BEL Student Employability Team (SET)
Community Engagement Program

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THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

SO BRAVE

So Brave: Australia's Young Women's Breast Cancer Charity

Financial Impact Study of Young Women with Breast Cancer

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Project Team

Table 1: Project Team Members

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Table 2: Project Stakeholders

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Executive Summary

Background

So Brave is an Australian Breast Cancer charity aimed at providing awareness of the social and economic effects of the disease on young (less than 40 years of age) women in Australia. Founded in 2017, the objective of the charity is to continue to provide access to medical resources and information on the risks and diagnosis specifically pertaining to this demographic. The charity travels all across Australia to continue to build awareness even in regional Australia, areas that are typically limited in medical resources and access.

Objective and Scope

The scope of this report has been designed to focus on the financial impacts of breast cancer on young women as incurred from; medical costs and loss of income. Services and the scope of work will focus on the following:

1. Undertake a literature review to assess the current data on financial toxicity and the medical costs associated with breast cancer for young women
2. Complete a case study on mammograms and ultrasound pricing to showcase a small element of costs
3. Ultimately, understand the direct financial impact of respective specific medical costs and the cost factors of breast cancer on young women, between ages 18-40.

Loss of income will primarily be assessed as the financial impact of taking time off work after the diagnosis of breast cancer with a focus on:

4. Assessing the effect on future earning capacity from having time off work as contributed to by qualitative and subjective factors
5. Assessing income support services and options such as; Centrelink services, private health insurance / income protection and personal savings
6. Ultimately, create a quantifiable measure of net income loss over time as a result of breast cancer.

Findings

The findings identified during our research are detailed below within the pages that follow. Directly below is a summary of these findings:

- There is restricted transparency regarding itemized medical costs.
- Cost of medical procedures related to pre and post treatment are not easily accessible and are inconsistent, varying between medical centres and varying depending on public or private health insurance.
- The loss of income is highly subjective to the variables in the individual's life. Variables such as age, financial stability, level of income, number of dependents and amount of support available personally to the individual all play an important factor in how significant a breast cancer diagnosis will be on their financial stability.
- Younger women suffer a greater loss of income from the larger financial impact a sudden diagnosis brings due to the early stage in the woman's career and the potential income losses from career progression. The financial impact is strong due to the possible low levels of financial support available in items such as personal savings, government assistance and income protection insurance.

1. Introduction

Breast cancer affects approximately 1000 young women (under 40) each year in Australia. Aside from the significant health impacts on these young women, there are also substantial financial and social impacts as result of this disease. For young women breast screening is often not recommended as it is not very successful at giving correct results and thus breast cancer is often diagnosed at later stages. Thus, it is often more aggressive and has a higher mortality rate than in older women (National Breast Cancer Foundation, 2019). There are also a number of other factors that increase the direct and indirect financial burden of breast cancer on young women (Australian Institute of Health and Welfare, 2015). Often young women will be at the start of their careers and as such do not have the financial base to rely on, have young children who are dependent on them, and can also have significant psychological and emotional change as a result of breast cancer diagnosis and treatment.

From preliminary research we found that there were four major areas of direct and indirect financial impact on young women with breast cancer. As detailed in the scope, full analysis of these was out of the scope of this report, however, the team felt it was important to outline these for future evaluation. The team found that the major financial impacts of breast cancer on young women are:

1. Financial toxicity: Direct medical costs from consultations, treatments, medication and adjuvant therapies;
2. Indirect costs through loss of income related costs due to time off work while receiving treatment and also the ongoing cost of that time off work in relation to career timelines;
3. Indirect costs associated with childcare, transport and wellbeing care such as psychological therapy;

In this report the team will deliver thorough analysis of the first two costs and will outline our initial findings on impact 3.

2. Purpose of the Project

The purpose of this project is to undergo a financial impact study to research the costs associated with being diagnosed with breast cancer for women ages 18-40. This research will help provide important information for further research So Brave are undertaking to assist in advocating to the government for both funding and policy changes. The desired outcome of this project will provide So Brave with quantifiable data that can be used to assess the costs of breast cancer- both direct medical costs and the further costs associated through career impacts, support costs and loss of income etc. This report will be able to assist So Brave with further education for the medical community, young women with breast cancer and for their families to be able to adequately understand costs prior to them being incurred and to further the progression of support options available to them.

3. Project Scope

The scope of this report has been designed to focus on the financial impacts of breast cancer on young women as incurred from; medical costs and loss of income.

Medical costs will be used as a baseline for which the different individual variables will be built upon. Services and the scope of work will focus on the following:

1. Undertake a literature review to assess the current data on financial toxicity and the medical costs associated with breast cancer for young women
2. Complete a case study on mammograms and ultrasound pricing to showcase a small element of costs
3. Understand the direct financial impact of respective specific medical costs and the cost factors of breast cancer on young women, between ages 18-40.

