

Cancer care costs – Were you informed?

Introduction

One in two Australians will be diagnosed with cancer by the age of 85 years.¹ Although healthcare in Australia is largely publicly funded, out-of-pocket costs associated with cancer diagnosis, treatment, and survival can place a huge burden on patients and their families. These can include costs associated with gap payments, imaging, medications, travel, accommodation, and parking, compounded by loss of income. The average lifetime cost of cancer for individuals aged 15-64 is \$126,280, with people who live outside major cities being 17 times more likely to report locational or financial barriers to care compared to those living in metropolitan areas.² This is particularly relevant to Western Australia with a large proportion of the population living in rural or remote areas.

The Health Consumers' Council (HCC) has partnered with Cancer Council WA to find out whether people are making informed financial decisions about where to get their cancer care.

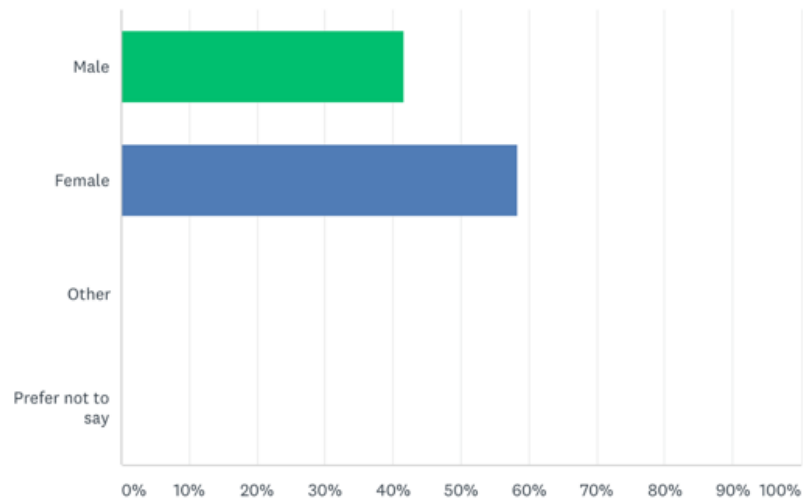
Methods

A 12 question survey was designed by the HCC, Cancer Council WA, and Cancer and Palliative Care organisations to determine the level of patient understanding of the financial aspect of cancer treatment. This was distributed through each organisation's network and was available in hard copy format in cancer clinics throughout Western Australia, and as an online survey through each network's website. Survey results were collected between November 2018 until April 2019.

