Deloitte.
Access Economics

Financial impacts of breast cancer in Australia

Breast Cancer Network Australia

November 2016

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Glossary

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ASCO	American Society of Clinical Oncology
BCNA	Breast Cancer Network Australia
BRCA	Breast Cancer susceptibility gene
DXA	Duel energy X-ray absorptiometry
EBC	Early breast cancer
ECG	Electrocardiogram
ER	Oestrogen receptor
GP	General Practitioner
HER2	Human epidermal growth factor receptor 2
MBC	Metastatic breast cancer
MBS	Medicare Benefits Schedule
OOP	Out-of-pocket
PBS	Pharmaceutical Benefits Scheme
PET	Positron emission tomography
PHI	Private health insurance
PR	Progesterone receptor

Executive summary

Breast cancer is one of the most common cancers in Australia. In 2016, 15,934 females and 150 males are estimated to receive a diagnosis of breast cancer.[1] Since 1983 there has been an increase in both the incidence of breast cancer and survival rates[2]. As a result, there are more people than ever before living in Australia who have had a diagnosis of breast cancer.

People with breast cancer may incur significant out-of-pocket (OOP) costs due to their cancer diagnosis and treatment. Existing research suggests that OOP costs are associated directly with the diagnosis and treatment of breast cancer, where financial coverage through public and private insurance schemes is not fully aligned with the clinical services required[3]. People with breast cancer may also incur other costs related to paid home help, child care services, transportation and accommodation to access treatment, garments, aids, psychosocial support and medicines[4]. In addition, a person receiving breast cancer treatment may need to decrease their hours of paid employment. This may lead to an overall decrease in household income and increased financial stress.[5]

About this project and survey

Deloitte Access Economics was engaged by Breast Cancer Network Australia (BCNA) to estimate the financial impact of breast cancer on women diagnosed with breast cancer and their families living in Australia. To this end, an online survey was developed to gather data relating to the OOP costs incurred by:

- women with early breast cancer (EBC) who are within the active treatment phase (up to 12 months post diagnosis);
- women with EBC who have completed the active treatment phase (1 to 5 years post diagnosis); and
- women diagnosed with metastatic breast cancer (MBC).

The survey covered healthcare costs directly related to breast cancer (Figure i). It also covered costs associated with a range of ancillary healthcare services and costs indirectly related to breast cancer (Figure ii).

The online survey was emailed to 12,737 BCNA members and remained open for completion between 19 August 2016 and 20 September 2016. The survey had a 15.2% response rate with 1,932 valid responses received.

[1] AIHW, 2012, *Breast cancer in Australia, an overview,* Cancer Series, no. 71, Cat. no. CAN 67, Canberra: AIHW.
[2] AIHW, 2016, *Australian Cancer Incidence and Mortality (ACIM) books: Breast cancer*. Canberra: AIHW. <http://www.aihw.gov.au/acim-books>.
[3] Spence, D, Morstyn, L and Wells, K, 2015, *The support and information needs of women with secondary breast cancer* (Breast Cancer Network Australia). Available at: https://www.bcna.org.au/media/2936/bcn1166-sbc-report-2015.pdf.
[4] Spence, D, Morstyn, L and Wells, K, 2015, *The support and information needs of women with secondary breast cancer* (Breast Cancer Network Australia). Available at: https://www.bcna.org.au/media/2936/bcn1166-sbc-report-2015.pdf.
Gordon, L, Scuffham, P, Hayes, S and Newman, B, 2007, *Exploring the economic impact of breast cancers during the 18 months following diagnosis*, Psycho-Oncology. 16:1130-1139.
[5] Spence, D, Morstyn, L and Wells, K, 2015, *The support and information needs of women with secondary breast cancer* (Breast Cancer Network Australia). Available at: https://www.bcna.org.au/media/2936/bcn1166-sbc-report-2015.pdf
Gordon, L, Scuffham, P, Hayes, S and Newman, B, 2007, *Exploring the economic impact of breast cancers during the 18 months following diagnosis*, Psycho-Oncology. 16:1130-1139.
Paul, C, Boyes, A, Searles, A, Carey, M, Turon, H, Hall, A and Bisquera, A, 2015, *Cancer medicine and financial impacts of cancer in Australia: Impacts on decision-making and perceived financial burden*, November, https://www.cosa.org.au/media/314448/cosa-media-release-financial-burden-of-cancer-treatmentfinal.pdf.

Figure i: Direct healthcare cost items associated with breast cancer – cost categories and cost items in the survey

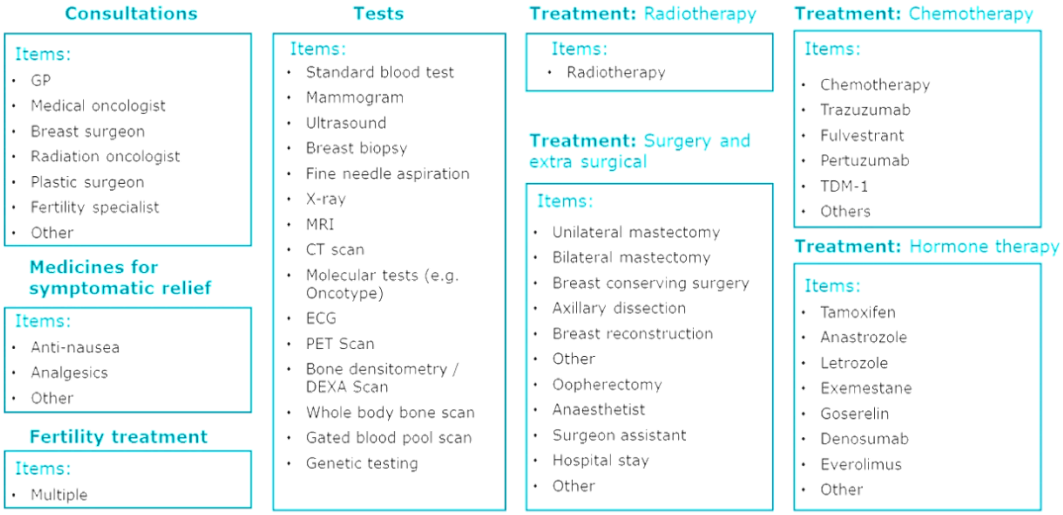
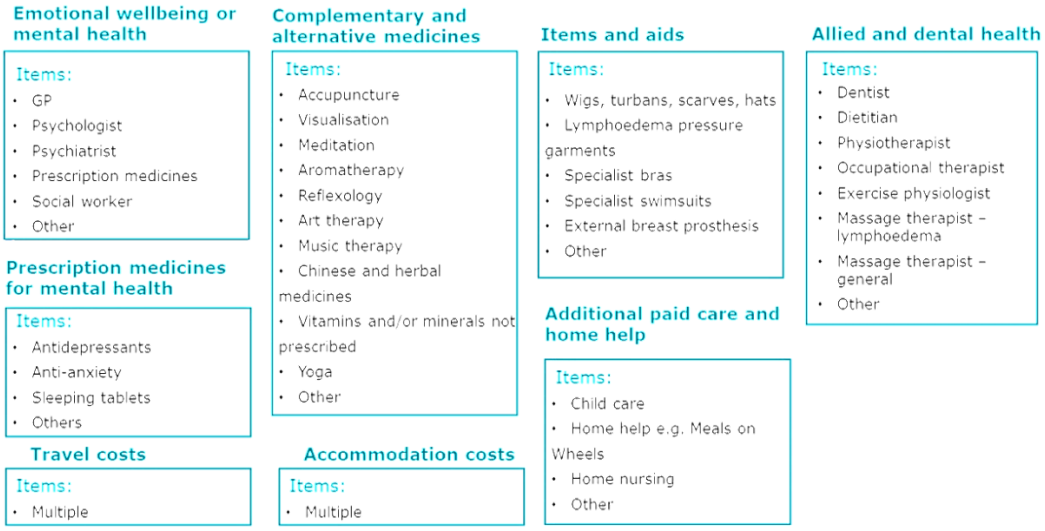


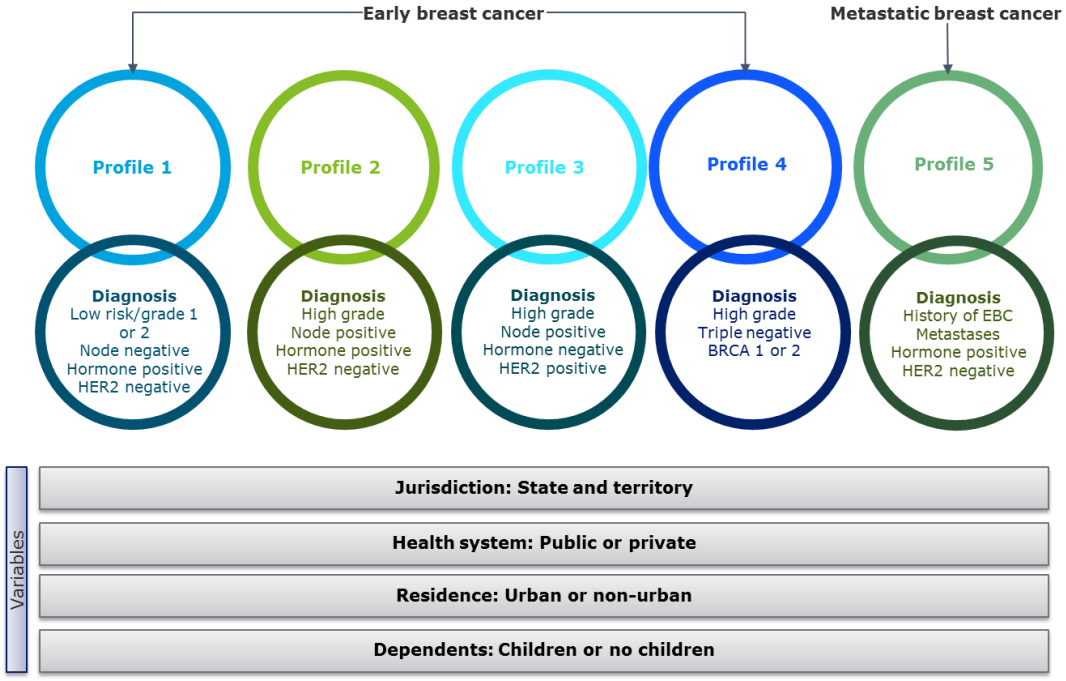
Figure ii: 'Other' or indirect cost items associated with breast cancer – cost categories and cost items in the survey



Data analysis

The data was analysed using descriptive statistics, with the respondents stratified into five breast cancer Profiles and other demographic characteristics (Figure iii). The analysis identified medical and demographic factors that may influence differences in OOP costs. Statistical hypothesis testing was not performed as there was no pre-existing evidence to indicate the plausible extent of cost variations by different medical and demographic factors. All costs were presented as medians to best represent the most typical costs faced by women with breast cancer, rather than using averages. This is because a number of respondents reported very high costs that 'skewed' the average costs higher than the costs experienced by most women. Throughout the report, 'reported costs' are referring to the median unless otherwise specified.

Figure iii: Survey diagnostic criteria (Profiles 1 to 5) and variable demographic factors



Main findings

Based on 1,919 responses received from women with breast cancer, the survey found that:

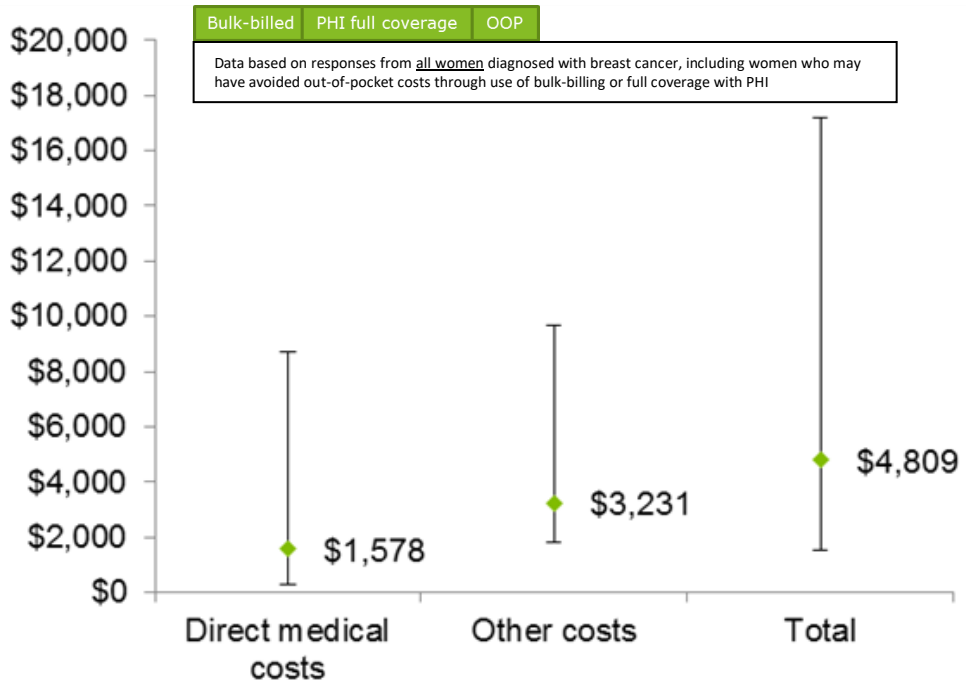
- About half of the medical services and items reported did not result in any OOP costs. Despite this, the reported overall OOP costs were considerable. The OOP costs were also highly variable even among women with the same breast cancer Profile.
- Breast surgeries, radiotherapy, chemotherapy, hormone therapy, targeted therapy and other medications resulted in significant OOP costs. The highest OOP costs were associated with breast reconstructive surgery, radiotherapy, and specific tests such as Oncotype DX tests, genetic tests and MRIs.
- Survey respondents living in urban and non-urban areas during treatment reported similar overall median costs. However, respondents in non-urban locations reported using less treatments, items, and services than their urban resident counterparts. Furthermore, the indirect financial impacts are higher for non-urban respondents because they experienced larger decrease in total household income and household workforce participation compared to urban respondents. Out of pocket costs also represented a more significant proportion of household income for non-urban patients.
- Having private health insurance (PHI) also appears to be associated with higher OOP costs. Respondents with PHI paid an OOP cost for more items and services, and at higher overall prices than respondents without PHI.

These findings are discussed in detail below.

What is a typical OOP cost for women with breast cancer?

A woman typically incurs a total OOP cost of $4,809 in the first five years following a diagnosis of breast cancer. The majority of costs are incurred during the first 12 to 24 months after diagnosis. The reported OOP costs was highly variable, with the middle 50% of respondents (25th to 75th percentile) reporting OOP costs of between $1,510 and $17,200 (chart i).

Chart i: Median cost with interquartile range, 25th to 75th percentile, for women all women diagnosed with breast cancer (including women who may have avoided out-of-pocket costs due to bulk-billing or full PHI coverage of items and services)

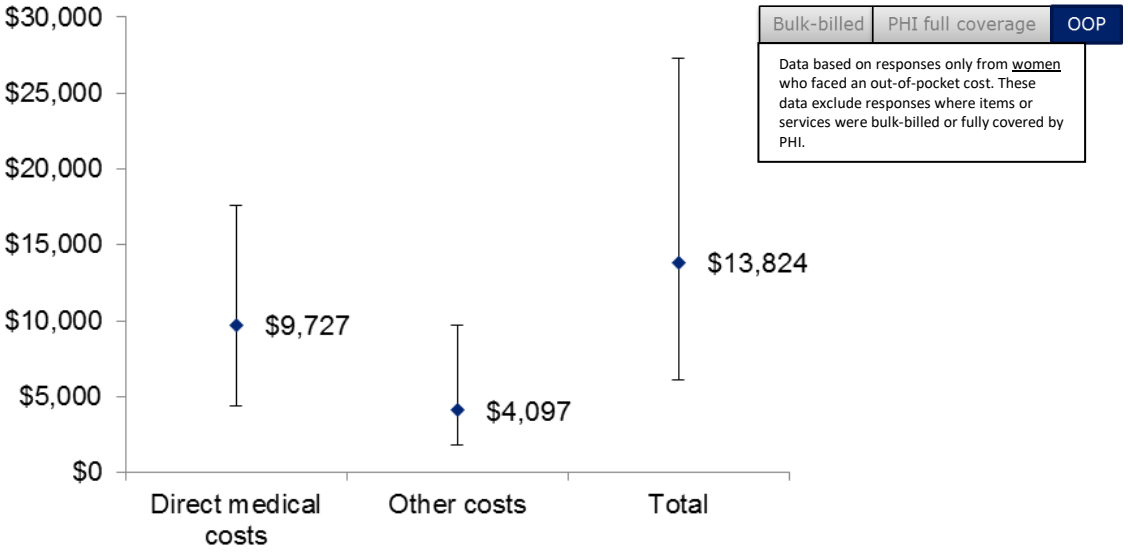


Number of respondents: 1,919. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category

What are the sources of OOP costs? How significant are the costs?

Chart i provides an indication of the out-of-pocket costs for all women diagnosed with breast cancer, which includes women who may not have avoided out-of-pocket costs through use of bulk-billing or full PHI coverage. When analysis removed services that were fully covered through bulk billing and PHI, the direct medical OOP cost increased over six-fold to $9,727 (Chart ii). This suggests that OOP costs associated with medical services could be substantial for women who had no or insufficient insurance coverage for medical treatments and services.

Chart ii: Median costs and interquartile range, 25th to 75th percentile, for women who faced an out-of-pocket cost (excluding bulk-billed or PHI covered items and services)

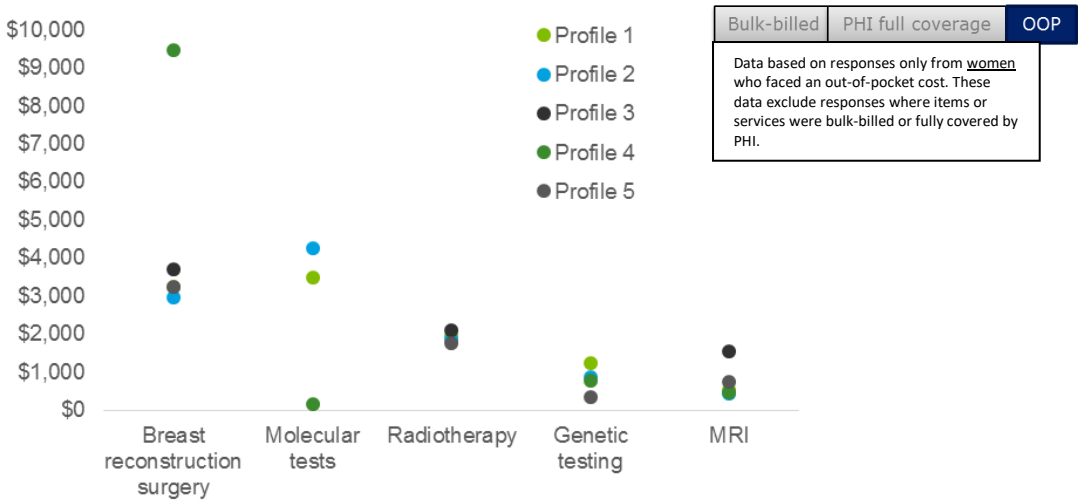


Number of respondents: 1,919 See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

The analysis found that breast surgeries, radiotherapy, diagnostics and medicines are major contributors to the overall OOP costs (Chart iii). The treatments associated with the highest OOP costs include:

- Breast reconstructive surgery ($2,957- $9,472)
- Radiotherapy ($1,751-$2,101)
- Specific pathology tests such as Oncotype DX test ($3,500-$4,250)
- Genetic tests ($774-$1,251)
- MRIs ($451-$1,554).

Chart iii: Median costs for each category by Profile, for women who faced an out-of-pocket cost (excluding bulk-billed or PHI covered items and services)

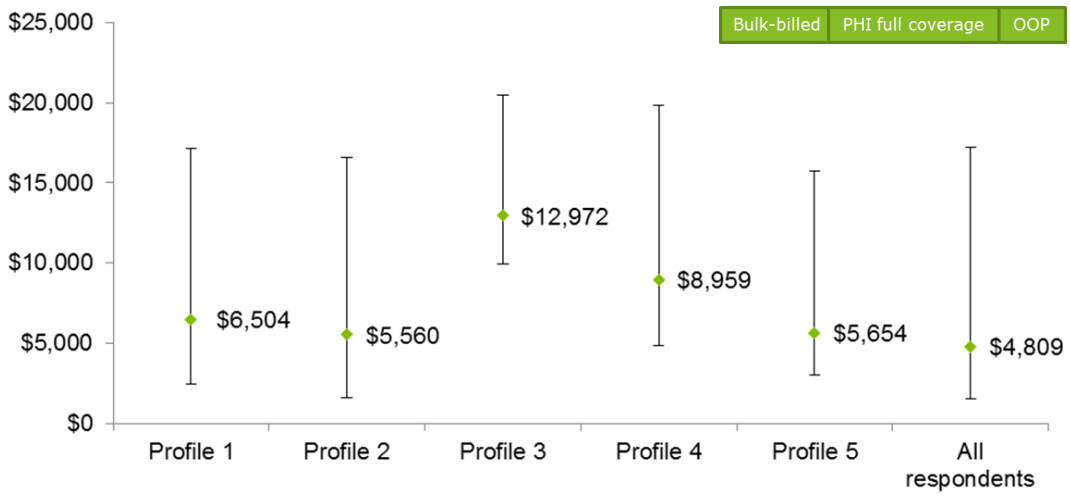


Number of respondents: Profile 1 – 577, Profile 2 – 346, Profile 3 – 29, Profile 4 – 25, Profile 5 – 68, All – 1919.

Do OOP costs vary by different breast cancer profiles?

Women with breast cancers categorised in Profiles 3 and 4 reported the highest OOP costs, followed by Profiles 1, 5 and 2 (Chart iV). Women with breast cancer in Profiles 3 and 4 incurred higher OOP costs possibly because their disease state generally requires more testing and intensive treatments. Furthermore, a larger proportion of survey respondents in Profiles 3 and 4 were under the age of 60 years (72% and 73%, respectively) than respondents in the other Profiles (57%, 65% and 60% for Profiles 1, 2 and 5, respectively). Among survey respondents, some of the high cost items, such as breast reconstruction surgery were more common under the age of 60 years: 86% of respondents who had breast reconstruction surgery were under 60 years old. However, there was substantial variability in the reported costs within each Profile and the interquartile ranges for each Profile overlap (chart iv). This suggests that there are factors other than breast cancer Profiles that influence variability in costs.

Chart iv: Median costs with interquartile range, 25th to 75th percentile, by profile for all women diagnosed with breast cancer (includes women who avoided out-of-pocket costs through bulk-billing or full PHI coverage of items or services)



Number of respondents: Profile 1 – 577, Profile 2 – 346, Profile 3 – 29, Profile 4 – 25, Profile 5 – 68, All respondents – 1919. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

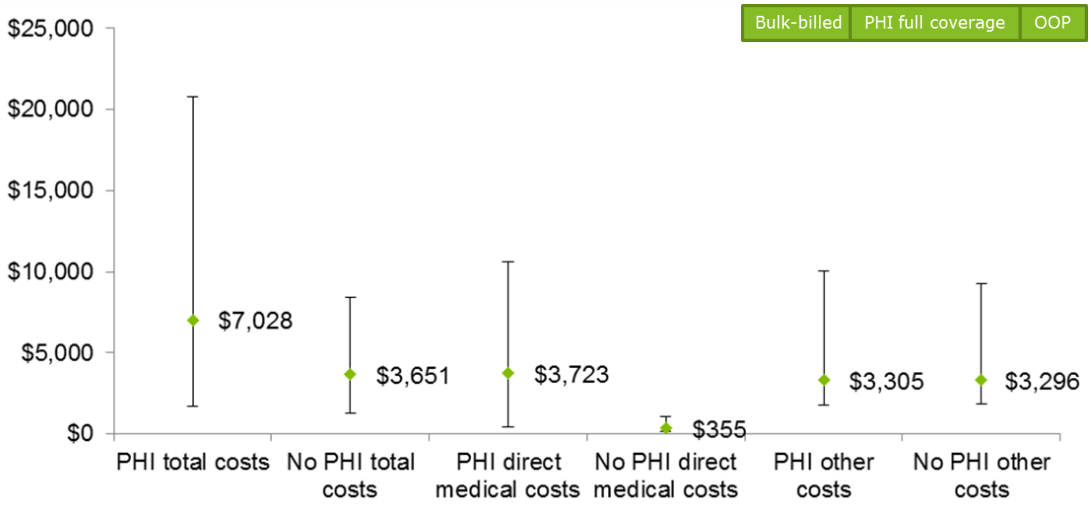
Does having PHI reduce OOP costs?

Compared to women without PHI, women with PHI appear to not only pay an OOP cost for more medical items and services directly related to their breast cancer, but they also pay higher OOP costs for these items.

Women with PHI coverage in this survey reported a median overall out-of-pocket cost which is double that of women without PHI, and direct medical OOP costs were found to be more than 10 times higher than that for women without PHI (Chart v).

Furthermore, women with PHI paid an OOP cost for 57% of their direct medical items or services compared to women without PHI who paid an OOP cost for 26% of their direct medical items and services.

Chart iii: Median costs and interquartile range, 25th and 75th percentiles by PHI status, data based on all women diagnosed with cancer (including bulk-billed and PHI covered items and services)

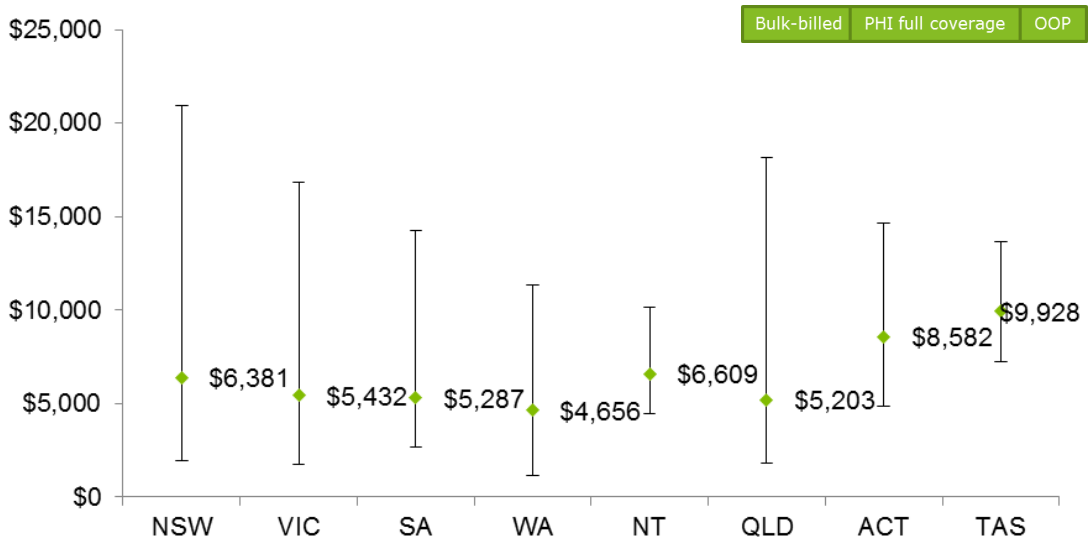


Number of respondents: PHI – 1419, No PHI – 500. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Do OOP costs vary by where women live?

Women with breast cancer living in the Australian Capital Territory, Tasmania and New South Wales reported the highest OOP costs (Chart vi). This may be driven by PHI coverage because a higher proportion of respondents in the Australian Capital Territory, Tasmania and New South Wales reported having PHI.

Chart v: Median costs and interquartile range, 25th and 75th percentiles, by jurisdiction (including bulk-billed and PHI covered items and services)



Number of respondents: NSW – 466, VIC – 521, QLD – 449, WA – 215, SA – 142, TAS – 60, ACT – 53, NT – 13. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under

each category. The result reported by respondents from the NT is not included in the analysis as there is a higher rate of error given the low sample size (n=13).

Urban or non-urban place of residence while receiving treatment did not drive a substantial difference in overall median costs reported. However, respondents in non-urban locations are accessing less treatments, items, and services than their urban resident counterparts (Table i), but spend more on accommodation than urban woman diagnosed with cancer.

Table i: Differences in access for urban and non-urban residents

Cost categories	Proportion of services/items/treatments accessed per person	
	Urban	Non-urban
Medical consultations	2.45	2.39
Tests	4.00	3.97
Treatments		
• Major surgical	0.81	0.81
• Breast reconstruction	0.21	0.14
• Extra surgical fee	1.03	0.82
• Radiotherapy	0.52	0.49
• Chemotherapy	0.50	0.47
• Hormone therapy	0.61	0.60
Medicine prescribed for symptomatic relief	0.57	0.59
Services for emotional wellbeing & mental health	0.75	1.29
Prescriptions for mental health	0.35	0.30
Allied and dental health	0.98	0.89
Items or aids	1.50	1.46
Additional paid care or home help	0.13	0.14
Travel costs	0.79	0.70
Accommodation costs	0.03	0.14
Complementary and alternative therapies	0.54	0.51

Note: this demonstrates whether a particular service or item was accessed, not the number of times it was accessed per person.

The financial impact on non-urban residents is also higher than urban residents. Non-urban respondents experienced a 19% decrease in total household income compared to a 16% decrease for urban respondents during the first two years of diagnosis. Non-urban respondents also experienced a larger decrease in household workforce participation compared to urban respondents.

Do OOP costs vary if a woman has dependent children?

Having dependent children during treatment was not associated with difference in the overall OOP costs reported in this study. However, this may be due to recruitment sampling in which a majority of respondents with dependent children were 40 to 59 years old. Hence, most of the dependent children may be old enough to not require paid childcare. The number of women with young children who responded to the survey was too small to draw any valid conclusions.

What are the impacts of breast cancer on paid employment?

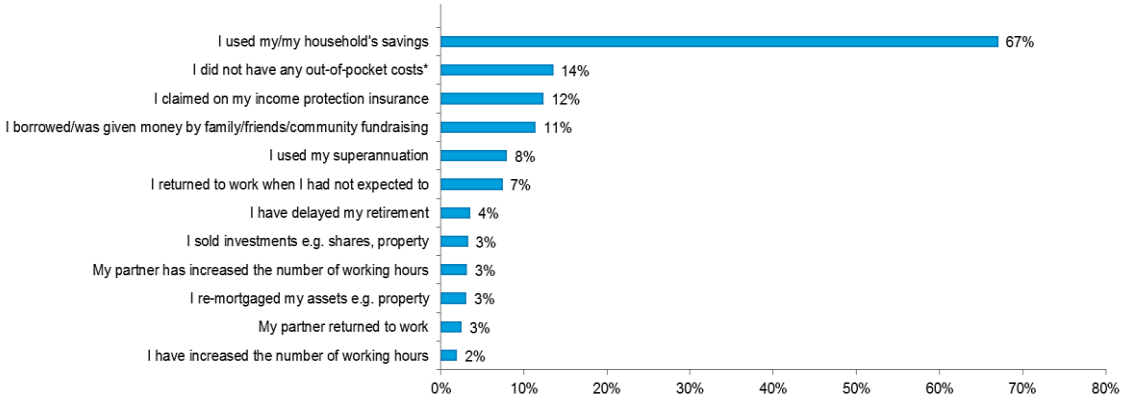
The median hours worked per week across the household in paid employment decreased by 50% during breast cancer treatment compared to the 12 months prior to diagnosis and remains 13% lower during the 12 months after treatment has been completed.

The median total financial loss during the first two years post diagnosis — this is, the sum of household income losses and total OOP costs — was estimated to be $9,389 with the middle 50 per cent of the sample reporting a total loss between $1,959 and $37,174 (n=850).

How did people pay for their OOP costs?

Over two-thirds (67%) of respondents covered the OOP costs associated with their breast cancer treatment by using their household savings (Chart vi). Claiming income protection insurance and borrowing money were also utilised by 12% and 11% of respondents, respectively.

Chart v: How respondents met the costs associated with their breast cancer diagnosis and treatment



Note: Respondents (n=1,613) could select more than one option.
*Although 14% of the sample reported that they did not have any out-of-pocket costs in this question, only 12% of the sample did not provide any costs in the subsequent questions. This differences is attributed to the fact that this question was at the start of the survey and some respondents realised that they had some costs when the specific questions were asked.

Implications of findings for BCNA

This report provides evidence indicating that the financial impact of breast cancer for most Australians can be significant. The survey findings suggests four opportunities for further review by the BCNA. These are:

- Reviewing policy settings relating to the coverage of medical services for breast cancer in the public and private insurance schemes, including in particular medical services for breast cancer management, such as surgery
- Reviewing the consistency and transparency of pricing of goods and services relating to breast cancer management so that women are able to make informed choices and mitigating the risks of differential pricing for women with PHI
- Reviewing policies to support women living in non-urban areas and some jurisdictions (e.g. NT and Tasmania) where access to breast cancer services may be more limited than in urban areas and other jurisdictions. Women living in these areas may require higher level of support because of potential higher financial impacts than their urban counterparts.
- Exploring the specific types of ancillary services that would most improve the wellbeing of women with breast cancer. This is in recognition of the survey observation that women are currently accessing a wide range of ancillary services that have contributed significantly to OOP cost but may have limited evidence to support their use. The BCNA can help close information gaps and guide women to the services which will most improve their wellbeing and quality of life.

Deloitte Access Economics

1 Background

Deloitte Access Economics was engaged by Breast Cancer Network Australia (BCNA) to undertake a project to estimate the financial impact of breast cancer on women diagnosed with breast cancer and their families living in Australia. The project involved desktop research and a survey of Australians with a diagnosis of breast cancer.

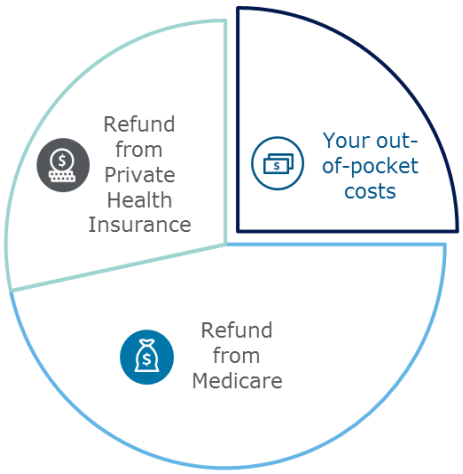
This report provides a summary of the findings from the research and survey. Specifically, it reports the survey findings on out-of-pocket (OOP) and indirect financial costs (such as loss of income) which may be faced by women diagnosed with breast cancer and their families. The costs were assessed according to factors that may influence the level of financial impact:

- clinical characteristics of breast cancer;
- private health insurance (PHI) status;
- state or territory of residence;
- location in an urban or non-urban place[6]; and
- family characteristics (i.e. with or without a dependent child/children).

1.1 About out of pocket costs

An OOP cost can be defined as when an individual meets the full cost of a health good or service or when they share the cost of goods and services with third-party payers such as governments (Medicare) or private health insurance (PHI) funds (Senate Community Affairs Committee Secretariat, 2014) (Figure 1.1).

Figure 1.1: Out of pocket costs



An out-of-pocket cost is the **total cost minus any amount received back** from Medicare and/or private health insurance.

[6] Urban and non-urban areas were defined using the ABS, Australian Statistical Geography Standard (ASGS) classification of Greater Capital City Statistical Areas (GCCSAs). This means that greater capital cities are classified as urban, everywhere else is non-urban.

Some examples of direct medical OOP costs associated with health care include:

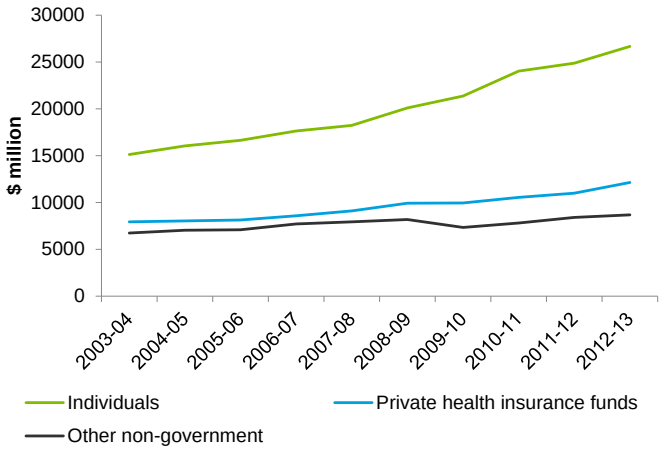
- the 'gap' between the fee for a medical service and rebates from public (Medicare) or private health insurers;
- the full cost of a medical service not within the coverage of the public or PHI schemes;
- the cost of prescription medicines after the subsidy for a medicine listed on the Pharmaceutical Benefits Scheme (PBS) listed medicines has been applied;
- the cost of 'over the counter' medicines;
- the cost of natural and complementary medicines; and
- the net cost of medical devices after any subsidies and rebates, such as prostheses, dental devices, and syringes.

In order to report the full financial impacts of breast cancer on Australian households, this report also examines other costs including:

- productivity losses due to being out of the workforce;
- travel costs, parking costs and accommodation costs for people to access treatment;
- the cost of wigs, turbans, and bras; and
- the cost of additional help at home, such as childcare, cleaning, meal preparation.

OOP costs are a known issue in the Australian healthcare system. Over the previous decade, funding by individuals in the form of OOP costs was the fastest growing area of non-government health expenditure. As shown in Chart 1.1, funding by individuals grew by an average of 6.2% a year in real terms compared with 5.3% for all non-government sources[7] and 5.0% for total health expenditure (AIHW, 2015). PHI premiums went up an average of 6.18% (Department of Health, 2016) from 2014 to 2015 putting additional cost pressures on patients.

Chart 1.1: Non-government sector funding of total health expenditure by source of funds, constant prices (2013-14 prices), 2003-04 to 2013-14



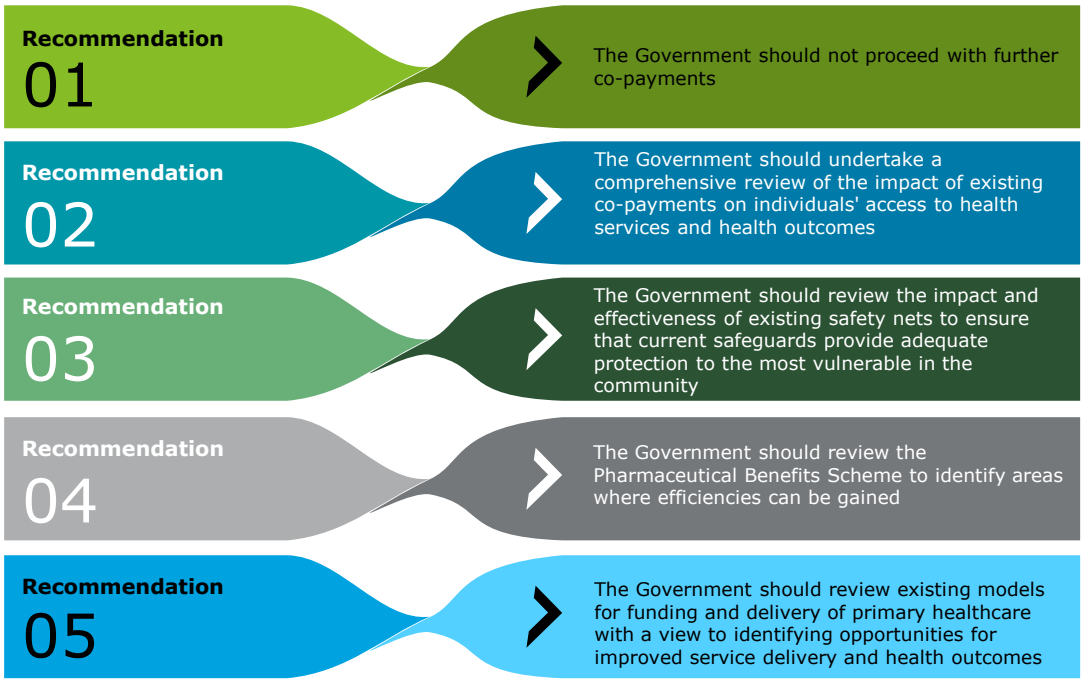
Source: AIHW 2015

[7] Non-government health expenditure includes OOP contributions from individuals, contributions from private health insurers and contributions from other insurers, mainly compulsory third party motor vehicle and workers compensation insurers.

During 2014, a Senate Inquiry into OOP costs in Australian healthcare (the Inquiry), investigated the current and future trends in OOP expenditure by Australian health consumers, the impact of co-payments on consumers, health outcomes and costs, and the role of PHI among other related trends in the healthcare system (Senate Community Affairs Committee Secretariat, 2014).

The Senate Committee returned five main recommendations as illustrated below.

Chart 1.2: Senate Inquiry into OOP costs in Australian healthcare



Source: Senate Community Affairs Committee Secretariat, 2014, Out-of-pocket costs in Australian healthcare, August, Canberra, p.xi

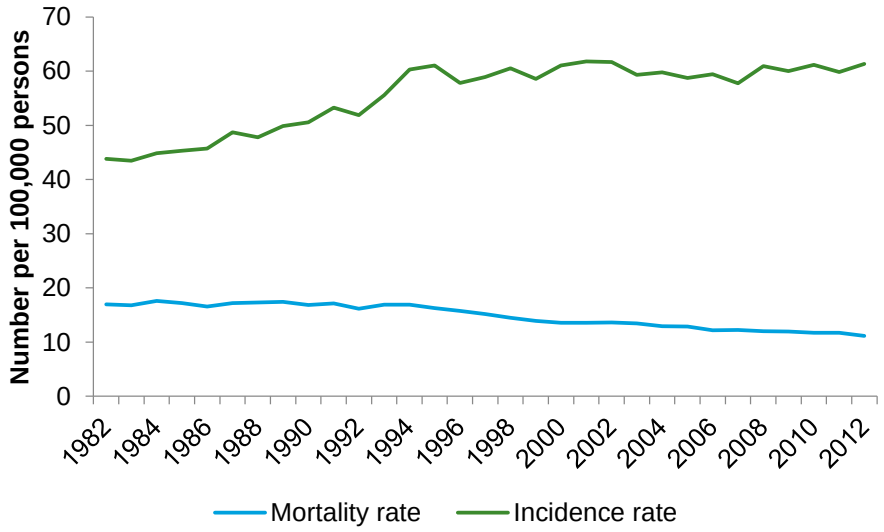
The Inquiry also noted under recommendation two that any review of the impact of existing co-payments on individuals' access to health services and health outcomes should pay particular attention to the impact on the most vulnerable groups in the community.

The incidence and survival rate of people with breast cancer is increasing.

In 2016, 16,084 new cases of breast cancer are estimated to be diagnosed in Australia. Of these, 150 are male and 15,934 are female. This makes up 12.3% of all new cancer cases diagnosed in 2016 (Cancer Australia, 2016).

Since 1983 there has been an increase in both the incidence of breast cancer and relative survival rates. As a result, there are more people than ever before living in Australia who have had a diagnosis of breast cancer and potentially faced the financial burden associated with diagnosis, treatment and ongoing monitoring of breast cancer. Chart 1.3 shows the increase in the age-standardised incidence rate and corresponding decrease in the age-standardised mortality rate between 1983 and 2012.

Chart 1.3: Age standardised incidence and mortality rates for breast cancer



Source: AIHW 2016

The total financial impact on individuals of breast cancer is currently not clear.

The literature reported in section 2.2 suggests that some Australians affected by breast cancer may face significant and often unexpected OOP costs related to their treatment and care. This is particularly relevant when PHI coverage is not aligned with the recommended treatment. We also know that costs are significantly higher for those living more than 100km from their treating hospital and for those treated with radiotherapy (Gordon et al, 2009). However, the full financial impact on individuals of breast cancer has not been quantified.

1.2 Report structure

The remainder of this report contains the following structure:

- **Chapter 2** describes the breast cancer diagnostic profiles (Profiles) included in the analysis and the main drivers of OOP costs. The prevalence and incidence of breast cancer across Australia is further discussed to provide an overview of the distribution of breast cancer by geography.
- **Chapter 3** describes the method used in determining the financial impact of breast cancer in Australia.
- **Chapter 4** describes the sample recruited and analytical considerations.
- **Chapter 5** describes the overall findings of the survey incorporating data from all respondents.
- **Chapters 6 to 10** report on the overall OOP costs for each Profile, the OOP costs associated with individual cost items when they are paid for (i.e. the patient is not bulk-billed) and the top ten cost items for each Profile.
- **Chapter 11** provides a discussion regarding the findings across the different Profiles.
- **Chapter 10** draws together the overall conclusions.
- **Chapter 11** discusses the implications of this report for BCNA.

2 Diagnostic profiles and main drivers of OOP costs

2.1 Five breast cancer diagnostic Profiles

Breast cancer is not a single disease. Subtypes of breast cancer have different biology and behaviour. These differences affect the treatment plan, as determined by the woman, their family, and treatment team, including their physician and surgeon.

Treatment options and recommendations are personalised according to several factors (American Society of Clinical Oncology, ASCO 2016). These include:

- age and general health;
- stage of the tumor;
- tumor's subtype, including hormone receptor status (oestrogen receptor (ER), progesterone receptor (PR)) and human epidermal growth factor receptor 2 (HER2) status;
- presence of known mutations in inherited breast cancer genes, such as *BRCA*;
- genomic markers; and
- other factors: menopausal status and individual preferences.

Breast cancer is a complex disease that can be quite variable between women in terms of its pathogenesis. Therefore there is not one typical diagnostic and treatment pathway in order to base costs upon. To represent this variability in disease and treatment pathways, and also to manage the estimation of cost variations, BCNA specified five Profiles for consideration when calculating the financial impact of breast cancer (Table 2.1). Profiles 1, 2, 3 and 5 were specified as they represent the most common breast cancer subtypes across Australia including early breast cancer (EBC) and metastatic breast cancer (MBC). Profile 4 was chosen as it represents the breast cancer diagnosis common for pre-menopausal women and breast cancer with the BRCA gene expression. The Profiles and their associated treatment pathway are fully described in at the beginning of each Profile in Chapters 6 to 10.

Table 2.1: Summary of breast cancer Profiles

Disease characteristics	Surgery	Chemotherapy	Radiotherapy	Herceptin	Hormone therapy	Breast Re-construction	Other
Profile 1 • BreastScreen* • Low risk, grade 1/2 • Node negative • Hormone positive • HER2 negative	☑ Breast conser-ving surgery	-	☑	-	☑	-	-
Profile 2 • Self-detected • High grade • Node positive • Hormone positive • HER2 negative	☑ Unilateral mastec-tomy	☑	-	-	☑	☑ Expander and implant	-
Profile 3 • BreastScreen* • High grade • Node positive • Hormone negative • HER2 positive	☑ Breast conser-ving surgery	☑	☑	☑	-	-	-
Profile 4 • Self-detected • High grade • Triple negative • BRCA 1 or 2 • Neo-adjuvant chemotherapy pathway	☑ Bilateral mastec-tomy	☑	-	-	-	☑ Autologous re-construction (using own tissue)	☑ Genetic testing ☑ Fertility treat-ment
Profile 5 • MBC • History of early breast cancer • Self-detected^ • Hormone positive • HER2 negative • Post-menopausal	-	☑	☑	-	☑	-	☑ Bone streng-thener

*BreastScreen Australia is the national breast cancer screening program.
^through experiencing pain in the bone
Source: BCNA, internal project document, 2016

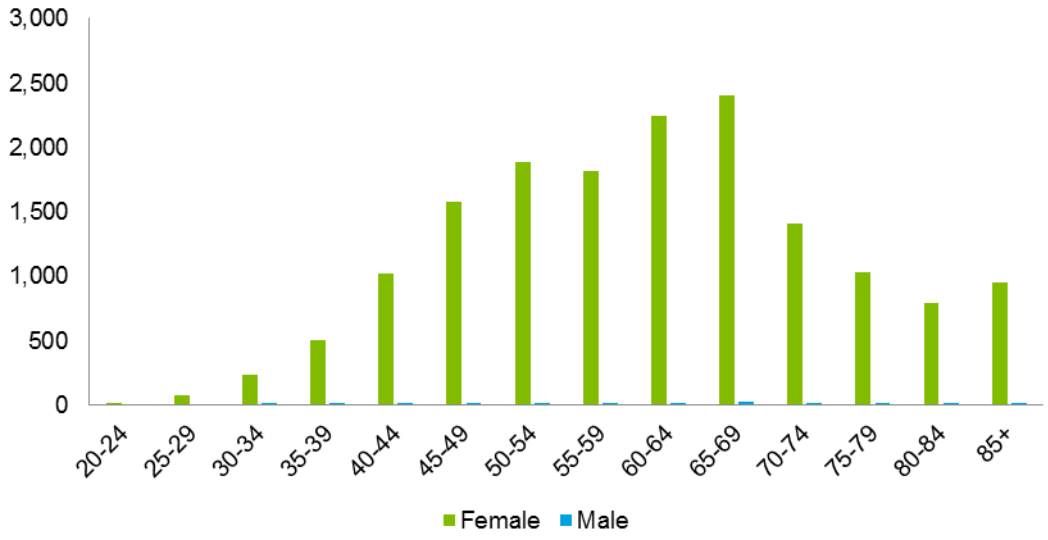
2.2 Breast cancer in Australia

2.2.1 Age distribution

In 2016, 15,934 females and 150 males are estimated to be diagnosed with breast cancer. The incidence of breast cancer will peak in the 65-69 age group (Chart 2.1). However, the majority (59%), of people with a new diagnosis are estimated to be less than 65 years old. This incidence profile follows a similar profile for prevalence; the largest prevalent group (27%) being the 60-69 age group, followed by the 50-59 age group (Australian Institute of Health and Welfare (AIHW), 2012).

Mortality rates increased with age, demonstrating that those who were older are more likely to develop breast cancer. Australia's response to breast cancer is improving. Mortality due to breast cancer as a portion of all cancer deaths has decreased, from 19% of total female cancer deaths in 1982 to 6.5% in 2016 (AIHW, 2012 and AIHW, 2016).

Chart 2.1: Incidence of breast cancer by age and gender in 2016



Source: AIHW (2016)

2.2.2 Geographical distribution

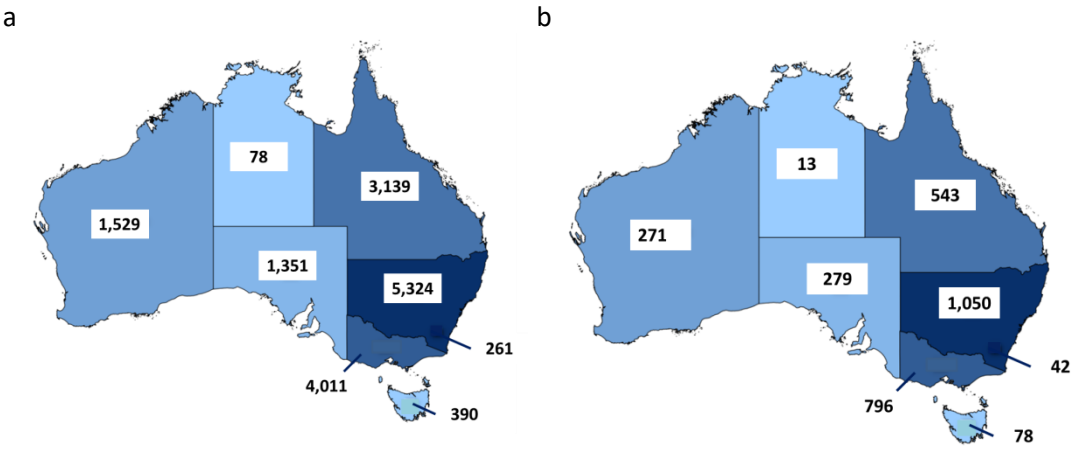
The incidence, mortality and prevalence follow the general distribution of population across Australia (Table 2.2). New South Wales has the largest proportion of cases in Australia, while ACT has the least. Both New South Wales, Victoria have a greater share of mortality compared to their incidence or prevalence which may be reflecting the older ages in these states.

Table 2.2: Incidence, mortality and prevalence of breast cancer by State and Territory

Jurisdiction	Incidence in 2016		Mortality in 2016		29 year prevalence*	
	Number	%	Number	%	Number	%
New South Wales	5,324	33.1%	1,050	34.2%	59,861	33.9%
Victoria	4,011	24.9%	796	25.9%	44,210	25.0%
Queensland	3,139	19.5%	543	17.7%	32,699	18.5%
South Australia	1,529	9.5%	271	8.8%	16,747	9.5%
Western Australia	1,351	8.4%	279	9.1%	15,081	8.5%
Tasmania	390	2.4%	78	2.5%	4,221	2.4%
Northern Territory	261	1.6%	42	1.4%	2,911	1.6%
Australian Capital Territory	78	0.5%	13	0.4%	826	0.5%
Australia	**16,084**	100%	**3,073**	100%	**176,556**	100%

Incidence and mortality have been estimated by taking the 2016 estimates as identified by the AIHW (2016) and applied to the States and Territories using the rates relative to each other as reported by AIHW (2012) *Breast cancer in Australia, an overview.* 29 year prevalence is based on the longest duration that can be calculated, based on the earliest (1982) and latest (2010) years of data available.
Source: Deloitte Access Economics analysis of AIHW (2012)

Figure 2.1: Number of estimated (a) new cases and (b) deaths of breast cancer in Australia, 2016



The incidence, mortality and prevalence rates of breast cancer are variable by jurisdiction (Table 2.3). New South Wales, South Australia, Tasmania and Northern Territory have a greater share of the number of new breast cancer cases than the expected numbers based on population sizes. New South Wales, Victoria, South Australia, Tasmania and the Northern Territory also have a greater share of mortality than their population share.

Table 2.3: Difference in breast cancer incidence and mortality to population by State and Territory

Jurisdiction	Percentage difference of incidence to population	Percentage difference of mortality to population
New South Wales	1.1%	2.2%
Victoria	-0.2%	0.8%
Queensland	-0.6%	-2.4%
South Australia	2.4%	1.7%
Western Australia	-2.5%	-1.8%
Tasmania	0.3%	0.4%
Northern Territory	0.6%	0.4%
Australian Capital Territory	-1.2%	-1.2%

Source: Deloitte Access Economics analysis based on AIHW (2016) *Australian Cancer Incidence and Mortality (ACIM) books*, and Australian Bureau of Statistics (ABS) population data.