Loss of income will primarily be assessed as the financial impact of taking time off work after the diagnosis of breast cancer with a focus on:

4. Assessing the effect on future earning capacity from having time off work as contributed to by qualitative and subjective factors
5. Assessing income support services and options such as; centrelink services, private health insurance / income protection and personal savings
6. Ultimately, create a quantifiable measure of net income loss over time as a result of breast cancer.

3.1. Original Scope

The objective of this University of Queensland Community Engagement Project (CEP) is to complete a preliminary research for So Brave, on the financial impact of breast cancer on younger women between ages 18-40 in Australia contributing to further research and future policy recommendations. Our research included reviewing and analysing comparative data aiming to provide as accurate as possible statistics and conclusions. Services and scope focused on the following:

- Medical costs were used as a baseline for which different individual variables were built upon;
- Gained an understanding of the different types of breast cancer and their correlated stages as profile types;
- Used those profiles to categorize and quantify direct out-of-pocket medical costs to individuals, e.g., radiation, prescription drugs, hospital stays, carer costs, cosmetic surgery etc.
- Ultimately, understand the direct financial impact of respective medical costs on individuals with said stages of breast cancer on younger women between ages 18-40.

The variables on top of this that will create additional costs for the individual will be:

- Loss of work
- Rural vs urban
- Childcare costs

3.2. Process of Refining Scope

The team found that there was no clear correlation between the stages of cancer and financial impact. It was also found that it was difficult to quantify the difference in financial impact for rural vs urban residents with breast cancer. Therefore, the team was divided into 2; half focusing on medical costs and the other focusing on loss of income as two primary causes of financial impact on young women with breast cancer. Within these topics, qualitative and quantitative factors were explored. Between both sub-teams, a clear correlation was found between financial impact and private health insurance.

4. Objectives

The objective of this project is to complete a preliminary research on the financial impact of breast cancer on younger women between ages 18-40 in Australia contributing to future policy recommendations.

4.1. Qualitative Study

- Undertake a literature review and qualitative study to assess the data on medical costs of the treatment.
- Gain a perspective on the factors that have an effect on earning capacity in young women due to time off work.

4.2. Understanding Financial Impact

- Understand the direct financial impact of medical costs and their factors.
- Evaluate some income support options to help women arrange their savings and income.

4.3. Quantifying Costs

- Use the study to categorize and quantify direct out-of-pocket medical costs to individuals.
- Assess the income lost due to breast cancer in young women between ages 18-40.

5. Process

Our research approach consisted of the following three phases:

5.1. Understanding of the Subject Matter

The first phase of our research consisted primarily of inquiry with our main point of contact, Rachell Panitz, managing Director and Co-founder, in an effort to obtain an understanding of the scope and risks relevant to the objectives stated above. The following procedures were completed as a part of this phase:

- Conducted meetings with appropriate So Brave representatives to discuss the scope and objectives of the project, obtained preliminary data, and established working arrangements;
- Researched and reviewed several key academic papers, scientific journals, government reports, NGO reports, and social service websites, gathering applicable details in order to gain a comprehensive understanding of current breast cancer diagnosis, treatment, and post treatment processes in the Australian healthcare system.
- Contacted health care centres in Queensland to gather information on their itemized cost for relevant medical procedures.
- Interviewed a breast cancer research professor, Ray Chan, to gain a better understanding of any further information or constraints to the subject matter that were relevant to our objectives.

5.2. Evaluation of Information Gathered

The purpose of this second phase was to conduct analysis of the preliminary information gathered and identify areas that need further research and inquiry. Below are brief descriptions of how this was approached:

- Per discussion with our client, the team focused on two key areas of focus
  (1) Medical costs and
  (2) Loss of Income directly or indirectly caused by the illness.
- Divvied up the research allowing smaller teams of three to each focus on the identified key areas of gathering, summarizing, and analysing the relevant data.

5.3. Reporting

At the conclusion of this project, we summarized our findings into this report. We have reviewed these with our project advisor Emmanuel Michaelides as well as So Brave management, Rachelle Panitz, and have incorporated their responses and feedback into the report. The sections to follow provide further detail our research, findings, and related recommendations.

6. Medical Costs

Medical costs make up a significant portion of the costs associated with breast cancer, a survey from Deloitte and BCNA reports that approximately 50% of the out-of-pocket costs are the result of direct medical costs (Deloitte Access Economics, 2017). These costs range from diagnostic to post-treatment procedures that include major surgical treatments, chemotherapy, medication, consultations, fertility treatment and tests just to name a few. An important term related to these medical costs is financial toxicity, the difficulties patients have related to the cost of medical care. With the focus of this report being on young women, but the majority of data concentrating on women in general or focussed on women over 40, the relationship between age and financial toxicity must be established. Research has found that a younger age is a significant factor in increased financial toxicity (Gordon, Merollini, Lowe, & Chan, 2016). Thus, population data can broadly be extrapolated on the low side, to young women where data is not available.

