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The Consumers Health Forum of Australia is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs, with a network reaching millions of Australian consumers.

CHF has the capacity, credibility and authenticity to ensure that governments and decision makers hear and understand the consumer perspective. Our members are diverse: they cover health consumer organisations and individuals with key conditions and issues across the health system and include professional, research and other health sector bodies.

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Executive Summary

Private patients routinely face bills running into thousands of dollars, in a system characterised by high cost, complexity and confusion, the Consumer Health Forum's *Out of Pocket Pain* survey has found. An added challenge is the variation in levels of health literacy across the Australian community.

More than a quarter of those having treatment for cancer who responded to the survey incurred costs of more than $10,000 in the past two years. Of the 1,200 who responded to the survey, one in six reported that costs had a significant impact on their lives, with some having to draw down on their superannuation. Well over one third of respondents said that no-one had discussed the possibility that they may face significant out of pocket costs with them and that they had the right to 'shop around'.

The survey results graphically highlight a fundamental dilemma now besetting the public/private health system: Australians facing heavy medical bills are now shocked to find that the private insurance they have paid so much for over many years exposes them to yet more expense when they require treatment.

Responses strongly support the establishment of an independent and authoritative website which consumers can consult to ascertain the fees and charges of individual specialists and allied health professionals. More than 70 per cent of respondents supported the concept.

The competing forces of cost and timeliness are confronting patients already saddled with life-threatening illness with uncertain and costly choices. Many are choosing the private course in order to avoid what they have been told will be long delays in getting treatment if they were to rely on the public system.

The choice of immediate care often can also mean an immediate bill. Some respondents reported that their surgeons demanded fees running into thousands of dollars before surgery. This means patients wait until after surgery to claim the small Medicare benefit. It also means that patients may have weakened recourse in the event of complications if they have paid upfront.

Anaesthetist fees pose a contrasting problem in that the fee and consequent out of pocket costs were frequently reported as being difficult to ascertain before surgery and can add hundreds of dollars to patients’ expenses.

One of the most common complaints about expenses were those for diagnostic imaging generally, but particularly MRIs, for which in frequent instances involving breast cancer scans, there is no Medicare benefit.

Out of hospital care for those with chronic illness requiring frequent specialist consultations posed difficulty for many such patients because of the difference between fees and the Medicare benefit available. As a result of their condition, these patients are often unable to work and/or earn a reasonable income.

For patients from rural and regional Australia, costs of travel, accommodation and hospital parking present daunting cost issues on top of the out of pocket medical costs.

Out of pockets medical costs are the difference between doctors' fees and what the third party payer - Government and/or or private health fund - contributes for the service. If we want to ensure that our hybrid public/private health system continues to meet Australians needs and deliver accessible quality healthcare then we need action by all parties otherwise we will move to a two tier system where your income determines your health care. We put forward some suggested areas for action. However, the extent and complexity of the problem requires an integrated approach.

This survey has revealed profound problems with Australia's public-private health system with many patients facing harsh choices between long delays in treatment or exorbitant out of pocket costs. The causes are deep-seated, complex and difficult to resolve. Our overarching recommendation is that there should be an independent Productivity Commission investigation into the cause of this crisis and all aspects of private health. This should include a rigorous analysis of the causes of ever increasing out of pocket expenses and some possible policy solutions designed to ensure access to reasonably priced medical care and the stability and sustainability of Australia's public-private health system. We acknowledge and support the package of private health insurance reform measures announced in October 2017 by Minister Hunt. We make a number of additional recommendations for nearer term action that could be taken by government, private health insurers and healthcare providers.
**Introduction**

Out of pocket costs in healthcare, and how to make changes to affordability and value in healthcare that benefit consumers, is a wicked problem. It involves a wide range of stakeholders, federal and state laws and regulation, and the private and public health systems.

Despite healthcare expenditure in Australia being around the OECD average, Australian consumers face higher than average out of pocket costs. The impact of this is evidenced by high rates of missed appointments and failure to fill prescriptions due to cost. In 2015-16, one in five people avoided visiting a GP and one in six people failed to fill a script due to cost. Further, of Australians aged over 45 who needed to see a specialist, nearly half (45%) did not because of cost.

A confounder is the variation in levels of health literacy across the Australian community. Health literacy is the extent to which people can navigate and makes sense of the system in order to access and use health information and services and is an important determinant of health outcomes.