Question 1

A bit about you - are you

Answered: 108 Skipped: 0

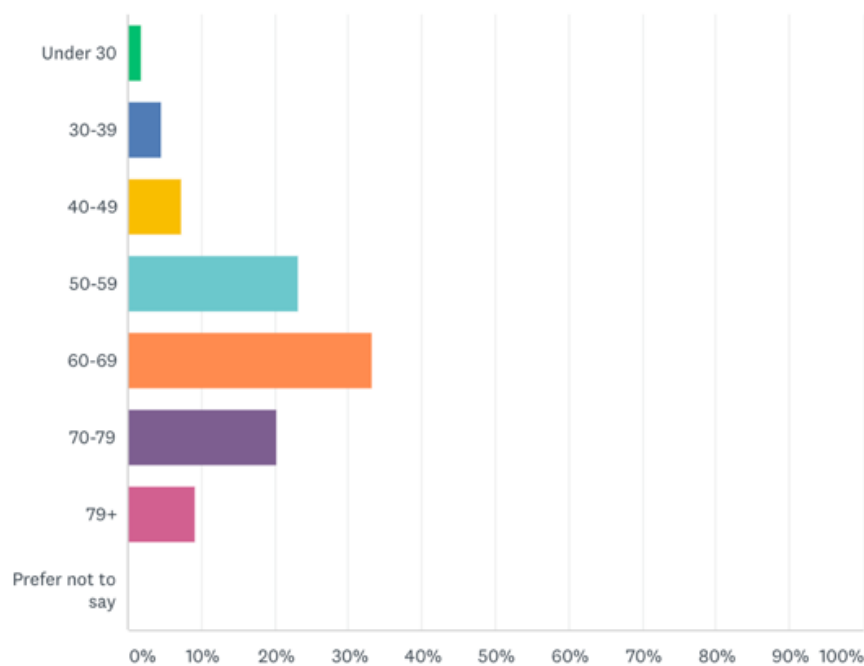


ANSWER CHOICES	RESPONSES	
▼ Male	41.67%	45
▼ Female	58.33%	63
▼ Other	0.00%	0
▼ Prefer not to say	0.00%	0
Total Respondents: 108		

Question 2

Your age?

Answered: 108 Skipped: 0

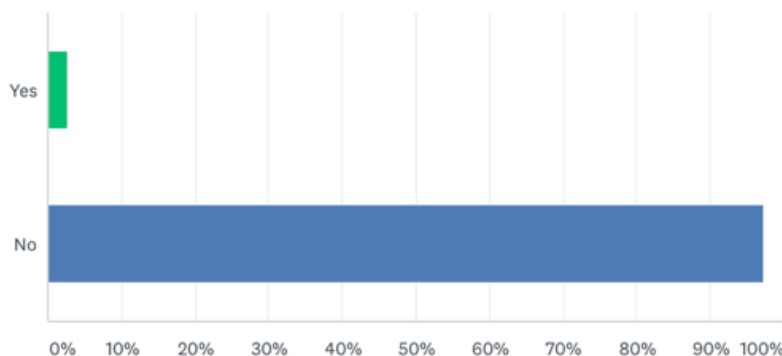


ANSWER CHOICES	RESPONSES
Under 30	1.85% 2
30-39	4.63% 5
40-49	7.41% 8
50-59	23.15% 25
60-69	33.33% 36
70-79	20.37% 22
79+	9.26% 10
Prefer not to say	0.00% 0
Total Respondents: 108	

Question 3

Do you identify as Aboriginal/ Torres Strait Islander

Answered: 108 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	2.78%	3
No	97.22%	105
Total Respondents: 108		

Question 4

What is your postcode?

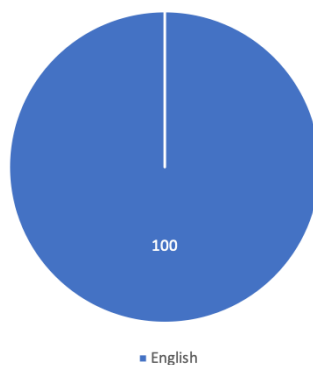
Displayed graphically:



Question 5

What language do you speak at home?