6.1. Variability in Costs

While there was limited data on the financial toxicity of breast cancer one study was found that allowed the team to quantitatively understand the numerical out-of-pocket costs associated with breast cancer. This study was undertaken on out-of-pocket medical expenses for Queenslanders with a major cancer. While the mean expenses 2 years after diagnosis for a patient with breast cancer are $4192 the range was large, varying from approximately $90 out-of-pocket up to $18,000 with other sources suggesting they can be significantly higher. (Gordon, Elliott, Olsen, Pandeya, & Whiteman, 2018) This study highlighted one of the prominent issues that was consistently raised in literature; that while it is difficult for doctors and patients to predict future costs, there is very little transparency of costs alongside poor discussion between doctors and private health insurance, and patients about the possible costs incurred. The lack of communication of costs of breast cancer treatment has an increased effect on young women as they often will not have had considerable experience with the medical system and the associated costs compared to their older counterparts. Costs should not be based on how well patients understand the system but should be clearly accessible and easily available so patients can understand what is best for them, medically and financially. Under the 'Competition and Consumer Act 2010', medical practitioners are required to set their fees independent of other medical practitioners, however, this means that out-of-pocket costs are very unclear to patients (Australian Government, 2018). The team attempted, as part of the case study, to find the costs of simple scans such as mammograms online, however they were not available for the large majority of clinics. As Kirsten Pilatti, the CEO of Breast Cancer Network Australia, notes, "What we've found was the financial discussions are not happening for women after a breast cancer diagnosis" (Marciniak, 2018).

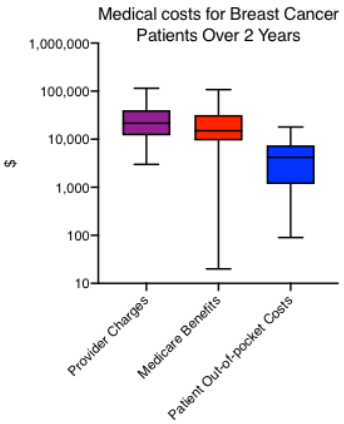

Figure 1: Queensland study of variability in costs for breast cancer patients

6.2. Cost Transparency

Cancer council Australia has also set a directive to increase quality of care through increased information provided to patients about "all treatment options and their financial implications, both direct and indirect," in their 'Standard for informed financial consent' (Cancer Council Australia, 2019). As Jill Margo, the health editor of the Australian Financial Review reports, "only those patients who meticulously pre-call every doctor, allied health professional and service provider to ensure they will be bulk-billed, will drastically reduce their overall expenses." Subsidies such as medications put on the Pharmaceutical Benefits Scheme (PBS) and subsidies for early detection and screening, as mentioned above, are crucial in decreasing the costs of treatment alongside increasing rates of early detection and, in turn, survivorship. Increasing the transparency of costs at all steps of the journey is also necessary though, for decreased financial hardship, alongside decreased chance of "bill shock" and the psychological effects that can have on patients. Evidence has shown that increasing the medicare rebate will not change the out of pocket costs faced by patients and it is unlikely that it will "reduce variations within medical specialties, or reduce the extreme out-of-pocket fees charged by some practitioners." (Mcrae & Van Gool,

2018). As Dr Ian Mcrae, a health economist with a background in health policy and administration states, "Improving the transparency of pricing could increase competition and place downward pressure on unreasonable fee-setting, and may provide the most affordable and fair approach to the problem [of significant out-of-pocket costs]."

Responses from the government to increase cost transparency are headlined by the medical cost finder website initiated at the end of 2019. (Department of Health, 2020) While it is a promising initiative as it highlights that the government is interested in providing schemes to increase cost transparency, there are some concerns with the implementation. Firstly, it involves limited surgeries with only breast biopsy, reduction, lumpectomy, mastectomy and IVF being relevant to young women with breast cancer. This needs to be expanded to be of benefit. Secondly, with the current surgeries available it further highlights the perplexing variability in costs for treatments. Figure 2 shows an example of breast biopsy in the metro south region. Even with as small a region as one can look up on the website there is still an extraordinary variability in costs. Originally a key element of the website was including individual specialist's fees. This did not go ahead in the initial version of the website and without this feature the overall value of the website is lost. Patients are still somewhat in the dark as to the costs they will have to pay for treatments. (Aubusson, 2019) This feature must clearly be advocated for to benefit patients.

Figure 2: Government medical cost finder; breast biopsy in metro south

6.3. Case study

While initially the team intended to model a holistic approach to medical costs including physiotherapy, dietary, and mental health costs associated with treatment, issues were discovered with that approach. Namely, the lack of listed costs for treatments was a significant problem discovered. Instead a heavy reliance on previous case studies and their findings informed our approach, consolidating our research and focussing on just a few early treatment procedures. A case study conducted in Sydney in the early 90s, focused solely on the implementation of an early screening program providing mammograms, ultrasounds and consultations.(Gerard, Salkeld & Hall, 1990) The objective of the study was to showcase the importance of early detection procedures in order to ultimately reduce the overall cost of breast cancer treatment, as this tends to be higher if not detected in the early stages. Even with these noted benefits, the study was limited to a population of Australian women ages 45-70 years. In alignment with So Brave's objectives, the performance of future case studies such as these, that clearly illustrate the sweeping benefits of early detection, would be prudent to also include younger women as their target demographic, allowing for quantitative support to inform future policy.