Many attempts have been made, and are ongoing, to address this challenge. Recent efforts have focused specifically on the problem of out of pocket costs associated with private health insurance. Government, opposition, industry, healthcare professionals and consumer groups all agree that out of pocket costs are increasing, that they are a concern and that changes need to be made.

Other than consumers, the key parties in this discussion are:

- Healthcare providers and health administrators, who set and charge the fees

- Health insurers who determine what proportion of these fees are covered by health insurance and who play a role in determining costs through negotiating contracting arrangements

- Government (both state and federal) who set and administer rebates, safety nets and reimbursement schemes such as travel reimbursement programs.

At the heart of this challenge is the consumer. Australian consumers are frequently left out of conversations regarding regulation and policy changes when they should be at the centre of these conversations. To keep consumers at the heart of this discussion, the Consumers Health Forum of Australia (CHF) undertook an online survey about out of pocket costs in January 2018.

The survey was prompted by the formation of a government-appointed expert committee to consider out-of-pocket medical costs. Despite this being a key consumer centric issue, CHF is the only representative on the committee. The survey, and this report, was undertaken to ensure that CHF’s advocacy was relevant, accurate and representative of the experiences of Australian healthcare consumers.

The survey was the most shared and responded to in CHF’s history. This shows that the issue is of key concern and interest to Australian consumers. Over 1200 responses were obtained, describing a wide range of experiences from a wide range of people.

The participants in the survey self-selected: the survey was not a random population sample. Nonetheless, the volume of respondents and the variety of experiences highlight the scope of the issue and its importance to the community.

This report summarises the results of the survey and discussed the implications of them. Following the results, the demographic characteristics of the sample and the survey method are described.

This report focusses predominately on the costs associated with hospital visits, with some consideration given to out of hospital costs such as medication and GP costs. Future reports will focus on the out of pocket costs associated with accessing allied health services and may provide profiles of specific respondent groups.

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**Out of pocket costs refer to:**

‘those additional costs for treatment inside or outside of hospital which are not covered by health insurance or Medicare and which consumers are required to fully pay yourself, or where they paid a gap for services attracting a Medicare and/or health insurance rebate’.
Health Costs - The Big Picture

How much does it cost to be sick in Australia?

The survey results show that being sick in Australia is expensive. Figure 1 presents the overall costs reported by survey respondents. It shows that the average spend was higher for those who had been in hospital compared to those out of hospital.

Of the participants who reported the illness or condition they had, the highest costs were borne by consumers with breast cancer and other cancers. Over a quarter of the participants with each of these conditions had spent over $10 000 in the last two years. What constitutes the costs that participants incurred is described in the later sections of this report.

As of November 2017, the average full time adult income in Australia was $84 656 per year[iv]. If reported costs were spread evenly over two years, a consumer spending $10 000 out of pocket per year on health care would have spent over 5% of their pre-tax income on healthcare costs.

Add to this the high cost of private health insurance yearly premiums, and private health care posts push out to around 10% of pre-tax income for those with health insurance.

Table 1 reports the health conditions for which there were more than 20 respondents. It shows how costs vary between health conditions.

Given the ongoing nature of chronic illnesses, the high proportion who had spent between $5000 and $10 000 in the previous two years is of concern. While it is unclear from the survey which stage of illness these consumers were at,

**Figure 1** Out of pocket costs incurred by respondents in the last two years – hospital and out of hospital costs compared

<table>
<thead>
<tr>
<th>Cost Range</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 499</td>
<td>50</td>
</tr>
<tr>
<td>500 - 999</td>
<td>100</td>
</tr>
<tr>
<td>1000 - 1999</td>
<td>500</td>
</tr>
<tr>
<td>2000 - 4999</td>
<td>1000</td>
</tr>
<tr>
<td>5000 - 9999</td>
<td>2000</td>
</tr>
<tr>
<td>More than 10 000</td>
<td>3000</td>
</tr>
</tbody>
</table>

by consumers with breast cancer and other cancers. Over a quarter of the participants with each of these conditions had spent over $10 000 in the last two years. What constitutes the costs that participants incurred is described in the later sections of this report.

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or the nature of their illness it does suggest that further work is required to understand the costs of living with a chronic illness.