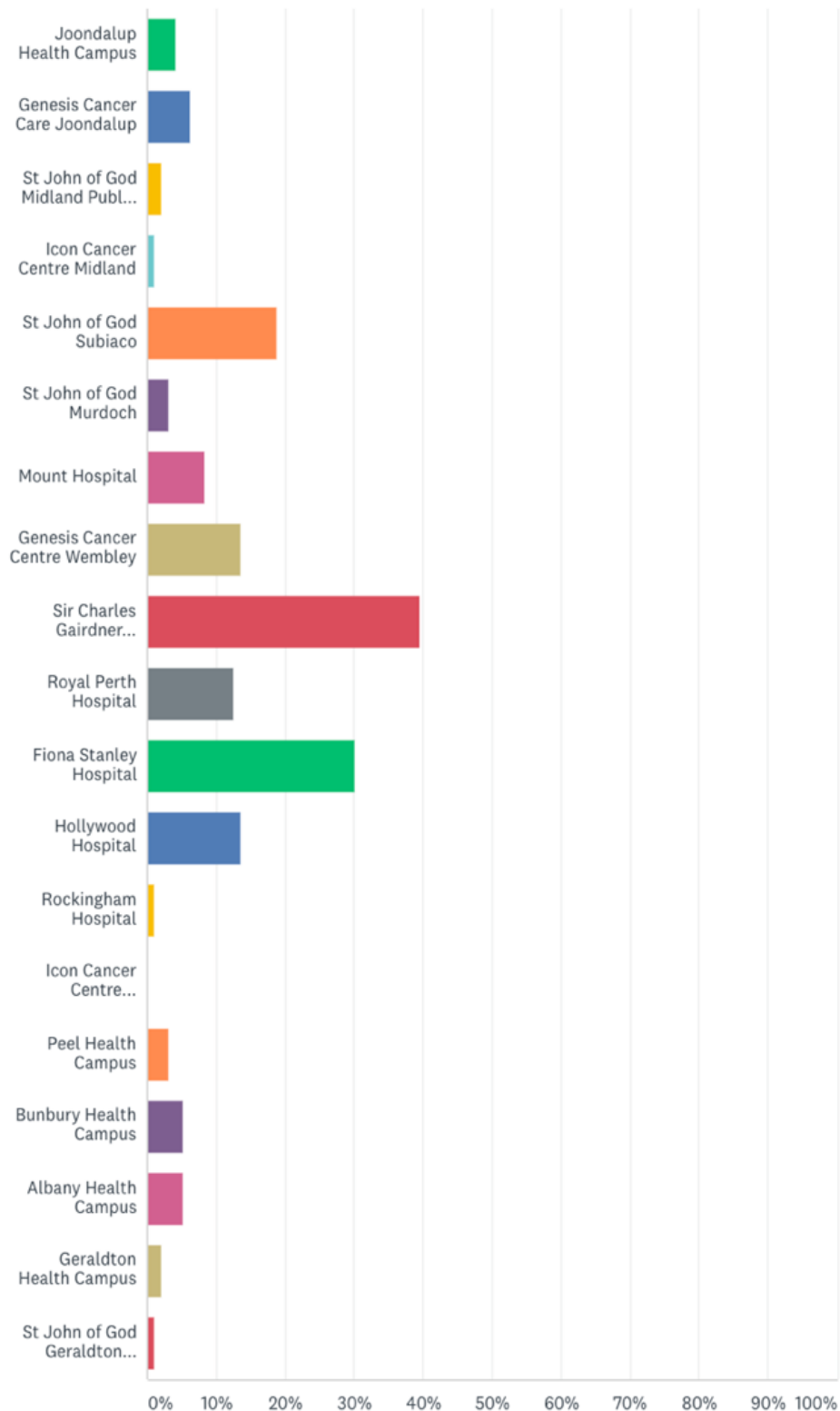
Answered: 100 Skipped: 8



ANSWER CHOICES	RESPONSES	
English	100%	100
Total Respondents: 100		

Question 6

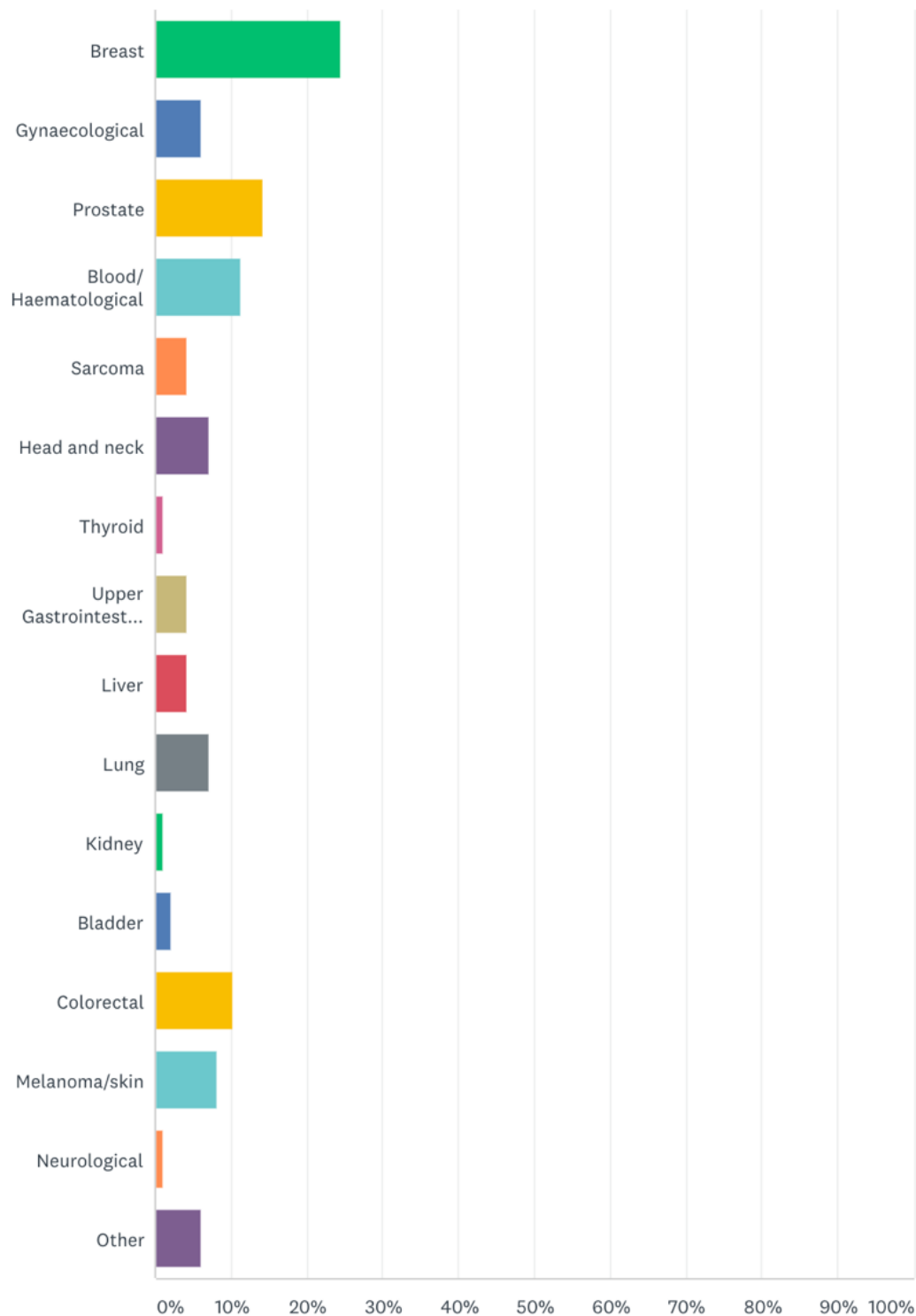
Where were you treated? Tick all that apply.



ANSWER CHOICES ▼	RESPONSES ▼
▼ Joondalup Health Campus	4.17% 4
▼ Genesis Cancer Care Joondalup	6.25% 6
▼ St John of God Midland Public Health Campus	2.08% 2
▼ Icon Cancer Centre Midland	1.04% 1
▼ St John of God Subiaco	18.75% 18
▼ St John of God Murdoch	3.13% 3
▼ Mount Hospital	8.33% 8
▼ Genesis Cancer Centre Wembley	13.54% 13
▼ Sir Charles Gairdner Hospital	39.58% 38
▼ Royal Perth Hospital	12.50% 12
▼ Fiona Stanley Hospital	30.21% 29
▼ Hollywood Hospital	13.54% 13
▼ Rockingham Hospital	1.04% 1
▼ Icon Cancer Centre Rockingham	0.00% 0
▼ Peel Health Campus	3.13% 3
▼ Bunbury Health Campus	5.21% 5
▼ Albany Health Campus	5.21% 5
▼ Geraldton Health Campus	2.08% 2
▼ St John of God Geraldton Health Campus	1.04% 1
Total Respondents: 96	

Question 7

What type of cancer do you have?