This difference is also noted in remoteness. While incidence is likely to be higher in a major city, mortality is higher in regional areas. This might be reflective of lower awareness, detection and follow up care that individuals have in regional areas.

Table 2.4: Difference in incidence and mortality to population by remoteness

Jurisdiction	Percentage difference of incidence to population	Percentage difference of mortality to population
Major Cities of Australia	1.0%	-1.6%
Inner Regional Australia	-0.1%	1.1%
Outer Regional Australia	-0.5%	0.5%
Remote Australia	-0.2%	0.0%
Very Remote Australia	-0.1%	0.0%

Source: Deloitte Access Economics analysis based on AIHW (2016) *Australian Cancer Incidence and Mortality (ACIM) books*, and ABS population data.

2.2.3 PHI status

PHI status among people diagnosed with breast cancer varies between 50% to 70% by State and Territory (ABS, 2016). People with breast cancer in Queensland and ACT reported the lowest rates of coverage at close to 50%, while people with breast cancers in New South Wales and Victoria reported rates of 66% and 64% respectively. All other jurisdictions reported rates close to 70%. However, the jurisdictions with rates over 70% were associated with higher rates of error due to the small sample.

Table 2.5: PHI among people with breast cancer, by jurisdiction

Jurisdiction	With private health insurance	Without private health insurance
New South Wales	66%	34%
Victoria	64%	36%
Queensland	50%	50%
South Australia	75%*	25%*
Western Australia	71%	29%
Tasmania	71%*	29%*
Northern Territory	100%*	0%*
Australian Capital Territory	54%^	46%^

Note: ^Estimate has a relative standard error of 25% to 50% and should be used with caution; *Estimate has a relative standard error greater than 50% and is considered too unreliable for general use
Source: ABS (2016), *National Health Survey, 2014-15.*

People with breast cancer in major cities are more likely to have access to PHI than those in regional areas. Of those who had PHI, 15% had hospital cover only, 6% had ancillary cover only, and 79% had both hospital and ancillary cover.

Table 2.6: PHI status among patients with breast cancer, by remoteness

Remoteness	With private health insurance	Without private health insurance
Major Cities of Australia	64%	36%
Inner Regional Australia	52%	48%
Outer Regional Australia	*	*

Note: *Estimate has a relative standard error greater than 50% and is considered too unreliable for general use; the National Health Survey did not report any statistics for those with breast cancer in Remote or Very Remote Australia.
Source: ABS (2016)*, National Health Survey, 2014-15.*

The rates of PHI did not change much (less than 3%) between women with breast cancer who were currently receiving care, and those women who had received care. Women with breast cancer who did not have PHI cited a primary reason that they could not afford it (49%), that Medicare was sufficient (18%), or concession cards as influencing their choice (16%), followed by those who were disillusioned about having to pay OOP costs/gap fees (8%) or saw a lack of value for money (6%). Only 3% were prepared to pay the cost of private treatment from their own funds.

2.2.4 Indirect effects of breast cancer on income

The incidence rate of breast cancer in the population tended to increase with improving socioeconomic status with the rate in the highest group being 20% higher than the lowest group (AIHW, 2012). This is in contrast to most other cancers that affect people of lower socioeconomic status. As noted by the AIHW (2012), this may be explained, at least to some degree, by differences in fertility, reproductive and lifestyle factors associated with higher

socioeconomic status. Consequently, breast cancer may result in higher level of lost incomes due to reduced earning capacity following a breast cancer diagnosis.

2.2.5 Dependents

Based on the National Health Survey data (ABS, 2016), a majority of people with breast cancer did not report having children between the ages of 0 and 17 (60%). Among the ABS survey respondents, 24% were a couple who had children, and 15% were a one-parent family supporting their children, and 1% classified themselves as otherwise.

2.3 Drivers of OOP costs

In 2014, a BCNA survey of women with metastatic breast cancer (MBC) found that OOP costs over the previous month ranged from $0-$25,000 in the private system and $0-$10,500 in the public health system (Spence et al., 2015). Non-PBS drugs, surgery, radiotherapy, scans and PBS drugs were all identified as having significant OOP costs for women diagnosed with breast cancer up to several thousand dollars. The survey did not quantify any other costs associated with breast cancer treatment and care such as travel and accommodation costs, associated treatment for dental issues, lymphoedema treatments, psychological support, complementary and alternative treatments, wound dressings, wigs and turbans, post-surgery bras or practical assistance such as home help and child care. However, the survey did measure the impact of changes in income during breast cancer treatment. Spence et al. (2015) identified productivity losses with more than four in ten women working full-time before being diagnosed with MBC and only one in ten working full-time after diagnosis.

A longitudinal, population-based study of 287 women in Queensland explored the economic impact of breast cancers during the 18 months following diagnosis from 2002 to 2004 (Gordon et al., 2007). Direct costs measured included OOP costs for garments and aids, health services (e.g. co-payments, pharmaceuticals) and paid home services. Other costs measured included the value of lost income, unpaid help, and lost unpaid work. Gordon et al. (2007) reported that the total median cost per person was US$1,781[8] (range: US$0 – US$43,727) for women zero to 18 months post-diagnosis. In 2005, lost income at zero to 18 months following diagnosis was identified as the greatest source of financial burden (media of US$1,891) followed by OOP costs for health services (median of US$1,317), and then lost unpaid work (median of US$614). All values are in 2005 US dollars.

Paul et al. (2015) presented findings of a study that investigated the financial impacts of cancer in Australia at the Clinical Oncology Society of Australia conference. It found that:

- One third (33%) of patients reported experiencing moderate or heavy financial burden in the three months prior due to prescribed medicines.
- 66% of patients indicated a change in their employment following their diagnosis.
- 63% of patients who had been employed at diagnosis reported a reduced income since being diagnosed with cancer.

[8] This study was conducted in Australia, however all the cost information has been published in $US.

- The most common financial factors influencing treatment decision making were the cost of travelling to and from treatment (15%) and loss of income (14%).
- Most (71%) of those impacted by a financial factor indicated that the financial factor made the decision difficult, but did not change their treatment decisions.

In 2005, using population level data, Access Economics (2007) estimated that the average lifetime financial cost faced by households for people (all ages and both sexes) with breast cancer was $28,500 with the average lifetime cost for females aged 15-64 years estimated at $10,300 ($11,242 in $2016)[9] and for females 65 years and over at $9,100 ($9,933 in $2016)[10] (Access Economics, 2007). The financial costs included in the Access Economics analysis of household financial included:

- a reduction in income (for example, productivity); and
- an increase in OOP expenses (for example, health costs and other financial costs).

The following sections describe the various factors influencing the level of OOPs among women diagnosed with breast cancer based on the available literature.

2.3.1 Disease severity and age

Gordon et al. (2007) found that OOP costs for patients with breast cancer were found to be positively-correlated to both disease severity and age. Women with positive lymph nodes had reported nearly twice the costs of women with negative lymph nodes (US$6,674 versus US$3,533; $US 2005)[11]. Also, due to loss of income and productivity among the working age-group, younger women with positive nodes had average total costs 80% greater than older women with invaded nodes (USUS$8,880 versus $4,937; $US 2005). With regard to cancer generally, Paul et al. (2015) found that having a reduced income since being diagnosed with cancer quadrupled the odds of reporting a heavy or extreme financial burden associated with prescribed medicines for cancer.

2.3.2 Treatment in the private or public system

The diagnosis and treatment for breast cancer in Australia is delivered in both the public and private health care system. If a treatment or test is delivered in a public hospital, the patient may incur low or no OOP as the cost of most items will be covered by the Medicare Benefits Schedule (MBS) (Commonwealth funded) and the hospital (State government funded). If it is delivered in the private system, although it may attract an MBS rebate, it will often also have an associated 'gap' fee that must be paid to the treating physician, surgeon, hospital or company. The gap fee may or may not be fully covered by a patient's PHI in which case the patient will make up the short fall and incur an OOP cost[12].

Physicians and surgeons may order more diagnostic tests for their patients in the private system which do not attract a Medicare rebate such as Oncotype Dx molecular test during

[9] Using Consumer Price Index, Australia (ABS, 2016)

[10] Using Consumer Price Index, Australia. (ABS, 2016)

[11] Gordon et al. 2007 conducted research on Australian women in Queensland but all prices are published in $US.

[12] Overall finding from consultations with clinical specialists conducted as part of this report.

treatment planning and/or MRIs and PET scans during pre-surgical work-up. Patients in the public system can also elect to have these tests done[13].

Patients with breast cancer may move between the public and private health systems when receiving their care. This is not necessarily dependent on whether they have PHI coverage. Patients without PHI, may choose to pay the costs of certain treatments in the private system due to easier accessibility, choice of physician or surgeon and to avoid waiting for non-urgent treatments (e.g. breast reconstruction in a public hospital). Patients with PHI, may choose to be treated publicly if they cannot make up the shortfall in gap payments not covered by their PHI in the private system. Both groups may receive some items fully bulk-billed (e.g. some pathology items).[14]

Spence et al. (2015) found that women treated for MBC breast cancer in the private system in Australia had higher estimated costs during the previous month ($0 to $25,000) compared to women treated in the public system ($0 to $10,500). Women treated in the private system most often nominated OOP costs associated with their treatment as their greatest source of financial difficulty (44%) followed by loss of income (36%). In contrast, women treated in the public system nominated loss of income (37%) followed by OOP costs (28%) as their greatest source of financial difficulty. The average monthly OOP cost for women in the private system was $816.69 and in the public system it was $530.80 with women in the private system listing higher average OOP costs for radiotherapy and surgery.

2.3.3 Location of primary residence

For people with cancer living rurally, Gordon et al. (2009) found that OOP costs were significantly higher if they lived more than 100km from their treating hospital and if they were treated with radiation therapy. Mackenzie (2014) describes the higher cost of travel for rural Victorians receiving treatment as encompassing not just fuel and time costs, but also possible accommodation costs if a daily commute was not an option. Mackenzie (2014) describes decreased access for rural Victorians to treatment facilities (i.e. radiotherapy treatment is typically only available in capital cities and a few large regional centres). Many patients reported travelling to the nearest regional town (which may be up to 200km away as described in the study) for their treatment. Patients' rural place of residence was also found to play a part in their decision-making regarding their treatment types and hence, the types of costs incurred. One of the main considerations parents/carers made in their treatment decisions was how disruptive the frequency of different treatment types would be for their children.

2.3.4 Time since diagnosis

Gordon et al. (2007) also found that overall costs for women with breast cancer declined in value over time. The greatest cost burden for the women was found to occur within the first six month post-diagnosis, after which the cost burden was found to gradually decline over the following months, finally being substantially lower by the 13-18 month period. Despite the overall decline in costs over time, and the reduction in lost income as the women started

[13] BCNA provided this information during their mapping of the Profiles through consultation with clinical specialists.

[14] Information provided by BCNA during discussions regarding this report.

returning back to work, several sources of costs remained ongoing (i.e. ongoing health service costs and costs associated with purchasing specialised garments/aids)).

2.3.5 Case studies and other anecdotal evidence

Case studies demonstrating high OOP costs of breast cancer have been reported in mainstream media (Medew, 2014 and Dunlevy, 2014)[15]. They report patients accessing their superannuation funds and borrowing money against their mortgages to pay for treatment as the gap widens between specialist charges and health fund rebates (Dunlevy, 2014).

OOP costs referenced by Dunlevy (2014) and Medew (2014) include:

- $9,270 charged by a surgeon for a mastectomy (MBS rebate for this item is $1,040);
- $800 for positron emission tomography (PET) scan that is not included on the MBS;
- $15,000 for breast reconstruction;
- $2,500 for chemotherapy; and
- $400 for a wig.

These costs accord with two case studies presented by BCNA to the Senate Inquiry into OOP costs (Senate Community Affairs Committee Secretariat, 2014):

- $12,022 for bilateral mastectomy;
- $657 for breast Magnetic Resonance Imaging (MRI); and
- $1,939 for anaesthetist costs.

In BCNA's *'Submission to the Medicare Benefits Schedule Review Taskforce'* in 2015 (BCNA, 2015) a number of items which are commonly recommended to women with breast cancer by their specialists which are not listed on the MBS were identified including:

- Bone Mineral Density Scans using Dual Energy X-Ray Absorptiometry (DXA) for women being treated with an aromatase inhibitor;
- Breast MRI in certain circumstances;
- PET scans for women with locally advanced or MBC;
- Lymphoedema compression garments and massage services; and
- Oncotype DX Gene Expression Profiling or similar molecular profiling tests.

As well as introducing MBS rebates for these interventions, BCNA also recommended that the Government increase rebates for existing MBS items to bring them in line with contemporary costs of treatment.

2.4 Summary

Although Australian women with breast cancer identify financial implications of a breast cancer diagnosis as an important issue, the financial impact of breast cancer has not been extensively quantified in the Australian literature. Extant literature suggests that the financial impact of breast cancer on individuals and their families is significant and in the range of

[15] Sources include Newscorp and the Sydney Morning Herald

several thousand dollars. It includes the OOP costs associated directly with the diagnosis and treatment of breast cancer and with other additional costs that occur such as additional paid home help, child care, travelling to receive treatment, accommodation, garments, aids, counselling and psychological support and medicines. Additionally, the financial impact is increased due to the losses in household income as a person receiving breast cancer treatment may need to decrease their hours of work.

The average OOP costs reported in the literature have large ranges indicating the variability in the cost of items. Variability was found to depend on several factors including the disease subtype, the woman's age, treatment in the private or public system, how far a woman lives from their treatment centre(s), and time since diagnosis.

3 Survey methodology

The project undertook the following methodological components to ascertain the OOP costs associated with a breast cancer diagnosis, as defined by the diagnostic Profiles. These components included:

- Clinical pathway mapping for each of the Profiles conducted by BCNA and their stakeholder reference group consisting of clinical specialists (see Appendix A).
- Development of an online survey of the BCNA members, including:
    - consultations with clinical specialists;
    - a detailed sampling and recruitment strategy; and
    - survey piloting.
- Using the data from the survey to build a selector tool in Microsoft Excel for data analysis according to the predefined Profiles. Specifically, the tool allows for inputs describing demographic characteristics and breast cancer diagnosis to be varied and uses survey data to produce outputs describing median, minimum and maximum OOP costs.
- Summarising the key findings from the survey regarding OOP costs for respondents overall and across the Profiles in this report.

3.1 Survey design

A survey of BCNA members was conducted to collect detailed data describing OOP costs relating to breast cancer diagnosis, with a view to assessing the financial impact of breast cancer among Australian women and their families.

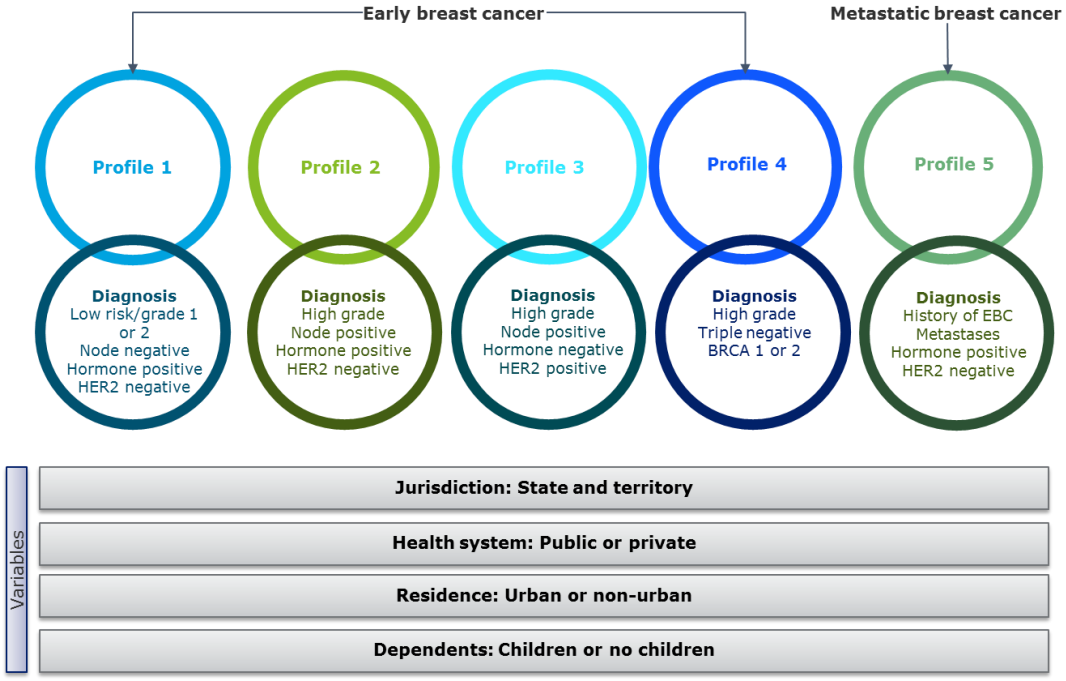
The survey was designed to collect information pertaining to the five predefined Profiles, as described in Table 2.1. Furthermore, the survey was designed to permit descriptive subgroup analysis by predefined factors: jurisdiction of residence while receiving breast cancer treatment, PHI or no PHI, remoteness classification of the place of residence, and whether the respondents had dependent children (Figure 3.1, p.17).

The survey collected information from respondents across four subjects:

- Demographic, income and employment information;
- Breast cancer history and diagnosis;
- OOP costs directly related to their most recent diagnosis of breast cancer (i.e. medical consultations, tests and treatments, see Figure 3.2); and
- 'Other' OOP costs related to their most recent diagnosis of breast cancer (see Figure 3.3).

The survey was hosted on an online survey platform called Survey Monkey™.

Figure 3.1: Survey diagnostic criteria (Profiles 1 to 5) and variable demographic factors



NOTE: **HER2+** human epidermal growth factor receptor 2 positive **HER2-** human epidermal growth factor receptor 2 negative; **BRCA** mutation of the tumour suppressor genes known as BRCA1 or BRCA2.
*Recruitment was initially aimed at people 1-5 years post their *most recent* diagnosis based on information contained in the BCNA database. However, 74 respondents had possibly had another diagnosis of breast cancer since registration with BCNA and specified that they were within 12 months post their *most recent diagnosis.* Given the focus of the analysis was on the OOP cost associated with items and services and these people had accessed several direct medical items and services, their results were included in the analysis. Analysis of the impact of that these respondents had on the overall estimated OOP costs and overall estimated OOP cost by Profile was only 1.3%, hence their results were included in the analysis.
**Nine respondents indicated that they had been diagnosed more than five years post their most recent diagnosis. However, for the same reasons above*, their results were included in the analysis.
#Urban and non-urban location was allocated according to the main place of residence while receiving treatment. Urban and non-urban areas were defined using the ABS, Australian Statistical Geography Standard (ASGS) classification of Greater Capital City Statistical Areas (GCCSAs). This means that greater capital cities are classified as urban, everywhere else is non-urban.

Semi-structured interviews by telephone were conducted with seven clinical specialists who are members of the BCNA Strategic Advisory Group. The information was used to develop a better understanding of the likely OOP costs incurred by women diagnosed with breast cancer treated in both the public and private health systems. The seven clinical specialists consulted were:

- Two medical oncologists (one practicing regionally);
- One private provider of radiotherapy services;
- One breast surgeon;
- Two plastic surgeons providing breast reconstructions, surgical scar removal and other oncoplastic techniques; and

- One fertility specialist providing services to women with breast cancer and/or a previous breast cancer diagnosis.

The consultations were also used to inform survey design by developing a better understanding of the way in which women diagnosed with breast cancer would comprehend their diagnostic and treatment pathway, and the points at which they would receive an invoice. The discussion guide used is provided in Appendix C.

The cost categories and items included in the survey were guided by the breast cancer diagnostic and treatment mapping completed for each Profile by BCNA, the information provided by clinical specialists during the consultations and a scan of the literature (findings reported in section 2.2).

To aid survey respondents in their recollection of their OOP costs associated directly with their diagnosis and treatment of breast cancer, questions were split into two sections, OOP costs associated with diagnosis and OOP costs associated with treatment and follow-up (follow-up was not used for those with MBC in recognition that their condition would be likely to require ongoing medical care).

The pilot survey was tested by eight members of the BCNA Review & Survey Group who were representative of the five Profiles. The final survey sought responses from eligible BCNA members between 19 August and 20 September 2016.

A paper based example of the survey is included in Appendix D and can be viewed for further description of the items and services within each category.

Figure 3.2: Direct health cost items associated with breast cancer – cost categories and cost items in the survey

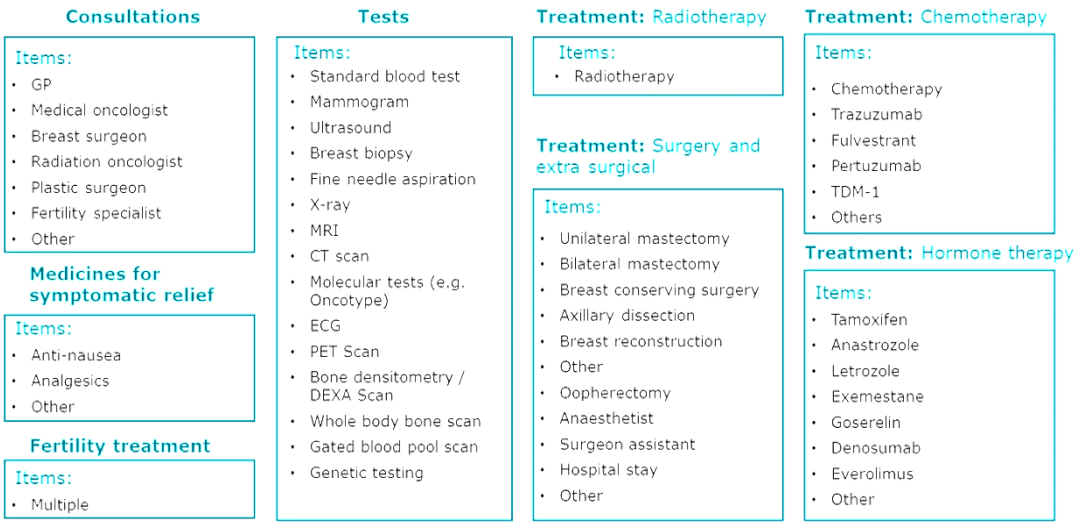
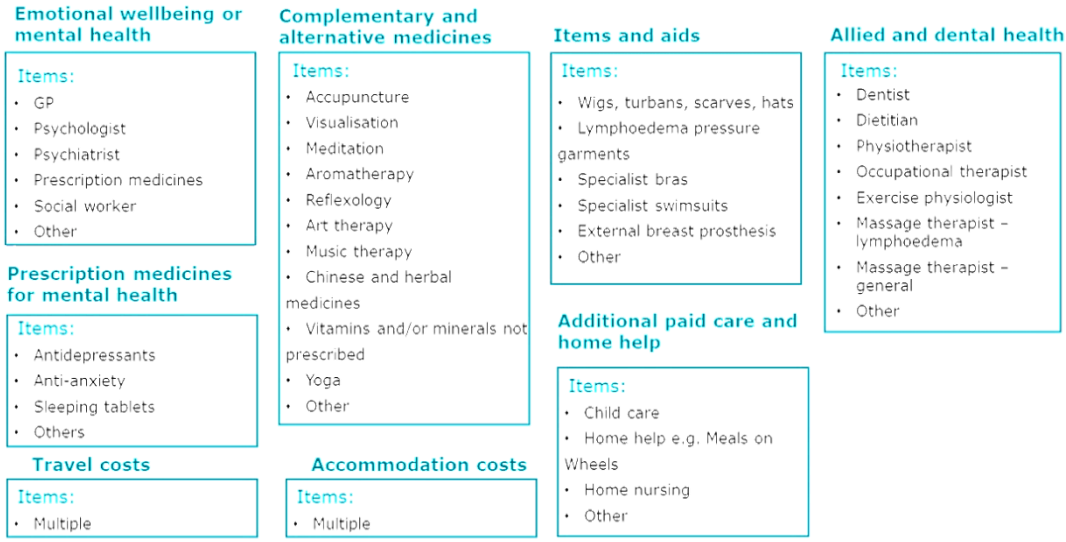


Figure 3.3: 'Other' or indirect cost items associated with breast cancer – cost categories and items from survey



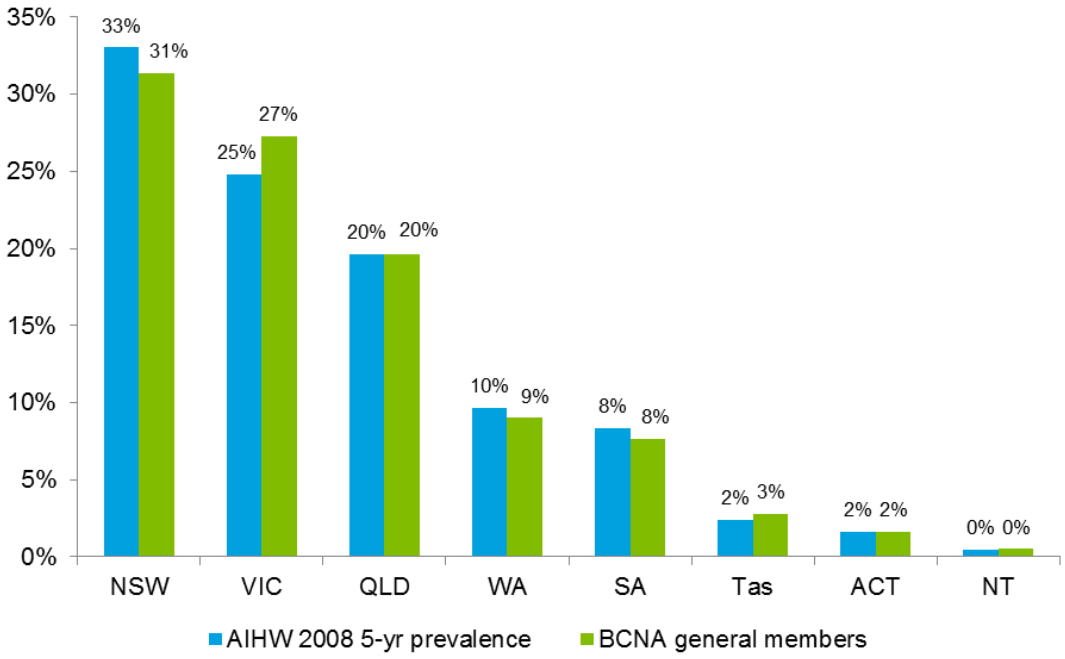
3.2 Recruitment strategy

The recruitment strategy was formulated with consideration for the representativeness of BCNA membership to the characteristics and distribution of Australian women with breast cancer.

3.2.1 Representativeness of BCNA membership to Australians with a diagnosis of breast cancer

The distribution of the BCNA general membership on the 7-8 July 2016 was broadly representative of the distribution of people with breast cancer across Australia, by jurisdiction and by remoteness classifications (Chart 3.1). It was therefore pragmatic to recruit a sample for the survey using the BCNA membership database.

Chart 3.1: Proportion of Australians* and BCNA members* with breast cancer, by jurisdiction

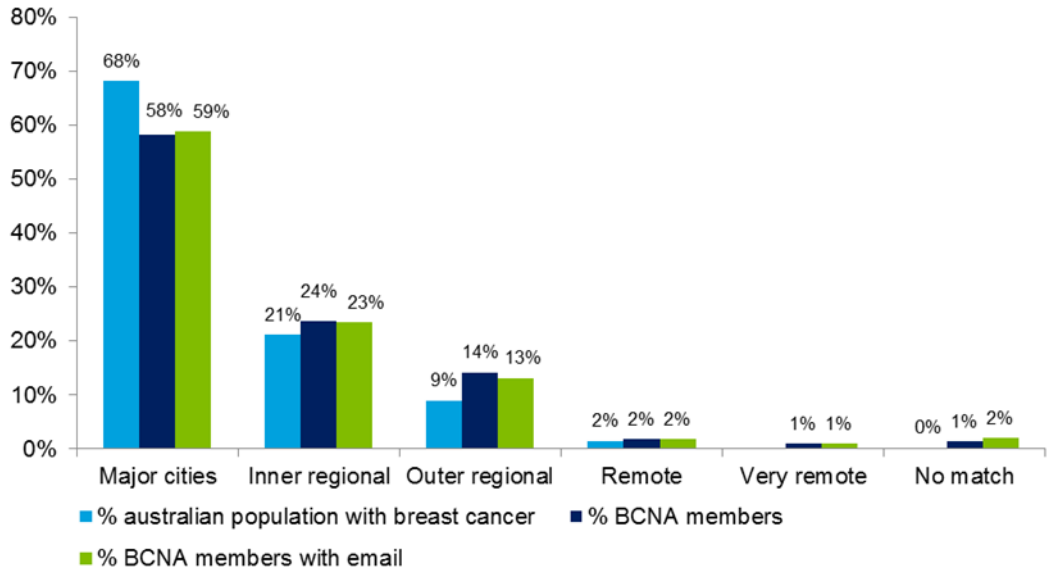


Source: BCNA membership on 7-8 July 2016[16] and AIHW, 2012. *5-year prevalence of breast cancer in Australia in 2008, N = 57,327, **BCNA membership on 7-8 July 2016, n= 117,891

The survey was fielded in an online format. Hence, it was only made available to BCNA members with an email address. The BCNA membership base with an email address by location is broadly representative of the total BCNA membership base and the Australian population with breast cancer (Chart 3.2).

[16] BCNA membership numbers fluctuated slightly during the two days of analysis (7 July 2016 and 8 July 2016). Percentages were calculated on the basis of the particular number of members at the time of analysis of each specific section.

Chart 3.2: Proportion of Australians* and BCNA members with breast cancer, by remoteness**



Source: BCNA membership on 7-8 July 2016 and AIHW 2012. AIHW data regarding remote and very remote classifications were collapsed together and represent incidence rather than prevalence. *Prevalence of breast cancer in Australia, N = 63,519 (BCNA calculation of distribution by remoteness index based on 2004-2008 incidence data from AIHW, 2012) **BCNA membership on 7-8 July 2016, n= 117,891; BCNA members with an email address, n = 37,804

3.2.2 Anticipated number of people within each Profile

The BCNA membership database indicated that 89.7% of the members had EBC, 3.3% of members had MBC, and the remaining members had not reported their disease status. However, the database did not collect further diagnostic information, for example, by molecular subtypes. There is also no known data source that reported breast cancer diagnosis by subtypes.

For these reasons, the literature was used to estimate the expected number of eligible BCNA members who may be categorised into one of the diagnostic Profiles. Based on the literature (Howlader et al. 2014, Kim et al. 2006, Colleoni et al. 2002) the expected prevalence of breast cancer by molecular subtype, node involvement, and tumour grading were applied to the estimated number of BCNA members with email addresses who were 12 months to 5 years post-diagnosis (n=17,012). Appendix E presents the specific methodology for these calculations. It is important to emphasise that this estimation method was likely to underestimate the true proportion because it assumed that molecular subtype, node involvement and tumour grading were independent characteristics.

Overall, it was estimated that approximately 1 in 5 (19.8%) of the 17,012 BCNA members with email addresses who were 12 months to 5 years post diagnosis, would have diagnostic characteristics that fit into one of the five Profiles (Table 3.1). It was anticipated that Profiles

3 and 4 would have very low number of respondents due to the lower incidence of the disease characteristics applicable to both of these profiles.

Table 3.1: Estimated number of eligible BCNA members, by Profile

Total number of BCNA members= 117,913

Members between 1 and 5 years post-diagnosis = 53,064

32.06% of members with available email addresses (eligible members) = 17, 012

Profile	1	2	3	4	5	Total
Estimated number of eligible members within each Profile	2,352	568	121	25	296	3,362
Estimated proportion of total members with available email addresses within each Profile	13.8%	3.3%	0.7%	0.1%	1.7%	19.8%
Target sample size	181	49	11	2	26	240

Source: Deloitte Access Economics calculation

3.2.3 Recruitment strategy

Due to the anticipated low numbers of people in Profiles 3 and 4 (Table 3.1) and to recruit a sufficient number of respondents for subgroup analyses, a broad recruitment strategy was employed. Therefore, the survey was sent to BCNA members who had the following information recorded in the membership database:

- a diagnosis of breast cancer between 1 year and 5 years ago; and
- an email address.

BCNA estimated that the survey response rate from the general membership would be 10%, therefore, the expected number of responses was around 1,700 across all members sent the survey. Using the estimated values for the total sample size in each diagnostic Profile, the number of required responses for a representative sample across each Profile was calculated (Table 3.1).

3.3 Data analysis

Data from the online survey was imported into Microsoft Excel. Data on OOP cost information was 'cleaned' and/or validated using visualisation of scatter plots to identify outliers.

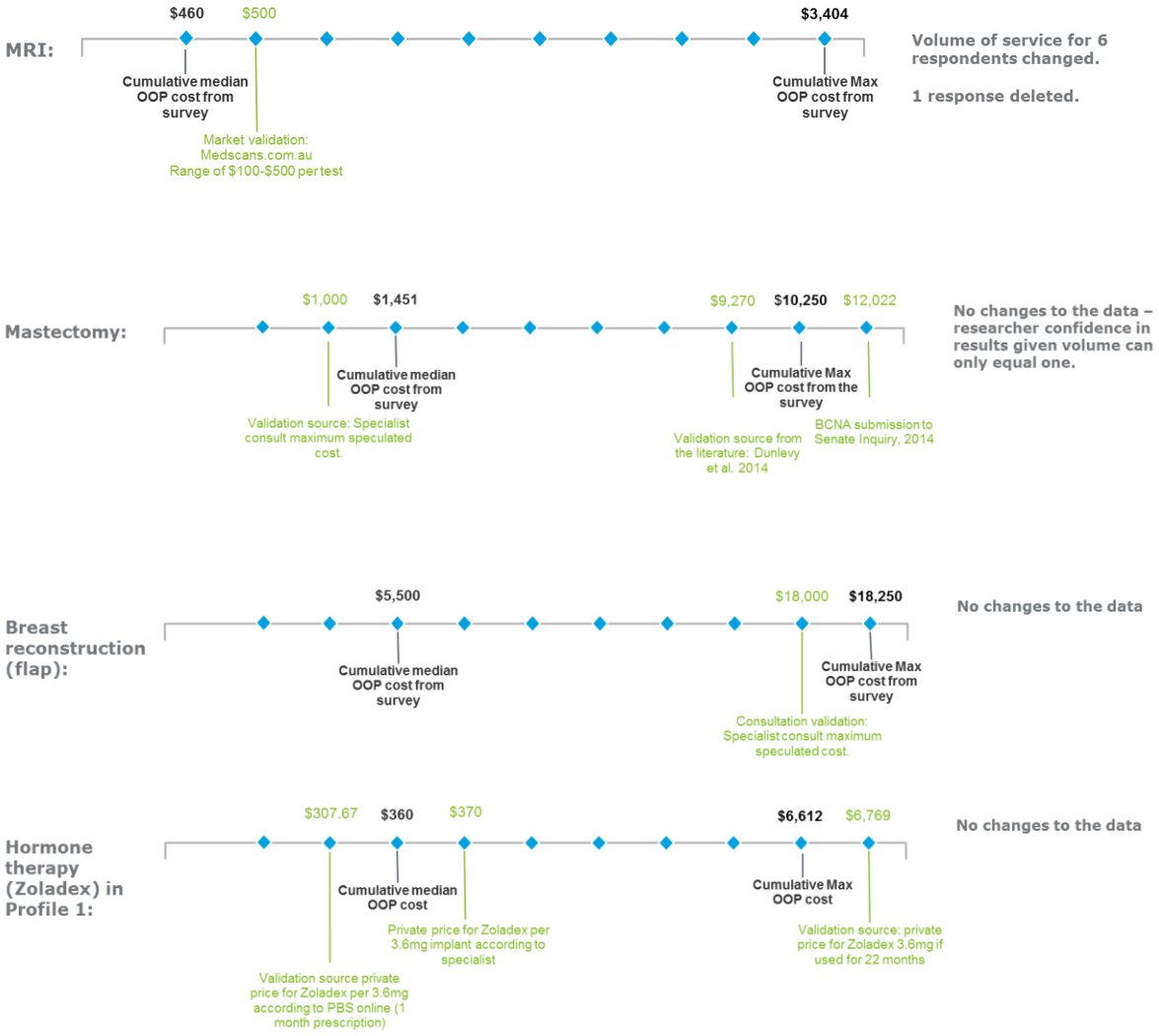
Sources of validation for the data outliers and estimations for maximum OOP cost per service/item included:

- market advertised rates;
- cost information from consultations with the specialists;
- values obtained in the literature; and
- maximum data received from respondents who provided a frequency equal to one item/service and an OOP cost for that service.

If there was no known price set for an item or service, the conservative approach was to double the estimated maximum OOP cost and use this as a per item/service threshold. Data outside this range was removed if it was too large to represent a cumulative cost based on the frequency of services/items used. To do this, two team members corrected responses when respondents reported total costs rather than unit cost. For example, if a respondent reported 10 GP consultations and OOP cost of $1,000 'per consultation', the unit cost data was corrected to $100 per visit.

Using these methods, any values declared invalid were removed by consensus between two project team members. A high-level example of how various sources of information were used to validate the maximum OOP costs for four items is provided in Figure 3.4. Given the wide range of OOP costs reported for most items, the **median and middle 50%** of data for each OOP cost are reported as headline results.

Figure 3.4: High-level examples for data validation for four OOP cost items – charts are not to scale and are demonstrative only



The data was analysed according to univariate descriptive statistics as agreed with BCNA during the project establishment phase. Given there was no quantified hypothesis for the

differences in OOP costs according to the Profile of respondents or the impact of the demographic factors, descriptive statistics were used in the analysis.

4 Sample recruited and analytical considerations

BCNA sent survey invitations to 12,737 members on 19 August 2016. A total of 1,932 valid responses were received; this corresponds to a response rate of 15.2%. From this sample, thirteen responses from men were excluded from the analysis because the clinical treatment pathways for each Profile were specifically related to women. Hence, the total sample of female and 'I prefer not to say' respondents was 1,919. Of these, 1,045 (54.4%) people had reported a breast cancer diagnosis matching one of the five Profiles. Table 4.1 presents the number of the survey respondents by subgroups. The representativeness of the sample is discussed in the following sections.

Table 4.1: Number of survey respondents, by Profile and subgroup

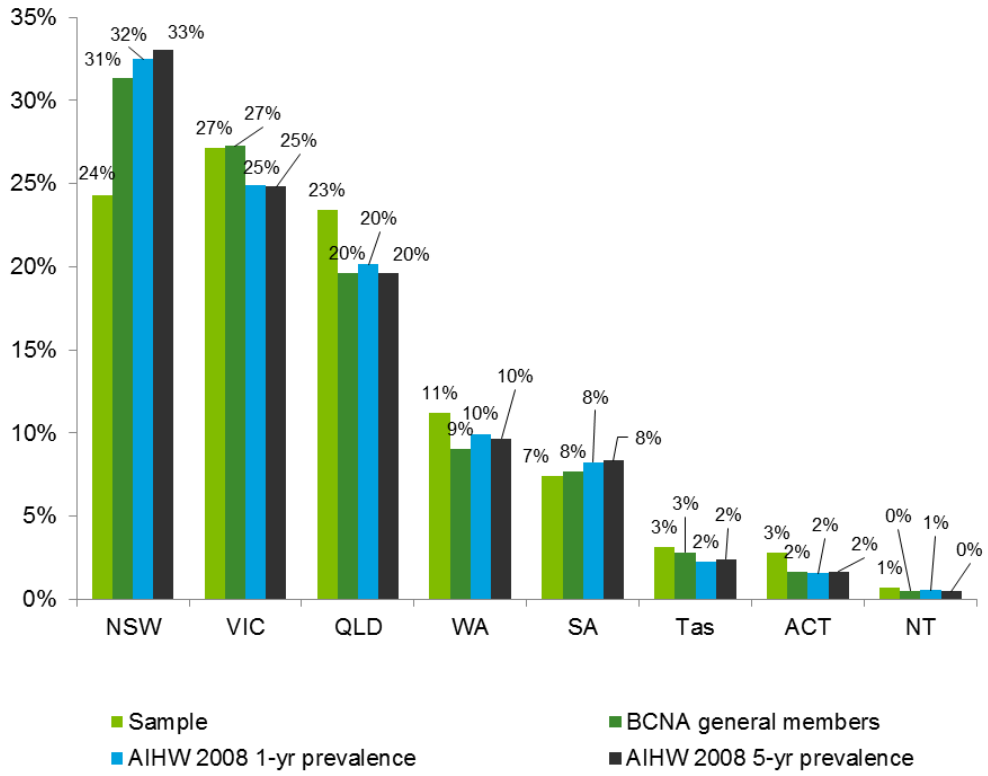
Category	Total	Profile					
		Total	Profile 1	Profile 2	Profile 3	Profile 4	Profile 5
Total	**1,919**	**1,045**	**577**	**346**	**29**	**25**	**68**
Jurisdiction							
NSW	466	262	146	87	8	8	13
VIC	521	298	163	100	10	8	17
QLD	449	245	142	77	5	3	18
WA	215	108	57	41	2	1	7
SA	142	76	30	34	2	4	6
TAS	60	23	13	4	2	1	3
ACT	53	28	23	2	0	0	3
NT	13	5	3	1	0	0	1
Location							
Urban	1,240	711	390	233	20	18	50
Non-urban	576	333	186	113	9	7	18
Incomplete	103	1	1	0	0	0	0
PHI							
Yes	1,419	806	447	265	21	20	53
No	500	239	130	81	8	5	15
Dependent children							
Yes	668	384	193	138	15	12	26
No	1,246	661	384	208	14	13	42
Age							
18-29	7	1	0	1	0	0	0
30-39	86	45	15	22	1	6	1
40-49	366	203	97	72	13	6	15
50-59	695	387	218	130	7	7	25
60-64	299	159	86	53	4	1	15
65-69	277	155	93	48	3	3	8
70-79	177	92	66	20	1	2	3
80+	10	3	2	0	0	0	1
I prefer not to say	2	0	0	0	0	0	0

4.2 Sample representativeness

4.2.1 Jurisdiction

Overall, the survey respondents were representative of the distribution of people with breast cancer according to 1-year and 5-year prevalence rates across the states and territories of Australia (Chart 4.1). The response rate in New South Wales and South Australia was lower than the expected proportion based on their share of breast cancer cases. This may reflect that BCNA has lower proportion of members in New South Wales, South Australia and Western Australia and higher proportion of members from other jurisdictions, especially in Victoria.

Chart 4.1: Sample representativeness by jurisdiction



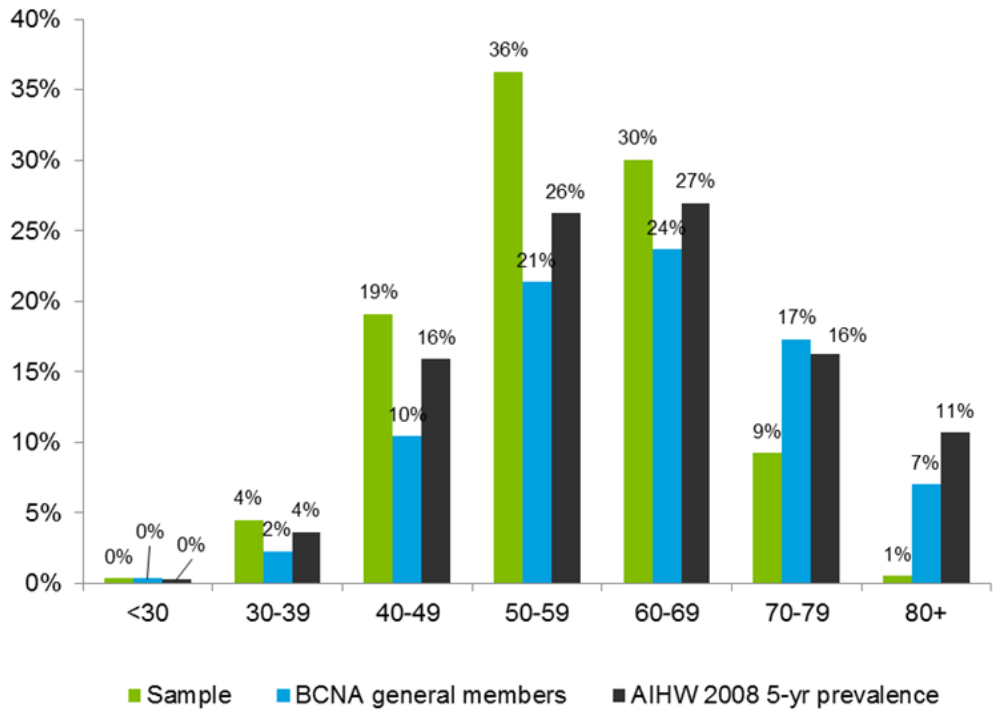
Data source: BCNA membership database and AIHW (2012) Total number of respondents in the sample = 1,919; AIHW 2008 1-year prevalence, N= 13,198; AIHW 2008 5-year prevalence, N=57,327; Total number of BCNA general members: 117,891 on 7-8 July 2016.

4.2.2 Age groups

The highest proportion of respondents to the survey was in the 50-59 year age group (Chart 4.2). This was higher than expected based on the age distribution of the BCNA general members and the 5-year prevalence in Australia. The respondents in the 30-39, 40-49 and 60-69 year age groups were higher than expected, whereas the 70-79 and 80+ year age groups were lower than expected. This may reflect a lower proportion of people in these age

groups with email addresses recorded in the database and internet access. It may also reflect their lower willingness to participate in an online survey.

Chart 4.2: Sample representativeness by age group

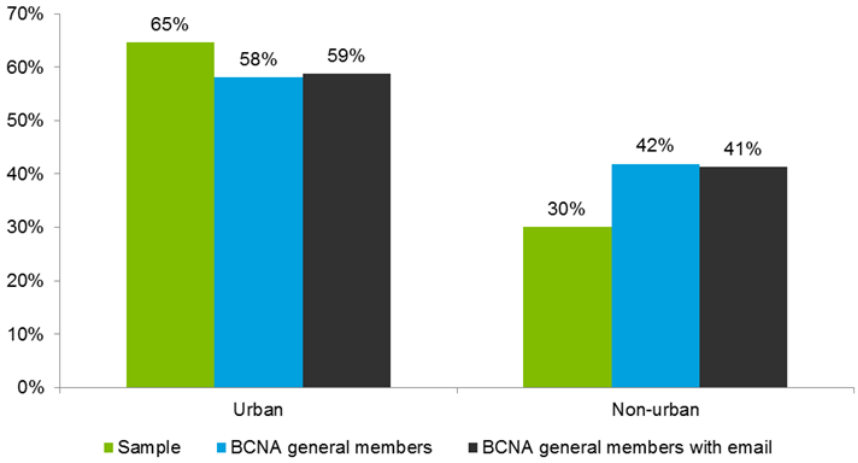


Data source: BCNA membership database and AIHW 2012 Total number of respondents in the sample = 1,919; AIHW 2008 5-year prevalence, N=57,327; Total number of BCNA general members: 117,891 on 7-8 July 2016

4.2.3 Location

The residential location of BCNA members has been categorised by remoteness area, based on The Australian Standard Geographical Classification Remoteness Area Classification. The location of survey respondents was determined by postcode of residence while receiving treatment for breast cancer, and was classified into “urban” and “non-urban” according to the population size of that postcode. Based on this classification method, the survey received more responses from BCNA members living in urban locations than anticipated based on the proportion of BCNA members with email addresses registered with BCNA living in ‘Major cities’ (Chart 4.3, p.28). However, this analysis is limited because it is assumed that the ‘Major cities’ classification aligns with the ‘urban’ location definition adopted in this analysis.

Chart 4.3: Sample (n=1,919) representativeness by location



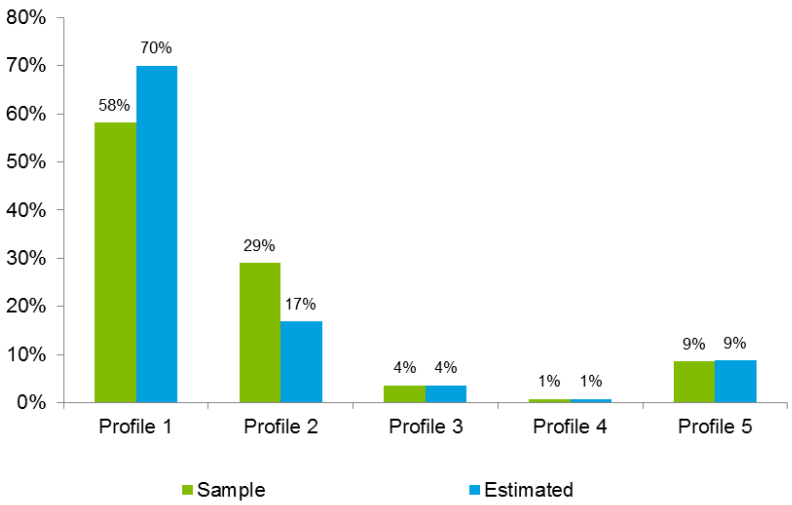
Note: 5.4% of the sample did not provide complete enough postcode information to allow for classification as urban or non-urban. Classification based on the ASGC classification of Greater Capital City Statistical Areas (GCCSAs). Source: BCNA membership database Total number of respondents in the sample = 1,919; Total number of BCNA general members: 117,891 on 7-8 July 2016; Total number of BCNA general members with email: 37,804 on 7-8 July 2016.

4.2.4 Profiles

While planning for and fielding the survey, the inclusion criteria were restricted by age groups. The proportional representation of the Profiles amongst all respondents to the survey is under representative of estimations for Profile 1 and over representative of estimations for Profile 2. It is very similar for Profiles 3, 4 and 5 see Chart 4.4.

During the analysis phase, the age restriction was removed from all Profiles to increase the number of responses for analysis.

Chart 4.4: Sample Profile proportion and estimated Profile proportion



Total number of respondents in the sample = 797* Note: Based on original age-restricted sample of 797 respondents Source: Deloitte Access Economics Analysis.

4.3 Analytical considerations

Although there is a main treatment pathway that most women with breast cancer across the five different Profiles will take, whether or not women will have their treatment in the private or public health systems is not necessarily determined by whether or not they have PHI. A woman may not choose to have all of her treatment in the private health system or all in the public health system, moving between the two for different aspects of their care.

4.3.1 Accounting for items and services without an OOP cost in the overall cost estimates

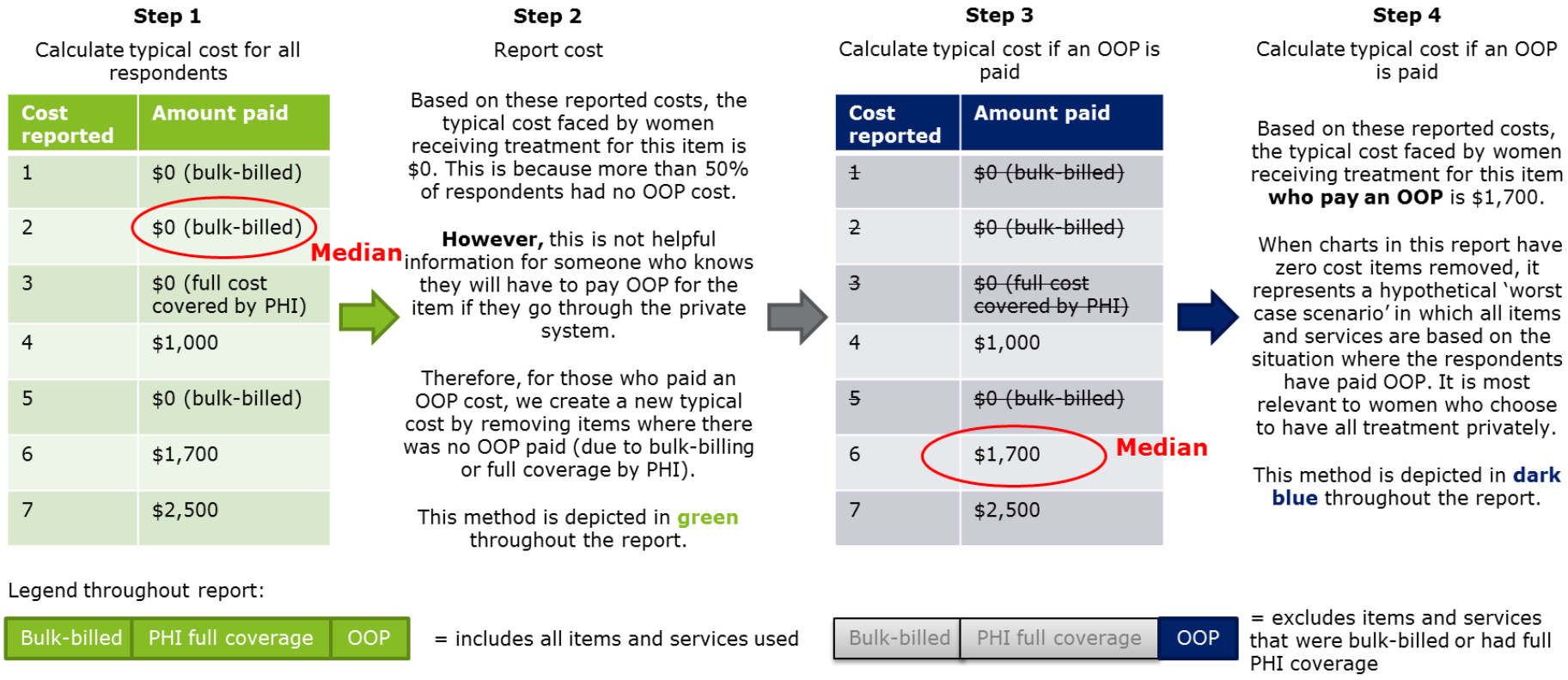
The sections below report for the OOP costs reported by women across the different Profiles the median and where applicable, other summary statistical measures including minimum, maximum and interquartile range.

To provide an overall estimation of the OOP cost a woman in each Profile is likely to face, all items and services they used (as captured in the survey) were included in the calculation. They were included if a woman recorded that she had paid no OOP cost (i.e. $0 recorded) or had paid an OOP cost. Therefore, the overall estimation of the OOP cost a woman in each Profile is likely to face accounts for the proportion of women who do not pay for an item or service because they are 'bulk-billed' or receive full financial coverage from PHI. Throughout the report, charts with the bulk-billed and PHI covered items included are identified in the chart titles and with green dots depicting the median point.