A concerning finding to emerge from the survey was that there is a perception amongst consumers that using public health insurance is more expensive than not using it. Careena from NSW commented:

*I had private health cover however it would have cost more if I was to use it. I also found being category 1 there was no delay for any treatment. The main expenses were chemo and scans.*
Table 1  Out of pocket costs incurred by respondents in the last two years – health conditions compared

<table>
<thead>
<tr>
<th>Cost Range ($)</th>
<th>Autoimmune conditions (n=21)</th>
<th>Cancer – other (n=150)</th>
<th>Cancer – breast (n=224)</th>
<th>Chronic illness (n=28)</th>
<th>Multiple conditions (n=67)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 499</td>
<td>0</td>
<td>8%</td>
<td>4.1%</td>
<td>7.1%</td>
<td>7.4%</td>
</tr>
<tr>
<td>500 - 999</td>
<td>0</td>
<td>3.3%</td>
<td>2.7%</td>
<td>3.5%</td>
<td>4.4%</td>
</tr>
<tr>
<td>1000 - 1999</td>
<td>9.5%</td>
<td>6.6%</td>
<td>6.7%</td>
<td>17.8%</td>
<td>13.4%</td>
</tr>
<tr>
<td>2000 - 4999</td>
<td>28.2%</td>
<td>22%</td>
<td>32.1%</td>
<td>14.2%</td>
<td>35.8%</td>
</tr>
<tr>
<td>5000 - 9999</td>
<td>14.3%</td>
<td>21.3%</td>
<td>18.7%</td>
<td>32.1%</td>
<td>14.9%</td>
</tr>
<tr>
<td>More than 10000</td>
<td>38%</td>
<td>26%</td>
<td>27.2%</td>
<td>17.8%</td>
<td>13.4%</td>
</tr>
</tbody>
</table>

What's the impact of the costs on their lives?

One in every six respondents reported that these health costs had had a significant impact on their lives. These rates are higher than those reported in the 2016 Australian Bureau of Statistics Patient Experience Survey which found that 4% of those who needed to see a GP had delayed doing so because of cost, and 7% had delayed or decided against filling a script because of cost[viii]. However, they encompass a broader range of costs and behaviours than the patient experience survey captures. This suggests that further investigation is needed into the impact of costs on Australians’ healthcare choices. Should the rates in this survey be found to be indicative of consumers choosing not to access healthcare that is of critical concern.

Responses were classified as having a significant impact if a participant mentioned that they were facing costs they were unable to pay, had skipped appointments or medication because of costs, or were unable to pay for other costs in their lives. Rurality, income, and health condition were not related to the proportion that reported that costs had a significant impact on their lives. Mel is one such consumer. She has stage 2b breast cancer, and her health is not good. When she was diagnosed with metastatic breast cancer recently, she was told she would need a hysterectomy.

Having elected to use her private health insurance, she asked her surgeon if they would use the no gap arrangement from her health fund. The surgeon agreed, but she was not able to discuss the costs with the anaesthetist, and as a result was out of pocket over $1200. The impact on her life has been substantial, as she says:

I can't afford to pay my normal weekly/fortnightly bills when I have these huge out of pocket expenses and being a single mum trying to keep my head above the water and coping with cancer treatments on top. - Mel

The impact costs are related to being on a low income. Respondents who reported that their household income was less than $40 000 were twice as likely as respondents earning more than $130 000 per year to report that it was having a significant impact on their lives.

Pensioners and those living on fixed incomes find that the costs have a particularly substantial impact. One way that they do make ends meet is by being selective in the types of treatment they use.
Paul is a pensioner who describes the choices he has had to make:

I am currently sitting in a waiting room to have an ultrasound on a knee I can’t walk on because an MRI which would give a better diagnostic result would cost me $200 and on a pension with a number of chronic illness I am unable to afford it all. After the big bills we have had in the last two years I have to go for the cheap options now.

A number of parents who support their children responded to the survey, and many of them commented that if they were not able to do this their children would not be able to pay. Lisa’s son was diagnosed with epilepsy at 18. They live in rural NSW and must travel to Albury to access a specialist who does not bulk bill. She says:

The money we needed at first visit for EEG and consult was $570. The challenge for people is not only meeting the gap but having that full amount up front. We receive roughly $270 back on that first visit- paying a $300 gap. My son is lucky to have us paying his medical costs.

