Evaluation of the National External Breast Prostheses Reimbursement Program

Final Report
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Executive Summary

In June 2009, the Department of Health and Ageing (the Department) commissioned Urbis to undertake an evaluation of the National External Breast Prostheses Reimbursement Program.

This evaluation involved two parts – a review of the administration of the Program; and a review of the impact of the Program on the lives of women who have had a mastectomy as a result of breast cancer.

The administration review evaluated the appropriateness, effectiveness and efficiency of the Program’s administration in reference to the Business Rules and the principles for the administration of the Program for the first twelve months of its operation (December 2008 to December 2009). This review also explored opportunities for future improvements or directions to the Program’s administration.

The impact review evaluated the impact of the Program in meeting its objectives which include, but are not limited to, improving the quality of life of women who have undergone a mastectomy as a result of breast cancer. The impact review also heard from women regarding issues of concern and suggestions which may strengthen the Program’s effectiveness and maximise its potential for success.

The evaluation was conducted by Urbis over an eleven month period and included documentation review, consultations with 44 individuals from 27 stakeholder organisations either face to face or through telephone interviews; and consultations with 377 women through a survey, telephone interviews, emails and focus group.

Key findings

Administration of the Program

Overall, the Program demonstrated a number of achievements in its first year.

- In total 17,997 claims had been processed and 19,962 reimbursements paid by 31 December 2009; the total cost of the reimbursement program to the Commonwealth amounted to $6,130,011.52.

- The reimbursement scheme was considered to be nationally consistent, easily accessible; efficient in process; and sensitive to the needs of women accessing the Program.

- Respondents considered that the Program had contributed to the quality of life for women who had undergone a mastectomy as a result of breast cancer and required a breast prosthesis.

- The Business Rules and Service Arrangement between the Department and Medicare Australia provided an acceptable and appropriate structure for the Program.

Impact of the Program

Consultations with representatives of stakeholder organisations and women who had accessed the Program indicated primarily positive perceptions of the Program.

- Over three quarters of women responding to the survey (77%) agreed or strongly agreed that the Program had improved their quality of life.

- More than three quarters (81%) of women surveyed agreed or strongly agreed that they were treated with sensitivity whilst making their claim.

- Over three quarters (76%) said that they had been pleased with their overall experience of the Program.

- Breast care nurses and breast prostheses suppliers were the leading sources of information about the Program. Forty-two percent of women surveyed reported hearing about the Program from their breast care nurses, and over one third (34%) reported hearing about the Program through a breast prostheses supplier.
EXECUTIVE SUMMARY

- The large majority of women consulted (83%) reported that the Program had made it easier to afford a breast prosthesis.
- The Program was praised for its simplified claims process. More than three quarters of women surveyed (79%) said that they had found the process of being reimbursed was straightforward.
- Overall, respondents reported that the Program was a significant improvement on previous state and territory-based schemes.

Several areas of improvement or concern were identified.

- A number of respondents commented that the Program required wider promotion.
- Only half (50%) of women surveyed agreed that a reimbursement every two years is sufficient.
- The inability to afford the upfront payment for an external prosthesis, particularly for women experiencing financial hardship, was a concern of many respondents, although the extent of this is not quantified.

The following proposals are made for the future.

- The Program is promoted in a more targeted way to clinicians and consumers, through the media, at BreastScreen units, and through targeted advertising.
- Consideration is given as the Program progresses to research which will quantify the number of women who may be prevented from accessing the Program because they are not able to afford the initial purchase of a prosthesis.
- Consideration is given to providing discretion for reimbursements within the two-year time frame within a carefully described set of circumstances, particular weight loss due to cancer treatment.
- Information and promotional resources are developed in languages other than English, and promoted to a wide range of culturally diverse community groups.
1 Introduction and background

In June 2009, the Department of Health and Ageing (the Department) commissioned Urbis to undertake an evaluation of the National External Breast Prostheses Reimbursement Program. The intent of the Program is to provide financial support to women who wear an external breast prosthesis as a result of a mastectomy due to breast cancer, through a nationally consistent reimbursement Program.

1.1 Breast Cancer in Australia

Breast cancer is the most commonly diagnosed cancer among females in Australia according to a report from the Australian Institute of Health and Welfare (AIHW) in 2009, ‘Breast Cancer in Australia: An overview’. While breast cancer also affects males, the incidence rate is much lower than amongst women, about .11% of cancer deaths for males. Latest data shows that in 2006, 12,614 women were diagnosed with invasive breast cancer and projections suggest that this figure is likely to rise to around 15,400 cases by 2015 due to the ageing of the population. The number of new breast cancer cases in women has more than doubled in the 25-year period from 1982, rising from 5,289 new cases to 12,614 new cases in 2006. AIHW also note that in 2006, the number of cases diagnosed was 3% higher than the number diagnosed in the previous year and is the largest number of new breast cancer cases in women reported in any year to date. Data on the estimated incidence rates of breast cancer around the world by region show Australia to be in fourth place, following North America, New Zealand and Western Europe. The average age of diagnosis of breast cancer in Australia is approximately 60 years and women living in the areas of highest urbanisation reportedly have higher rates of diagnosis. There are significant variations in the rates of diagnosis between different racial and cultural groups in Australia, with Indigenous Australians having lower rates of diagnosis than non-Indigenous Australians, and some migrant groups having higher or lower rates of diagnosis depending on country of origin (Australian Institute of Health and Welfare, 2009).

1.1.1 Detection, treatment and impact

Early detection of breast cancer produces better chances of survival. BreastScreen is one of three national screening programs that have been implemented to raise awareness and early detection of the disease. Since the introduction of BreastScreen in 1991, deaths from breast cancer have decreased from 31 per 100,000 in 1991 to 22 per 100,000 in 2006 (Australian Institute of Health and Welfare, 2008).

In 2007–08 a Simple mastectomy was the eighth most common procedure for female patients with a principal diagnosis of breast cancer with 5,187 separations, after Excision of lesion of breast which was fifth most common with 10,035 separations. The four most common procedures for breast cancer-related hospitalisations included (in order): administration of pharmacotherapy, cerebral anaesthesia, loading of drug delivery device, and excision procedures on lymph node of axilla (Australian Institute of Health and Welfare, 2008).

A mastectomy involves the removal of the whole breast and is performed as part of the treatment procedure for breast cancer. In some cases women are given a partial mastectomy depending on the nature, location and severity of the cancer. Some women choose to have a mastectomy as their first surgery to avoid having radiotherapy or further surgery to the breast (Australian Institute of Health and Welfare 2009).

Breast cancer not only affects women physically (through surgery, chemotherapy and radiotherapy), but their social and emotional wellbeing, and everyday lives. Cancer care today often provides state-of-the-science biomedical treatment, but fails to address the psychological and social problems associated with the illness, which can compromise the effectiveness of health care and adversely affect the health of cancer patients (Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, 2007).

It has been argued that major psychological and social stressors experienced by women with breast cancer are related to a woman’s understanding of her disease, its prognosis, the complexity of treatment, and her access to care and/or choice of providers (Ganz P, 2008). Even the most
psychologically strong individuals can be overwhelmed by the number of medical visits, procedures and waiting times during initial diagnostic processes (Ganz P, 2008). Distress exists on a continuum beginning with the ‘normal’ and expected feelings of fear, worries, sadness and vulnerability in coping with cancer and its treatment; however distress can extend to more severe and disabling forms leading to a formal diagnosis of major depression (Hewitt M, Herdman R & Holland J, 2004).

Common psychological concerns experienced by women with breast cancer include (Ganz P, 2008).

- fear of recurrence
- body image disruption
- sexual dysfunction
- treatment-related anxieties
- intrusive thoughts about illness/persistent anxiety
- marital/partner communication
- feelings of vulnerability
- existential concerns regarding mortality.

Research conducted in the United States found that around 30% of women with breast cancer show significant distress at some point of the illness; the number is greater in women with recurrent disease whose family members are also distressed (Hewitt M, Herdman R & Holland J, 2004). The loss of a breast and the consequent body disfigurement can not only cause physical discomfort but affect a woman’s self-image and identity. Women may choose to re-construct their figure in a number of ways in order to regain a sense of wholeness.

1.1.2 Reconstructive surgery and breast prostheses

Women who have a mastectomy or partial mastectomy can choose to have reconstructive surgery to rebuild the size and shape of the breast, either at the time of mastectomy or following radiation treatment once the tissue has healed. This involves the insertion of silicon gel bags into the breast or tissue flaps from other parts of the body to build up the breast, and is performed by a plastic surgeon. Most women are able to have reconstructions, however people with conditions such as obesity, circulation problems, diabetes and high blood pressure are at risk of serious complications. Some women are also put off at the prospect of having another major surgery following their mastectomy.

For other women, the costs associated with reconstruction, the waiting list in the public health system to have a reconstruction, and the thought of having another major surgery, mean that the choice of wearing an external prosthesis is an easier alternative. Some women also choose to wear a prosthesis while they decide whether they would like to have reconstructive surgery. A breast prosthesis is an artificial breast worn inside the bra which helps gives shape to clothes, improves balance and posture, and can restore body image for women who have had a mastectomy. It is different to a temporary breast form which is a temporary pillow-like breast shape given to women in hospital after surgery.

Breast prostheses are commonly made from silicon gel and are available in a variety of sizes, shapes and colours to match the remaining breast or tissue. Prostheses need to be fitted professionally so that they are properly weighted to the remaining breast and to the contours of the body. The prosthesis is worn inside a specially made bra and closely copies the natural shape of the breast. Women are also able to use a self-adhesive prosthesis that sticks to the chest using special glue. These do not last as long as non-adhesive prostheses however. Generally a prosthesis will last up to two years (with the majority of manufacturers providing a warranty for this period), however in many cases prostheses can last up to five years with proper care. The cost of a prosthesis (depending on materials used) ranges from $130 to $400 (Breast Cancer Network Australia, 2010).

The Breast Cancer Network Australia (BCNA) estimates that around 6,000 women each year will require a breast prosthesis following surgery for breast cancer.
1.2 The National External Breast Prostheses Reimbursement Program

1.2.1 Program overview and objectives
Funding for the National External Breast Prostheses Reimbursement Program was announced by the Commonwealth Government in May 2008 and the Program was announced by the Minister later in 2008. The Program has been operating since December 2008. Prior to the implementation of the national Program, all states and territories arranged their own schemes for women who purchased breast prostheses as a result of breast cancer.

The objectives for this national Program 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
- improve the quality of life of women who have undergone a mastectomy as a result of breast cancer.

1.2.2 Administration of the Program
The Program is administered by Medicare Australia on behalf of the Department under the terms of a Service Arrangement and Business Rules. Under the Service Arrangement, the Department is obliged to provide policy advice to Medicare Australia in a timely manner and to respond to queries and complaints that relate to policy issues under the Program.

Medicare Australia is required to provide monthly and end-of-financial year statistics to the Department on a number of items identified on the Program claim form, including: the number of reimbursements, amount reimbursed, demographic data and process performance. Medicare Australia is required to process 90% of all claims within ten days of lodgement, as part of its obligations as administrator of the Program.

Women claiming for the reimbursement through Medicare Australia can do so by downloading and completing a claim form from the Medicare Australia website, going to a Medicare Australia branch for a hard copy, or calling Medicare Australia. Those receiving financial assistance from the Department of Veterans’ Affairs (DVA) are able to claim their entitlement through DVA.

1.2.3 The principles for the administration of the Program and eligibility criteria
The principles for the administration of the Program are:
- ease of access to reimbursement for all eligible women
- efficiency of reimbursement to eligible women
- efficiency of implementation of the Program through minimal additional infrastructure costs
- appropriate accountability structures in place to monitor and audit the Program
- consistent national approach across all jurisdictions
- sensitivity to the needs of the eligible women accessing the reimbursement.

The eligibility rules for the Program are:
- women who have had a mastectomy as a result of breast cancer – the mastectomy may be recent or in the past (no time limit)
- women who have purchased a first or replacement breast prosthesis on or from 1 July 2008
- women who are permanent residents of Australia and have current Medicare Australia entitlements
women who have not received financial assistance for the claimed prosthesis from the Department of Veterans Affairs (DVA)

women who have not received financial assistance for this prosthesis from a private health insurer, state or territory or other organisation, or have received a refund or financial assistance through their private health insurer, state or territory or other organisation less than the maximum Commonwealth reimbursement.

Eligible women can claim up to $400 reimbursement for each new or replacement external breast prosthesis. This limit applies for each prosthesis for each breast. If a claim under the Program has been made, a subsequent reimbursement can be claimed no earlier than two years from the date of purchase.

1.3 This evaluation

This evaluation involved two parts – a review of the administration of the Program; and a review of the impact of the Program on the lives of women who have had a mastectomy as a result of breast cancer.

The administration review evaluated the appropriateness, effectiveness and efficiency of the Program’s administration in reference to the Business Rules and the principles for the administration of the Program for the first twelve months of its operation (December 2008 to December 2009). This review also explored opportunities for future improvements or directions to the Program’s administration.

The impact review evaluated the impact of the Program in meeting its objectives which include, but are not limited to, improving the quality of life of women who have undergone a mastectomy as a result of breast cancer. The impact review also heard from women regarding issues of concern and suggestions which may strengthen the Program’s effectiveness and maximise its potential for success.
2 Methodology

The methodology for this evaluation included the following activities and was divided into two phases (the administrative review and the impact review) which proceeded concurrently.

2.1 Development of the evaluation framework

An evaluation framework was developed to provide a conceptual framework through which to: guide the two reviews, summarise the intended outcomes of the Program, identify key evaluation questions, and set out the process for gathering evidence.

A program logic identified a hierarchy of outcomes for the evaluation, which allowed for analysis of a range of factors that contributed to the outcomes at each level. The evaluation assessed the extent to which the Program was achieving these outcomes as set out in the evaluation framework.

The evaluation framework was submitted to the Department in August 2009 and can be found at Appendix A.

2.2 Administration review

2.2.1 Review of Medicare Australia program data

Medicare Australia is required to provide monthly end-of-financial year data to the Department on a number of items identified on the Program claim form, including the number of reimbursements, total amount reimbursed, demographic data and process performance.

Urbis undertook two reviews of Medicare Australia data prior to both the first progress report in November 2009, and the second progress report in March 2010. These findings are discussed further in section 3.2 of this report.

2.2.2 Review of relevant documentation

A review of other relevant documentation was also undertaken to inform the evaluation. This included a review of the Service Arrangement and Business Rules between the Department and Medicare Australia, as well as recent research on breast cancer. A discussion of relevant documentation is included in chapter three of this report.

2.2.3 Interviews with stakeholders

The stakeholder interviews were conducted through the months of March to May 2010 and formed the final phase of the evaluation. The aim of these interviews was to inform both the administrative and impact components of the evaluation.

Stakeholders included the following individuals and organisations:

- Medicare Australia
- the Department
- selected state and territory government departments
- state and territory Cancer Councils
- peak bodies and advocacy groups for women with breast cancer
- cancer support groups and services
- health care professionals, including breast cancer surgeons and McGrath Foundation breast care nurses
breast prosthesis fitters and suppliers.

A full list of the stakeholders consulted can be found at Appendix B. Altogether, 44 individuals from 27 organisations were consulted as part of this component.

The interviews were conducted by telephone except for consultations with the Department, Medicare Australia and the National Breast Cancer Foundation which were conducted face to face. Two stakeholders provided written feedback.

The interviews followed formal discussion guides which were developed in consultation with the Department. All discussion guides can be found at Appendix C.

### 2.3 Impact review

The aim of the impact review was to canvass women’s experiences with, and response to, the Program. The methodology was developed in order to best obtain the available information, and to give as many women as possible the chance to participate in the study, within the given scope of the evaluation.

#### 2.3.1 Scoping interviews

Scoping interviews were conducted in September/October 2009 with key stakeholders to seek their views regarding the Program and evaluation methodology. The scoping interviews provided insight into the support available to women following a mastectomy, and identified some additional informants for the evaluation. The focus of these interviews was also to determine the best way of approaching women to participate in the survey, particularly women of an Aboriginal and Torres Strait Islander or culturally and linguistically diverse background, as it was recognised that these groups may be less likely to access the Program.

The list of stakeholders consulted for the scoping interviews was agreed in consultation with the Department. Stakeholders included key individuals from the main breast cancer and cancer organisation networks, and are detailed in the table below. All stakeholders were sent a letter by the Department prior to Urbis contacting them, which notified them of the research and invited them to participate. Interviews followed a formal discussion guide which was developed in consultation with the Department (see Appendix C). The majority of interviews were conducted face to face, however two interviews were conducted over the phone.

Table 1 – List of stakeholders for scoping interviews

<table>
<thead>
<tr>
<th>Organisation</th>
</tr>
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<tbody>
<tr>
<td>National Breast and Ovarian Cancer Centre (NBOCC)</td>
</tr>
<tr>
<td>Breast Cancer Network Australia (BCNA)</td>
</tr>
<tr>
<td>Cancer Council Australia (CCA)</td>
</tr>
<tr>
<td>National Breast Cancer Foundation (NBCF)</td>
</tr>
<tr>
<td>Cancer Voices of Australia</td>
</tr>
<tr>
<td>McGrath Foundation</td>
</tr>
<tr>
<td>Peter McCallum Cancer Centre</td>
</tr>
</tbody>
</table>

#### 2.3.2 Online survey

An online survey was developed, in consultation with the Department, for women who had a mastectomy as a result of breast cancer and who were using an external breast prosthesis. The aim of the survey was to ensure an anonymous means of providing feedback for women who may have heard about, or accessed the National External Breast Prostheses Reimbursement Program. Key areas of
exploration included: awareness of the Program, participation in the Program, and experience of using the Program. A paper version of the survey was also developed for women who did not have access to the internet or who were not comfortable completing the survey online. Women could request a paper survey by phoning a toll free number (arranged by Urbis). These surveys were posted to women with a reply paid envelope so that no costs were incurred in participating in the survey.

A pilot of the survey was sent as an online link to 60 women and in paper form to 10 women through the Breast Cancer Network Australia (BCNA) at the end of November 2009. The purpose of the pilot survey was to establish readability and clarity of the survey instrument. The decision to use BCNA to pilot the survey was taken in consultation with the Department, as BCNA has within their membership a group of women who had experienced breast cancer and who had volunteered to participate in research projects. This provided timely feedback on the pilot survey before the final version of the survey was made publicly available. As no changes were required following the pilot survey, the pilot results have been included in the survey results.

A number of organisations were invited to assist in promoting the survey to women. By promoting the survey through a range of channels, the research team sought to minimise bias and reach as many women as possible. The following were undertaken in an effort to promote the survey:

- advertising the survey in BCNA’s Beacon newsletter, which has a circulation of 38,000 breast cancer survivors and supporters
- hosting the link to the survey on the NBOCC website
- inviting Cancer Councils in each state and territory to distribute information about the survey and/or the link to the survey to individuals and members of affiliated support groups, particularly Aboriginal and Torres Strait Islander and culturally and linguistically diverse women
- extending invitations to organisations including the Country Women’s Association, Probus, Migrant Resource Centres in Northern Queensland and Western Sydney
- distributing a flyer and the survey link to contacts at eleven major hospitals treating breast cancer across Australia
- communicating the survey through breast care nurses and at a national breast care nurse conference
- communicating the survey through academics from Sydney University, Queensland University, Monash University and University of Melbourne who have expertise in the area and networks within various communities
- communicating the survey through the Clinical Oncological Society of Australia (COSA).

The survey was originally intended to be live from the first week of December 2009 to the middle of February 2010, however early responses indicated a lack of participation by women under 40 years, women of a culturally and linguistically diverse background and Aboriginal and Torres Strait Islander women. Further efforts were made to communicate the survey via additional avenues and the decision was made to keep the survey open for another two weeks to the end of February 2010.

Additional efforts made during the survey period to communicate the survey to young women, women of a culturally and linguistically diverse background or Aboriginal and Torres Strait Islander women included the following:

- an invitation to the Young Ones (a support organisation for young women with breast cancer)
- the Aboriginal and Torres Strait Islander and culturally and linguistically diverse sub-committees of the Cancer Council Australia
- distributing the survey via Aboriginal and Torres Strait Islander Health Info Net’s e-message stick and posted on their website
- contacting BreaCan to promote the survey to used of its program for younger women.
Preliminary results from the survey were presented in the second progress report in March 2010. Demographic characteristics of survey respondents are provided below; other results from the survey are discussed in greater detail in chapters 3 and 4 of this report.

A copy of the survey can be found at Appendix D. Promotional material used to disseminate information about the survey can be found at Appendix E.

2.3.3 Characteristics of survey respondents

**Age**

There was some variation in the age of respondents, although the majority were clustered in the middle age ranges. Approximately two thirds of respondents (64.7%) were aged between 50 and 69 years. A further 22.4% were aged 30 to 49 years. The remaining 8.9% were aged over 70 years. The results are shown in Table 2.

Table 2 – Age of women who completed the survey and who have accessed the Program (n=214)

<table>
<thead>
<tr>
<th>Age group</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 49 years</td>
<td>24%</td>
</tr>
<tr>
<td>50 to 69 years</td>
<td>64%</td>
</tr>
<tr>
<td>70 years and over</td>
<td>8%</td>
</tr>
<tr>
<td>Preferred not to say</td>
<td>4%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

An effort was made by the evaluation team to invite further women aged 70 to 80 years to participate in our research due to inconsistency with Medicare Australia data on age range. According to Medicare Australia data, 23% of women who had accessed the Program between December 2008 and December 2009 were aged 70 to 80 years, yet only 8% of the survey sample was in this age range.

The number of women who completed the survey aged 49 years and under was in accordance with Medicare Australia data. Some stakeholders suggested that younger women were more likely to consider breast reconstruction surgery, both because they were more inclined to feel self conscious about their bodies post-mastectomy, and because they were more open minded to having plastic surgery. It was noted however, that young women may still require an external prosthesis whilst waiting for surgery, undergoing chemotherapy or radiation treatment, or waiting for their scar tissue to heal. Breast care nurses reported that few women chose to have reconstructive surgery at the time of, or closely following, their mastectomy.

**State of residence**

As shown in Figure 1, respondents came from all states and territories. The rate of response per jurisdiction roughly approximates the spread of population across the jurisdictions (Australian Bureau of Statistics, 2009).
Interestingly, latest data shows that during the period of 1998 to 2002 the Australian Capital Territory had the highest average annual age-standardised rate of breast cancer with 127 new cases per 100,000 (AIHW, 2009). Evaluation survey data and Medicare Australia data for the Program however are in accordance with the population ratios for each state and territory according to the most recent census data. Women living in areas in the highest socioeconomic status quintile have been shown to have significantly higher rates of breast cancer (AIHW, 2009).

**Location of residence (remoteness)**

As shown in Figure 2, respondents resided in a variety of settings. While the highest proportion (41.4%) lived in a capital city, more than a third (35.4%) lived in a regional city. Smaller proportions resided in more remote locations, as would be expected based on the general distribution of population to such areas.

**Level of education**

Survey respondents were a reasonably educated group as indicated in Figure 3 below, with over a quarter (29%) having completed a university degree and one fifth (19%) having attended TAFE or technical college.
Other evaluation respondents did not report level of education to be a particular determinant of access to the Program. However, socioeconomic status was recognised as an important indicator of whether a woman could afford the up-front payment of a prosthesis.

Figure 3 – What level of education have you completed? (n=362; multiple response)

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>University</td>
<td>29%</td>
</tr>
<tr>
<td>TAFE or technical college</td>
<td>19%</td>
</tr>
<tr>
<td>Apprenticeship or cadetship</td>
<td>6%</td>
</tr>
<tr>
<td>Year 12 or equivalent</td>
<td>15%</td>
</tr>
<tr>
<td>Year 10 (school certificate) or equivalent</td>
<td>31%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>3%</td>
</tr>
<tr>
<td>Others</td>
<td>12%</td>
</tr>
</tbody>
</table>

Aboriginal and Torres Strait Islander women, women of a culturally and linguistically diverse background, women with a disability

Survey respondents were asked to specify whether they belonged to three potentially disadvantaged groups: people with a disability, Aboriginal or Torres Strait Islander people or people who speak English as a second language. Only a few respondents identified as having one or more of these characteristics, as shown in Table 3. Close to one quarter of respondents chose not to answer this question.

It is unclear how many Aboriginal and Torres Strait Islander women or women from a culturally and linguistically diverse background are accessing the Program. There is anecdotal evidence from evaluation respondents that many of these women face barriers in accessing the Program (as discussed in section 3.1.1), however it was not possible to determine the number of Aboriginal and Torres Strait Islander women or those of a culturally and linguistically diverse background who fall into this category. Stakeholders have suggested possible improvements to the administration of the Program to these women to improve access (as discussed in section 3.4.1).

Table 3 – Do any of the following apply to you? (n=362)

<table>
<thead>
<tr>
<th>Statement of belonging</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I identify as Aboriginal or Torres Strait Islander</td>
<td>0%</td>
</tr>
<tr>
<td>I speak English as a second language</td>
<td>3%</td>
</tr>
<tr>
<td>I identify as having a disability</td>
<td>6%</td>
</tr>
<tr>
<td>None of the above</td>
<td>69%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>23%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>
**Time and type of surgery**

The time of survey respondents’ breast surgery covered a broad spectrum, as shown in Figure 4. As indicated in figure 5, the largest proportion of survey respondents (42%) had had their most recent procedure within the *last two years*. Approximately one in three respondents (33%) had had their surgery *two to five years ago*, and a further 23% had had their surgery *more than five years ago*.

Figure 4 – How long ago did you have your breast surgery? (n=362)

![Bar chart showing time of surgery](chart1)

As shown in Figure 5, the bulk of survey respondents had a full mastectomy and thus met the eligibility criteria for participation in the Program. The majority of respondents (76%) had had a *full, single mastectomy*. A further 18% had had a *bi-lateral mastectomy*.

Figure 5 – What kind of breast surgery have you had? (n=362)

![Bar chart showing type of surgery](chart2)

**Previous use of state/territory assistance schemes for breast prostheses**

A minority of survey respondents (36%) had previously received financial assistance for a breast prosthesis under state or territory-based schemes.

Of the 131 women who had previously used such schemes, approximately one in three (33%) did so in Victoria. Notwithstanding possible interstate migration in the period after accessing state-based schemes, it is interesting to compare respondents’ current state of residence with frequency of access to schemes in these states. The comparison suggests a considerable level of variation in respondents’ usage of schemes across jurisdictions. Whereas 63% of respondents currently living in Victoria accessed a scheme in this state, 23% of respondents in NSW have previously used an assistance scheme in this state and 14% of those residing in NT have accessed an NT based scheme.
Involvement with breast cancer-related groups and networks

As shown in Table 4 a number of survey respondents had some involvement (slightly or very involved) with one or more breast cancer related groups. However the extent of their involvement in the groups listed was not substantial. For each group listed, those describing themselves as ‘very involved’ were a small minority. It should also be noted that a number of women who completed the postal survey chose not to answer this question, so caution needs to be given to the sample size for each group listed.

The group in which the highest proportion was involved was Breast Cancer Network Australia. Half of the survey respondents (50%) described themselves as ‘slightly involved’ in this organisation, and a further 7% was ‘very involved’. About 1 in 3 respondents (34%) were involved in local support groups; those who were involved in such groups were almost as likely to be very involved as slightly involved.

Table 4 – How involved are you with the following groups? (n=362)

<table>
<thead>
<tr>
<th>Group</th>
<th>Not involved (%)</th>
<th>Slightly involved (%)</th>
<th>Very involved (%)</th>
<th>Number of women who did not answer this question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer Network Australia</td>
<td>31%</td>
<td>50%</td>
<td>7%</td>
<td>41</td>
</tr>
<tr>
<td>Local breast cancer support groups</td>
<td>52%</td>
<td>18%</td>
<td>16%</td>
<td>51</td>
</tr>
<tr>
<td>McGrath Foundation</td>
<td>65%</td>
<td>11%</td>
<td>2%</td>
<td>79</td>
</tr>
<tr>
<td>Cancer Council</td>
<td>48%</td>
<td>27%</td>
<td>6%</td>
<td>69</td>
</tr>
<tr>
<td>National Breast Cancer Foundation</td>
<td>50%</td>
<td>27%</td>
<td>2%</td>
<td>76</td>
</tr>
</tbody>
</table>

Note: the totals for each row above do not equal 100% as not all women answered each question.

2.3.4 Follow-up interviews and focus groups with women

Following the survey, it was evident that there were groups of women who were under-represented in the survey responses. It was noted that some of these women were generally also under-represented in incidence rates of breast cancer. Women of a culturally and linguistically diverse background, Aboriginal
and Torres Strait Islander women, and women over 70 years of age were all underrepresented in the survey. Despite the wide promotion of the survey, a survey instrument may not be the preferred format for some women in discussing such a sensitive issue. It may also exclude women who are not computer literate or do not have high English literacy skills.

Younger women (aged 40 years and under) were also recognised as a group early in the evaluation that may be under-represented in accessing the reimbursement program.

In order to provide alternative opportunities for participation in the evaluation, assistance was sought from a number of people or organisations. Contact was made with the following:

- McGrath breast care nurses in locations with high proportions of Aboriginal and Torres Strait Islander, culturally and linguistically diverse, younger or older patients
- Urbis’s Aboriginal sub-consultants and sub-consultants of a culturally and linguistically diverse background due to their respective community networks
- National Aboriginal Community Controlled Health Organisation (NACCHO).

These individuals or groups were asked to promote the evaluation to the networks. Where women expressed a willingness to participate, interviews or focus groups were arranged. No individual was contacted by Urbis without having first given her consent to participate.

The following were arranged as part of the follow-up consultation process:

- A focus group with five women of Arabic-speaking background arranged by an Arabic-speaking sub-consultant of Urbis. An evaluation team member facilitated the focus group, and the sub-consultant acted as an interpreter.
- Follow up consultations with eight women who had accessed the Program and were willing to provide verbal feedback.

A focus group was arranged with a small number of Aboriginal women (organised by one of Urbis’s Aboriginal sub-consultants), however this was later cancelled as women withdrew for various reasons. This was not rescheduled due to reasons of sensitivity and difficulty in obtaining participants.

Follow up consultations with women followed a structured discussion guide which was developed in consultation with the Department (found at Appendix C).

Altogether, 377 women who had experienced breast cancer participated in the evaluation through surveys, emails, interviews, or focus groups.

### 2.4 Results and limitations

#### 2.4.1 Summary of results

Overall, the vast majority of people consulted considered the Program to be operating well, and to be meeting the needs of women who require a breast prosthesis following a mastectomy for breast cancer.

The administration of the Program appears to be operationally sound, and relationships between Medicare Australia and the Department of Health and Ageing appear to be productive and to facilitate the resolution of any policy or operational questions which have arisen during the year. The administration of the Program will be discussed further in chapter 3.

All interview participants considered that the Program provided essential support to address a significant need for women who have had a mastectomy. The majority of women who participated in the consultation were satisfied with the Program and with their interaction with the Program through Medicare Australia. The impact of the Program on women and their perceptions of the Program are discussed further in chapter 4.
At the same time, several key themes emerged in consultation with the broad range of stakeholders – clinical, organisational, or individual. One was the promotion of the Program

2.5 Limitations of the data

There are a number of limitations to the data presented here.

It is not possible to quantify the number of women in Australia who are eligible for the Program. For that reason, it was not possible to devise a sample which was statistically representative of the eligible population. There were several factors influencing the development of the sample:

- the lack of knowledge regarding the number of women in Australia who are eligible for the Program
- the lack of any data source which could identify who eligible women may be or where they may be located
- the consequent need to seek potential respondents through a variety of networks for women with breast cancer, and the
- the likelihood that many potential respondents are currently living with a recent cancer diagnosis, surgery and/or treatment, and the corresponding sensitivity and ethical issues which arise.

The research team sought to reach women through representative organisations such as BCNA and breast cancer support groups. However, we acknowledge that there are many women who may not choose to join a group or identify with a particular organisation. For that reason, we sought to advertise the survey (which could be accessed anywhere by anyone via the Internet) as widely as possible. It is likely that the respondents are not representative of the range of eligible women across Australia; potentially, women who do not join groups, are older and perhaps more isolated, have had their surgery a long time ago, are not English-speaking, or are not Internet-savvy or do not have Internet access, are not represented within this survey. It is likely that those women who are more articulate and willing to express their opinions, those who have particular views which they are keen to share, and those who are more educated are over-represented in the pool of respondents.

At the same time, a consultation of over 350 women has provided reasonably consistent feedback through the range of opportunities provided (survey, interview, email, focus group), so that the issues which have been identified, while not many in number, have been expressed across a wide diversity of respondents.

What the evaluation does provide is a snapshot of perspectives regarding the Program in its first year of operation, as viewed by those in roles within stakeholder and representative organisations or those consumers who have accessed the Program. The picture which is presented here is based on the views of those who have had some interaction with the Program through their professional role or their personal lives.

A discussion of the key themes of the evaluation is found in chapter 5, with recommendations for the future.

2.6 Summary of results

Overall, the vast majority of people consulted considered the Program to be operating well, and to be meeting the needs of women who require a breast prosthesis following a mastectomy for breast cancer.

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All interview participants considered that the Program provided essential support to address a significant need for women who have had a mastectomy. The majority of women who participated in the consultation were satisfied with the Program and with their interaction with the Program through Medicare Australia. The impact of the Program on women and their perceptions of the Program are discussed further in chapter 4.

At the same time, several key themes emerged in consultation across the broad range of stakeholders – clinical, organisational, or individual.

One theme was the promotion of the Program, to both consumers and health care providers. While those who had accessed the Program appreciated its existence, it was felt that the promotion of the Program could be improved to ensure that older women, Aboriginal and Torres Strait Islander women, and women of a culturally and linguistically diverse background were aware of the Program. A number of respondents also considered that awareness amongst clinicians was relatively low, other than amongst breast care nurses. Some people felt that GPs, breast physicians and breast surgeons might be better able to assist women if they had more awareness of the Program.

A second theme was the requirement for women to pay for their prosthesis and then claim reimbursement. There were some reports of financial hardship experienced by women; a few of these were individual comments provided anonymously in the survey, while in interviews a number of people expressed general (but unsubstantiated) concerns that other women may not be able to afford the initial cost of the prosthesis. The number of respondents actually reporting financial hardship for themselves within the survey was small, and it is therefore not possible to quantify whether this is a significant hardship more generally for women.

A third theme was the access to the Program by particular groups of women, such as Aboriginal and Torres Strait Islander women, and women of culturally and linguistically diverse backgrounds. As Program information is only available in English, it was identified that many women who do not speak English may not be receiving information about the Program. While Aboriginal and Torres Strait Islander women have lower rates of breast cancer compared to the non-Indigenous population, it was also suggested that Aboriginal and Torres Strait Islander women, particularly in rural and remote communities, may not be aware of or accessing the Program.
3 Administration Review

This chapter addresses the following terms of reference for the evaluation:

- Extent to which the Program, within the first 12 months of operation, has met the goals defined by the principles for the administration of the Program
- Outcomes achieved as a result of Medicare Australia administering the Program
- Effective integration of the Program within the broader policy environment
- Improvements in the administration of the Program and duplication
- Appropriate administration of the right levels of service to achieve the principles of the Program and comply with the Business Rules.

3.1 Meeting the principles for the administration of the Program

The principles for the administration of the Program included the following:

- ease of access to reimbursement for all eligible women
- efficiency of reimbursement to eligible women
- efficiency of implementation of the Program through minimal additional infrastructure costs
- appropriate accountability structures in place to monitor and audit the Program
- consistent national approach across all jurisdictions
- sensitivity to the needs of the eligible women accessing the reimbursement.

As part of the administration component of the evaluation, Urbis were asked to review the extent to which the Program had met the goals as defined by the principles above. Each of these are discussed in further detail below.

3.1.1 Ease of access to reimbursement for all eligible women

It was agreed by all respondents that overall, the Program had resulted in an improvement in access to reimbursement for external breast prostheses, due to the following factors:

- the Program is administered through Medicare Australia and offices are located in most major towns across the country
- some previous state and territory programs covered only a “one-off” prosthesis for each woman, or provided a smaller fee of reimbursement to women than currently offered under the national program
- breast prostheses are now more affordable under the Program
- the claims process under the national program is more straightforward than previous programs
- women no longer require a letter from their surgeon validating their mastectomy in order to be eligible to receive the reimbursement
- greater numbers of women are able to choose their prosthesis fitters (in the past, women in some states and territories were fitted whilst in hospital by an assigned fitter).

The large majority of women surveyed (83%) said that the Program had made it easier to afford a breast prosthesis; over three quarters (76%) said that they had been pleased with their overall experience of the Program. Some women who had not been able to access the previous state and territory schemes commented that they had been buying external prostheses for many years (for some
20-30 years) and that this was the first time they had received any financial assistance for these purchases.

Overall, whilst respondents were extremely positive about what the Program offered women, and the fact that it provided a consistent approach to administering reimbursements to all women across Australia and had improved women’s access to reimbursement, it was clear from consultations that there are groups of women who are not accessing the Program for a number of reasons outlined below.

Problems in affording the up-front payment for prostheses

Among respondents, it was widely believed that whilst the Program provided the impetus for women to purchase an external prosthesis, there were still those who, due to lack of funds, were unable to afford the up-front payment of the prosthesis and thus could not access the reimbursement. One representative of a stakeholder organisation commented that “it’s a really good program - if you’re wealthy”.

All evidence for the inability to afford the up-front cost was anecdotal and it was not possible to quantify the number of women who were suffering financial hardship. The Department reported that it had received approximately 45 letters or emails from members of the public, breast care nurses, breast prosthesis suppliers and Members of Parliament regarding the potential financial hardship of the reimbursement nature of the Program. In particular, concerns had been expressed for women who are on a pension or health care card, who are elderly, who are single parents, Aboriginal and Torres Strait Islander or financially disadvantaged. One breast care nurse said that the most reliable indicator for her was the women who she knew continually postponed purchasing a prosthesis – she estimated these to be around 20% of her patients, mostly from older age groups. Another breast care nurse commented that many families on low or no income were struggling with “multiple problems” and that purchasing a prosthesis was not a financial priority for them. She believes that there are many women out there who will never be able to have a breast prosthesis because of financial disadvantage. It was also recognised that women, and the families of women who have breast cancer, have significant financial outlays to consider following surgery and treatment, and many are not able to justify the $400 up-front payment for a prosthesis, due to other competing financial demands.

One woman who had lived with breast cancer for over a decade said it was "a big ask for women to afford a prosthesis up-front after however many rounds of chemo[therapy]". She had initially been excited to hear about the introduction of the Program, but later was greatly disappointed to learn that it would not be a cash payment. She said that some women had thought about donating their prostheses when they passed away, as “although it isn’t very nice to think about, other women [who cannot afford a prosthesis up-front] would be very grateful”. Another woman who had not yet accessed the Program because she could not afford the up-front payment reported that “life is just paying for day to day living and medical procedures at the moment”. She was unsure as to when she would be able to save enough money for a prosthesis as she wasn’t able to go back to work for some time; whilst she had private health insurance, this only covered her hospital stay.

It was recognised that whilst some women could charge the cost of the prosthesis to a credit card or borrow money from family or friends, there were many others who did not have these avenues of financial support – particularly elderly women. One breast care nurse reported that some women had to “save up” for the cost of a breast prosthesis for months before being in a position to afford one. Another commented that she had seen women who were too embarrassed to seek financial help to pay the up-front payment and so had simply gone without. It was also noted that women who had bilateral mastectomies were in a particularly financially challenging situation – as commented by one stakeholder, “nobody just has $800 lying around to pay for this up-front”.