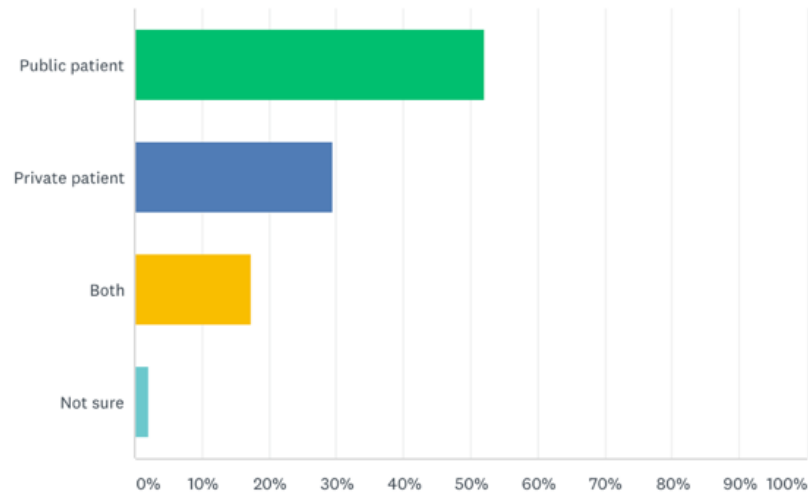


ANSWER CHOICES ▼	RESPONSES ▼
▼ Breast	24.49% 24
▼ Gynaecological	6.12% 6
▼ Prostate	14.29% 14
▼ Blood/ Haematological	11.22% 11
▼ Sarcoma	4.08% 4
▼ Head and neck	7.14% 7
▼ Thyroid	1.02% 1
▼ Upper Gastrointestinal cancer (oesophagus/stomach/pancreas)	4.08% 4
▼ Liver	4.08% 4
▼ Lung	7.14% 7
▼ Kidney	1.02% 1
▼ Bladder	2.04% 2
▼ Colorectal	10.20% 10
▼ Melanoma/skin	8.16% 8
▼ Neurological	1.02% 1
▼ Other	6.12% 6
Total Respondents: 98	

Question 8

Are you being treated as a:

Answered: 98 Skipped: 10

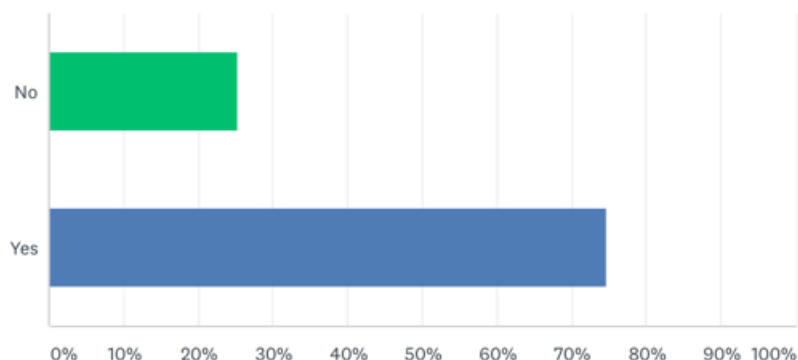


ANSWER CHOICES	RESPONSES	
▼ Public patient	52.04%	51
▼ Private patient	29.59%	29
▼ Both	17.35%	17
▼ Not sure	2.04%	2
Total Respondents: 98		

Question 9

Have you experienced out of pocket expenses?