Sharyn lives in Queensland, and because of her cancer treatment is unable to work.

Since my diagnosis I have given up work we are struggling financially due to only one wage and we are finding it very hard to cope.

**Indirect Costs**

An important aspect of out of pocket costs are those costs which are indirect or hidden. These costs include travel to and from appointments, parking and time off work.

Because these costs are not as easily captured, they are often forgotten in policy discussions.

Rosemary lives in an inner regional district of Victoria. She has a number of chronic health conditions, and regularly must travel to Melbourne to access specialist care. As she describes:

That means travel expenses plus overnight accommodation plus out of pocket cost for specialists. Sometimes the receptionist will mention cost when booking appointments, not always. Doctors don’t seem to consider this when making referrals.

While travel subsidy arrangements do exist, and many consumers had accessed them, they frequently found them inadequate and confusing. Even when they are accessible, these schemes function as reimbursement schemes. Because of this, consumers who are unable to pay the cost up front struggle to use them. Maleeta, who lives in a remote community in Queensland, described his struggle in using these services:

Living in rural and remote community in Queensland, the cost to travel as well as out of gap payment for a specialist is extraordinary. To travel to the closest specialist appointment from my home town of Charlestonville to Brisbane is 10 hours trip. Accommodation is another burden as well as feed ourselves along the way. PTSS [The Patient Travel Subsidy Scheme] only pays for $66 per night accommodation and will only reimburse travel (fuel) on our return which does not help if you don’t have money up front to travel a couple of days before the specialist appointment.
Hospital costs and private health insurance

A substantial minority (40.4%, n=482) of respondents had incurred the costs they discussed when they were in hospital. Of this group, 91.5% had private health insurance.

Costs incurred in hospital were considerably higher than those incurred out of hospital. Of those who incurred costs in hospital, 28.2% (n=136) incurred costs over $10,000, compared to 12.1% (n=86) of those not in hospital. Higher costs tend to be associated with conditions which require surgery. A high number of respondents who reported this level of costs had breast cancer.

Melissa, who lives in NSW, has spent $15,000 since her diagnosis in July 2017. As a young woman, she chose to undergo IVF in addition to her breast cancer treatment, which increased the costs. She lists the costs that she incurred:

...the Excess gap for the health fund, the medications I had to take while having chemo that the hospital had for me to buy, the gap for my breast surgery x 2... the cost of seeing the breast surgeon appointments, oncologist appointments, to get my port fitted, IVF, IVF costs, excess for IVF hospital, medications to prevent or stop reactions (i.e. gastro stop, numbing cream), scans

Other conditions with associated high costs reported by respondents were joint and bone conditions. Geoffrey has had two surgeries: a spinal operation and a carpal tunnel operation. He was given information about the costs associated but, as he notes, this doesn't improve a person's ability to pay them:

We were given printed costs with the refunds we could expect to get but the gaps came to $11,000. I was in so much pain that I had to go ahead with the spinal op and recently a carpal tunnel op. The spinal op was the bulk of the gap, being $10,000.

Costs over $10,000 incurred outside of hospital were predominately associated with chronic illnesses. Regular specialists' costs build up considerably, as described by Tina.

I have Bipolar disorder and see my psychiatrist once per week at a cost of $450. I can claim back $154 from Medicare each visit until we reach the safety net (I have spent $2080 out of pocket)... I also see a Neurologist every 3 months as I have an autoimmune disease which costs around $80 out of pocket.

Who tells people about Out of Pocket Costs?

Consumers who had incurred costs in hospital were asked to indicate who had discussed their out of pocket costs with them. The options presented to them were: ‘specialist’, ‘GP’, ‘other’ and ‘no one’. Of the 62% (n=740) of the sample who chose to respond to this question, 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).

These rates are considerably higher than the most recent figures published by the Department of Health, which in 2007 found that 15% of hospital admissions, which had used private health insurance, had had no informed financial consent procedures administered[viii]. Given that the Medical Board of Australia regards most health professionals as having a legal duty to inform patients of financial implications of treatment, these figures should and do raise considerable concern.