In conjunction with So Brave, the team also undertook a small case study of 3D mammography and ultrasound prices among Brisbane radiology clinics to ascertain the variability in out of pocket costs. While the sample size is small, the findings further supported the continued theme that out of pocket costs even for very similar treatments vary significantly. For a single breast ultrasound, all in in-hospital clinics, the out of pocket cost varies between just over $90 and just under $200. This exemplifies the outrageous variability with out of pocket costs and showcases how hard it is for young woman to understand what they should be paying for treatments adding stress to an already stressful time.

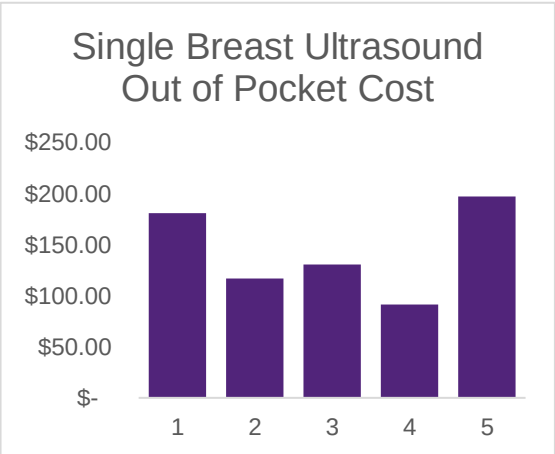

Figure 3: Out of pocket cost comparison for Single Breast Ultrasound

6.4. Standard Treatment of Care

Although treatment varies depending on the type and severity of the breast cancer, and the age of the patient there are still standard treatment procedures that are offered subsequent to diagnosis. Breast cancer standard treatments are methods that experts agree are appropriate, accepted, and widely used. These standard procedures have proven useful in fighting breast cancer in the past (National Breast Cancer Foundation, 2019).

TABLE 1: Standard Breast Cancer Treatments

Breast Surgery	Breast Reconstruction Surgery	• Surgical insertion of a breast implant • Transfer of a portion of tissue, skin and often muscle from another part of the body to the chest area – this is called a tissue flap breast reconstruction.
	Breast- Conserving Surgery/lumpectomy	• The surgeon removes the tumour and some surrounding healthy tissue, leaving as much breast tissue as possible.
	Mastectomy	• The removal of the entire breast.
Radiotherapy May be given externally or internally	External Radiation	• Uses a machine outside the body to treat the cancer.
	Internal Radiation	• Uses a radioactive source put inside the body for a short period of time. The source is placed directly into or near the cancer.
Hormonal Therapy Intravenously (injected into your vein) or orally		
Chemotherapy Intravenously (injected into your vein) or orally	neoadjuvant chemotherapy	• Chemotherapy performed prior to surgery.
	Adjuvant chemotherapy	• Chemotherapy that occurs following surgery. • May be used to kill any cancer cells that remain or to lower the risk of cancer recurrence.
Targeted Therapy Orally, injected or given intravenously (through a vein		• Targeted therapy works by "targeting" those differences that help a cancer cell to survive and grow.

(Australian Government- Cancer Australia and National Breast Cancer Foundation, 2019)

7. Loss of Income costs

A breast cancer diagnosis affects careers, financial status and loss of income for young women. According to a survey conducted by Deloitte Economic Access, 577 respondents were asked to estimate the average number of hours they worked per week in paid employment during the 12 months prior to the breast cancer diagnosis, during the treatment and during the 12 months after the completion of the treatment (Deloitte, 2016). Also, including their partner's working hours and income. The data shows that the respondents didn't work post diagnosis for an average of 12 months, also the household hours decreased from a median 40 hours per week to 20 hours per week (Deloitte, 2016). Post treatment, individual hours decreased to 15 hours per week from 25hpw before the diagnosis, whereas for households the hours decreased from 40 hours per week to 38 per week (Deloitte, 2016). This led to a reduction in 16% average household weekly income during treatment as compared to the 12 months prior to diagnosis (Deloitte, 2016). Of the 577 respondents, 66%, reported that they used household savings to meet the costs for the treatment (Deloitte, 2016). 9% claimed income protection, 8% used their superannuation and the rest 8% used borrowings (Deloitte, 2016). In some cases, despite lower income and work hours, 3% of respondents reported that their partner increased their work hours to meet the cost requirement (Deloitte, 2016).