Answered: 99 Skipped: 9

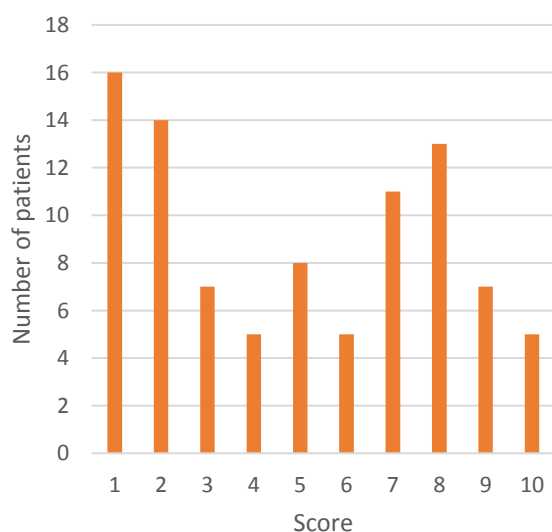


ANSWER CHOICES	RESPONSES
No	25.25% 25
Yes	74.75% 74
Total Respondents: 99	

Question 10

What impact has this had on you on a scale of 1-10, where 1=no impact, 10=catastrophic impact?

Answered:91 Skipped 17



ANSWER CHOICES	RESPONSES
1	17.58% 16
2	15.38% 14
3	7.69% 7
4	5.49% 5
5	8.79% 8
6	5.49% 5
7	12.09% 11
8	14.29% 13
9	7.69% 7
10	5.49% 5
Total Respondents: 91	

Question 11

What is the reason for your score?

Many of the patient responses to question 11 contained themes related to the difficulties associated with the cost of their cancer treatment. The most common was the theme of *opportunity cost* (12 responses), where these patients reported difficulties regarding work and income. Examples of these responses included “Had to cash out leave from work” and “Wife had to give up work to care for me”. This is in keeping with the published literature, as Zajacova et al. (2015) found that employment rates and number of hours worked decreased in the first year after a cancer diagnosis, and was associated with a drop in household income.³

Another common theme was the theme of *additional burden* (9 responses), where patients described having to cope with paying medical fees on top of their preexisting costs of living. One patient stated that “I have a house full of bills and four children to support”, which echoed many of the other responses within this theme. Increased financial burden has also been identified as the strongest independent predictor of poor quality of life amongst cancer survivors.⁴

Many patients also reported concerns with the cost of their treatment and shared a theme of *limited funds* (10 responses). One patient described themselves as a “low income earner living in the country”, highlighting the difficult situation in which patients can find themselves especially if they are from lower socioeconomic groups. In addition, many patients experience a financial burden associated with the purchase of medicines and that some go as far as to not use or to not purchase medicines.² These cost concerns are common amongst patients with cancer, and should be a topic of focus between healthcare providers and patients.⁵ This ties in with another theme of *unexpected cost*, which can be divided into subthemes of *higher cost than expected* (8 responses) and *more varied cost than expected* (8 responses). Some patients described not knowing the full cost of their treatment or being surprised at the amount, and gave responses such as “Lots of out of pocket expenses” and “Didn’t expect such a high cost”. Others portrayed the many hidden costs of treatment, whose responses included “Taxi fares”, “Parking is expensive for patients”, and “Travel – expenses not covered by Medicare or health insurance”. A more detailed and thorough explanation of the future costs that the patient is likely to bear may help to prepare them for the financial burden that they will endure.

On the other hand, several patients mentioned an easier financial journey through their treatment, and raised the theme of *financial ease* (8 responses). There was no correlation of

this theme between the publicly and privately treated patients. Examples of these responses include “Mostly treated at FSH without cost” and “Affordable”.

Question 12

What would you have liked to have known about cost before you started your treatment?