The challenge of finding out about costs only after the process has started was demonstrated by the following participant. This experience shows that consumers need to be informed about costs in an upfront and timely manner, as soon as possible after diagnosis:
The delay and added stress or 'shopping around' or waiting in the public system by then seem like irrational choices. If you can afford it, you just pay. You just want to get your treatment started and done, at the time the costs seem like the lesser consideration, but they add up quickly, especially when you have also lost your income. In a less emotional state, you might choose to do things differently - apply more rationale and logic to your decisions - Nicola, VIC

Different, but complementary, suggestions were provided by Ben from WA. He suggested that:

It would be most useful and transparent for all involved if there was a public access listing of surgeons and costs associated with particular types of surgery. This would certainly have allowed us to make our own decisions and reduce stress levels at a time that was already stressful enough.

These results show that there is broad support amongst consumers for the creation of a website through which they could become better informed about their health costs and how the private health system in Australia works.

CHF, and others in the health sector, have previously suggested that one way to help consumers become better informed is through the establishment of an authoritative and independent website which publishes health practitioner fees and, ideally, performance indicators. Nearly three quarters of participants (72.1%, n=860) agreed that such a website would be a good idea, with only 7% (n=83) not agreeing. Many consumers provided suggestions for what should be included in the website in their comments. Based on these comments, consideration should be given to including information about where consumers can get assistance with out of pocket costs, or places where they could go to get more information. Kay's suggestions include:

This website could also include information on where you can get assistance (not commonly mentioned by health providers) for example ITPAAS, Canassist, Cancer Council, these are all great support but people need to know what is available to them.
Specific types of costs

Specialists

Non-surgical specialist costs were of considerable concerns for consumers. Unlike surgical costs, these costs tend to be ongoing and thus have a different impact on people’s lives. This concern was reported by 29.4% (n=351) of the entire sample, 35.4% (n=252) of those who incurred costs out of hospital and 20.5% (n=99) of those who incurred costs in hospital. Consumers who discussed these costs frequently noted that they are more challenging to deal with because they are ongoing. Josephine, from NSW, described that she sometimes has to miss appointments because of the cost. As she says:

I was supposed to see three specialists for ongoing treatment... Each specialist was between $320 and $360. However, I was informed that it was all right I would get some back. Yes, Medicare will refund approx. $90 on each. As a pensioner that does not even cover one weeks rent let alone what else I would need.

Other consumers found the high cost of initial visits to be a barrier to accessing care. Respondents such as Karen are concerned that they need to attend an initial appointment to understand the cost of ongoing care:

You must pay for that initial consultation to get the information you need to decide whether or not you can afford further treatment. Then if you think the estimates to treat your condition are too high, you would have even more large charges to get a second opinion from another specialist.

Some consumers demonstrated that they were aware that they were being charged more than the Medicare Benefits Schedule fee but felt powerless to change or act on this. Diana, who lives with multiple conditions and is a pensioner, is concerned about the lack of regulation around what practitioners are able to charge:

Finding the $240 to start with is often difficult when you are a pensioner. There is variation on the amount of gap I pay depending on individual specialists and what they want to charge. There appears to be no regulation on gap fees for specialists in primary care whereas there is some transparency about gap fees for hospital booked admissions.

Diagnostic Imaging

The most frequently mentioned specific cost were costs related to diagnostic imaging. Over one quarter (27%, n=322) of participants had faced this type of cost. These costs were among the most confusing for consumers because of the complex rules around when and if tests and procedures are eligible for Medicare rebates. For example, Breast Screen only covers screening mammograms for women who are asymptomatic and over 40 years of age. While clinically appropriate, these eligibility criteria are confusing and unclear for many consumers. Rachel, from South Australia, found this particularly irritating. She incurred over $5000 in out of pocket costs, including $1330 for diagnostic imaging:

Included in this cost are 2 breast MRIs ($375 each) neither attracting a Medicare rebate. I find this Medicare rebate ruling particularly irritating. I’m still under 50 and currently asymptomatic; doesn’t a personal history of breast cancer not qualify as being at high risk of breast cancer or recurrence?
Other consumers said that costs for tests and scans are not mentioned by practitioners, and because of this, they are found to be a hidden and ongoing cost. Lori reported that she was made aware of most of the costs of her treatment by her specialist before her treatment, but that the scans were a ‘surprise’ cost after the surgery:

2 weeks after my first surgery I was hospitalised with infection for four weeks, and the main “surprise” costs were always associated with scans, running into the hundreds to thousands of dollars out of pocket.