Due to the lack of concrete data available for Australian young women and how breast cancer affects them the team decided to use some additional statistics provided by the American Association for Cancer Research which conducted a study on the employment trends in young women following a breast cancer diagnosis. In the study, the financial impact was discussed through the impact on employment, describing job changes and identifying factors associated with transitioning out of the workforce after diagnosis. (Partridge AH,2015) Like in the case of Australia, logistic regression is used here to identify the impact of diagnosis on pre and post-employment status (Partridge AH,2015). In this case, out of 730 respondents 555 i.e. 76% of women were employed both before diagnosis and at 1 year; 13% were not employed at either time point; 7% were employed pre-diagnosis but unemployed at 1 year; 4% were not employed prior to diagnosis but reported employment at 1 year (Partridge AH,2015) . Among women employed 1 year after diagnosis, 74% were somewhat or completely satisfied with their job and only 6% said cancer or treatment limited their ability to perform their job significantly; 38% said their ability was affected somewhat. (Partridge AH,2015) . Most (63%) said their employers had made accommodations for them, and almost all women (93%) said it was very likely they would be working in 1 year (Partridge AH,2015). Women with stage 3 disease (vs. stage 1), were more likely to transition out of the workforce following diagnosis, while women with a college or graduate degree (vs. no college degree) were less likely to transition out (Partridge AH,2015).

In the case of Australia, household income, hours of work and partners' income and working hours were considered as factors affecting the return to work among young women. However, in the US study, the socio-economic status, college degree and job type were also considered in addition to the above working hours and treatment. Most young women with early stage BC remain employed and report a willingness by their employer to make accommodations following a breast cancer diagnosis (Partridge AH,2015). While few women reported that their dx or treatment limited their job performance, the finding that women with more advanced disease were more likely to transition out of the workforce suggests an impact of dx/treatment burden on employment (Partridge AH,2015).

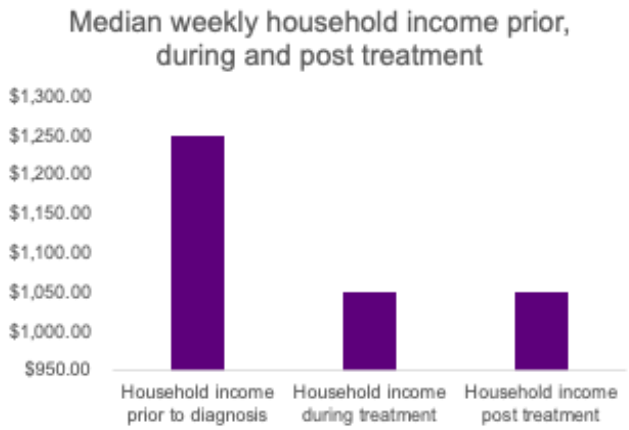

Figure 4: Change in median weekly income during surgery (Deloitte, 2016)

When extrapolated to an Australian landscape, we can quantify the loss of income from the 1 year employment gap from breast cancer, as experienced by 76% of women in the US.

Average weekly earnings for women between 21 and 44 = $1,316 - as taken from the Australian Bureau of Statistics (2019)

= $68,432 yearly income lost for 76% of women who take time off work after diagnosis of breast cancer.

Based on a lack of specific data available for loss of income for young women with breast cancer, maternity leave has been used as a proxy when determining the effects on earning capacity after taking 1 year off from employment. The Australian Institute of Family Studies determined that "Women returning to work within 12 months of taking leave experience an average wage penalty of more than 7% in the first year back at work."

Table 2: Loss of Income in first 4 years from receiving breast cancer diagnosis:

	Y0: Year off Work	**Y1:** First year returned to work	**Y2:** Second year back at work	**Y3**: Second year back at work
Income % Loss	**100%**	**7%**	**12%**	**12%**
Average Income Lost per woman	$68,432	$4,790	$8,212	$8,212

Total Income Lost in first 4 years from receiving breast cancer diagnosis = $89,646 per woman

Superannuation

Based on a 9.5% superannuation payment on top of the income, this would amount to a superannuation loss of $8,516. Superannuation holds a compounding interest rate meaning this value would grow exponentially on average. This study considers women up until the age of 40, therefore women in this study would face this income loss at least 25 years before the average Australian retirement age, when the superannuation balance would become relevant. Therefore, this value of $8,516 is a minimum representation of the short-term effects of breast cancer and does not represent the compounded loss women would face at retirement from this loss of income in their youth. The compounded value would vary largely depending on the age at which women experience this income loss.

However, as these figures are taken from maternity leave data, they may not represent the full amount of income lost for young women with Breast Cancer. Particularly, as the Australian Bureau of Statistics lists "Ill health or Disability" being the 6th leading cause of "Difficulty in finding work in Australia" and determining that 10% of unemployed people fit into this category. However, data is too ambiguous at this stage to fully quantify the financial effects of facing difficulties in finding employment after being diagnosed with breast cancer as a young woman. Therefore, we suggest using the above figures (Table 1) as minimums.

Please note: The time value of money has not been considered based on an inability to predict the cash rate and inflation.

7.1. Income Support Options

There are a vast array of services available to women with breast cancer and a multitude of avenues to take when financing breast cancer. Firstly, the Australian government department of health provides free breast cancer screening for women over the age of 50. However, as this service does not extend to women under this age, the upfront cost of such services impacts the financial burden right from the get-go. Moreover, later detection creates a greater financial burden due to the higher invasive methods of treatment for breast cancer. This financial burden can be combatted through supports such as welfare services, income protection insurance and previous savings.