In addition, a hypothetical 'worst case scenario' overall OOP cost estimate is also provided. This 'worst case scenario' analysis removes all the direct medical and other items and services that were reported as having a $0 OOP. Therefore, it removes the influence of bulk-billing or other funding arrangements. Throughout the report, charts with the bulk-billed and PHI covered items removed are identified in the chart titles and with dark blue dots depicting the median point.

Figure 4.1 below shows the steps in this analytical process and the legend used throughout the report.

Figure 4.1: Accounting for items and services without an OOP cost in the overall cost estimates



4.3.2 Accounting for variability in treatment pathways

Women across each Profile will not access every single medical consultation, test, medical treatment or other services (such as allied health, or emotional support) associated with their breast cancer Profile. To ensure that the findings are representative of the overall experience, and understanding that each course of treatment can vary between cohorts' or individuals' circumstances, the median cost of care was weighted by the volume of services reported. This has been demonstrated in a hypothetical example. Figure 4.2 shows the variation in usage of five items by five hypothetical respondents. As shown, the median OOP cost for the five items in the category is calculated by summing the median cost of each item. This comes to $1,460, but it does not account for the fact that within the sample, some items were not used by all the respondents and may therefore drive up the median OOP cost without reflecting actual service use. For example, item C has a median OOP cost of $1000 but was only used by one respondent. Without weighting for frequency of use, item C falsely inflates the median OOP cost. Therefore, median cost of each item weighted by the number of times it was used of provides a more accurate calculation of the median overall OOP cost i.e. $538.

Figure 4.2: Hypothetical example demonstrating methodology for weighting the median

Items in category	Median OOP cost	Respondent 1	Respondent 2	Respondent 3	Respondent 4	Respondent 5	Number of times item is used	Weighting for number of uses	Weighted median cost
Item A	$10	✓	✓	✓	✓	X	4	4/5 = 0.8	$8
Item B	$50	✓	✓	✓	✓	✓	5	5/5 = 1.0	$50
Item C	$1000	✓	X	X	X	X	1	1/5 = 0.2	$200
Item D	$300	X	X	✓	✓	✓	3	3/5 = 0.6	$180
Item E	$100	✓	✓	✓	✓	✓	5	5/5 = 1.0	$100
Total median OOP cost of for the category	$1,460 (unweighted)								$538 (weighted)

✓ Item used by respondent

X Item not used by respondent

4.3.3 Providing estimates of OOP costs for individual items or categories of service

In providing estimates for individual OOP cost for items or services, only items or services where the respondent has recorded an OOP cost greater than $0 have been included in the analysis. This provides an estimation of the OOP cost for an item or service when an OOP cost is incurred and removes any impact of bulk-billing or full PHI coverage.

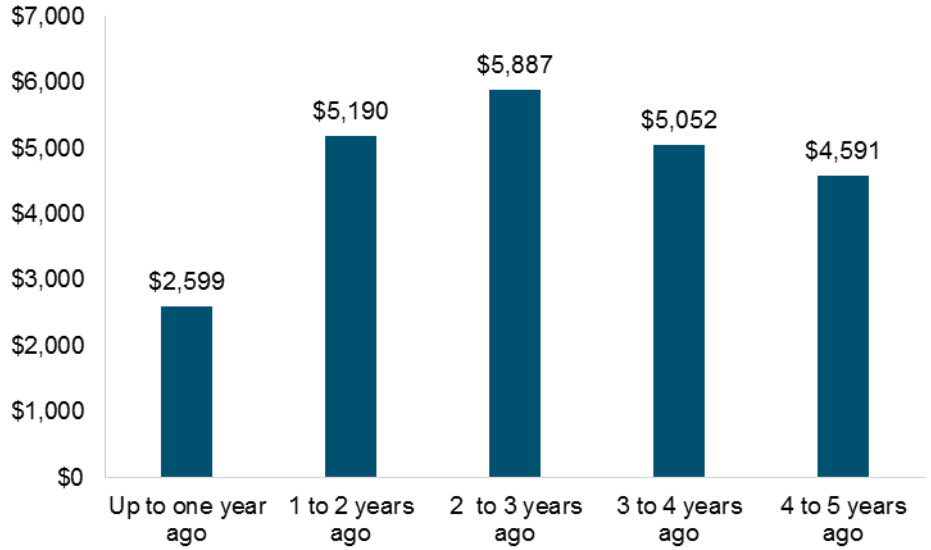
4.3.4 The time since diagnosis

Respondents to the survey were asked to indicate the number of years since their most recent diagnosis i.e. Up to 1 year[17]; 1 to 2 years; 2 to 3 years; 3 to 4 years; 4 to 5 years; and more than 5 years. The analysis reports all OOP costs across this time period and does not stratify the OOP cost by number of years since diagnosis. No adjustments were made for the number of years since diagnosis for the following reasons:

- the survey did not ask respondents to list their OOP costs by number of years since diagnosis, therefore applying a weighting for number of years since diagnosis was not possible;
- after 1-2 years post diagnosis, a respondent may still be incurring OOP costs related to their diagnosis, but the strength of attribution and the accuracy of a respondents recall may decrease.
- as demonstrated in Chart 4.5, the bulk of medical costs are incurred within 1-2 years of a diagnosis of breast cancer after which, they will diminish with time. In the first year, $2,599 is incurred; in the second year an additional $2,591 is incurred; and in the third year, another $697 is added. Respondents who were 3-4 years and 4-5 years from diagnosis indicated a lower OOP total cost than respondents that were 1-2 years and 2-3 years from diagnosis. This may be due to poorer recall of costs accumulated and items/services used over the longer time period.

[17] The survey was emailed to BCNA members who were registered as having a diagnosis of breast cancer between one and five years prior. However, given that some of these people may have had another more recent diagnosis after their registration with BCNA which was within 12 months of receiving the survey, 'up to 1 year ago' and over 5 years ago, were included as response categories. Seventy four respondents indicated that their most recent diagnosis was 'Up to 1 year ago' and only nine respondents indicated that more than 5 years had elapsed. Given that a priority of the analysis was to determine the OOP costs associated with individual items or services, a majority of medical treatments are accessed within 12 months of diagnosis, these results were included in the analysis. Additional analysis was done to check whether inclusion of these results impacted the overall OOP cost estimates. The impact was found to be small (decreasing the total cost by 1.3%) relative to the estimated overall OOP costs, hence the decision was made to include these responses.

Chart 4.5: Median total OOP costs reported by time since diagnosis



Number of respondents: Up to one year ago – 74, 1 to 2 years ago – 850, 2 to 3 years ago – 460, 3 to 4 years ago – 339, 4 to 5 years ago – 137, More than 5 years ago – 9.

4.3.5 Large variation in the OOP costs reported

Finally, the median has been selected as the most appropriate measure of representativeness based on the distribution of the data. This means that a number of respondents reported very high costs skewing the average to costs higher than most experienced by most women. Throughout the report, 'reported costs' are referring to the median unless otherwise specified.

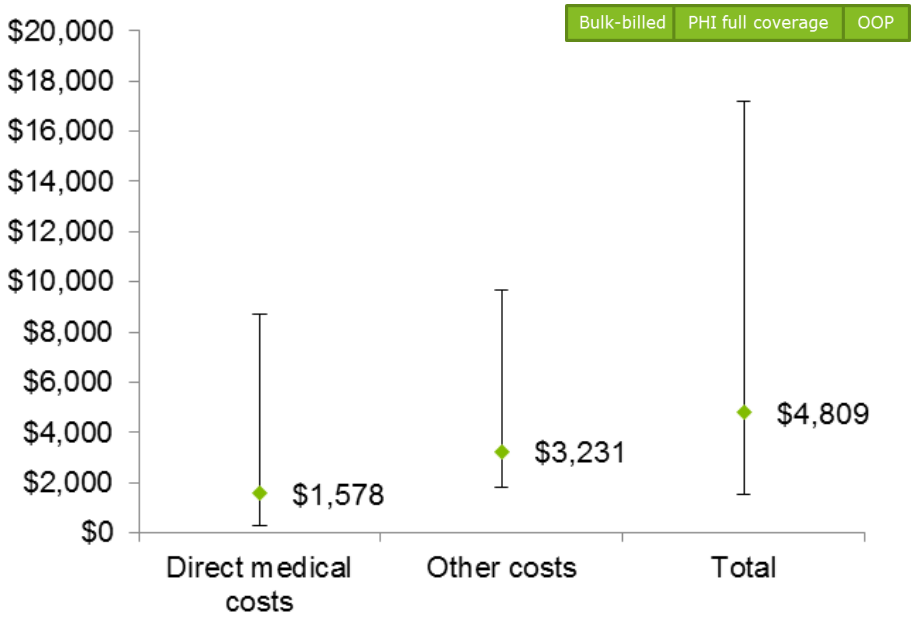
5 Overall costs

The following chapter reports overall results from all 1,919 female respondents to the survey. Results stratified by Profile are reported in later chapters.

Overall, there was a large variety in OOP costs reported by respondents with half of all respondents reporting total OOP costs across the five years from their most recent diagnosis between $1,500 and $17,200. The overall median direct medical OOP cost is $1,578 and the median other OOP costs is $3,231 bringing the total OOP cost reported to $4,809, see Chart 5.1.

The median direct medical OOP cost reported includes data from a total of 20,002 items or services used by the 1,919 respondents. Of those, 10,213 items or services (51%) had no OOP cost ($0 OOP cost) reported as they were either bulk billed or fully covered by PHI. Of the 7,897 other cost items or services reported, only 29 (0.004%) had a $0 OOP cost reported.

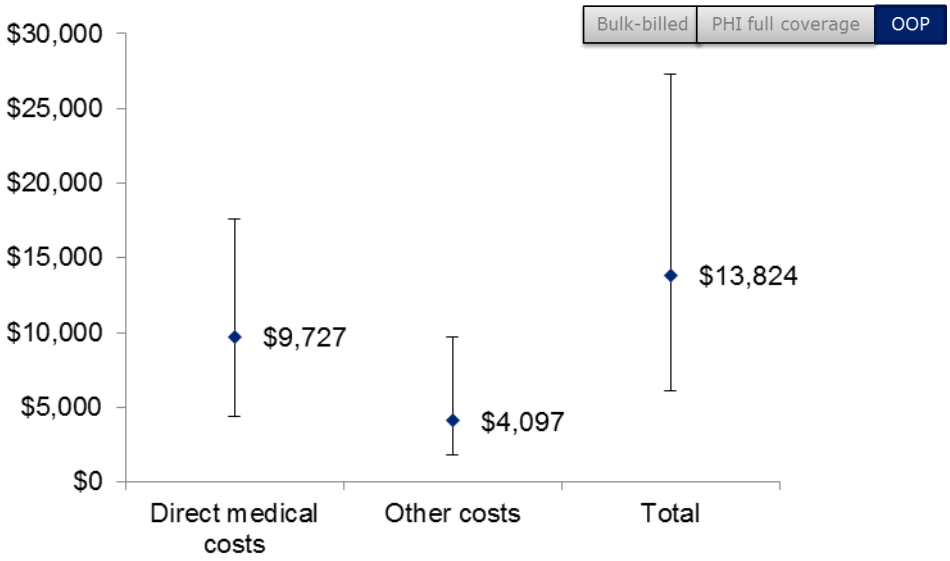
Chart 5.1: Median costs and interquartile range, 25th to 75th percentile, including bulk-billed and PHI covered items and services, (for all respondents in sample)



Number of respondents: 1,919. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 5.2 shows the overall data with all the direct medical and other items and services that were reported as having a $0 OOP cost removed from the sample. This removes the influence of bulk-billing or other funding arrangements, thus describing a hypothetical 'worst case scenario'. Under this scenario, the overall median OOP cost increases to $13,824 driven by a median direct medical cost of $9,727. The median for other OOP costs increases to $4,097. This is based on 9,789 direct medical services and items that had an OOP cost greater than $0 and 7,868 other items and services that had an OOP cost greater than $0.

Chart 5.2: Median costs and interquartile range, 25th to 75th percentile, excluding bulk-billed and PHI covered items and services, (for all respondents in sample)

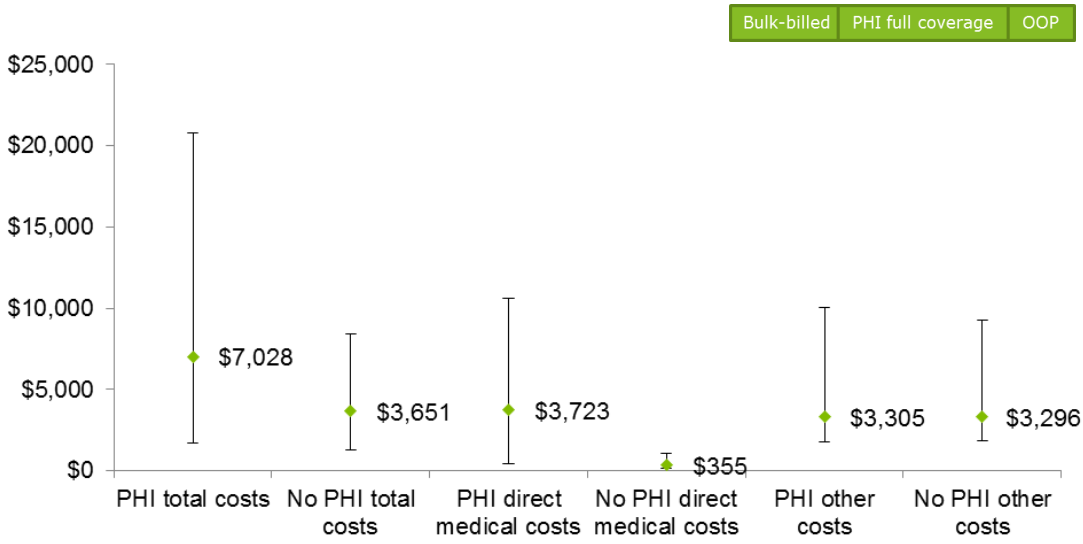


Number of respondents: 1,919 See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

5.1.2 Influence of PHI status

Nearly three-quarters (1,419 or 73.9%) of respondents to the survey reported they had PHI coverage at the time of their breast cancer diagnosis. Respondents with PHI reported higher overall median OOP costs than those without PHI, $7,028 versus $3,651. This is driven by the difference in direct medical OOP costs between the two groups. Those with PHI report a median direct OOP cost of $3,723 which is over 10 times higher than those without PHI who have a median direct OOP cost of $355. 'Other' OOP costs in both groups is similar, see Chart 5.3.

Chart 5.3: Median cost with interquartile range, 25th to 75th percentile, by PHI status, including bulk-billed and PHI covered items and services (for all respondents in sample)



Number of respondents: PHI – 1419, No PHI – 500 See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

The additional observations regarding the impact of PHI were made:

- Respondents with PHI paid more than $0 for 57% of their direct medical items or services used whereas respondents without PHI paid more than $0 for 25.7% of their direct medical items or services.
- When all medical items and services that had an OOP cost of $0 are removed, respondents with PHI paid a median of $10,440 for their direct medical OOP costs whereas respondents without PHI paid a median of $3,723 for their direct medical OOP costs. This indicates that when direct medical services incur an OOP cost, those with PHI may be paying more.

Later chapters describe the influence of PHI for survey respondents that fit into each sample. For all Profiles except Profile 5, individuals with PHI have higher OOP costs. As demonstrated above, this is driven by a difference the OOP costs reported for direct medical costs. Some of the possible explanations for this include:

- **Supply induced demand.** This means that respondents may have been recommended additional tests or treatments simply because they had access to PHI.
- **Insurance misalignment.** Respondents may have been directed toward, or recommended to use, the private system because they had PHI without any assessment of their levels of coverage. If this misalignment between coverage and costs exists, OOP costs will increase.
- **Higher prices in the private system.** Suppliers may charge higher prices to individuals in the private health system.
- **Individual preferences** mean that respondents have deliberately chosen to pay more to have treatment in the private system. Rationale for this may include having a shorter waiting list, or being able to choose a specific physician.

5.1.3 Influence of geographic factors

5.1.3.1 By jurisdiction

Overall, respondents living in New South Wales, Australian Capital Territory and Tasmania reported the highest median total OOP costs relative to the other states and territories, at $6,381, $8,582 and $9,928, see Chart 5.4.

Chart 5.4: Median cost with interquartile range, 25th to 75th percentile, by jurisdiction, including bulk-billed and PHI covered items and services (for all respondents in sample)

Number of respondents: NSW – 466, VIC – 521, QLD – 449, WA – 215, SA – 142, TAS – 60, ACT – 53, NT – 13. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category. The result reported by respondents from the NT is not included in the analysis as there is a higher rate of error given the low sample size (n=13).

The higher OOP costs in New South Wales, Australian Capital Territory and Tasmania relative to the other states and territories may be driven by their proportion of respondents with PHI. New South Wales, the Australian Capital Territory and Tasmania are in the top five jurisdictions by proportion of PHI coverage. The Northern Territory which represents the highest proportion of respondents with PHI coverage has a low sample size of 13 and therefore may have a higher rate of error so can not be relied upon in this analysis. Western Australia also has a higher rate of PHI than Tasmania, indicating that PHI is not be the sole driver of higher total OOP costs by jurisdiction, see Table 5.1.

Table 5.1: Proportion of all respondents with PHI by jurisdiction

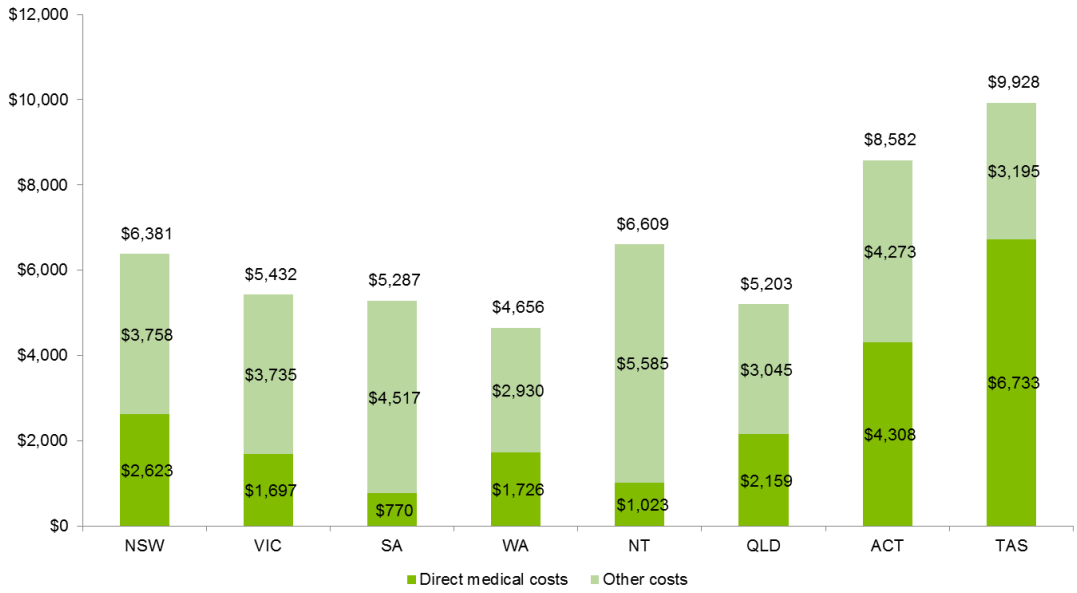
Jurisdiction	Proportion of respondents with PHI
Northern Territory	92%
Australian Capital Territory	81%
New South Wales	81%
Western Australia	77%
Tasmania	75%

Jurisdiction	Proportion of respondents with PHI
South Australia	73%
Victoria	70%
Queensland	70%

Number of respondents: 1,919

The overall median OOP costs reported by Tasmania, the Australian Capital Territory and New South Wales appear to be driven by the highest median direct medical OOP costs, see Chart 5.5.

Chart 5.5: Median OOP direct medical and other costs by jurisdiction, including bulk-billed and PHI covered items and services (for all respondents in sample)



Number of respondents: NSW – 466, VIC – 521, QLD – 449, WA – 215, SA – 142, TAS – 60, ACT – 53, NT - 13

It was suggested by stakeholders that women with breast cancer living in the Australian Capital Territory and Tasmania may travel further for treatment which may also drive up their OOP costs. Although women in the Australian Capital Territory and Tasmania reported the second and third highest median OOP costs for travel and accommodation, women in South Australia reported the highest median OOP cost for travel and accommodation.

Table 5.2: Unweighted median OOP costs for travel and accommodation by jurisdiction, including all bulk-billed and PHI covered travel and accommodation responses

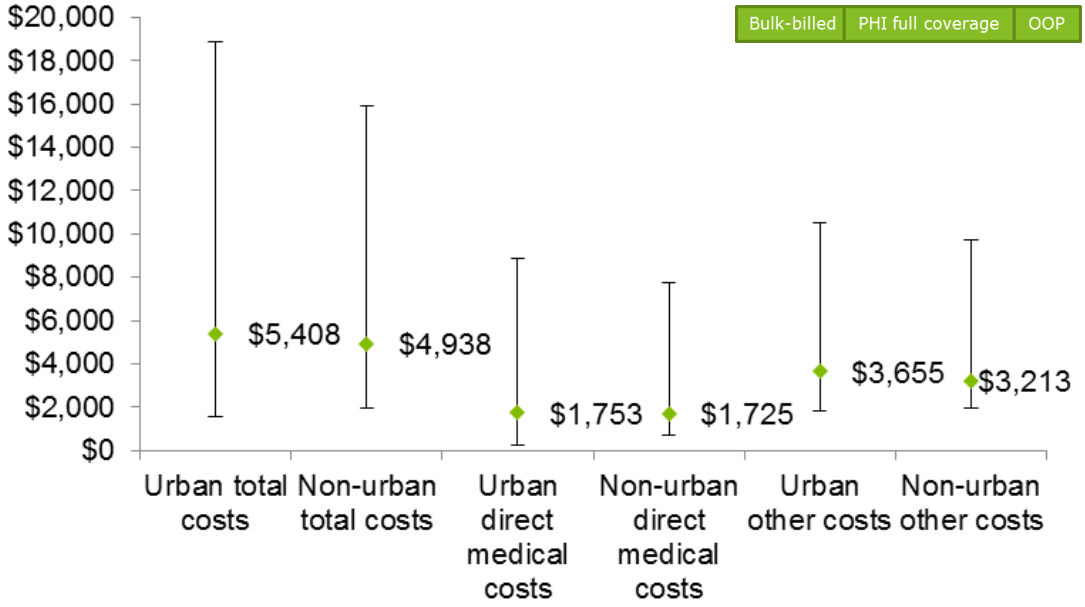
Jurisdiction	Median OOP cost	Number of respondents
South Australia	$2,622	11
Australian Capital Territory	$2,606	4
Tasmania	$1,504	6

Victoria	$1,491	36
New South Wales	$1,317	27
Queensland	$1,208	36
Western Australia	$1,012	10
Northern Territory	$483	7

5.1.3.2 By urban or non-urban place of residence

Overall, the urban, non-urban divide during treatment is not driving a substantial difference in overall median costs reported, see Chart 5.6 The overall OOP costs reported were also similar for Profiles 1, 3 and 4 when stratified by urban and non-urban place of residence during treatment. Profile 2 reported slightly higher OOP costs for non-urban residents and Profile 5 higher OOP costs for urban residents (See Chapters 6 through 10 for more detail).

Chart 5.6: Median cost with interquartile range, 25th to 75th percentile, by urban and non-urban regions, including bulk-billed and PHI covered items and services (for all respondents in sample)*



Number of respondents: Urban – 1240, Non-urban – 576. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category. * Note that this sample includes all respondents, and is therefore lower than the numbers reported in each Profile which focused just on the median costs excluding people who were bulk billed.

The difference may be explained by two factors:

- As indicated in Section 2.2.3, a higher proportion of people with breast cancer living in major cities have PHI compared to other areas. This may contribute to driving up the costs of medical treatment.
- Respondents in non-urban locations are accessing less treatments, items, and services than their urban resident counterparts (rather than being charged less for the same services). This hypothesis is supported by Table 5.3 which shows that on a per person

basis, respondents in non-urban areas access less medical consultations, tests, and some treatments such as breast reconstruction than urban residents.

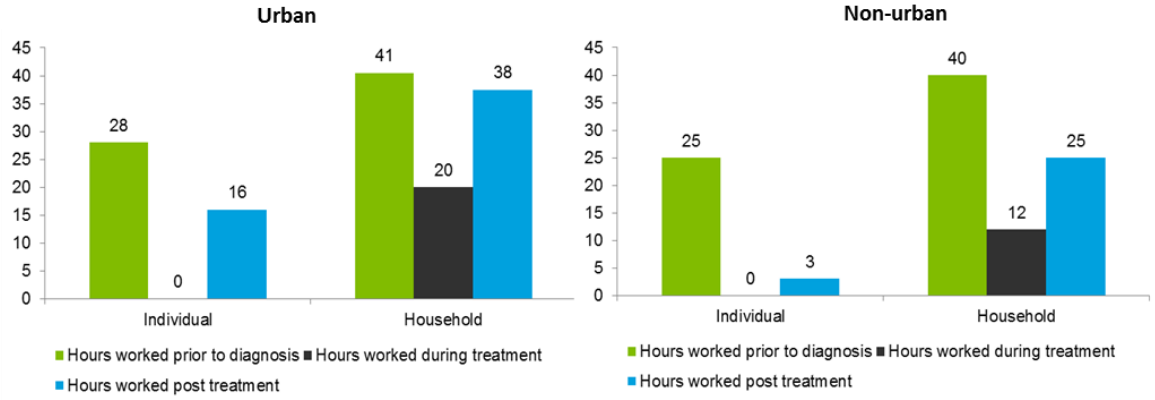
Table 5.3 : Differences in access for urban and non-urban residents

Cost categories	Proportion of services/items/treatments accessed per person in sample	
	Urban	Non-urban
Medical consultations	2.45	2.39
Tests	4.00	3.97
Treatments		
• Major surgical	0.81	0.81
• Breast reconstruction	0.21	0.14
• Extra surgical fee	1.03	0.82
• Radiotherapy	0.52	0.49
• Chemotherapy	0.50	0.47
• Hormone therapy	0.61	0.60
Medicine prescribed for symptomatic relief	0.57	0.59
Services for emotional wellbeing and mental health	0.75	1.29
Prescriptions for mental health	0.35	0.30
Allied and dental health	0.98	0.89
Items or aids	1.50	1.46
Additional p aid care or home help	0.13	0.14
Travel costs	0.79	0.70
Accommodation costs	0.03	0.14
Complementary and alternative therapies	0.54	0.51

Note: this demonstrates whether a particular service or item was accessed, not the number of times it was accessed per person.

Although there is not a large difference in the costs for urban and non-urban respondents, respondents in non-urban areas report a larger percentage decrease in household income and hours worked in the two years post diagnosis than urban respondents, see Chart 5.7 and Chart 5.8.

Chart 5.7: Median hours worked per week prior, during and post treatment



Number of respondents: Urban – 1240, Non-urban – 576.

Chart 5.8: Median weekly household income prior, during and post treatment

Number of respondents: Urban – 1240, Non-urban – 576.

Non-urban respondents experienced a 70% decrease in household hours worked in the first twelve months, and 38% decrease (from prior to diagnosis in the second twelve months post diagnosis. This contrasted with a 51% and 7% decrease for urban respondents. Non-urban respondents also experienced a 19% decrease in household income in the first and second years post diagnosis. This contrasted with only a 16% decrease for urban respondents.

This shows that although the costs are relatively similar for women living in urban and non-urban locations, the overall financial losses associated with a diagnosis of breast cancer is higher for women in non-urban areas.

Looking specifically at the travel and accommodation cost by urban and non-urban residents, urban residents report higher OOP costs for accommodation and non-urban residents report higher OOP costs for travel, see Chart 5.9. Although the urban median cost for accommodation is higher than for non-urban, only 3.4% of urban respondents reported accommodation costs. In comparison 14.6% of non-urban respondents reported accommodation costs.

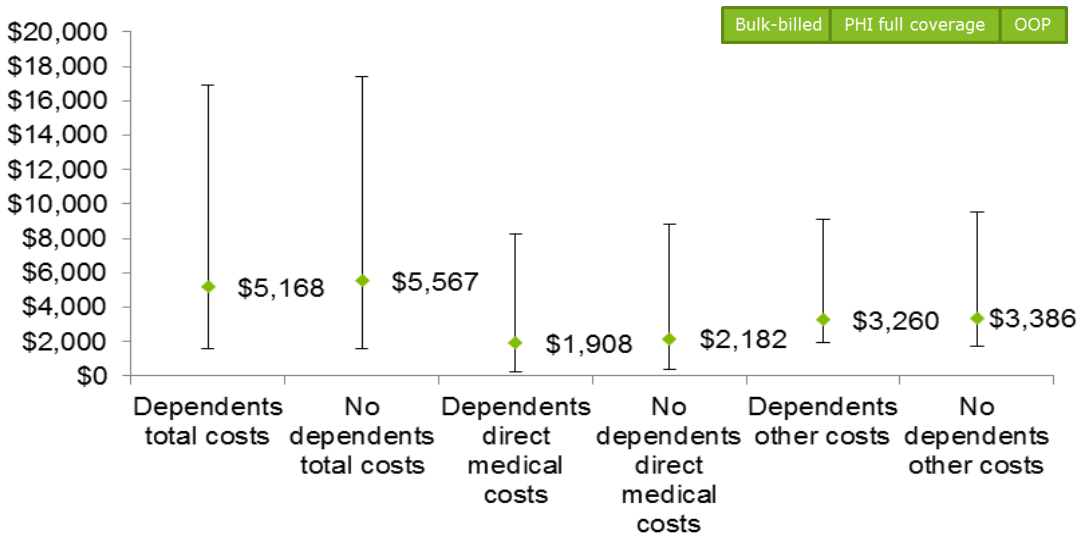
Chart 5.9: Median cost with interquartile range, 25th to 75th percentile, by urban and non-urban regions, for travel and accommodation costs, including bulk-billed and PHI covered items and services (for all respondents in sample)

Number of respondents: Urban travel – 993, Non-urban travel – 407, Urban accommodation – 42, Non-urban accommodation – 84.

5.1.4 Influence of dependent children

It was hypothesised that any difference between costs reported by dependent child status would be driven by childcare costs. However, out of all 1,919 respondents included in the analysis, only nine reported OOP costs for childcare. This could be due to family and friends assisting with childcare duties where required. Overall, dependent child status during treatment is not driving a substantial difference in overall median costs reported, see Chart 5.10.

Chart 5.10: Median cost with interquartile range, 25th to 75th percentile, by dependent child status, including all bulk-billed and PHI covered items and services (for all respondents in sample)



Number of respondents: Dependent children – 668, No dependent children – 1,246. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category. *Note that this sample includes all respondents, and is therefore lower than the numbers reported in each Profile which focused just on the median costs excluding people who were bulk billed.

Of the nine respondents that did report OOP costs for childcare:

- Seven were aged 40-49 years, one was 18-29 years and one was 30-39 years.
- Five fit into Profile 2, one in Profile 3 and two did not fit into a Profile.
- None reported a total OOP cost higher than the median for their Profile.

Given the age breakdown of the 668 women who reported having dependent children, it is possible that a majority of these dependent children were old enough to not require paid childcare. As shown in Chart 5.11 and Table 5.4 below, 46.6% of the women with dependent children were 50-59 years old. A majority of women (84.6%) were aged 40 to 59 years old.

Chart 5.11: Proportion of women with dependent children by age group (N=668)

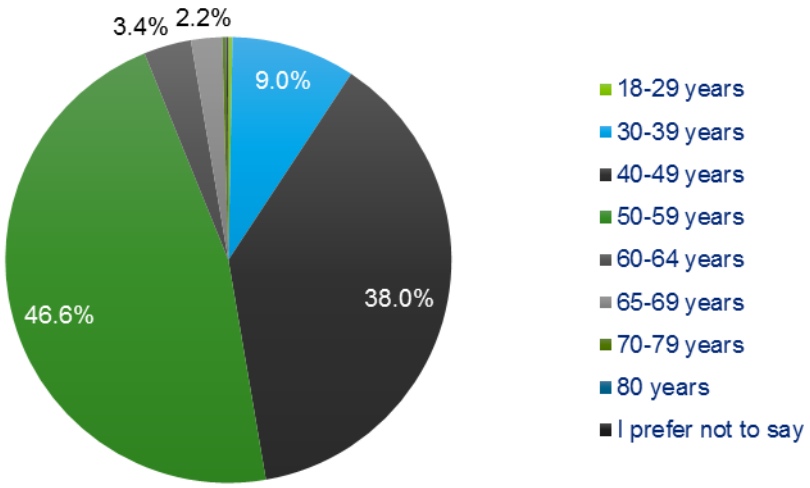


Table 5.4: Proportion of women with dependent children by age group (n=668)

Age group	Number of women	Proportion of total
18-29 years	2	0.3%
30-39 years	60	9.0%
40-49 years	254	38.0%
50-59 years	311	46.6%
60-64 years	23	3.4%
65-69 years	15	2.2%
70-79 years	2	0.3%
80 years	0	0.0%
I prefer not to say	1	0.1%
Total	668	100.0%

5.1.5 Costs per test reported

The report predominantly reports cumulative costs, meaning, the total amount spent by respondents on a particular item or service, rather than the amount paid per consultation, prescription or other treatment. As an exception to this, the average cost paid per test is provided in Table 5.6 below. This excludes tests where no OOP cost was paid.

Table 5.5: Average cost per test reported, excludes bulk-billed and PHI covered tests

	Average number tests	Median cost reported	Average cost per test	Number of respondents
Molecular tests	1.82	$3,750	$2,059	28
Genetic testing	1.15	$1,102	$961	39
MRI	1.72	$451	$263	216
Ultrasound	2.57	$315	$123	549
CT scan	2.50	$292	$117	178
Whole body bone scan	1.32	$232	$175	154
Mammogram	2.17	$196	$90	428
X-ray	2.47	$212	$86	100
PET scan	1.49	$551	$370	42
Fine needle aspiration	1.49	$166	$112	194
Breast biopsy	1.50	$196	$131	380
Standard blood test	5.77	$212	$37	98
Gated blood pool scan	3.11	$384	$124	25
Bone densitometry/ DEXA scan	1.63	$156	$96	258
ECG	2.87	$168	$59	51
Tumour marker	12.00	$712	$59	2

5.1.6 Total financial loss

At an individual respondent level, total financial loss was calculated by summing their reported household income loss during the 24 months post diagnosis (using income during the 12 months prior to diagnosis as the baseline) and their total reported OOP costs over the two years post diagnosis. The median total financial loss for respondents 24 months post diagnosis was found to be $9,389, with the middle 50 per cent of the sample (i.e. the 25th and 75th percentile) reporting an income loss between $1,959 and $37,174. This analysis was limited to 850 respondents who were within 1-2 years post diagnosis as the survey did not capture household income data beyond two years post diagnosis.

In 2005, using population level data, Access Economics (2007) estimated that the average lifetime financial cost faced by households for people (all ages and both sexes) with breast cancer was $28,500 with the average lifetime cost for females aged 15-64 years estimated at $10,300 ($11,242 in $2016)[18] and for females 65 years and over at $9,100 ($9,933 in $2016)[19] (Access Economics, 2007). The financial costs included in the Access Economics analysis of household financial cost were similar to the information collected in the Financial Impact of Breast Cancer Survey and included:

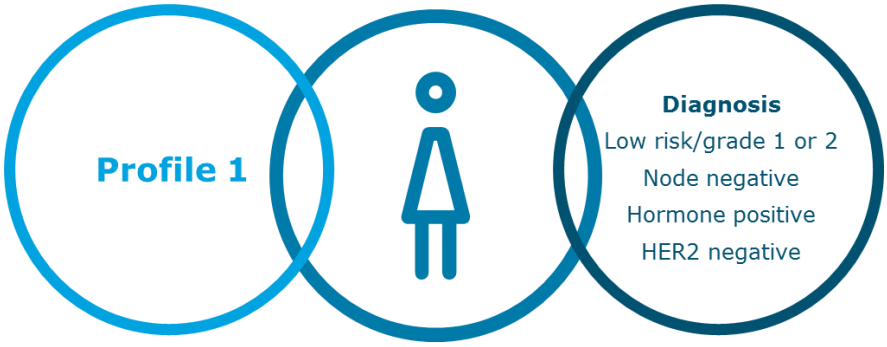
- a reduction in income (for example, productivity); and
- an increase in OOP expenses (for example, health costs and other financial costs).

[18] Using Consumer Price Index, Australia (ABS, 2016)
[19] Using Consumer Price Index, Australia. (ABS, 2016)

The costs estimated by Access Economics (2007) were lifetime costs which refer to the expected costs over the person's lifetime from diagnosis to death. The Financial Impact survey estimates total financial losses from diagnosis for the first two years only.

6 Profile 1

A total of 577 respondents to the survey had a diagnosis of breast cancer that fits to the characteristics of Profile 1. The following sections provide the overall direct medical costs and other OOP costs associated with the first five years of their most recent breast cancer diagnosis. Below, the diagnostic characteristics of respondents who were placed in Profile 1 are summarised.

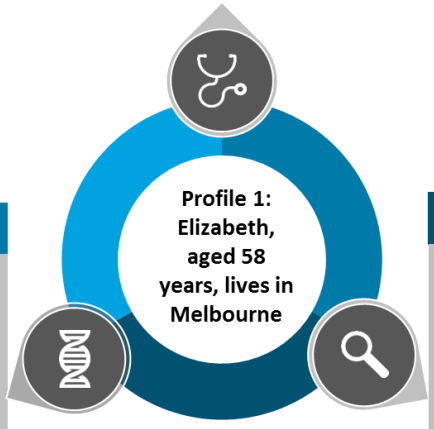


Step 2: Treatment

The breast surgeon performs breast conserving surgery and removes the tumour from Elizabeth's breast and does a sentinel node biopsy to ensure that the cancer has not spread to the guardian lymph nodes. Histopathology confirms no spread. Elizabeth sees the surgeon weekly for two weeks for follow-up. She also sees a medical oncologist and radiation oncologist for further treatment.

After her treatment planning with a radiotherapy service provider, she undertakes 15 radiation treatments (1 x per day , 5 days a week). She consults with the radiation oncologist once per week and at the end of her treatment.

Her medical oncologist conducts standard blood tests and a bone mineral density (DEXA) scan and prescribes her tamoxifen, an oral hormone therapy she will take daily for 5 to 10 years.



Step 1: Diagnosis

One year ago, Elizabeth's breast cancer is discovered during a routine BreastScreen mammogram and ultrasound. Histopathology tests show that the cancer cells are grade 1, hormone positive, HER negative . BreastScreen refers her to a breast surgeon for further tests and treatment planning.

The breast surgeon conducts a fine needle aspirate (FNA) that comes back negative. Sentinel node mapping is performed prior to surgery .

Step 3: Follow-up

Elizabeth has a follow-up mammogram within 12 months after her original mammogram. She visits her medical oncologist once per year and must see her GP at least twice a year for tamoxifen prescriptions.

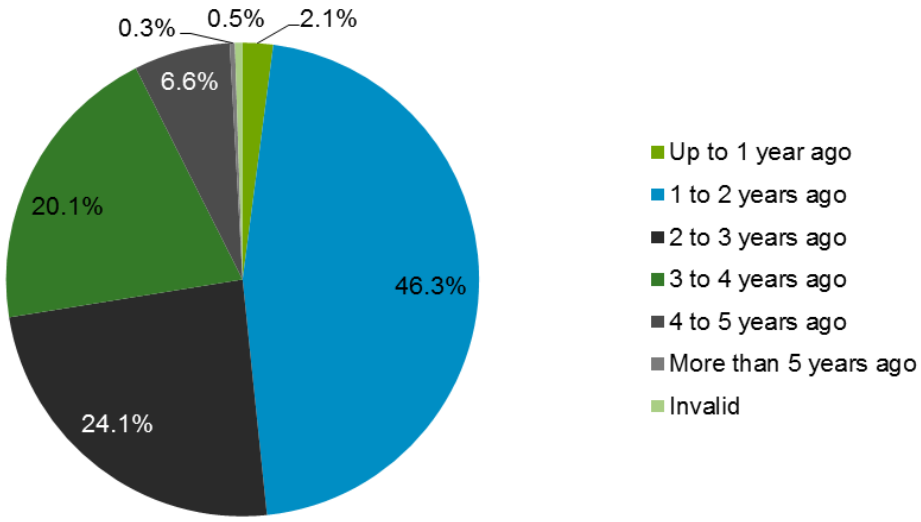
Elizabeth is now in full remission.

6.1 Respondent characteristics

6.1.1 Number of years following the most recent diagnosis

Close to half (46.3%) of respondents in Profile 1 had their most recent diagnosis of breast cancer 1 to 2 years ago. Accordingly, close to half of the reported OOP costs relate to the first 2 years of diagnosis, treatment and follow-up. 24.1% of respondents had their most recent diagnosis of breast cancer 2 to 3 years ago. For the proportion of respondents in Profile 1 and the number of years since their most recent breast cancer diagnosis, see Chart 6.1.

Chart 6.1: Proportion of Profile 1 by years since diagnosis, n=579



6.1.2 No OOP costs versus OOP costs

The proportion of respondents in Profile 1 who reported no OOP costs varied for each individual cost item. This is because each respondent may have received some items 'bulk-billed' under Medicare, whereas other items may have been received privately regardless of whether they had PHI. Table 6.1 presents the proportions of items in each cost category that were received with no OOP cost, and those for which there were OOP costs.

Table 6.1: The proportion and number of direct medical diagnosis and treatment items with no OOP cost and an OOP cost for respondents in Profile 1 (n = 577 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Medical consultations	787	55%	656	45%	1443
Tests	784	36%	1,423	64%	2207
Treatments					

• Major surgical	248	46%	288	54%	536
• Breast reconstruction	50	53%	44	47%	94
• Extra surgical fee	337	60%	227	40%	564
• Radiotherapy	92	30%	218	70%	310
• Chemotherapy	43	33%	89	67%	132
• Hormone therapy	421	97%	15	3%	436
Medicine prescribed for symptomatic relief	260	97%	9	3%	269
Fertility treatment	18	82%	4	18%	22
Total number of responses	3,040	50.6%	2,973	49.4%	6,013

Similarly for 'other cost' items, the proportion of respondents who reported an OOP varied by the cost category. Table 6.2 reports the proportion of items in each cost category that were purchased with no OOP cost and those for which there was an OOP cost.

Table 6.2: The proportion and number of other items and services with no OOP cost and an OOP cost for respondents in Profile 1 (n = 577 respondents)

Cost category	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Services for emotional wellbeing and mental health	170	51%	163	49%	333
Prescriptions for mental health	167	99%	2	1%	169
Allied and dental health	346	78%	96	22%	442
Items or aids	523	88%	72	12%	595
Additional paid care or home help	49	89%	6	11%	55
Travel	421	99%	3	1%	424
Accommodation	37	97%	1	3%	38
Complementary and alternative therapies	247	88%	33	12%	280
Total number of responses	1,960	83.9%	376	16.1%	2,336

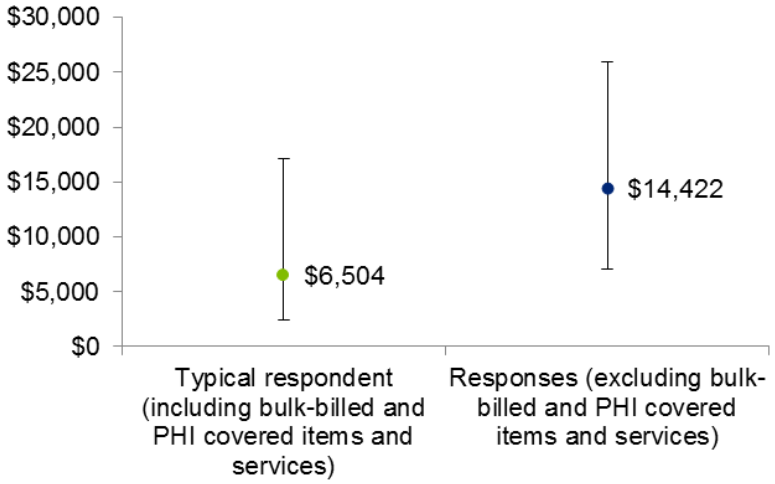
6.2 Direct medical and other OOP costs of breast cancer

6.2.1 Overall costs

The overall reported OOP costs for individuals in Profile 1 is $6,504 (Chart 6.2). To reflect the full range of costs that an individual in Profile 1 may expect to incur, these calculations include all respondents who received each treatment, service, care, or item regardless of whether they paid OOP or not. After removing bulk-billed and PHI covered items and services, the hypothetical worst case scenario, the overall OOP costs increases to $14,422 (Chart 6.2). See 4.3.1 for detail on the methodological difference between these two numbers.

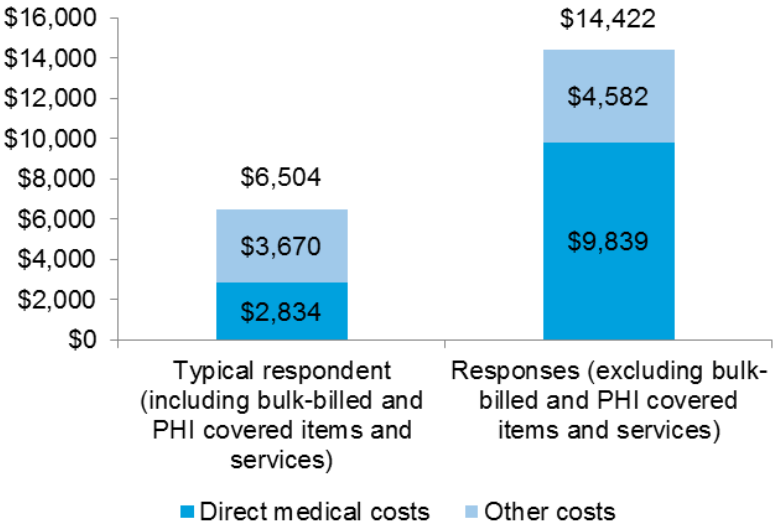
The reported OOP cost for all respondents in Profile 1 for direct medical costs is $2,834. For instances excluding bulk-billed and PHI covered items and services the reported cost is $9,839, see Chart 6.3. Finally, the other costs for all respondents in Profile 1 and for instances excluding bulk-billed and PHI covered items and services are $3,674 and $4,582 respectively.

Chart 6.2: Profile 1: Median total costs and interquartile range, 25th to 75th percentile



Number of respondents: 577. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 6.3: Profile 1: Median direct medical and other costs



Number of respondents: 577

Table 6.3 below provides full detail of the OOP costs for each item excluding bulk-billed and PHI covered items and services (instances where women were bulk-billed or had their total costs covered by PHI or other funding arrangements). The data is split by jurisdiction, region, dependent children and PHI status during treatment.

Table 6.3: Profile 1: Total costs for people reporting an OOP cost

Item	Overall median costs	Min	Max	N	% with OOP cost	Median cost by State/Territory								Median cost by region		Median cost by status of dependent children		Median cost by PHI status	
						NSW	VIC	SA	WA	NT	QLD	ACT	TAS	Urban	Non-urban	0	>0	PHI	No PHI
Direct medical costs																			
Medical consultations	**$549**	$6	$7,020	787	55%	$628	$561	$578	$498	$1,872	$504	$522	$591	$540	$545	$614	$539	$560	$461
Tests	**$286**	$6	$5,950	784	36%	$352	$313	$184	$188	$86	$303	$325	$340	$289	$296	$364	$250	$299	$256
Treatment	**$9,004**	$6	$18,250	1806	67%	$10,955	$9,158	$4,122	$4,154	$741	$8,496	$2,185	$6,637	$8,844	$9,152	$8,354	$8,728	$9,156	$7,757
Major surgery	$987	$6	$11,750	248	46%	$1,505	$1,047	$217	$595	$401	$809	$1,114	$86	$1,001	$852	$1,194	$771	$995	$382
Breast reconstruction	$3,250	$6	$18,250	50	53%	$3,489	$4,111	$451	$1,601	$0	$2,450	$0	$5,750	$3,082	$3,375	$3,341	$3,250	$3,292	$4,900
Extra surgical fees	$451	$6	$5,250	337	60%	$690	$444	$219	$394	$102	$440	$470	$275	$479	$459	$500	$432	$451	$1,494
Radiotherapy	$1,951	$6	$9,750	92	30%	$2,250	$1,701	$2,101	$851	$0	$2,250	$0	$116	$1,951	$1,951	$2,101	$1,851	$1,951	$451
Chemotherapy	$351	$26	$1,251	43	33%	$251	$451	$651	$251	$0	$451	$251	$0	$251	$451	$401	$351	$451	$209
Hormone therapy	$279	$6	$6,612*	421	97%	$295	$282	$416	$377	$66	$246	$296	$232	$295	$237	$287	$272	$280	$252
Fertility	$74	$6	$2,120	18	82%	$64	$60	$68	$85	$172	$118	$54	$178	$68	$94	$79	$69	$75	$70
Medication	**$1,661**	$86	$6,750	260	97%	$2,411	$1,062	$0	$0	$0	$1,732	$0	$0	$1,718	$1,732	$451	$1,732	$1,661	$0
Other costs																			
Health & wellbeing	**$1,092**	$13	$15,109	930	76%	$1,088	$1,323	$1,257	$1,226	$1,079	$973	$1,327	$1,549	$1,210	$1,116	$1,187	$1,131	$1,061	$1,397
Allied health service	$573	$13	$7,510	346	78%	$651	$494	$878	$377	$0	$543	$751	$520	$480	$619	$657	$546	$603	$538
Emotional wellbeing / mental health	$564	$13	$11,275	337	67%	$562	$728	$629	$518	$76	$665	$462	$1,067	$628	$605	$650	$571	$559	$724
Complementary or alternative therapy	$528	$13	$15,109	247	88%	$525	$595	$628	$708	$1,003	$308	$865	$482	$582	$511	$537	$560	$502	$673
Items or aids	**$331**	$13	$6,384	523	88%	$314	$285	$452	$240	$826	$379	$555	$479	$315	$315	$323	$325	$328	$333
Paid care and home help	**$648**	$26	$18,763	49	89%	$790	$450	$751	$1,359	$0	$606	$76	$415	$637	$755	$648	$696	$667	$651
Childcare	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Home help	$604	$26	$18,763	47	92%	$677	$450	$751	$1,359	$0	$606	$76	$415	$562	$755	$660	$604	$604	$679
Home nursing	$1,691	$380	$3,002	2	50%	$1,691	$0	$0	$0	$0	$0	$0	$0	$1,691	$0	$380	$3,002	$3,002	$380
Travel and accommodation	**$1,938**	$13	$11,265	457	99%	$2,833	$2,336	$2,420	$1,474	$376	$1,375	$5,387	$1,056	$1,902	$1,738	$1,481	$1,971	$1,940	$1,658
Travel	$437	$13	$2,106	415	99%	$579	$459	$682	$346	$376	$444	$618	$554	$396	$648	$428	$469	$436	$532
Accommodation	$1,501	$226	$25,910	37	100	$2,254	$1,878	$1,738	$1,128	$0	$931	$4,769	$502	$1,506	$1,090	$1,053	$1,502	$1,504	$1,127

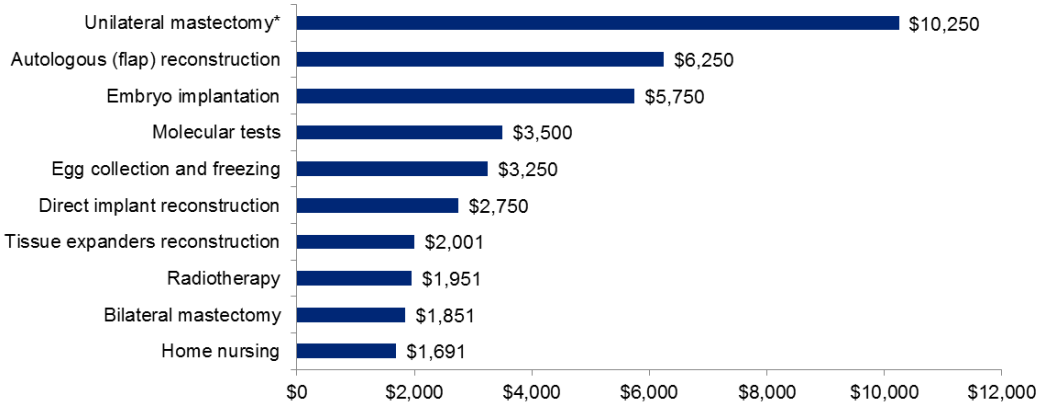
* This cost was reported by one person using Zoladex

6.2.2 Most expensive categories, items services and tests

Chart 6.4 shows the top ten items with the highest reported costs. The item with the highest OOP costs for Profile 1 was unilateral mastectomy. Other observations include:

- All three different types of breast reconstruction are in the top ten cost items;
- Nine out of ten of the most expensive items are direct medical costs;
- Two of the most expensive items relate to fertility treatment; and
- The only item from the 'other cost' category is home nursing.