Confusion exists around whether or not consumers are able to choose which diagnostic imaging provider to attend. Survey respondents described feeling that they had no choice but to use the provider that the practitioner they were attending chose for them, even if doing so led to greater out of pockets. Jones, who has an ongoing health issue, has to delay going for tests every time they are requested because his specialist will not use public diagnostic imaging providers:

This vascular surgeon will not use public diagnostics and has continually referred me to private hospital/specialists for testing. I have had to delay testing in order to save the $ for the test. Mostly totalling $300 each time. I am now at a time when I am revisiting diagnostics and I’m about ready to tell the surgeon to go stick it.

**Surgeon and Surgery**

Costs related to surgery, or fees charged by surgeons, were mentioned by one quarter of participants (25.1%, n=121). Unlike other categories, consumers who reported this concern were more aware of the Medicare schedule fee, and thus were able to recognise that they had been charged more than that. One consumer who was aware of this was Narelle, from Queensland, who said:

Major portion was the balance of surgeon's fees for two operations being over the scheduled fees.

An unexpected and highly concerning finding was that some surgeons are asking consumers to pay upfront before surgery. Consumers described experiences of being told that they would not be able to proceed with their appointment or with surgery unless they were able to pay up front. The range of these costs varied, with surgical costs being as much as $5000.

The following consumer chose not to leave their name or identifying details, but their sad story illustrates the real and damaging impact that these charges can have on consumers:

When I made the appointment I was told of the cost and if I couldn't afford it at the time of the appointment they would delay the appointment until I could afford to pay. I'm only on the pension so my family had to help me. We were all very stressed at the time, I also had to get my sister to drive me as I don't have a car, we live about 110km from this specialist, my sister had to take the day off work to take me to this appointment as the community transport was booked out on this day. I have had to do this two times already and they want me to go back but it is just so expensive and I can't afford to pay the money back at the moment.

The impact of these requirements should be considered in light of research from 2015 that showed that 16.6% of Australians could not raise $2000 in a week in a case of emergency[lix].

Surgeons and surgical costs was the theme about which respondents most frequently mentioned private health insurance gaps. Nancy, who has breast cancer, has spent more than $30 000 in the last two years. She knew about the costs she would face prior to surgery because they were discussed with her by her specialist. As she shows, however, the gaps she faced after her surgery were larger than she had been advised:
While my top level private health insurance covered my hospital expenses and Medicare made a small payment towards the surgeons and anaesthetist fees, the gap was enormous, and greater than I had been advised.

**Anaesthetists**

Costs related to anaesthesia, or anaesthesiologists’ fees were mentioned by 15.8% (n=76) of respondents who had incurred costs in hospital. Many participants felt that they had little control over these costs and were confused or upset that they did not meet or have much contact with the practitioners. They reported feeling disempowered and that they had no choice over the practitioner that they used. Paula contacted her anaesthetist and reported the following experience:

> ...conducted his pre-surgery questions over the phone, and informed me his costs would be $250.00 more than what he would get from Medicare and my top cover healthcare insurance. I asked why, what was he going to be doing differently than the other Dr would have done? He said nothing, that this was his fee.

Anaesthetists costs were unexpected by some consumers, and because of this they are an unexpected burden. It would seem that the lack of a clear outline of the range of providers and estimated costs involved in an episode of care is a major contributing factor to this scenario. Dianne from NSW had a partial knee replacement in September 2017 for which her out of pocket costs were close to $6000. She had expected $4000 for the surgeon, but:

... but then there were extras such as X-rays, ultrasounds, medications. They all added up. The anaesthetist was 1200 out of pocket.

**Medication Costs**

Nearly one in five (19.4%, n=231) participants reported that their out of pocket costs included medication costs. While a small proportion of these were over the counter medications, the majority were prescription medications. A key area of concern and cost were medications which were not on the PBS. Lori, from Queensland, is only able to afford access to a drug for her cancer treatment because of a compassionate access programme:

> Did not go private due to huge out of pocket expenses, yet we pay $3700 a year on private health insurance. Latest drug for my cancer would have cost $5000 per month but fortunately as public receive it on compassionate access programme... and its working yet not on PBS and if I had to pay for it I would have had to sell my home.