One breast care nurse reported that the hospital where she worked had managed to “facilitate financial assistance for those who could not afford the up-front payment through some very difficult methods, through the social work area as a ‘financial need’”, and that whilst all loans were repaid eventually, this was indicative of the great need they perceived in some women for assistance at the time of purchase.

State and territory-based Cancer Councils reported that they had received a number of requests from women to provide financial assistance for the up-front payment of a prosthesis. Whilst they did not have
the capacity to provide direct financial assistance for the Program, some had “financial assistance programs” in place to assist with paying bills and other basic needs (such as food and clothing) which helped to free up money for women or families to afford the cost of a prosthesis. One representative of a Cancer Council said that whilst this was of great assistance to some women, it was still not helping those who were most disadvantaged and had no hope of being able to afford the initial payment of a prosthesis.

Similarly, some breast prosthesis fitters reported providing loans for women who were unable to pay the cost of a prosthesis out of sympathy or goodwill. One fitter commented: “I will not allow one woman who I fit to go without a prosthesis – it is too important for them not to have one”. Whilst these loans were always paid back, some fitters said that it could at times be a financial burden for their clients.

A handful of respondents reported that they knew of some women obtaining loans from Centrelink through the advance payment scheme, which allowed lump sum interest free loans of between $250 and $500 in advance from future Centrelink payments (repaid through fortnightly deductions from a pension or allowance).

It was noted by some that previous state and territory-based programs (in particular the Victorian and Northern Territory schemes) had been able to avoid this issue of up-front payments by providing a prosthesis to all women who had undergone a mastectomy, or by covering the cost of cheaper models of prostheses so at least a woman would have a prosthesis.

**Lack of knowledge about the Program**

It was also clear that whilst the Program is accessible, this was only the case for those women who know it exists. According to women’s responses to the evaluation survey, the most common means through which women found out about the Program was their breast care nurse (42% of responses) or their breast prosthesis supplier (34% of responses). Many women commented that they did not know how they would have found out about the Program if they hadn’t received information through these avenues.

Whilst the evaluation survey was not representative of all women who have accessed the Program, it suggests that for those who had their mastectomies some time ago or who weren’t wearing a prosthesis, there are many barriers faced in finding out about the Program due to the following:

- they may have had their mastectomy some time ago and therefore are not finding out about the Program through clinical pathways
- they may not currently wear a prosthesis and therefore are not aware of the process of purchasing a prosthesis and the fact that there is a reimbursement program available
- they may have had their mastectomy some time ago and do not know that external prostheses exist (many breast care nurses and prosthesis fitters reported that they had come across women who had made bags of bird seed to put into their bras, or that they were using their husband’s socks)
- they may not be ‘plugged in’ to breast cancer organisations, support groups or communication channels (such as the Cancer Council, NBOCC or BCNA) which have publicised the Program
- they may live in a rural area and not have ready access to mainstream services (including a Medicare Australia office), or may have trouble accessing a prosthesis fitter.

A number of state and territory Cancer Councils representatives reported that they had received calls from women enquiring about how to purchase a new prosthesis. The New South Wales Cancer Council reported that within the first full year (1st of January 2009 to 31st of December 2009) of the Program operating, 16% (3,132 of 18,799 calls) of all helpline enquires were related to breast cancer – and of these calls, 9% (275 calls) were specifically related to obtaining a breast prosthesis. These were generally women who had had their mastectomies some time ago, who had received a prosthesis through the previous state/territory-based program and were needing to replace their prosthesis.

Consultations with medical practitioners and others also suggested that GPs and surgeons knew very little about the Program, suggesting that the Program is being communicated by the breast care nurse, following surgery. This was a concern raised by respondents, particularly in that GPs and surgeons
could be an important source of information for women who had their mastectomy some time ago and no longer access a breast care nurse. One surgeon suggested that “clinicians [in particular surgeons and GPs] treating women with breast cancer should be made more aware of the Program.”

Women on private health cover

Some respondents expressed concern that women with private health cover are at a disadvantage in accessing the Program due to lack of communication about their options. Firstly, it was recognised that women may not know about the Program due to the fact that many private hospitals do not assign breast care nurses to breast cancer patients (breast care nurses have been identified in the evaluation as being a primary communication point about prostheses). Secondly, it was understood that women may be discouraged from accessing the Medicare Australia reimbursement because they believe they have to claim for their prosthesis through their private health insurance, if available. Respondents noted that some women have been disadvantaged in the amount they have been reimbursed by their private health insurance, and the time taken for the reimbursement to be received. By claiming for an external prosthesis through private health cover, some women also jeopardise their capacity to claim for other items in their recovery from breast cancer, for instance chemotherapy, as some health insurers only allow members to claim from a group of items for breast cancer, with a limited ceiling of reimbursement available.

One woman commented: “I would have preferred not to pay the up-front cost of a prosthesis, but at least it is an improvement on what I was offered [monetarily] under my private health care”. She had claimed previous prostheses through her health cover and was reimbursed only one third of the up-front payment despite having the highest level of insurance cover.

Some breast care nurses reported that they “steer” both their public and private patients towards the Medicare Australia Program, and suggest to private patients that they also approach their health funds. In addition, some fitters advise women to try and claim for their prosthesis through their private health cover, and then to claim the remaining amount through Medicare Australia. It was noted by both Medicare Australia and other respondents that this ‘double reimbursement’ process caused problems as private health companies preferred to keep the original receipt of purchase, which is also required by women in order to claim through Medicare Australia. Often, due to misinformation or lack of communication, women were having to go back to their prosthesis fitter to obtain a duplicate receipt to submit with their Medicare claim.

Some women were frustrated with their private health insurer for either not providing a reimbursement for a breast prosthesis or paying a minimal amount. One woman commented: “I pay for my private health cover and do not agree that they are now avoiding their share of the cost. The Government should insist that we claim from our private health cover first and then pick up the rest as the Government is [in effect] subsidising private health cover”. Other respondents shared this view.

Cultural or language barriers

Many challenges were faced during the evaluation in gaining feedback from women of a culturally and linguistically diverse or Aboriginal and Torres Strait Islander background about their experiences with the Program. As such it was difficult to determine to what extent they were accessing the Program. Reports from stakeholders and the focus group with women of an Arabic-speaking background suggested that there may be many women who experience problems in accessing the Program due to cultural and language barriers.

Some breast prosthesis fitters reported that they had fitted many women of a culturally and linguistically diverse background who had gone on to access the Program, and some breast care nurses reported that they had informed a number of patients of a culturally and linguistically diverse or Aboriginal and Torres Strait Islander background about the Program. However, other stakeholders felt that generally there was a need for greater information resources which are accessible to women who may not be aware of the Program or may not be comfortable negotiating the system to claim reimbursement.

Some Cancer Councils and support and advocacy groups reported that they had difficulties themselves in learning about the needs of women from particular community groups. One advocacy organisation reported that it was of concern to them that they did not know who may be in need of assistance
in terms of developing services to support culturally and linguistically diverse and Aboriginal and Torres Strait Islander women. They themselves were trying to improve their networks and communication to women who may not access their services.

There were some reports from urban-based breast care nurses that Aboriginal and Torres Strait Islander women are purchasing prostheses, and that they appear to be aware of the Program. A breast care nurse who works in metropolitan Sydney commented that she had had a number of Aboriginal patients who were “very excited about the Program”. It was not clear whether Aboriginal and Torres Strait Islander women in urban areas are more informed about, and feel comfortable accessing, Medicare Australian and other support services such as breast cancer networks than their sisters in rural areas however.

Many respondents were unable to comment on whether women from culturally and linguistically diverse backgrounds were accessing the Program. However, of the five Arabic-speaking women who participated in the evaluation focus group, only one had heard of the Program. Some breast care nurses reported that they had communicated the Program to numerous patients of a culturally and linguistically diverse background either directly face to face, or by explaining the Program to their families where the woman did not speak English. These nurses felt that if a woman had a breast care nurse, she would most likely find out about the Program from the nurse. Some of the prosthesis fitters said that whilst they had fitted many women who didn’t speak English, knowledge about the Program or the fact that external prostheses existed as an option post-mastectomy was dependent on how well-known the Program was amongst a woman’s cultural or language group, as news generally spread quickly through word of mouth. This was consistent with suggestions given by focus group participants for greater awareness of the Program to be disseminated amongst the Arabic community, for instance through Arabic community centres or Arabic women’s groups.

Language barriers to the Program are compounded by the fact that all written information about the Program was in English. Many breast care nurses reported using an interpreter to explain the Program to women if their English wasn’t proficient. Some breast prosthesis fitters assisted women who didn’t speak English to complete their claim form.

Eligibility for the Program

It was evident through discussions with some respondents that there was a degree of confusion as to who is eligible for the Program, particularly with regard to lumpectomies. Queries over eligibility are regularly received by Medicare Australia and are referred to the Department as a matter of policy.

Many respondents could not understand why a lumpectomy was not included in the eligibility criteria and it is evident that there is a disparity between what is available to women with a lumpectomy, as opposed to a mastectomy, in terms of financial support. As commented by one breast care nurse: “for small breasted women this (a lumpectomy) can be the same as losing a whole breast”. One woman whose claim had been rejected said that she could not understand why a partial prosthesis was not eligible for reimbursement through the Program, as she had “lost enough tissue to affect [her] appearance without some kind of prosthesis”. She felt that the information she had received about the Program’s eligibility was misleading, and worried that women in her position would purchase a prosthesis thinking they would be reimbursed and then find themselves out of pocket.

There were also questions over whether other conditions should be included in the reimbursement program. For instance breast care nurses reported that gene mutation carriers who choose to have prophylactic mastectomies as a preventative for breast cancer were not covered under the Program, “yet they are in effect saving the tax payer thousands by making this sacrifice”. She noted that “there are a small number of women out there who feel discriminated against by not being able to benefit from this Program”.

There was also confusion over whether women who have a mastectomy on one breast who then choose to have the other breast removed as a preventative would be eligible – “we can only presume they are fine as you don’t need a doctor’s letter, however it is still not clear in the eligibility documentation.”
It was reported by some respondents that previous state and territory programs included “those who slipped through the cracks” in their schemes but that the national Program was disadvantaging some women because of the distinction between lumpectomy and mastectomy.

3.1.2 Efficiency of reimbursement to eligible women

Generally, positive feedback was given regarding the efficiency of reimbursements in terms of effort expended in applying for the reimbursement. Many stakeholders noted this was one of the key strengths of the Program, as it was a straightforward process for women (and relatively hassle free). The Program was also praised for its reliability and consistency in its process of reimbursement.

Of women surveyed, more than three quarters (79%) said they had found the process of getting reimbursed straightforward; and a similar number (81%) said that they had found it easy to gather the necessary supporting information for the claim.

Overall the Program had been well accepted by women, and stakeholders reported that they had received little negative feedback regarding the reimbursement process (other than the up-front payment). As one breast care nurse commented, “no news is generally good news”. Both breast care nurses and fitters felt that the new Program was a huge improvement on previous state and territory schemes, and that there were few barriers in the claiming process for women.

A mixed response was given regarding the timeliness of receiving reimbursement payments however. Some breast care nurses and fitters commented that they had heard women say “it was quite quick”. Others said that they had heard of women who had to wait up to six weeks. This was also reflected in the evaluation survey, as just over two thirds of the women surveyed (68%) said they had been pleased with the timeliness in which they had received their reimbursement. Whilst just over half of women surveyed (59%) had received their payment within ten business days, around one tenth (8%) said that it had taken three weeks. Five per cent of survey respondents had received the payment after one month.

These results are interesting as according to Medicare Australia data for the Program’s first year of operation (December 2008 to December 2009), the great majority of reimbursement payments were made within the stated timeframe of 10 working days as is evident in the table below. By December 2009, 99.78% of payments were processed within ten business days. Medicare Australia also reported that they believed the majority of payments were processed within four business days.

Table 5 – Medicare Australia data - percentage of claims processed within 10 business days

<table>
<thead>
<tr>
<th>Month</th>
<th>% of claims processed within 10 business days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dec 2008</td>
<td>68.29</td>
</tr>
<tr>
<td>Jan 2009</td>
<td>56.58</td>
</tr>
<tr>
<td>Feb 2009</td>
<td>97.64</td>
</tr>
<tr>
<td>Mar 2009</td>
<td>98.26</td>
</tr>
<tr>
<td>Apr 2009</td>
<td>95.09</td>
</tr>
<tr>
<td>May 2009</td>
<td>98.96</td>
</tr>
<tr>
<td>Jun 2009</td>
<td>99.83</td>
</tr>
<tr>
<td>Jul 2009</td>
<td>99.65</td>
</tr>
<tr>
<td>Aug 2009</td>
<td>99.82</td>
</tr>
<tr>
<td>Sep 2009</td>
<td>98.94</td>
</tr>
<tr>
<td>Oct 2009</td>
<td>99.35</td>
</tr>
</tbody>
</table>
The disparity between women’s perceptions of timeliness and the Medicare Australia data cannot be explained. However, possible influences may include recall bias, a high proportion of survey respondents who accessed the Program in its early months (when processing was not as quick), or a bias for women who were unhappy with their payment to complete the survey.

3.1.3 Efficiency of implementation of the Program through minimal additional infrastructure costs

There were no reports of additional infrastructure costs to the implementation of the Program during consultations with relevant stakeholders.

3.1.4 Appropriate accountability structures in place to monitor and audit the Program

It is evident that the Program has appropriate accountability structures in place to both monitor and audit the Program. These are outlined in the Business Rules and Service Arrangement between the Department and Medicare Australia. Medicare Australia has a monitoring and audit system in place, as well as a coding system to facilitate program specific reporting and monitoring as stipulated in its Business Rules with the Department. There are quality processes in place to ensure the accuracy of claim details. Also under the Business Rules, Medicare Australia is required to provide to the Department:

- monthly statistics for the previous month/s, with updated monthly statistics being available within five working days of the previous month
- annual statistics with updated financial year statistics being available from within ten working days of the end of financial year
- processing performance on the percentage of claims processed within the reported period by national and state levels
- the number of refunds made, item code, the total and average amount of refunds paid, the total and average amount of purchase costs claimed, presented at national, state and postcode levels, and also broken up into five year age groups at the national, state and postcode levels
- the number of rejected claims processed, by reject code, at the national and state levels.

Whilst a formal audit has not been requested by the Department for this Program, it is understood that the Department is satisfied with the compliance checks Medicare Australia has applied to the administration of the Program in terms of issues such as privacy and eligibility. It is also understood that the Department has reserved the right to request a formal audit of the Program at any time should they feel the need for this to take place.

Both Medicare Australia and the Department consult with one another regularly to ensure accountability for all enquiries or policy issues that may arise. Under Clause 8.2 of the Business Practice Agreement (BPA), Medicare Australia is required to consult with the Department prior to introducing any changes to the current arrangements including:

- administrative changes
- changes/enhancements to the systems that run the Program
- other changes that may alter or affect the delivery of service
emerging policy issues.

As reported by Medicare Australia and the Department, this system appears to work well and has the capacity to detect any emerging issues which need to be addressed.

3.1.5 Consistent national approach across all jurisdictions

The Program has been successful in implementing a consistent national approach across all jurisdictions. Both the Department and Medicare Australia were satisfied that the Program had achieved this objective, and respondents were appreciative that all women nationwide were able to take advantage of a streamlined system of reimbursement. The Program’s consistency was recognised by respondents as a key strength of the Program, in that it provides all eligible women equitable access to a reimbursement, and provides access to reimbursement to a larger pool of women nationally.

Overall, respondents reported that the Program was a significant improvement on previous state and territory-based schemes. Some 76% of women who completed the survey gave a favourable rating to their overall experience of the Program. Under the former state and territory programs women were receiving varying degrees of financial support for their prostheses (all of which were lower than the reimbursement currently offered through the national program). For instance: in New South Wales each area health service (AHS) covered a flat fee of $180 for each prosthesis and the woman would then pay the difference; the Tasmanian scheme contributed $230 towards the purchase of a prosthesis; and in the Australian Capital Territory, the local government would provide a $200 one off reimbursement per person for the purchase of one prosthesis.

The nationalised program was also praised for its simplified claims process. The great majority of women surveyed reported it was easy to obtain an application form, lodge the application form, and obtain the reimbursement following lodgement of application.

3.1.6 Sensitivity to the needs of the eligible women accessing the reimbursement

There was general consensus amongst respondents that the Program provides an appropriate level of sensitivity to the needs of women.

Many commented that this was largely due to the channels through which the Program has primarily been communicated – through breast care nurses, breast prosthesis fitters and breast cancer advocacy groups. For instance BCNA and NBOCC present the Program with general informational material on life after breast cancer, and many breast care nurses include written information about the Program in a general ‘breast cancer kit’ which they give to their patients following surgery.

A number of women who were interviewed reported that they had been impressed with the empathic handling of their claims and any queries they had. More than three quarters (81%) of women surveyed agreed or strongly agreed that they were treated with sensitivity whilst making their claim.

One stakeholder commented that the process is an improvement on previous schemes and doesn’t require the burden of proof. Previously women needed a signed letter from their surgeon; now women are only required to bring the receipt and claim form to Medicare Australia.

Overall feedback was positive regarding Medicare Australia’s sensitivity in administering the Program, however some women commented that they felt a little uncomfortable going to a Medicare Australia office to claim as they felt self-conscious that staff would know they were wearing a prosthesis. One fitter reported that she provided women with the claims form and submitted the form for them, as often her clients had felt uneasy about going into Medicare Australia due to the fact that they had had recent surgery and didn’t feel comfortable going out in public. She also reported submitting claim forms for elderly women or for women in regional areas who were not located near a Medicare Australia office.
3.2 Outcomes achieved as a result of Medicare Australia administering the Program

Consultations suggest that Medicare Australia has been successful in its administration of the Program. Many respondents said that they had been supportive of the Department's decision to appoint Medicare Australia to the administration of the Program. Overall, it was seen as appropriate that Medicare Australia administer the Program due to the fact that:

- women were familiar with Medicare Australia, and the organisation’s processes
- Medicare Australia has administered other programs of a sensitive nature and therefore had experience in ensuring a sensitive approach in its dealings with women
- Medicare Australia has existing infrastructure on which this Program could build and it has experience in managing large national programs
- the process allows women to remain anonymous – previous programs required women to come into a hospital or Cancer Council offices (depending on the state or territory) to obtain a prosthesis
- it is a less stressful process for women as it is just a “one stop shop” visit to a Medicare Australia office
- Medicare Australia is best suited to administer a national program due the fact that it operates on a national scale and has offices in all metropolitan and regional areas
- Medicare Australia is a Government agency and is familiar with Commonwealth financial accountabilities and privacy requirements
- the contractual arrangements with the Department allow for an appropriate accountability structure to be put in place by Medicare Australia to monitor the measure nationally
- by facilitating a nationalised program, Medicare Australia can collect standardised data for women who use a prosthesis, how much these women are paying for their prostheses, and the reimbursement women are receiving
- Medicare Australia has the capacity and IT systems in place to process timely payments
- Medicare Australia has a centralised claims assessment system, which allows for consistency in assessments and tailored training of Medicare Australia processing staff for the Program.

3.2.1 Consistent and straightforward approach

One of the key outcomes achieved as a result of Medicare Australia administering the Program has been that the reimbursement process is straightforward, efficient and requires little effort on the part of women. One stakeholder commented that administration of the Program by Medicare Australia has proven that it is possible to have a streamlined process for reimbursement, and that this has made it more simple for women who have “so many things to deal with in their battle with cancer”. Another commented that women see it as a “Medicare program, that it doesn’t need to be glossed, that it’s seen as professional”.