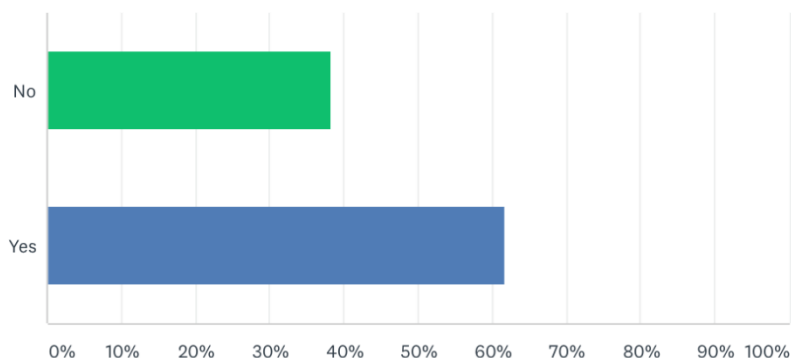
The most common theme amongst the responses to Question 12 was the theme of *private insurance benefits* (13 responses). Many patients were unsure of how their private health insurance could be used to ease the burden of their treatment costs, and the majority were disappointed at the large gap payments that they were still required to pay. One patient was concerned at “why there is such a large gap” in cost, while another was “referred to a private radiology clinic which had out of pocket expenses” despite having private health insurance. It may be difficult to provide general information to patients as each situation is very individualized depending on the type of treatment and level of cover the patient has. Having a healthcare professional who is available to guide patients through this process could help ease the burden and worry during a stressful and difficult period.

The theme of *unexpected cost* (6 responses) was also present in this question, with many patients reporting that they would have liked to have been warned about potential costs not directly related to their treatment, such as parking and transport. These costs are relatively more standard and applicable to many patients, so provision of broader information may be appropriate, unlike the previous example.

Question 13

Were you aware that there would be out of pocket expenses for your care?

Answered: 89 Skipped: 19

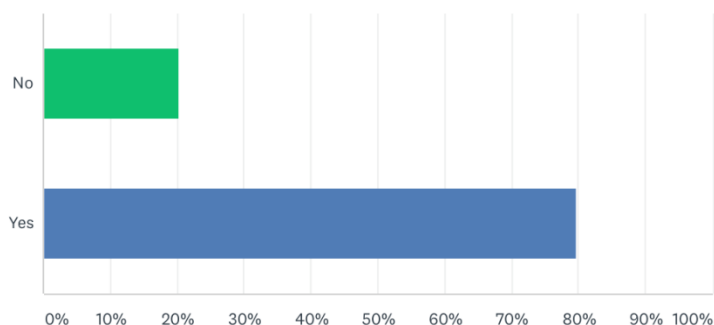


ANSWER CHOICES	RESPONSES	
▼ No	38.20%	34
▼ Yes	61.80%	55
Total Respondents: 89		

Question 14

Are you aware you could be treated in a public hospital for no cost?

Answered: 94 Skipped: 14

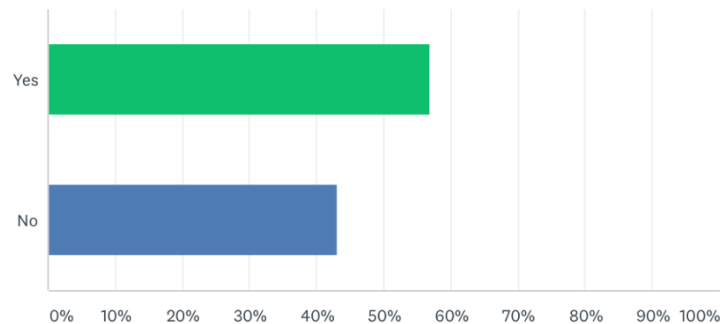


ANSWER CHOICES	RESPONSES	
▼ No	20.21%	19
▼ Yes	79.79%	75
Total Respondents: 94		

Question 15

Do you think you were well informed by your caregivers about costs related to your treatment?

Answered: 86 Skipped: 22



ANSWER CHOICES	RESPONSES
Yes	56.98% 49
No	43.02% 37
TOTAL	86

Discussion

Over 86% of patients who participated in the survey were above the age of 50. This reflects the ageing population who are more likely to experience cancer-related illnesses, and emphasises the importance of this survey as the financial burden of cancer costs in Western Australia is likely to grow.