Medication costs are of concern because they are small, yet ongoing costs. Many consumers find that medication is not a cost which is considered by other people, because it is used after surgery, or other treatment. Liz, from NSW, had a broken leg. She found the follow up costs to be the really challenging costs. She describes:

> But the private health and Medicare did not cover the high fees from the surgeon, anaesthetic and post-surgery medications, physiotherapy or follow up visits... it's not the hospital, it's all the post-surgery follow ups, medications and physio that are the real costs.
**GP Costs**

Out of pocket costs for GP consultations were an area of concern for 12% (n=145) of respondents. Those affected particularly were consumers in rural areas who are unable to access bulk billing services and for those with chronic or ongoing illnesses. John from Victoria illustrated the divide between metro and rural and regional services in the following quote:

*My wife and I have gone from $0 out-of-pocket to around $40 o-o-pocket every visit as there is no choice for bulk billing in Benalla 3672. Just two visits for me and six visits for my wife - $320 approx. in 10 months. This is an infinite % increase!*

Lauren, who lives in Victoria and has a chronic illness, demonstrates that even small gaps between the Medicare rebate and a GP out of pocket cost can be challenging. She describes:

*I am a 26-year-old female and do not have private health insurance. I have recently been diagnosed with Chronic Fatigue, and this journey to diagnosis involved many visits to the GP (with approx. a $20 gap payment each time), and referrals to the chiropractor (covered under chronic condition GPMP with approx. $30 gap per visit), naturopath (approx. $80 per visit) and kinesiologist (approx. 80 per visit).*
Conclusions and Recommendations

The high response to our survey and the information included shows that Australia has a growing problem with out of pocket health costs. Many people are being priced out of the market for private health insurance and for private health care. The Australian health system is a hybrid public/private model and if that model is to continue there needs to be action to make sure the private sector is affordable and delivers value for many for consumers and tax payers.

Out of pocket medical costs are the difference between what the health professional charges and the amount third party payers - government and/or private health funds - contribute. There needs to be action by governments, providers and insurers if out-of-pocket costs are to be contained and the private health system is to continue to be a viable part of the Australian health system.

Based on the stories and information people so generously shared with us we have identified the following key areas of action – an overarching recommendation that is more long-term, and a suite of others that are more near-term.

Overarching recommendation

Our overarching recommendation is that there should be an independent Productivity Commission investigation into the cause of this crisis and all aspects of private health. This should include a rigorous analysis of the causes of ever increasing out of pocket expenses and some possible policy solutions designed to ensure access to reasonably priced medical care and the stability and sustainability of Australia’s public-private health system.

For government

· The freeze on Medicare rebates for diagnostic imaging should be lifted in line with the staged removal of the freeze on other Medicare rebates.
· The Federal and State/ Territory governments should work together to improve access to and the range of travel reimbursement schemes.
· The Department of Health should work with
health professionals and other key stakeholders to develop a process for a single quote for any episode of treatment that includes all health professionals’ costs.
· Consideration should be given to the role that a ‘system navigator’ role could play to assist people to understand the private health system and to promote awareness and use of the transparency website. These could be piloted in the first instance, engaged locally by Primary Health Networks and linked to general practices, given GPs are the main referrers.

For private health insurance funds

· Rural and regional travel benefits need to be improved with the reforms announced in October 2017 being adopted by all funds.
· There needs to be more promotion of no gap providers and assurances that there are no hidden costs.
· Informed financial consent procedures need to be strengthened and insurers should work with consumers and providers to ensure this happens.

For health service providers

· There should be a move to a system of unnamed referrals so consumers can better exercise their right to choose a provider.
· Further investigation should be conducted into the impact of ‘no gap’ or ‘known gap’ arrangements on the quality, choice and availability of healthcare.
· Health professionals should make their fees publicly available on an independent and website which will allow consumers to be better informed and compare their costs prior to accessing any treatment. The website should also carry information to educate consumers about how the Australian health system works, particularly the private component.
Acknowledgements

CHF would like to thank the over 1200 Australian health consumers who so generously shared their stories. The survey responses were genuine, heartfelt and at times, heartbreaking. CHF, and our members, could not do our work without you and your commitment to improving the health sector for others.

The survey was disseminated by a range of CHF’s members. CHF would like to thank them for their ongoing support and for partnering with us in this important topic.

The design of both the survey and the report were inspired by the work of the Breast Cancer Network Australia, and their report ‘the financial impact of breast cancer’. Specific thanks goes to Ellie Kirk, Senior Policy Officer, for her input.
Survey Method

The ‘Out of Pocket Pain’ survey was launched on 18 January 2018 by CHF and closed on 1 March 2018. It was available at https://chf.org.au/out-pocket-pain.

The survey was disseminated through CHF’s social media channels on Facebook and Twitter. It was also emailed to CHF’s mailing list that have nominated to receive media releases. An email was sent to a group of our organisational members and partners with the request that they also share it with their appropriate social media and email lists. A particularly large response came from the audiences of Breast Cancer Network Australia and the National Rural Health Alliance. A number of users came to the survey as well from a news article posted on http://yourlifechoices.com.au on 29 January 2018 titled, ‘Official figures hiding true cost of private health gap charges’.

The total number of responses received was 1350, with 1200 used in analysis.

The survey opened with a preamble about the purpose of the survey and CHF’s place on the Expert Committee on out of pocket costs. Participants were offered the opportunity to respond over the phone, but this opportunity was not taken up.

Participants were optionally able to provide their name, the state they lived in, their educational attainment, household income, and health status.

A number of pathways through the survey were possible. The figure on page 17 describes the questions and illustrates the pathways open to respondents.

Sample Characteristics

Consumers were asked questions about their: state, level of educational attainment and household income. Based on participants’ IP address, their location was classified into remoteness using the Australian Standard Geographic Classification. The majority of the sample (86.8%, n=1036) was from major cities, 8.5% (n=101) were from inner regional areas 4.2% (n=50) were from outer regional areas and the remaining 0.6% were from remote and very remote areas.

The distribution of income was broad. The proportion of the sample who earned less than $40 000 was 22.9% (n=248), the proportion earning $40 000 - $75 000 was 25.3%, $75 000 - $130 000 was 30.7% and the proportion who earned more than $130 000 was 21.1%.

The state and territory that participants were from was broadly nationally representative. NSW was under represented (24.7% of respondents compared to 31.9% of the national populations) and the ACT was over represented (3.7% of the sample compared to 1.6% of the national population).
Survey Method

Your out of pocket costs
We’re interested in hearing about your experience with out of pocket costs. Below we ask a few short questions, then ask you to share your experience with us. When sharing your experience, you might tell us about:
- Whether your out of pockets costs were at a level you expected or whether they exceeded that
- What impact they had on you and your family
- Were they a reason why you chose not to take up a referral to a specialist
- Did they influence the care you got

Were the out of pocket costs in hospital?
Yes → Did you have private health insurance at the time?
No →

Did you have private health insurance at the time?
Yes →
No →

Who discussed the out of pocket costs with you?
- GP
- Specialist
- Nobody
- Other
- Please tell us about your experience with out of pocket costs (open ended)

Did you know about the out of pocket costs before going into hospital? (yes/no)
Who discussed the out of pocket costs with you?
- GP
- Specialist
- Nobody
- Other
- Please tell us about your experience with out of pocket costs (open ended)

Do you consent for us to use your experience?
Strengths and Limitations

The participant sample was a convenience sample, recruited through CHF and its members' networks. As shown by the high number of participants who identified as having breast cancer, particular CHF members chose to disseminate the survey further. As a result, some biases exist in the findings. The convenience sample can also be considered a strength, as it shows the level of interest and importance placed on this issue by the consumer community. The size of the sample – over 1200 – was larger than anticipated and should be taken as an indication of how important this issue is to the community.

The majority of the results, including the health conditions of the participants, were derived from qualitative responses. In order to reduce participant burden, and to allow participants to tell their own story, the number of quantitative questions were limited. This limits the amount of information that was collected about the demographic characteristics of the sample, which may limit the generalisability of the results. However, given the limited amount of consumer-focused work on the topic, the open text responses allowed consumers to tell their own story, and not to be constrained by pre-defined ideas. Future work, including by CHF, should consider using the results of the qualitative investigation to develop more structured surveys to delve into specific issues.

The survey was hosted online, and participant recruitment was predominately conducted through online newsletters. Participants were offered the opportunity to submit responses over the phone, but this option was not taken up. