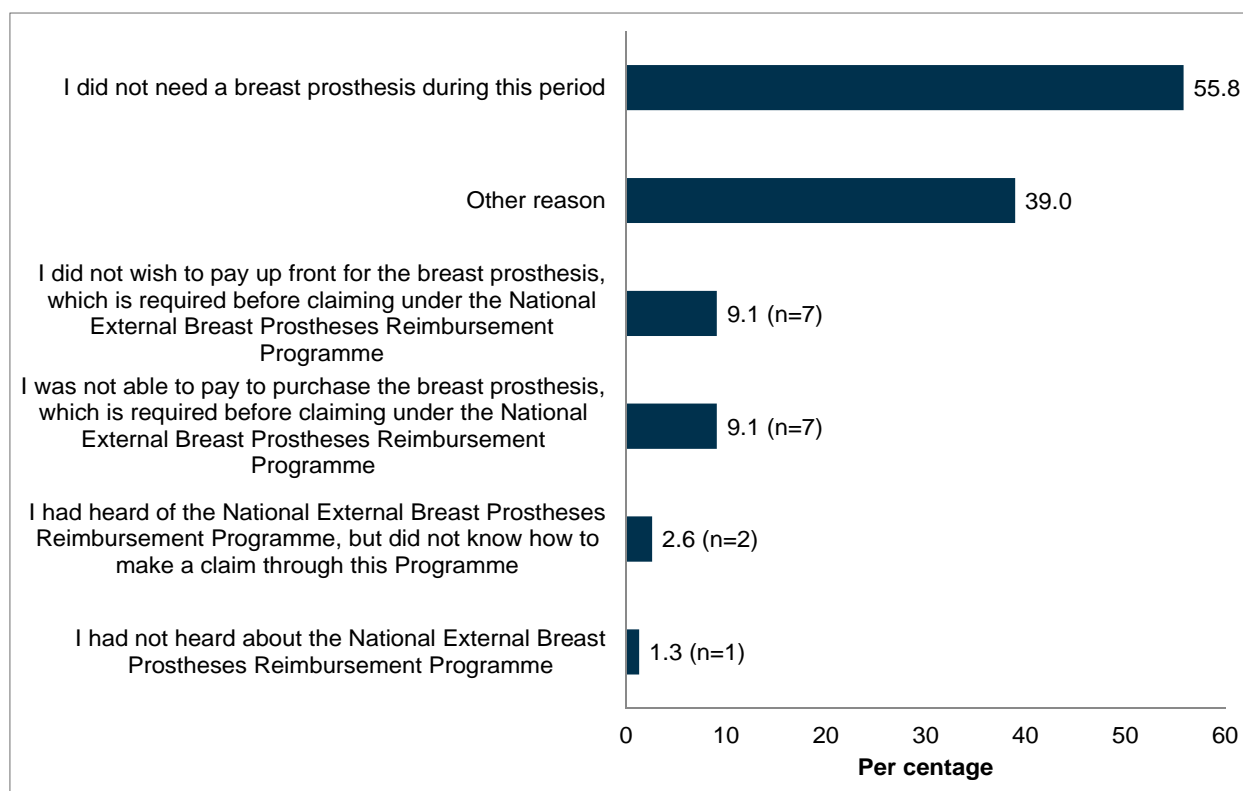
Evidence of Programme access, and improved access over time, is, on the whole, supported by available Programme data. Over six years, from financial year 2009-10 to 2014-15, there has been a total of 96,514 breast prostheses provided to women across Australia. The sum of the value of the reimbursement over this time is \$34,111,819. The uptake of the service has increased over the last six years with a compound annual growth rate of 2.49%. There was, however, a significant decrease in the number of prostheses reimbursed in 2014-15, dropping by 941 prostheses.

FIGURE 3 – TOTAL NUMBER OF CLAIMS AND SUM VALUE



Evidence of Programme access is further supported by survey results: almost two thirds (62%) of respondents indicated that they had made a claim for reimbursement from the Programme in the last two years. The most common reason for not claiming for a prosthesis during this period was not needing one (56% of those who did not claim); this suggests that lack of knowledge (mentioned by only one respondent) and lack of understanding (mentioned by only two respondents) are not significant barriers to Programme access (see Figure 4). It should be noted that an additional 12 respondents who selected 'other' cited that they did not want a new prosthesis, either because they do not like wearing them or because their old prosthesis is sufficient. Other reasons for not claiming included undergoing a reconstruction (nine respondents) or a double mastectomy (three respondents). Eighteen per cent of respondents cited up-front cost as the primary barrier for Programme access.

FIGURE 4 – REASON FOR NOT MAKING A CLAIM



Question: What were your reasons for not making a claim for reimbursement through the Programme for an external breast prosthesis in the last 2 years? Please select all that apply  
Base: n=77

### 3.1.2 REJECTIONS

Only a very small number of survey respondents (n=5) and no interview participants indicated they had had a claim rejected for reimbursement. In addition, interview participants were unaware of any women in their acquaintance having a claim rejected. This low incidence among the survey respondents is supported by Programme administrative data: as shown in Table 10, the number of claims that have been rejected for reimbursement has hovered around 300 to 400 per year since Programme inception, which is less than 2% of the total claims processed by DHS. It should further be noted that the figures shown in Table 10 may overestimate the number of rejections, as there is the potential for refusals to be reversed upon provision of additional documentation (i.e. the claim is paid under the medical discretion policy criteria).

TABLE 10 – REJECTED CLAIMS BY YEAR

YEAR	REJECTIONS
2010-11	368
2011-12	329
2012-13	410



2013-14	365
2014-15	393

Awareness of women's claims being rejected for reimbursement, and typical reasons for rejections, was low amongst external stakeholders, with most stating that they were either not aware that claims could be rejected or had not come across a woman whose claim had been rejected. Most attributed the small number of rejections, and the consequent low awareness, to the simple, clear Programme eligibility criteria (i.e. women who are ineligible make a decision not to submit a claim after reviewing the criteria). Eligible women also attributed perceived low rates of rejections to clear Programme eligibility criteria, and also to suitability of reimbursement frequency (i.e. there is no need for women to claim more than once every two years). It should be noted that survey respondents whose claim reportedly had been rejected did not provide a clear reason for the rejection, instead simply stating that the reimbursement had not been deposited into their designated bank account.

Stakeholders who were aware of claims being rejected for reimbursement – typically stakeholders from DoH and DHS – suggested that claims were most commonly rejected because a claimant had undergone a mastectomy (or were missing a breast) for a reason other than breast cancer (n.b. most commonly another breast disease) or because a claimant had submitted a claim more frequently than once every two years without a valid reason (e.g. weight gain or weight loss, preference for a difference type of prosthesis). Stakeholders typically were hesitant for the eligibility criteria to be expanded to cover these situations, especially if it complicated the Programme, but did stress that current discretionary arrangements should be maintained (e.g. ability to apply for an additional prosthesis for medical reasons or in situations where prostheses had been destroyed through natural disaster). One stakeholder further suggested that claims are occasionally rejected because medical practitioners do not clearly outline the medical reason necessitating additional prostheses.

*People can claim more frequently than two years if there is a medical reason, but I get the impression that a small handful of women have medical practitioners who don't necessarily write what's needed to explain the medical reason. There are practitioners who think they just need [to say] 'needs a new/second prosthesis' where we need them to demonstrate a medical reason.*

Stakeholder

## 3.2 BARRIERS TO ACCESS

Stakeholders suggested that factors influencing the women's access to the Programme may include lack of awareness, financial hardship, remoteness, and surgery timing. It is also evident from the Programme and consultation data that Aboriginal and Torres Strait Islander women and women from diverse cultural and language backgrounds are underrepresented and may experience barriers in accessing the Programme. Each of these factors is considered below.

### 3.2.1 AWARENESS

While evidence (including Programme and evaluation data) suggests the Programme awareness and understanding, and consequent access, has improved over time, a significant number of Programme participants suggested that awareness (or lack thereof) remains a barrier to access.

*I'm amazed the number of women who I've met in various support groups who didn't know about it.*

Programme participant

Many interview participants considered it 'a shame' that some women continue to miss out on accessing an uncommonly simple, well-functioning, and important Programme through lack of awareness. Some women also noted that they had been unaware of the Programme for some time prior to access, or that they had learned about the Programme via informal, rather than formal, mechanisms (i.e. recommendation of a friend).

*I think the program is fantastic and I do my bit too, to promote it to people who have undergone mastectomies just to make sure they do know it's there because from what I've gathered there's a lack of information for a lot of women out there still.*

As noted above, women did acknowledge that communication about, and understanding of, the Programme had improved in recent years, with one interview participant stating *It was quite confused at first, no one really knew what it was* and another arguing *there may be a little bit more around now, but I wouldn't say it's in your face*. Suggestions for improved communication activities are included in Chapter 2 of this report.

### 3.2.2 FINANCIAL HARDSHIP

Programme access for women in financial hardship or on fixed incomes was raised by stakeholders as the most consistent challenge. Key concerns focused on the difficulties for some women of affording the up-front costs to purchase prostheses and related items under the 'reimbursement' model of the Programme. Concern for this issue is known to DoH, as identified in feedback from the public, which has generated more than 40 pieces of correspondence since the Programme was launched in 2008. However, the number of comments received related to financial hardship has been small as a proportion of the number of women who have participated in the Programme.

*The issue that has come across most strongly from the [Breast Care] nurses is the concern for women that couldn't afford it...I'm just wondering whether there is a system that could be put in place for people who perhaps can't afford the costs upfront.*

Stakeholder

Programme participants too expressed concern about the reimbursement model, with most either agreeing that it had been difficult to afford the up-front payment or suggesting that it may be tough (and sometimes impossible) for women on a fixed income to afford the payment. For example, while 93% of survey respondents agreed or strongly agreed that the Programme had made it **easier to afford a prosthesis** (see Table 9, above), 41% indicated that it was **difficult to afford the up-front payment** (see Table 11).

TABLE 11 – UP-FRONT PAYMENT

STATEMENT	AGREE	DISAGREE
It was difficult to afford the up-front payment required for a reimbursement under the Programme (n=169)	41%	31%

*Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme.*

*Base: Contained in table.*

Similarly, some interview respondents mentioned, unprompted, that while the Programme had enabled access to a prosthesis, they were curious as to why the Programme did not function in similar fashion to Medicare, or explicitly suggested that alternatives to a reimbursement approach should be considered by the DoH or DHS. This view was especially common amongst single women and women who rely on a pension. A number of women also reflected that they would not have been able to afford the up-front payment if they did not have access to a credit card. Other women expressed concern that they may not be able to afford the up-front fee post-retirement, or if their circumstances were substantially altered (e.g. death of spouse). Finally, some women indicated that the Medicare branding had led them to assume that the rebate would be immediate, and were dismayed when they learned of the gap between payment and reimbursement.

*I'm 70 years of age and I don't have an income so I'm pretty much at a loss as to how I'm going to do it this time but I'm sure there will be some way that we can do this.*

Programme participant

*Look I think for me it has worked because a) I've had access to the credit card and so I was able to get it without having to find other ways which I probably could have borrowed or something but that has been really helpful. If I wasn't in that situation, then it would be a completely different question.*

Programme participant

Specific suggestions for alternative Programme arrangements (including arrangements that cover only select Programme participants) included:

- vouchers that could be exchanged for a prosthesis at select or all suppliers

*Whether they could perhaps get a voucher, apply for a voucher, I don't know that Medicare would ever do that, a voucher to go into and so they've got upfront payment.*

Programme participant

- a capacity for women to apply for up-front funding in special circumstances (i.e. when they are unable to afford to make the payment)
- a system similar to Medicare, in which women are only required to pay the gap between the cost of the prosthesis and the reimbursement.

These alternative arrangements, especially the latter two suggestions, would substantially increase the level and complexity of the Programme's administrative processes.

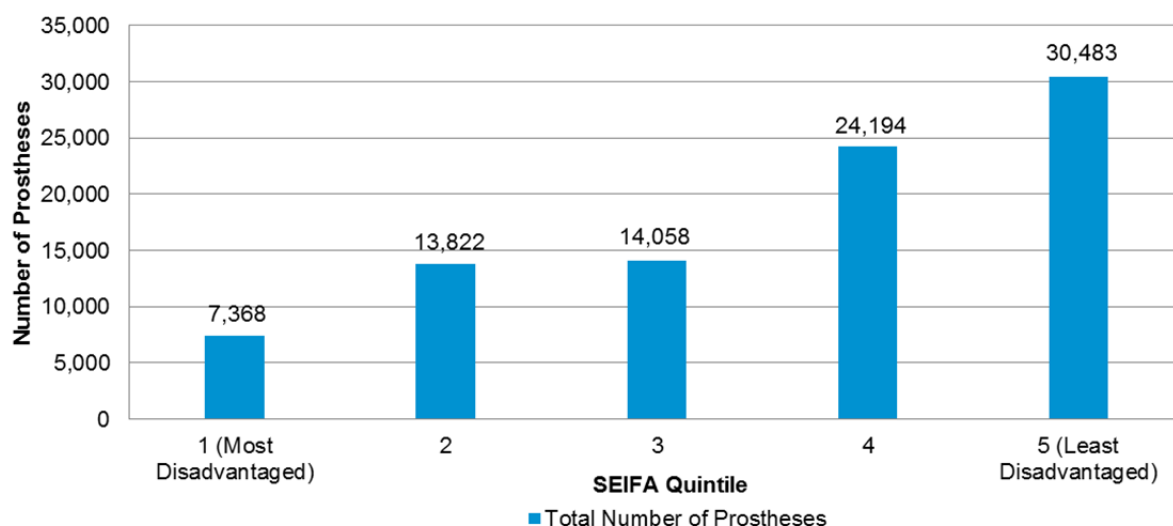
It should, however, be noted that under DHS regulations women who have received an income support payment (including age pension) for more than three months may be eligible for an advance up-front payment of a proportion of their benefit, which could (subject to approval of application) be used to cover the cost of purchasing a prosthesis. Further information on advance payment options is available at: <https://www.humanservices.gov.au/customer/enablers/advance-payment-options>. Awareness of this option was non-existent amongst interview participants, and direct promotion could assist in alleviating concerns about the reimbursement model. In addition, DHS is able to expedite claims for women who require urgent payment – awareness of this option was also non-existent amongst Programme participants, and could be promoted to select women (e.g. income support recipients).

It is also noteworthy that Programme administrative data indicates that women across all level of socio-economic advantage and disadvantage are currently accessing the Programme. Socio-Economic Indexes for Areas (SEIFA) is a product developed by the ABS that ranks Local Government Areas in Australia according to relative socio-economic advantage and disadvantage. The indexes are based on information from the five-yearly Census. Figure 5 below shows the number of prostheses claimed across SEIFA quintiles:

- the left vertical axis indicates the total number of prostheses accessed by women over a five-year period from 2009 to 2013
- the horizontal axis displays SEIFA quintiles, with lower quintile indicating lower socio-economic advantage.

Collectively, the data suggests that while women across all levels of socio-economic advantage and disadvantage are accessing the Programme, access is most common for women residing in areas with a high SEIFA index (i.e. 4th and 5th quintile). It should be noted that we have no information to account for this variance at this time, and it may warrant further examination.

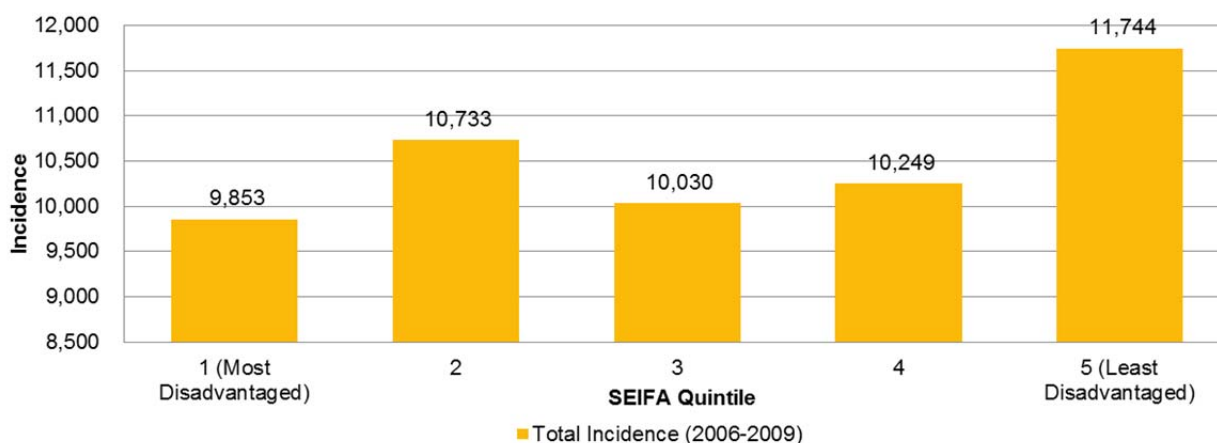
FIGURE 5 – CLAIMS BY SEIFA INDEX



It is possible that the more common Programme access amongst women residing in areas with a high SEIFA index could, at least partially, be attributed a higher incidence of breast cancer in those areas. Figure 6 below shows the incidence of breast cancer across SEIFA quintiles:

- the left vertical axis displays the total number of breast cancer cases over a four-year period from 2006 to 2009
- the horizontal axis displays SEIFA quintiles, with lower quintile indicating lower socio-economic advantage.

FIGURE 6 – BREAST CANCER INCIDENCE BY SEIFA INDEX



### 3.2.3 REMOTENESS

Women in regional and remote areas are affected by geographic accessibility, a problem which is not unique to this Programme, or indeed to health or even government services. Stakeholders explicitly, and consistently, stated that women in remote and regional locations in Australia can experience difficulty accessing health and retail services, and sometimes need to travel long distances to attend a DHS Service Centre to claim under the Programme. Another stakeholder noted that the Programme may be more important for women outside metropolitan areas, as limited treatment options available for women post-surgery, such as breast reconstruction surgery, may make external prostheses a more desirable option. Online processing was commonly suggested as a potential method for improving Programme access for women outside of metropolitan areas, and for improving Programme access more generally.

It should, however, be noted that available Programme data suggests that women outside metropolitan areas are successfully accessing the Programme, which is partly safeguarded by its integration into Medicare (see Table 12).

TABLE 12 – NUMBER OF PROSTHESES CLAIMED BY REMOTENESS

REMOTENESS	NUMBER OF PROSTHESES 2009-2015	INCIDENCE 2005-2009
Major Cities of Australia	62,603	44,292
Inner Regional Australia	23,136	13,789
Outer Regional Australia	8,591	5,825
Remote Australia	887	714
Very Remote Australia	296	252

In addition, survey respondents located in metropolitan areas were in fact *less likely* than respondents located in regional/remote areas to indicate that they had made a claim under Programme in the past two years, providing further evidence that remoteness is not significantly impacting Programme access. Consistent with this finding, interview participants located in regional or remote areas typically recounted that they purchased their prosthesis (and submitted their claim for reimbursement) during regular shopping trips to large regional centres. These women were satisfied with this arrangement, and spoke favourably of the relationship they had developed with prosthesis supplier staff since Programme inception.

TABLE 13 – PROGRAMME ACCESS BY REMOTENESS

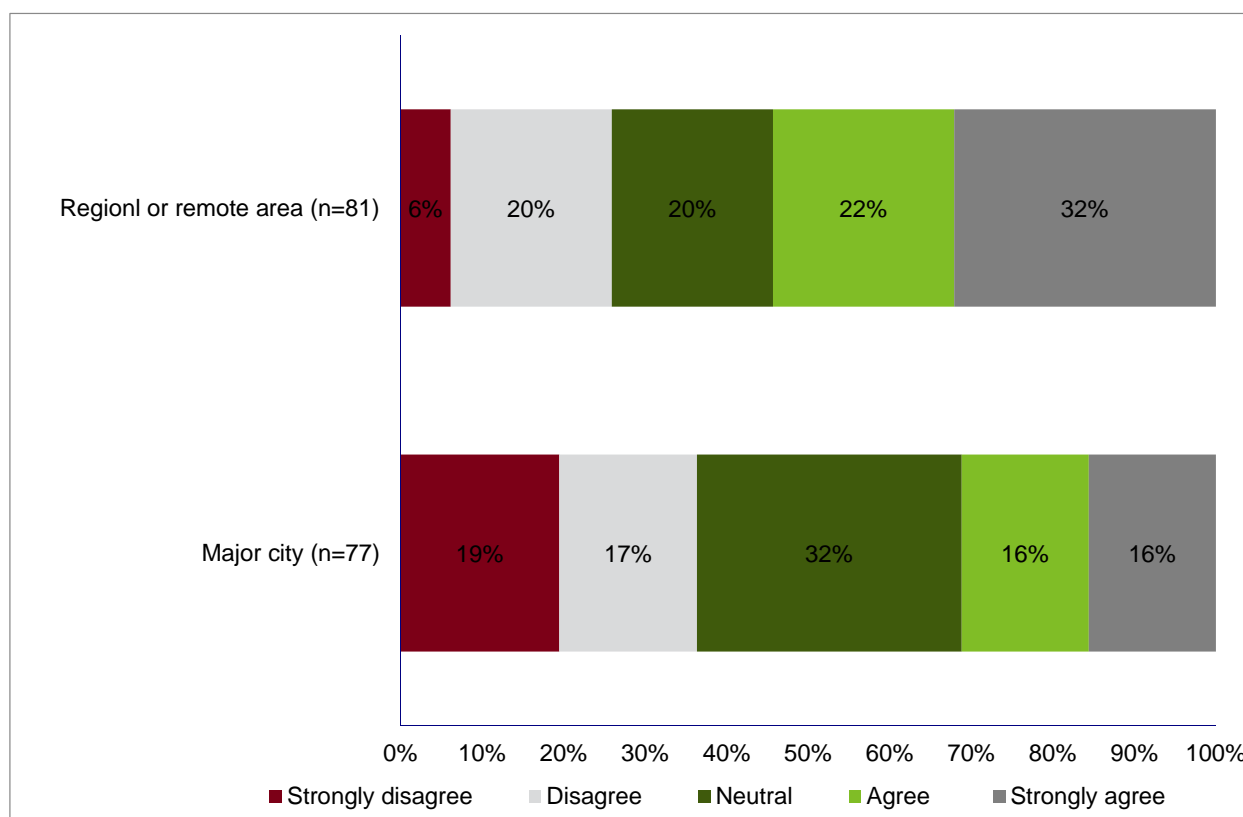
	MAJOR/CAPITAL CITY (N=125)	REGIONAL CITY/LARGE COUNTRY TOWN (N=61)	SMALL TOWN (N=39)	REMOTE VILLAGE/ AREA AWAY FROM TOWN (N=17)
Claimed for reimbursement made in the past two years	65%	74%	82%	71%

*Question: In the last two years, have you made a claim for reimbursement through the National External Breast Prostheses Reimbursement Programme?*

*Base: Contained in table.*

Survey data suggests that women located outside of metropolitan areas are much more likely to agree that it was difficult to afford the upfront payment for reimbursement, with 54% of respondents in regional/remote areas agreeing or strongly agreeing (compared to 31% for respondents located in metropolitan areas).

FIGURE 7 – AFFORDABILITY OF UPFRONT PAYMENT BY REMOTENESS



Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme. It was difficult to afford the up-front payment required for a reimbursement under the Programme  
 Base: Contained in figure.

### 3.2.4 SURGERY TIMING

As noted above, survey evidence suggests that Programme awareness amongst eligible women is high: around 95% of survey respondents who had their most recent breast surgery more than five years ago indicated that they were aware of the Programme. Despite this, interview participants (including stakeholders and Programme participants) suggested that, in their experience, Programme awareness was still sometimes lacking amongst women who had undergone their breast surgery prior to 2008 (i.e. Programme inception). Both stakeholders and Programme participants were of the view that greater engagement of GPs (and other specialist clinicians) would assist women who had undergone mastectomy some years ago to learn about and access the Programme. This cohort of women are hard to reach as they are not easily identifiable, and would have missed the opportunity for 'point-of-operation' information provision (i.e. written information or communication with breast care nurse). GPs, it was suggested, could fill the information gap by having brief discussions with women about the Programme during designated check-ups (which reportedly last for several decades), and by ensuring that written information is available in surgery waiting rooms. Other suggested communication channels for women who had a breast surgery prior to 2008 included:

- targeted campaign via BCNA website and newsletter
- advertisement in senior magazines
- advertisement in oncology waiting rooms.

Most interview participants struggled to suggest appropriate communication channels, and instead noted that it will be very difficult to reach women who are no longer engaged with breast cancer support organisations, or undergoing regular check-ups. Nevertheless, most women were of the view that the number of women failing to access to Programme due to inadequate awareness has most likely decreased over time, as only one successful communication activity is required for ongoing access (i.e.



women only need be informed of the Programme once). Increasing Programme access over time supports this assertion.

### 3.2.5 ABORIGINAL AND TORRES STRAIT ISLANDER WOMEN AND WOMEN FROM CALD BACKGROUNDS

There is little data available to quantify Programme access for women from culturally and linguistically diverse backgrounds or Aboriginal and Torres Strait Islander communities. That said, a number of stakeholders identified the lack of available translated information resources as a potential barrier to women from culturally and linguistically diverse backgrounds from accessing the Programme. One breast care nurse highlighted the importance of translated information that would allow nursing and cancer care staff to share information about the Programme with women who have poor English language proficiency.

*It is challenging if you are someone providing information to patients and obviously there is only so much they can take in at a consult, and you want to be able to guide them, there is no way to be able to necessarily guide them to get information in other languages.*

Stakeholder

The importance of culturally sensitive communication material for culturally and linguistically diverse women, who may not feel comfortable talking about the topic, was also noted by a Programme participant, who suggested: *I think you need to feel comfortable talking about it. And if you're not comfortable talking about it, you're not going to claim anything are you?* This point was also made with regard to Aboriginal and Torres Strait Islander women, with one Programme participant suggesting: *If you're out in country or in remote communities and I would imagine for a lot of cultures it's something that's not easy to speak about.*

Stakeholders commented that Aboriginal and Torres Strait Islander community access to the Programme may also be impacted by financial hardship and geographic isolation. One stakeholder provided an example of an isolated community where women face multiple issues that may inhibit their ability to access the Programme:

*I met with some Indigenous women in a geographically isolated community in WA who just couldn't access breast prostheses at all because they just couldn't afford the \$400 up front and they don't have access to credit cards. There is a whole community there where women can't access prostheses.*

Stakeholder

Consistent feedback with regard to the experience of Aboriginal and Torres Strait Islander women was included in open-ended survey responses:

*As a member of a support group in a remote region, I am aware that it is virtually impossible for Aboriginal women to be able to pay up front to purchase a breast prosthesis. Also in many places it can be difficult to access a fitting by a qualified person.*

Programme participant

*I work with Aboriginal women and they cannot afford to pay upfront for a prosthesis so go without. It appears they cannot pay for it in stages. I feel for those on very low incomes this is not something they can afford. There should be means for them to be able to have a breast prosthesis.*

Programme participant

Like any other women, there may be many reasons why women from culturally and linguistically diverse backgrounds or Aboriginal and Torres Strait Islander women do not access the Programme including, for instance, women choosing not to wear a bra, or women who do not feel the need to replicate their previous body shape following mastectomy. Appendix A provides a brief summary of some factors identified within the literature which may influence women's access to a breast prosthesis. However, it should be noted that due to the low number of culturally and linguistically diverse or Aboriginal and Torres Strait Islander women participating in the Programme, there is little information regarding the reasons why women may not be accessing reimbursements for breast prostheses through the Programme, and to avoid speculation further research is required to understand some of the particular needs of these diverse groups.

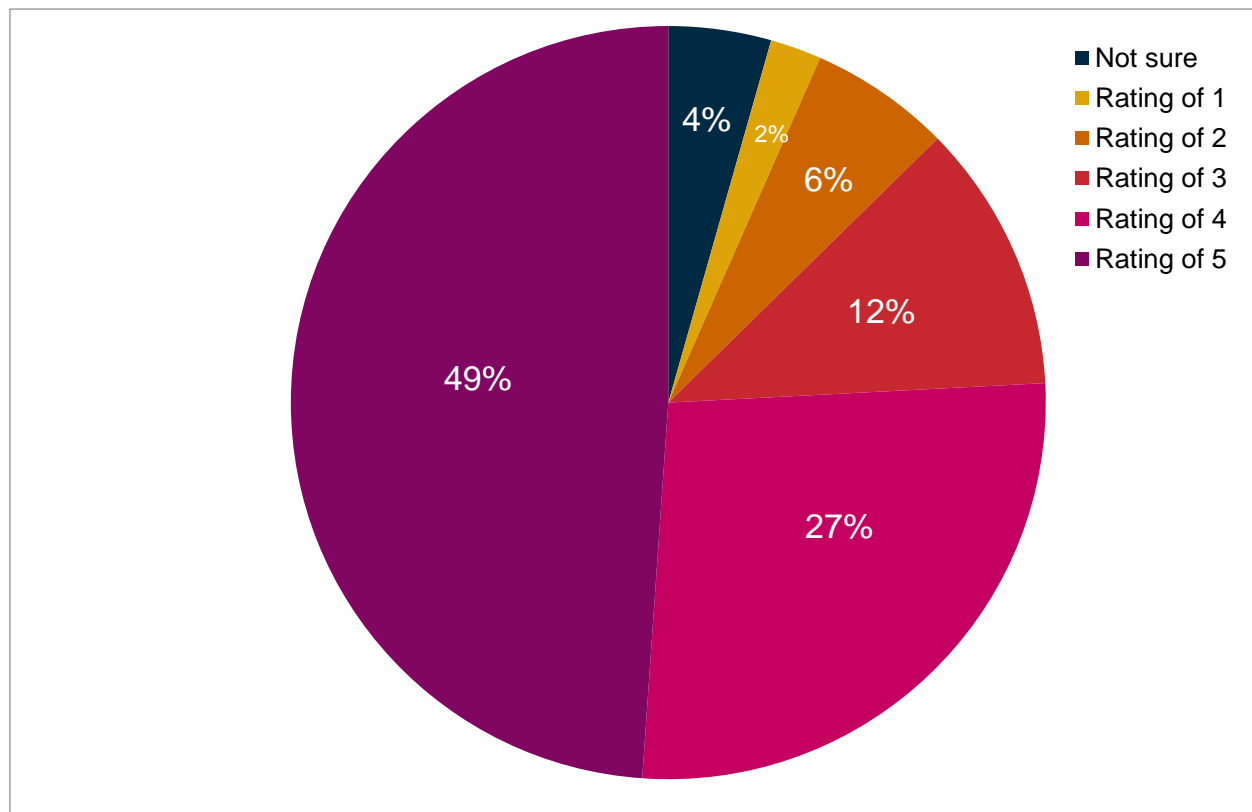
## 4 Programme experience

### 4.1 OVERALL EXPERIENCE

The survey results suggest that eligible women, on the whole, have had a positive Programme experience (see Figure 8):