7.1.1. Centrelink Services

Centrelink support is available through the sickness allowance to those who are over the age of 22 and either have a job or have austudy/abstudy as a full-time student. This is available to individuals who meet an income and assets test, pass residency rules, are unable to work or study for a short time due to illness and have work or study to return to when they are better. The amount of support available is dependent on an income and assets test- meaning the more the individual has in savings/assets, the less is available. The current fortnightly maximum depending on the situation are:

Table 3: Comparison of Centrelink support options

Single with no children	$559.00
Single with dependent children	$604.70
Single, 60 years or older but under Age Pension age, after 9 months of regular payment	$604.70
Partnered	$504.70 each

(Centrelink, 2020)

Other supports available through Centrelink include the carers payment that is available to individuals who are providing support through day-to-day care. " Today, most cancer treatment is given in outpatient treatment centres – not in hospitals. This means someone is needed to be part of the day-to-day care of the person with cancer and that sicker people are being cared for at home." (American Cancer Society, 2020) "Caregiving itself can be a full-time job, but many caregivers already have paying jobs. This can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers even need to take unpaid leave, turn down promotions, or lose work benefits." (American Cancer Society, 2020) However, this Centrelink payment holds the key requirement of 'constant care' and thus is difficult to assess and is dependent upon the severity of the illness/ level of assisted care needed.

As the sickness allowance is only available for individuals over the age of 22, government assistance for anyone under the age of 22 is limited due to the 'dependency rule'. Individuals under the age of 22 are categorized as dependent on parents irrespective if they still live at home (unless there are extenuating circumstances that prevent that from being able to happen). Thus, assistance from the government is available in the form of the low-income health care card and the youth allowance. Youth allowance is the income support option that is similar to Jobseeker and is thus different to sickness allowance as it is for individuals who are: "16 to 21 and looking for full time work, 18 to 24 and studying full time, 16 to 24 and doing a full time Australian Apprenticeship, 16 to 17 and independent or needing to live away from home to study or 16 to 17, studying full time and have completed year 12 or equivalent." (Centrelink, 2020). The low-income health care card is available for any individual who passes similar income and assets tests that Centrelink deem to be low income earners. The benefits of a low-Income Health Care card include access to discounted medicine available on the pharmaceutical benefits scheme, bulk billed doctors' visits (at the discretion of the doctor, or discounted visits) and a bigger refund for medical costs when the Medicare safety net is reached.

7.1.2. Income Protection Insurance

Income protection insurance is a possible supplement to the loss of income from illness if the individual is unable to work. Income protection insurance can pay up to 85% of your pre-tax income if you are unable to work. The amount individuals can receive depends upon the product disclosure statement and what each company has included within the policy. Many different companies have different waiting periods from 14 days to up to 2 years. Quote examples indicate the high out of pocket costs for income protection insurance not included in superannuation:

Table 4: Income Protection Insurance quotes

Basic quote requirements: 30-year-old, $75000 income, non-smoker, 75% income coverage, lives in Queensland, 28 day waiting period and 12 month benefit.	
AAMI	$966
Virgin Money	$840.32
MediBank	$1178
NRMA	$826.80

However, it has been found that a significantly lower percentage of young people have income protection insurance meaning the likelihood of having income protection insurance prior to diagnosis significantly reduces. (Metlife, 2019) (Shepherds Friendly, 2020) Thus, those who decide to purchase income protection insurance post-diagnosis will have higher premiums due to pre-existing medical conditions, increasing out of pocket costs.

The alternative to purchasing income protection insurance out of pocket is to include the premium as part of superannuation-59% of income protection insurance is taken out this way (ASFA, 2017). However, it is known that individuals are, on average, not actively engaged in their superannuation fund meaning that many are left uneducated about their type and level of cover (Parrish, C, 2018). Factors that are affecting this include having multiple superannuation accounts- meaning individuals are paying for multiple insurance policies, the removal of automatic insurance on superannuation funds for people under 25 and the latest legislation that states superannuation balances under $6000 are uninsured completely. “Many people do not realise they have insurance cover through their membership of a superannuation fund; do not investigate the detail of the cover they receive; do not seek out additional cover to suit their needs in the event they become unable to work due to disability; and only become aware of any limitations of their existing cover when they come to make a claim – the time when they need the benefit the most”. (Parrish, C, 2018). Thus, more education and involvement by individuals into their superannuation funds is needed to determine the level of cover they want/need and to determine what they are insured for.

7.1.3. Personal Savings

Personal savings can supplement a loss of income to cover not only out of pocket medical costs, but the costs of day to day expenditure. Dependent upon the type of support available to an individual (family support/support of a partner) can also greatly impact the necessity of personal savings accounts. A multitude of studies have been conducted on the ability of a household to raise emergency funds quickly, notably finding that a significant portion of individuals will struggle to come up with the funds necessary to tackle the expense in a timely manner. JPMorgan Chase found that the recommended savings buffer for changes in income and expenses should be six weeks, however, only about a third of households held that recommended buffer in savings (JPMorgan Chase, 2019). In Australia, a similar study was conducted that built upon that which found that:

> "There are already many public programs aimed at helping socioeconomically disadvantaged households, including income support, unemployment, disability and pension benefits, dependent spouse rebates and allowances, child support and endowment and concessional benefits. However, few of these mechanisms provide low cost emergency funds. This is a concern because even when a household is able to raise emergency funds, it may be through relatively high cost sources such as loans on credit cards. Second, it appears that the capacity to raise emergency funds is very much a function of a household's engagement with the financial sector" (Worthington, A.C. 2004).

It also found that the greatest influences on accessing emergency funds include the level of disposable income, drawing money from retirement plans and investments and those who already own their own home- meaning women with higher incomes, age and asset levels are in a greater position to weather a loss of income or increase in expenditure (Worthington, A.C 2004). Personal savings is thus disproportionally helpful to younger women or women on lower incomes.

8. Summary/Conclusion

The team's key findings were that, in regard to medical costs; there was limited transparency regarding itemized costs, a large variability in costs and that current attempts by government to minimise these issues were insufficient to benefit young woman with breast cancer. The team also found that there was a significant loss in income as result of diagnosis and treatment for breast cancer. This has considerable long-term implications in terms of super and also long-term career options. Furthermore, while there is a vast array of income support services available there is little education surrounding these options. We have thus provided recommendations below which we believe So Brave can enact to improve financial outcomes for young women with breast cancer in Australia.

9. Recommendations

There are several recommendations that the team have developed based on research and analysis that can be enacted in both the short and long term by the respective parties.

9.1. Short Term Recommendations

1. Review of Financial Consent Documentation

- The AMA document only touches upon questions on page 13 of 16.
- From a Breast Care nurse and Clinical Nurse Consultant, the AMA document is not readily available in hospitals and is not known about by many key stakeholders.
- BCNA and Cancer council documents are the main guides but don't include consultation with clinics and specialists.
- The team recommends creating and dispersing a concise document among all necessary stakeholders containing:

1. Key questions for patients to ask doctors and specialists
2. Clarity surrounding the Public/Private decision for patients
3. Guide/Resources on Private health insurer policies and levels of rebates

2. Transparent cost Documentation

- As Dr Ian Mcrae, a health economist with a background in health policy and administration states, “Improving the transparency of pricing could increase competition and place downward pressure on unreasonable fee-setting and may provide the most affordable and fair approach to the problem [of significant out-of-pocket costs].”
- This would involve more public disclosure of clinics and specialist fees especially around regular treatments such as; mammograms, ultrasounds, (other regular standard treatments you find Aisha).
- While the website is a terrific start it is still incredibly ambiguous and general and so including specialist fees as promised is critical to allow patients to benefit from its service.

3. Doctor Education on Private vs Public decision

- From the graph below it can be seen that there is considerably higher out of pocket costs with PHI but also considerably more patients use it.
- no one had discussed costs with 37%(n=274). Specialists had discussed costs with 47.2%(n=316) and GPs had discussed costs with only 3.4%(n=25). (Consumers Health Forum of Australia, 2018)
- Professor Ray Chan is currently undertaking a study with colleagues to understand the processes behind GPs making decisions with patients. Our recommendation would be to support this work and also through a channel such as the AMA suggest implementing GP education to properly run through the financial and treatment implications of going through the private or public system, in the first few consults with patients.

4. Education for employers on how to manage employees with cancer

- There is minimal education required by employers to understand the challenges associated with assisting an employee with any cancer. The Cancer Council has released a document to provide a framework for employers, however it is not compulsory and provides limited recommendations about flexibility beyond what is required by WorkChoices:
- Education regarding the benefits of supporting and adapting to employees with cancer is recommended so that there is a positive environment within the workforce and the value of keeping the individual in the workplace is easily seen.

5. Provide resources for employees to engage in stronger relationships with their employees

- Education and assistance resources regarding how to have open conversations to employers are needed so that there is greater understanding about what is required from both the employer and employee. This will help with a smooth transition from treatment phases and the ability to have open conversations with employers about working arrangements, possible change in hours and general flexibility.
- Engagement of employers/employees whilst on leave for treatment would be beneficial so that the return to work process is smooth and the likelihood of return is greater. The cancer council has a document outlining its recommendations as part of the same series as above.
- However, this document has not been updated in over 10 years and has outdated information. Also, breast cancer specific education would also be beneficial as each cancer is different and employee/employer understanding of severity and impact on working ability would be beneficial

6. Education and more active engagement by individuals with their superfund

- The productivity commission’s report into the superannuation industry found that there is not an active engagement from individuals into their superannuation (Parrish, C 2018). BCNA has provided a Submission to The Parliamentary Joint Committee on Corporations and Financial Services inquiry into the Life Insurance Industry in 2017 which has deeper recommendations regarding the entire superannuation industry and is a valuable tool to look at previous recommendations.
- However, many of the recommendations have not been implemented and some have been rejected- the ‘opt out’ model has been rejected for an ‘opt in’ model for cover for under 25’s in

2018. Thus, due to the legislation changes many individuals are now no longer covered or their coverage has been reduced.
- The short-term recommendation is for more education about superannuation coverage and the necessity for Australians to become more involved in superannuation so that individuals have a greater understanding of costs and coverage. This could be implemented through employer programs or marketing from superannuation companies.