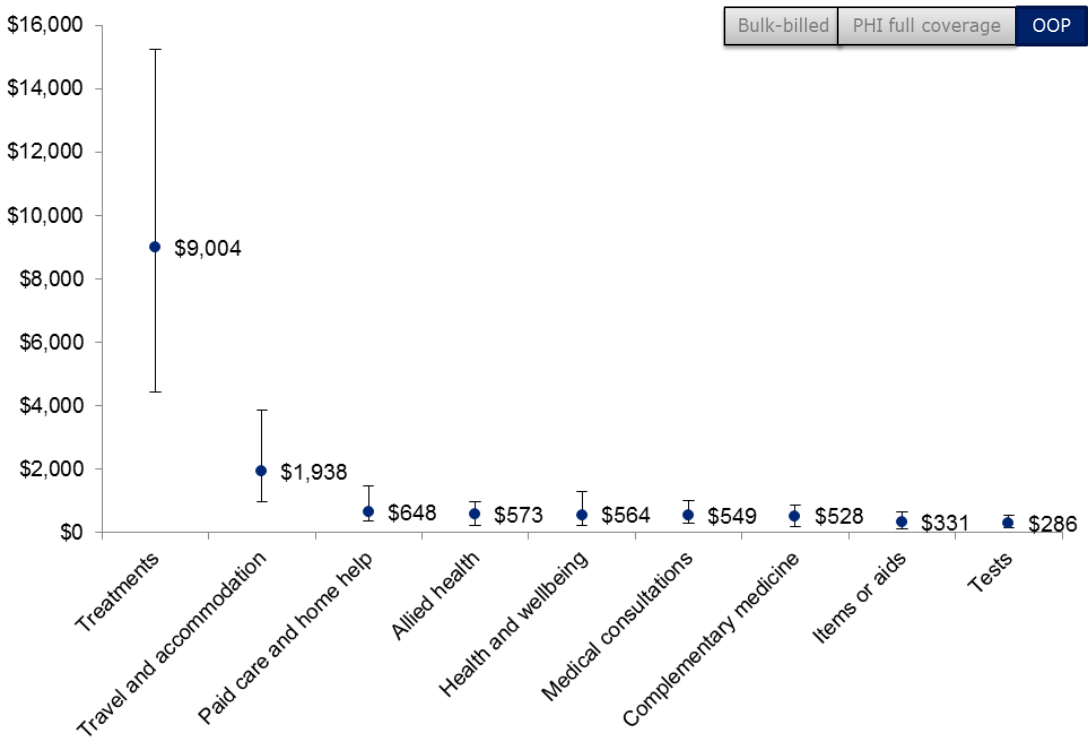
Chart 6.4: Profile 1: Top ten median cost items (includes both direct medical costs and other costs), excludes bulk-billed and PHI covered items and services



Note: Median costs are not weighted. *Only one respondent in Profile 1 reported costs for a unilateral mastectomy. Number of respondents: 577. Responses per item/service: Unilateral mastectomy - 1, Autologous (flap) reconstruction – 11, Embryo implantation - 1, Molecular tests – 8, Egg collection and freezing – 5, Direct implant reconstruction – 21, Tissue expanders reconstruction – 18, Radiotherapy – 92, Bilateral mastectomy – 20, Home nursing – 2.

When comparing the various cost categories including both direct medical costs and other costs, respondents in Profile 1 have incurred highest OOP costs for their treatment at a median cost of $9,004. This is than more than $7,000 higher than the median of the next highest cost category – Travel and accommodation (Chart 6.5, p.53). However, there is considerable variability in the reporting OOP costs for treatment, with an interquartile range of between approximately $4,000 and $15,000. This analysis excludes bulk-billed and PHI covered items and services.

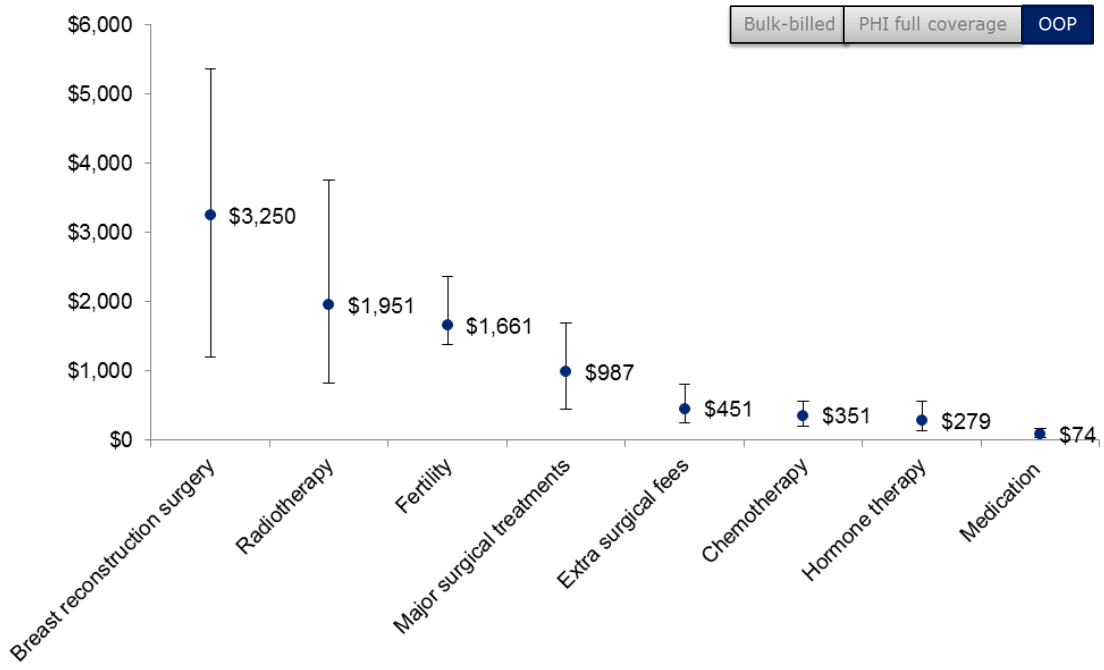
Chart 6.5: Profile 1: Median costs and interquartile range, 25th to 75th percentile, by cost type (direct medical and other costs) excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 577. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 6.6 shows the breakdown of reported costs between types of treatment. It shows that the high reported treatment costs are driven by breast reconstruction surgery (in line with the top ten high cost items), radiotherapy and fertility treatment.

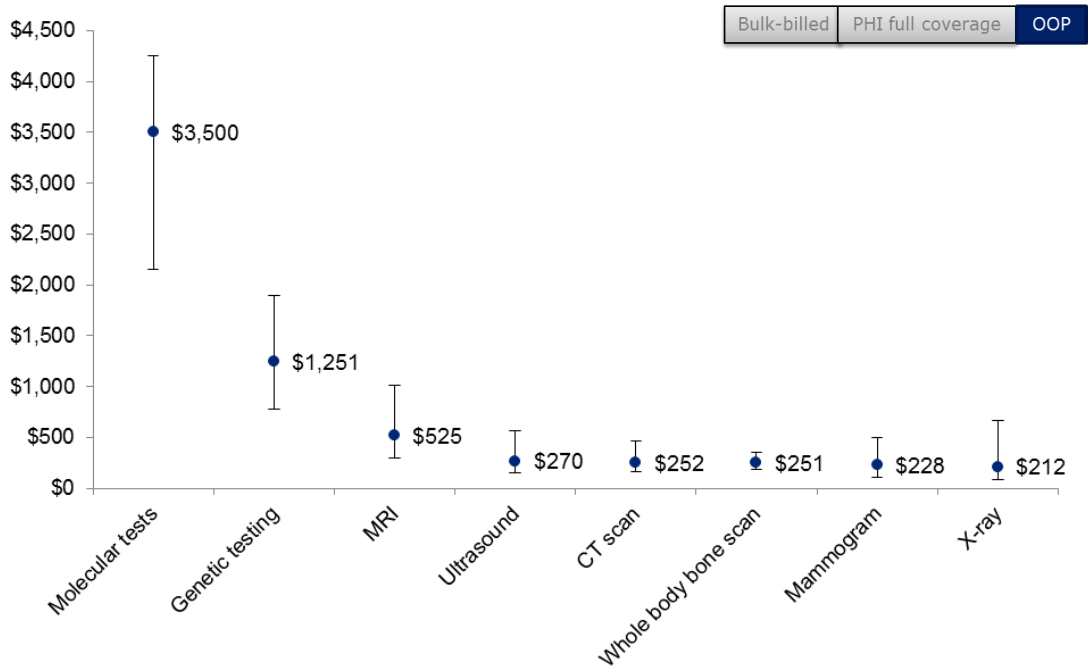
Chart 6.6: Profile 1: Median costs and interquartile range, 25th to 75th percentile, of direct medical treatments, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 577. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

A breakdown of the various types of tests for Profile 1 is included in Chart 6.7 below. This breakdown shows that for those who face a cost, the most was spent on molecular tests and genetic tests. These tests are not weighted; therefore the chart shows that 50% of people who paid for molecular test paid more than $3,500 for them. Likewise, more than 50% of those who paid for genetic testing paid more than $1,250.

Chart 6.7: Profile 1: Median costs and interquartile range, 25th to 75th percentile, excluding bulk-billed and PHI covered tests (top eight items)

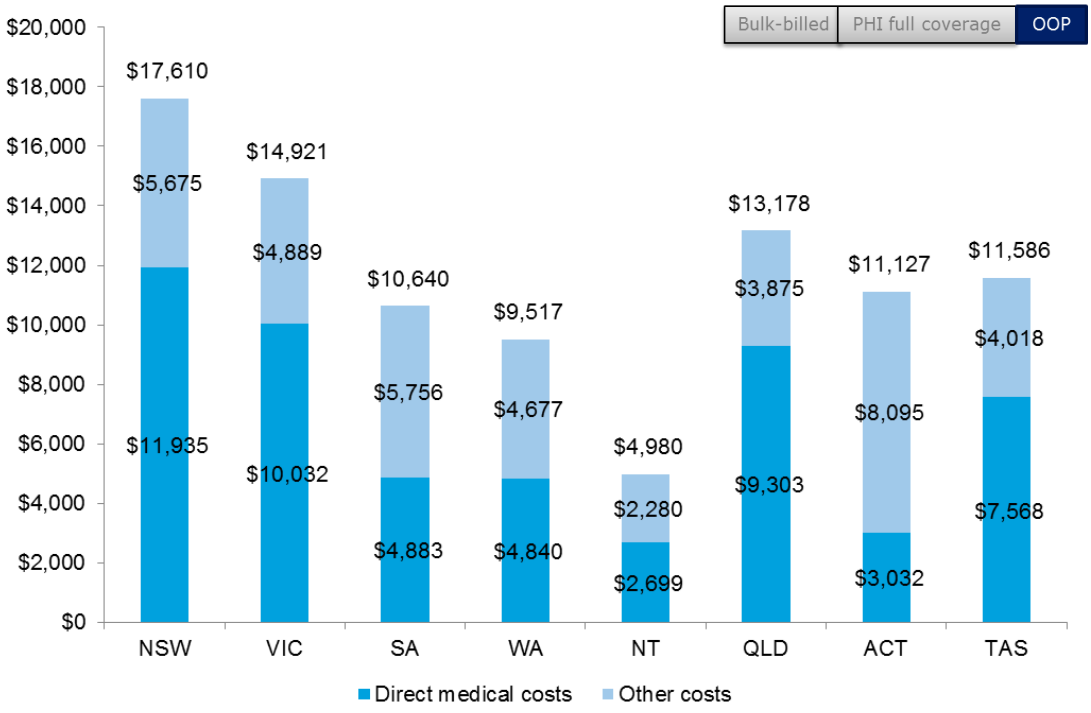


Note: Median costs are reported without weighting. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 577. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

6.2.3 Geographic considerations

When costs are presented by jurisdiction, direct medical costs are reported higher than other costs in all jurisdictions except for South Australia and Australian Capital Territory (Chart 6.8). The overall reported costs were lowest for Northern Territory. However, there were only three respondents in Profile 1 from the Northern Territory. Individuals in New South Wales, Victoria and Queensland report the highest overall costs.

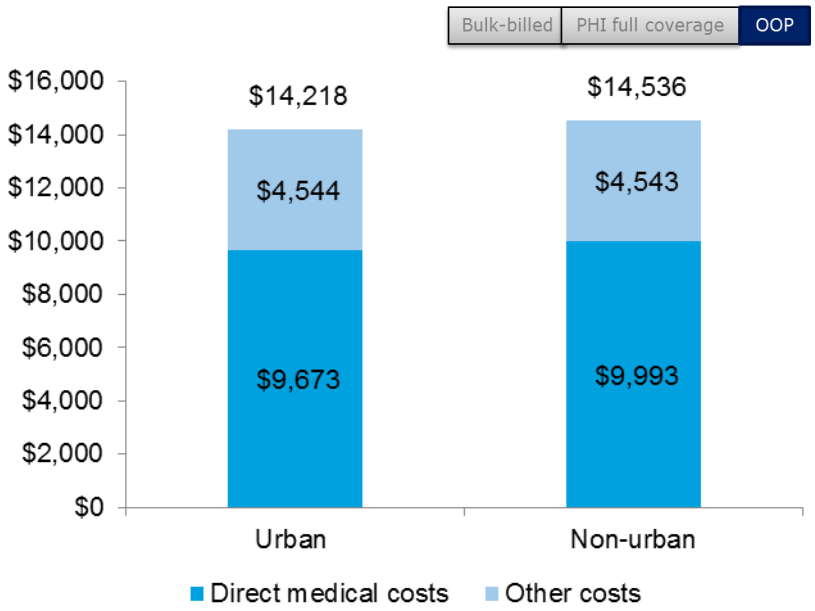
Chart 6.8: Profile 1: Median direct medical and other costs by jurisdiction, excluding bulk-billed and PHI covered items and services



Notes: Median costs have been weighted for number of services/items used. Number of respondents: NSW – 146, VIC – 163, SA – 30, WA – 57, NT – 3, QLD – 142, ACT – 23, TAS – 13.

The overall reported costs are similar for women affected by breast cancer who lived in urban and non-urban postcodes of main residence when receiving treatments. The direct medical costs are slightly lower for non-urban residents and the other costs are similar, see Chart 6.9. This finding is reflective of the overall findings in relation to urban and non-urban place of residence during treatment. A full discussion of this finding is included in Section 5.1.3.

Chart 6.9: Profile 1: Median direct medical costs and other costs by region, excluding bulk-billed and PHI covered items and services

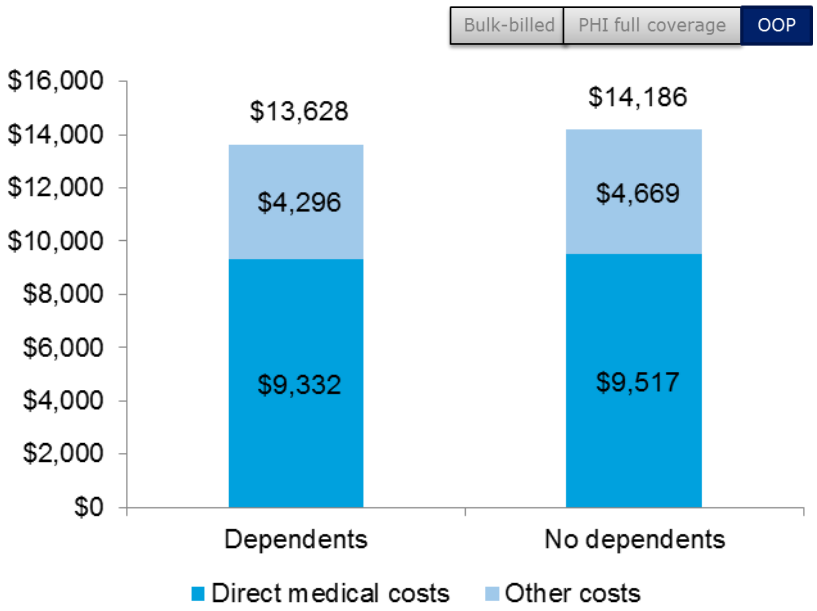


Notes: Median costs have been weighted for number of services/items used. Number of respondents: Urban – 390, Non-urban – 186.

Dependent children

The overall reported total cost among women diagnosed with breast cancer with dependent children is similar for those women without dependent children. This is likely because women in Profile 1 did not report any childcare costs in their responses (Table 6.3). Although women had dependent children at their time of treatment, they may not have incurred costs in this area if their children were old enough, or family and friends were able to assist. A full discussion of these differences for the overall sample is included in Section 5.1.4.

Chart 6.10: Profile 1: Median direct medical and other costs, by dependent child status, excluding bulk-billed and PHI covered items and services

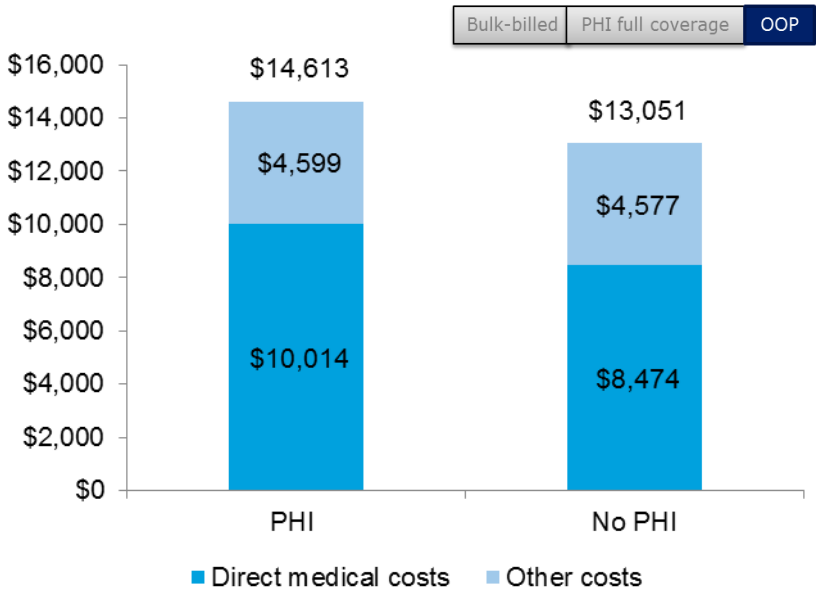


Notes: Median costs have been weighted for number of services/items used.
Number of respondents: Dependents = 193, No dependents = 384.

6.2.4 PHI

The overall reported total cost for those with PHI is approximately $1,600 more than those without PHI. The difference was made up of higher direct medical costs, see Chart 6.10. A full discussion of these differences for the overall sample is included in Section 5.1.2.

Chart 6.11: Profile 1: Median direct medical costs and other costs by PHI status, excluding bulk-billed and PHI covered items and services



Notes: Median costs have been weighted for number of services/items used. Number of respondents: PHI – 447, No-PHI – 130.

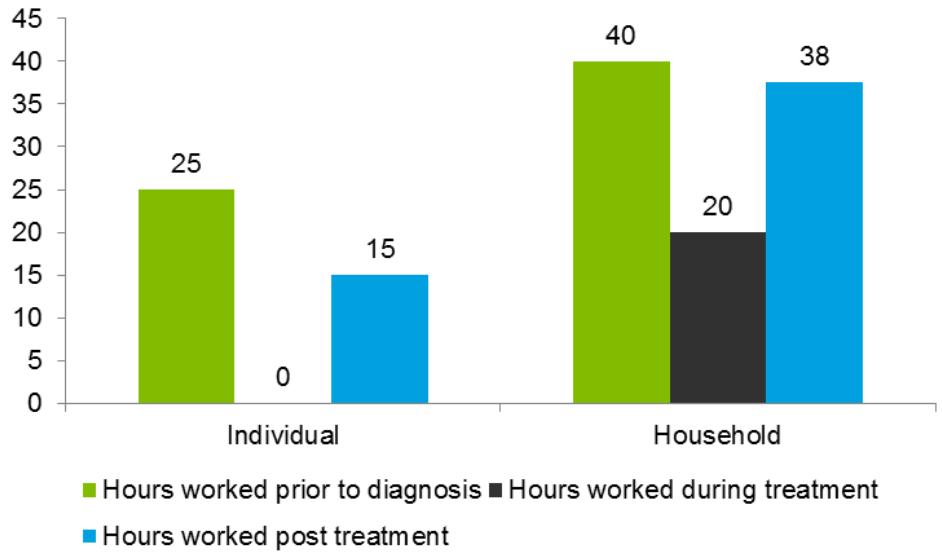
6.3 Indirect impacts: Income changes

In order to get an indication of the changes households' face on their income and wealth after a diagnosis of breast cancer, respondents were asked to estimate the average number of hours they worked per week in paid employment during the 12 months prior to their breast cancer diagnosis, during their treatment for breast cancer (treatment usually lasts 12 months) and during the 12 months after their completion of treatment. Likewise if they had a partner, they were asked to estimate the average number of hours their partner worked per week during the 12 months prior to their breast cancer diagnosis, during their treatment for breast cancer and during the 12 months after their completion of treatment, to get a complete picture of household hours worked.

The data shows that for those with a breast cancer diagnosis in Profile 1, most respondents did not work during the first 12 months post diagnosis (median value drops from 25 hours per week pre diagnosis to zero). The reported household hours also decreases from a median 40 hours per week prior to diagnosis to 20 hours per week.

During the 12 months post completion of treatment, individual reported hours increased to 15 hours per week. However, this is ten hours a week less than prior to diagnosis. For households overall, post treatment, the reported weekly hours increases up to 38 hours, two hours less than prior to a breast cancer diagnosis.

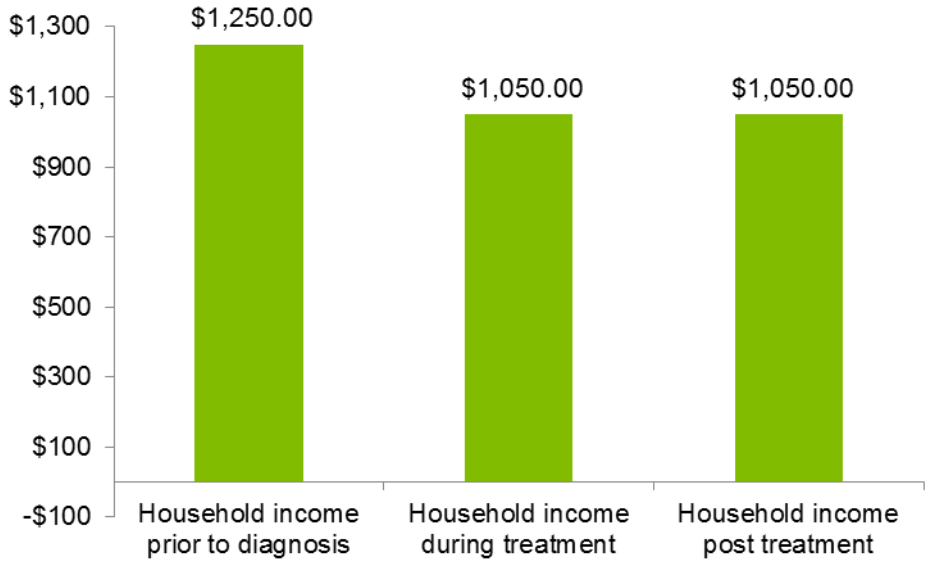
Chart 6.12: Profile 1: Median hours worked per week prior, during and post treatment (n= 577 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

As a result of the decrease in hours worked by individuals and households in total, there is a corresponding decrease in household income observed, see Chart 6.13. The chart shows a 16% decrease in the average household weekly income during treatment for breast cancer compared to the 12 months prior to diagnosis. There is no increase observed during the 12 months after treatment completion, and it remains at 16% lower than prior to diagnosis.

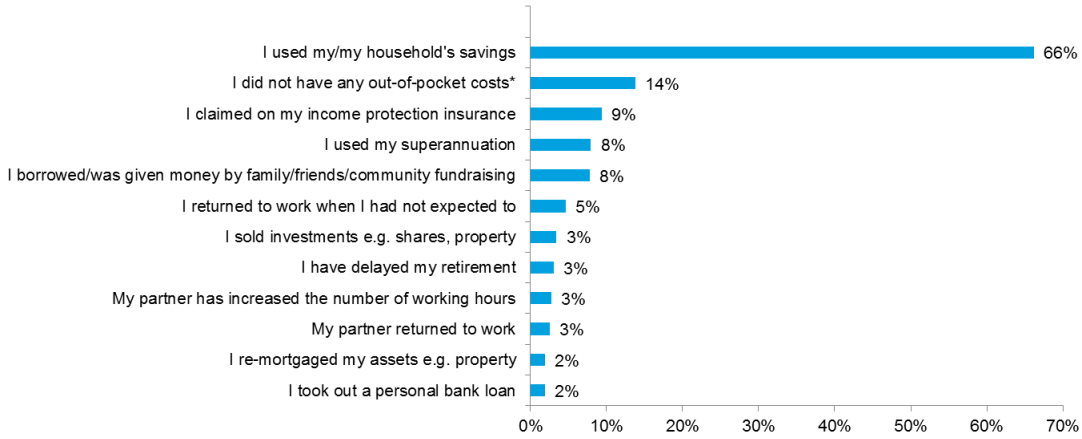
Chart 6.13: Profile 1: Median weekly household income prior, during and post treatment (n = 577 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

In addition to changes in workforce participation and income, respondents were asked to indicate how they met the costs associated with their breast cancer treatment. Of the 577 respondents in Profile 1, 66% reported that they used household savings, 9% claimed income protection, 8% used their superannuation and another 8% either borrowed or was given money from family and friends or through community fundraising (Chart 6.14). Of note, even though households reported decreased work hours and income, 3% of respondents reported that their partner increased their work hours in order to meet the costs associated with the breast cancer diagnosis.

Chart 6.14: Profile 1: How did you meet the costs associated with your breast cancer diagnosis and treatment?



Note: Respondents (n=577) were allowed to select more than one answer.

6.4 Profile summary

Overall out-of-pocket costs = $6,504

Cost of medical treatment = $2,834

- Consults
- Tests
- Surgery
- Radiotherapy
- Chemotherapy
- Prescriptions

Cost of other treatment = $3,670

- Emotional health and wellbeing (e.g. psychology)
- Items and aids (e.g. wigs, breast prosthetics, special garments)
- Additional allied and dental health
- Travel and accommodation to access treatment
- Complementary and alternative medicines

Household income losses = $ 10,400*

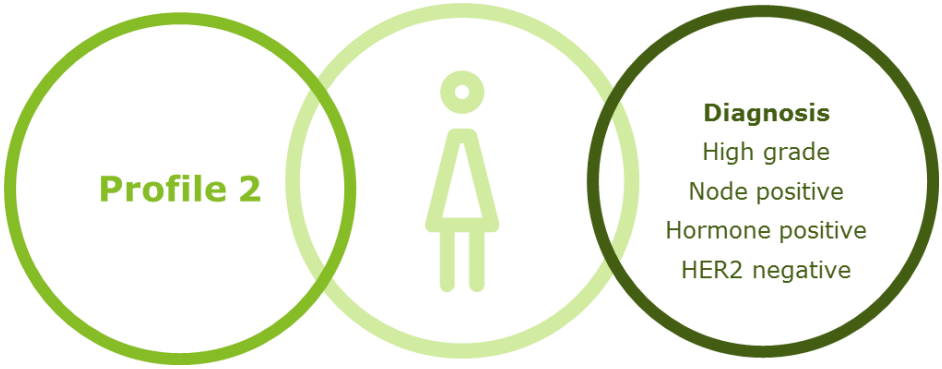
Highest medical cost items

- Molecular testing = $3,500
- Breast reconstruction = $3,250
- Radiotherapy = $ 1,951
- Fertility treatment = $1,661
- Genetic testing = $1,251
- Other major surgeries = $ 987

*$200 per week for 52 weeks

7 Profile 2

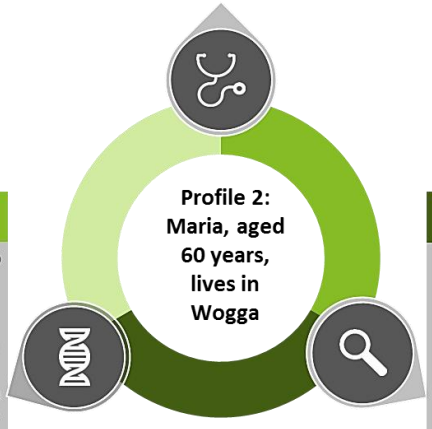
A total of 346 respondents to the survey had a diagnosis of breast cancer that matched Profile 2. The following sections provide the overall direct and other OOP costs associated with the first five years of their most recent breast cancer diagnosis (i.e. from diagnosis to five years post diagnosis). Below, the diagnostic characteristics of respondents who were placed in Profile 2 are summarised.



Step 2: Treatment

The breast surgeon does a unilateral mastectomy and removes her left breast and because the cancer has spread to Maria's nodes, she removes the lymph nodes in her left armpit. Maria has her breast reconstructed and a plastic surgeon performs the reconstruction during the same operation. Over the next couple of weeks she sees the breast surgeon and plastic surgeon so they can assess her wounds. She must take antibiotics for a short time after the surgery.

She sees a medical oncologist and is put on six cycles of chemotherapy over 18 weeks. She takes prescription medicines for nausea and at the end of her treatment she follows-up with her medical oncologist. Given her cancer is hormone positive and she is post-menopausal, her oncologist also prescribes her onto a hormone therapy called an aromatase inhibitor which she will purchase from her pharmacy. She will take it as a tablet for five to 10 years. Her oncologist also checks her bone mineral density with a DEXA scan.



Step 1: Diagnosis

Two years ago, Maria discovered a lump in her left breast. Her GP who confirms this and sends her for a mammogram and ultrasound. The GP orders a breast biopsy and histopathology tests confirm that the cancer cells are grade 4, hormone positive, HER2 negative. She is referred to a breast surgeon for further tests and treatment planning. The breast surgeon does a FNA that comes back positive. A CT scan of her abdomen, chest and pelvis and a whole body bone scan is done to check whether the cancer has spread.

Step 3: Follow-up

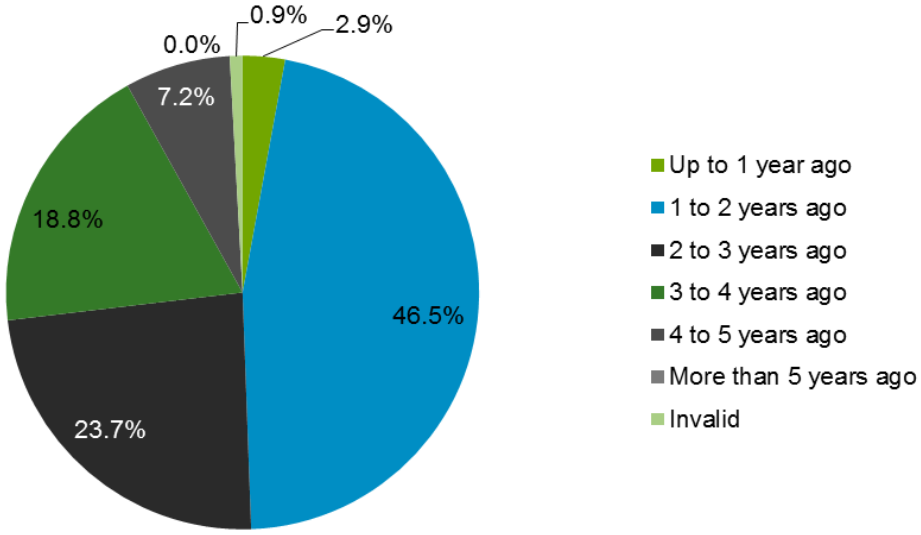
Maria has a follow-up mammogram 12 months after her original mammogram. She visits her medical oncologist twice per year and has regular follow-ups with her GP for aromasin prescriptions and health checks. Her cancer is now in remission.

7.1 Respondent characteristics

7.1.1 Number of years following the most recent diagnosis

Close to half (46.5%) of respondents in Profile 2 had their most recent diagnosis of breast cancer 1 to 2 years ago and 23.7% of the respondents in Profile 2 were diagnosed 2 to 3 years ago (Chart 7.1).

Chart 7.1: Proportion of Profile 2 by years since diagnosis, N=346



7.1.2 No OOP costs versus OOP costs

Table 7.1 reports the proportion of items overall in each cost category under direct medical costs that were received with no OOP cost and those for which there was an OOP cost. It shows that 53% of medical items, services and treatments in Profile 2 (n=2,244) had an OOP cost, while the remaining services were provided with full financial coverage.

Table 7.1: The proportion and number of direct medical diagnosis and treatment items with no OOP cost and an OOP cost for respondents in Profile 2 (n = 346 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Medical consultations	560	59%	392	41%	952
Tests	647	41%	921	59%	1568
Treatments					
• Major surgical	133	45%	163	55%	296
• Breast reconstruction	47	65%	25	35%	72

• Extra surgical fee	195	53%	176	47%	371
• Radiotherapy	64	30%	149	70%	213
• Chemotherapy	59	30%	135	70%	194
• Hormone therapy	296	96%	13	4%	309
Medicine prescribed for symptomatic relief	225	97%	7	3%	232
Fertility treatment	18	64%	10	36%	28
Total number of responses	2,244	53%	1,991	47%	4,235

Whether or not a respondent incurred an OOP cost or no OOP cost for an 'other cost' item varied. Table 7.2 reports the proportion of items in each cost category that were purchased with no OOP cost and those for which there was an OOP cost. It shows that close to 90% of items, treatment and services in the 'other costs' category incurred an OOP cost.

Table 7.2: The proportion and number of other items and services with no OOP cost and an OOP cost for respondents in Profile 2 (n = 346 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Services for emotional wellbeing and mental health	567	85%	97	15%	664
Prescriptions for mental health	136	98%	3	2%	139
Allied and dental health	355	79%	95	21%	450
Items or aids	651	88%	93	13%	744
Additional paid care or home help	52	85%	9	15%	61
Travel costs	303	99%	2	1%	305
Accommodation costs	30	100%	0	0%	30
Complementary and alternative therapy	204	88%	28	12%	232
Total number of responses	2,298	87.5%	327	12.5%	2,625

7.2 Direct medical and other OOP costs

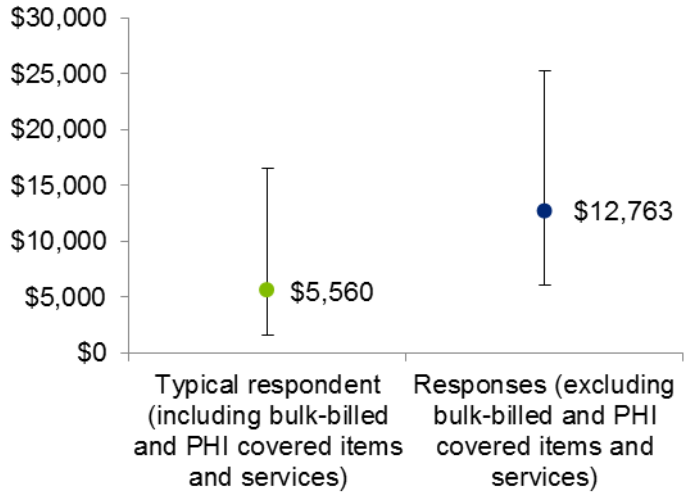
7.2.1 Overall costs

The overall reported OOP costs for individuals in Profile 2 is $5,560 (Chart 7.2). To reflect the full range of costs that an individual in Profile 2 may expect to incur, these calculations include all respondents who received each treatment, service, care, or item regardless of whether they paid OOP or not. After removing bulk-billed and PHI covered items and services, the hypothetical worst case scenario, the overall OOP costs increases to $12,763.

The reported OOP cost for all respondents in Profile 2 for direct medical costs is $2,029 (Chart 7.3). For instances excluding bulk-billed and PHI covered items and services, the reported

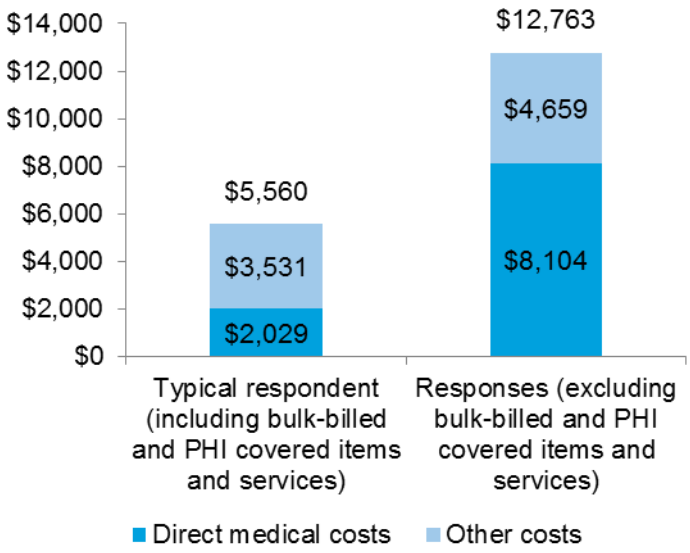
cost is $8,104. Finally, the other costs for all respondents in Profile 2 and for instances excluding bulk-billed and PHI covered items and services are $3,531 and $4,659 respectively.

Chart 7.2: Profile 2: Median total costs and interquartile range, 25th to 75th percentile



Number of respondents: 346. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 7.3: Profile 2: Median direct medical and other costs



Note: Median costs have been weighted for number of services/items used. Number of respondents: 346.

Table 7.3 below provides full detail of the OOP costs for each item excluding bulk-billed and PHI covered items and services (instances where women were bulk-billed or had their total costs covered by PHI or other funding arrangements). The data is split by jurisdiction, region, dependent children and PHI status during treatment.

Table 7.3: Profile 2: Total costs for people reporting an OOP cost

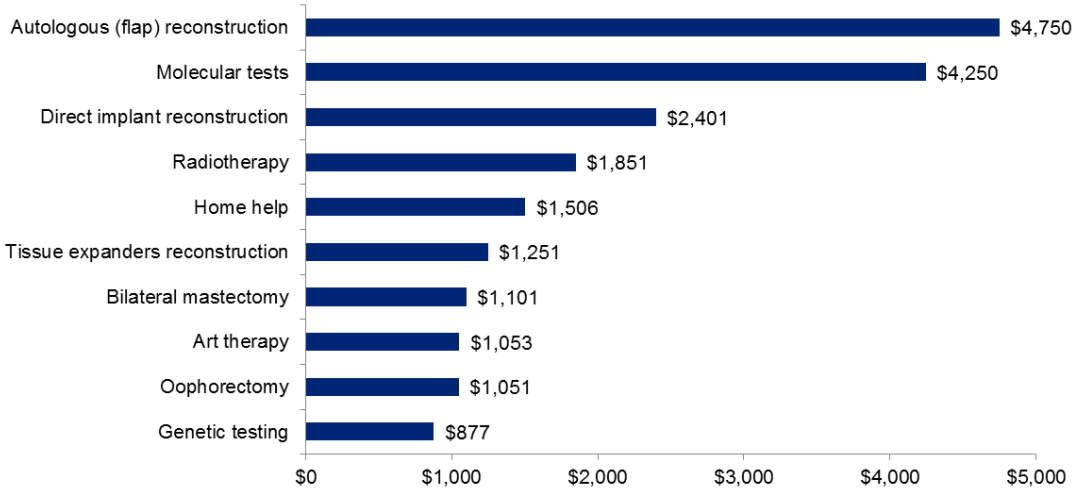
Item	Overall median costs	Min	Max	N	% with OOP cost	Median cost by State/Territory								Median cost by region		Median cost by status of dependent children		Median cost by PHI status	
						NSW	VIC	SA	WA	NT	QLD	ACT	TAS	Urban	Non-urban	0	>0	PHI	No PHI
Direct medical costs																			
Medical consultations	**$555**	$18	$5,931	560	59%	$569	$538	$490	$649	$0	$588	$522	$296	$555	$607	$637	$514	$590	$380
Tests	**$318**	$6	$5,000	647	41%	$415	$376	$254	$221	$0	$314	$214	$176	$305	$370	$336	$306	$317	$387
Treatment	**$7,232**	$6	$15,750	1232	65%	$13,941	$7,954	$4,446	$6,357	$1,002	$7,361	$2,912	$449	$7,578	$9,515	$7,355	$8,392	$8,172	$4,853
Major surgery	$752	$6	$11,750	133	45%	$1,082	$846	$434	$363	$751	$1,103	$46	$0	$758	$695	$816	$666	$782	$1,127
Breast reconstruction	$2,957	$156	$15,750	47	65%	$7,568	$3,027	$777	$3,583	$0	$2,969	$251	$0	$2,666	$5,083	$2,540	$4,225	$3,339	$1,401
Extra surgical fees	$473	$6	$6,250	195	53%	$615	$467	$359	$359	$251	$463	$1,851	$0	$471	$546	$498	$429	$471	$584
Radiotherapy	$1,851	$56	$7,750	64	30%	$2,750	$2,250	$1,251	$951	$0	$2,001	$0	$0	$2,500	$1,351	$2,250	$1,751	$2,250	$1,051
Chemotherapy	$451	$36	$2,250	59	30%	$251	$651	$801	$651	$0	$401	$156	$0	$451	$451	$651	$351	$551	$146
Hormone therapy	$309	$6	$3,906	296	96%	$388	$332	$198	$319	$0	$314	$564	$389	$309	$302	$278	$316	$297	$303
Fertility	$345	$96	$3,250	18	64%	$1,211	$275	$551	$0	$0	$0	$0	$0	$317	$1,008	$227	$566	$394	$146
Medication	**$94**	$6	$1,800	225	97%	$75	$106	$74	$130	$0	$110	$44	$60	$105	$78	$96	$87	$88	$95
																			Other costs
Health & wellbeing	**$1,163**	$13	$18,024	820	79%	$1,116	$1,343	$2,135	$1,224	$0	$1,061	$663	$1,049	$1,214	$1,081	$1,141	$1,038	$1,139	$1,625
Allied health service	$592	$13	$15,020	355	79%	$642	$410	$665	$730	$251	$309	$151	$826	$553	$645	$619	$605	$646	$243
Emotional wellbeing / mental health	$688	$13	$6,275	261	72%	$638	$842	$578	$701	$0	$595	$251	$992	$723	$753	$682	$596	$699	$1,024
Complementary or alternative therapy	$475	$13	$18,024	204	88%	$478	$501	$1,557	$524	$0	$466	$412	$58	$491	$328	$459	$442	$440	$601
Items or aids	**$367**	$13	$4,510	651	88%	$424	$353	$343	$232	$626	$388	$359	$334	$340	$394	$411	$319	$354	$390
Paid care and home help	**$1,369**	$76	$30,020	52	85%	$755	$1,156	$1,248	$1,029	$3,753	$1,999	$0	$456	$1,329	$1,510	$1,359	$1,450	$1,373	$1,549
Childcare	$755	$226	$3,138	5	100	$755	$1,946	$0	$226	$0	$2,252	$0	$0	$755	$0	$755	$0	$755	$0
Home help	$1,506	$76	$30,020	44	92%	$755	$1,057	$1,278	$1,510	$3,753	$1,963	$0	$456	$1,501	$1,510	$1,510	$1,501	$1,510	$1,501
Home nursing	$390	$378	$1,883	3	38%	$0	$0	$1,130	$390	$0	$0	$0	$0	$390	$0	$1,136	$378	$384	$1,883
Travel and accommodation	**$1,168**	**$13**	$18,775	340	97%	$1,662	$1,147	$4,067	$1,833	$0	$1,006	$520	$1,028	$1,122	$1,362	$1,183	$1,972	$1,161	$1,316
Travel	$415	$13	$2,252	303	99%	$365	$396	$1,118	$417	$0	$396	$520	$1,028	$371	$547	$432	$376	$409	$501
Accommodation	$753	$126	$6,342	30	100	$1,297	$751	$2,949	$1,416	$0	$609	$0	$0	$751	$815	$751	$1,596	$752	$815

7.2.2 Most expensive categories, items services and tests

Chart 7.4 shows the top ten items with the highest reported costs. For Profile 2 the most expensive item reported was a type of breast reconstruction surgery - autologous surgery or flap surgery. Other observations include:

- All three different types of breast reconstruction surgery are in the top ten cost items;
- Eight out of ten of the most expensive items are direct medical costs;
- Two of the most expensive items are tests, genetic testing and molecular tests; and
- The two items from the 'other cost' category are home help (such as hiring cleaners, or gardeners), and art therapy.

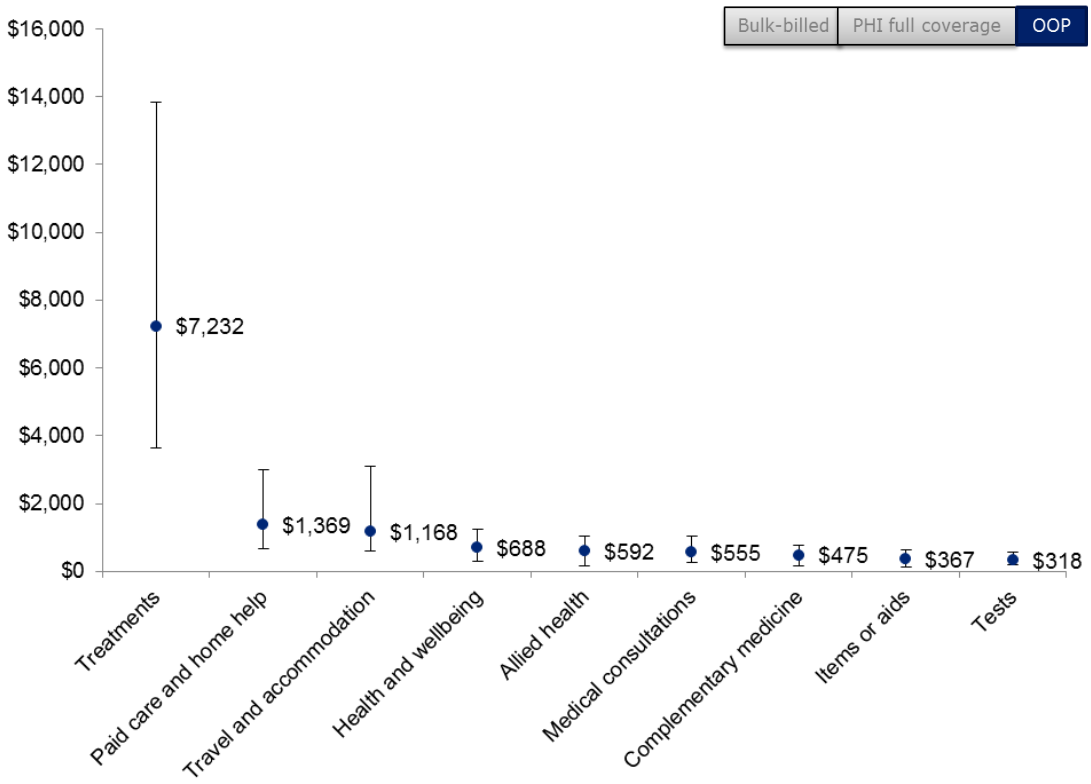
Chart 7.4: Profile 2: Top ten median cost items (includes both direct medical costs and other costs), excludes bulk-billed and PHI covered items and services



Note: Median costs are not weighted. Number of respondents: 346. Responses per item/service: Autologous (flap) reconstruction – 17, Molecular tests – 12, Radiotherapy – 64, Home help – 44, Tissue expanders reconstruction – 12, Bilateral mastectomy – 24, Art therapy – 3, Oophorectomy – 17, Genetic testing – 10.

When comparing the various cost categories including both direct medical costs and other costs for Profile 2, 'Treatments' is substantially higher, at approximately $6,000 more than other categories, see Chart 7.5. The bars on the chart indicate that 50% of the sample falls between the range of approximately $3,600 and $14,000 for treatment costs.

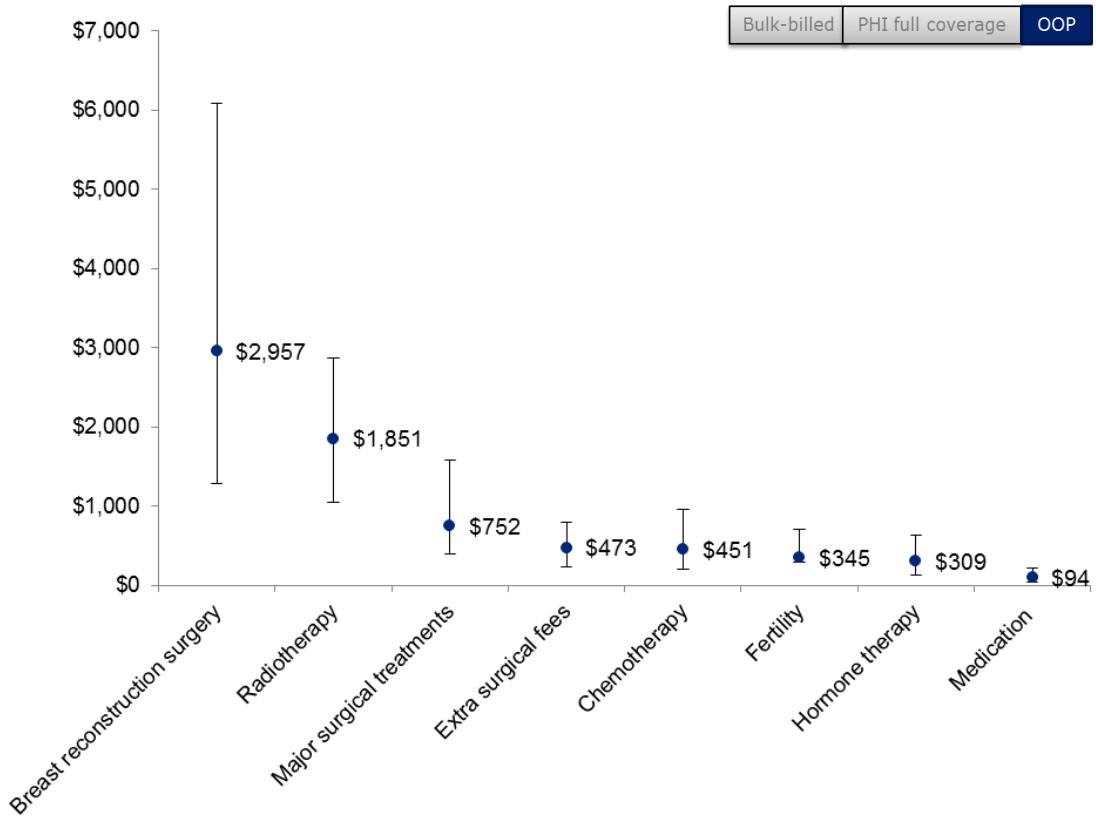
Chart 7.5: Profile 2: Median costs and interquartile range, 25th to 75th percentile, by cost type (direct medical and other costs) excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: 346. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

To further examine the treatments category, Chart 7.6 shows the breakdown of reported costs between types of treatment. It shows that the high reported costs are driven by breast reconstruction surgery (in line with the top ten high cost items), radiotherapy and major surgical treatments (excludes reconstruction).

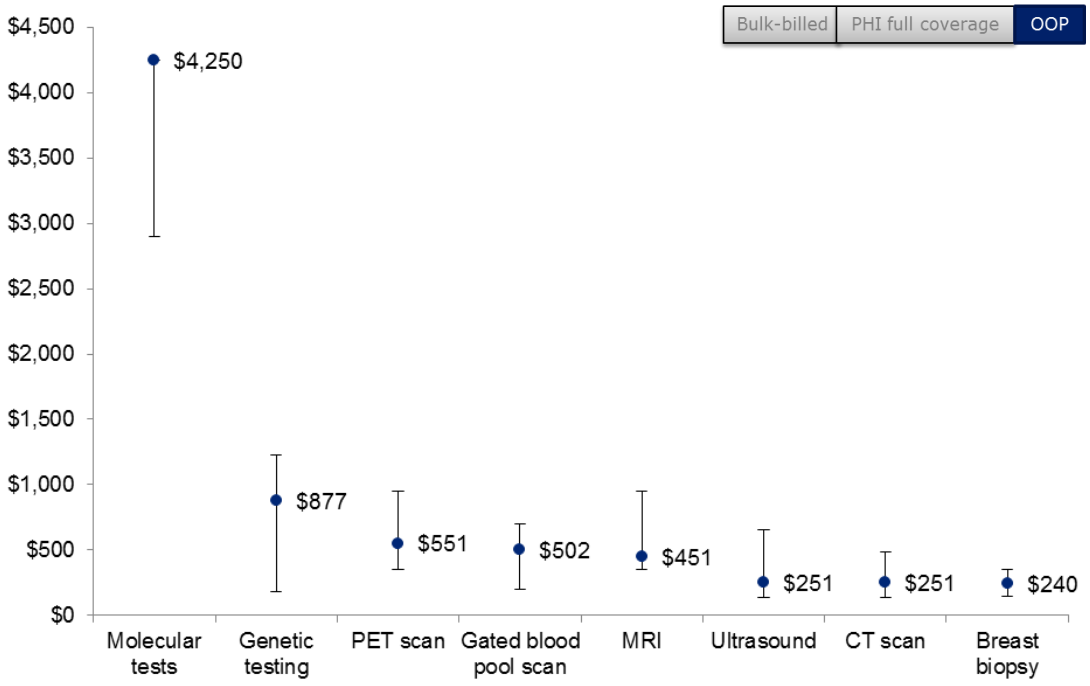
Chart 7.6: Profile 2: Median costs and interquartile range, 25th to 75th percentile, of direct medical treatments, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: 346. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

A breakdown of the various types of tests for Profile 2 is included in Chart 7.7. This breakdown shows that for those who face a cost, the most was spent on molecular tests and genetic tests. These tests are not weighted; therefore the chart shows that 50% of people who paid for molecular test paid at least $4,250 for them. The molecular tests do not have an upper bar indicating the third interquartile range as all these respondents reported the same OOP cost. The second, third and fourth most expensive costs reported are genetic testing, PET scans, and gated blood pool scans.

Chart 7.7: Profile 2: Median costs and interquartile range, 25th to 75th percentile, excluding bulk-billed and PHI covered tests (top eight items)

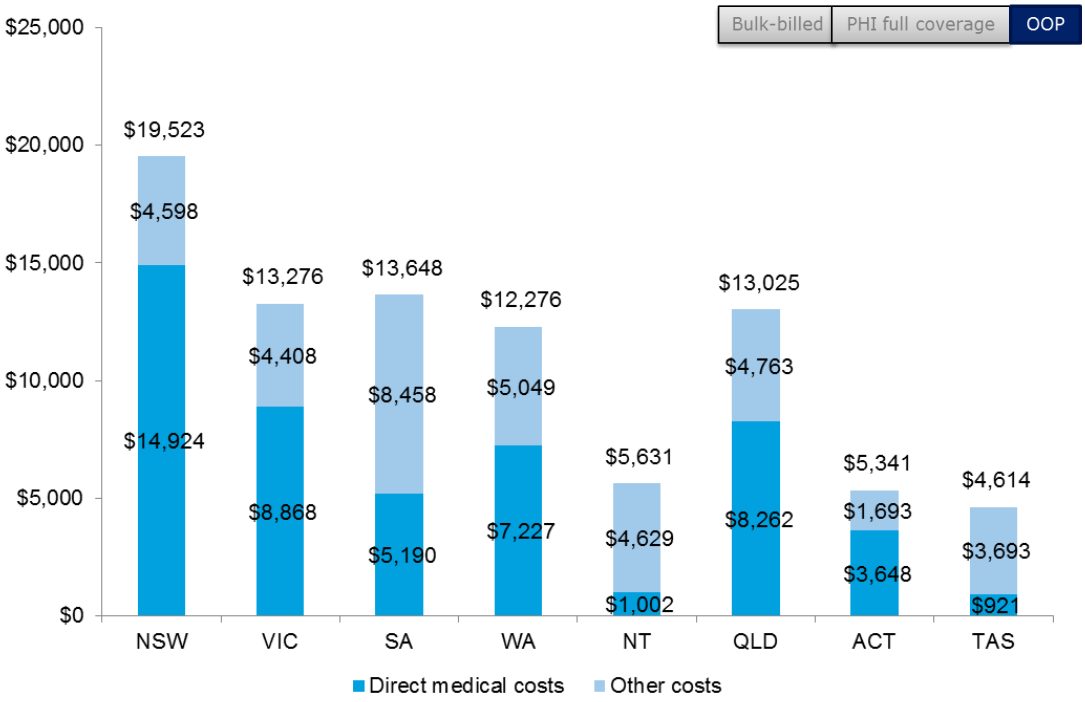


Note: Median costs are reported without weighting. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 346. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

7.2.3 Geographic considerations

When costs are presented by jurisdiction of residence while receiving treatment, direct medical costs are higher than other costs except for in South Australia. The Australian Capital Territory, Tasmania and Northern Territory have been excluded due to sample size being lower than 30 responses. Respondents from New South Wales report higher overall costs for Profile 2 by more than $6,000 (Chart 7.8). Despite reporting varying levels of direct medical costs, Victoria, South Australia, Western Australia and Queensland have all reported similar overall costs of between $12,200 and $13,200.

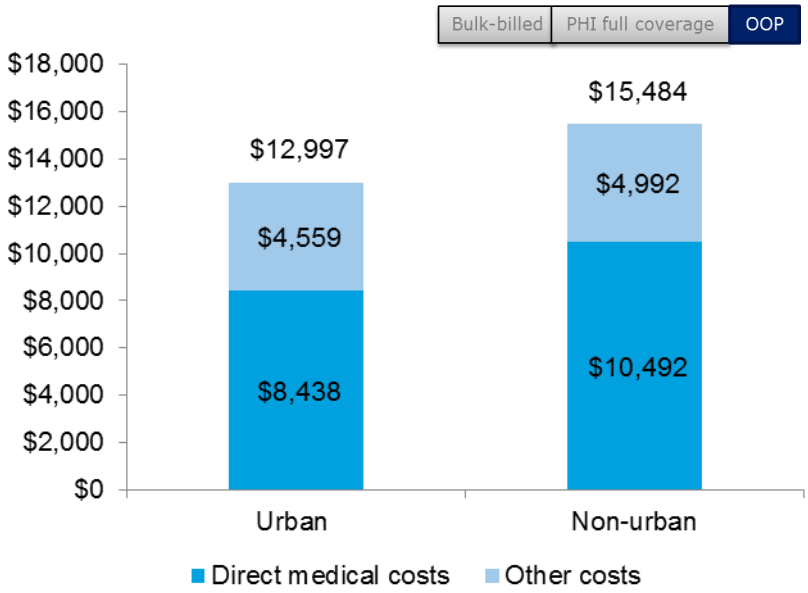
Chart 7.8: Profile 2: Median direct medical costs and other costs by jurisdiction, excluding bulk-billed and PHI covered items and services



Notes: Median costs have been weighted for number of services/items used. Number of respondents: NSW – 87, VIC – 100, SA – 34, WA – 41, NT – 1, QLD – 77, ACT – 2, TAS – 4.

When the overall OOP costs are presented by urban and non-urban postcodes of main residence while receiving treatment, the costs are higher for non-urban residents. The direct medical costs predominantly drive this difference with non-urban residents reporting costs approximately $2,000 higher than urban residents, (Chart 7.9).

Chart 7.9: Profile 2: Median direct medical costs and other costs by region

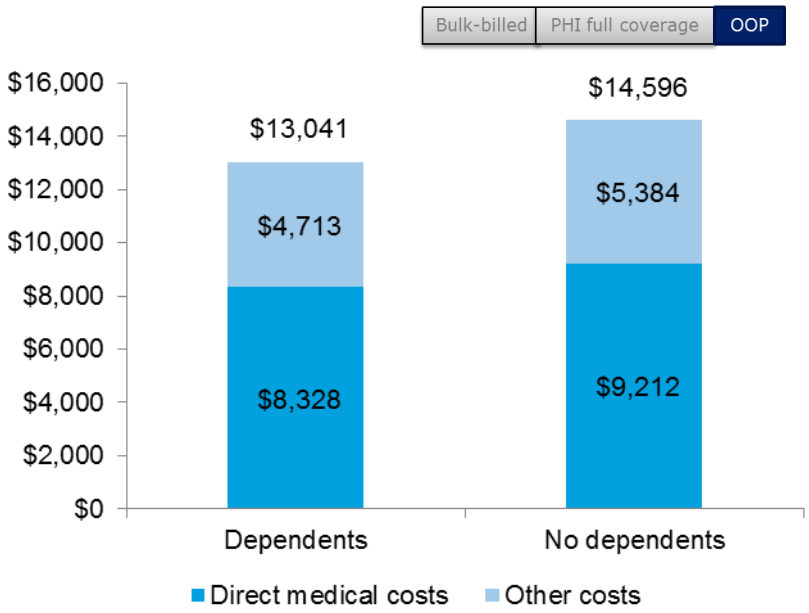


Note: Median costs have been weighted for number of services/items used. Number of respondents: Urban – 233, Non-urban – 113.

7.2.4 Dependent children

The reported total cost is approximately $1,500 higher for women without dependent children than women with dependent children. This is despite respondents with dependent children reporting costs for childcare. The extra costs are made up of approximately $880 of direct medical costs and $670 of other costs. This may be due to sampling variations or may reflect that women without dependent children had more disposable income for accessing non-core services ('other costs').

Chart 7.10: Profile 2: Median direct medical and other costs, by dependent child status, excluding bulk-billed and PHI covered items and services

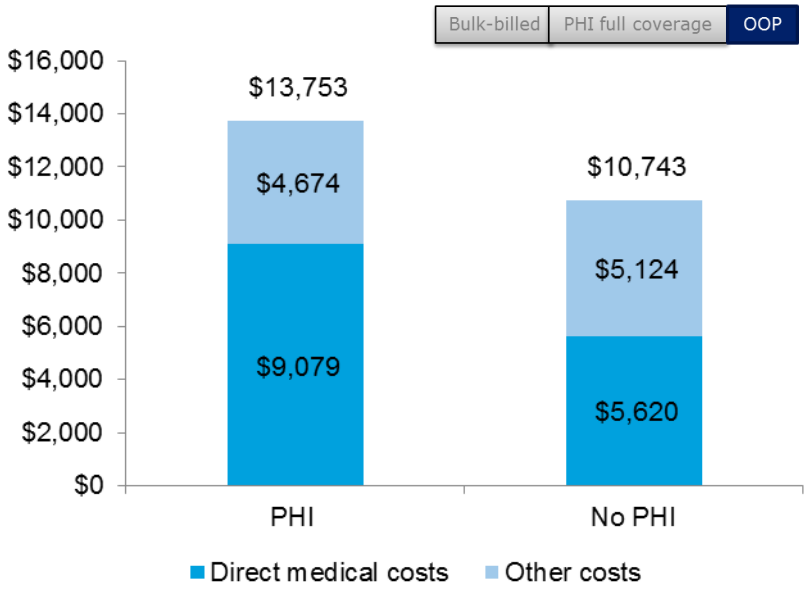


Note: Median costs have been weighted for number of services/items used. Number of respondents: Dependents – 138, No dependents – 208.

7.2.5 PHI

The reported total cost for women with PHI is approximately $3,000 higher than for those women without PHI. Women without PHI reported higher OOP costs for the other costs category (approximately $500), but approximately $3,500 less for direct medical costs, see Chart 7.11.

Chart 7.11: Profile 2: Median direct medical costs and other costs by PHI status, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: PHI – 265, No PHI - 81

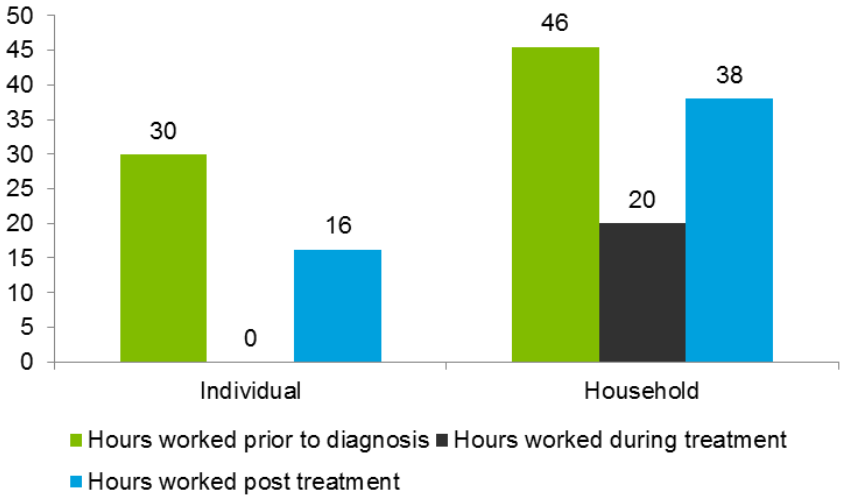
7.3 Indirect impacts: Income changes

Most respondents with a breast cancer diagnosis in Profile 2 did not work in paid employment during the first twelve months following their breast cancer diagnosis: the median value drops from 30 hours per week before diagnosis to zero hours during treatment (Chart 7.12). The reported household hours worked in paid employment also decreases from a median of 46 hours per week prior to diagnosis to 20 hours per week (Chart 7.12).

From 12 months to 24 months, the workforce participation increases to 16 hours per week. However, this is still 14 hours a week less than prior to diagnosis, which corresponds to a 46% decrease. For households the reported weekly workforce participation increases up to 38 hours after treatment, but it is eight hours less than prior to diagnosis – a 16% decrease.

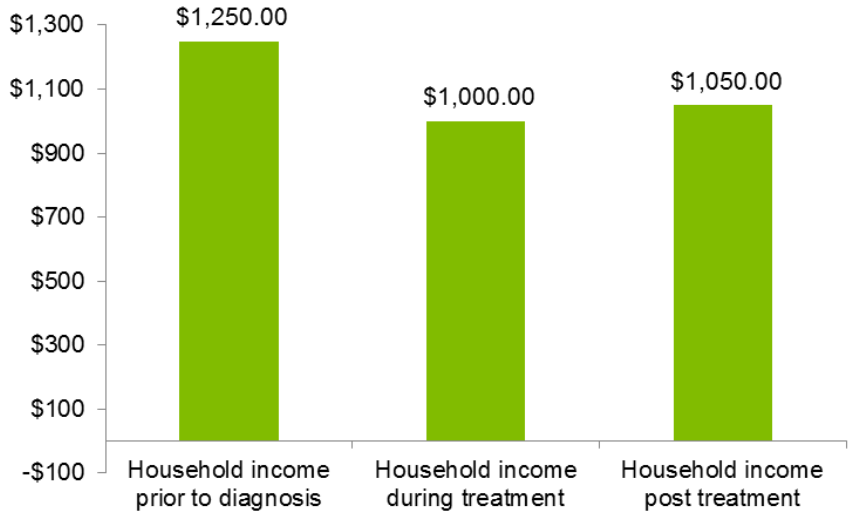
As a result of the decrease in hours worked by individuals and households in total, there is a corresponding decrease in household income observed (Chart 7.13). The chart shows a 20% decrease in the average household weekly income during treatment for breast cancer compared to the 12 months prior to diagnosis. There is an increase of $50 per week observed during the 12 months after treatment completion, and is therefore 16% lower than prior to diagnosis. It is possible that there is not a decrease in income commensurate to the decrease in household workforce participation during treatment due to respondents being able to access paid leave (whether this be sick or annual leave), or and/or income protection insurance.

Chart 7.12: Profile 2: Median hours worked per week prior, during and post treatment (n = 346 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

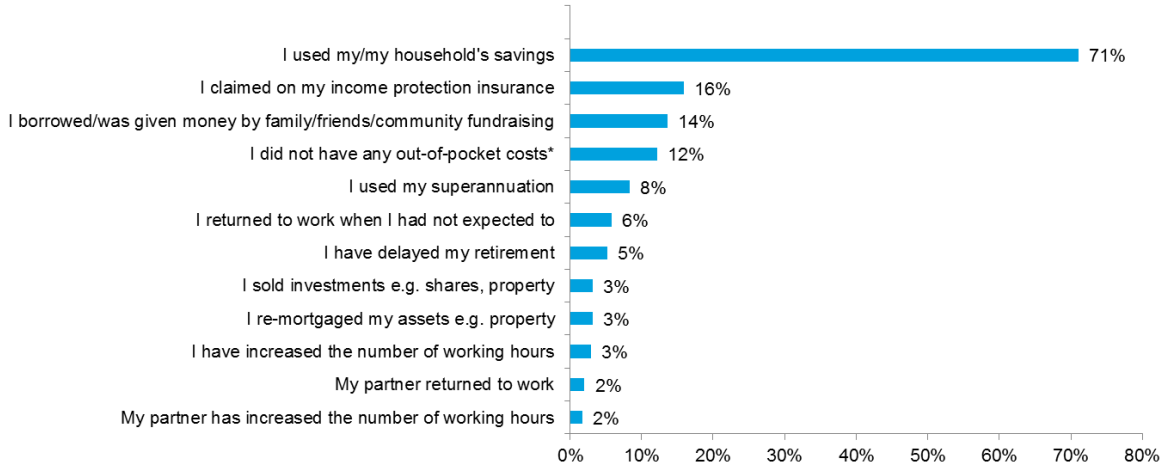
Chart 7.13: Profile 2: Median weekly household income prior, during and post treatment (n= 346 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

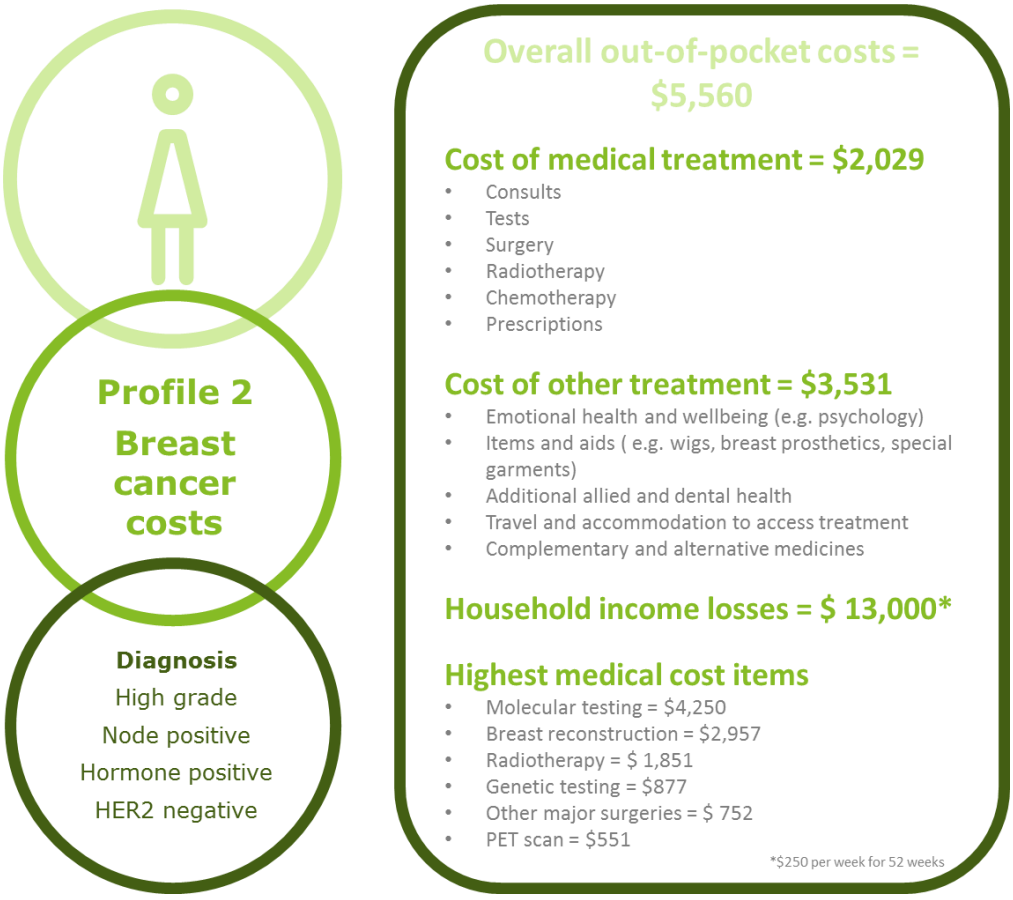
Of the 349 respondents in Profile 2, 71% reported that they used household savings, 16% claimed income protection, 14% either borrowed or were given money from family and friends or through community fundraising, and 8% used their superannuation. Of note, even though households reported decreased work hours and income, 4% of respondents reported that either their partner increased their work hours or went back to work in order to meet the costs associated with the breast cancer diagnosis. Full results for Profile 2 are reported in Chart 7.14 below.

Chart 7.14: Profile 2: How did you meet the costs associated with your breast cancer diagnosis and treatment?



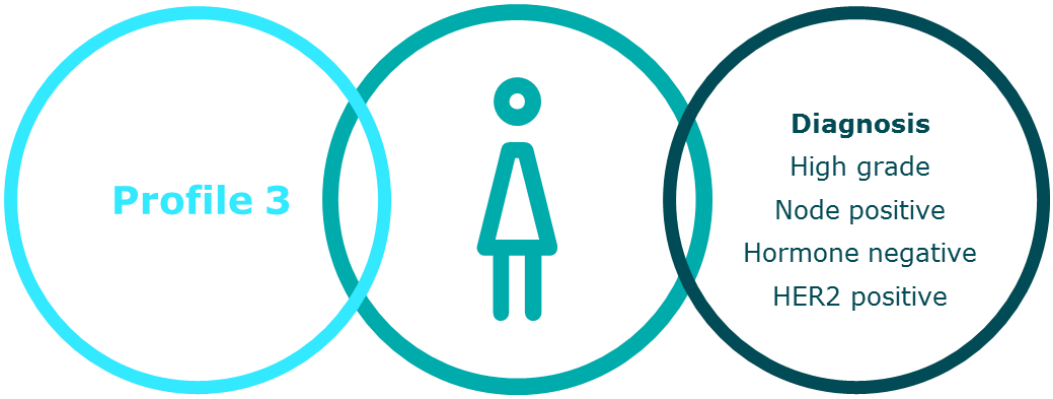
Note: Respondents (n=346) were allowed to select more than one answer.

7.4 Profile summary



8 Profile 3

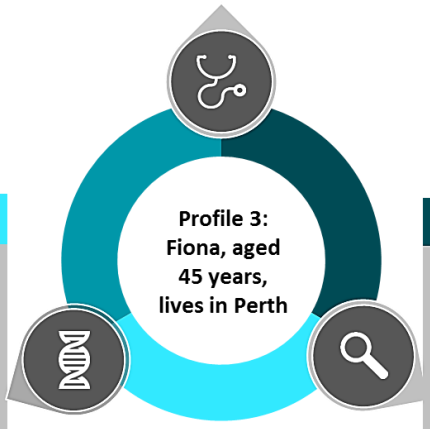
A total of 29 respondents to the survey had a diagnosis of breast cancer that matched Profile 3. The following sections provide the overall direct and other OOP costs associated with the first five years of their most recent breast cancer diagnosis (i.e. from diagnosis to the five years post diagnosis). Below, the diagnostic characteristics of respondents who were placed in Profile 3 are summarised.



Step 2: Treatment

Nuclear medicine does a sentinel node map and the breast surgeon does breast conserving surgery to remove the tumour from Fiona's breast . The sentinel nodes are also removed biopsied to ensure that the cancer has not spread. Histopathology confirms that the cancer has spread to the lymph nodes and Fiona returns to surgery to have the lymph nodes from her right armpit removed. Elizabeth sees the surgeon weekly for two weeks for follow-up. She must take antibiotics for a short time after the surgery.

She sees a medical oncologist and is put on six cycles of chemotherapy over 18 weeks. Her cancer is HER2 positive, so she also is prescribed trastuzumab (Herceptin) targeted therapy intravenously for 12 months which she has with her chemotherapy and then every three weeks after. She must have blood tests and an echocardiogram before each chemotherapy and trastuzumab dose. She takes prescription medicines for nausea caused by her chemotherapy and sees her oncologist during all of her treatments. At the end of her treatment she follows-up with her medical oncologist. Fiona also must see a radiation oncologist after the completion of her chemotherapy. She is put on 30 cycles of radiation treatment that is five times a week for six weeks and consults her radiation oncologist weekly and at the end of her treatment.



Step 1: Diagnosis

18 months ago, Fiona discovered a lump in her right breast. Her GP confirms this and sends her for a mammogram and ultrasound. The GP orders a breast biopsy and histopathology tests confirm that the cancer cells are grade 4, hormone negative, HER2 positive. She is referred to a breast surgeon for further tests and treatment planning. The surgeon does a FNA that comes back negative. A CT scan of her abdomen, chest and pelvis and a whole body bone scan is done to check if the cancer has spread.

Step 3: Follow-up

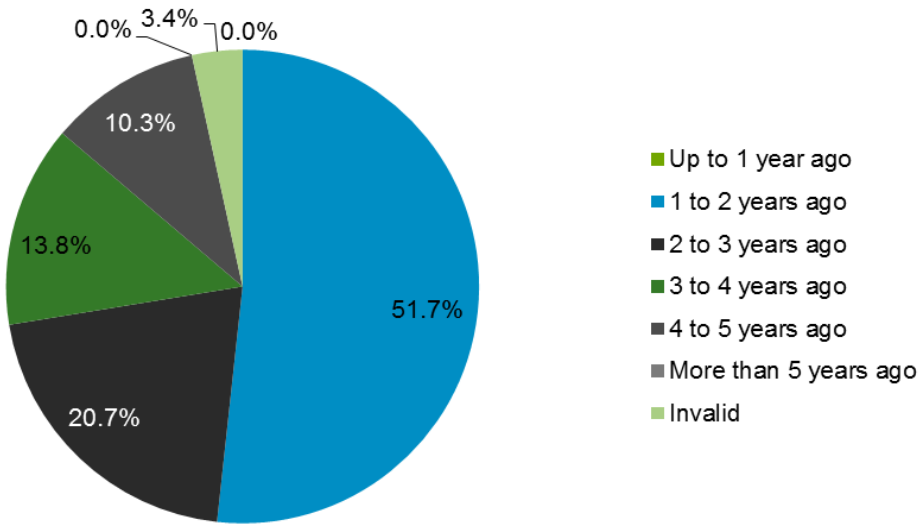
Maria has a follow-up mammogram 12 months after her original mammogram. She visits her medical oncologist twice per year and has regular follow-ups with her GP for health checks. Her cancer is now in remission.

8.1 Respondent characteristics

8.1.1 Number of years following the most recent diagnosis

Over half (51.7%) of respondents in Profile 3 (15 respondents) had their most recent diagnosis of breast cancer 1 to 2 years ago and 20.7% (6 respondents) of Profile 3 were diagnosed 2 to 3 years ago. For the proportion of respondents in Profile 3 and the number of years since their most recent breast cancer diagnosis, see Chart 8.1.

Chart 8.1: Proportion of Profile 3 by years since diagnosis, N=29



8.1.2 No OOP costs versus OOP costs

Table 8.1 reports the proportion of items overall in each cost category that were received with no OOP cost and those for which there was an OOP cost.

Table 8.1: The proportion and number of direct medical diagnosis and treatment items with no OOP cost or an OOP cost for respondents in Profile 3 (n = 29 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/services
	N1	%	N2	%	N1+N2
Medical consultations	41	48%	45	52%	86
Tests	58	39%	89	61%	147
Treatments					

• Major surgical	12	55%	10	45%	22
• Breast reconstruction	5	45%	6	55%	11
• Extra surgical fee	18	50%	18	50%	36
• Radiotherapy	4	20%	16	80%	20
• Chemotherapy	7	15%	39	85%	46
• Hormone therapy	1	100%	0	0%	1
Medicine prescribed for symptomatic relief	28	88%	4	13%	32
Fertility treatment	0	0%	1	100%	1
Total	174	43%	227	57%	401

Likewise, whether or not a respondent incurred an OOP cost or no OOP cost for an 'other cost' item varied. Table 8.2 reports the proportion of items in each cost category that were purchased with no OOP cost and those for which there was an OOP cost.

Table 8.2: The proportion and number of other items and services with no OOP cost or an OOP cost for respondents in Profile 3 (n = 29 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/services
	N1	%	N2	%	N1+N2
Services for emotional wellbeing and mental health	567	98%	13	2%	580
Prescriptions for mental health	10	100%	0	0%	10
Allied and dental health	35	83%	7	17%	42
Items or aids	77	91%	8	9%	85
Additional p aid care or home help	10	91%	1	9%	11
Travel costs	26	100%	0	0%	26
Accommodation costs	2	100%	0	0%	2
Complementary and alternative therapies	10	91%	1	9%	11
Total number of responses	737	96%	30	4%	767

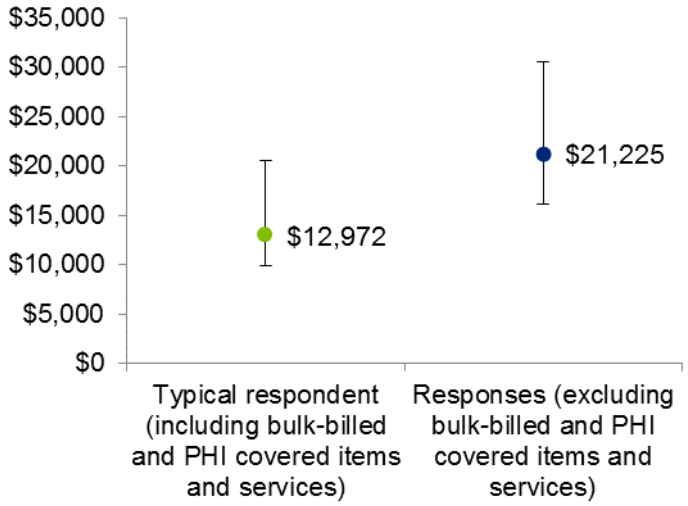
8.2 Direct medical and other OOP costs

8.2.1 Overall costs

The overall reported OOP costs for individuals in Profile 3 is $12,972 (Chart 8.2). To reflect the full range of costs that an individual in Profile 3 may expect to incur, these calculations include all respondents who received each treatment, service, care, or item regardless of whether they paid OOP or not. After removing bulk-billed and PHI covered items and services, the hypothetical worst case scenario, the overall OOP costs increases to $21,225. It is important to note that these estimates are based on only 29 respondents.

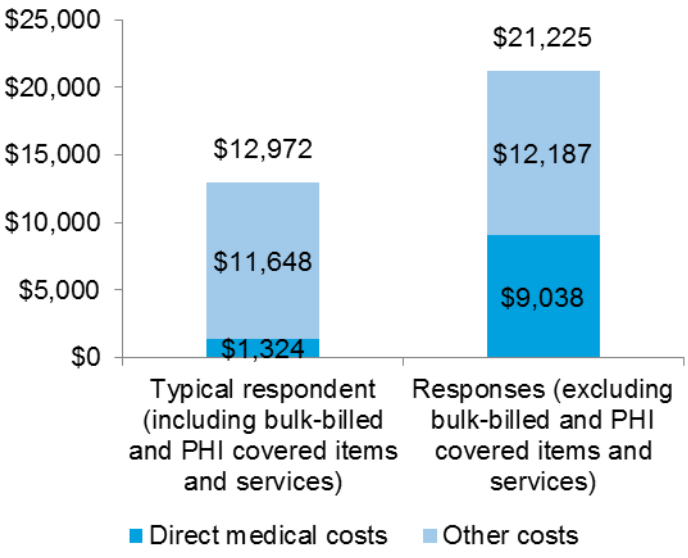
The reported OOP cost for all respondents in Profile 3 for direct medical costs is $1,324 (Chart 8.3). For instances excluding bulk-billed and PHI covered items and services, the reported cost is $9,038. Finally, the other costs for all respondents in Profile 3 and for instances excluding bulk-billed and PHI covered items and services are $11,648 and $12,187 respectively.

Chart 8.2: Profile 3: Median total costs and interquartile range, 25th to 75th percentile



Number of respondents: 29. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 8.3: Profile 3: Median direct medical and other costs



Number of respondents: 29

Table 8.3 below provides full detail of the OOP costs for each item excluding bulk-billed and PHI covered items and services (instances where women were bulk-billed or had their total costs covered by PHI or other funding arrangements). The data is split by jurisdiction, region, dependent children and PHI status during treatment.

Table 8.3: Profile 3: Total costs for people reporting an OOP cost

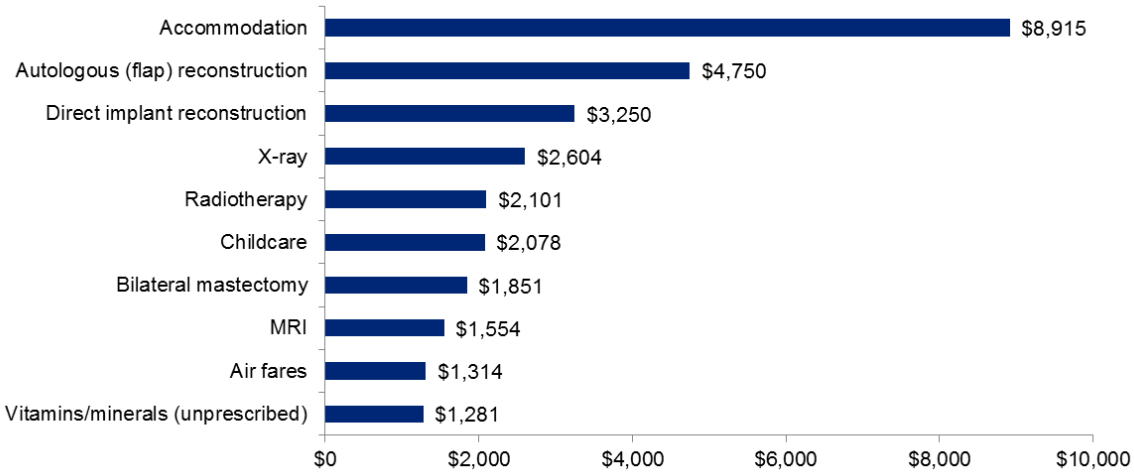
Item	Overall median costs	Min	Max	N	% with OOP cost	Median cost by State/Territory								Median cost by region		Median cost by status of dependent children		Median cost by PHI status	
						NSW	VIC	SA	WA	NT	QLD	ACT	TAS	Urban	Non-urban	0	>0	PHI	No PHI
Direct medical costs																			
Medical consultations	$476	$26	$4,192	41	48%	$470	$516	$357	$771	$698	$0	$0	$1,176	$521	$482	$456	$528	$517	$298
Tests	$411	$32	$2,604	58	39%	$373	$329	$472	$647	$707	$0	$0	$0	$499	$371	$394	$471	$491	$249
Treatment	$8,152	$6	$11,750	93	50%	$3,602	$10,280	$479	$8,632	$5,517	$0	$0	$0	$8,579	$7,636	$10,249	$5,759	$8,159	$79
Major surgery	$774	$106	$3,250	12	55%	$657	$826	$251	$3,250	$401	$0	$0	$0	$649	$1,551	$1,137	$553	$774	$0
Breast reconstruction	$3,710	$1,051	$11,750	5	45%	$0	$8,250	$0	$2,151	$1,951	$0	$0	$0	$4,750	$2,151	$5,200	$1,951	$3,710	$0
Extra surgical fees	$723	$96	$2,750	18	50%	$826	$601	$111	$374	$1,951	$0	$0	$0	$966	$471	$508	$978	$723	$0
Radiotherapy	$2,101	$156	$5,750	4	20%	$1,451	$0	$0	$2,750	$0	$0	$0	$0	$1,451	$2,750	$2,750	$1,451	$2,101	$0
Chemotherapy	$680	$196	$1,951	7	15%	$551	$451	$0	$0	$1,074	$0	$0	$0	$671	$551	$551	$676	$680	$0
Hormone therapy	$72	$72	$72	1	100%	$0	$72	$0	$0	$0	$0	$0	$0	$0	$72	$0	$72	$72	$0
Fertility	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Medication	$92	$6	$4,212	28	88%	$117	$80	$117	$108	$141	$0	$0	$0	$92	$91	$103	$78	$99	$79
Other costs																			
Health & wellbeing	$1,158	$13	$2,510	73	78%	$1,750	$978	$39	$0	$1,307	$0	$0	$57	$1,255	$201	$669	$1,458	$1,306	$746
Allied health service	$325	$38	$3,755	35	83%	$1,505	$299	$532	$0	$91	$0	$0	$0	$639	$52	$386	$327	$711	$154
Emotional wellbeing / mental health	$538	$13	$1,888	28	68%	$1,187	$731	$39	$0	$378	$0	$0	$57	$635	$201	$340	$705	$701	$366
Complementary or alternative therapy	$620	$52	$2,510	10	91%	$563	$247	$0	$0	$929	$0	$0	$0	$620	$0	$329	$752	$606	$380
Items or aids	$297	$13	$12,016	77	91%	$402	$284	$352	$501	$415	$0	$0	$0	$290	$298	$255	$484	$286	$276
Paid care and home help	$951	$65	$19,513	10	91%	$11,644	$318	$3,765	$0	$1,510	$0	$0	$0	$1,224	$351	$999	$9,947	$847	$1,510
Childcare	$2,078	$380	$3,775	2	100%	$3,775	$380	$0	$0	$0	$0	$0	$0	$2,078	$0	$2,078	$0	$2,078	$0
Home help	$755	$351	$19,513	7	100%	$19,513	$366	$3,765	$0	$1,510	$0	$0	$0	$1,133	$351	$755	$9,947	$568	$1,510
Home nursing	$65	$65	$65	1	50%	$0	$65	$0	$0	$0	$0	$0	$0	$65	$0	$65	$0	$65	$0
Travel and accommodation	$9,457	$65	$3,116	30	97%	$11,281	$562	$466	$1,653	$7,873	$0	$0	$0	$7,889	$11,808	$10,973	$7,932	$9,419	$618
Travel	$542	$65	$650	26	100%	$959	$562	$466	$1,653	$365	$0	$0	$0	$381	$1,485	$650	$424	$504	$618
Accommodation	$8,915	$7,508	$10,323	2	100%	$10,323	$0	$0	$0	$7,508	$0	$0	$0	$7,508	$10,323	$10,323	$7,508	$8,915	$0

8.2.2 Most expensive categories, items services and tests

Chart 8.4 shows the top ten items with the highest reported costs. For Profile 3 the most expensive item reported was accommodation. Other features of note include:

- Two types of breast reconstruction are in the top ten cost items;
- Seven out of ten of the most expensive items are direct medical costs; and

Chart 8.4: Profile 3: Top ten median cost items (includes both direct medical costs and other costs), excludes bulk-billed and PHI covered items and services

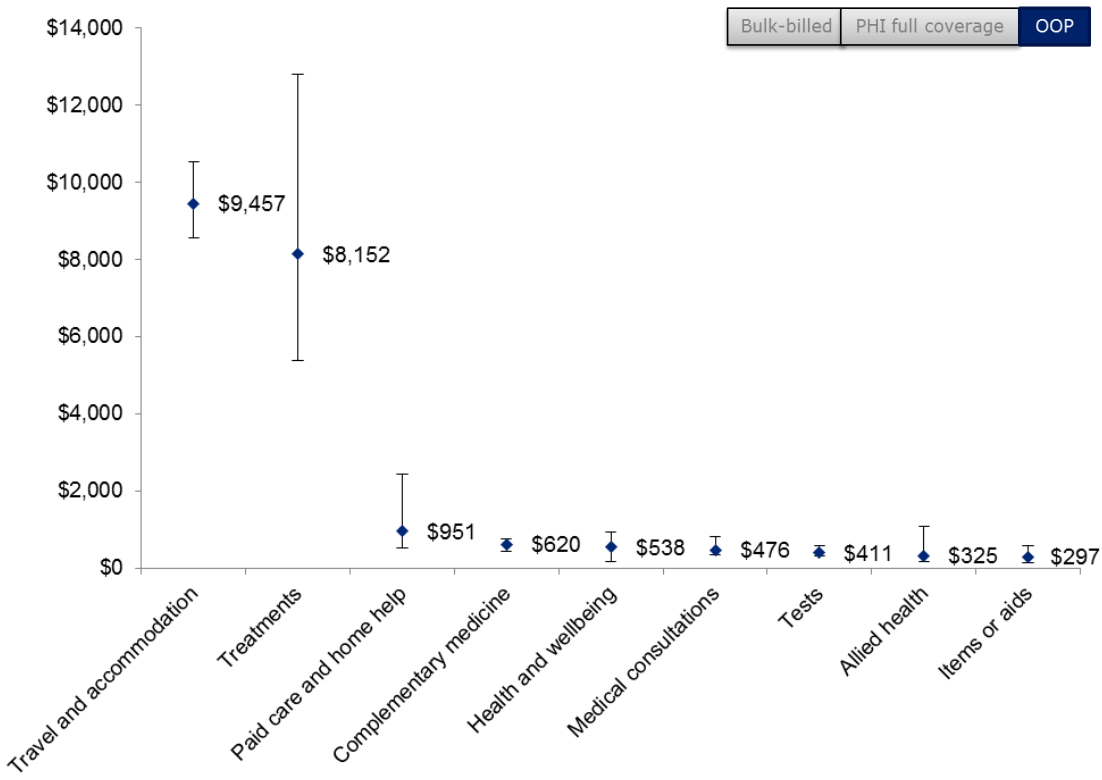


Note: Median costs are not weighted. Number of respondents: 29. Responses per item/service: Accommodation – 2, Autologous (flap) reconstruction – 3, Direct implant reconstruction – 2, X-ray – 1, Radiotherapy – 4, Childcare – 2, Bilateral mastectomy – 2, MRI – 2, Air fares – 2, Vitamins/minerals (unprescribed) – 2.

When comparing the various cost categories including both direct medical costs and other costs for Profile 3, 'Travel and Accommodation' and 'Treatments' are substantially higher (more than $8,000) than other categories, see Chart 8.5. Although travel and accommodation reports median costs higher than treatments, the variation in costs for treatment faced is wider, with 50% of the sample falls between approximately $5,400 and $12,800).

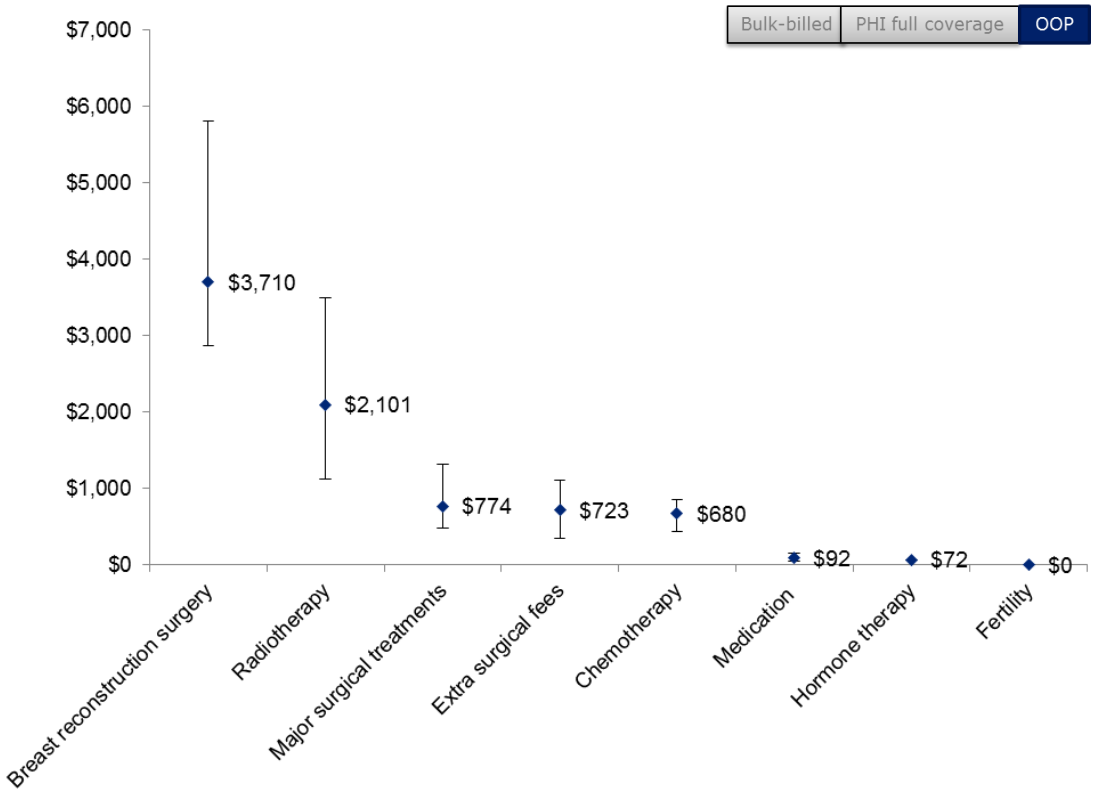
To further examine the treatments category, Chart 8.6 below shows the breakdown of reported costs between types of treatment. It shows that the high reported costs are driven by breast reconstruction surgery (in line with the top ten high cost items), radiotherapy and major surgical treatments (excludes reconstruction).

Chart 8.5: Profile 3: Median costs and interquartile range, 25th to 75th percentile, by cost type (direct medical and other costs), excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: 29. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

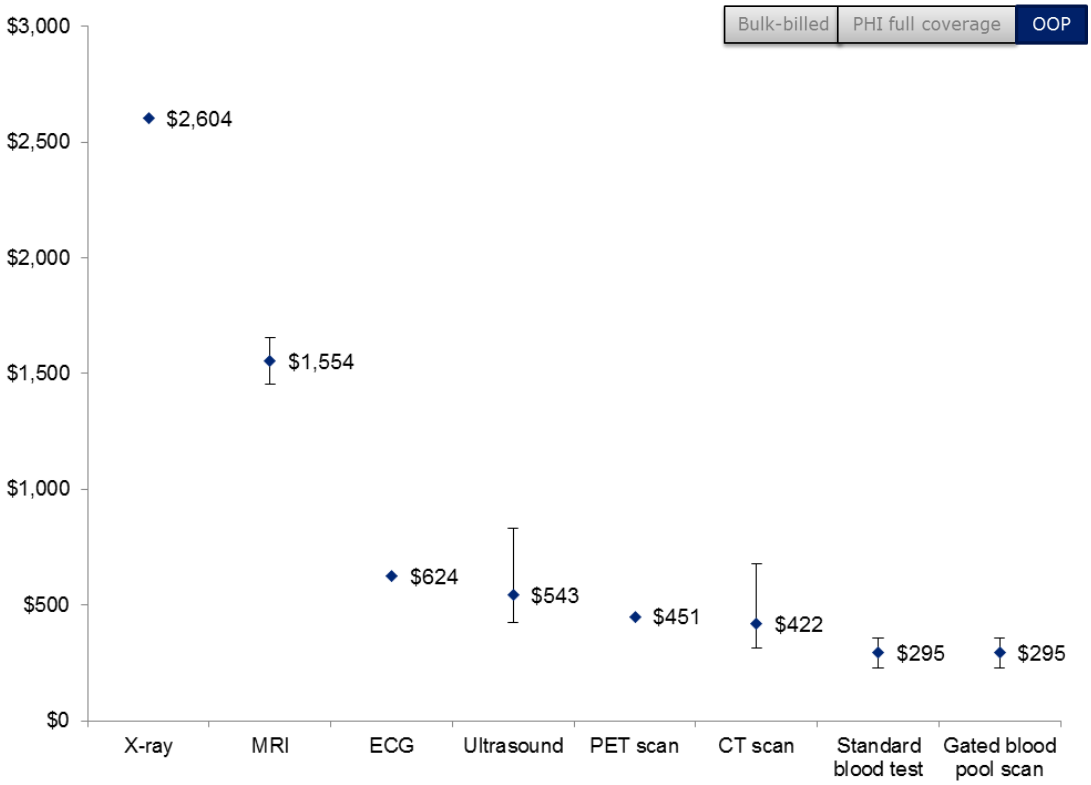
Chart 8.6: Profile 3: Median costs and interquartile range, 25th to 75th percentile, of direct medical treatments, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: 29. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

A breakdown of the various types of tests for Profile 3 is included in Chart 8.7. This breakdown shows that for those who face a cost, the most was spent on X-rays and MRIs. These tests are not weighted; therefore the chart shows that 50% of people who paid for X-rays paid at least $2,604 in total for all their X-rays. The X-ray data point does not have bars indicating the second and third interquartile ranges as it was based on only one reported OOP cost (n=1). The second, third and fourth most expensive costs reported are MRIs, ECGs, and ultrasounds.

Chart 8.7: Profile 3: Median costs and interquartile range, 25th to 75th percentile, of tests, excluding bulk-billed and PHI covered items and services (top eight items)

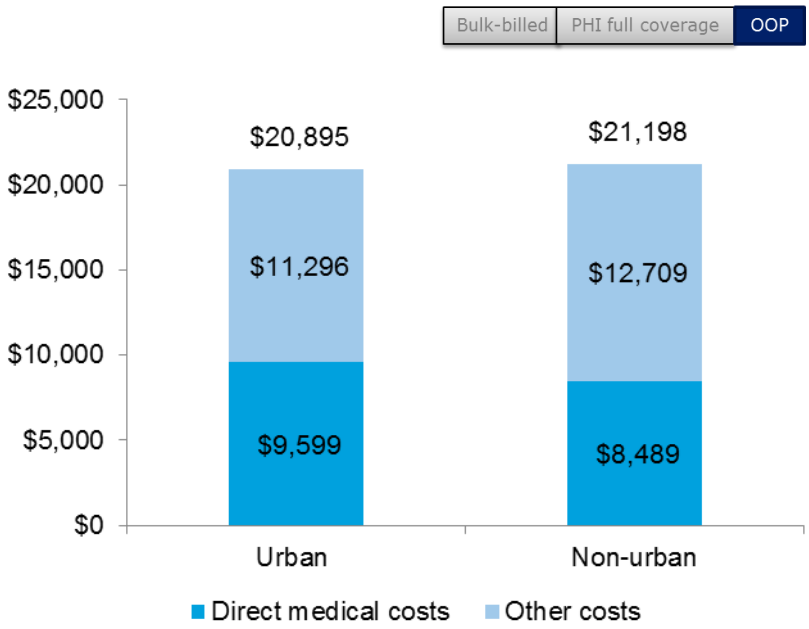


Note: Median costs are reported without weighting. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

8.2.3 Geographic considerations

There was insufficient number of responses to Profile 3 to present the sample by jurisdiction. However, when costs are divided into urban and non-urban postcodes of main residence while receiving treatment, the overall reported costs are similar (approximately $300 higher for non-urban residents). The direct medical costs are slightly higher (approximately $1,100) for urban residents and the other costs are higher (approximately $1,400) for non-urban residents, see Chart 8.8.

Chart 8.8: Profile 3: Median direct medical and other costs by region, excluding bulk-billed and PHI covered items and services

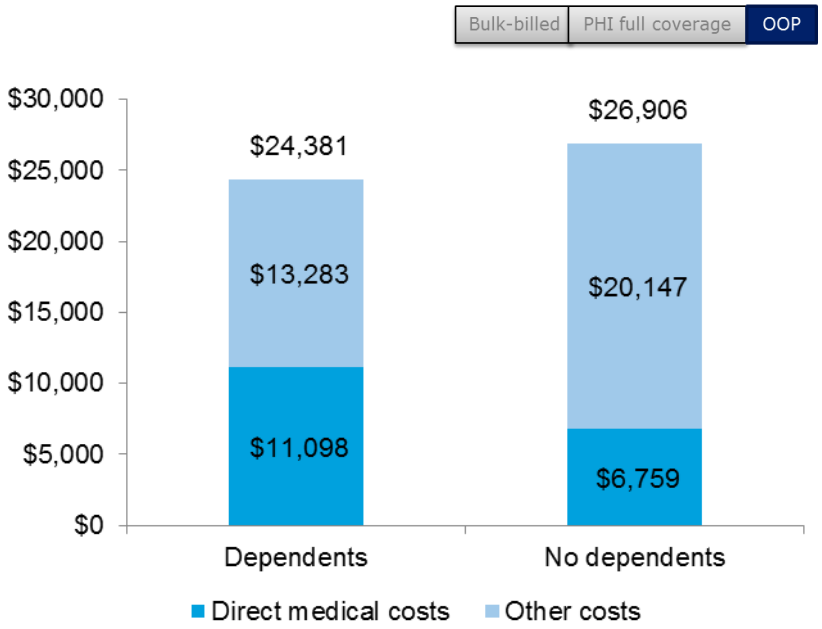


Note: Median costs have been weighted for number of services/items used. Number of respondents: Urban – 20, Non-urban – 9.

8.2.4 Dependent children

The reported total cost is higher (approximately $2,500) for those without dependent children compared to those with dependent children. This is despite respondents with dependents reporting costs for childcare. The respondents with dependents reported paying approximately $4,300 more direct medical costs and $6,900 less for other costs than their counterparts without dependents.

Chart 8.9: Profile 3: Median direct medical costs and other costs by dependent child status, excluding bulk-billed and PHI covered items and services

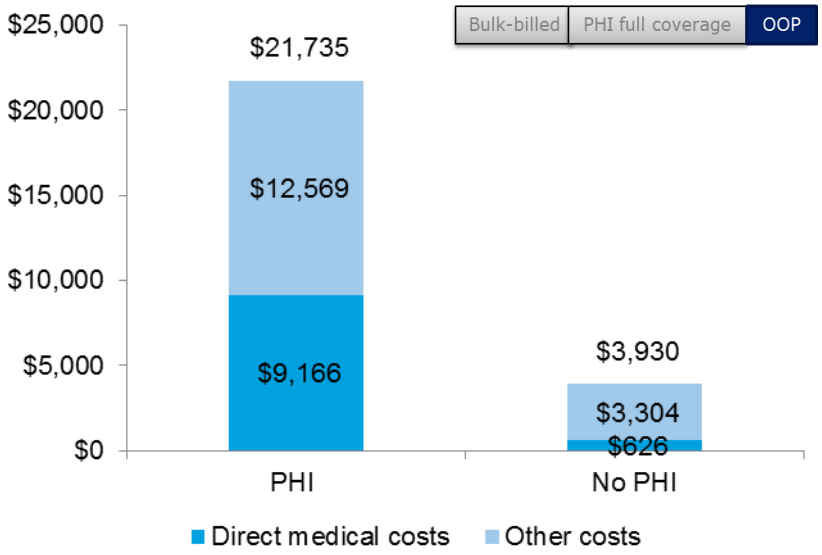


Note: Median costs have been weighted for number of services/items used. Number of respondents: Dependents – 15, No dependents – 14.

8.2.5 PHI

The reported total cost for those with PHI for Profile 3 is substantially higher (approximately $17,800) than for those without PHI. Those with PHI reported higher OOP costs for both the other costs category (approximately $8,500) and the direct medical costs (approximately $9,300), see Chart 7.11.

Chart 8.10: Median direct medical costs and other costs by PHI status, excluding bulk-billed and PHI covered items and services



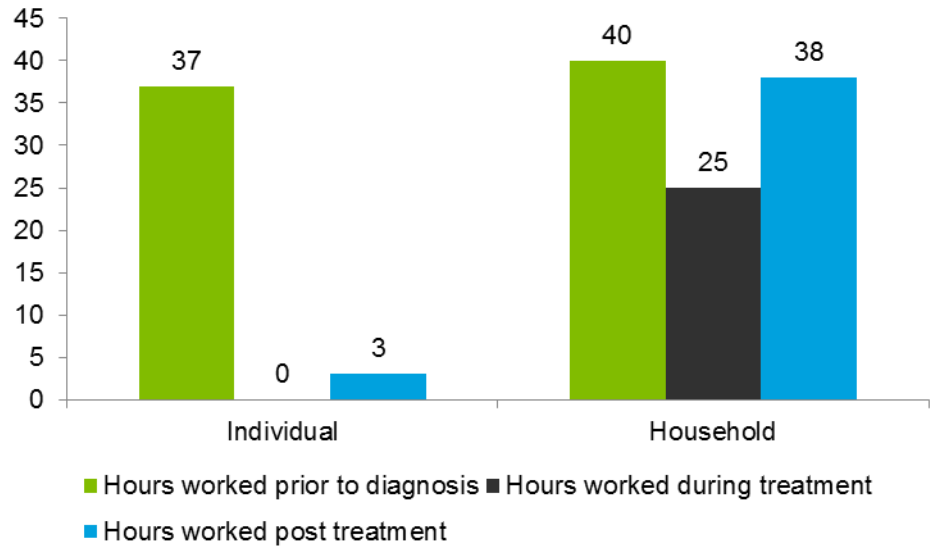
Note: Median costs have been weighted for number of services/items used. Number of respondents: PHI – 21, No-PHI – 8.

8.3 Indirect impacts: Income changes

Most respondents with a diagnosis in Profile 3 did not work in paid employment during the first twelve months post diagnosis (median value drops from 37 hours per week pre diagnosis to zero). The reported household workforce participation also decreases from a median of 40 hours per week prior to diagnosis to 25 hours per week (a 38% decrease), see Chart 8.11.

From 12 months to 24 months (post treatment), individual workforce participation increases back up to 3 hours per week, however this is still 35 hours a week less than prior to diagnosis (a 92% decrease). For households, post treatment, the reported weekly hours increase up to 38 hours, two hours less than prior to diagnosis (a 5% decrease).

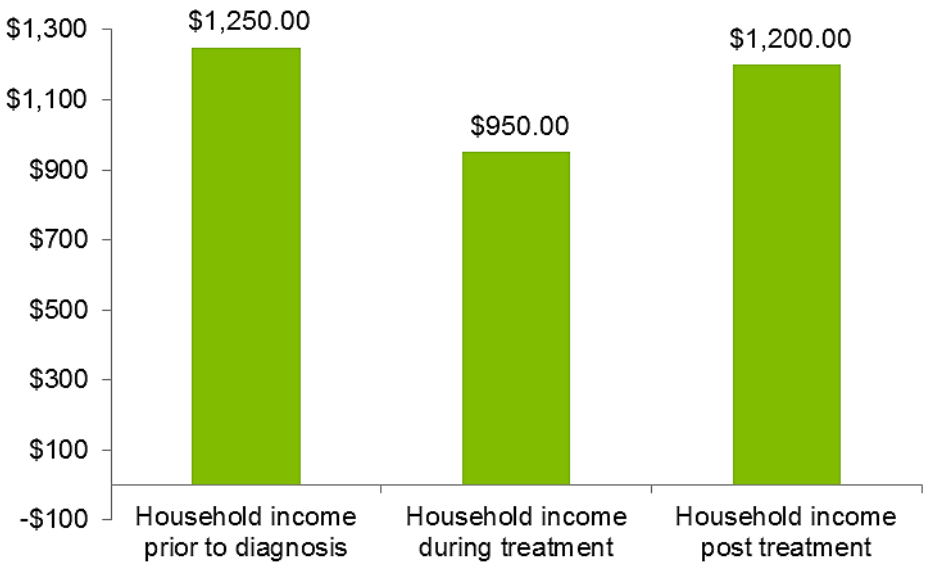
Chart 8.11: Profile 3: Median hours worked per week prior, during and post treatment (n = 29 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

There is a corresponding decrease in household income observed during treatment and after treatment completion, see Chart 8.12. The chart shows a 24% decrease in the average household weekly income during treatment for breast cancer compared to the 12 months prior to diagnosis. There is an increase of $250 per week observed during the 12 months after treatment completion, making household income after completion of treatment 4% lower than prior to diagnosis.

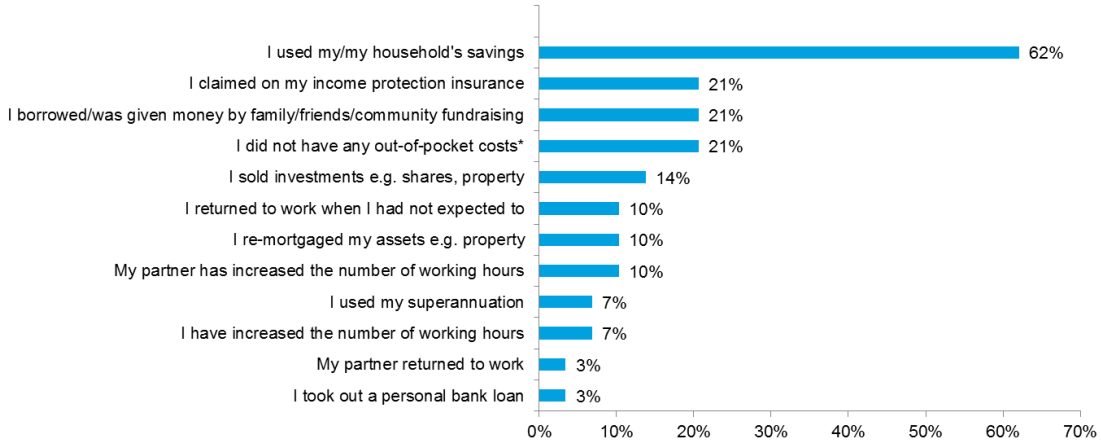
Chart 8.12: Profile 3: Median weekly household income prior, during and post treatment (n = 29 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

Of the 29 respondents in Profile 3, 62% reported that they used household savings, 21% claimed income protection, 21% either borrowed or was given money from family and friends or through community fundraising, and 14% sold investments such as property or shares. Of note, even though households reported decreased work hours and income, 10% of respondents reported that their partner increased their work hours and 3% said their partner went back to work in order to meet the costs associated with the breast cancer diagnosis. Full results for Profile 3 are reported in Chart 8.13 below.

Chart 8.13: Profile 3: How did you meet the costs associated with your breast cancer diagnosis and treatment?



Note: Respondents (n=29) were allowed to select more than one answer.

8.4 Profile summary

Overall out-of-pocket costs = $12,972

Cost of medical treatment = $1,324

- Consults
- Tests
- Surgery
- Radiotherapy
- Chemotherapy
- Prescriptions

Cost of other treatment = $11,648

- Emotional health and wellbeing (e.g. psychology)
- Items and aids (e.g. wigs, breast prosthetics, special garments)
- Additional allied and dental health
- Travel and accommodation to access treatment
- Complementary and alternative medicines

Household income losses = $ 15,600*

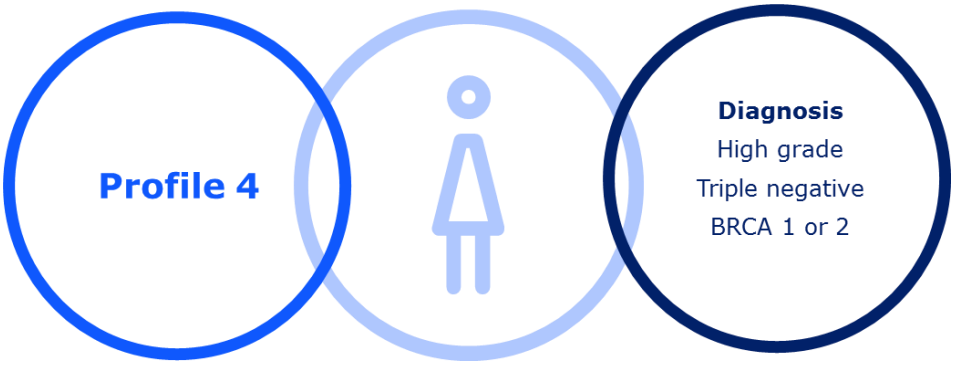
Highest medical cost items

- Breast reconstruction = $3,710
- X-Ray = $2,604
- MRI = $1,544
- Other major surgeries = $774
- Extra surgical fees = 723

*$300 per week for 52 weeks

9 Profile 4

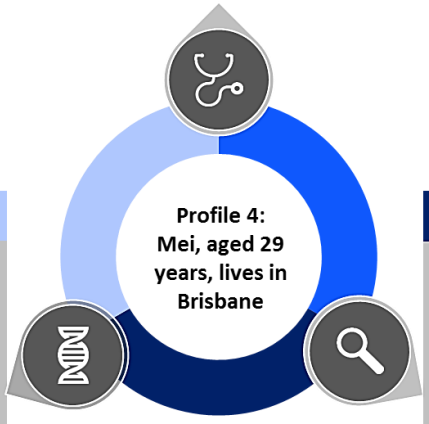
A total of 25 respondents to the survey had a diagnosis of breast cancer that fit into Profile 4. The following sections provide the overall direct and other OOP costs associated with the first five years of their most recent breast cancer diagnosis (i.e. from diagnosis to the five years post diagnosis). Below, the diagnostic characteristics of respondents who were placed in Profile 4 are summarised.



Step 2: Treatment

Her IVF specialist harvests and freezes her eggs which can then be made into embryos and implanted in her uterus should she ever decide to have children. She may also wish to have her embryos tested at further cost for the BRCA1 or BRCA2 gene or other genetic mutations.

She has six rounds of chemotherapy over 18 weeks. Prior to every dose, she has a blood test, consults her medical oncologist and takes medicines to prevent nausea. She also has two ultrasounds during her course to check her response to the chemotherapy. As she is still of child baring age, she has Zoladex administered while she is on chemotherapy once per month. After her chemotherapy is complete, she has a sentinel node biopsy to check her response to the chemotherapy. She also has an MRI of her other breast. Her breast surgeon does a bilateral mastectomy to remove any further risk of breast cancer and removes the lymph node from her right armpit as the left nodes had no spread. A plastic surgeon does a breast reconstruction using tissue from her thigh. She stays in hospital for five nights, is on pain relief medicines and antibiotics and she must follow-up with both surgeons twice. She returns to the plastic surgeon for nipple tatooing six months later.



Step 1: Diagnosis

2 years ago, Mei discovers a lump in her right breast. Her GP confirms this and sends her for a mammogram and ultrasound. The GP orders a breast biopsy and tests confirm that the cancer cells are grade 4, triple negative. She is referred to a breast surgeon for further tests and treatment planning. The surgeon does a FNA which is negative. Given her age, and family history of breast cancer, she consults Genetic Counselling at a Familial Cancer Centre. She has a BRCA mutation test which comes back positive. She also consults a fertility specialist and decides to have her eggs harvested and frozen.

Step 3: Follow-up

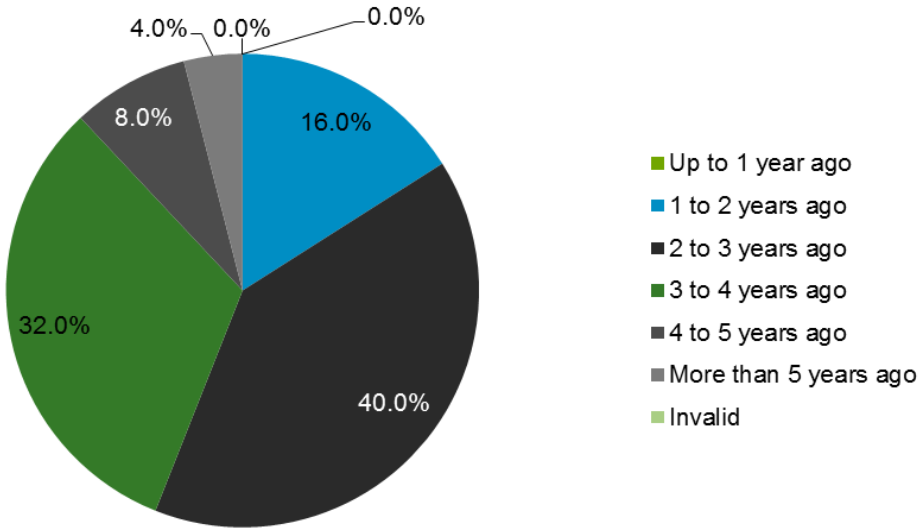
Mei must see her medical oncologist every three months for 12 months and she sees her GP for regular health checks. She pays the IVF clinic a yearly fee to keep her eggs frozen. She is currently cancer free but is also considering an oophorectomy (having her ovaries removed) before turning 40 years old to prevent ovarian cancer for which she is highly susceptible given her BRCA mutation.

9.1 Respondent characteristics

9.1.1 Years post diagnosis

Forty percent of respondents in Profile 4 had their most recent diagnosis of breast cancer 2 to 3 years ago. 32% were diagnosed 3 to 4 years ago and 16% were diagnosed 1 to 2 years ago. For the proportion of respondents in Profile 4 and the number of years since their most recent breast cancer diagnosis, see Chart 9.1

Chart 9.1: Proportion of Profile 4 by years since diagnosis, N=25



9.1.2 No OOP costs versus OOP costs

Table 8.1 reports the proportion of items overall in each cost category that were received with no OOP cost and those for which there was an OOP cost.

Table 9.1: The proportion and number of direct medical diagnosis and treatment items with no OOP cost and an OOP cost for respondents in Profile 4 (n = 25 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Medical consultations	44	65%	24	35%	68
Tests	57	44%	74	56%	131
Treatments					
• Major surgical	27	59%	19	41%	46
• Breast reconstruction	9	56%	7	44%	16
• Extra surgical fee	26	67%	13	33%	39
• Radiotherapy	0	0%	5	100%	5
• Chemotherapy	5	28%	13	72%	18

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
• Hormone therapy	1	100%	0	0%	1
Medicine prescribed for symptomatic relief	23	79%	6	21%	29
Fertility treatment	2	100%	0	0%	2
Total number of responses	194	55%	161	45%	355

Likewise, whether or not a respondent incurred an OOP cost or no OOP cost for an 'other cost' item varied. Table 8.2 reports the proportion of items in each cost category that were purchased with no OOP cost and those for which there was an OOP cost.

Table 9.2: The proportion and number of other items and services with no OOP cost and an OOP cost for respondents in Profile 4 (n = 25 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/services
	N1	%	N2	%	N1+N2
Services for emotional wellbeing and mental health	567	98%	10	2%	577
Prescriptions for mental health	11	100%	0	0%	11
Allied and dental health	29	91%	3	9%	32
Items or aids	47	90%	5	10%	52
Additional p aid care or home help	1	100%	0	0%	1
Travel costs	25	100%	0	0%	25
Accommodation costs	2	100%	0	0%	2
Complementary and alternative therapies	15	79%	4	21%	19
Total number of responses	697	97%	22	3%	719

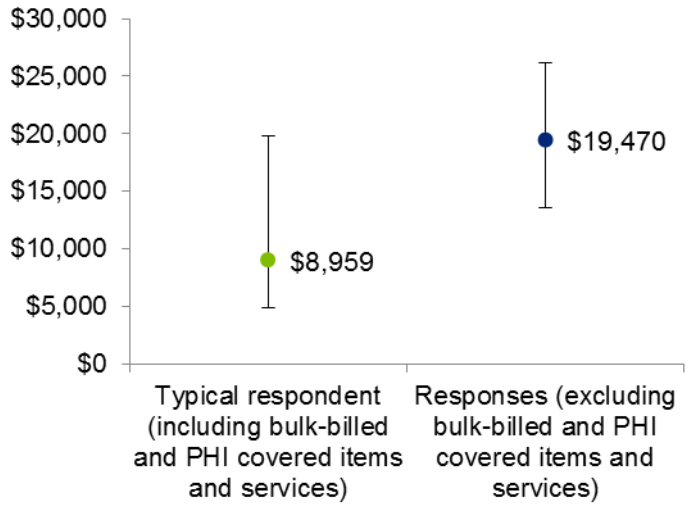
9.2 Direct medical and other OOP costs

9.2.1 Overall costs

The overall reported OOP costs for individuals in Profile 4 is $8,959 (Chart 9.2). To reflect the full range of costs that an individual in Profile 4 may expect to incur, these calculations include all respondents who received each treatment, service, care, or item regardless of whether they paid OOP or not. After removing bulk-billed and PHI covered items and services, the hypothetical worst case scenario, the overall OOP costs increases to $19,470. It is important to note that these estimates are based on only 25 respondents.

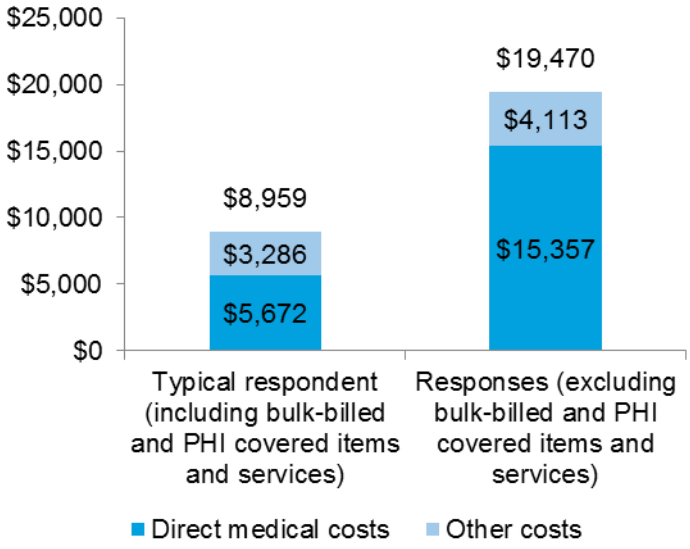
The reported OOP cost for all respondents in Profile 4 for direct medical costs is $5,672 (Chart 9.3). For instances excluding bulk-billed and PHI covered items and services, the reported cost is $15,357. Finally, the other costs for all respondents in Profile 4 and for instances excluding bulk-billed and PHI covered items and services are $3,286 and $4,113 respectively.

Chart 9.2: Profile 4: Median total costs and interquartile range, 25th to 75th percentile



Number of respondents: 25. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 9.3: Profile 4: Median direct medical and other costs



Number of respondents: 25.

Table 9.3 below provides full detail of the OOP costs for each item excluding bulk-billed and PHI covered items and services (instances where women were bulk-billed or had their total costs covered by PHI or other funding arrangements). The data is split by jurisdiction, region, dependent children and PHI status during treatment.

Table 9.3: Profile 4: Total costs for people reporting an OOP cost

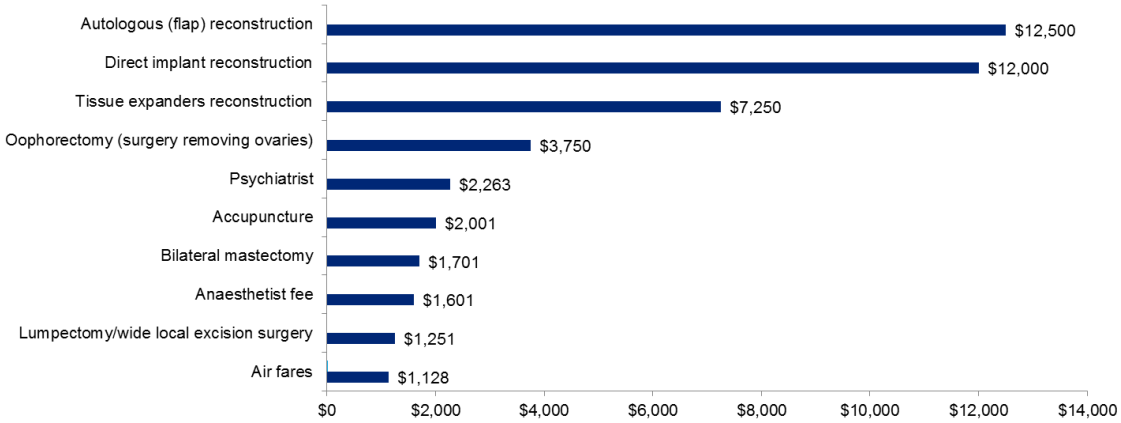
Item	Overall median costs	Min	Max	N	% with OOP cost	Median cost by State/Territory								Median cost by region		Median cost by status of dependent children		Median cost by PHI status	
						NSW	VIC	SA	WA	NT	QLD	ACT	TAS	Urban	Non-urban	0	>0	PHI	No PHI
Direct medical costs																			
Medical consultations	$688	$26	$6,450	44	65%	$1,021	$695	$342	$0	$461	$0	$0	$1,428	$724	$667	$645	$757	$669	$850
Tests	$365	$36	$2,591	57	44%	$352	$306	$663	$0	$951	$0	$0	$0	$355	$498	$254	$386	$362	$682
Treatment	$14,304	$6	$16,250	119	65%	$13,252	$14,309	$3,754	$0	$22,694	$0	$0	$7,791	$14,557	$13,839	$14,352	$13,069	$13,939	$5,348
Major surgery	$2,051	$176	$5,250	27	59%	$2,683	$1,401	$984	$0	$5,250	$0	$0	$0	$1,623	$2,273	$1,130	$2,529	$1,543	$4,250
Breast reconstruction	$9,472	$4,250	$16,250	9	56%	$9,417	$10,250	$0	$0	$16,250	$0	$0	$7,250	$10,333	$9,750	$10,650	$8,375	$9,472	$0
Extra surgical fees	$1,028	$146	$4,750	26	67%	$842	$1,501	$1,201	$0	$0	$0	$0	$451	$857	$1,061	$1,389	$671	$1,184	$901
Radiotherapy	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Chemotherapy	$1,051	$251	$1,051	5	28%	$251	$801	$1,051	$0	$1,051	$0	$0	$0	$1,051	$651	$1,051	$801	$1,051	$0
Hormone therapy	$368	$368	$368	1	100%	$0	$0	$368	$0	$0	$0	$0	$0	$368	$0	$0	$368	$368	$0
Fertility	$199	$146	$251	2	100%	$0	$199	$0	$0	$0	$0	$0	$0	$199	$0	$0	$199	$199	$0
Medication	$136	$6	$251	23	79%	$59	$158	$150	$0	$143	$0	$0	$90	$126	$104	$133	$126	$122	$197
Other costs																			
Health & wellbeing	$1,655	$13	$3,775	65	79%	$1,722	$416	$76	$0	$1,376	$0	$0	$4,312	$1,709	$1,191	$2,032	$2,296	$1,970	$426
Allied health service	$312	$76	$3,755	29	91%	$1,044	$565	$257	$0	$0	$0	$0	$76	$325	$302	$934	$247	$341	$1,053
Emotional wellbeing / mental health	$1,154	$13	$3,775	21	68%	$925	$253	$0	$0	$1,376	$0	$0	$4,107	$1,147	$529	$548	$2,150	$1,416	$262
Complementary or alternative therapy	$501	$52	$3,775	15	79%	$797	$163	$76	$0	$0	$0	$0	$206	$563	$662	$1,484	$146	$554	$163
Items or aids	$284	$26	$2,255	47	90%	$304	$340	$715	$76	$827	$0	$0	$236	$270	$271	$293	$256	$317	$357
Paid care and home help	$751	$751	$751	1	100 %	$751	$0	$0	$0	$0	$0	$0	$0	$0	$751	$751	$0	$751	$0
Childcare	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Home help	$751	$751	$751	1	100%	$751	$0	$0	$0	$0	$0	$0	$0	$0	$751	$751	$0	$751	$0
Home nursing	$0	$0	$0	0	0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Travel and accommodation	$1,111	$65	$4,563	28	100%	$1,144	$1,042	$4,563	$488	$0	$0	$0	$390	$398	$1,624	$1,097	$725	$1,170	$488
Travel	$358	$65	$1,128	25	100%	$265	$414	$4,563	$488	$0	$0	$0	$390	$398	$871	$344	$725	$417	$488
Accommodation	$753	$628	$879	2	100%	$879	$628	$0	$0	$0	$0	$0	$0	$0	$753	$753	$0	$753	$0

9.2.2 Most expensive categories, items services and tests

Chart 9.4 shows the top ten items with the highest reported costs. For Profile 4 the most expensive item reported was the autologous, or flap, breast reconstruction surgery type. Other features of note include:

- The top three costs are all types of breast reconstruction;
- Seven out of ten of the most expensive items are direct medical costs;
- The seven direct medical expenses are all related to surgical treatments; and
- The three items from the 'other cost' category are consultations with a psychiatrist, receiving acupuncture and airfares.

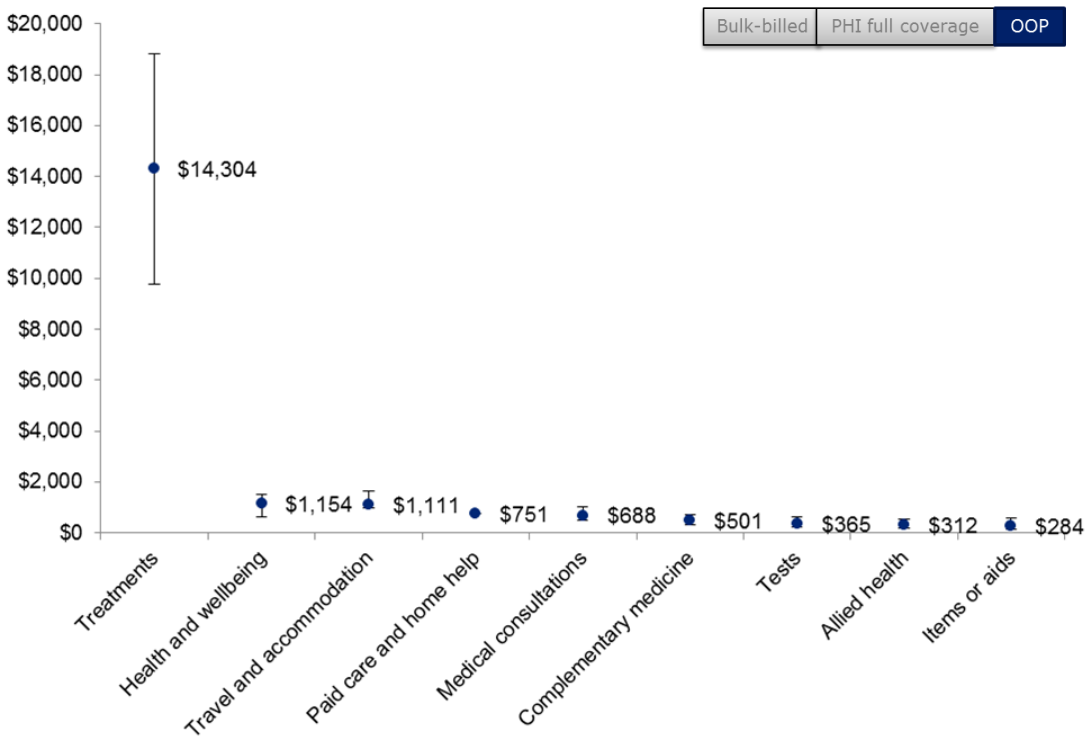
Chart 9.4: Profile 4: Top ten median cost items (includes both direct medical costs and other costs), excludes bulk-billed and PHI covered items and services



Note: Median costs are not weighted. Number of respondents: 25. Responses per item/service: Autologous (flap) reconstruction – 2, Direct implant reconstruction – 2, Tissue expanders reconstruction – 5, Oophorectomy – 9, Psychiatrist – 2, Acupuncture – 2, Bilateral mastectomy – 8, Anaesthetist fee – 12, Lumpectomy/wide local excision – 5, Air fares – 1.

When comparing the various cost categories including both direct medical costs and other costs for Profile 4, 'Treatments' is substantially higher (approximately $13,000) than other categories, see Chart 9.5. The bars on the chart indicate that 50% of the sample falls between this range (between approximately $9,800 and $18,800 for treatment costs). As such, the spread of the treatment data is very wide.

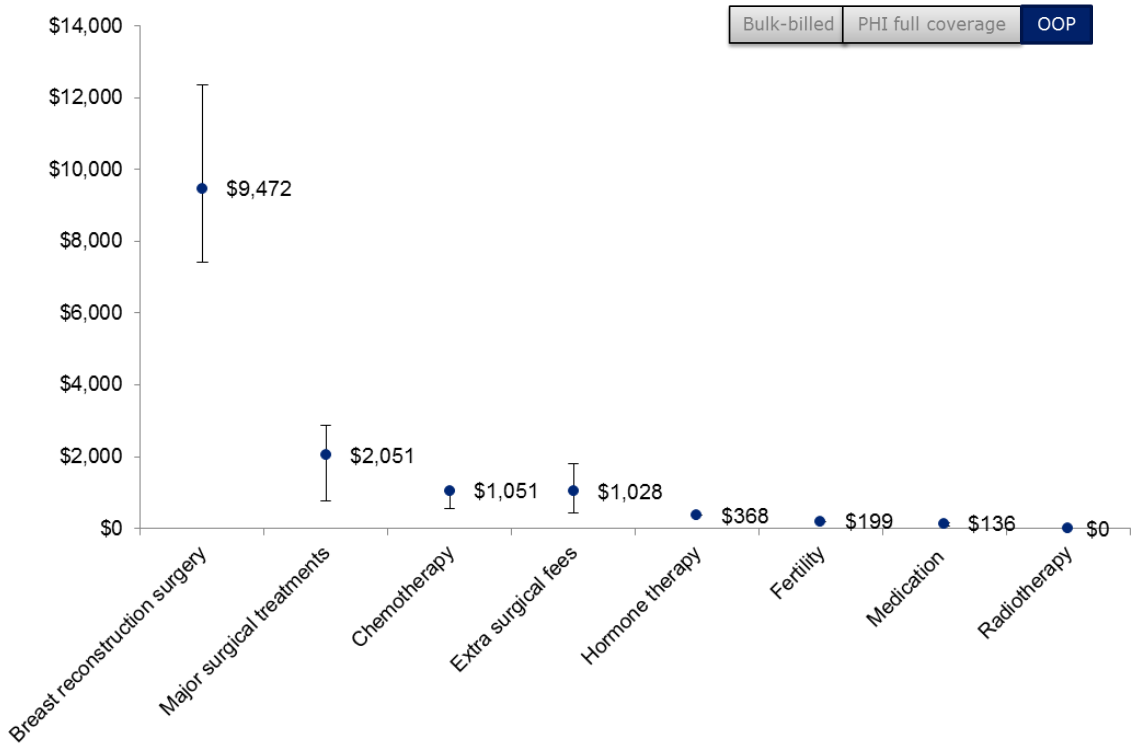
Chart 9.5: Profile 4: Median costs and interquartile range , 25th to 75th percentile, by cost type (direct medical and other costs), excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 25. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

To further examine the treatments category, Chart 9.6 below shows the breakdown of reported OOP costs between types of treatment. It shows that the high reported costs are driven by breast reconstruction surgery (in line with the top ten high cost items), major surgical treatments (excludes reconstruction) and chemotherapy.

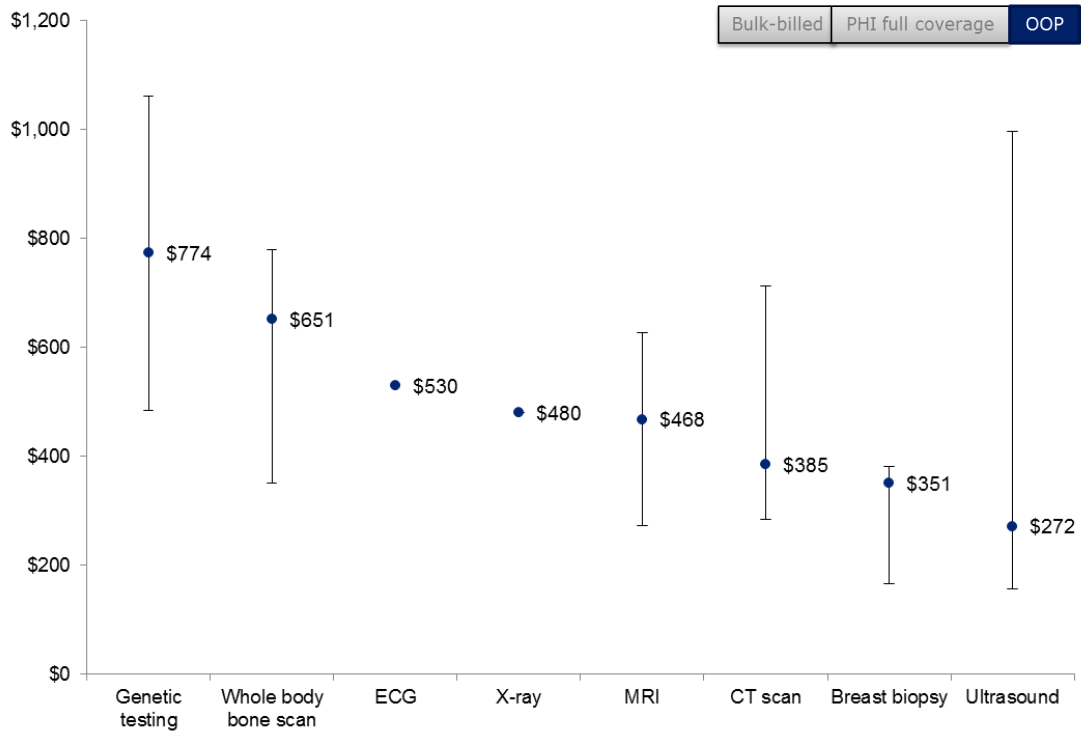
Chart 9.6: Profile 4: Median costs and interquartile range, 25th to 75th percentile, of direct medical treatments, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 25. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

A breakdown of the various types of tests for Profile 4 is included in Chart 9.7 below. This breakdown shows that for those who face a cost, the most was spent on genetic testing and whole body scans. These tests are not weighted; therefore the chart shows that 50% of people who paid for genetic testing paid at least $774.

Chart 9.7: Profile 4: Median costs and interquartile range, 25th to 75th percentile, of tests, excluding bulk-billed and PHI covered items and services (top eight items)

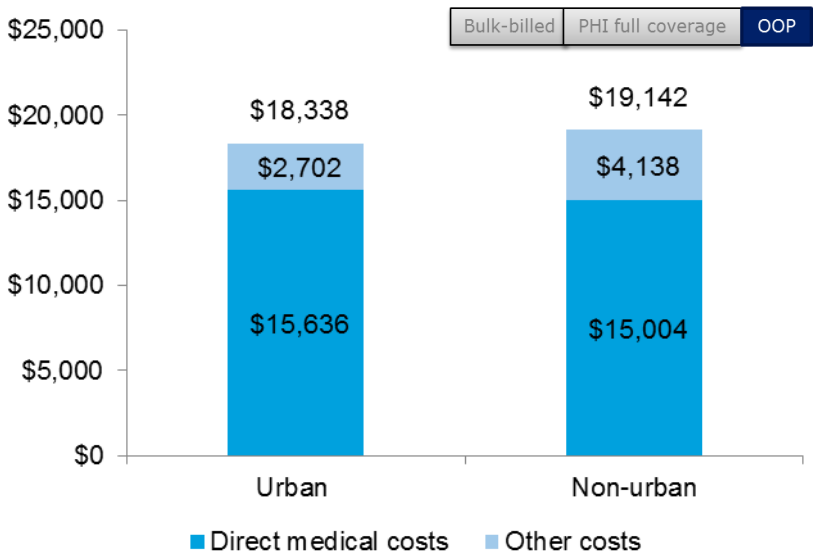


Note: Median costs are reported without weighting. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

9.2.3 Geographic considerations

There were insufficient responses to Profile 4 to divide the sample by jurisdiction. However, when costs are divided into urban and non-urban postcodes of main residence while receiving treatment, the overall reported costs are similar (approximately $800 higher for non-urban residents). The direct medical costs are slightly higher (approximately $600) for urban residents and the other costs are higher (approximately $1,400) for non-urban residents, see Chart 9.8.

Chart 9.8: Profile 3: Median direct medical costs and other costs by region, excluding bulk-billed and PHI covered items and services

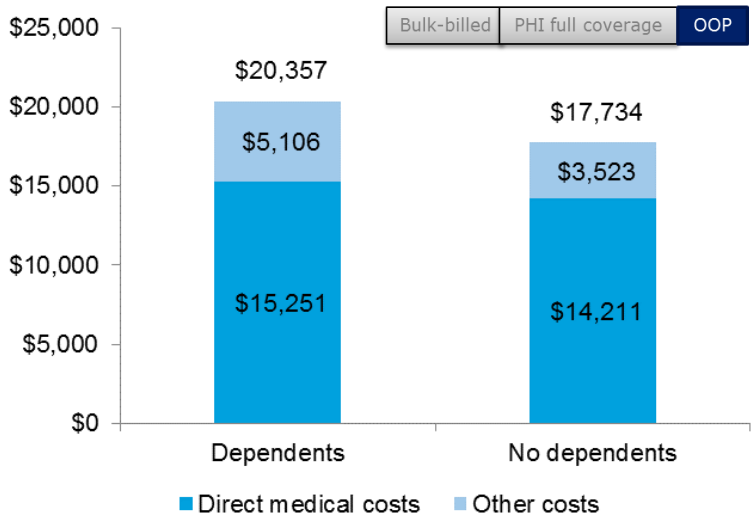


Note: Median costs have been weighted for number of services/items used. Number of respondents: Urban – 18, Non-urban – 7.

9.2.4 Dependent children

For Profile 4, the reported total cost is higher (approximately $2,600) for those with dependent children compared to those without dependent children. However, respondents in Profile 4 did not report any costs associated with childcare. The additional reported costs are divided by approximately $1,000 more for direct medical costs and $1,600 more for other costs, see Chart 9.9.

Chart 9.9: Profile 4: Median direct medical costs and other costs by dependent child status, excluding bulk-billed and PHI covered items and services

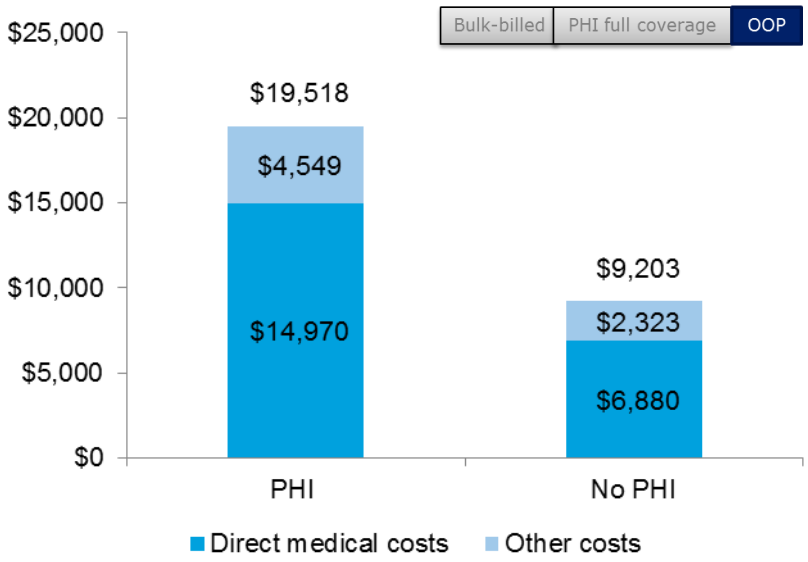


Notes: Median costs have been weighted for number of services/items used. Number of respondents: Dependents – 12, No dependents – 13.

9.2.5 Impact of PHI

The reported total cost for those with PHI for Profile 4 is substantially higher (approximately $10,300) than for those without PHI. Those with PHI reported higher OOP costs for both the other costs category (approximately $2,200) and the direct medical costs (approximately $8,500), see Chart 9.10.

Chart 9.10: Profile 4: Median direct medical costs and other costs by PHI status, excluding bulk-billed and PHI covered items and services



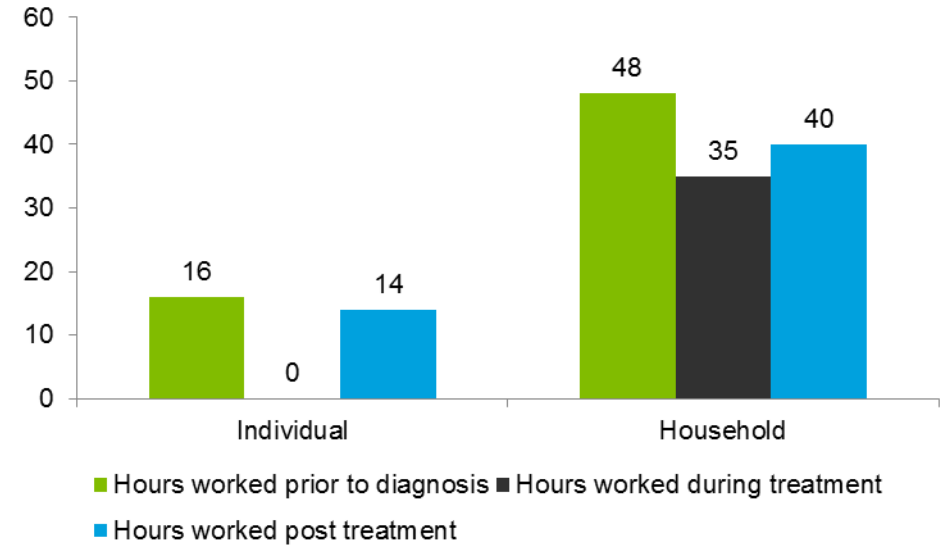
Note: Median costs have been weighted for number of services/items used Number of respondents: PHI – 20, No-PHI – 5.

9.3 Indirect impacts: Income changes

Most respondents with a breast cancer diagnosis in Profile 4 did not work in paid employment during the first twelve months post diagnosis (median value drops from 16 hours per week pre diagnosis to zero). The reported household workforce participation also decreases from a median 48 hours per week prior to diagnosis to 35 hours per week (a 27% decrease), see Chart 9.11.

From 12 months to 24 months, individual reported workforce participation increases back up to 14 hours, this is 2 hours a week less than prior to diagnosis (a 13% decrease). For households overall, post treatment workforce participation increases up to 40 hours, eight hours less than prior to diagnosis (a 17% decrease).

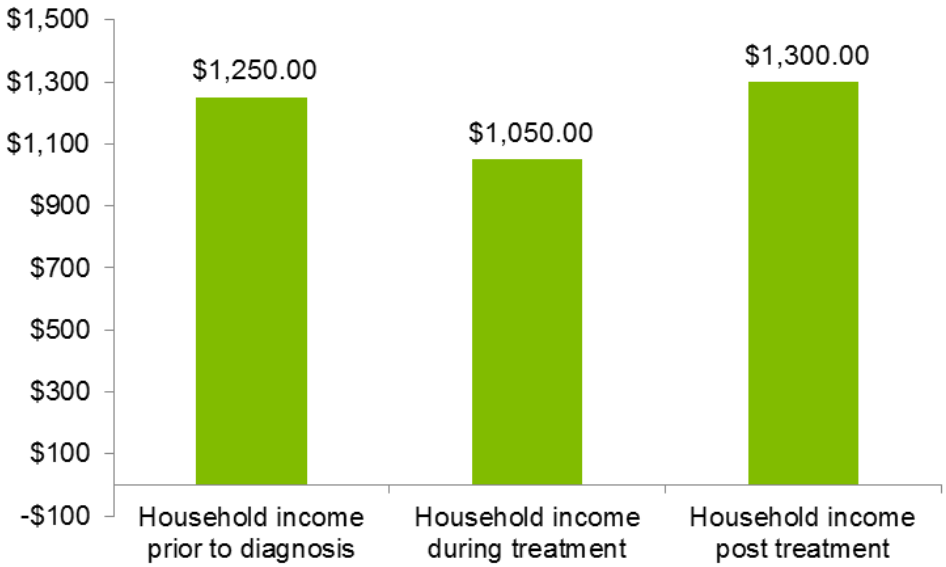
Chart 9.11: Profile 4: Median hours worked per week prior, during and post treatment (n= 25 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

There is a corresponding decrease in household income observed, see Chart 9.12. The chart shows a 16% decrease in the average household weekly income during treatment compared to the 12 months prior to diagnosis. However in the 12 months after treatment completion, there is a 4% increase in weekly income compared to the 12 months prior to diagnosis.

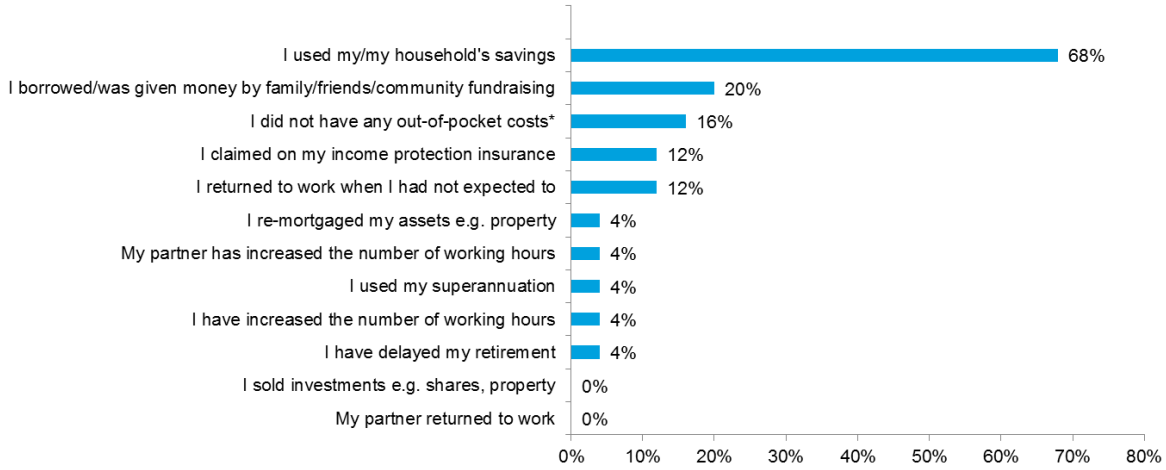
Chart 9.12: Profile 4: Median weekly household income prior, during and post treatment (n= 25 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

Of the 25 respondents in Profile 4, 68% reported that they used household savings to meet the OOP costs associated with their treatment. Twenty percent either borrowed or were given money from family and friends or through community fundraising, 12% returned to work when they had not expected to and 12% claimed income protection insurance. Full results for Profile 4 are reported in Chart 9.13 below.

Chart 9.13: Profile 4: How did you meet the costs associated with your breast cancer diagnosis and treatment?



Note: Respondents (n = 25) were allowed to select more than one answer.

9.4 Profile summary

Overall out-of-pocket costs = $8,959

Cost of medical treatment = $5,672

- Consults
- Tests
- Surgery
- Radiotherapy
- Chemotherapy
- Prescriptions

Cost of other treatment = $3,286

- Emotional health and wellbeing (e.g. psychology)
- Items and aids (e.g. wigs, breast prosthetics, special garments)
- Additional allied and dental health
- Travel and accommodation to access treatment
- Complementary and alternative medicines

Household income losses = $ 10,400*

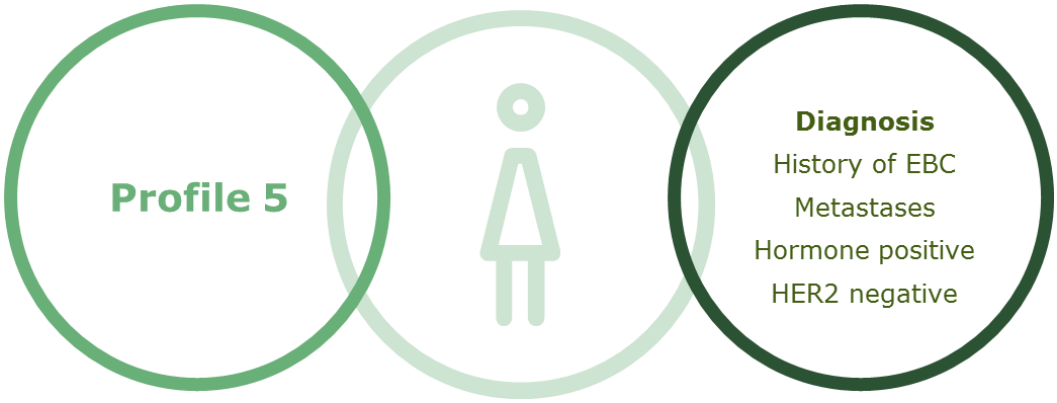
Highest cost items

- Breast reconstruction = $9,472
- Other major surgeries = $2,051
- Chemotherapy = $1,051
- Extra surgical fees = $1,028
- Genetic testing = $774
- Whole body bone scan = $651

*$200 per week for 52 weeks

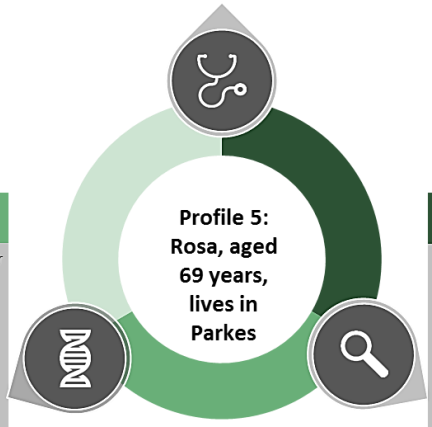
10 Profile 5

A total of 68 respondents to the survey had a diagnosis of breast cancer that fit into Profile 5. The following sections provide the overall direct and other OOP costs associated with the first five years of their most recent breast cancer diagnosis (i.e. from diagnosis to the five years post diagnosis). Below, the diagnostic characteristics of respondents who were placed in Profile 5 are summarised.



Step 2: Immediate treatment

Prior to her chemotherapy, Rosa is treated with 10 sessions of radio therapy – five sessions per week for two weeks to shrink the tumours. She is placed on two hormone prescription medicines, afinitor and exemestane and stops taking tamoxifen (which she was taking for her EBC diagnosis). She must also have a bone strengthening medicine, denosumab (Xgeva), which her GP injects every four weeks. Her medical oncologist prescribes her six cycles of chemotherapy over 18 weeks. Prior to each session, she must have blood tests, consult her medical oncologist and take medicines to prevent nausea. At the end of her chemotherapy, she must have another CT scan of her chest, abdomen, pelvis and brain, a bone scan and more blood tests. These scans must be done twice a year and she must have blood tests and tumour marker tests every three months.



Step 1: Diagnosis

2 years ago, Rosa falls and breaks a shoulder bone. She attends hospital where they do an x-ray and CT scan and confirm that she has tumours in her shoulder bones. Rosa has a history of hormone positive, HER2 negative breast cancer for which she was treated 10 years prior with breast conserving surgery, chemotherapy, radiotherapy and hormone therapy and it has now spread to her bones. She has a CT scan of her chest, abdomen, pelvis and brain and a bone scan which confirms no further identifiable spread. She is referred directly to a medical oncologist and radiation oncologist for further treatment.

Step 3: Ongoing treatment

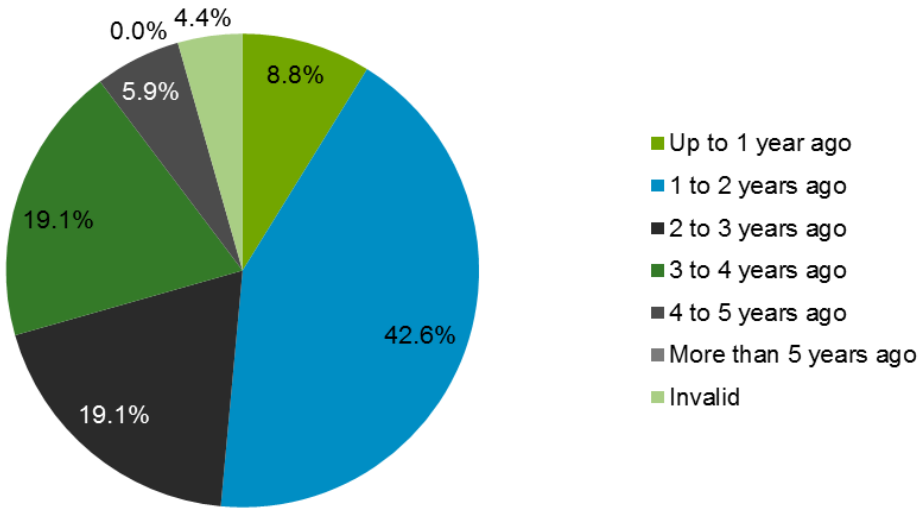
Rosa continues to take afinitor and exemestane and has monthly injections of denosumab. She also continues to have CT scans, bone scans, blood tests and tumour marker tests to look for evidence that her cancer may have spread. So far, the tumours in her shoulder have shrunk but are still painful, so she takes a long acting opioid for pain relief. She may have to have further radiotherapy and chemotherapy in the future.

10.1 Respondent characteristics

10.1.1 Years post diagnosis

Close to half, (42.6%) of respondents in Profile 5 had their most recent diagnosis of breast cancer 1 to 2 years ago and 19.1% of respondents were diagnosed 2 to 3 years ago. For the proportion of respondents in Profile 5 and the number of years since their most recent breast cancer diagnosis, see Chart 10.1.

Chart 10.1: Proportion of Profile 5 by years since diagnosis, N=68



10.1.2 No OOP costs versus OOP costs

Table 10.1 reports the proportion of items overall in each cost category that were received with no OOP costs and those for which there was an OOP cost.

Table 10.1: The proportion and number of direct medical diagnosis and treatment items with no OOP cost and an OOP cost for respondents in Profile 5 (n = 68 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/services
	N1	%	N2	%	N1+N2
Medical consultations	98	58%	72	42%	170
Tests	93	31%	207	69%	300
Treatments					
• Major surgical	18	45%	22	55%	40
• Breast reconstruction	2	50%	2	50%	4
• Extra surgical fee	31	58%	22	42%	53

• Radiotherapy	14	48%	15	52%	29
• Chemotherapy	12	41%	17	59%	29
• Hormone therapy	56	85%	10	15%	66
Medicine prescribed for symptomatic relief	54	92%	5	8%	59
Total number of responses	378	50%	372	50%	750

Likewise, whether or not a respondent incurred an OOP cost or no OOP cost for an 'other cost' item varied. Table 10.2 reports the proportion of items in each cost category that were purchased with no OOP cost and those for which there was an OOP cost.

Table 10.2: The proportion and number of other items and services with no OOP cost and an OOP cost for respondents in Profile 5 (n = 68 respondents)

Cost categories	OOP cost		No OOP cost		Total number of items/ services
	N1	%	N2	%	N1+N2
Services for emotional wellbeing and mental health	567	95%	29	5%	596
Prescriptions for mental health	35	100%	0	0%	35
Allied and dental health	89	86%	14	14%	103
Items or aids	80	89%	10	11%	90
Additional p aid care or home help	14	82%	3	18%	17
Travel costs	62	98%	1	2%	63
Accommodation costs	6	100%	0	0%	6
Complementary and alternative therapies	59	84%	11	16%	70
Total number of responses	912	93%	68	7%	980

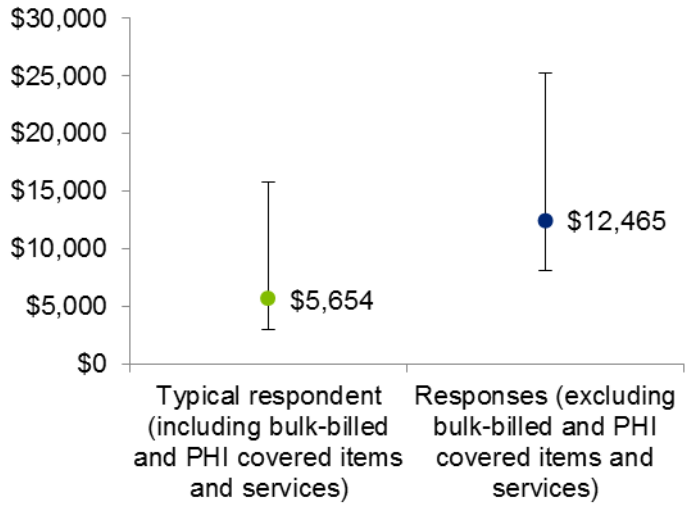
10.2 Direct medical and other OOP costs

10.2.1 Overall costs

The overall reported OOP costs for individuals in Profile 5 is $5,654 (Chart 10.2). To reflect the full range of costs that an individual in Profile 5 may expect to incur, these calculations include all respondents who received each treatment, service, care, or item regardless of whether they paid OOP or not. After removing bulk-billed and PHI covered items and services, the hypothetical worst case scenario, the overall OOP costs increases to $12,465.

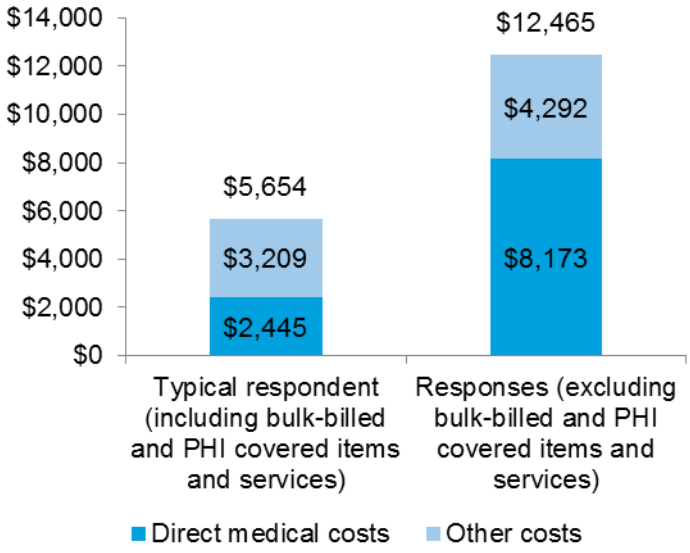
The reported OOP cost for all respondents in Profile 5 for direct medical costs is $2,445 (Chart 10.3). For instances excluding bulk-billed and PHI covered items and services, the reported cost is $8,173. Finally, the other costs for all respondents in Profile 5 and for instances excluding bulk-billed and PHI covered items and services are $3,209 and $4,292 respectively.

Chart 10.2: Profile 5: Median total costs and interquartile range, 25th to 75th percentile



Notes: Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 68. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Chart 10.3: Profile 5: Median direct medical cost and other costs



Number of respondents: 68

Table 10.3 below provides full detail of the OOP costs for each item excluding bulk-billed and PHI covered items and services (instances where women were bulk-billed or had their total costs covered by PHI or other funding arrangements). The data is split by jurisdiction, region, dependent children and PHI status during treatment.

Table 10.3: Profile 5: Total costs for people reporting an OOP cost

Item	Overall median costs	Min	Max	N	% with OOP cost	Median cost by State/Territory								Median cost by region		Median cost by status of dependent children		Median cost by PHI status	
						NSW	VIC	SA	WA	NT	QLD	ACT	TAS	Urban	Non-urban	0	>0	PHI	No PHI
Direct medical costs																			
Medical consultations	$518	$26	$9,755	98	58%	$665	$596	$357	$784	$454	$690	$882	$591	$531	$453	$437	$561	$494	$1,285
Tests	$420	$46	$2,853	93	31%	$471	$534	$352	$747	$440	$251	$269	$1,044	$389	$471	$443	$428	$416	$437
Treatment	$7,235	$6	$10,040	218	70%	$6,923	$4,512	$3,625	$4,790	$3,922	$573	$5,738	$1,867	$7,981	$3,706	$6,844	$4,772	$7,053	$6,081
Major surgery	$595	$96	$4,750	18	45%	$0	$988	$551	$0	$614	$451	$0	$651	$728	$527	$522	$642	$614	$121
Breast reconstruction	$3,250	$3,250	$3,250	2	50%	$0	$0	$0	$3,250	$0	$0	$0	$0	$3,250	$0	$3,250	$0	$3,250	$0
Extra surgical fees	$419	$96	$2,750	31	58%	$0	$301	$651	$141	$1,365	$96	$2,017	$96	$455	$357	$657	$318	$418	$351
Radiotherapy	$1,751	$96	$5,750	14	48%	$4,750	$2,001	$0	$1,151	$601	$0	$0	$0	$2,500	$751	$1,151	$2,500	$1,751	$2,601
Chemotherapy	$576	$46	$2,250	12	41%	$651	$451	$499	$0	$409	$0	$2,250	$701	$522	$771	$534	$701	$501	$701
Hormone therapy	$478	$6	$10,040*	56	85%	$1,289	$410	$1,800	$37	$708	$0	$1,121	$229	$381	$1,078	$512	$446	$380	$2,117
Fertility	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Medication	$166	$6	$1,512	54	92%	$234	$361	$125	$211	$225	$26	$350	$190	$145	$222	$216	$165	$140	$191
																			Other costs
Health & wellbeing	$1,139	$13	$45,030	207	79%	$1,321	$1,500	$284	$956	$1,612	$0	$1,225	$569	$1,224	$1,416	$1,063	$1,236	$1,094	$2,058
Allied health service	$540	$26	$37,525	89	86%	$18,877	$607	$3,753	$1,170	$507	$2,253	$1,247	$312	$927	$452	$501	$1,679	$517	$1,404
Emotional wellbeing / mental health	$505	$13	$9,006	59	67%	$510	$788	$133	$428	$423	$0	$807	$393	$612	$280	$540	$433	$473	$870
Complementary or alternative therapy	$634	$76	$45,030	59	84%	$811	$712	$151	$528	$1,189	$0	$418	$176	$612	$1,136	$523	$803	$621	$1,188
Items or aids	$410	$38	$6,004	80	89%	$607	$500	$390	$473	$661	$829	$634	$246	$472	$414	$243	$573	$379	$395
Paid care and home help	$977	$76	$15,010	14	82%	$12,008	$1,382	$453	$1,506	$983	$0	$130	$0	$1,399	$357	$357	$1,398	$977	$0
Childcare	$0	$0	$0	0	0%	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0
Home help	$981	$76	$15,010	12	92%	$12,008	$1,595	$453	$1,506	$983	$0	$130	$0	$1,510	$357	$357	$1,508	$981	$0
Home nursing	$956	$156	$1,755	2	67%	$0	$956	$0	$0	$0	$0	$0	$0	$956	$0	$0	$956	$956	$0
Travel and accommodation	$1,226	$26	$12,016	71	99%	$1,144	$522	$261	$766	$3,924	$0	$1,025	$0	$718	$2,065	$2,168	$1,350	$1,082	$2,883
Travel	$375	$26	$195	62	98%	$292	$522	$261	$766	$671	$0	$648	$0	$341	$939	$353	$499	$330	$712
Accommodation	$852	$251	$3,765	6	100%	$852	$0	$0	$0	$3,253	$0	$377	$0	$377	$1,127	$1,815	$852	$752	$2,171

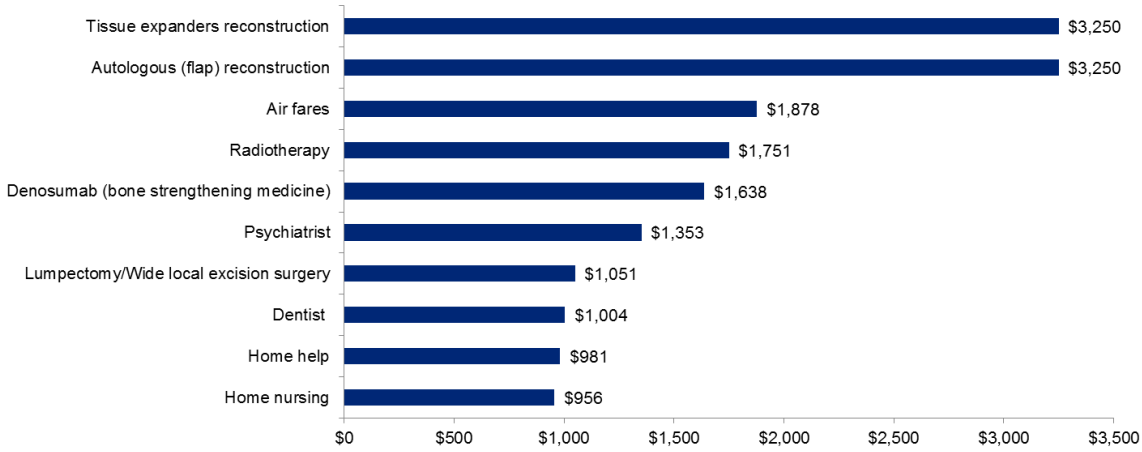
*This OOP cost was reported by one respondent for 40 prescriptions of Xgeva

10.2.2 Most expensive categories, items services and tests

Chart 10.4 shows the top ten items with the highest reported costs. For Profile 5 the most expensive item reported was equal between autologous and tissue expander breast reconstruction surgery. Other features of note include:

- Five of the most expensive items are direct medical costs, three of which are surgical;
- Bone strengthening medicine, denosumab (Xgeva), is the fifth highest OOP cost item;
- Two of the most expensive items relate to breast reconstruction; and
- The 'other cost' category items include home nursing, home help (such as a cleaner), dentist, psychiatrist and air fares.

Chart 10.4: Profile 5: Top ten median cost items (includes both direct medical costs and other costs), excludes bulk-billed and PHI covered items and services

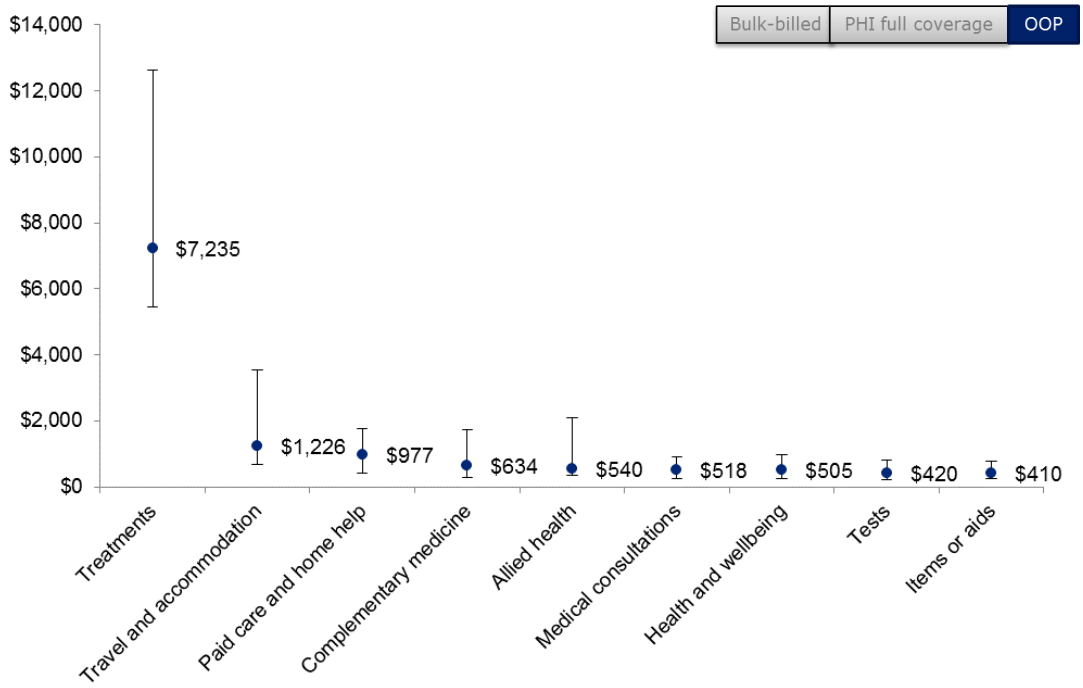


Note: Median costs are not weighted. Number of respondents: 68. Responses per item/service: Tissue expanders reconstruction – 1, Autologous (flap) reconstruction – 1, Air fares – 3, Radiotherapy – 14, Denosumab – 8, Psychiatrist – 1, Lumpectomy/Wide local excision – 3, Dentist – 27, Home help – 12, Home nursing – 2.

When comparing the various OOP cost categories including both direct medical costs and other costs for Profile 5, 'Treatments' is substantially higher (approximately $6,000) than other categories, see Chart 10.5. The bars on the chart indicate that 50% of the sample falls between this range (between approximately $5,400 and $12,600 for treatment costs). As such, the spread of the treatment data is very wide.

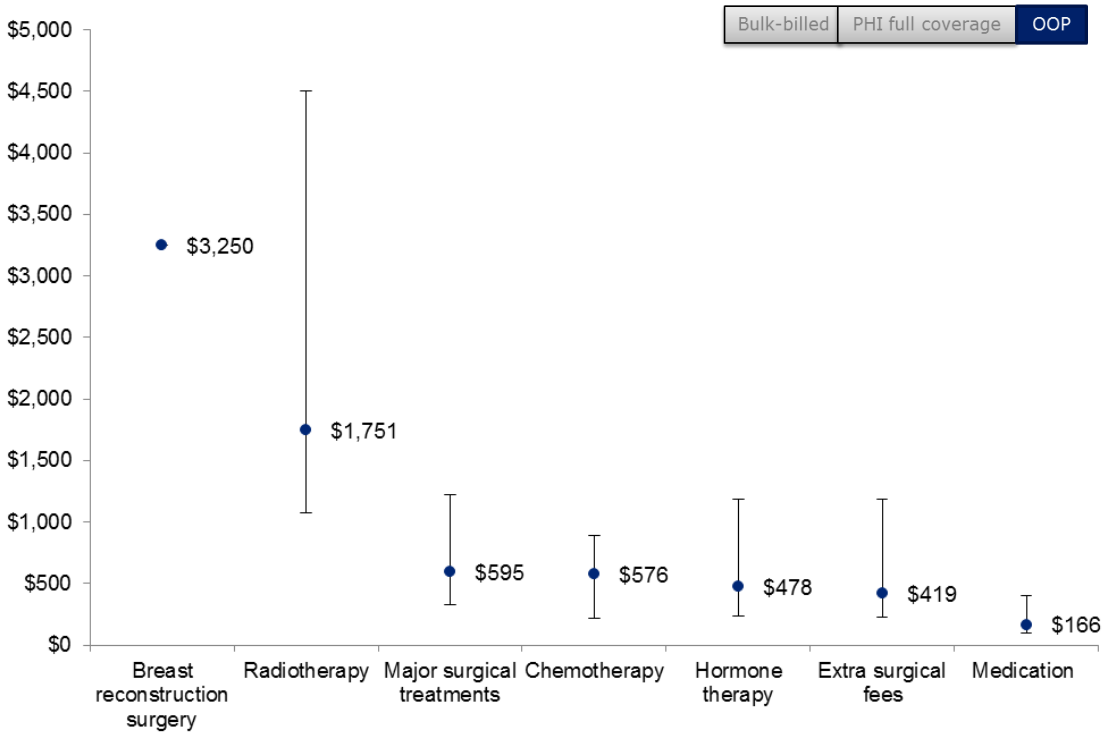
To further examine the treatments category, Chart 10.6 below shows the breakdown of reported costs between types of treatment. It shows that the high reported OOP costs are driven by breast reconstruction surgery (in line with the top ten high cost items), radiotherapy and major surgical treatments (excludes reconstruction).

Chart 10.5: Profile 5: Median costs and interquartile range , 25th to 75th percentile, by cost type (direct medical and other costs), excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 68. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

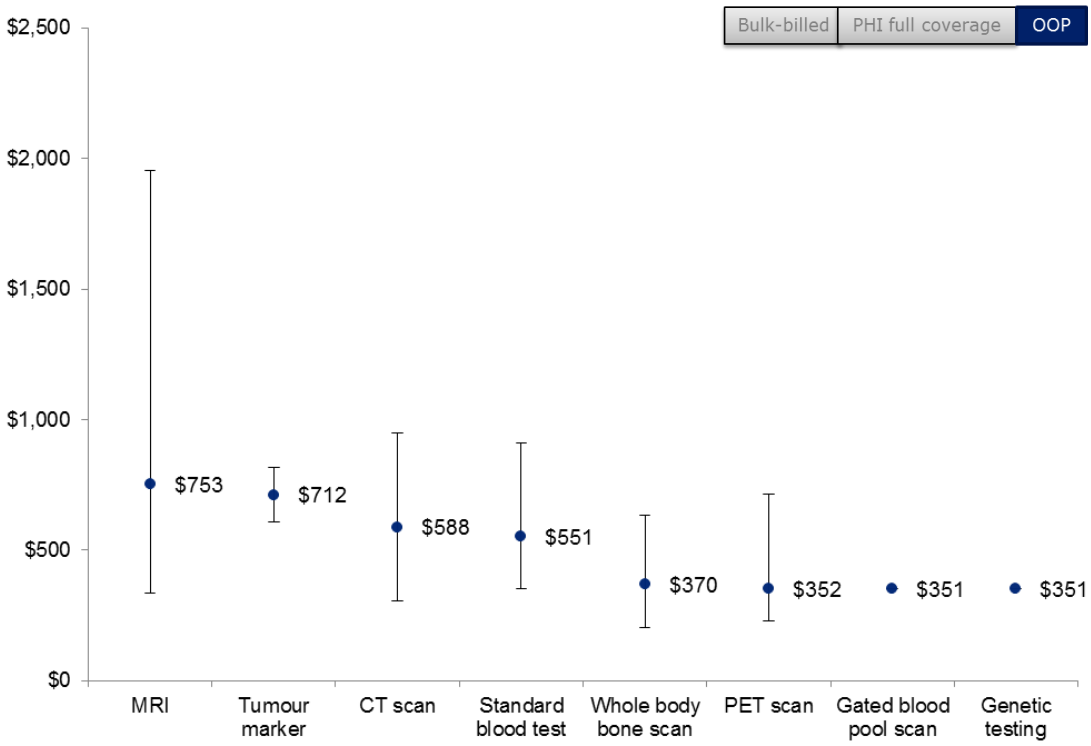
Chart 10.6: Profile 5: Median costs and interquartile range, 25th to 75th percentile, of direct medical treatments, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 68. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

A breakdown of the various types of tests for Profile 5 is included in Chart 10.7 below. This breakdown shows that for those who face a cost, the most was spent on MRIs and a tumour market test. These tests are not weighted; therefore the chart shows that 50% of people who paid for MRIs paid at least $753. The MRI test has a very wide range for Profile 5 with the third interquartile range falling between $753 and approximately $2,000.

Chart 10.7: Profile 5: Median costs and interquartile range, 25th to 75th percentile, of tests, excluding bulk-billed and PHI covered items and services (top eight items)

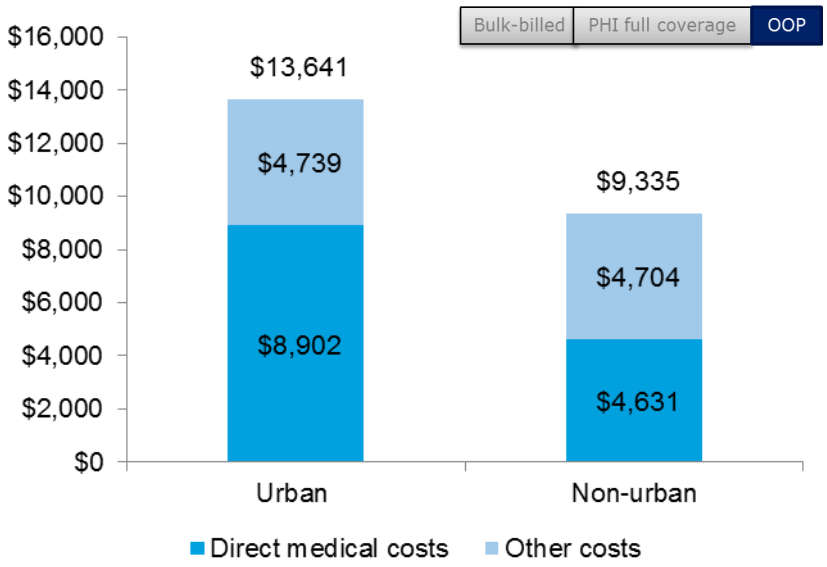


Note: Median costs are reported without weighting. Bars around the median indicate the second and third interquartile ranges (middle 50% of people). Number of respondents: 68, See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

10.2.3 Geographic considerations

There were insufficient responses to Profile 5 to divide the sample by jurisdiction. However, when OOP costs are divided into urban and non-urban postcodes of main residence while receiving treatment, the overall reported costs are higher (approximately $4,300) for urban residents. The difference in costs reported is driven by the higher direct medical OOP costs. The other costs paid are almost identical, see Chart 10.8.

Chart 10.8: Profile 5: Median direct medical and other costs, by region, excluding bulk-billed and PHI covered items and services

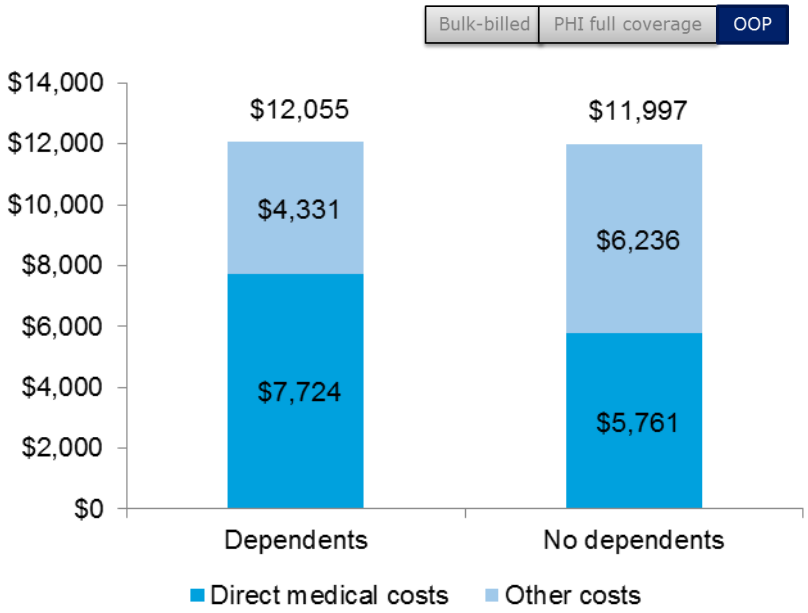


Note: Median costs have been weighted for number of services/items used. Number of respondents: Urban – 50, Non-urban – 18.

10.2.4 Dependent children

The reported total cost is almost equal (only a $60 difference) for those with dependent children compared to those without dependent children. However, those with dependent children reported costs of approximately $1,960 more for direct medical costs and $1,900 less for other costs, see Chart 10.9. Respondents in Profile 5 did not report any OOP costs associated with childcare.

Chart 10.9: Profile 5: Median direct medical and other costs by dependent child status, excluding bulk-billed and PHI covered items and services

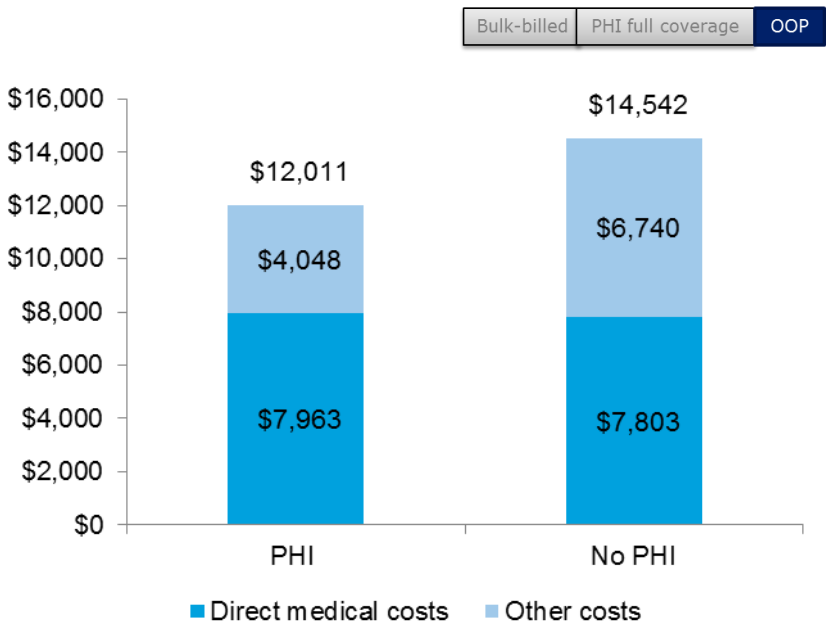


Note: Median costs have been weighted for number of services/items used. Number of respondents: Dependents – 26, No dependents – 42.

10.2.5 PHI

The reported total OOP cost for those without PHI is higher (approximately $10,300) than for those with PHI. Those without PHI reported higher OOP costs for the other costs category (approximately $2,700), see Chart 10.10.

Chart 10.10: Median direct medical costs and other costs by PHI status, excluding bulk-billed and PHI covered items and services



Note: Median costs have been weighted for number of services/items used. Number of respondents: PHI – 50, No-PHI – 18.

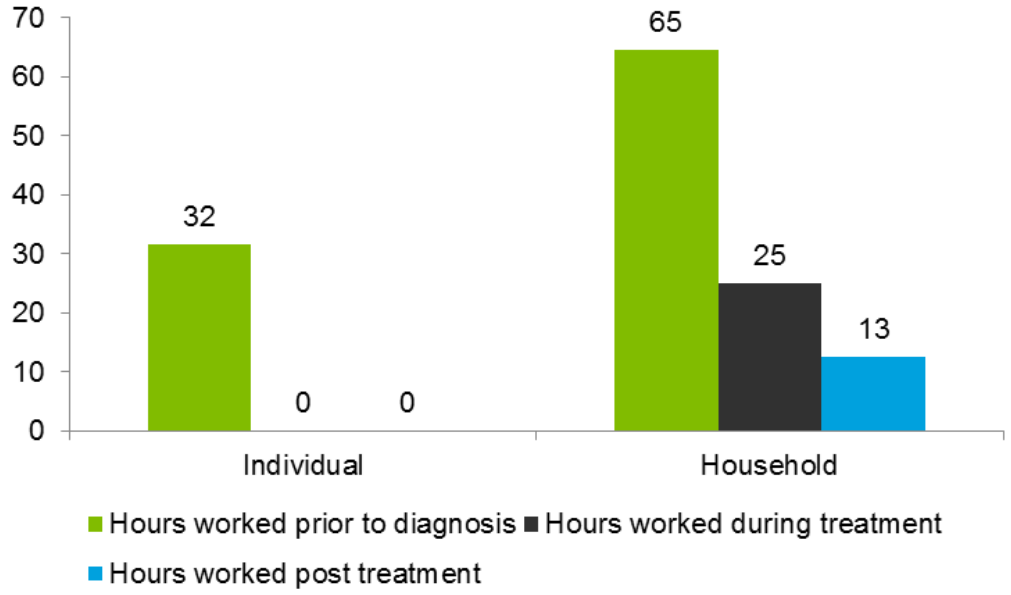
10.3 Indirect impacts: Income changes

Most respondents in Profile 5 did not work in paid employment during the first twelve months post diagnosis (median value drops from 16 hours per week pre diagnosis to zero) or go back to work after the first 12 months of treatment. The reported household workforce participation also decreases from a median of 65 hours per week prior to diagnosis to 25 hours per week during the first 12 months of treatment (a 61% decrease), see Chart 10.11.

From 12 months to 24 months post-diagnosis, household workforce participation decreases again to 13 hours per week (an 81% decrease from prior to diagnosis).

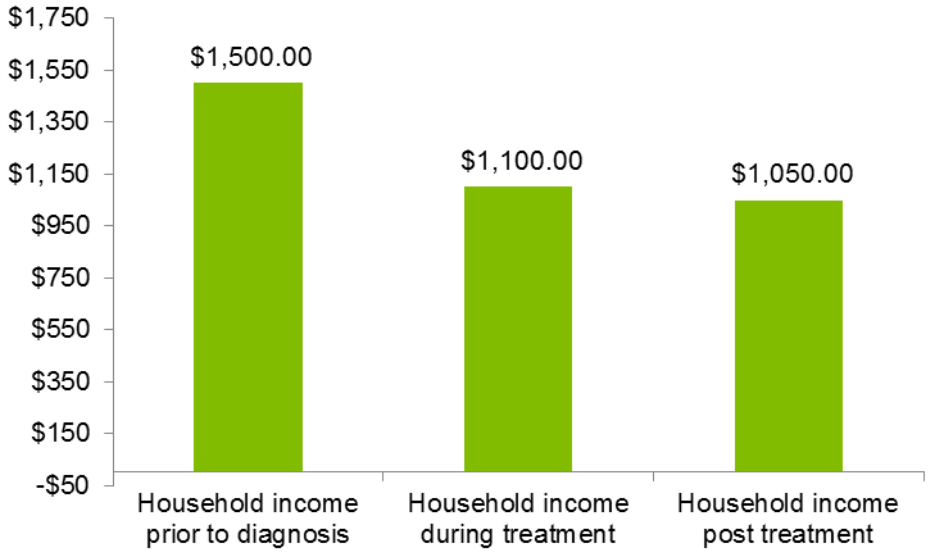
There is a corresponding decrease in household income observed, see Chart 10.12. The chart shows a 27% decrease in the average household weekly income during treatment for breast cancer compared to the 12 months prior to diagnosis. In the 12 months after treatment completion, there is a further $50 per week decrease, which is a total of 30% decrease from the household income prior to diagnosis

Chart 10.11: Profile 5: Median hours worked per week prior, during and post treatment (n = 68 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

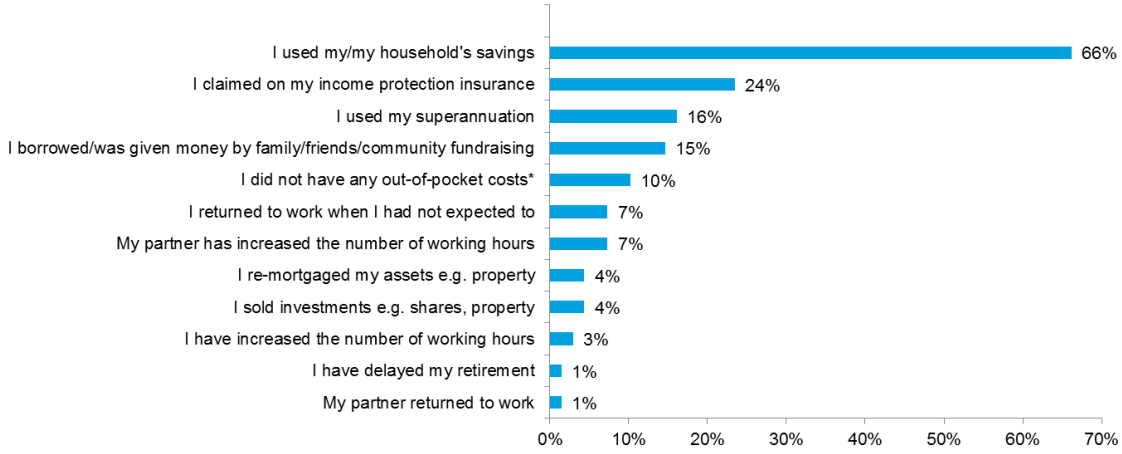
Chart 10.12: Profile 5: Median weekly household income prior, during and post treatment (n = 68 respondents)



Notes: 'Prior' is the 12 months prior to diagnosis, 'during treatment' is defined as the twelve month period after diagnosis, 'post treatment' between 12 and 24 months post diagnosis.

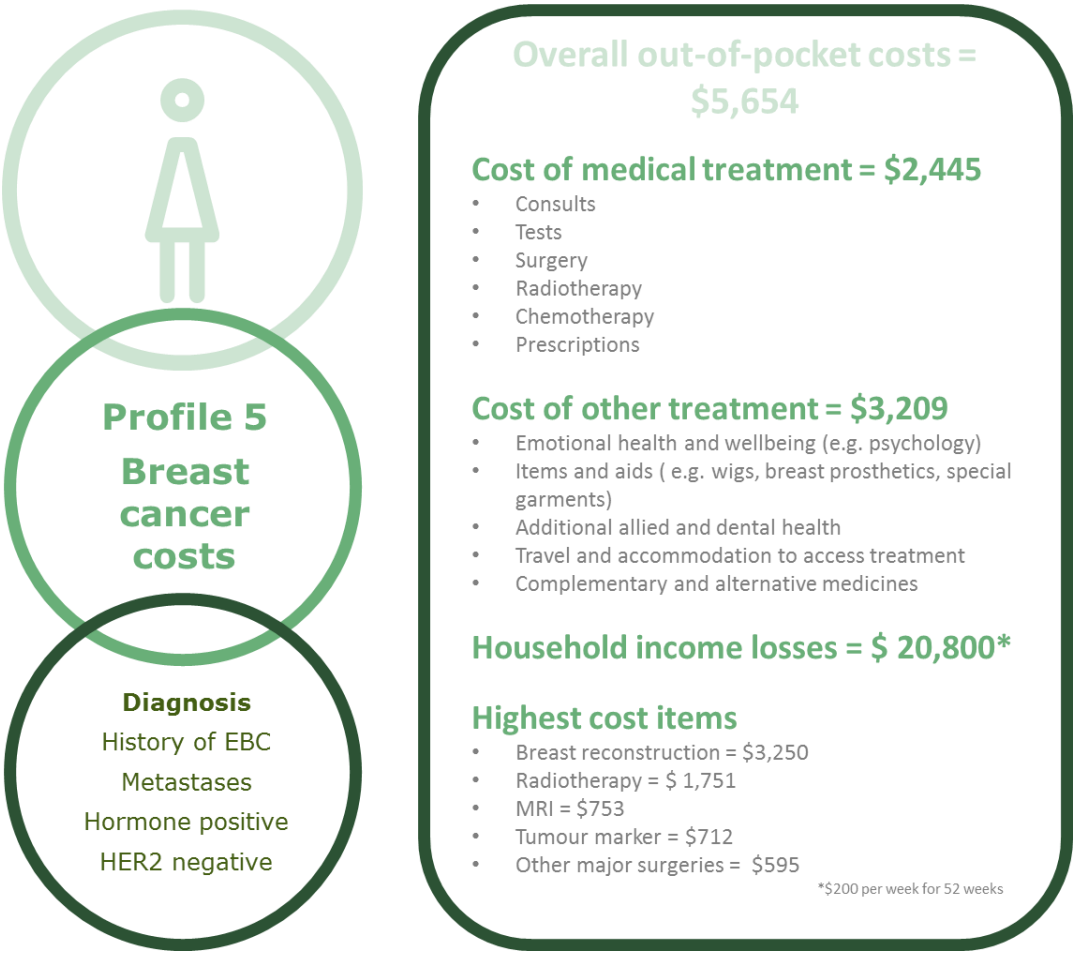
To cover the OOP costs associated with their breast cancer diagnosis and treatment, 66% reported that they used household savings, 24% claimed on income protection insurance, and 16% used their superannuation. Full results for Profile 5 are reported in Chart 10.13 below.

Chart 10.13: Profile 5: How did you meet the costs associated with your breast cancer diagnosis and treatment?



Note: Respondents (n = 68) were allowed to select more than one answer.

10.4 Profile summary

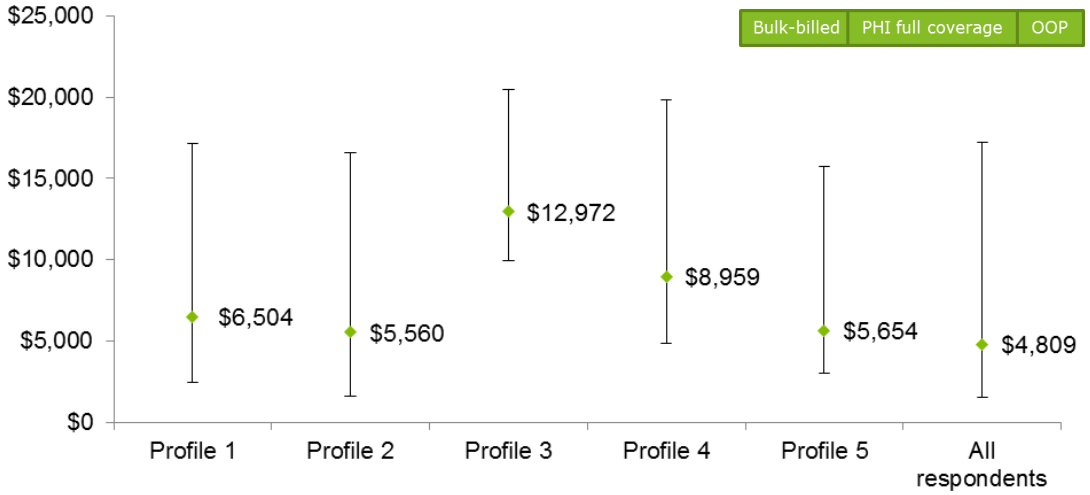


11 Discussion of Profile findings

The survey found that women with breast cancer fitting diagnostic Profile 3 had the highest overall OOP costs, followed by Profile 4, Profile 1, Profile 5 and Profile 2. However, Chart 11.1 shows that there is substantial variability in the reported costs within each Profile, with the reported interquartile ranges for each Profile overlapping. This indicates that there is similarity in the overall OOP costs incurred by respondents in fitting different diagnostic Profiles.

Women with breast cancer in Profiles 3 and 4 incurred higher OOP costs possibly because their disease states required more testing and intensive treatments. Furthermore, respondents in Profiles 3 and 4 were younger than the other Profiles, with 72% and 73% respectively under the age of 60 years, respectively. This is compared to only 57%, 65% and 60% for Profiles 1, 2 and 5 respectively under the age of 60 years. Some of the high OOP cost items, such as breast reconstruction surgery were more common for respondents under the age of 60 years: 86% of respondents who reported that they had breast reconstruction surgery were under the age of 60 years.

Chart 11.1: Median costs and interquartile range, 25th to 75th percentile, by Profile, including bulk-billed and PHI covered all items and services



Number of respondents: Profile 1 – 577, Profile 2 – 346, Profile 3 – 29, Profile 4 – 25, Profile 5 – 68, All respondents – 1919. See Appendix F for exact values for 25th and 75th percentile ranges and number of items and services reported under each category.

Women in Profile 5 may have incurred lower OOP costs because respondents were only reporting costs relating to their most recent, in the case of Profile 5, MBC diagnosis. As such, many respondents from Profile 5 may have incurred substantial OOP costs from surgeries, tests and other treatments from earlier breast cancer diagnoses, which, as intended, were not captured in this survey. Respondents in Profile 5 were provided with the option of documenting 'other surgery related to your metastatic breast cancer', but only three of the 68 respondents in Profile 5 selected this option. In addition, Profile 5 was defined by a woman being HER2 negative, rather than HER2 positive, meaning that high cost targeted therapy drugs such as pertuzumab (Perjeta), trastuzumab (Herceptin) and ado-trastuzumab

(Kadcyla), were not relevant treatments for their diagnosis. Women with MBC who were HER2 positive were likely to have incurred much greater costs if they had needed to purchase these medicines prior to July 2015[20].

Although survey data was methodically cleaned, the costs reported within each Profile showed wide variability for the overall OOP costs reported, OOP cost by categories and OOP costs related to individual items. This variability may have been due to a number of reasons:

- It may be reflective of the variation in the actual treatments offered to people within each treatment Profile. Although detailed clinical mapping was completed for each Profile to provide an indication of the likely treatments, it was found that people within the Profiles reported receiving other treatments outside the clinical pathways.
- The OOP costs reported are cumulative costs across 0-5 years post diagnosis. Hence, the variability within each Profile would have been influenced by the number of years since diagnosis, which in turn, would have influenced the frequency of cost items used.
- Profiles 3 and 4 had low sample sizes (n = 25 and n = 29 respectively) possibly resulting in larger sampling variance.

When comparing between Profiles, there was not as much spread in the median OOP cost values reported by category, except for two outliers: treatment for Profile 4 and travel and accommodation for Profile 3, see Chart 11.2and Table 11.2. The travel and accommodation outlier for Profile 3 may be influenced by the low number of responses, n = 2, and the relatively high costs reported compared to costs reported by respondents in the other Profiles[21]. For Profile 4, a low sample size and high cost of breast surgery (respondents in Profile 4 are likely to require a bilateral mastectomy and autologous breast reconstruction, see Table 2.1) possibly caused a higher median treatment cost than the other Profiles.

[20] These targeted therapies were placed on the PBS on 1 July 2015.

[21] Given the low total sample size Profile 3 (n = 25) these results weren't discarded. Also, it is possible that they were reported accurately given that there were only two respondents that reported travel and accommodation costs and there is no reason why their costs may not have been higher than the rest of the survey respondents.

Chart 11.2: Median costs for each category by Profile, excluding bulk-billed and PHI covered items and services*

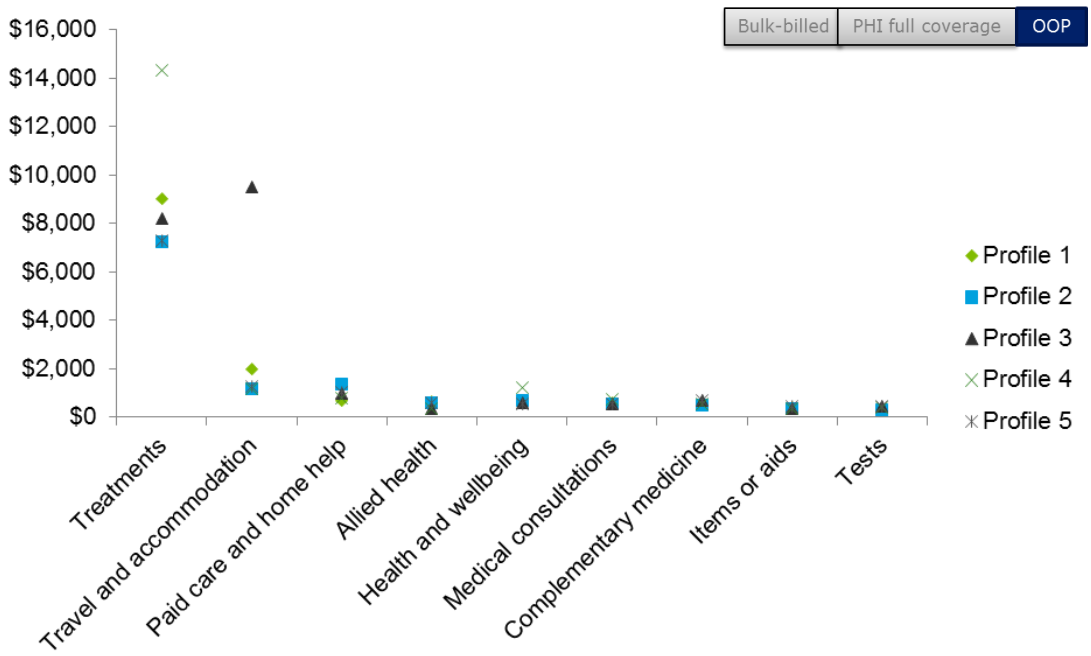


Table 11.2: Median costs for each category by Profile excluding bulk-billed and PHI covered items and services*, (n = number of items/services reported[#])

Category	Profile 1 (n)	Profile 2 (n)	Profile 3 (n)	Profile 4 (n)	Profile 5 (n)
Treatments	$9,004 (1,469)	$7,232 (1,037)	$8,152 (75)	$14,304 (93)	$7,235 (187)
Travel and accommodation	$1,938 (457)	$1,168 (340)	$9,457 (30)	$1,111 (28)	$1,226 (71)
Paid care and home help	$648 (49)	$1,369 (52)	$951 (10)	$751 (1)	$977 (14)
Allied health	$573 (346)	$592 (355)	$325 (35)	$312 (29)	$540 (89)
Health and wellbeing	$564 (337)	$688 (261)	$538 (28)	$1,154 (21)	$505 (59)
Medical consultations	$549 (787)	$555 (560)	$476 (41)	$688 (44)	$518 (98)
Complementary medicine	$528 (247)	$475 (204)	$620 (10)	$501 (15)	$634 (59)
Items or aids	$331 (523)	$367 (651)	$297 (77)	$284 (47)	$410 (80)
Tests	$286 (784)	$318 (647)	$411 (58)	$365 (57)	$420 (93)

*Only includes items when OOP costs were incurred. The costs per category are reflective of weighted median costs. That is, each category is made up of multiple cost items and services reported. The weighted median takes in to account the number of times each cost item was used (and incurred an OOP cost) within the category of items and services.

[#]n stands for the number of times an item or service was reported within a category and does not necessarily equal the frequency with which it was used. For example in Profile 1, for medical consultations, n = 787. This means that across the 577 respondents in Profile 1, there were 787 reports of consultation with different medical

specialists. However, each reported consultation may have been made up of multiple visits. That is, if a respondent said they saw their medical oncologist four times, the cumulative cost was calculated and this was counted as one item/service, not four.

The median OOP costs reported for treatments are also fairly consistent across the Profiles with the main outlier for breast reconstruction from Profile 4, see Chart 11.3 and Table 11.3.

Chart 11.3: Median costs for each treatment by Profile, excluding bulk-billed and PHI covered items and services*

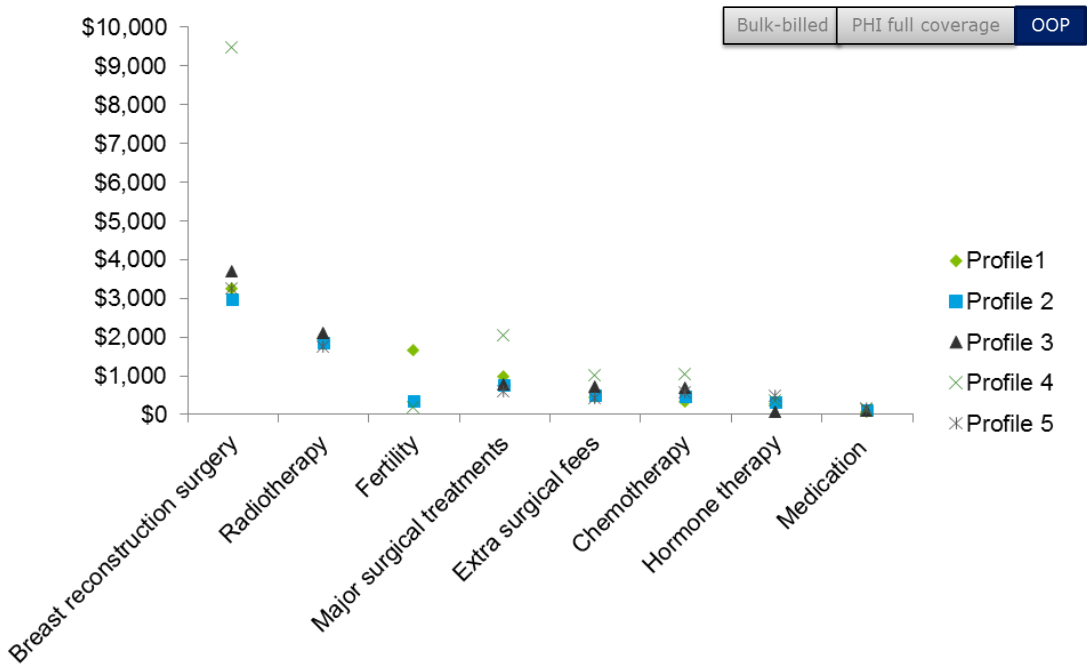


Table 11.3: Median costs for each treatment by Profile, excluding bulk-billed and PHI covered items and services*, (n = number of items/services reported#)

	Profile1 (n)	Profile 2 (n)	Profile 3 (n)	Profile 4 (n)	Profile 5 (n)
Breast reconstruction surgery	$3,250 (50)	$2,957 (47)	$3,710 (5)	$9,472 (9)	$3,250 (2)
Radiotherapy	$1,951 (92)	$1,851 (64)	$2,101 (4)	NA (0)	$1,751 (14)
Fertility	$1,661 (18)	$345 (18)	NA (0)	$199 (2)	$NA (0)
Major surgical treatments	$987 (248)	$752 (133)	$774 (12)	$2,051 (27)	$595 (18)
Extra surgical fees	$451 (337)	$473 (195)	$723 (18)	$1,028 (26)	$419 (31)
Chemotherapy	$351 (43)	$451 (59)	$680 (7)	$1,051 (5)	$576 (12)
Hormone therapy	$279 (421)	$309 (296)	$72 (1)	$368 (1)	$478 (56)

Medication	$74 (260)	$94 (225)	$92 (28)	$136 (23)	$166 (54)

*Only includes items when OOP costs were incurred. The costs per treatment are reflective of weighted median costs. That is, each treatment may be made up of multiple cost items or services reported. The weighted median takes in to account the number of times each cost item was used (and incurred an OOP cost) within the treatment category. This means that some treatment costs may seem lower than they would otherwise appear at an individual response level if all cost items associated with that treatment were used.

#n stands for the number of times an item or service was reported within a treatment and does not necessarily equal the frequency with which it was used. For example in Profile 1, for hormone therapy, n = 421. This means that across the 577 respondents in Profile 1, there were 421 reports of hormone therapy used. However, each reported hormone therapy may have been made up of multiple prescriptions. That is, if a respondent said they purchased 12 prescriptions for tamoxifen, the cumulative cost for the 12 prescriptions was calculated and this was counted as one item/service, not twelve.

The reason for high breast reconstruction costs in Profile 4 is outlined above and is possibly a reflection of the larger surgical requirement for people in this Profile. Consistent with this, Profile 4 also has a higher median OOP cost for other 'major surgical treatments' and 'extra surgical fees' than the other Profiles. People in Profile 4 are also unlikely to require radiotherapy (see Table 2.1) which is consistent with no respondents reporting an OOP cost for this treatment.

The median chemotherapy OOP cost is higher for Profile 4 than the other Profiles, but this result is limited by a low number of respondents (n=5) reporting costs. The median costs of fertility treatment are limited by low sample sizes and report a weighted average median OOP cost where fertility treatment was used (Profiles 1, 2 and 4 only). Given that fertility treatment is made up of a number of items, the weighted median OOP cost for fertility treatment was calculated depending on the frequency of use of each fertility cost item (see explanation of weighting methodology in section 1.1.1). Therefore, the full OOP cost of an individual's fertility treatment, if they used all the associated items, is not fully reflected in the calculation.

Across the Profiles, there was some variability in the median OOP costs for each test. However, the data is reported as a cumulative total OOP cost for each test from 0 to 5 years post diagnosis of breast cancer. Given that some tests may be required multiple times during the diagnosis and treatment for breast cancer, the known limitations are the sample size in each Profile and the proportional years post-diagnosis represented in each Profile. However, except for molecular tests, genetic tests, MRIs and X-rays, the cumulative total OOP cost for each test is mostly under $1000 with a greater proportion under $500, see Chart 11.4 and Table 11.4.

Chart 11.4: Median costs for each test by Profile, excluding bulk-billed and PHI covered items and services*

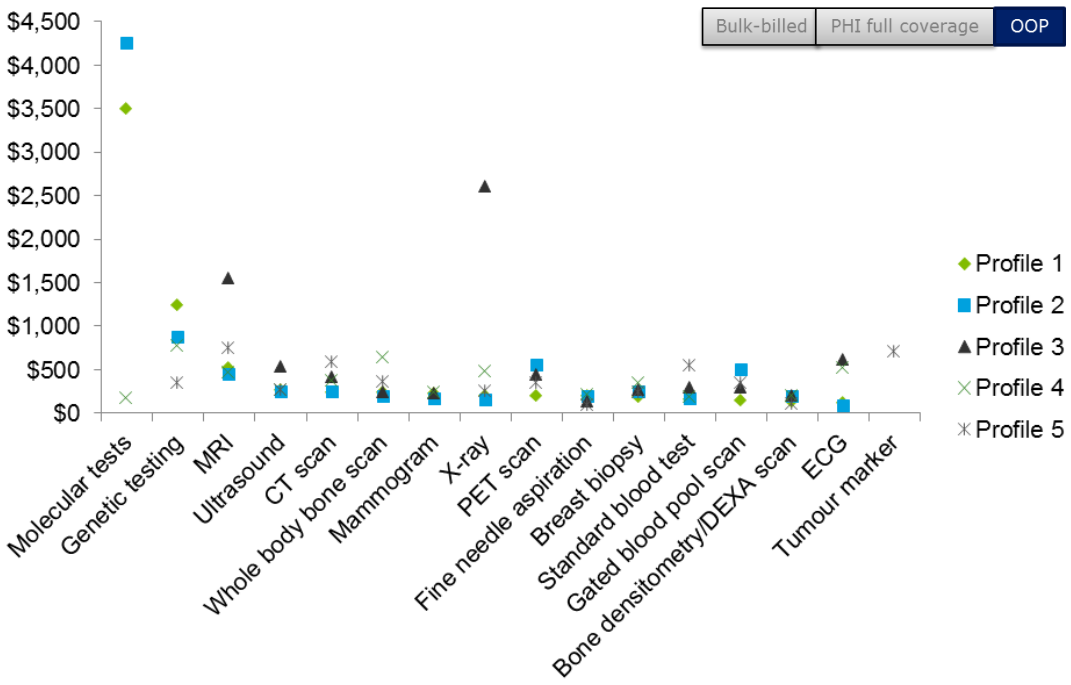


Table 11.4: Median costs for each test by Profile*, (n = number respondents who used the test#)

	Profile 1 (n)	Profile 2 (n)	Profile 3 (n)	Profile 4 (n)	Profile 5 (n)
Molecular tests	$3,500 (8)	$4,250 (12)	NA (0)	$172 (1)	NA (0)
Genetic testing	$1,251 (10)	$877 (10)	NA (0)	$774 (2)	$351 (1)
MRI	$525 (58)	$451 (40)	$1,554 (2)	$468 (7)	$753 (13)
Ultrasound	$270 (172)	$251 (119)	$543 (12)	$272 (11)	$278 (14)
CT scan	$252 (40)	$251 (46)	$422 (6)	$385 (4)	$588 (17)
Whole body bone scan	$251 (33)	$186 (41)	$251 (7)	$651 (5)	$370 (10)
Mammogram	$228 (131)	$166 (107)	$232 (6)	$251 (8)	NA (0)
X-ray	$212 (35)	$146 (13)	$2,604 (1)	$480 (1)	$262 (10)
PET scan	$212 (4)	$551 (13)	$451 (1)	NA (0)	$352 (4)
Fine needle aspiration	$204 (52)	$196 (48)	$136 (8)	$224 (4)	$96 (3)
Breast biopsy	$192 (109)	$240 (92)	$269 (8)	$351 (10)	$249 (8)

Standard blood test	$166 (25)	$170 (20)	$295 (2)	$198 (1)	$551 (5)
Gated blood pool scan	$146 (3)	$502 (5)	$295 (2)	NA (0)	$351 (1)
Bone densitometry/DEXA scan	$141 (96)	$196 (69)	$209 (2)	$212 (2)	$106 (5)
ECG	$121 (8)	$91 (12)	$624 (1)	$530 (1)	NA (0)
Tumour marker	NA (0)	NA (0)	NA (0)	NA (0)	$712 (2)

*Only includes tests when OOP costs were incurred. As the median costs relate to individual cost items (tests), they are not weighted

#n stands for the number of times test was reported by respondents, not the frequency of use by each respondent. For example, in Profile 1, 58 of the 577 respondents used had at least one MRI. That is, if a respondent reported they had two MRIs, the cumulative cost of the MRIs was calculated and this was counted as one response for MRI, not two.

The spread of OOP costs for molecular tests is likely to be influenced by low sample sizes where for Profile 1; n = 8 respondents, Profile 2; n =12, Profile 3; n = 0, Profile 4; n= 1 and Profile 5; n = 0. Likewise, the spread for genetic tests is likely due to low sample sizes. However, the reported OOP costs are realistic, with the quoted OOP cost being around $4000 to $5000 for the Oncotype DX molecular test (no Medicare rebate or PHI rebate) and between $2900 and $4200 for tumour genomic analysis (genetic tests) (BCNA, 2014 and BCNA, 2016).

Profile 3's median OOP cost for MRIs is an outlier at over $1500 and for X-rays at over $2000; however, these results are based on a sample size of only two people and one person respectively. Although they are outliers when compared to the median costs reflected in other Profiles, they have not been excluded as they are possibly accurate given that they may account for more than one of each test.

12 Conclusions and implications

In Australia, public and private health insurance schemes provide financial coverage for a range of medical services for the management of breast cancer. This report shows that about half of all services used by survey respondents did not incur an OOP cost. However, this report also shows that the financial impact may be significant for some women with breast cancer. The financial impact is caused by OOP costs associated with medical treatments and other services, combined with decreased workforce participation and household income.

In the first five years following a diagnosis of breast cancer, the analysis estimates that a woman will typically incur OOP costs of $4,809. Breast surgeries, radiotherapy, chemotherapy, hormone therapy, and medicines are the major contributors to OOP costs. The highest OOP costs were associated with breast reconstructive surgery, radiotherapy, and specific tests such as Oncotype DX tests, genetic tests and MRIs. Most of the costs were incurred within 2 years from diagnosis.

There is large variability in the reported OOP costs even among women with the same breast cancer Profile (e.g. interquartile range around the median OOP costs was from $1,500 to $17,200). This suggests that a range of factors other than breast cancer Profile has an impact on the level of OOP costs. Indeed, the analysis found that place of residence is one of the factors influencing the level of OOP costs. For example, survey respondents living in urban and non-urban areas during treatment reported similar overall median costs, but respondents in non-urban locations reported using less treatments, items, and services than their urban resident counterparts. Furthermore, financial impacts are higher for non-urban respondents because they experienced larger decrease in total household income and household workforce participation compared to urban respondents.

The analysis also found that having PHI may be associated with higher OOP costs. Respondents with PHI paid an OOP cost for more items and services, and at higher overall prices than respondents without PHI. Consistent with the literature reported in Chapter 2, whether or not a person with breast cancer has PHI during their treatment was found to drive OOP costs. Overall, the median direct medical OOP cost for women with PHI was over 10 times higher than for women without PHI. Women with PHI also paid an OOP cost for a larger proportion of direct health items and services compared to women without PHI (57% compared to 26%).

People will draw on multiple resources in order to cover the OOP costs associated with their breast cancer diagnosis, treatment and other associated cost items. Over two-thirds of people surveyed reported using their own or their household's savings, 12% claimed income protection and 11% borrowed money from family and friends. The longer term impact of these strategies was not studied as part of this research. However, they are all likely to have future consequences that may lead to more financial burden for individuals and their families such as decreasing retirement funds and increasing personal debt. Quality of life may also be adversely affected through return to the workforce in older age and the additional stress of financial burden and poor health.

Implications for BCNA

In view of the survey findings presented, BCNA may explore four opportunities for potential policy reform. These are:

- Reviewing policy settings relating to the coverage of medical services for breast cancer in the public and private insurance schemes, including in particular medical services for breast cancer management, such as surgery
- Reviewing the consistency and transparency of pricing of goods and services relating to breast cancer management so that women are able to make informed choices and mitigating the risks of differential pricing for women with PHI
- Reviewing policies to support women living in non-urban areas and some jurisdictions (e.g. NT and Tasmania) where access to breast cancer services may be more limited than in urban areas and other jurisdictions. Women living in these areas may require higher level of support because of potential higher financial impacts than their urban counterparts.
- Exploring the specific types of ancillary services that would most improve the wellbeing of women with breast cancer. This is in recognition of the survey observation that women are currently accessing a wide range of ancillary services that have contributed significantly to OOP cost but may have limited evidence to support their use. The BCNA can help close information gaps and guide women to the services which will most improve their wellbeing and quality of life.

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Appendix A: Diagnostic and treatment maps

BCNA in consultation with clinical specialists developed the following clinical treatment pathways for each of the five diagnostic Profiles. These treatment pathways were used to guide survey development in terms of the asking respondents for their OOP costs for identified consultations, tests and treatments.

Breast Cancer Network Australia

Financial Impact of Breast Cancer Project

Breast Cancer Profiles

Version 6
16 Jun 2016

BCNA Reference Group

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Understanding breast cancer treatment pathways

Diagnosis

Diagnosis of breast cancer is typically conducted through one of two pathways: 1) BreastScreen or 2) GP (through investigation of a self-detected lump). Each will involve a mammogram and ultrasound.

BreastScreen's screening and assessment services provide all clinical services from the initial screening mammogram to any further procedures required to the point of diagnosis. The national service invites women aged between 50 and 74 for a free mammogram every two years.

Most GP screening and assessment services will likely attract a Medicare rebate. However, many will also come with out of pocket costs to the patient, which can vary depending on if they have private health insurance. For more information on GP guidelines for the diagnosis of a new breast lesion, see here.

Once a breast cancer diagnosis is confirmed, there are three treatment options:

1) Surgery – either mastectomy or breast conserving surgery
2) Systemic therapy – e.g., chemotherapy, hormone therapy
3) Radiation.

Referral to Surgeon

As soon as a breast cancer diagnosis is confirmed through Breast Screen or GP, the woman will likely be referred to a breast surgeon.

Pre-surgery work-up

A breast surgeon will conduct further tests to determine the extent of the breast cancer. There are two areas where cancer can be found in early breast cancer: 1) in the breast 2) in the axilla (armpit).

1) **Breast** – There are two options for surgical management of breast cancer:
    a. Mastectomy (unilateral, bilateral)
    b. Breast conserving surgery/lumpectomy.

2) **Axilla -** To assess the axilla prior to surgery ultrasound +/- FNA is performed:
    a. If FNA is positive - axillary dissection will be added to breast surgery Axillary dissection involves removing several or all of the lymph nodes from the armpit. This will be done during breast surgery (breast conserving surgery or mastectomy) and may be done through the same incision as the breast surgery itself. However, it may be done as a separate operation.

    b. If FNA is Negative – Sentinel Node Biopsy (or sentinel lymph node biopsy) will be added to surgery.

SNB is a procedure in which the sentinel or 'guardian' lymph nodes are identified, removed, and pathologically examined to determine whether cancer cells are present. Sentinel node biopsy is usually done at the same time as breast surgery (lumpectomy or mastectomy) but sometimes it may be performed as a separate procedure. Three costs will be incurred here (pathology, surgery, radiology)

Surgery

Surgical treatment options include the following:

a. Removal of cancer in the breast: Lumpectomy or partial mastectomy almost always followed by radiation therapy or mastectomy, with or without immediate reconstruction.

b. Lymph node evaluation: Sentinel lymph node biopsy and/or axillary lymph node dissection. **If the lymph nodes have been proven positive in the preoperative assessment, the axillary dissection is performed**. **If they have not been shown to be involved, the Lymphatic mapping (nuclear medicine) is performed prior to surgery** – a small amount of radioactive material is injected into the breast. The radioactive tracer travels to the sentinel nodes, along the same lymphatic channels that cancer cells could travel and can be seen on a nuclear medicine scan (lymphoscintogram). After this, a sentinel node biopsy is performed during the operation.

Women with a very high risk of developing a new cancer (i.e., BRCA 1/2 gene carriers) in the other breast may consider a bilateral mastectomy, meaning both breasts are removed.

Radiation Therapy

Radiation therapy is the use of high-energy X-rays or other particles to kill cancer cell and is managed by a radiation oncologist. The most common type of radiation treatment is called external-beam radiation therapy, which is radiation given from a machine outside the body.

Systemic Therapy – chemotherapy

There are three general categories of systemic therapy used for breast cancer: chemotherapy, hormonal therapy, and targeted therapy.

Chemotherapy

Chemotherapy may be given before surgery to shrink a large tumour and make surgery easier, called neoadjuvant or preoperative chemotherapy. It may also be given after surgery to reduce the risk of recurrence, called adjuvant chemotherapy. Chemotherapy may also be given if a patient has a metastatic breast cancer recurrence.

A chemotherapy regimen (schedule) consists of a specific treatment schedule of drugs given at repeating intervals (cycles) for a set period of time.

Hormone Therapy

Hormonal therapy, also called endocrine therapy, is an effective treatment for most tumours that test positive for either estrogen or progesterone receptors (called ER-positive or PR-positive) in both early-stage and metastatic breast cancer. Types of hormonal therapy include Tamoxifen (pre-menopausal women) and a number of aromatase inhibitors (AIs) (post-menopausal women).

Targeted Therapy

Targeted therapy is a treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. These treatments are very focused and work differently than chemotherapy. This type of treatment blocks the growth and spread of cancer cells while limiting damage to healthy cells.

One common type of targeted therapy is HER2 targeted therapy. This therapy targets a particular protein on the cancer cell that promotes growth of the cell – the HER2 protein. A biopsy of the cancer cells is conducted to determine HER2 status – either positive or negative.

Types of HER2 targeted therapy include:

- Trastuzumab (Herceptin) - treatment of advanced HER2-positive breast cancer and as an adjuvant therapy for non-metastatic HER2-positive breast cancer
- Pertuzumab (Perjeta)
- Ado-trastuzumab emtansine or T-DM1(Kadcyla)
- Lapatinib (Tykerb).

For a more detailed overview of breast cancer treatment options, see:
http://www.cancer.net/cancer-types/breast-cancer/treatment-options

Diagnostic Pathways

1. Breast Screen

- Consult: BreastScreen appointment
    - Test: mammogram
- Consult: BreastScreen f/up recall appointment
    - Test: mammogram
    - Test: ultrasound
    - Test: breast biopsy +/- under ultrasound
        - Histopathology: biopsy specimen (including immunochemistry for receptors and FISH for Her 2 if contemplating neoadjuvant chemo)
- Test: ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will often be conducted by surgeon after referral)
- Consult: GP (discusses diagnoses, refers to breast surgeon for management).

Surgical workup

- Consult: breast surgeon (diagnosis and treatment plan discussion)
    - Test: blood pathology
    - Test: +/- ultrasound (depending on if conducted in Breast Screen)
    - Test +/- chest X-ray (not standard, depending on age and fitness level , typically older women)
    - Test +/- ECG (not standard, depending on age and fitness level, typically older women)
- Consult: medical oncologist
- Consult: radiation oncologist.

2. Self-detected

Screening and diagnostic work-up (~3 weeks)

- Consult: GP (history taking, breast exam)
    - Test: mammogram
    - Test: ultrasound
    - Test: breast biopsy +/- under ultrasound
    - Histopathology: biopsy specimen (including immunochemistry for receptors)
- GP may order ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will often be conducted by surgeon after referral)
- Consult: GP (confirms diagnosis and refers to breast surgeon – public or private).

PROFILE 1
• Detected via BreastScreen • Low risk / grade 1 or 2 • Node negative • Hormone positive • HER2 negative • Age 50 – 74 years (post-menopausal)

Note: +/- indicates where tests or procedures may be ordered depending on the condition of the patient. This is included to calculate the range of costs possible.

Screening and diagnostic work-up (~2 weeks)

- Consult: BreastScreen appointment
  - Test: mammogram
- Consult: BreastScreen f/up recall appointment
  - Test: mammogram
  - Test: ultrasound
  - Test: breast biopsy +/- under ultrasound
    - Histopathology: biopsy specimen (including immunochemistry for receptors and ISH for Her 2 if contemplating neoadjuvant chemo)
  - Test: ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will often be conducted by surgeon after referral) (Result = positive, have SNB)
- Consult: GP (discusses diagnoses, refers to breast surgeon for management)

Breast surgeon consultation

- Consult: breast surgeon (diagnosis and treatment plan discussion)
  - Test: blood tests
  - Test: +/- ultrasound (depending if conducted in breast screen)
  - Test +/- chest X-ray (not standard, typically done in very old women)
  - Test +/- ECG (not standard, depending on age and fitness level)

Breast conserving surgery (~4 to 6 weeks) and further treatment planning

- Procedure: sentinel node mapping (Lymphoscintigram: nuclear medicine, Item 30299)
- Procedure: wide local excision (Item 31512) + histopathology
- Procedure: breast conserving surgery
- Procedure: + sentinel node biopsy (Item 30300)
- Consult: breast surgeon (post-surgery 1 week f/up)
- Consult: breast surgeon (post-surgery 2 week f/up)
- Consult: medical oncologist (treatment planning)

- Consult: radiation oncologist (treatment planning MDT Items 871 for surgeon and 872 for others including pathology)

Radiation treatment (~3-4weeks based on CA guidelines)

- Treatment: radiation treatments x 15-20 treatments (each day x 5 days x 3-4 weeks)
- Consult: radiation oncologist (treatment f/up – weekly)
- Consult: radiation oncologist (end treatment f/up)

Hormone therapy (5 to 10 years)

- Consult: medical oncologist (treatment planning: MBS item 872 for MDT + 110 for first consult)
    - Test: initial blood test (to check calcium, vitamin D)
    - Test: bone mineral density scan (DXA)
- Consult: medical oncologist (treatment planning, MBS Item 116)
    - Prescription: hormone therapy (tamoxifen x 6/year, aromatase inhibitor x 12/year)
- Consult: medical oncologist f/up x 1 visit per year.

Primary care

- Consult: GP x 4 visits per year

Other

- Test: f/up mammogram at 12 months post original screening mammogram

Public versus private pathway:

- Same for both pathways except costs incurred for all consults (except for initial BreastScreen appointment) and all tests (except initial and f/up mammogram) and prescriptions (possible Health Care Card/Pensioner discounts)
- Private medical oncologist may order Molecular tests (i.e., Oncotype Dx) in treatment planning phase before radiation starts to determine risk of recurrence or need for chemotherapy (if grade 2). Public patients can also elect to have these tests.

PROFILE 2
• Self-detected • High grade • Node positive • Hormone positive • HER2 negative • Age 50 – 65 years (post-menopausal)

+/- indicates where tests or procedures may be ordered depending on the condition of the patient. This is used to calculate the range of costs possible.

Sentinel node mapping is part of the operation should sentinel node biopsy be performed. It is listed as a dot point "Lymphoscintigram" + surgery. This is part of the management, rather than the workup.

Screening and diagnostic work-up (~3 weeks)

- Consult: GP (history taking, breast exam)
  - Test: mammogram
  - Test: ultrasound
  - Test: breast biopsy +/- under ultrasound
    - Histopathology: biopsy specimen (including immunochemistry for receptors)
- GP may order ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will often be conducted by surgeon after referral)
- Consult: GP (confirms Dx and refers to breast surgeon – public or private)

Breast surgeon: pre-operative workup

- Consult: breast surgeon (diagnosis and treatment plan discussion)
  - Test: blood pathology
  - Test: +/- ultrasound (depending on breast screen)
  - Test: +/- CT (chest, abdomen, pelvis)
  - Test: +/- bone scan (whole body)
- Procedure: wide local excision (Item 31512)
- Procedure: lymphatic mapping (Lymphoscintigram: nuclear medicine, Item 30299)
  - Test +/- chest X-ray (not standard, depending on age and fitness level)
  - Test +/- ECG (not standard, depending on age and fitness level)
- Consult: medical oncologist
- Consult: radiation oncologist

Unilateral Mastectomy (~4 to 6 weeks) and further treatment planning

- Consult: plastic surgeon
- Procedure: unilateral mastectomy
- Procedure: axillary dissection

- Consult: plastic surgeon
- Procedure: breast reconstruction (optional)
- Consult: breast surgeon (post-surgery 1 week f/up – surgical fees included in follow-up)
- Consult: plastic surgeon (x2-3 for tissue expansion – NB Will vary according to whether reconstruction is done and what type of reconstruction)
- Consult: breast surgeon (post-surgery 2 week f/up – surgical fees included in follow-up)
- Consult: medical oncologist (treatment planning)
    - Test: +/- echocardiogram (ECG)
- Consult: Medical oncologist (confirm results, prepare for chemo) (NB this patient may be suitable for neoadjuvant chemotherapy)

Adjuvant chemotherapy (4-6 weeks, 3 weekly cycles)

- Treatment: 3 weekly cycles of chemotherapy for 18 weeks (6 cycles in total. MBS Item: 13918 x 6). Each cycle includes:
    - Test: blood pathology (before chemotherapy)
- Consult: medical oncologist (to review blood tests to proceed to chemotherapy)
    - Prescription: +/- antiemetics (NB: may be included in health fund bundle for day only admission in private hospital)
- Consult: medical oncologist (end of treatment)
    - Test: blood pathology
    - Test : +/- DXA bone mineral density

Hormone therapy (5 to 10 years)

- Consult: medical oncologist (treatment planning)
    - Prescription: hormone therapy (pre-menopausal: tamoxifen x 6/year, post-menopausal: aromatase inhibitor x 12/year)
- Consult: medical oncologist f/up x 2 visits per year

Primary care

- Consult: GP x 4 visits per year

Other

- Test: f/up mammogram at 12 months post original screening mammogram
- This patient could be suitable for neoadjuvant chemotherapy

Public versus private pathway:

- Private patients will likely be offered more tests in the pre-Mastectomy diagnostic workup including +/- breast MRI or +/- PET (in high risk disease)
- Same for both pathways except costs incurred for all consults (except for initial BreastScreen appointment) and all tests (except initial and f/up

mammogram) and prescriptions (possible Health Care Card/Pensioner discounts)

- Public patients will likely have chemotherapy charged to Medicare.
- Private patients will likely have chemotherapy charged to private funds, but there may be gaps in private if the doctor does not have a no-gap policy

PROFILE 3
• Detected via BreastScreen • High grade • Node positive • Hormone negative • HER2 positive • Age not defined

+/- indicates where tests or procedures may be ordered depending on the condition of the patient. This is used to calculate the range of costs possible.

Screening and diagnostic work-up (~2 weeks)

- Consult: BreastScreen appointment
    - Test: mammogram
- Consult: BreastScreen f/up recall appointment
    - Test: mammogram
    - Test: ultrasound
    - Test: breast biopsy +/- under ultrasound
        - Histopathology: biopsy specimen (including immunochemistry for receptors and ISH for Her 2 if contemplating neoadjuvant chemo)
- Test: ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will often be conducted by surgeon after referral)
- Consult: GP (discusses diagnoses, refers to breast surgeon for management)

Breast surgeon pre-operative workup

- Consult: breast surgeon (diagnosis and treatment plan discussion)
    - Test: blood test
- Procedure: wide local excision (Item 31512)
    - Histopathology for wide local excision
    - Test: +/- CT
    - Test: +/- bone scan
    - Test: +/- ultrasound (depending on breast screen)
    - Test: +/- chest X-ray (not standard, typically done in very old women)
    - Test: +/- ECG (not standard, depending on age and fitness level)

Breast conserving surgery

- Procedure: breast conserving surgery
- Procedure: axilla dissection
    - Histopathology
- Consult: breast surgeon follow-up (surgical fees mostly included in follow-up)

Hormone treatment and adjuvant chemotherapy (4-6 months)

- Consult: medical oncologist (for cardiac workup and treatment planning (MBS Items 110 plus MDT 872)
    - Test: pathology blood
    - Test: gated blood pool OR echocardiogram always before chemotherapy and Herceptin
    - Prescription: trastuzumab (i.e Herceptin) for 12 months (3 month prescriptions x 4)
- Treatment: 3 weekly cycles of chemotherapy for 18 weeks. Each cycle includes:
    - Test: blood pathology (before every chemotherapy)
    - Test: Gated blood pool OR echocardiogram (every 3 months for the duration of chemotherapy)
    - Consult: medical oncologist (up to 10/year, Item 116)
    - Prescription: +/- antiemetics
- Consult: medical oncologist (end of treatment)
- Consult: radiation oncologist

Radiation Therapy (~3-4weeks)

- Treatment: radiation treatments x 30 treatments (each day x 5 days x 6 weeks)
- Consult: radiation oncologist (treatment f/up – weekly)
- Consult: radiation oncologist (end treatment f/up)

Primary care

- Consult: GP x 4 visits per year

Other

- Test: f/up mammogram at 12 months post original screening mammogram
- Test: +/- ultrasound
- NB: For Herceptin every dose (18) is charged for but the health funds will pay prescription charges for private day only patients if given in IV form, not if its given subcutaneously

PROFILE 4

- Self-detected
- High grade
- Triple negative
- BRCA 1 or 2
- Age <35 years
- Neo-adjuvant chemotherapy pathway

+/- indicates where tests or procedures may be ordered depending on the condition of the patient. This is used to calculate the range of costs possible.

Screening and diagnostic work-up (~3 weeks)

- Consult: GP (history taking, breast exam)
  - Test: mammogram
  - Test: ultrasound
  - Test: breast biopsy +/- under ultrasound
    - Histopathology: biopsy specimen (including immunochemistry for receptors)
  - GP may order ultrasound guided FNA biopsy (NOTE: This could be done in diagnostic phase, if not it will be conducted by surgeon after referral)
- Consult: GP (confirms diagnosis and refers to breast surgeon – public or private)

Decision making – medical oncologist (2-4 weeks)

- +/- Consult: Medical oncologist if neoadjuvant chemotherapy is being planned
  - Test: CT (chest, abdomen, pelvis)
  - Test: bone scan
- Consult medical oncologist (to review tests)
- Consult: plastic surgeon

Familial Cancer Centre and Fertility Options

- Consult: Genetic Counselling at Familial Cancer Centre (to test for BRCA mutation)
- IVF Consult: Fertility Centre (first consult is Medicare rebatable, there should be no out pof pocket costs to patient)
  - Test: AMH blood test for ovarian reserve (~$75)
- IVF Consult: Fertility workup
  - Test: Infection screen
  - Procedure: Egg Freezing (typically $4000/cycle to collect 8-12 eggs. Another cycle may happen after chemo)
  - Storage cost for eggs: $300/yr (not covered by MBS)

Neo-Adjuvant Chemotherapy (~4-6 months at 3 weekly cycles)

- Treatment: 3 weekly cycles of chemotherapy for 18 weeks. Adjuvant Chemotherapy x 4 then 12 weeks of Taxol with option to add in carboplatin x 4 for gene carriers – total of 16 visits.
    - Each cycle includes:
        - Test: blood pathology (before every chemotherapy)
        - Consult: medical oncologist
        - Prescription: +/- antiemetics
    - Test: ultrasound once or twice during chemo to assess response to chemo
- IVF Prescription: Zoladex (regardless of egg collection, patient will be on Zoladex during chemo) = 4-6 injections at $370/injection +/- GP fee if administered outside of hospital.
        - NOTE: HER2 + will not pay as covered by PBS indication, HER2- will pay $370 out of pocket fee
- IVF Consult: Post chemo consult for treatment planning. Then follow-up once every two years.

Post-chemo and preoperative work up (~4-6 weeks)

- Consultation: medical oncologist (every 3 weeks)
    - Test: +/- blood pathology
    - Test: +/- chest x-ray
- Procedure: +/- sentinel node biopsy (if good response to chemo)\

Surgical workup

- Consult: breast surgeon
    - Test: sentinel node mapping
    - Test: MRI for other breast (may or may not be funded)
    - Test: +/- ultrasound
    - Test: CT scan to assess the vessles

Surgery and breast reconstruction and follow-up:

- Procedure: bilateral mastectomy plus autologous reconstruction
- Procedure: axilla clearance (one side only if sentinel node is negative)
- Consultation: plastic surgeon x 2
- Consultation: breast surgeon x 2
- Consultation: medical oncologist (every 3 months for 12 months).

Primary care

- Consult: GP x 4 visits per year

Other

- BRCA1/2 Likely consideration of bilateral oophorectomy before turning 40– which means this woman may want to have more eggs frozen before that procedure.
    - Consult: Medical Oncologist
    - Consult: IVF Consult
    - Procedure: Embryo freezing
- Some clinics may offer discretionary discount for egg freezing (Cost to patient would then be ~$500/cycle).

- If the breast surgeon does the reconstruction him/her self - in which case, there would be an extra consultation to discuss reconstruction At surgery, in addition to the mastectomy would be 'insertion of tissue expander – approximately how many?
- Then there would be a number of visits for tissue expansion. Then there would be another operation for exchange of the tissue expander to a final implant.

NEED TO INCLUDE DOWNSTREAM FERTILIT ASSESSMENT AND POSSIBILITY FOR FERTILITY ASSISTANCE/USE OF EGGS OR FURTHER FERTILTIY PRESERVATION

PROFILE 5
• History of early breast cancer • Self-detected (pain in bones experienced) • Bone metastases • Hormone positive • HER2 negative • post-menopausal

+/- indicates where tests or procedures may be ordered depending on the condition of the patient. This is used to calculate the range of costs possible.

Screening and diagnostic work-up (~3 weeks)

- Consult: GP (history taking, breast exam)
    - Test: CT scan (chest, abdomen, pelvis, brain)
    - Test: Bone scan
    - Test: Blood pathology
- Consult: GP (confirms diagnosis and refers to medical oncologist)
- Consult: medical oncologist (refers onto radiation oncologist)

Radiation therapy (~2 w) (to shrink metastasis)

- Consult: radiation oncologist for pre-radiation workup
- Treatment: 10 radiotherapy (5 treatments/week x 2 weeks)
- Consult: medical oncologist

The cycle below may continue depending on the progression of the cancer

- Consult: medical oncologist
- Treatment: hormone treatment (change prescription from early to metastatic indication x 12/ year. If two drugs, e.g. afinitor and exemestane = 24/ year)
    - Prescription: Subcutaneous injections (i.e. Xgeva every 4 weeks)
- Consult: GP fee to inject Xgeva
- Consult: medical oncologist (every 3 months)
    - Test: CT (2x /year)
    - Test: bone scan (2x / year)
    - Test: blood pathology (every 3 months)
    - Test: tumour marker (every 3 months)

+/- chemotherapy pathway depending on cancer spread

- Consult: medical oncologist
- Treatment: 3 weekly cycles of chemotherapy for 18 weeks. Each cycle includes:
    - Test: blood pathology (before every chemotherapy)
    - Consult: medical oncologist
    - Prescription: +/- antiemetics
- Consult: medical oncologist (ongoing – 3 monthly follow-up)
- End of chemotherapy scans and tests
    - Test: CT scan (chest, abdomen, pelvis, brain)
    - Test: bone scan
    - Test: blood pathology

Hormone therapy

(Managed by medical oncologist)

- Treatment: hormone treatment (prescription x 12/ year. If two drugs, e.g. afinitor and exemestane = 24/ year)
    - Prescription: Subcutaneous injections (i.e Xgeva every 4 weeks)
- Consult: GP to inject Xgeva

Other

- Note: Possible oophorectomy pathway (surgical removal of ovaries) if woman is premenopausal. This will happen after radiotherapy, before hormone treatment.
- Prescription: monthly long acting opioid
- Prescription: anti-nausea drug

Appendix B: Overview of breast cancer diagnosis and treatment

The diagnosis of breast cancer is typically conducted through one of two pathways:

- BreastScreen or
- GP (through investigation of a self-detected lump). Each will involve a mammogram and ultrasound.

BreastScreen's screening and assessment services provide all clinical services from the initial screening mammogram to any further procedures required to the point of diagnosis. The national service invites women aged between 50 and 74 for a free mammogram every two years.

Most GP screening and assessment services will likely attract a Medicare rebate. However, many will also come with OOP costs to the patient.

Once a breast cancer diagnosis is confirmed, there are three treatment options:

- Surgery – either mastectomy or breast conserving surgery
- Systemic therapy – e.g., chemotherapy, hormone therapy
- Radiotherapy

As summarised in Table 2.1, the treatments chosen by the patient, their family and physician(s) will depend on the diagnostic profile of their breast cancer. Other factors such as accessibility and cost may be taken into consideration. An overview of the major treatments and where OOP costs may occur is provided below. This information is fully described by BCNA in Appendix A.

Surgery

As soon as a breast cancer diagnosis is confirmed through Breast Screen or GP, the woman will likely be referred to a breast surgeon. For EBC, the breast surgeon will conduct a pre-surgery work-up to assess whether the cancer has spread to the axilla. This may be done by a fine needle aspirate (FNA) prior to surgery or during surgery to remove the cancer. If the FNA is negative, during surgery to remove the cancer from the breast or in a separate procedure, a biopsy of the sentinel nodes (SNB) will be performed to determine whether any cancer cells are present in the 'guardian' lymph nodes. Lymphatic mapping will also be performed prior to surgery to establish the location of 'guardian' sentinel nodes.

Depending on the findings from the pre-surgical work-up, surgical treatment options will include the following:

- Removal of cancer in the breast: Lumpectomy or partial mastectomy almost always followed by radiation therapy or mastectomy, with or without immediate reconstruction.
- If the FNA or SNB are positive, axillary lymph node dissection during the cancer removal or as a separate procedure.

- Women with a very high risk of developing a new cancer (i.e., BRCA 1/2 gene carriers) in the other breast may consider a bilateral mastectomy.

The patient may then wish to have breast reconstructive surgery which will be done by a specialist plastic surgeon during the same procedure or during additional an operation(s). There are several different options for breast reconstruction which will depend on the clinical and physical features of the patient. Some may be performed in a single operation or over two or more procedures with minor procedures in between.

There are likely to be OOP costs associated with the medical consultations, pathology items, and surgery. During surgery, a patient may incur fees for the surgery, the anaesthetist, the surgeon's assistant and the hospital stay. Although most of these items may attract a Medicare rebate, if they are delivered through the private health system, they will often also attract a gap fee. Patients may also pay for analgesic medicines and antibiotics after surgery. For some breast cancers, private patients may be offered more tests in the pre-mastectomy diagnostic work-up such as breast MRI and/or a PET scan (in higher risk disease)

Radiotherapy

Radiotherapy is the use of high-energy X-rays or other particles to kill cancer cell and is managed by a radiation oncologist. The most common type of radiation treatment is called external-beam radiation therapy, which is radiation given from a machine outside the body.

If delivered privately, there may be an upfront OOP fee for the patient on top of their Medicare rebate. The fee may depend on the number of radiotherapy sessions required. In the public system, there is likely to be no OOP cost for the patient. As it is normally delivered as an outpatient service, PHI does not provide a rebate unless the patient is in hospital during treatment.

Systemic Therapy – chemotherapy

There are three general categories of systemic therapy used for breast cancer: chemotherapy, hormonal therapy, and targeted therapy.

- A chemotherapy regimen (schedule) consists of a specific treatment schedule of drugs given at repeating intervals (cycles) for a set period of time. It may be given before surgery to shrink a large tumour and make surgery easier. It may also be given after surgery to reduce the risk of recurrence of the tumour(s). It is prescribed by a medical oncologist
- Hormone therapy, is an effective treatment for most tumours that test positive for either estrogen or progesterone receptors in both EBC and MBC cancer. These therapies are often prescribed by a medical oncologist and GPs and are taken as oral medicines for five to 10 years. Types of hormonal therapy include Tamoxifen (pre-menopausal women) and a number of aromatase inhibitors (AIs) (post-menopausal women).

There are generally no OOP costs associated with chemotherapy as it is paid by the patient's PHI in the private system or by Medicare in the public system. Privately, there may be OOP costs associated with consultations with the medical oncologist. Some chemotherapies are

still experimental and are not subsidised in Australia in which case the patient may pay several thousand dollars for them whether treated privately or publicly.

Although most hormone medicines are subsidised under the Pharmaceutical Benefits Scheme (PBS), they may still attract an OOP cost, the amount depending on whether the patient has general, concessional, pensioner or safety net status.

Targeted Therapy

Targeted therapy is a treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. This type of treatment blocks the growth and spread of cancer cells while limiting damage to healthy cells. One common type of targeted therapy is HER2 targeted therapy. A biopsy of the cancer cells is conducted to determine HER2 status – either positive or negative.

There may be OOP costs associated with targeted therapy depending on their level of subsidisation in Australia and the type of breast cancer they are used to treat. This can be several thousand dollars and may or may not be covered by a patient's PHI

Appendix C: Stakeholder discussion guide

We have some questions regarding the **out-of-pocket costs** patients are likely to face when undergoing [treatment] for breast cancer and how these may vary according to whether they have private health insurance or other reasons. Additionally, we are interested in how a patient with breast cancer would most likely view their [treatment] in terms of cost e.g. do they pay a one-off payment or do they pay multiple itemised payments? This will help us refine the questions regarding out-of-pocket costs for patients with breast cancer.

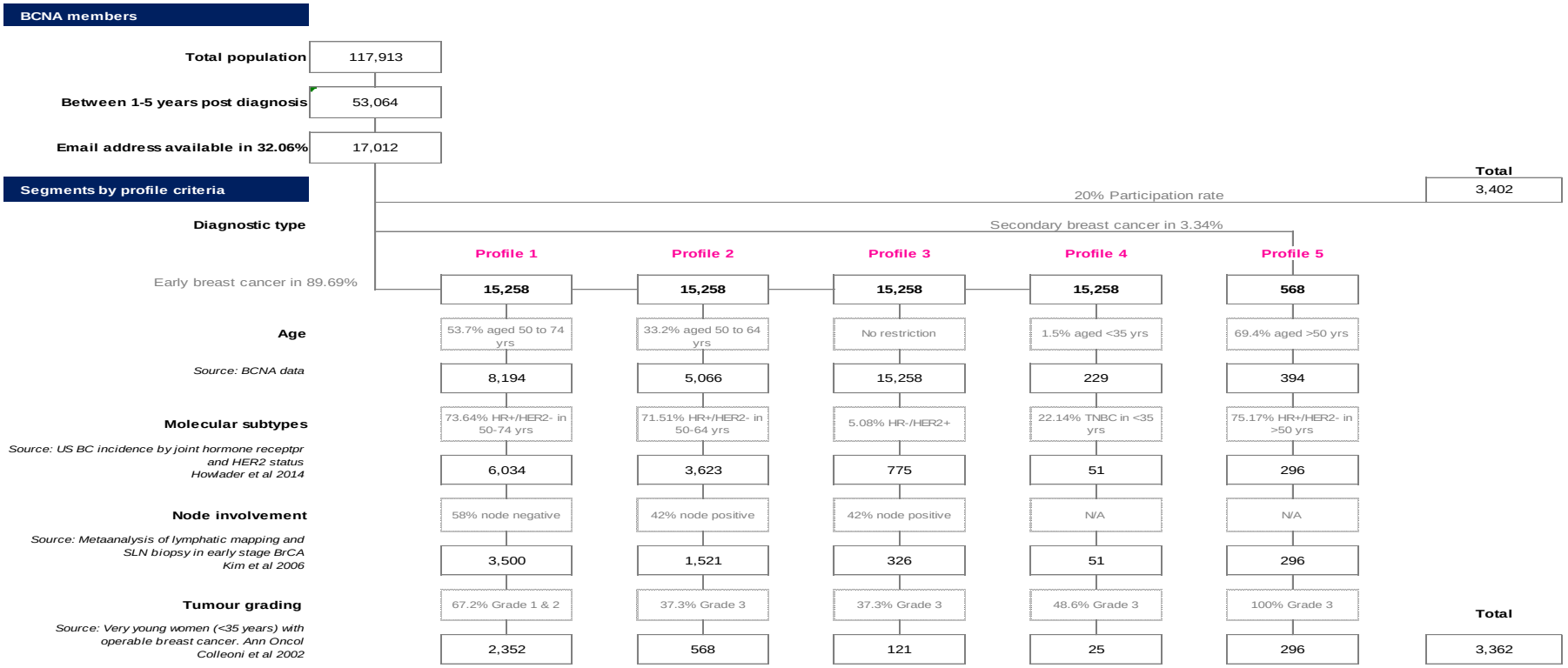
- How is a patient likely to view their costs/invoicing?
    - *Discussion regarding when patients pay during their treatment e.g. for the initial consultation and then as a bulk upfront payment covering all other services and tests for the required procedure/treatment or on a per consultation basis/per test basis.*
    - *Specific questions regarding surgeries for the plastic surgeons e.g.:*
        - *If patients have a tissue expander inserted, do they pay a separate cost for the subsequent surgery?*
        - *Does the patient pay separately for the final operation i.e. nipple reconstruction and fat graft or is this included in the total surgical cost?*
- Do you provide services to patients who are both privately and non –privately health insured?
- Are any services you provide subsidised by Medicare for patients who have breast cancer?
    - Do you charge an additional gap-payment to patients for any of these services? Can you provide a dollar range for each?
    - Is the gap payment varied depending on the patient's ability to pay or level of private health insurance coverage (or any other factors)? Can you provide an indication of dollar ranges for any variations
- Are any services you provide for patients with breast cancer not subsidised by Medicare?
    - What ranges of cost do patients pay for these services?
    - Does this vary depending on the patient's ability to pay or level of private health insurance coverage (or other factors)? Can you provide and indication of dollar ranges for any variation?
    - Are there any other items associated with [the treatment(s)] where patients will have out-of-pocket costs? E.g. anaesthetist fees, analgesic medicines, dressings etc.

Appendix D: Survey

Appendix E: Methodology for diagnostic Profile sample size estimation

There is no available data providing an indication of the proportion of people with breast cancer in Australia that would have a diagnosis consistent with diagnostic Profiles 1 to 5. Therefore, the literature was reviewed to find multipliers that could be applied to all people sent the online survey in order to estimate the total sample size for each Profile (i.e. the total number of people meeting the inclusion criteria for each Profile). The multipliers for achieving the estimated sample sizes are presented in Figure E.1.

Figure E.1: Multipliers for estimating total and target sample sizes in each diagnostic Profile



Sample size calculation						
Proportion (p)	13.8%	3.3%	0.7%	0.1%	1.7%	19.8%
p*(1-p)	11.9%	3.2%	0.7%	0.1%	1.7%	15.9%
Confidence	97.5%	97.5%	97.5%	97.5%	97.5%	97.5%
Z2	3.84	3.84	3.84	3.84	3.84	3.84
Error (e)	5%	5%	5%	5%	5%	5%
e2	0.0025	0.0025	0.0025	0.0025	0.0025	0.0025
Target sample	181	49	11	2	26	240

Appendix F: Supplementary charts and data

	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Chart 5.1: Median cost with interquartile range, 25th to 75th percentile, overall (including bulk-billed and PHI covered items and services)					
Direct medical costs	$1,578	$281	$8,710	1,919	20002
Other costs	$3,231	$1,796	$9,681	1,919	7897
Total	$4,809	$1,510	$17,200	1,919	27899
Chart 5.2: Median cost with interquartile range, 25th to 75th percentile, overall (excluding bulk-billed and PHI covered items and services)					
Direct medical costs	$9,727	$4,340	$17,607	1919	9789
Other costs	$4,097	$1,796	$9,681	1919	7868
Total	$13,824	$6,137	$27,287	1919	17657
Direct medical costs	$9,727	$4,340	$17,607	1919	9789
Chart 5.6: Median cost with interquartile range, 25th to 75th percentile, by Urban or Non-urban status (for all respondents in sample)					
Urban total costs	$5,408	$1,579	$18,896	1240	18485
Non-urban total costs	$4,938	$1,968	$15,883	576	8238
Urban direct medical costs	$1,753	$243	$8,861	1240	13316
Non-urban direct medical costs	$1,725	$702	$7,762	576	5939
Urban other costs	$3,655	$1,817	$10,538	1240	5169
Non-urban other costs	$3,213	$1,954	$9,735	576	2299
Chart 5.10: Median cost with interquartile range, 25th to 75th percentile, by dependent child status (for all respondents in sample)					
Dependents total costs	$4,610	$1,615	$16,934	668	7238
No dependents total costs	$4,906	$1,560	$17,391	1246	17009
Dependents direct medical costs	$1,330	$219	$8,226	668	3900

	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
No dependents direct medical costs	$1,633	$376	$8,821	1246	12451
Dependents other costs	$3,280	$1,905	$9,111	668	3338
No dependents other costs	$3,273	$1,708	$9,503	1246	4558
Chart 5.4: Median cost with interquartile range, 25th to 75th percentile, by jurisdiction (for all respondents in sample)					
NSW	$6,381	$1,953	$20,910	466	6928
VIC	$5,432	$1,721	$16,869	521	7395
SA	$5,287	$2,654	$14,242	142	1850
WA	$4,656	$1,176	$11,349	215	3135
NT	$6,609	$4,471	$10,151	13	187
QLD	$5,203	$1,838	$18,147	449	6751
ACT	$8,582	$4,864	$14,661	53	790
TAS	$9,928	$7,257	$13,667	60	863
Chart 5.3: Median cost with interquartile range, 25th to 75th percentile, by PHI status (for all respondents in sample)					
PHI total costs	$7,028	$1,706	$20,783	1419	20751
No PHI total costs	$3,651	$1,294	$8,408	500	7148
PHI direct medical costs	$3,723	$430	$10,613	1419	14795
No PHI direct medical costs	$355	$126	$1,057	500	5207
PHI other costs	$3,305	$1,764	$10,044	1419	5956
No PHI other costs	$3,296	$1,868	$9,275	500	1941
Chart 11.1: Median cost with interquartile range, 25th to 75th percentile, by profile (for all respondents in sample)					
Profile 1	$6,504	$2,439	$17,136	577	7925
Profile 2	$5,560	$1,592	$16,584	346	6116
Profile 3	$12,972	$9,935	$20,508	29	594
Profile 4	$8,959	$4,875	$19,856	25	492
Profile 5	$5,654	$3,002	$15,749	68	1124
All respondents	$4,809	$1,510	$17,200	1919	7897

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Chart 5.9: Median costs and interquartile range, 25th to 75th percentile, for travel and accommodation by urban or non-urban residence (bulk-billed and PHI covered items/services removed)					
Urban travel	$375	$215	$694	1240	993
Non-urban travel	$565	$333	$1,386	576	407
Urban accommodation	$1,356	$477	$3,692	1240	42
Non-urban accommodation	$841	$379	$2,163	576	78

Profile 1

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Profile 1: Median total costs and interquartile range, 25th to 75th percentile					
Typical respondent (including bulk-billed and PHI covered items/services)	$6,504	$2,439	$17,136	577	7925
Responses (excl. bulk-billed and PHI covered items/services)	$14,422	$7,039	$25,937	577	4999
Profile 1: Median total costs and interquartile range, 25th to 75th percentile, by category					
Treatments	$9,004	$4,447	$15,231	557	1469
Travel and accommodation	$1,938	$974	$3,875	557	457
Paid care and home help	$648	$356	$1,467	557	49
Allied health	$573	$233	$974	557	346
Health and wellbeing	$564	$218	$1,306	557	337
Medical consultations	$549	$312	$1,008	557	787
Complementary medicine	$528	$196	$877	557	247
Items or aids	$331	$137	$656	557	523
Tests	$286	$165	$543	557	784
Profile 1: Median total costs and interquartile range, 25th to 75th percentile, by treatment type					
Breast reconstruction surgery	$3,250.18	1192	5360	557	50
Radiotherapy	$1,951.00	826	3750	557	92
Fertility	$1,660.67	1381	2355	557	18

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Major surgical treatments	$987.25	436	1683	557	248
Extra surgical fees	$451.00	251	803	557	337
Chemotherapy	$351.00	196	551	557	43
Hormone therapy	$278.75	133	557	557	421
Medication	$74.35	32	171	557	260
Profile 1: Median total costs and interquartile range, 25th to 75th percentile, by test					
Molecular tests	$3,500	$2,150	$4,250	557	8
Genetic testing	$1,251	$776	$1,901	557	10
MRI	$525	$304	$1,014	557	58
Ultrasound	$270	$156	$568	557	172
CT scan	$252	$168	$463	557	40
Whole body bone scan	$251	$186	$351	557	33
Mammogram	$228	$111	$502	557	131
X-ray	$212	$89	$668	557	35
PET scan	$212	$167	$314	557	4
Fine needle aspiration	$204	$106	$351	557	52
Breast biopsy	$192	$106	$372	557	109
Standard blood test	$166	$52	$438	557	25
Gated blood pool scan	$146	$136	$179	557	3
Bone densitometry/DEXA scan	$141	$96	$251	557	96
ECG	$121	$74	$178	557	8
Tumour marker	$0	$0	$0	557	0

Profile 2

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Profile 2: Median total costs and interquartile range, 25th to 75th percentile					
Typical respondent (including bulk-billed and PHI covered items/services)	$5,560	$1,592	$16,584	346	6116
Responses (excl. bulk-billed and PHI covered items/services)	$12,763	$6,116	$25,240	346	4107
Profile 2: Median total costs and interquartile range, 25th to 75th percentile, by category					
Treatments	$7,232	$3,631	$13,852	346	1037
Paid care and home help	$1,369	$668	$2,987	346	340

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Travel and accommodation	$1,168	$601	$3,091	346	52
Health and wellbeing	$688	$281	$1,257	346	355
Allied health	$592	$173	$1,045	346	261
Medical consultations	$555	$272	$1,038	346	560
Complementary medicine	$475	$161	$772	346	204
Items or aids	$367	$138	$635	346	651
Tests	$318	$189	$562	346	647
Profile 2: Median total costs and interquartile range, 25th to 75th percentile, by treatment type					
Breast reconstruction surgery	$2,957	$1,290	$6,085	346	47
Radiotherapy	$1,851	$1,051	$2,875	346	64
Major surgical treatments	$752	$398	$1,574	346	133
Extra surgical fees	$473	$237	$802	346	195
Chemotherapy	$451	$196	$951	346	59
Fertility	$345	$295	$712	346	18
Hormone therapy	$309	$122	$638	346	296
Medication	$94	$41	$216	346	225
Profile 2: Median total costs and interquartile range, 25th to 75th percentile, by test					
Molecular tests	$4,250	$2,902	$4,250	346	12
Genetic testing	$877	$181	$1,226	346	10
PET scan	$551	$351	$951	346	13
Gated blood pool scan	$502	$196	$702	346	5
MRI	$451	$351	$951	346	40
Ultrasound	$251	$134	$659	346	119
CT scan	$251	$139	$489	346	46
Breast biopsy	$240	$146	$351	346	92
Fine needle aspiration	$196	$114	$297	346	48
Bone densitometry/DEXA scan	$196	$96	$312	346	69
Whole body bone scan	$186	$76	$451	346	41
Standard blood test	$170	$102	$396	346	20
Mammogram	$166	$106	$408	346	107
X-ray	$146	$112	$312	346	13
ECG	$91	$50	$251	346	12
Tumour marker	$0	$0	$0	346	0

Profile 3

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Profile 3: Median total costs and interquartile range, 25th to 75th percentile					
Typical respondent (including bulk-billed and PHI covered items/services)	$12,972	$9,935	$20,508	29	594
Responses (excl. bulk-billed and PHI covered items/services)	$21,225	$16,065	$30,543	29	364
Profile 3: Median total costs and interquartile range, 25th to 75th percentile, by category					
Travel and accommodation	$9,457	$8,573	$10,534	29	30
Treatments	$8,152	$5,391	$12,812	29	75
Paid care and home help	$951	$508	$2,438	29	10
Complementary medicine	$620	$436	$748	29	10
Health and wellbeing	$538	$171	$921	29	28
Medical consultations	$476	$357	$824	29	41
Tests	$411	$321	$584	29	58
Allied health	$325	$160	$1,095	29	35
Items or aids	$297	$147	$587	29	77
Profile 3: Median total costs and interquartile range, 25th to 75th percentile, by treatment type					
Breast reconstruction surgery	$3,710	$2,871	$5,810	29	5
Radiotherapy	$2,101	$1,127	$3,500	29	4
Major surgical treatments	$774	$483	$1,321	29	12
Extra surgical fees	$723	$345	$1,107	29	18
Chemotherapy	$680	$437	$851	29	7
Medication	$92	$57	$151	29	28
Hormone therapy	$72	$72	$72	29	1
Fertility	$0	$0	$0	29	0
Profile 3: Median total costs and interquartile range, 25th to 75th percentile, by test					
X-ray	$2,604	$2,604	$2,604	29	1
MRI	$1,554	$1,454	$1,655	29	2
ECG	$624	$624	$624	29	1
Ultrasound	$543	$426	$834	29	12
PET scan	$451	$451	$451	29	1
CT scan	$422	$317	$678	29	6
Standard blood test	$295	$231	$360	29	2

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Gated blood pool scan	$295	$231	$360	29	2
Breast biopsy	$269	$153	$375	29	8
Whole body bone scan	$251	$176	$577	29	7
Mammogram	$232	$152	$401	29	6
Bone densitometry/DEXA scan	$209	$178	$241	29	2
Fine needle aspiration	$136	$44	$179	29	8
Molecular tests	$0	$0	$0	29	0
Tumour marker	$0	$0	$0	29	0
Genetic testing	$0	$0	$0	29	0

Profile 4

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Profile 4: Median total costs and interquartile range, 25th to 75th percentile					
Typical respondent (including bulk-billed and PHI covered items/services)	$8,959	$4,875	$19,856	25	518
Responses (excl. bulk-billed and PHI covered items/services)	$19,470	$13,522	$26,201	25	335
Profile 4: Median total costs and interquartile range, 25th to 75th percentile, by category					
Treatments	$14,304	$9,777	$18,809	25	93
Health and wellbeing	$1,154	$622	$1,511	25	21
Travel and accommodation	$1,111	$975	$1,634	25	28
Paid care and home help	$751	$751	$751	25	1
Medical consultations	$688	$515	$1,022	25	44
Complementary medicine	$501	$335	$718	25	15
Tests	$365	$227	$606	25	57
Allied health	$312	$181	$559	25	29
Items or aids	$284	$140	$591	25	47
Profile 4: Median total costs and interquartile range, 25th to 75th percentile, by treatment type					

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Breast reconstruction surgery	$9,472	$7,417	$12,361	25	9
Major surgical treatments	$2,051	$763	$2,865	25	27
Chemotherapy	$1,051	$551	$1,051	25	5
Extra surgical fees	$1,028	$424	$1,799	25	26
Hormone therapy	$368	$368	$368	25	1
Fertility	$199	$199	$199	25	2
Medication	$136	$56	$166	25	23
Radiotherapy	$0	$0	$0	25	0
Profile 4: Median total costs and interquartile range, 25th to 75th percentile, by test					
Genetic testing	$774	$485	$1,062	25	2
Whole body bone scan	$651	$351	$780	25	5
ECG	$530	$530	$530	25	1
X-ray	$480	$480	$480	25	1
MRI	$468	$274	$627	25	7
CT scan	$385	$285	$714	25	4
Breast biopsy	$351	$166	$382	25	10
Ultrasound	$272	$156	$997	25	11
Mammogram	$251	$169	$364	25	8
Fine needle aspiration	$224	$186	$426	25	4
Bone densitometry/DEXA scan	$212	$162	$262	25	2
Standard blood test	$198	$198	$198	25	1
Molecular tests	$172	$172	$172	25	1
PET scan	$0	$0	$0	25	0
Gated blood pool scan	$0	$0	$0	25	0
Tumour marker	$0	$0	$0	25	0

Profile 5

Table	Median	25th percentile	75th percentile	Number respondents	Number items/services (n)
Profile 5: Median total costs and interquartile range, 25th to 75th percentile					
Typical respondent (including bulk-billed and PHI covered items/services)	$5,654	$3,002	$15,749	68	1190

Responses (excl. bulk-billed and PHI covered items/services)	$12,465	$8,121	$25,210	68	750
Profile 5: Median total costs and interquartile range, 25th to 75th percentile, by category					
Treatments	$7,235	$5,440	$12,638	68	187
Travel and accommodation	$1,226	$669	$3,550	68	71
Paid care and home help	$977	$411	$1,756	68	14
Complementary medicine	$634	$269	$1,717	68	59
Allied health	$540	$351	$2,095	68	89
Medical consultations	$518	$247	$896	68	98
Health and wellbeing	$505	$262	$982	68	59
Tests	$420	$225	$809	68	93
Items or aids	$410	$248	$767	68	80
Profile 5: Median total costs and interquartile range, 25th to 75th percentile, by treatment type					
Breast reconstruction surgery	$3,250	$3,250	$3,250	68	2
Radiotherapy	$1,751	$1,076	$4,500	68	14
Major surgical treatments	$595	$330	$1,220	68	18
Chemotherapy	$576	$219	$889	68	12
Hormone therapy	$478	$237	$1,186	68	56
Extra surgical fees	$419	$228	$1,189	68	31
Medication	$166	$100	$404	68	54
Profile 5: Median total costs and interquartile range, 25th to 75th percentile, by test					
MRI	$753	$336	$1,953	68	13
Tumour marker	$712	$608	$816	68	2
CT scan	$588	$304	$951	68	17
Standard blood test	$551	$351	$912	68	5
Whole body bone scan	$370	$205	$635	68	10
PET scan	$352	$228	$714	68	4
Gated blood pool scan	$351	$351	$351	68	1
Genetic testing	$351	$351	$351	68	1
Ultrasound	$278	$153	$546	68	14
X-ray	$262	$118	$382	68	10
Breast biopsy	$249	$114	$639	68	8
Bone densitometry/DEXA scan	$106	$56	$116	68	5
Fine needle aspiration	$96	$86	$146	68	3
Mammogram	$0	$0	$0	68	0
ECG	$0	$0	$0	68	0
Molecular tests	$0	$0	$0	68	0

Limitation of our work

General use restriction

This report is prepared solely for the internal use of Breast Cancer Network Australia. This report is not intended to and should not be used or relied upon by anyone else and we accept no duty of care to any other person or entity. The report has been prepared for the use of BCNA in raising awareness of the financial impact of breast cancer and to help BCNA understand where efforts may be best placed to work towards reducing out-of-pocket costs for Australians diagnosed with breast cancer. You should not refer to or use our name or the advice for any other purpose.

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