- just over three quarters (76%) of survey respondents rated their **overall Programme experience** as either four (27%) or five (49%) on a 5-point scale.
- only four survey respondents (2%) gave their **overall Programme experience** a rating on one out of five on a 5-point scale.

FIGURE 8 – OVERALL PROGRAMME EXPERIENCE



Question: On a scale of 1 to 5, where 5 is the best score, how would you rate to following aspects of the Programme?  
The overall experience of the Programme.

Base: n=182

This result is consistent with the qualitative research findings: Programme participants consistently reported, via in-depth interviews, a very positive overall Programme experience, with most suggesting, unprompted, that the process for claim submission was simple and that they had received their reimbursement in a timely fashion. Women who had experience of past state-based schemes tended to reflect that the process for claim submission was much improved under the national scheme. Similarly, stakeholders noted that the consistent national approach to delivering an external breast prosthesis program reflected an overall improvement on previous schemes that were much more difficult for claimants to navigate. Programme participants also suggested that the claim submission process, and subsequent deposit of reimbursement, compared favourably to private health insurance claim submission processes, with one interview participant noting: *It was difficult... Actually the private health people are more of a difficulty... It was quite some time later that the health fund said I wasn't eligible and then I had to get letters from David Jones to say it was a legitimate claim.* The following quote was typical of the positive comments made by eligible women about their Programme experience:

*The fact that I've been able to even go through the public health system and have the reimbursement has been fantastic. Without that, it wouldn't have been simple. It would have been difficult. So it's been wonderful.*

Programme participant

The remainder of this section will more specifically consider eligible women and, to a lesser extent, stakeholder views on:

- the process for claim submission
- efficiency, effectiveness, and adequacy of the reimbursement.

## 4.2 CLAIM SUBMISSION

Survey respondents who had made a claim in the past two years typically held the claim submission process (including obtaining, completing, and submitting the application form) in high-regard: over 70% of respondents indicated that **obtaining and lodging** the application form was easy (74% and 72% respectively rated four or five out of five) and 85% indicated that **completing** the application form was easy (85% rated four or five) (see Table 14).

TABLE 14 – ASPECTS OF MAKING A CLAIM (RATING OUT OF FIVE)

	ONE	TWO	THREE	FOUR	FIVE
<b>Obtaining</b>	4%	9%	14%	27%	46%
<b>Completing</b>	4%	2%	9%	23%	61%
<b>Lodging</b>	6%	5%	18%	18%	53%

*Question: On a scale of 1 to 5, where 5 is the best score, how would you rate to following aspects of the Programme? The ease of obtaining an application form; The ease of completing the application form; The ease of lodging the application form.*

*Base: Obtaining-n=170; Completing-n=166; Lodging-n=172*

Similarly, more than seven out of ten survey respondents agreed or strongly agreed that:

- it was **easy to gather the necessary supporting information** for the claim (85% agree or strongly agree)
- they were **treated with sensitivity** while making the claim (76% agree or strongly agree) (see Table 15).

TABLE 15 – ASPECTS OF MAKING A CLAIM (AGREEMENT SCALE)

STATEMENT	AGREE	DISAGREE
It was easy to gather the necessary supporting information for the claim (n=170)	83%	4%
I was treated with sensitivity while making my claim (n=169)	76%	9%

*Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme.*

*Base: Contained in table.*

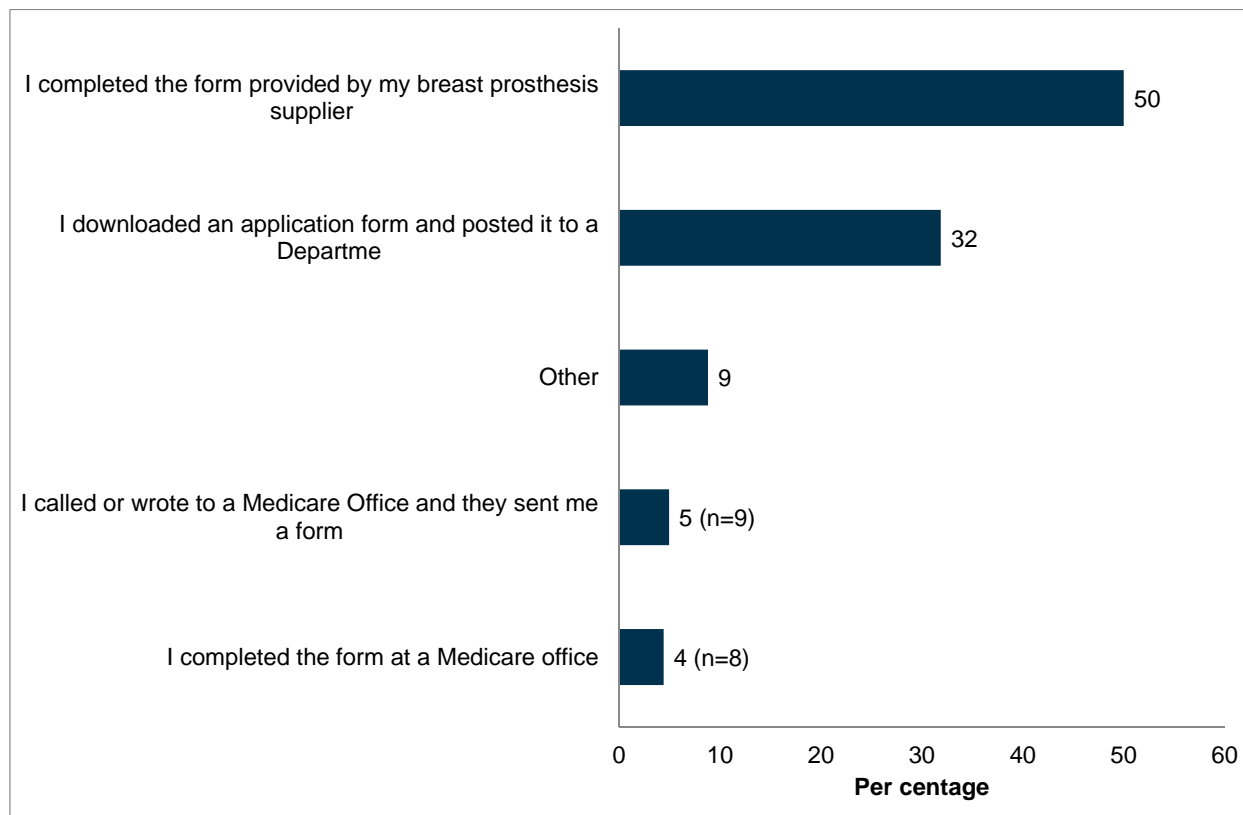
These results are consistent with findings from the qualitative research, with most interview participants either providing unprompted praise for the claim submission process (especially the simplicity of the form in comparison to other government paperwork), or indicating that the process had been so seamless that they could not recall the specific submission activities.