41% of survey participants were from the Perth metropolitan area, with the majority of patients coming from rural areas. The distribution of the survey was designed to reach areas outside the Perth metropolitan area, such as Albany and Geraldton. One common theme in questions 11 and 12 was the unexpected costs of transport and accommodation which especially applies for patients living in rural areas. As this is an important factor for these patients, more emphasis on ensuring that patients are aware of the Patient Assisted Travel Scheme (PATS) may be beneficial so that they are able to benefit from this government program. In addition, fully educating patients regarding treatment options and facilities that are available in regional areas is imperative so that patients can make fully informed decisions in regards to affordability and treatments that best suit their needs.

All participants of this survey spoke English at home. Further research could be directed at CaLD populations by making surveys more accessible to cover a larger population of the Western Australian population.

Most of the respondents were treated solely in the public system (52%) with privately-treated patients (30%) and patients treated in both systems (18%) making up smaller proportions. As of March 2019, 45% of the Australian population has private health insurance covering hospital treatment.⁶ However, health insurance does not eliminate financial distress or health disparities among cancer patients.⁷ This was echoed in the results of the thematic analysis of question 11 where many individuals found themselves with large gap payments despite having private health insurance. This may come as a result of a mismatch between a patient's private health cover and their treating doctor's preferred provider. As such, better patient education regarding the different options of public vs. private vs. both in order to find the optimal choice for each patient may help to improve satisfaction and outcomes. Additionally, clinicians should make aware their preferred providers to newly referred patients so that they can make informed financial decisions. Further research could investigate the number of patients who are treated only in the public system who happen to have private health insurance as well.

The impact of the financial burden was evaluated in question 10, and the most frequent responses to this question were scores of 1-2 and 7-8 out of 10. This could be interpreted as groups of patients either not being severely affected by out of pocket costs, or being fairly affected but finding ways to deal with the situation. An area of future research could be to look into the relationship between socioeconomic status and the financial impact of medical treatment to assess for any discrepancies or health inequalities. This will allow for targeted interventions to be created in order to address these.

Questions 13-15 assessed the level of patient understanding about financial costs as well as their expectations. 57% of patients felt that they were well informed about cost of treatment, and 62% being aware of out of pocket costs. This means that 43% of respondents did not feel that they were well informed about their treatment cost, and 38% were not aware about out of pocket costs which was evident from the thematic analysis of questions 11 and 12. Gaining an understanding of the patient's financial situation is imperative as severe financial distress has been shown to be a risk factor for mortality.⁸ Given that 75% of patients do experience out of pocket expenses during cancer treatment, it is important that actions are put into place to aid financial decision making. Further research should be done to identify patients who are at the greatest risk of financial distress in order to improve patient outcomes.

References

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- ⁵ Stump TK, Eghan N, Egleston BL, Hamilton O, Pirollo M, RN, et al. Cost Concerns of Patients With Cancer. *J Oncol Pract*. 2013 Sep; 9(5): 251–57.
- ⁶ Quarterly Private Health Insurance Statistics [internet]. Sydney: Australian Prudential Regulation Authority; 2019 [cited 2019 Jun 23]. Available from: https://www.apra.gov.au/sites/default/files/quarterly_private_health_insurance_statistics_-_march_2019.pdf
- ⁷ Zafar SY, Peppercorn JM, Schrag D, Taylor DH, Goetzing AM, Zhong X, Abernethy AP. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013;18(4):381-90.
- ⁸ Ramsey SD, Bansal A, Fedorenko CR, Blough DK, Overstreet KA, Shankaran V, Newcomb P. Financial Insolvency as a Risk Factor for Early Mortality Among Patients With Cancer. *J Clin Oncol*. 2016 Mar 20; 34(9): 980–6.