7. Provide financial counselling

- Provide financial counsel services to women who cannot afford the treatment due to their financial situation throughout the diagnosis and during the treatment process. It is noted that 73% of women do not get financial advice from their clinicians which impacts their budget and, in some instances, lead to loss of income.
- Implications of breast cancer should be discussed with the patients. A financial planner can be created wherein information such as debt, budget, loss time at work should be disclosed.
- Discussion of such finances and its impact on the career of young women will lessen the worry and burden among people.

9.2. Long Term Recommendations:

It's noted that the following long-term recommendations will require a lengthier time frame, and policy intervention with the help of relevant government bodies and fellow advocacy groups. Regardless, an attempt to set these in motion will be of benefit not only for the organization but also for the overall mission of helping young breast cancer patients.

1. Provide assistance to employers for greater adaptability for working arrangements for people undergoing cancer treatments

- Currently employers are only required under WorkChoices to provide four weeks annual leave and 10 days personal/carer's leave and two days emergency unpaid leave. These minimums can cause difficulties for employees facing cancer treatment and thus government regulated assistance through policy intervention would be beneficial to support workers stay in the workforce if their employer is not flexible.
- A return to work plan can be formulated wherein women can state their return date and mention their goals and abilities to work. In case of any health emergency or restrictions from their clinicians, prior arrangements can be made to ease out the working culture for them.
- Engagement between employers and employees related to leave for treatment can be increased in order to increase the likelihood of women returning and to smooth out the return to work process.

2. Reduce insurance claim waiting periods

- Insurance companies need to enact more personable service in income protection insurance claims- especially regarding claim waiting periods to ease financial strain for individuals with illness that prevents working ability.
- Previous regulation strategies such as The Insurance in Superannuation Voluntary Code of Practice (2018) have relied on self-regulation but "Self-regulation by the industry has provided insufficient protection for consumers and does not appear to be the answer to the problems which have been identified" (Parrish, C 2018). This self-regulation has not been effective in reducing claim waiting periods and multiple breaches continue to occur with individuals waiting over 6 months regularly for decisions (Parrish, C 2018) - which is significantly longer than needed especially with pressing medical costs associated with a breast cancer diagnosis.
- Thus, government intervention is needed to assist with the regulation of these industries.
- More support (government or independent organisations) for young people who do not have the same personal savings/emergency savings as older individuals.
- Creating a return-to-work plan might help women to determine the abilities, goals and in case of any adjustments or restrictions needed, it can be immediately resolved.

3. Include younger women in the National Breast Cancer Screening Program

- Per our research early detection determined through mammograms has a significant impact on the reduction of mortality and overall medical costs; earlier detection more than often removes the need for more complicated and prolonged medical procedures thus reducing overall medical costs.
- The National Breast Cancer Screening Program in Australia, BreastScreen, invites women aged 50-74 to undergo free mammograms every two years. Women aged 40-49 and those aged over 74 can also be screened free of charge, however they are not sent invitation letters (Cancer Council Australia, 2019).
- It's understood that women under 40 aren't recommended to undergo mammograms due to the higher density of their breast tissue making detection harder. In lieu of this, breast MRIs are typically performed in order to screen young women with a noted higher risk of breast cancer, e.g. strong family history of the disease (Cleveland Clinic, 2019).
- With the noted benefits of early detection, we recommend that the National Breast Cancer Screening Program include the option of screening methods best suited for women less than 40 years of age, allowing them the access of free screening services.

4. Subsidies for Major Medical Costs

- Based on recent surveys, the highest out of pocket medical costs are breast reconstructive surgery, radiotherapy, and specific tests such as Oncotype DX tests, genetic tests and MRI, costing upwards of $9,000 for some treatments (Deloitte Access Economics, 2016).
- As mentioned for young women who are just starting in their careers and financial independence, they will more than likely not have the funds to afford such necessary medical procedures, an initiative that helps subsidies some of these costs will be of a tremendous benefit in the long run by not depleting what little they have saved up.
- The Australian government currently offers subsidies for medical procedures and treatments, such as the Pharmaceutical Benefits Scheme which helps cover the cost of some medicines for Medicare card holders (Breast Cancer Network Australia, 2019).
- An extension of such subsidies to include these high medical cost procedures as well as including patients that may not qualify for Medicare but still prove financial hardship will be of tremendous economic benefit.

Legal Disclaimer

Official project disclaimer (from UQ Legal Office June 2013)

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