*I was amazed how easy it was actually... the form was very easy; it was well set-out... It was one of the easiest things I've had to do right throughout my treatment actually.*

Programme participant

When asked to indicate how they made their last claim submission, 50% of survey respondents indicated that they completed the application form provided by their breast prosthesis suppliers and 32% indicated that they downloaded that application form and posted it to a DHS office (see Figure 9).

FIGURE 9 – CLAIM SUBMISSION



Question: How did you make your last claim for reimbursement for an external breast prosthesis?

Base: n=182

This result is, again, consistent with findings from the qualitative research, with interview participants typically recounting one of the following two scenarios:

**Scenario one:** Around half of Programme participants reported that they had obtained the application when visiting a breast prosthesis supplier (commonly major department stores), and that supplier staff had either completed the form on their behalf, or assisted with the completion of the form. The prosthesis supplier then, reportedly, took responsibility for mailing the completed application to DHS. This scenario was especially common for women living in regional areas, who sometimes reported that they do not have ready access to a Medicare office. The majority of women who reported this scenario were satisfied with the claim submission process, and did not make any additional suggestions for improvement. Women were pleased that prosthesis purchase (including professional fitting) and claim submission could be completed at a single location. Women also reported that prosthesis supplier staff tended to be very knowledgeable about the Programme, especially the details required for correct completion of the application form.

**Scenario two:** The remaining Programme participants typically reported that they had (a) purchased a prosthesis (most commonly using a credit card), (b) downloaded an application form, and (c) either mailed the application form to DHS or submitted the form at a Medicare office. A small number of women indicated that they had obtained and completed the application form at a Medicare office. Women who reported this scenario were generally satisfied with the process for claim submission; however, a number were frustrated that the form could not be submitted online. Support for online claim submission was especially strong amongst women who had reported submitting their claim form at a Medicare office, many of whom suggested that the number of Medicare offices, and therefore convenient access, had decreased since being co-located with Centrelink. Support for online claim submission (either by the claimant or supplier), with a number of survey respondents requesting this service via an open-ended question; for example:

*Now that the Medicare offices are co-located with Centrelink it is more difficult to make a claim as these offices are poorly located. For this reason, I think it would be more helpful for the prosthesis provider to be able to claim on-line to Medicare with client to pay if gap required.*

Programme participant

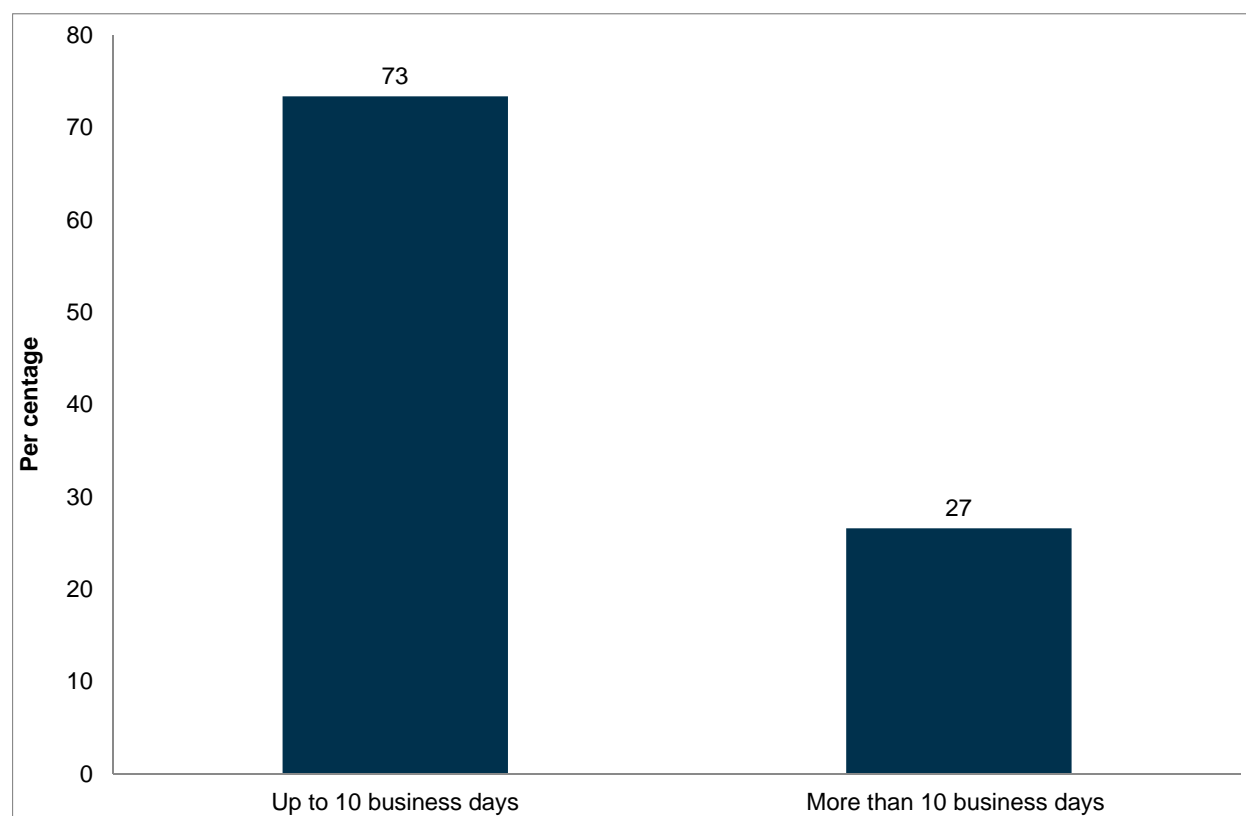
## 4.3 REIMBURSEMENT

### 4.3.1 EFFICIENCY

DHS have a service KPI which states that 90% of all reimbursements must be processed within 10 working days of a claim. DHS stakeholders reported that the Department has been successful in meeting this KPI since the program was launched in 2008. This is confirmed by Programme data: approximately 40% of claims were processed within 3 days and more than 85% of claims were processed within 6 days. Less than 2% of claims have fallen outside of the 10 day KPI set by DHS for service delivery. The speed of reimbursement has been relatively consistent over the five years of data captured with only minor variations in processing time.

The survey data also suggests that claims for reimbursement are being processed in a timely fashion: 73% of survey respondents indicated that they had received their reimbursement (i.e. it was in their bank account) within 10 business days (see Figure 10).

FIGURE 10 – TIME BETWEEN CLAIM SUBMISSION AND REIMBURSEMENT



Question: Approximately how long did it take to receive reimbursement for the breast prosthesis into your bank account after you had lodged the claim?

Base: n=169

In addition, survey respondents tended to highly rate the **ease** and **efficiency** with which they received a reimbursement:

- just over four out of five respondents (83%) rated the ease of obtaining a reimbursement following claim submission as either a four (24%) or five (59%).
- almost three quarters of respondents (73%) rated the timeliness of receiving a reimbursement as either a four (25%) or five (49%).

TABLE 16 – EASE AND EFFICIENCY OF RECEIVING REIMBURSEMENT

	ONE	TWO	THREE	FOUR	FIVE
<b>Ease</b>	7%	2%	8%	24%	59%
<b>Timeliness</b>	7%	7%	13%	25%	49%

Question: On a scale of 1 to 5, where 5 is the best score, how would you rate to following aspects of the Programme? The ease of obtaining the reimbursement following lodgement of your application; The timeliness of receiving reimbursement.

Base: Ease-n=166; Timeliness-n=167

Similarly, almost all Programme participants noted, via in-depth interviews, that they were satisfied with the amount of time it took for the reimbursement to be deposited into their bank account, and many noted that they were pleasantly surprised by the quick turnaround between claim submission and reimbursement.

*From memory it might have been a few days to a week. I can't remember very well but I know it wasn't something where I had to chase it. I'm pretty sure it was in my account within a reasonable time.*

Programme participant

#### 4.3.2 EFFECTIVENESS

As noted above, all interview participants (including Programme participants and stakeholders) commented positively regarding the existence and effectiveness of the Programme in providing financial assistance to women who have undergone a breast surgery as a result of breast cancer. Reimbursement was typically considered to be an effective payment method, as it allows women to retain autonomy over their choices (e.g. everyday versus contact prosthesis).

*We've got a free choice of what we want, because... more than this reimbursement, is that just to decide what we want to do.*

Programme participant

However, Programme participants also tended to reiterate their lack of understanding as to why they were required to pay an up-front fee, and to suggest alternative Programme arrangements (e.g. payment of 'gap' only by claimants).

*While I am able to easily afford the upfront payment I am sure there are women who would find it difficult or impossible. In such cases it would help if the \$400 "re-imbursement" was made direct to the supplier and the woman purchasing the prosthesis only had to find the extra \$45.*

Programme participant

It was also suggested that the form could be simpler and the process smoother, so that the transaction is between the supplier and DHS, without the woman as a 'middle man':

*I know that there are certain questions that need to be asked but I think, I didn't find it invasive, but I think some people would have problems... I think people are quite vulnerable in the beginning initially.*

Programme participant

### 4.3.3 ADEQUACY

The survey results suggest that Programme participants are, on the whole, satisfied with the level of the reimbursement: three quarters of respondents who had accessed the Programme in the past two years (75%) rated the level of reimbursement amount as either four (25%) or five (50%) (see Table 17).

TABLE 17 – ADEQUACY REIMBURSEMENT AMOUNT (RATING OUT OF FIVE)

	ONE	TWO	THREE	FOUR	FIVE
Amount	7%	7%	10%	25%	50%

Question: On a scale of 1 to 5, where 5 is the best score, how would you rate to following aspects of the Programme?

The level of the reimbursement amount

Base: n=167

In addition, 75% of survey respondents who had accessed the Programme in the past two years agreed or strongly agreed that the level of the reimbursement for an external breast prosthesis under the Programme was sufficient (see Table 18).

TABLE 18 – ADEQUACY REIMBURSEMENT AMOUNT (AGREEMENT SCALE)

STATEMENT	AGREE	DISAGREE
The level of the reimbursement for an external breast prosthesis under the Programme was sufficient (n=169)	75%	7%

Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme.

Base: Contained in table.

Programme participants also tended to report, via in-depth interviews, that they were satisfied with the value of the reimbursement. While the majority of these women indicated that they had been required to cover small out-of-pocket costs (between \$10 and \$50), these costs were typically considered to be manageable.

*Yeah and they charged me I think \$420. I don't know why it was \$420 but \$20 is nothing to get a breast.*

Programme participant

Some participants, however, suggested that the reimbursement amount should be increased slightly to be in line with current market conditions:

*My first prosthesis was around half the reimbursement amount but I noticed when I had to replace it 4 years later (the original had deteriorated) the cost had gone up to just over the reimbursement allocated amount. I feel the market has priced to the government reimbursement and it's sad that the suppliers think it's OK to price gouge the community (taxpayers) who fund this program to support us when we feel so vulnerable.*

Programme participant

It should be noted that when adjusted for Consumer Price Index (CPI), a breast prosthesis reimbursement valued at AU\$400 in 2009 is worth AU\$467.89 in current (2016) dollars. That said, Programme data shows that while the average total cost per prosthesis (i.e. purchase price) has increased steadily over the life of the Programme, it remains below the specified reimbursement amount (n.b. \$389.96 compared to \$400 in 2014-15; see Table 19).

TABLE 19 – AVERAGE COST PER PROSTHESIS OVER TIME

YEAR	AVERAGE COST OF PROSTHESIS
2010-11	\$362.39
2011-12	\$373.24
2012-13	\$382.33



2013-14	\$385.54
2014-15	\$389.96

#### 4.3.4 FREQUENCY

Most Programme participants reported that they were satisfied with the frequency of reimbursement given the life-time of a prosthesis, with the following comments being typical of feedback provided through in-depth interviews and via the open-ended survey questions:

*The prostheses are quite well made and if you do care for them and wash them and store them carefully when they're not in use, I think the 2 years is excellent.*

*Yeah it's just on right because it starts to deteriorate around the 2 year mark.*

*And then every 2 years it means that, yes you're sort of aware that you're able to replace it and... get a new one without having to worry about 'oh that's going to cost me \$400 or that'.*

*Yeah I think that's fair. I mean by 2 years the prosthesis is starting to lose a little bit of its shape. It's not as perky you might say.*

In addition, 67% of survey respondents agreed or strongly agreed that the frequency of reimbursement for an external breast prosthesis under the Programme (i.e. every 2 years) is sufficient (see Table 20).

TABLE 20 – FREQUENCY OF REIMBURSEMENT

STATEMENT	AGREE	DISAGREE
The frequency of reimbursement for an external breast prosthesis under the Programme (i.e. every 2 years) is sufficient (n=169)	67%	17%

*Question: On a scale of 1 to 5 where 1 is 'strongly disagree' and 5 is 'strongly agree' please indicate how much you agree or disagree with the following statements about the National External Breast Prostheses Reimbursement Programme.*

*Base: Contained in table.*

One interview participant expressed a preference for the reimbursement to be structured so that women could spend the funds over the two year period as required (i.e. a single premium prosthesis or numerous cheaper prostheses). This woman reported a preference for wearing her prosthesis without a bra, and as a result, required lower cost prostheses that could be replaced more often. A very small number of women requested an increase in reimbursement frequency (i.e. annual), and one woman requested a decrease in reimbursement frequency.

*The 2 years can be very long sometimes and as I wear adhesive prosthesis's the adhesive can wear out before the 2 years - I can replace just the backing but cannot claim this even though it is much less than the whole prosthesis.*

Programme participant

*From experience my prosthesis had lasted 7 years. I bought my first one in 2005. I don't think a replacement every 2 years is necessary and is wasting govt. money. I feel every 3-4 years would be sufficient if people care for it properly.*

Programme participant

## 5 Conclusions and recommendations

The National External Breast Prosthesis Reimbursement Programme is continuing to positively impact the lives of Australian women who undergo breast surgery as a result of breast cancer. Programme participants experience substantial physical and, especially, psychological benefits as a result of being able to access affordable prostheses in an ongoing basis. Service engagement (i.e. claim submission) is minimally burdensome, especially given the substantial Programme impacts, and Programme participants consistently reported a very high level of satisfaction with the Programme experiences. The simplicity of the Programme is key to its success: more complicated Programme guidelines (including coverage of bras and additional discretionary claims criteria) should only be implemented after careful consideration, and only in ways that maintain the simplicity of the Programme. These recommendations for Programme enhancement included below have been developed with this broad aim in mind.

### 5.1 RECOMMENDATION ONE

Financial hardship is not a significant enough Programme access barrier to prompt a substantial Programme redesign. A number of stakeholders and Programme participants argued that women may have trouble affording the up-front payment; however there was limited evidence to suggest this phenomenon is widespread. Programme data indicates that the average total cost per prosthesis (i.e. purchase amount) has steadily increased over the life of the Programme; however, this average is still below the specified limit of \$400. Despite this, evidence from the qualitative research suggests that at least some women are being required to cover out-of-pocket costs. As such, we recommend that the amount of reimbursement allowed under the National External Breast Prosthesis Reimbursement Programme be reviewed on an annual basis (i.e. comparison of annual average amount claimed to specified limit) to ensure that the reimbursement amount remains in line with current market rates.

**Recommendation one:** *The amount of reimbursement allowed under the National External Breast Prosthesis Reimbursement Programme should be reviewed on an annual basis, including a comparison of average annual amount claimed to specified limit.*

### 5.2 RECOMMENDATION TWO

While financial hardship is not a significant barrier to Programme access, it appears that some women on limited means (including Aboriginal and Torres Strait Islander women) are not accessing the Programme because they are unable to afford the up-front payment. As noted above, there is insufficient evidence to suggest that a substantial Programme redesign is required (i.e. implementation of a Medicare-style approach in which women, or select women, are only required to pay a 'gap'); however, promotion of mechanisms for obtaining the required funds up-front could positively impact Programme access for women on limited means and women who do not have access to a credit card. As such, we recommend that the advance payment options that may be available to women receiving an income support payment be explicitly promoted as a possible option for obtaining the required funds for an external breast prosthesis prior to reimbursement. This promotion should include, but not be limited to, information on the DHS website.

**Recommendation two:** *The advance payment options available to women receiving an income support payments should be explicitly promoted as an option for obtaining the funds for an external breast prosthesis prior to reimbursement.*

### 5.3 RECOMMENDATION THREE

As noted above, most Programme participants were highly satisfied with the process of claim submission and processing; however, there was a general consensus the process could be even more streamlined through the introduction of an online claim submission portal. This would be in line with a large number of government services, and would assist in ensuring equity in Programme access (i.e. the claim submission process would not be easier for Programme participants located close to Medicare office or Post Office). It should, however, be noted that the demographic profile of Programme participants is skewed to an older age group, some of whom may be less tech-savvy. Despite this, we recommend that the claim submission process for the National External Breast Prosthesis Reimbursement Programme be expanded to include an online submission portal.

**Recommendation three:** *The claim submission process for the National External Breast Prosthesis Reimbursement Programme should be expanded to include an online submission portal.*

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## Appendix A

## Literature Scan

## A.1 LITERATURE SCAN

A literature scan on the use and experience of Aboriginal and Torres Strait Islander women and CALD women in relation to breast prostheses also suggests a dearth of evidence and knowledge within Australia and internationally. However, literature suggests that CALD women are often under-served in a breast cancer related services, and they are less likely to engage in cancer support services in general (Cancer Australia 2012). In addition, there is evidence of disproportional breast cancer health outcomes between Aboriginal and Torres Strait Islander women and non-Indigenous women. For instance, Cancer Australia (2012) reported that based on BreastScreen data originated from 1996 to 2005, Aboriginal and Torres Strait Islander women (aged 50-69) were more likely to receive a mastectomy than complete local excision of their breast cancers than non-Indigenous women. It has been suggested that this disproportional outcome may reflect differences in choice, detected tumour size and accessibility to radiotherapy services among Aboriginal and Torres Strait Islander women compared to non-Indigenous women. This is reflected in research showing that breast cancer is often detected at a more advanced stage among Aboriginal and Torres Strait Islander women than non-Aboriginal women (AIHW and Cancer Australia 2013; Cancer Australia 2012). Moreover, there is evidence that Aboriginal and Torres Strait Islander women show lower survival rates of breast cancer than non-Indigenous women (AIHW 2014; AIHW 2015; AIHW and Cancer Australia 2013; Cancer Institute 2012, Cancer Australia 2012).

Importantly, Aboriginal and Torres Strait Islander women and CALD women often fall behind non-Aboriginal women and non-CALD women in terms of participation rates in breast cancer related health programmes. For example, in 2011-2012 38% of Aboriginal and Torres Strait Islander women in the Australian population had received a screening mammogram through BreastScreen Australia compared to 54% of non-Aboriginal women. Within that same period, women who spoke a language other than English at home fell 5.4% behind in participation rates compared to English-speaking women (49.9% compared to 55.3% respectively) (AIHW, 2014).

A growing body of research and evaluation suggests that breast cancer related health programmes require a specific cultural context for providing support and services to both subgroups. Therefore, an understanding of cultural barriers that women from both subgroups may face is important.

However, the literature describes a diverse set of barriers that could not only apply to breast cancer related services and support, but also to other health programmes and services. These barriers can range from specific cultural beliefs and views on personal health and the health system, towards socio-economic barriers such as low literacy levels, limited access to appropriate transport and limited access to financial options.

Notwithstanding this broad range of barriers, three key barriers can be identified as particular relevant for the Programme to create a better understanding of cultural beliefs and attitudes towards breast cancer and breast cancer related health services among Aboriginal and Torres Strait Islander women and CALD women. A summary of these three key barriers are outlined below:

### **Fatalistic beliefs and attitudes**

The literature suggests that within Aboriginal and Torres Strait Islander cultures, cancer can be associated with fatalistic beliefs and attitudes. In some cultures, being diagnosed with cancer is viewed as being 'cursed' or punished, leading to fatalism and acceptance of the disease, without seeking any form of cancer related support or treatment (Shahid, Finn, Bessarab and Thompson 2009; WHGNE 2010).

It has also been reported that in some Indigenous cultures, cancer is viewed as a 'deadly disease', and that seeking treatment is futile (Shahid et al 2009; WHNE 2010; Koefler 2012).

Similar to Indigenous cultures, fatalistic beliefs in relation to cancer can also apply within CALD communities. For instance, it has been described that Chinese and Arabic speaking communities can view cancer as a fatal illness, and associate cancer with 'bad luck', 'a higher power', karma or fate (Cancer Australia 2010; Philipson, Larsen-Truong, Jones and Pitts 2012). Importantly, it has been suggested that these fatalistic views can negatively influence participation in cancer related services and support (Philipson et al 2012).



### **Fear of stigmatisation**

Fear of stigmatisation when being diagnosed with cancer is also an important key barrier for members of Aboriginal and Torres Strait Islander communities and CALD communities to participate in cancer related health programmes. The literature describes that within these specific communities, cancer is often associated with shame and isolation, particularly when cancer is being linked to 'being cursed', or when cancer is being viewed as a contagious disease (Shahid and Thompson 2009; Phillipson et al 2012; Kwok, Cant and Sullivan 2005).

For example, it has been found that members of Arabic speaking communities can experience stigma, fear and secrecy as barriers to actively engage in accessing cancer related health services (Saleh et al 2012 in: Philipson et al 2012). Kwok et al (2005) reported that Chinese-Australian women associated cancer with stigmatisation from friends and relatives that could not only impact the individual with cancer, but also the individual's family. Therefore, women in this study felt less inclined to participate in breast cancer related health services.

### **Shame and embarrassment for undergoing breast related procedures**

Literature also reports on fear of shame and embarrassment as a barrier for women in general when undergoing breast related health procedures. This is often described as a cultural issue and of particular relevance for Aboriginal and Torres Strait Islander women and CALD women (Somkin, McPhee, Nguyen et al., 2004; Department of Health and Ageing 2009; Kwok et al. 2005). For instance, one study reports on Aboriginal women who associate their breasts with womanhood, sexuality and reproduction, but they also regard them as private. It was expected that exposing their breast to a health care provider could cause great feelings of shame and embarrassment (WHGNE, 2010).

Literature suggests that experiencing shame and embarrassment during a breast cancer related treatment can actually have long-term negative effects on the future intention of a woman to further engage in breast cancer related services (Department of Health and Ageing 2009; Kwok et al 2005). For example, Kwok et al (2005) found that some Chinese-Australian women, after a first mammogram, refused to re-screen due to the shame and embarrassment experienced during the procedure.

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