Medicare Australia was also praised for its consistency in making payments to women. Whilst there were some concerns about the timeliness of women receiving payments, overall, stakeholders and women reported that they had been satisfied with the payment process and the fact that the reimbursement was paid directly into their account electronically. The claim form was also praised for its simplicity and objectivity. One woman commented that the “procedure was extremely swift and competent.” Women found the claim form easy to obtain and to complete and were pleased that they did not have to provide other proof of surgery or personal details.

3.2.2 Communication of the Program to the sector and general public
The following communication strategies were undertaken by Medicare Australia in consultation with the Department, to communicate the Program to the sector and the general public:

- A4 claim form incorporating a fact sheet available in Medicare Australia offices and on the Medicare Australia website
- information provided on the Medicare Australia website in *In Focus* and *Let’s talk about*
- display of posters, brochures and other promotional material in Medicare Australia offices
- promotion of the Program through LCD screens in Medicare Australia offices
- through the monthly theme in Medicare Australia offices
- placement of colour posters and placemats in all Medicare Australia offices during events and awareness periods (for instance during Breast Cancer Awareness month in October 2009)
- website links to key breast cancer organisations
- external promotion via: website link with BCNA, NBOCC; supply of claim form and information sheets to the McGrath Foundation; mail outs (electronic and post) to major hospitals providing breast cancer surgery or support services, including a supply of claim forms and information sheets
- editorials in relevant departmental health service publications, such as ‘Carer’s News’, ‘Rural News’ and ‘News for Seniors’
- media monitoring
- media release regarding *key messages* (how many women have used the Program), and *distribution* (targeted at women’s publications and health publications)
- internal communication about the Program for Medicare Australia staff as needed
- through use of eReference regarding information related to Q&A, claim forms and information sheets.

### 3.2.3 Medicare Australia data on claims made to date

The following presents a summary of Medicare Australia data for the Program for the period of 24th November 2008 to the 31st of December 2009. The data includes the total number of reimbursements since the inception of the Program, the total amount reimbursed, a demographic breakdown of those who had been reimbursed, and process performance.

By 31 December 2009, following a full year of operation:

- some 17,997 claims had been processed and 19,962 reimbursements paid
- the average purchase cost of a prosthesis was $373.65 and the average reimbursement per claim was $340.69
- the total cost of the reimbursement program to the Commonwealth had amounted to $6,130,011.52; rebates through private health funds had totalled $353,221.35 and state and territory rebates had totalled $58,615.50. ‘Other’ rebates had totalled $26,434.06.

An age breakdown of the data shows that by the end of the first year of the Program, just over three quarters (77.4%) of women who received reimbursements were aged between 50 and 80 years (as indicated in the table below). Close to one third (32.6%) of the women were aged between 60 and 70 years.
Table 6 – Age breakdown of women who had been reimbursed (November 2008 to December 2009)

<table>
<thead>
<tr>
<th>Age range</th>
<th>% of those reimbursed (n=19,962)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20 years</td>
<td>0.0%</td>
</tr>
<tr>
<td>20-30 years</td>
<td>0.3%</td>
</tr>
<tr>
<td>30-40 years</td>
<td>2.1%</td>
</tr>
<tr>
<td>40-50 years</td>
<td>10.4%</td>
</tr>
<tr>
<td>50-60 years</td>
<td>21.6%</td>
</tr>
<tr>
<td>60-70 years</td>
<td>32.6%</td>
</tr>
<tr>
<td>70-80 years</td>
<td>23.3%</td>
</tr>
<tr>
<td>80-90 years</td>
<td>8.8%</td>
</tr>
<tr>
<td>90 years and over</td>
<td>0.9%</td>
</tr>
</tbody>
</table>

By 31 December 2009, the state with the greatest number of reimbursements was New South Wales (37.8%) as indicated in the table below.

Table 7 – Reimbursements by state or territory (November 2008 to December 2009)

<table>
<thead>
<tr>
<th>State/territory</th>
<th>% of total reimbursements provided (n=19,962)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>37.8%</td>
</tr>
<tr>
<td>QLD</td>
<td>20.0%</td>
</tr>
<tr>
<td>VIC</td>
<td>17.1%</td>
</tr>
<tr>
<td>WA</td>
<td>10.8%</td>
</tr>
<tr>
<td>SA</td>
<td>8.8%</td>
</tr>
<tr>
<td>TAS</td>
<td>2.7%</td>
</tr>
<tr>
<td>ACT</td>
<td>2.3%</td>
</tr>
<tr>
<td>NT</td>
<td>0.5%</td>
</tr>
</tbody>
</table>

The following points of comparison can be made from the data.

- The number of total claims increased quite rapidly, from 11,899 in August 2009 to 17,997 in December 2009; however so did the number of claims that were rejected (an increase of 45%; from 70 in August to 153 in December).
- The number of total reimbursements also increased from 13,208 in August 2009 to 19,962 in December 2009.
- The average purchase cost of a prosthesis increased only marginally ($5.26) from $368.39 to $373.65 per prosthesis.
- The total cost to the Commonwealth in providing reimbursements had almost doubled during the four months from August to December 2009, rising from $3,933,223.27 to $6,130,011.52.
- Rebates through private health funds also increased from $273,729.51 in August 2009 to $353,221.35 in December 2009.
Rebates through state and territory governments stayed roughly the same ($57,335.50 in August and $58,615.50 in December); and there was only a marginal increase in ‘other’ rebates from $24,732.91 in August 2009 to $26,434.06 in December 2009.

Program activity was higher during the four months between August and December than in previous months, suggesting information about the Program was successfully reaching women. There was an information campaign in October 2009 for Breast Cancer Awareness Month (organised by the Breast Cancer Foundation), with flyers posted in all Medicare Australia offices and through other organisations. This may have assisted in raising awareness of the Program.

Whilst it is not possible to estimate what proportion of women who use prostheses nationwide are accessing the Program (as it is not known how many women choose to use prostheses), on the whole it appears that Medicare Australia has been successful in its administration of the Program to date. The data above is reflective of the overall feedback received from respondents for this evaluation.

Some respondents suggested that some of the Medicare Australia Program data be made public to organisations such as the Cancer Council and advocacy groups, as it would be useful for them to gauge how many women were using the Program.

3.2.4 Timeliness of reimbursement payments

As discussed in section 3.1.2, Medicare Australia data shows that by December 2009, 99.78% had received their reimbursement payment within the stated ten business days. This is well within the performance indicators specified in the Business Rules for administration of the Program.

Generally women consulted were satisfied with the period of time taken to receive their reimbursement. A small number of women reported that they had had to wait up to six weeks to receive their payment.

3.2.5 Responsiveness to the needs of women

Overall, women felt that they were treated with sensitivity and compassion by Medicare Australia when submitting their claim for a reimbursement, and reported that their enquiries were handled well by Medicare Australia. Some 81% of women who completed the survey said that they were treated with sensitivity while making their claim. It was also felt by the Department that “enquiry management arrangements [were] well established and managed properly” by Medicare Australia.

One woman noted that there was a delay in claim forms being available at her local Medicare Australia office, but that she had no problems once she had obtained a form.

3.3 Effective integration of the Program within the broader policy environment

The National Service Improvement Framework for Cancer (National Health Priority Action Council, 2006) sets out the Government’s approach to cancer, including early detection and treatment, ongoing care, and provision of management and support during and after treatment, including practical issues. The Program, in addressing a very practical need for women who have had a mastectomy due to breast cancer, addresses this key intervention point of the Framework. The Framework also points out the need to improve services to Aboriginal and Torres Strait Islander people, and people in rural and remote areas. In establishing a nationally consistent scheme through Medicare Australia, the Program increases the opportunity for women in rural and remote areas to access the same level of support for the cost of a breast prosthesis as that available to women in metropolitan regions. There is anecdotal evidence suggesting that Aboriginal and Torres Strait Islander women may not have as much access to the Program, however it is not possible to make a definitive statement regarding this and it may be that women living in urban areas have better information about the Program than women living in more remote communities.

The Program is also clearly identified as a component of the Commonwealth Government’s approach to cancer care as stated in the recently released paper, Delivering Better Cancer Care (Commonwealth of...
The Program provides a counterpart for the increasing focus on breast cancer and investment in screening, early detection and treatment, providing support to women after the cancer has been detected and treated, as women live with the ongoing consequences of the loss of a breast due to breast cancer.

The Program complements other Government breast cancer initiatives through the National Breast and Ovarian Cancer Centre (NBOCC), Breast Cancer Network Australia (BCNA) and the McGrath Foundation, which focus on treatment and support for women with breast cancer. Information about the Program is actively disseminated by all of these organisations to eligible women who may benefit from the Program.

Issues for consideration as to how the Program might be improved to ensure that the Program fully meets the needs of eligible women are discussed below and in chapter 5 of this report.

3.4 Improvements in the administration of the Program and duplication

3.4.1 Improvements to processes and administration of the Program

The following suggestions were made by respondents with regards to possible improvements to the administration of the Program.

Communication and promotion of the Program

The large majority of respondents agreed that the most effective means of finding out about the Program was either through a breast care nurse or a breast prosthesis fitter. However it was believed that more could, and should, be done to promote the Program more widely for those who may not have access to these specialists. For instance one woman who lived in a regional area said that it had taken some time for her to find out about the Program because there were no prosthesis fitters in the area. Many commented that lack of promotion was a significant weakness of an otherwise sound program - "it's a fantastic program [however] all the benefits are outweighed by the lack of information out there for women [about the Program]". Whilst some respondents acknowledged that they had received initial communication about the Program from Medicare Australia and a few women had seen promotional material displayed in Medicare Australia offices (as per Medicare Australia's communication plan detailed in section 3.2.2), it was felt that "the Program has very much relied upon the initial press flurry when the Program was first announced [and] this has since died off". There was concern that "for people going through the pathway now, you can only hope their breast care nurse or prosthesis fitter is telling them about the Program".

Whilst information provided on the Medicare Australia website is useful, it was thought that this shouldn’t be relied upon as a primary form of communication. The fact that all communication about the Program is in English was also seen as a barrier to those from a cultural and linguistically diverse background, or to Aboriginal and Torres Strait Islander women accessing the Program. A number of respondents stated that there needed to be written information about the Program provided in other languages other than English. Medicare Australia reported that a review of this is due to take place later this year.

The promotional flyer/stand in Medicare Australia offices throughout October 2009 was praised as a good idea and it was suggested that this should be in place permanently.

It was also argued that women didn’t necessarily realise that they had the option available to post claims.

Areas where respondents felt information could be promoted about the Program included:

- brochures at prosthesis suppliers, hospitals and Medicare Australia offices
- radio and television commercials
- through general practitioners and practice nurses during consultations
• BreastScreen units
• advertising at breast cancer events, such as the Mother’s Day Classic Marathon in May.

Concerns were also voiced regarding communication on the reimbursement amount. One woman thought she would be reimbursed for a total fee of $400 and so purchased a soft inexpensive prosthesis post surgery for $66 and claimed on this, not knowing that this was all she could receive a reimbursement for the next two years. Other women have also been confused about the $400 amount and have purchased special bras for their prostheses thinking that because they had spent less than $400 for their prosthesis, they could include the cost of a bra to bring them up to the full amount.

Some women reported feeling uncomfortable or self conscious about going into a Medicare Australia office to claim. Many fitters and breast care nurses said that they had taken forms into Medicare Australia for women because of this. It was acknowledged however, that some women may be deterred from sending the claim form by post due to the additional time it would take for Medicare Australia to receive their claim. Very few women in fact reported that they had submitted their claim by post.

Availability of claim forms
It was felt that more could be done to improve the availability of claim forms for women, in particular for those who were not familiar with using the internet or who were some distance from a Medicare Australia office. It was suggested that hard copy claim forms be distributed to fitters and breast care nurses to make them more available to women, as these two avenues are generally where women first find out about the Program.

Cash payments and bulk billing
It has been reported that there is a perception that the Program forms part of the Medicare Benefits Schedule, and this has led to queries from some women regarding the ability to receive over the counter reimbursements under the Program.

It was suggested by some respondents that the Program be administered through a cash payment or bulk billing system. It was thought that fitters could register with Medicare Australia and use a HICAPS terminal when charging women for their prosthesis, so that their payment would be bulk billed up front. This would place a large degree of risk on fitters, however, and would potentially incur an enormous cost to establish in terms of IT software required.

While currently the program operates as a reimbursement Program, this may need to be monitored over the next few years of the Program to assess whether there would be benefits in changing the mode of reimbursement.

Including the cost of prostheses-specific bras in the $400 reimbursement
It was also suggested that women be able to include the cost of prostheses-specific bras in the $400 reimbursement amount, as these bras are more expensive than the average bra. For instance if a woman spent $320 on a prosthesis, she could also claim $80 on a bra to bring the full amount up to $400.

As reported by one breast care nurse, “some women will go without a fitted prosthesis if they cannot afford the bra, as they consider the prosthesis useless without the bra”.

It was noted that Department of Veterans Affairs reimbursement scheme included reimbursement for a breast prosthesis and two bras.

3.4.2 Duplication
There were no reports where duplication was an issue for the administration of the Program.
3.5 Appropriate administration to achieve the principles of the Program and comply with the Business Rules

It is evident from this evaluation that there are mechanisms in place to ensure appropriate administration of the Program with regards to providing service to women as per the principles of the Program, and that these are in accordance with the Business Rules of the Program.

For instance, Medicare Australia has established processes to assist in the management of enquiries of varying complexity and a tiered approach is used to separate simple and complex enquiries.

- Tier 1 or simple enquiries (e.g. the provision of claim form and/or fact sheet) are handled by Medicare Australia staff in person or over the phone
- Tier 2 or more complex enquiries (payment or rejection determinations) are transferred to the dedicated processing site for resolution
- Tier 3 or queries of a policy or legislative nature are referred to the Department for assessment.
4 Impact review

This chapter addresses the following terms of reference for the evaluation:

- **assessment of the extent to which the outcomes of the Program have met the goals as defined by the objectives of the measure**

- **whether the Program provides outcomes that meet the needs of women requiring an external breast prosthesis following a mastectomy as a result of breast cancer**

- **opportunities for future improvements or directions to the Program.**

This chapter discusses findings from the survey conducted with 362 women, and follow up telephone consultations, emails and focus groups with a further 15 women. Although it is important to note that the survey respondents (and for that matter the interview participants) are not necessarily representative of all women eligible to access the Program, the data provides useful insights into awareness and access to the Program and in particular women’s experiences in using it.

Feedback from some other stakeholders, in particular breast care nurses and breast prosthesis fitters, is also included in the following discussion of findings.

4.1 Awareness and use of the National External Breast Prostheses Reimbursement Program

4.1.1 Awareness

As indicated by the graph below, 88% of the 362 respondents who completed the survey were aware of the Program prior to the survey. Less than one tenth (8%) of women who had not accessed the Program said that this was because they had not heard about the Program before.

Only one out of the five Arabic-speaking women who participated in the focus group was aware of the Program, suggesting that levels of awareness of the Program may differ considerably among Australian communities.

Figure 7 – Have you heard of the National External Breast Prostheses Reimbursement Program? (n=362)

Survey respondents were asked how, or where, they had heard about the Program. Results are shown in figure 8 below. The leading source of information about the Program was breast care nurses, with around four in ten respondents (42%) hearing about the Program through this avenue.

About one in three women had been informed about the Program by breast prosthesis suppliers (34%). Other major sources of information about the Program included the Breast Cancer Network Australia.
(BCNA) website (19%), through word of mouth (16%), at Medicare Australia offices (14%) and through local breast cancer support groups (12%).

It is apparent from the total number of responses to this question (636, nearly twice the number of respondents), that most respondents encountered information about the program in more than one place.

Figure 8 – How did you hear about the National External Breast Prostheses Reimbursement Program? (n=362; multiple response)

Respondents consulted during the administrative review expressed concern that there were women who were not aware of the Program. As discussed in section 3.1.1, it was reported that lack of awareness was a primary factor in women not accessing the Program. The results highlighted in the figure above suggest that there are a number of avenues through which women are finding out about the Program, however these are not necessarily being utilised to their full potential, and not all women will have had exposure to one of these sources during the life of the Program.

Among survey respondents, awareness of the Program varied significantly according to jurisdiction, with those in Australia’s Capital Territory (100%), Victoria (96%), New South Wales (91%) and Tasmania (90%) having greater awareness than those in Queensland (88%), Western Australia (85%), South Australia (82%), and considerably less awareness in the Northern Territory (36%).
4.2 Participation in the Program

Of the 362 survey respondents, around two thirds (67%; 214 women) had taken part in the Program.

The remaining third of survey respondents, who did not claim under the Program, provided a number of reasons for not doing so. However, the primary reason given (by almost half of non-claimers), was that they did not require a prosthesis during this period. About one quarter of non-claimers said that difficulty lodging an application form for the Program prevented them making a claim. A range of other reasons applied to smaller proportions of respondents. These results are shown in figure 9.

Figure 9 – What was the reason/s that you did not make a claim for reimbursement through the Program (n=105; multiple response)
4.2.1 Characteristics affecting women’s use of the Program

As noted, survey respondents are not statistically representative of all women who have accessed the Program due to the limitations in reaching all women who had claimed through the Program. However, as creating a profile of the respondents who had not accessed the Program could potentially indicate some barriers to access, cross tabulations and chi square tests were performed on a selection of characteristics, including age, state and remoteness of residence, previous use of state and territory prosthesis programs, involvement with one or more support groups, recency and type of mastectomy.

Only two factors proved to be statistically significant:

- Respondents whose mastectomy had been in the last 24 months were significantly more likely to have made a claim through the Program (83%) than those who had had a mastectomy 2 to 5 years ago (54%) or more than 5 years ago (58%).

- Interestingly, those who had previously accessed a state or territory based prosthesis program were significantly less likely to have made a claim through the national Program (56%) than others (72%).

Some stakeholders interviewed suggested remoteness of residence was a barrier for women accessing the Program, particularly because those in rural areas or small towns may not have access to the wider range of health services and networks available in urban areas.

Some stakeholders also expressed concern that older women were not accessing the Program due to the fact that:

- they may have had their mastectomy some time ago and are no longer regularly seeing a health care provider in relation to their experience of breast cancer

- they may not know that external prostheses are available or that there is a reimbursement Program to assist

- they may not be involved with breast cancer organisations, support groups or communication channels which have publicised the Program

- they may live in rural areas and not have ready access to mainstream services or access to a prosthesis fitter.

Some stakeholders considered that knowledge about the Program was influenced by women’s involvement with breast cancer-related groups and networks, due to the fact that this is where information has primarily been disseminated about the Program, and where women are likely to find out about the Program from other women who have used it. However, the primary means of access to information (as identified in interviews and in figure 2 above) does appear to be breast care nurses and prosthesis fitters and suppliers. It may be that women first hear about the Program from their breast care nurse or prosthesis fitter, and are able to find out further information, or receive encouragement to access the Program, from their own breast cancer network or support group.

It is important to treat participation in the Program as distinct from access to the Program (which may be affected by factors such as those listed above, as well as awareness and understanding of the Program). As shown in the previous section, the Program may be unused by women until they require a replacement prosthesis. It is also significant that not all women who have had a mastectomy may need or want to use the Program, particularly if they undergo reconstruction surgery soon after their mastectomy. It may be that many women are aware of the Program but have not chosen to access it yet, although they may do so in the next year or two as their current prosthesis wears out or they complete current treatment regimes.
4.3 The experience of using the Program

4.3.1 Information about the Program

Figure 10 – On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program? (n= 214)

- The usefulness of information about the Program
  - 4% 8% 17% 31% 39%
  - Not Sure 1 2 3 4 5

- The availability of information about the Program
  - 8% 12% 29% 25% 26%
  - Not Sure 1 2 3 4 5

Survey respondents were asked to give both the availability and usefulness of information on the Program a rating out of 5. As can be seen in Figure 10, over 75% gave the program a favourable score (ie 3 to 5 out of 5). The usefulness of the information was rated more favourably, with over 85% of respondents giving a favourable score.

- Among respondents, some groups gave higher ratings of the information than others. Availability of information was rated less favourably by women aged 70 years and over (68%) than those aged 50 to 69 years (87%) and those aged up to 49 years (79%). A similar pattern was found in relation to usefulness of information: less favourable ratings were given by respondents aged 70 years and over (67%) than those aged 50 to 69 years (91%) and up to 49 years (83%).

- The availability of information about the program was also rated less favourably by women who had had a partial mastectomy (75%) or double mastectomy (70%) than those who had had a full mastectomy (84%).

It was suggested by women that greater promotion of the Program is needed (also discussed in section 3.4.1). It is apparent that levels of awareness of the Program are inconsistent and depends to some extent on contact with breast care nurses. This was highlighted through the following comments made by women:

“This Program seems to not be [reaching] women who have had breast cancer and are over 65 years old.”

The Program is good but should have been advertised more widely. The lymphedema group I am in [generally don’t know] about the Program.”

“I heard about the Program from the breast care nurse only...A woman who had a lumpectomy then another lumpectomy a week later, then a mastectomy a week later at the same hospital as myself did not know that prostheses were available let alone that they were government supported.”

It is also noteworthy that members of an Arabic speaking focus group had very limited awareness of the Program, which may suggest barriers relating to language spoken need specific attention.

It was also suggested that advertising in Medicare offices lacked impact:

“Access to me was unknown to me until I saw a tiny notice on a Medicare counter.”
“I thought that there wasn’t enough advertising about the scheme in the [Medicare Australia] office in Melbourne where I lodged the claim.”

4.3.2 The claiming process

Figure 11 below shows that women who participated in the survey used a range of methods for claiming under the Program, but that most women obtained a form in person either from a Medicare office (30%) or prosthesis fitter/supplier (24%). One in ten women (10%) downloaded and posted an application form. This supports findings from discussions with other evaluation respondents that prosthesis fitters play a key role in the application process.

The vast majority of claims for the reimbursement made by survey respondents (97%) were successful. A variety of reasons, with no apparent pattern, were given for unsuccessful claims.

Figure 11 – How did you make your claim for reimbursement of an external breast prosthesis? (n=214)

Note that the above figures do not add to 100%. The remaining 21% of respondents completed a postal version of the survey and did not answer this question.

Figure 12 – 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 Program (n=214)

Figure 12 above indicates that survey respondents were generally satisfied with aspects of the claiming process, nearly 80% agreeing it was straightforward overall and just over 80% agreeing it was easy to
gather supporting information for their claim. A similar proportion of respondents agreed that they were treated with sensitivity by Medicare staff while making their claim.

Figure 13 – On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program? (n=214)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Rating 1</th>
<th>Rating 2</th>
<th>Rating 3</th>
<th>Rating 4</th>
<th>Rating 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>The ease of obtaining an application form</td>
<td>10%</td>
<td>22%</td>
<td>58%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ease of lodging the application form</td>
<td>9%</td>
<td>20%</td>
<td>61%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ease of completing the application form</td>
<td>9%</td>
<td>22%</td>
<td>63%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Similarly positive views are indicated by the results shown in Figure 13. More than 90% of respondents gave a favourable rating (3 to 5 out of 5) relating to the ease of obtaining, completing and lodging an application form.

It is apparent that older respondents had more difficulty with the claiming process than others.

- Respondents aged 70 years and over were more likely to disagree that ‘the process of getting reimbursed was straightforward’ (10%) than those aged 50 to 69 years (7%) or those aged up to 49 years (8%).

- Similarly, respondents aged 70 years and over were less likely to agree that ‘it was easy to gather the necessary supporting information for the claim’ (55%) than those aged 50 to 69 years (84%) and those aged up to 49 years (84%).

- The ease of obtaining a form was rated less favourably by respondents aged 70 years and over (80%) than those aged 50 to 69 years (94%) and those aged up to 49 (93%).

- The ease of lodging a form was rated less favourably by respondents aged 70 years and over (75%) than by those aged 50 to 69 years (94%) and those aged up to 49 years (87%).

Affordability of the initial payment

Figure 14 – 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 Program (n=214)

<table>
<thead>
<tr>
<th>It was difficult to afford the up-front payment required for a reimbursement under the Program</th>
<th>Rating 1</th>
<th>Rating 2</th>
<th>Rating 3</th>
<th>Rating 4</th>
<th>Rating 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>21%</td>
<td>12%</td>
<td>26%</td>
<td>16%</td>
<td>24%</td>
</tr>
</tbody>
</table>
Responses to the more negative statement on affordability of paying up front for breast prostheses were ambivalent, with just over 40% agreeing, just over 25% neutral, and approximately one third disagreeing. This result suggests that there are a broad range of views on this aspect of the Program, including a substantial minority who feel it is difficult to afford the upfront payment.

The impact of the upfront payment on the Program’s participants is discussed further in section 4.3.4.

Confusion about eligibility and interaction of the Program with private health insurance

Many women reported that they were confused about whether to claim for a reimbursement from their private health insurance, Medicare Australia, or whether to claim through both. There are health insurance providers who provide a lower rate of reimbursement, link the reimbursement for prostheses to other breast cancer related items (therefore jeopardising women’s capacity to claim for these other items), or provide no reimbursement for prostheses at all. Breast care nurses interviewed also cited anecdotal evidence of health funds ceasing coverage of breast prostheses since the advent of the Program.

A number of different scenarios were mentioned by women (as relayed below). Noteworthy elements in these include an excessive amount of consultation back and forth with Medicare and private providers, difficulty retrieving receipts, and unwittingly losing entitlements due to lack of knowledge of how to navigate the dual claiming process.

“I claimed my prosthesis from my private fund first and was able to get $200 from them and then from Medicare I got $200. Unfortunately this eliminated all of our extra private benefits and if my husband or myself needed more reimbursement for other aides e.g. for teeth, physio etc, then we would not have been able to get any refunds. I feel that the reimbursement should be solely covered by Medicare."

“Having always paid for private health insurance I feel that reimbursement being lower for me was unfair.”

“As I was a very early claimant the private insurer/Medicare office people were unprepared. The big problem was my private health insurer (which had already reimbursed me for a portion of the cost) could not give me back the receipt from the prosthesis provider. I therefore had to go back to the provider to get another receipt before Medicare would cover the difference.”

“I was initially rejected by Medicare because I have private health insurance. So I had to apply through my health fund and then contact Medicare. However the health fund wanted my original receipt so I could only supply Medicare with a photocopy. I was rejected for a second time for not having the original receipt. I then had to go back to the prosthesis supplier in order to get a duplicate receipt. Finally Medicare accepted my claim.”

“I have private health cover and tried to claim from them first and recover the rest of the cost from the Government reimbursement. I pay for my health (private) cover and do not agree that they are now avoiding their share of the cost – they are not only covering the examination costs, not their basic liability. The Government should insist that we claim from our private health cover first and then pick up the rest.”

“The main difficulties for me were with the part of the claim covered by private health insurance…the Medicare part of it was straightforward.”

“I am privately insured including ancillary and my health fund stopped reimbursing for prostheses – no explanation was given.”

It is clear from these comments that there is a need for the issue to be examined and for the interaction of private cover and reimbursement under the Program to be clarified in communication materials, or streamlined, to ensure a smooth process and consistent outcomes.
4.3.3 The reimbursement process

Just over half of respondents (59%) reported that their reimbursement had been processed within ten business days. This is indicated in figure 15 below. A further 15% said that the processing time was longer than ten business days. The remaining respondents were either unsure of the processing time or did not answer the question. These results are in accordance with feedback given by stakeholders about the processing times of the reimbursement, and (as discussed in section 3.2.4) suggest that Medicare Australia has achieved its obligations as set under the Business Rules for administration of the Program.

Figure 15 – Approximately how long did it take to receive reimbursement for the breast prosthesis into your bank account after you had lodged the claim? (n= 207)

Note that the above figures do not add to 100%. The remaining 21% of respondents completed a postal version of the survey and did not answer this question.

Figure 16 – On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program? (n=214)

Although survey respondents did not overwhelmingly report that claims were processed within ten business days, they were very satisfied with the timeliness of the process. As shown in Figure 16, 88% of respondents gave a rating of 3 to 5 out of 5 to both the timeliness of the reimbursement and the ease of obtaining the reimbursement following lodgement of their claim.

The following were noted.
• Respondents who had previously accessed a state/territory based prosthesis program rated the ease of reimbursement under the National Program less favourably (79%) than others (91%). They also rated the timeliness of reimbursement less favourably (80%) than others (87%).

• Respondents aged 70 years and over rated the ease of reimbursement under the Program less favourably (70%) than those aged 50 to 69 years (90%) and those aged up to 49 years (91%). These respondents also rated the timeliness of reimbursement less favourably (80%) than those aged 50 to 69 years (87%) and those aged up to 49 years (85%).

4.3.4 Outcomes of participation in the Program

The reimbursement itself

Figures 17 and 18 below relate to the level and frequency of reimbursement available under the Program. Figure 17 shows that 88% of respondents gave a favourable rating (3 to 5) for the reimbursement amount. Similarly, Figure 18 shows that 75% of respondents agreed that the amount was sufficient.

The level of reimbursement was viewed less favourably by older respondents and those who had previously accessed another program.

• Respondents aged 70 and over were less likely to agree that 'The level of the reimbursement for an external breast prosthesis under the Program was sufficient' (60%) than those aged 50 to 69 years (80%) and those up to 49 years (71%).

• Respondents who had previously accessed a state/territory based prosthesis scheme were more likely to disagree that 'The level of the reimbursement for an external breast prosthesis under the Program was sufficient' (13%) than others (8%).

Figure 17 – On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program? (n=214)
In contrast to views on the amount reimbursed, attitudes to the frequency of reimbursement were somewhat ambivalent. Only half the respondents (50%) agreed that the reimbursements under the Program were sufficiently frequent, and almost one third (30%) disagreed.

Among survey respondents, younger respondents and those who had previously used other programs were least satisfied with this aspect of the Program.

- Respondents aged up to 49 years were less likely (37%) to agree that ‘the frequency of reimbursement for an external breast prosthesis under the Program (i.e. every 2 years) is sufficient’ than those aged 50 to 69 years (54%) and those aged 70 years or over (57%).

- Those who had accessed state/territory based prosthesis programs were less likely (47%) than others (53%) to agree that ‘the frequency of reimbursement for an external breast prosthesis under the Program is sufficient’.

Lower satisfaction with the frequency of reimbursement was echoed in verbatim responses and interviews. Some women felt that there were unavoidable circumstances where women would need replacement prostheses before the elapse of the required two year period. This was particularly the case with women who, due to hormone treatment and chemotherapy, lost or gained large amounts of weight within a period of months. In most cases these women were then unable to wear their prostheses which were moulded to their former body shape.

Whilst it is understood that most prostheses have a manufacturers guarantee for up to two years, type of prostheses and climate were also noted to affect their longevity, as was level of physical activity; the latter may explain why younger respondents who may be more physically active, were less satisfied with this aspect of the Program, and this link was also suggested in interviews with consumers.

The following comments were made with reference to the frequency of reimbursement:

“I purchased a prosthesis last year following my second mastectomy that is now four times too big for me. Due to the type of chemotherapy I’ve been receiving I have gone from 65kg to 47 kg. I can’t wear the prosthesis as it is much too big for me – unless I pump up the other breast [prosthesis], but this one is very old and falling apart and I can’t afford to replace it.”

“Because of the treatment that I am on (Tamoxifen), I have found that my right breast is getting less full and that my prosthesis is too large.”

“At the time I had lost a lot of weight and so got a prosthesis that was suitable for my size. Within six months I have put on weight and think I will have to get a bigger size of prosthesis soon, but realise I will not be reimbursed for it.”
“Two years is fine for people with stage one breast cancer. I have had stage four breast cancer for the last eight years. With weight gain and loss due to treatment I have had to purchase two prostheses myself [without reimbursement].”

“I think it would be much better for the government to provide the reimbursement yearly – I wear a ‘contact’ prosthesis [which is stuck onto the chest] and these only last just over a year.”

“Because I live in a tropical climate, every twelve months would be more appropriate for me, as the prostheses do not last long in this environment.”

Inclusions in the reimbursement
A number of women felt that the cost of prostheses-specific bras should be included in the $400 reimbursement amount (as discussed in section 3.4.1). Many reported that the cost of these bras was far more than for ordinary bras. It was also reported by women that swimming and aqua exercise was often recommended for recovery, but that they then had to purchase a second ‘swimming’ prosthesis. Some suggested that the swimming prosthesis could be covered under the Program too.

Women commented that:

“The Program would be improved if the reimbursement could include at least part of the cost for the bra to wear with the prosthesis. The price of a mastectomy bra is high and you need at least two garments to manage.”

“Reimbursement for a bra would be helpful because they cost more than ordinary bras.”

“For women who may require a second (swimming) prosthesis this could be quite an expensive outlay.”

Impact on affordability of a breast prosthesis

Figure 19 – 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 Program

Figure 19 above indicates a strong level of agreement that the Program enhanced the affordability of breast prostheses. Over 80% agreed that this was the case, with over 70% agreeing strongly.

A slightly lower level of agreement was found among those who had previously accessed a state/territory based program. This group were more likely to disagree with the statement (14%) than others (7%)

Effect of the required upfront payment on accessibility of the Program

However, as noted in previous sections of this report, the up-front payment for breast prostheses prior to reimbursement is apparently considered difficult to afford by a number of people.
Some women reported in verbatim survey responses and interviews that whilst the Program was of tremendous assistance to them, the initial up-front fee for the reimbursement was difficult to afford, particularly for older non-working women, and those having to pay for various aspects of their treatment. As discussed in section 3.4.1, many reported that they would have preferred not to have had to pay for their prosthesis up-front, and suggested that breast prosthesis fitters or suppliers bulk bill the prosthesis in order to address the up-front cost and “cut out the waiting period.”

One interview participant anticipated that while she was recuperating from treatment and unable to work, it would be some months before she could afford a prosthesis. Such instances were not isolated, according to breast care nurses. Several breast care nurses also mentioned cases where women had sought donations from support groups to fund the upfront payment.

Although the available data does not allow the extent of this issue to be quantified, the finding that a substantial minority of survey respondents found the payment difficult to afford, combined with consistent feedback from interviews, suggest that equitable access to prostheses may be compromised under the current arrangement.

The following comments made by survey respondents all relate directly to this aspect of the Program.

“What happens when someone is on a limited income (e.g. pension, unemployment, or very low income) and cannot afford the initial outlay?”

“The Program is a huge help but would find a cash rebate at time of claim a great benefit.”

“The big issue is coming up with the $400 up-upfront. I had to put it on my credit card then waited three weeks for reimbursement. After one week I enquired and was told there was a backlog.”

“Some women will find it very hard to pay up-front for their prosthesis. Maybe some sort of voucher system would financially be much easier those who cannot afford the initial outlay.”

“There is a need to look at the upfront payment as a lot of families have gone through tough times and some have reduced incomes.”

“It was difficult to afford the prosthesis before and now due to circumstances, it would be virtually impossible to pay upfront.”

“I know of women that have not been able to afford the money to pay up front for their prostheses, especially if they have had a bilateral mastectomy and are on a pension.”

“It was quite a hardship for me to find the money, being on a disability pension.”

“So many people could not afford to have $400 taken out of their cash flow for three weeks. What about the cost to those with a double mastectomy? I know that in poorer years of my life I would have had to make do with a badly sized, damaged prosthesis.”

“I haven’t yet made a claim as I can’t afford the up-front payment under the Program. I am unable to save up as I am struggling to pay living expenses.”

“I would really have liked to have just had to visit the Medicare office, fill in the claim form and receive the payment straightaway. It would have made paying for the prosthesis much easier…All other payments are upfront at Medicare with no questions asked.”

Overall satisfaction with the program and its impacts

Figure 20 and 21 below relate to respondent’s views of the Program overall. They indicate that overall attitudes to the Program are positive. Over 90% of respondents gave the overall experience of the Program a favourable rating. In addition, 77% of respondents agreed that the Program had had a positive impact on their overall quality of life.
Figure 20 – 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

- The Program had a positive impact on my quality of life
  - 16% Not sure
  - 18% Strongly disagree
  - 59% Agree

Figure 21 – On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program?

- The overall experience of the Program
  - 15% Not sure
  - 31% 1
  - 45% 5

Some variations were found between groups of respondents.

- Respondents who had previously accessed state/territory based prosthesis programs rated the overall experience of the national program less favourably (85%) than others (93%).
- Respondents aged 70 years and over rated the overall experience of the program less favourably than those aged 50 to 69 years (96%) and those aged up to 49 years (87%). They were also less likely to agree that ‘the program had a positive impact on my quality of life’ (68%) than those aged 50 to 69 years (78%) and those aged up to 49 years (74%).

The overwhelming response given by women who provided comments to the evaluation was gratitude. Women were appreciative that their needs had been recognised, and that they were able to access a reimbursement that was nationally consistent and straightforward in process. Almost all commented on how the Program had impacted on their quality of life.

Below are some of the unprompted comments that were received by survey participants which highlight their satisfaction with the Program.

“This is a wonderful Program…the recognition that it’s not just a cosmetic issue but is a medical issue was a real boost to my recovery – it reinforced for me that self image is so important to moving forward after breast (or any) cancer.”

“This is a valued Program for breast cancer survivors – the external prosthesis is a must (if one doesn’t have implants) and really helps to make one feel so much better about oneself.”
“The Program sent me into raptures – no more socks in my bra, no shoulder pads rising up outside my dress…thank you.”

“Thanks for this Program. I would not have been able to replace my breast prosthesis without this Program.”

“Thank heavens it’s available! I would have found it very hard to afford without the Government reimbursement being readily available!”

“Overall I was satisfied with the Program and very grateful.”

“Long time coming and just fantastic.”

“I was very happy when I found out about the Program as my prosthesis had split and I had to tape it up which was uncomfortable at times.”

“I think the Program is just the best thing for women after going through a mastectomy and knowing there is no hassle getting a new prosthesis every two years is very welcoming. Congratulations on a great Program.”

“I think that this Program is a wonderful way of making affordable the replacement of a missing breast for women who have had a mastectomy as the outward and visible adaptive prosthesis enhances ones’ self-esteem and self confidence. I am so grateful that this Program exists.”

“I think it is a great idea and was very pleased with all aspects of obtaining a reimbursement. It certainly made it easier for me financially as I might have resorted to a “birdseed bag”! Thanks, keep up the good work.”
5 Summary

Overall, the evaluation results indicate that the Program is operating effectively, and that claims are being processed in accordance with the Business Rules. In addition, those women who have accessed the Program have indicated satisfaction with the Program and the provision of a nationally consistent reimbursement scheme.

While generally positive, several key areas for improvement were raised across the range of evaluation respondents. These related to:

- further promotion and communication about the Program
- consideration of the up-front payment
- frequency of the reimbursement
- provision of support for women of an Aboriginal and Torres Strait Islander or culturally and linguistically diverse background.

5.1 Further promotion and communication about the Program

Although the Program has been demonstrated to improve women’s access to external breast prostheses, a general lack of awareness about the Program suggests that not all eligible women have been able to take advantage of the Program.

The Business Rules estimated that 50,000 reimbursements would be made in the first year. In reality, 19,962 reimbursements were made, roughly 39% of the estimated figure. It may be that the 50,000 figure was an over-estimate, or it may be that women were not aware of the Program. Data from Medicare Australia does indicate a gradual increase in claims over the year, presumably as awareness of the Program increased (see section 3.2.3).

It was agreed by respondents that breast care nurses and breast prosthesis fitters are the primary means by which women learn about the Program. However, for those who have not recently had a mastectomy, or who may not previously have used an external prosthesis, information about the Program is harder to access. Whilst women who are more involved in breast cancer networks, organisations and support groups may gain information about the Program through these avenues, conversely women who are not involved in these networks and groups may not be learning of the Program. Respondents provided a number of suggestions for greater promotion about the Program:

- brochures at prosthesis suppliers, hospitals and Medicare Australia offices
- radio and television commercials, particularly targeting non-English speaking communities
- providing general practitioners, practice nurses, breast surgeons, oncologists, breast care nurses and consultants with up to date information
- advertising at breast cancer events, such as the Mother’s Day Classic Marathon in May.

While it was recognised that promotional activities had taken place, regular ongoing information dissemination may assist in increasing levels of awareness.

Medicare Australia’s October promotion of the Program during Breast Cancer Awareness Month was noted by several women. Promotional activities need not be costly, but should be targeted to specific groups for most effective access. For example, general television advertisements may be costly without a clear return, but targeted radio promotions on non-English stations can be very inexpensive and reach a specific audience which might not access mainstream promotional materials. Occasional articles in newspapers or community magazines might also raise awareness without incurring the cost of advertising.

There does not appear to have been a significant budget for promotion in the first year, however the lower numbers of women accessing the Program may suggest a need to invest further in this area. The
increase in promotion would most likely increase the number of women accessing the Program, and therefore the overall costs of the Program.

5.2 Consideration of the up-front payment for some women

A number of respondents conveyed concern that the up-front cost of a breast prosthesis (prior to reimbursement) was a significant financial outlay for many women. It was felt to be particularly the case for women who are on pension or health care cards, who are elderly, who are single parents, Aboriginal and Torres Strait Islander or financially disadvantaged.

As noted earlier, it is not possible to quantify how many women may experience financial hardship. Many of those who commented on this were not referring to themselves but to the potential for others to be disadvantaged. The paradox remains that in speaking with women who have accessed the Program, we are not reaching those who have not tried to access the Program because of financial reasons.

In recognition of the lack of clarity regarding this concern, no recommendation is made regarding changes to the structure of the reimbursement scheme. However, this is an issue which would warrant further consideration, perhaps in a year’s time when the Program is further established and promoted. One possibility could be a focused research project working with breast care nurses to attempt to quantify the proportion of women who experience financial hardship which prevents them in purchasing a breast prosthesis.

5.3 Frequency of the reimbursement for some women

The two year frequency of reimbursement was considered by some respondents to disadvantage some women, particularly those who had either gained or lost significant amounts of weight during treatment. Some respondents suggested that requests from these women for intermittent reimbursements be assessed by the Department on a case by case basis.

The Business Rules specify the policy structure for the Program and it is recognised that the ability to ‘bend the rules’ will have cost implications. The ability to allow discretion for claims made, for instance one week short of the two-year mark, or within one year due to significant treatment consequences, is unlikely to create a large number of additional claims, but may improve the quality of life for a woman.

In order to make some assessment of how great a cost consideration this discretion might be, it could be valuable to monitor over a year the number of claims or queries regarding the time limitations, and the reasons for such requests, and to seek to quantify the extent of the need, before making a definitive policy change.

5.4 Support for women within particular language and cultural groups

There were few Aboriginal and Torres Strait Islander women or women of a culturally and linguistically diverse background who participated in the survey. As noted in section 3.1.1, challenges were faced by the evaluation team in gaining feedback from women of a culturally and linguistically diverse or Aboriginal and Torres Strait Islander background about their experiences with the Program, and as such it was difficult to determine to what extent these women have accessed the Program. Few respondents were able to estimate the numbers of culturally and linguistically diverse or Aboriginal and Torres Strait Islander women who may be aware of or access the Program.

The single focus group with Arabic-speaking women, while not representative, did suggest that further information about the Program needs to be disseminated amongst specific language groups. It was also suggested that greater focus be given to ensuring that culturally appropriate information is available.

The costs of this promotion need not be extensive, as discussed above in section 5.1, but has the potential to increase the number of women who access the Program, which in itself will increase the reimbursement costs of the Program.
5.5 Summary of Program objectives and principles

The evaluation of the National External Breast Prostheses Reimbursement Program provides evidence that the Program has achieved its guiding objectives 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
- improve the quality of life of women who have undergone a mastectomy as a result of breast cancer.

As discussed throughout this report, the Program has also been largely successful in achieving the principles of the Program, with regards to:

- ease of access to reimbursement for all eligible women
- efficiency of reimbursement to eligible women
- efficiency of implementation of the Program through minimal additional infrastructure costs
- appropriate accountability structures in place to monitor and audit the Program
- consistent national approach across all jurisdictions
- sensitivity to the needs of the eligible women accessing the reimbursement.

Findings from the evaluation show that the Program provides a nationally consistent reimbursement to eligible women towards the cost of an external prosthesis. Overall, women consulted during the evaluation, who have accessed the Program, were extremely pleased with the Program and reported that their experience with the Program has had a positive impact on their quality of life.
6 References


Australian Institute of Health and Welfare (AIHW), 2009, Breast Cancer in Australia: An overview, AIHW Cancer Series No 50


Appendix A  Evaluation framework
URBIS STAFF RESPONSIBLE FOR THIS REPORT WERE:

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
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<tr>
<td>Director</td>
<td>Linda Kurti</td>
</tr>
<tr>
<td>Consultant</td>
<td>Nichola Keevy</td>
</tr>
<tr>
<td>Support Staff</td>
<td>Alison Rees</td>
</tr>
<tr>
<td>Job Code</td>
<td>KAJ14909</td>
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1 Introduction

1.1 Overview of the program

The National External Breast Prostheses Reimbursement Program was announced by the Commonwealth Government in May 2008, and has been operating since December 2008. The aims of the project are to:

- provide financial reimbursement of up to $400 per external breast prosthesis for women who have undergone a full or partial mastectomy as a result of breast cancer
- ensure national consistency in the provision of support towards the cost of breast prostheses
- improve the quality of life of women who have undergone a full or partial mastectomy as a result of breast cancer.

The program is being administered by Medicare Australia on behalf of the Department under the terms of a Service Arrangement and Business Rules, with a business practice agreement to be signed in late 2009.

Women claiming reimbursement through Medicare can do so by downloading and completing a claim form from the Medicare website, going to a Medicare branch for a hard copy, or calling Medicare. Those receiving financial assistance from the Department of Veterans’ Affairs (DVA) are able to claim their entitlement through DVA.

1.1.1 Administration matters and reporting

Medicare is required to provide monthly and end-of-financial year statistics to the Department on a number of items identified on the Program claim form, including: the number of reimbursements, amount reimbursed, demographic data and process performance. Medicare is required to process 90% of all claims within ten days of lodgement, as part of its obligations as administrator of the Program.

Under the Service Arrangement, the Department is obliged to provide policy advice to Medicare in a timely manner and to respond to queries and complaints that relate to policy issues under the program.

1.2 Eligibility criteria for women receiving the reimbursement

Whilst the program has been in operation since December 2008, eligible women are able to submit claims from 1 July 2008. There are no time limits applied to when the mastectomy occurred, but there are time limits as to when prostheses may be claimed.

Other specific eligibility criteria include:

- recipients need to have had a mastectomy as a result of breast cancer
- recipients need to be permanent residents of Australia and have current Medicare entitlements
- women are eligible if they have not received financial assistance for the prosthesis from a private health insurer, state or territory government or other organisation; or have received a refund or financial assistance through their private health insurer, state or territory government or other organisation less than the maximum Commonwealth reimbursement
- eligible women can claim up to $400 reimbursement for new and replacement external breast prostheses
- if a claim under the program has been made, a subsequent reimbursement can be claimed no earlier than two years from the date of last purchase.
2 Methodology

2.1 Overview

This evaluation involves two parts – a review of the administration of the program; and a review of the program’s impact on the quality of life of women who have undergone a mastectomy as a result of breast cancer.

The review of the administration of the program will include an assessment of the efficiency, effectiveness and appropriateness of the program. These will be assessed specifically in relation to the following:

- how efficiently the program is being administered, such as the extent to which resources are optimally used, whether financial, human or procedural
- how effectively the program has been administered, for instance whether the resources, systems and processes lead to the achievement of the objectives or goals of the program
- the appropriateness of the program, specifically alignment between the program’s systems and intended outcomes.

The impact review will explore the impact of the program on improving the quality of life of women who have undergone a mastectomy as a result of breast cancer. This includes identifying any issues that may need to be addressed, and any modifications or opportunities for future improvements in order to strengthen the program’s effectiveness, and maximise its potential for success.

Our evaluation takes into account the following:

- the short period of time in which the Program has been operating (data taken from 1 December 2008 to 1 December 2009)
- the established business model between Medicare Australia and the Department and the importance of efficiency, effectiveness and appropriateness indicators in assessing the Program administration
- the need for sensitivity in interacting with organisations, support groups, and individuals regarding breast cancer
- the importance of seeking a range of views, including those of women who may not have used the service.

In summary, the methodology includes the following components:

- development of an evaluation framework
- assessment of the Program’s administration, including documentation and Medicare data analysis, and stakeholder consultation
- assessment of the Program’s impact, including consultation by online survey, telephone and face-to-face interviews
- data analysis and reporting.

The evaluation will run from July 2009 to August 2010.

2.2 Sampling procedure for consultations

We propose a multi-stage sampling process for consulting with stakeholders for this project. These are outlined as follows.
2.2.1 Administrative component

Face to face and telephone interviews will be conducted with the following stakeholders:

- The Department
- Medicare Australia
- Breast Cancer Network Australia (BCNA) – both administration and member groups
- National Breast and Ovarian Cancer Centre (NBOCC)
- Cancer Council Australia
- State and Territory Cancer Councils
- Health care professionals – includes: breast care nurses, Oncology nurses, care coordinators, social workers, general practitioners and breast surgeons.
- State Governments – program managers from VIC, QLD and WA
- Breast prostheses suppliers
- McGrath Foundation

Lists and contact details will be provided by the Department. An interview guide will be developed and finalised in consultation with the Department.

2.2.2 Impact component

Consultations with women who have had a mastectomy

An email survey will be distributed and telephone interviews and focus groups will conducted with:

- women who have had a mastectomy and have accessed the program;
- as well as women who have had a mastectomy and have not accessed the program. Methods of sampling will be finalised in consultation with the Department and consumer representative groups for women with breast cancer.

We will seek to consult with women across Australia, and in doing so will include women from a wide spectrum of the community, as outlined in the table below.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Indicators</th>
<th>Possible access strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Between the ages of 18 and 80</td>
<td>Work through Breast Cancer Network Australia and/or other support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>networks to invite eligible women to participate in study</td>
</tr>
<tr>
<td>Location</td>
<td>Urban, rural, remote; all States/Territories</td>
<td>Place notices in newsletters, bulletin boards, and other media for women who are not connected to the internet and would not otherwise be included in the study</td>
</tr>
<tr>
<td>Cultural background</td>
<td>Aboriginal, Torres Strait Islander, European Australian, CALD background</td>
<td></td>
</tr>
<tr>
<td>Eligible women who have not sought a prosthesis</td>
<td></td>
<td></td>
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<tr>
<td>Eligible women who have not sought reimbursement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women who do not have internet connection</td>
<td></td>
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</tbody>
</table>

A number of considerations have been made in ensuring sensitivity and anonymity to potential participants. Women will be able to participate in three ways (completion of an email survey, participation in a telephone interviews, and participation in focus groups), recognising that some women may not wish to speak to a stranger about their experiences, but may be willing to provide written commentary. In all instances, we will not contact any individual woman without her having first given permission for her contact details to be provided to us. Women will be asked to give consent to
participate and will be able to withdraw their consent at any time; if they do so any identifying data held by the research team will be destroyed. Confidentiality will be respected at all times and only aggregated, anonymised data will be presented in reports.

Consultations with other stakeholders
Face to face and telephone interviews with the following stakeholders:

- The Department
- Breast Cancer Network Australia (BCNA) – both administration and member groups
- National Breast and Ovarian Cancer Centre (NBOCC)
- Cancer Council Australia
- State and Territory Cancer Councils
- Health care professionals – includes: breast care nurses, Oncology nurses, care coordinators, social workers, general practitioners and breast surgeons.
- State Governments – program managers from VIC, QLD and WA
- Breast prostheses suppliers
- McGrath Foundation

Lists and contact details will be provided by the Department. Interview and focus group guides will be developed and finalised in consultation with the Department.
## 2.3 Timeline

* = billing milestones

<table>
<thead>
<tr>
<th>Week commencing Monday</th>
<th>Jul</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
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<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
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<td><strong>Project Planning</strong></td>
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<td>9 Jul</td>
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<tr>
<td>Submission of Evaluation Framework with Project Workplan</td>
<td>31 Jul</td>
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<td>Initial discussions with support organisations re consultations</td>
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<td>Survey of women</td>
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### 2.4 Workplan

<table>
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<tr>
<th>Workplan</th>
<th>Days allocated</th>
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<td><strong>Project management</strong></td>
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<td>Inception meeting</td>
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<td>09/07/2009</td>
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<td>Client liaison</td>
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<td><strong>Develop evaluation framework</strong></td>
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<tr>
<td>Develop framework</td>
<td>5</td>
<td>LK and NK.</td>
<td>31/07/2009</td>
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<tr>
<td><strong>Develop research tools</strong></td>
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<tr>
<td>Develop survey</td>
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<td>SR to manage, NK to assist, LK to oversee.</td>
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<tr>
<td>Develop interview guides</td>
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<td>KO and NK to develop, LK to oversee.</td>
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<td><strong>Stakeholder consultation - administration review</strong></td>
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<tr>
<td>Interviews</td>
<td>4</td>
<td>Managed by KO. Assistance from LK and NK.</td>
<td>07/12/2009</td>
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<tr>
<td>Write up</td>
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<td>KO and NK.</td>
<td>07/12/2009</td>
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<td>KO, NK, LK.</td>
<td>05/04/2010</td>
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<td><strong>Data analysis - administrative review</strong></td>
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<tr>
<td>Document analysis</td>
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<td>SR.</td>
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<tr>
<td>Medicare data analysis</td>
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<td>SR with assistance from NK to assist as required.</td>
<td>07/12/2009</td>
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<tr>
<td><strong>Stakeholder consultation - impact review</strong></td>
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<td>Survey dissemination and management</td>
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<td>NK to manage, LK to oversee.</td>
<td>07/12/2009</td>
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<tr>
<td>Interviews and write up</td>
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<td>KO, NK, LK.</td>
<td>01/02/2010</td>
</tr>
<tr>
<td><strong>Data analysis - impact review</strong></td>
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<td>Survey data entry</td>
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<td>SR to manage.</td>
<td>01/02/2010</td>
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<tr>
<td>Survey analysis</td>
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<td>SR.</td>
<td>08/02/2010</td>
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<tr>
<td>Interview coding and analysis</td>
<td>7</td>
<td>SR and NK, with LK to oversee.</td>
<td>05/04/2010</td>
</tr>
<tr>
<td><strong>Reporting</strong></td>
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<td>3</td>
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<tr>
<td>Progress report 2</td>
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<td>LK, SR, KO, NK.</td>
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<td>Final Report</td>
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<td>LK, SR, NK.</td>
<td>12/07/2010</td>
</tr>
<tr>
<td><strong>Total number of days</strong></td>
<td>107</td>
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</tbody>
</table>
Study Team

**Linda Kurti (LK)** has over 15 years of experience in health research and organisational development, working in the government, academic and non-profit sectors. Linda’s experience covers a range of areas including strategic planning, organisational change and development, system development and evaluation, and health services research in both England and Australia. Her research interests include health system development, health equity, global health, and the intersection of praxis and policy. Linda has worked as a facilitator and consultant with a range of organisations, and has held both executive and strategic roles.

**Samantha Ross (SR)** is a Senior Consultant with Urbis. She is a highly skilled qualitative researcher and project manager. Since joining the firm Samantha has been a significant contributor to projects involving stakeholder, consumer and community consultation, data collection and analysis on a range of issues, including health, drugs and alcohol, welfare delivery, ageing and aged care, crime and justice, community services and community development, communication and education materials and campaigns, Indigenous Australians, housing and changes to the built environment.

**Karen Olver (KO)** is a unique and highly skilled practitioner with over twenty years experience in the fields of health care, mental health, disability, justice and aged care including their legislative frameworks, strategic directions and service quality issues.

**Nichola Keevy (NK)** is a social researcher at Urbis. Nichola has been involved in a wide range of studies that have required stakeholder consultation through telephone interviews, qualitative and quantitative data analysis, literature reviews, in-depth interviewing and report writing. Nichola has research experience across a range of fields including law and justice, social welfare, indigenous education, media communications, program evaluation, community consultation, and aged care.
3 Evaluation Framework for the National External Breast Prostheses Reimbursement Program

This section details the program logic for evaluating the National External Breast Prostheses Reimbursement Program.

A program logic model presents a program in a systematic and visual way, highlighting underlying assumptions and providing a theoretical framework. Logic models are tools for service planning and management as well as evaluation. They can be used at any point in the evolution of a program and can lead to better program planning and management. Program logic models describe the sequence of events for bringing about change and relate activities to outcomes. A program logic is a tool for establishing the logical connections in a program (or a number of programs) from the inputs through to the ultimate outcomes. Each outcome level identifies what the program is seeking to achieve at various stages.

In this case, the program logic has been extended to identify a hierarchy of outcomes. This sets out the intended outcomes of a program in layers, from the broad overarching outcomes down to short-term outputs. It is structured as follows:

Figure 1: Hierarchy of outcomes model

(a) Ultimate outcomes – impact on overall issue and ultimate goals – progress towards or away from articulated goals

(b) Intermediate outcomes – impacts, outcomes and achievements across strategic and organisational frameworks

(c) Immediate outcomes – impacts, outcomes and achievements in specific program areas

(d) Outputs/activities – models of service delivery and provision, and how these have been implemented

(e) Needs – priority issues that the program must address, the evidence base and conceptual underpinnings for the program.

Urbis uses the hierarchy of outcomes as the central focus of an evaluation, allowing for analysis of a range of factors that may have contributed to the outcomes at each level. The evaluation will assess the extent to which the program is achieving these outcomes, as set out in the Evaluation Framework which follows. Essentially, the framework breaks down the Program into its outcome components and identifies how these outcomes can be measured. The evaluation framework has been structured around the hierarchy of outcomes model, aligning outcome areas with evaluation questions, evidence and data sources.
## 3.1 Program logic

<table>
<thead>
<tr>
<th>Ultimate outcome</th>
<th>Improvement to the quality of life of women who have undergone a mastectomy as a result of breast cancer, through a program of financial assistance for external breast prostheses.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intermediate outcomes</td>
<td>Improved access to and uptake of, the reimbursement program by eligible women. Demonstrated satisfaction of women with access to the reimbursement program. Streamlined reimbursement process for eligible women. Demonstrated sensitivity to the needs of the eligible women accessing the reimbursement. Appropriate accountability structures in place to monitor and audit the program. The program is embedded and integrated into Medicare Australia’s processes and procedures with smooth operation through the use of appropriate systems. Women have a choice of breast prostheses suppliers, such that the process of obtaining a prosthesis is consumer driven.</td>
</tr>
<tr>
<td>Immediate outcomes</td>
<td>The provision of reimbursement for external breast prostheses. Increased awareness of the Program by eligible women. National consistency in the reimbursement program. Ease of access to reimbursement for all eligible women. Efficiency and appropriateness of the administration of the program. Levels of knowledge among, promotion for, and support by, healthcare workers.</td>
</tr>
<tr>
<td>Activities/outputs</td>
<td>Financial support provided to eligible women by the Commonwealth towards the costs of external breast prostheses. Development of information sources and dissemination of these. Development of protocols and policy regarding claims processing. Implementation of Service Arrangement to provide one consistent national program.</td>
</tr>
<tr>
<td>Needs</td>
<td>Consistent national approach across all jurisdictions. Appropriate accountability structures in place to monitor and audit the program. Efficiency of implementation of the program through minimal additional infrastructure costs. Sensitivity to women’s needs.</td>
</tr>
</tbody>
</table>
## Evaluation Framework for the National External Breast Prostheses Reimbursement Program

<table>
<thead>
<tr>
<th>Outcomes Hierarchy</th>
<th>Measures</th>
<th>Information Sources</th>
<th>Analytical method</th>
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</thead>
<tbody>
<tr>
<td><strong>Ultimate outcomes</strong></td>
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<tr>
<td>Improvement to the quality of life</td>
<td>In what ways does the program improve the quality of life of women who</td>
<td>Women eligible for the program</td>
<td>Survey of women</td>
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<td>of women who have undergone a</td>
<td>have purchased a prostheses as the result of a full or partial mastectomy</td>
<td>Satisfaction with levels of financial assistance</td>
<td>Focus groups with women</td>
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<td>mastectomy as a result of breast</td>
<td>To what extent has the program been successful in achieving its</td>
<td>Extent to which the Department is satisfied with the process for</td>
<td>Qualitative consultations with breast cancer research/network/support organisations, and health care professionals</td>
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<td>cancer, through a program of</td>
<td>objectives?</td>
<td>reimbursement</td>
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<tr>
<td>financial assistance for external</td>
<td>What improvements could be made to increase the program’s effectiveness,</td>
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<td>breast prostheses.</td>
<td>efficiency or appropriateness?</td>
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<tr>
<td><strong>Intermediate outcomes</strong></td>
<td>How sensitive is the program to the needs of women who have undergone a</td>
<td>Medicare Australia</td>
<td>Survey of women who use breast prostheses as well as those who don’t</td>
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<td></td>
<td>mastectomy?</td>
<td>The Department</td>
<td>Focus groups with women</td>
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<td>How sensitive is the program to the needs of women who have undergone a</td>
<td>Eligible women</td>
<td>Qualitative consultations with Medicare, the Department, state governments, breast prostheses suppliers and breast cancer research/network/support organisations, and health care professionals</td>
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<td>mastectomy in regional/rural areas, of Indigenous or CALD background or</td>
<td>Health care professionals</td>
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<td></td>
<td>who are otherwise disadvantaged?</td>
<td>Breast prostheses suppliers</td>
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<td></td>
<td>Do women feel they have enough knowledge about all of the program</td>
<td>State governments</td>
<td></td>
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<td></td>
<td>components?</td>
<td>Breast cancer research/network/support organisations</td>
<td></td>
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<td></td>
<td>How well has the program been integrated into Medicare Australia’s</td>
<td></td>
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<td></td>
<td>processes?</td>
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<td></td>
<td>How can the program be monitored/evaluated periodically?</td>
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<td></td>
<td>How does the program function within the broader policy environment?</td>
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<td></td>
<td>What choice of breast prostheses suppliers do women currently have?</td>
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</tbody>
</table>

Administrative
Administrative challenges currently faced by Medicare Australia and the Department
Review of the Service Arrangement and Business Rules and analysis of current policy context
Impact
Reported levels of awareness and knowledge of the program among women – both generally, and those from regional/rural areas, or of CALD or Indigenous background, or who are otherwise disadvantaged
Reported experience and satisfaction with the program to date by women generally, and those from regional/rural areas, or of CALD or Indigenous background, or who are otherwise disadvantaged
<table>
<thead>
<tr>
<th>Outcomes Hierarchy</th>
<th>Measures</th>
<th>Information Sources</th>
<th>Analytical method</th>
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<tbody>
<tr>
<td><strong>Evaluation questions</strong></td>
<td><strong>Indicators (for example)</strong></td>
<td><strong>Administrative</strong></td>
<td><strong>Impact</strong></td>
</tr>
<tr>
<td>▪ What barriers are there for women in accessing the breast prostheses program?</td>
<td>Systems in place for information sharing and communication between women, breast cancer research/networks/support organisations and breast prostheses suppliers; with Medicare and the Department</td>
<td>Medicare Australia</td>
<td>Survey of women who use breast prostheses as well as those who don’t</td>
</tr>
<tr>
<td>▪ What is the uptake of the program in its first 12 months?</td>
<td>Systems in place for ongoing feedback and monitoring of the program</td>
<td>The Department</td>
<td>Focus groups with women</td>
</tr>
<tr>
<td>▪ Do women report consistency in access, awareness and experience of the program nationally?</td>
<td>Extent to which women feel comfortable with current accessibility</td>
<td>Eligible women</td>
<td>Qualitative consultations with Medicare, the Department, state governments and breast cancer research/network/support organisations</td>
</tr>
<tr>
<td>▪ What barriers are there to the efficiency and appropriateness of administering the program?</td>
<td></td>
<td>State governments</td>
<td></td>
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<tr>
<td>▪ How have claims been processed?</td>
<td></td>
<td>Breast cancer research/network/support organisations</td>
<td></td>
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<tr>
<td>▪ How are variations to eligibility assessed?</td>
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<tr>
<td>▪ What have been the benefits or limitations of the national program?</td>
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<tr>
<td>▪ Are there any gaps in the program?</td>
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</tbody>
</table>

**Immediate outcomes**

The provision of reimbursement for external breast prostheses.
Increased awareness of the Program by eligible women.
National consistency in the reimbursement program.
Ease of access to reimbursement for all eligible women.
Efficiency and appropriateness of the administration of the program.
Levels of knowledge among, promotion for, and support by, healthcare workers.
# Evaluation Framework for the National External Breast Prostheses Reimbursement Program

## Outcomes Hierarchy

<table>
<thead>
<tr>
<th>Evaluation questions</th>
<th>Measures</th>
<th>Information Sources</th>
<th>Analytical method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does current financial support provided to eligible women sufficiently cover costs of prostheses?</td>
<td>Administrative Medicare data – number of claims and demographic characteristics Review of the Service Arrangement and Business Rules</td>
<td>Medicare Australia The Department Eligible women who have and have not received the payment</td>
<td>Review of data Qualitative interviews with Medicare staff, Department staff and eligible women</td>
</tr>
<tr>
<td>What are women foregoing to pay for prostheses?</td>
<td>Impact Costs of prostheses compared to reimbursement</td>
<td></td>
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</tr>
<tr>
<td>What are the most efficient aspects of the program (from an administrative viewpoint)?</td>
<td>Extent to which women are enabled to make the choice to purchase prostheses with respect to the breast prostheses program</td>
<td></td>
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</tr>
<tr>
<td>How is program information disseminated? How effective is this dissemination?</td>
<td>Financial challenges experienced by women who have undergone mastectomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How well do current protocols operate in providing guidance to eligible women?</td>
<td>Reported information sources</td>
<td></td>
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</tbody>
</table>

## Needs

- Consistent national approach across all jurisdictions.
- Appropriate accountability structures in place to monitor and audit the program.
- Efficiency of implementation of the program through minimal additional infrastructure costs.
- Sensitivity to women’s needs.
Appendix B  List of stakeholders consulted
<table>
<thead>
<tr>
<th>Organisation</th>
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<tbody>
<tr>
<td>Medicare Australia</td>
</tr>
<tr>
<td>DoHA, Cancer Services Branch</td>
</tr>
<tr>
<td>Department of Human Services, VIC</td>
</tr>
<tr>
<td>Queensland Health</td>
</tr>
<tr>
<td>National Breast and Ovarian Cancer Centre (NBOCC)</td>
</tr>
<tr>
<td>Breast Cancer Network Australia (BCNA)</td>
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<tr>
<td>Cancer Council Australia (National)</td>
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<tr>
<td>Cancer Council NT</td>
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<tr>
<td>Cancer Council VIC</td>
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<tr>
<td>Cancer Council TAS</td>
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<tr>
<td>Cancer Council NSW</td>
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<tr>
<td>McGrath Foundation</td>
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<tr>
<td>National Breast Cancer Foundation (NBCF)</td>
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<tr>
<td>Cancer Voices of Australia</td>
</tr>
<tr>
<td>National Aboriginal Community Controlled Health Organisation</td>
</tr>
<tr>
<td>Royal Melbourne Hospital</td>
</tr>
<tr>
<td>Surgical Oncology – School of Surgery</td>
</tr>
<tr>
<td>Royal Adelaide Hospital Cancer Centre</td>
</tr>
<tr>
<td>Monash Medical Centre Southern Health</td>
</tr>
<tr>
<td>Peter McCallum Cancer Centre</td>
</tr>
<tr>
<td>NSW Breast Cancer Institute</td>
</tr>
<tr>
<td>Breast Care Nurses</td>
</tr>
<tr>
<td>Breast prostheses suppliers</td>
</tr>
<tr>
<td>Local support groups</td>
</tr>
</tbody>
</table>
Appendix C  Discussion guides
Interview Guide – Breast Care Nurses

INTRODUCTION

Thank you for meeting with me today. My name is # from Urbis. As you are aware, we are carrying out an evaluation of the National External Breast Prostheses Reimbursement Program for the Department of Health and Ageing (DoHA). In undertaking this research project, we are looking at both the administrative aspects of the program, and the impact of the program on women who have undergone a mastectomy as a result of breast cancer. Your responses in this interview will remain confidential to the research team and will not be attributed without your permission.

Do you have any questions before we start?

QUESTIONS

Relationship to the Program
1. What is your knowledge of the program?
2. What involvement or contact have you had with the program to date?

Feedback from women who have had a mastectomy and require a prosthesis
What feedback, if any, have you received from women about:
3. The information available about the program? (e.g. availability, usefulness of claim form and information sheet)
4. The program’s accessibility?
5. The claiming process? (e.g. ease of completing and submitting claim form)
6. Paying for the breast prostheses up-front and obtaining a reimbursement?
7. The amount of the reimbursement?
8. The timeliness of the program in making payments?
9. The frequency of reimbursements (2 years)?
10. Whether the program meets their needs (e.g. sensitive, responsive, appropriate)
11. Whether the program has had/is having an impact on their quality of life?
12. Have you received any feedback from Aboriginal and Torres Strait Islander women about whether the program is sensitive to their needs and circumstances? What about women from culturally and linguistically diverse backgrounds? Younger women?

Your view
Do you have a view about whether:
13. The program is being clearly communicated to women (prompt for women who have recently had a mastectomy and are accessing the program as part of the post-surgical pathway versus women who had their mastectomy long ago)?
14. The program meets the needs of women? (e.g. sensitive, straightforward), (Prompt, regarding: women in regional/rural areas, Aboriginal and Torres Strait Islander women or women from culturally and linguistically diverse backgrounds or who are otherwise disadvantaged)
15. The program has any particular strengths or weaknesses?
16. There any barriers that women may experience in accessing the program?
17. The program impacts on the quality of life of women? If so, in what ways?
18. Whether the reimbursement amount sufficient in covering the costs of the prostheses?
19. Do you have enough information about the program to inform or assist women to access the program? (Is there any way in which the availability and/or usefulness of information could be improved?)

Future directions
20. In your view, are there ways in which the program can be improved? If so, how?
21. Do you have any other comments about the program?
Interview Guide – Consumers

INTRODUCTION (5 mins)

Thank you all for meeting with me today. My name is # and I am from Urbis. We are a social research firm and specialise in conducting program evaluations for state and federal government. We are carrying out an evaluation of the National External Breast Prostheses Reimbursement Program for the Department of Health and Ageing. Today I will be asking you about your knowledge of the program, your experience with the program, and what impact the program has had on your quality of life.

It is important that you know that I will be taping our discussion to help with writing our report – specifically so that I can go back at a later stage and accurately describe exactly what was said today. In saying this however, whatever you say will be kept strictly confidential – you will in no way be identified or named in our research. Your comments will be completely anonymous.

It is also important that you feel at ease in participating in today’s discussion. I understand that this is a sensitive topic, and you may at times feel uncomfortable in disclosing information. Whilst I am keen to hear your views and experiences, you are in no way obliged to share sensitive or confidential information with us here today. Of course we would like to know what you feel may be working well or not so well, so that the program can be improved for women who use it in the future. Please remember that whilst I would like to hear from all of you, it would be appreciated if you could talk one at a time.

Do you have any questions about the evaluation before we start?

I’d be grateful if you could please turn off all mobile phones to avoid interruptions.

QUESTIONS

Information sources and claiming under the program (15 mins)

1. Could you please briefly introduce yourself?

2. Have you heard about the National External Breast Prostheses Reimbursement Program? (If all answer no go to ‘Participants who have not claimed under the program’)

3. What were your initial thoughts about the program?

4. How did you find out about the program? (Prompt: internet, Breast Care Nurse, GP, other medical practitioner, Medicare, DoHA, Department of Veterans’ Affairs, BCNA, NBOCC, NBCF, McGrath Foundation, Cancer Council, breast cancer support group, word of mouth, breast prosthesis supplier, migrant group, other)

5. How would you rate the availability of information about the program? (e.g. how easy or difficult was it to find all the information you needed about the program? Did it come from one source, or did you have to search for more information about the reimbursement? Where did you search?)

6. Do you think that there are any ways in which the availability of information could have been improved? If so, how?

7. In your view, what would be the best way to inform women about the program, particularly if they had their mastectomy some years ago and are not currently under the care of a health professional?

8. Have you claimed for reimbursement for an external breast prosthesis through the program? (If all answer no go to ‘Participants who have not claimed under the program’).
Making the claim (30 mins)
9. How did you find the process of claiming for your reimbursement? Was it:
   - Fair? (why/not?)
   - Efficient? (why/not?)
   - Easy to understand? (why/not?)
   - Easy to obtain and to complete the application forms? (why/not?)

10. How did you make your claim for reimbursement? (prompt: downloaded form, completed at Medicare office, called/wrote to Medicare and they sent the form, completed the form provided by supplier) How well did this process work for you?
   - Did you need any assistance with understanding the language used in the information sheet or claim form?

11. As part of making a claim through the program, did anyone also claim reimbursement from a private health fund? How well was this option communicated as part of the program? How well did this option fit with claiming through the program? If not, why was this?

12. How easy or difficult did you find it to collect the necessary supporting information for the claim?

13. Do you think that there are any ways in which the claim process could be improved? Do you think that there are there ways in which the process could be improved for women of a non-English speaking or Aboriginal or Torres Strait Islander background?

14. Do you think the program is equally available to all women? Do you think that there are any barriers to accessing the program? (probe for age group, social economic status, culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islander backgrounds, time since mastectomy, geographical location)

Purchasing the prosthesis and receiving the reimbursement (15 mins)
15. Was anyone’s claim rejected? (probe why)

16. For those of you who have received the reimbursement, did the reimbursement for an external breast prosthesis under the Program cover or mostly cover the cost?

17. Do you have any feedback about paying for the breast prostheses up-front and then obtaining a reimbursement? Did paying up-front impact on you?

18. Approximately how long did it take for you to receive the reimbursement payment into your bank account? Do you have any feedback about the timeliness of the program in making payments?

19. What do you think about the frequency of reimbursement (every two-years) for claiming a replacement prosthesis?

Impact of the program (20 mins)
20. Overall, what impact, if any, has the program had on your life?

21. Would you like to make any other comments?

Participants who have not heard about the program (25 mins)
Provide explanation about the program for those who haven’t heard about it – in particular that it is a national program that allows women who have had a mastectomy as a result of breast cancer, to claim for a reimbursement for the external breast prostheses through Medicare Australia.

22. From what you now know about the program, do you think you would be interested in claiming for a reimbursement through the program? (Probe why/not)

23. In your view, what would be the best way to inform women about the program, particularly if they had their mastectomy some years ago and are not currently under the care of a health care professional? (probe: internet, through breast care nurse, through breast cancer support organisation,
through local breast cancer support group, through Medicare Australia, through GP, through the Department of Health and Ageing, through word of mouth, other etc)

24. Are there any other comments you would like to make about this program?

**Participants who have not claimed under the program (25 mins)**

25. For what reason/s did you choose not to claim for the reimbursement? *(Prompt: have not heard about the program, claimed through private health cover or the Department of Veteran’s Affairs, could not afford the up front payment of a prosthesis, chose not to, felt it didn’t meet my needs or wasn’t appropriate for my condition, was advised by Medicare Australia that wouldn’t be able to claim, other etc)*

26. From what you now know about the program, do you think you would claim for a reimbursement through the program? *(Probe why/not)*

27. In your view, what would be the best way to inform women about the program particularly if they had their mastectomy some years ago and are not currently under the care of a breast nurse or other clinician?

28. Are there any other comments you would like to make about this program?
Thank you for meeting with me today. My name is # from Urbis. As you are aware, we are carrying out an evaluation of the National External Breast Prostheses Reimbursement Program for your Department. In undertaking this research project, we are looking at both the administrative aspects of the program, and the impact of the program on women who have undergone a mastectomy as a result of breast cancer, with reference to the program’s principles and objectives.

As you are aware, the Program’s principles are:
- Ease of access to reimbursement for all eligible women;
- Efficiency of reimbursement to eligible women;
- Efficiency of implementation of the program through minimal additional infrastructure costs;
- Appropriate accountability structures in place to monitor and audit the program;
- Consistent national approach across all jurisdictions; and
- Sensitivity to the needs of the eligible women accessing the reimbursement.

The Program’s objectives are to:
- Provide financial support towards the costs of external breast prostheses for women who have undergone 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 mastectomy as a result of breast cancer.

Medicare Australia administers the Program for the Department in accordance with a Service Level Arrangement and Business Rules in place between the two organisations. Today’s interview will focus on the Department’s satisfaction with the administration of the Program by Medicare Australia, across a range of areas identified in the Business Rules for the Program, such as claims assessment, claims processing, reporting and communication.

As the Department also receives some feedback from women about the Program’s impact, including through issues escalated by Medicare Australia and through written enquiries directed to the Minister or the Department, we also have some questions about the Department’s knowledge of women’s experience of the Program.

Your responses in this interview will remain confidential to the research team and will not be attributed without your permission.

Do you have any questions before we start?
QUESTIONS

Role description
1. To give me a clear understanding of your organisation's involvement in the program, please describe your organisation's role with respect to the Program.

Administrative review
2. In the first 12 months of the Program’s operation, to what extent has Medicare Australia administered the Program in accordance with the Program’s Business Rules, including:
   a) Establishing and managing appropriate consumer eligibility arrangements?
   b) Meeting specified reporting requirements (prompt for monthly and annual statistics etc)?
   c) Meeting specified performance indicators (prompt for processing timeframes)?
   d) Establishing and managing appropriate claims assessment arrangements?
   e) Establishing and managing appropriate payment arrangements?
   f) Establishing and managing appropriate enquiry management arrangements?
   g) Having adequate audit and access provisions?
   h) Undertaking relevant communication activities in relation to the program (prompt for display of posters, brochures and/or other promotional material in Medicare Offices)
   i) Consulting with the Department in a timely way in relation to any changes to Program administration arrangements (prompt for system enhancements, emerging policy issues etc)?
   j) Consulting with the Department in relation to any release of information about the Program (prompt for statistics, responses to media enquiries etc)

3. Are you aware of any opportunities for future improvements/directions for the administration of the Program? (e.g. increased efficiency)
4. What are the key outcomes achieved as a result of Medicare Australia administering the Program?
5. To what extent has the Program functioned effectively as part of the broader policy environment?

Impact review
6. To what extent is the Program appropriate, effective and efficient in meeting the goals defined by the objectives of the measure?
7. Does the Program provide outcomes that meet the needs of women requiring an external breast prosthesis following a mastectomy as a result of breast cancer? (If so, how? If not, why not? Is this assessment based on feedback that has been provided to the Department?)
8. Can you identify any opportunities for future improvements/directions for the Program (prompt to include consideration of the costs and benefits of these improvements)?
Interview Guide – General Stakeholders

INTRODUCTION

Thank you for meeting with me today. My name is # from Urbis. As you are aware, we are carrying out an evaluation of the National External Breast Prostheses Reimbursement Program for the Department of Health and Ageing (DoHA). In undertaking this research project, we are looking at both the administrative aspects of the program, and the impact of the program on women who have undergone a mastectomy as a result of breast cancer. Your responses in this interview will remain confidential to the research team and will not be attributed without your permission.

Do you have any questions before we start?

QUESTIONS

Relationship to the program
1. What involvement or contact has your organisation had with the program to date?

Feedback from women who have had a mastectomy and require a prosthesis
What feedback, if any, has your organisation received from women about:
2. The information available about the program? (e.g. availability, usefulness of claim form and information sheet)
3. The program’s accessibility?
4. The claiming process? (e.g. ease of completing and submitting claim form)
5. Paying for the breast prostheses up-front and obtaining a reimbursement?
6. The amount of the reimbursement?
7. The timeliness of the program in making payments?
8. The frequency of reimbursements (2 years)?
9. Whether the program meets their needs (e.g. sensitive, responsive, appropriate)
10. Whether the program has had/is having an impact on their quality of life?
11. Have you received any feedback from Aboriginal and Torres Strait Islander women about whether the program is sensitive to their needs and circumstances? What about women from culturally and linguistically diverse backgrounds? Younger women?

Organisation’s view
Does your organisation have a view about whether:
12. The program is being clearly communicated to women (prompt for women who have recently had a mastectomy and are accessing the program as part of the post-surgical pathway versus women who had their mastectomy long ago)?
13. The program meets the needs of women? (e.g. sensitive, straightforward), (Prompt, regarding: women in regional/rural areas, Aboriginal and Torres Strait Islander women or women from culturally and linguistically diverse backgrounds or who are otherwise disadvantaged)
14. The program has any particular strengths or weaknesses?
15. There any barriers that women may experience in accessing the program?
16. The program impacts on the quality of life of women? If so, in what ways?
Future directions

17. In your organisations’ view, are there ways in which the program can be improved? If so, how?

18. Do you have any other comments about the program?
Interview Guide – Medicare Australia

INTRODUCTION

Thank you for meeting with me today. My name is # from Urbis. As you are aware, we are carrying out an evaluation of the National External Breast Prostheses Reimbursement Program for the Department of Health and Ageing (DoHA). In undertaking this research project, we are looking at both the administrative aspects of the program, and the impact of the program on women who have undergone a mastectomy as a result of breast cancer, with reference to the program’s principles and objectives.

The Program’s principles are:
- Ease of access to reimbursement for all eligible women;
- Efficiency of reimbursement to eligible women;
- Efficiency of implementation of the program through minimal additional infrastructure costs;
- Appropriate accountability structures in place to monitor and audit the program;
- Consistent national approach across all jurisdictions; and
- Sensitivity to the needs of the eligible women accessing the reimbursement.

The Program’s objectives are to:
- Provide financial support towards the costs of external breast prostheses for women who have undergone 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 mastectomy as a result of breast cancer.

As the organisation responsible for the administration of the Program (through a Service Level Agreement and Business Rules in place with DoHA), Medicare Australia is clearly a key stakeholder in the review of the Program’s administration. The focus of today’s interview is the administration of the Program. In particular, we will be asking about the systems and processes that Medicare Australia has in place to underpin the administration of the Program.

As Medicare Australia also receives feedback from women about the Program’s impact, including through its customer service officers and written enquiries about the Program, we also have some questions that relate to women’s experience of the Program.

Your responses in this interview will remain confidential to the research team and will not be attributed without your permission.

Do you have any questions before we start?
QUESTIONs

Administrative Review

Role Description
1. To give me a clear understanding of your organisations’ involvement in the program, please describe your organisation’s role with respect to the Program.

Administrative Arrangements
2. In the first 12 months of the Program’s operation, what processes and systems has Medicare Australia put in place for the administration of the Program, under the Program’s Business Rules, including:

   a) Establishing and managing appropriate consumer eligibility arrangements?
   b) Meeting specified reporting requirements (prompt for monthly and annual statistics etc)?
   c) Meeting specified performance indicators (prompt for processing timeframes)?
   d) Establishing and managing appropriate claims assessment arrangements?
   e) Establishing and managing appropriate payment arrangements?
   f) Establishing and managing appropriate enquiry management arrangements?
   g) Having adequate audit and access provisions?
   h) Undertaking relevant communication activities in relation to the program (prompt for display of posters, brochures and/or other promotional material in Medicare Offices)
   i) Consulting with the Department in a timely way in relation to any changes to Program administration arrangements (prompt for system enhancements, emerging policy issues etc)?
   j) Consulting with the Department in relation to any release of information about the Program (prompt for statistics, responses to media enquiries etc)?

3. What are the key outcomes achieved as a result of Medicare Australia administering the Program? (prompt in areas such as: women’s access to breast prostheses, reimbursement timeframes, consistency in processes and results across jurisdictions, capacity to monitor program outputs and performance)

4. How accessible is the Program for women? How has access been maximized through the Program’s administrative arrangements? (prompt for particular groups, and Medicare responses to emerging issues of access)

5. What are the main reasons claims are refused? Are any of these preventable by Medicare Australia activity? (prompt for clearer information, reviewing eligibility criteria etc)?

6. Are there any ‘gaps’ in the program’s administrative arrangements that impact on the effectiveness the Program?

7. What gains have been made in cost efficiency during the Program (prompt eg infrastructure costs, efficiencies gained through Medicare Australia expertise in certain types of program delivery, fit with similar programs, ability to monitor outlay of resources centrally, etc)

8. Are there areas in which cost efficiency could improve? What is being done to address this, if anything? (prompt any areas of the program administration where duplication could be reduced to improve efficiency?)

9. What sort of risk assessment and mitigation has been carried out by Medicare Australia in relation to the Program? (prompt relating to cost, quality of customer experience, etc)

10. In administering the program, does Medicare Australia come into contact with any other agencies? (prompt for DVA, other providers of reimbursement/funding for breast prostheses). Are there any issues in working with these agencies (prompt eg are responsibilities clearly allocated)?

11. Are there any ‘gaps’ that impact on the efficiency of the Program?

12. Is there any duplication in the program’s administrative arrangements that that might be reduced to improve efficiency?

Relationship with the Department
13. In the first 12 months of the Program’s operation, has the Department provided appropriate support to Medicare Australia under the Program’s Business Rules, including:

   a) Consulting with Medicare Australia in a timely manner in relation aspects which may impact on MA’s administration of the program (prompt for proposed changes to the program, promotion of the program etc)?
   b) Provision of funding to Medicare Australia to administer the program?
   c) Adhering to governance arrangement set out in the MoU and the BPA?
Future directions

14. From Medicare Australia’s perspective, are there any aspects of the Program’s business rules or administrative processes which might be amended to improve administration of the Program?

Impact Review

Feedback from women who have had a mastectomy and require a prosthesis

15. What feedback, if any, has Medicare Australia received from women about:

- a) The information available about the Program? (prompt for availability, usefulness of claim form and information sheet)
- b) The Program’s accessibility?
- c) The claiming process? (prompt for ease of completing and submitting claim form)
- d) Paying for the breast prostheses up-front and obtaining a reimbursement?
- e) The amount of the reimbursement?
- f) The timeliness of the Program in making payments?
- g) The frequency of reimbursements (2 years)?
- h) Whether the Program meets their needs (prompt re sensitive, responsive, appropriate etc)
- i) Whether the Program has had/is having an impact on their quality of life?
- j) Have you received any feedback from Aboriginal and Torres Straight Islander women about whether the Program is sensitive to their needs and circumstances? What about women from culturally and linguistically diverse backgrounds? Younger women?
Thank you for meeting/speaking with us today. As you are aware, we are carrying out an evaluation of the External Breast Prostheses Reimbursement Program for the Department of Health and Ageing (DoHA). In undertaking this research project, we will be looking at both the administrative aspects of the Program, and the impact of the Program on women who have undergone a mastectomy as a result of breast cancer.

Today’s discussion is an initial scoping exercise to inform ways forward with our methodology. We would like to speak to you in general about your organisation, your involvement with the program, and any advice you have for us in moving forward with our research. We will be conducting another round of formal interviews with all stakeholders from December about specific aspects of the program, during which we would like to speak again with you or someone from your organisation.

Please know that everything you say during our discussion will remain confidential. Whilst we will be taking notes, your comments will not be identified and will rather inform general themes for reporting. We will note that we have spoken with a member of your organisation however we will not record your name in any of our reporting.

If you have any questions about the research or would like to speak with the Project Director following this discussion, I can give you her details. Otherwise do you have any questions before we start?

<table>
<thead>
<tr>
<th>1. Can you please tell me a little bit about your organisation?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2. What involvement or awareness do you have of the External Breast Prostheses Reimbursement Program? (If unsure, explain what the program entails)</th>
</tr>
</thead>
</table>
3. How best, from your point of view, can we access women who have had a mastectomy as a result of breast cancer and who would be willing to participate?

4. What about hard to reach women (CALD, Indigenous, rural/regional locations) and young women under the age of 30 years?

5. Is there anything that you think we need to know about or be aware of in conducting our research?

6. Do you have any other comments you would like to make?
Appendix D  Survey for women
### Part A - Awareness of the National External Breast Prostheses Reimbursement Program

**QA1 Have you heard of the National External Breast Prostheses Reimbursement Program?**

- [ ] Yes
- [x] No (please go to PART D)

**QA2 How did you hear about the National External Breast Prostheses Reimbursement Program? (Please select all that apply)**

- [ ] State/Territory aids and appliances or breast prostheses program
- [ ] Breast Care Nurse
- [ ] GP
- [ ] Specialist medical practitioner
- [ ] Medicare Australia office
- [ ] Medicare Australia website
- [ ] Medicare Australia information line
- [ ] Department of Health and Ageing
- [ ] Department of Veterans’ Affairs
- [ ] Breast Cancer Network Australia (BCNA) website
- [ ] Breast Cancer Network Australia (BCNA) information line
- [ ] National Breast and Ovarian Cancer Centre (NBOCC) website
- [ ] National Breast and Ovarian Cancer Centre (NBOCC) information line
- [ ] National Breast Cancer Foundation
- [ ] McGrath Foundation
- [ ] The Cancer Council
- [ ] Local breast cancer support group
- [ ] Word of mouth
- [ ] Breast prostheses supplier
- [ ] Other (please specify _________________________________)
Part B - Participation in the National External Breast Prostheses Reimbursement Program

The questions in Part B relate to whether you have participated in the National External Breast Prostheses Reimbursement Program.

The National External Breast Prostheses Program is an Australian Government program that has been operating since 24 November 2008. It is administered by Medicare Australia on behalf of the Department of Health and Ageing. It provides reimbursements of up to $400 for new or replacement external breast prostheses for Australian women who have had a mastectomy as a result of breast cancer.

<table>
<thead>
<tr>
<th>QB1 In the last 12 months, have you made a claim for reimbursement through the National External Breast Prostheses Reimbursement Program?</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Yes (please go to PART C)</td>
</tr>
<tr>
<td>□ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QB2 What was the reason/s that you did not make a claim for reimbursement through the Program for an external breast prosthesis in the last 12 months? (Please select all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ I had not heard about the National External Breast Prostheses Reimbursement Program</td>
</tr>
<tr>
<td>□ I did not have useful information about the Program</td>
</tr>
<tr>
<td>□ I had heard of the National External Breast Prostheses Reimbursement Program, but did not know how to make a claim through this Program</td>
</tr>
<tr>
<td>□ I had difficulty accessing an application form for the Program</td>
</tr>
<tr>
<td>□ I had difficulty completing an application form for the Program</td>
</tr>
<tr>
<td>□ I had difficulty lodging an application form for the Program</td>
</tr>
<tr>
<td>□ I did not need a breast prosthesis during this period</td>
</tr>
<tr>
<td>□ I claimed expenses for breast prostheses through private health insurance</td>
</tr>
<tr>
<td>□ I claimed expenses for breast prostheses through the Department of Veterans’ Affairs</td>
</tr>
<tr>
<td>□ I did not wish to pay up front for the breast prosthesis, which is required before claiming under the National External Breast Prostheses Reimbursement Program</td>
</tr>
<tr>
<td>□ I was not able to pay to purchase the breast prosthesis, which is required before claiming under the National External Breast Prostheses Reimbursement Program</td>
</tr>
<tr>
<td>□ I made a claim through a State/Territory aids and appliance or external breast prostheses program.</td>
</tr>
<tr>
<td>□ Other reason (please specify _____________________________)</td>
</tr>
</tbody>
</table>

After completing this question, please go to PART D.
Part C - Experience of Using the National External Breast Prostheses Reimbursement Program

**QC1** How did you make your claim for reimbursement for an external breast prosthesis?
(Please select one response only)

- [ ] I downloaded an application form and posted it to a Medicare office
- [ ] I completed the form at a Medicare office
- [ ] I called or wrote to a Medicare Office and they sent me a form, which I completed and returned to them
- [ ] I completed the form provided by my breast prosthesis supplier
- [ ] Other (please specify ____________________________)

**QC2** On a scale of 1 to 5, where 5 is the best score, how would you rate the following aspects of the Program?

<table>
<thead>
<tr>
<th>Aspect</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of information about the Program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usefulness of information about the Program</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of obtaining an application form</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of completing the application form</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of lodging the application form</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of obtaining the reimbursement following lodgement of your application</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeliness of receiving reimbursement</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Level of the reimbursement amount</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall experience of the Program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**QC3** Did you receive a payment from the Program as a result of your claim for reimbursement for an external breast prosthesis?

- [ ] Yes (please go to QC5)
- [ ] No

**QC4** If your claim was unsuccessful, what was the reason provided?

- [ ] I had received assistance through the Department of Veterans’ Affairs
- [ ] I had received assistance through another program in my State or Territory
- [ ] My breast prosthesis was purchased before 1 July 2008
- [ ] I could not produce a receipt or proof of purchase for the breast prosthesis
- [ ] Other (please specify ________________________________________________)

*After answering this question, please go to PART D.*
QC5  Approximately how long did it take to receive reimbursement for the breast prosthesis into your bank account after you had lodged the claim?

- [ ] Up to 10 business days
- [ ] More than 10 business days (please estimate time _________________________)

QC6  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 Program

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Program made it easier to afford a breast prosthesis</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>It was difficult to afford the up-front payment required for a reimbursement under the Program</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The Program had a positive impact on my quality of life</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The process of getting reimbursed was straightforward</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>It was easy to gather the necessary supporting information for the claim</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>I was treated with sensitivity while making my claim</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The level of the reimbursement for an external breast prosthesis under the Program was sufficient</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>The frequency of reimbursement for an external breast prosthesis under the Program (i.e. every 2 years) is sufficient</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

QC7  Do you have any other comments about the Program?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
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Part D - About You

Please take a moment to complete the questions in Part D about you, even if you have not previously heard of or used the Program. This will help us understand your responses and determine how well the Program is currently meeting women’s’ needs. All information collected in this survey will be treated as strictly confidential.

QD1 What kind of breast surgery have you had?
(Please select responses that apply to your most recent procedure)

- Partial mastectomy
- Full mastectomy
- Double or bilateral mastectomy
- Other (please specify)
- Prefer not to say

QD2 How long ago did you have your breast surgery? (If you have had more than one episode of breast cancer surgery, please indicate when you had your most recent procedure)

- Less than 1 month ago
- 1-23 months ago
- 2-5 years ago
- More than 5 years ago
- Prefer not to say

QD3 How involved are you with the following groups?

<table>
<thead>
<tr>
<th></th>
<th>Not at all involved</th>
<th>Slightly involved</th>
<th>Very involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer Network Australia</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Local breast cancer support groups</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>McGrath Foundation</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Council</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>National Breast Cancer Foundation</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Other breast cancer related groups or organisation/s (please specify __________________________________________________)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QD4</td>
<td>Have you received financial assistance in the past for breast prostheses from State/Territory aids and appliances or external breast prostheses program/s?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ No SKIP TO QD6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QD5</th>
<th>Which State/Territory program/s have you accessed? <em>(Please select all that apply)</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ NSW</td>
</tr>
<tr>
<td></td>
<td>□ VIC</td>
</tr>
<tr>
<td></td>
<td>□ WA</td>
</tr>
<tr>
<td></td>
<td>□ QLD</td>
</tr>
<tr>
<td></td>
<td>□ SA</td>
</tr>
<tr>
<td></td>
<td>□ TAS</td>
</tr>
<tr>
<td></td>
<td>□ NT</td>
</tr>
<tr>
<td></td>
<td>□ ACT</td>
</tr>
<tr>
<td></td>
<td>□ Prefer not to say</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QD6</th>
<th>In which State do you currently live?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ NSW</td>
</tr>
<tr>
<td></td>
<td>□ VIC</td>
</tr>
<tr>
<td></td>
<td>□ WA</td>
</tr>
<tr>
<td></td>
<td>□ QLD</td>
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<td></td>
<td>□ SA</td>
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<td></td>
<td>□ TAS</td>
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<td></td>
<td>□ NT</td>
</tr>
<tr>
<td></td>
<td>□ ACT</td>
</tr>
<tr>
<td></td>
<td>□ Prefer not to say</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>QD7</th>
<th>Which of these terms best describes where you currently live? <em>(Please select one response only)</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Major/capital city</td>
</tr>
<tr>
<td></td>
<td>□ Regional city/large country town</td>
</tr>
<tr>
<td></td>
<td>□ Small town</td>
</tr>
<tr>
<td></td>
<td>□ Regional city/large country town</td>
</tr>
<tr>
<td></td>
<td>□ Remote village/area away from a town</td>
</tr>
<tr>
<td></td>
<td>□ Prefer not to say</td>
</tr>
</tbody>
</table>
**QD8** What level of education have you completed? (Please select all that apply)

- [ ] Year 10 (school certificate) or equivalent
- [ ] Year 12 or equivalent
- [ ] Apprenticeship or cadetship
- [ ] TAFE or technical college
- [ ] University
- [ ] Other (please specify ______________________________________________________)
- [ ] Prefer not to say

**QD9** Which age range applies to you?

- [ ] Under 30
- [ ] 30-39
- [ ] 40-49
- [ ] 50-59
- [ ] 60-69
- [ ] 70-79
- [ ] 80 or over
- [ ] Prefer not to say

**QD10** Do any of the following apply to you? (Please select all that apply)

- [ ] I identify as Aboriginal or Torres Strait Islander
- [ ] I speak English as a second language
- [ ] I identify as having a disability
- [ ] Prefer not to say

**QD11** Can you please tell us how you found out about this survey?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Thank you for completing the survey and contributing to the evaluation of the National External Breast Prostheses Reimbursement Program. If you have any queries about the survey, please contact Samantha Ross at Urbis on 02 8233 9915.
Appendix E  Promotion of the survey
Invitation to participate in research on reimbursement payments for external breast prostheses

If you:
- have had a mastectomy as a result of breast cancer and
- currently use an external breast prosthesis...

We would like to hear from you.

We are a social research consultancy called Urbis and are conducting an evaluation of the National External Breast Prostheses Reimbursement Program on behalf of the Australian Government Department of Health and Ageing. We are seeking to learn about women’s experiences of accessing this Program.

Your feedback will be important in ensuring that the program benefits women who have had a mastectomy as a result of breast cancer and require external breast prostheses. All responses will be anonymous and confidential.

To complete a brief, 10-minute survey online, please visit this website: http://tinyurl.com/breastprosthesessurvey

If you would prefer to complete a postal survey, please ring this number and a survey will be sent to you: 1800 244 863.

If you would like more information about the National External Breast Prostheses Reimbursement Program, please contact Medicare Australia on 132 011.

If you would like more information about the evaluation, please call Nicky Keevy at Urbis on 02 8233 9962.
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Fax: +612 8233 9966

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Fax: +613 8663 4999

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West Perth, WA 6005
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Fax: +618 9321 7790

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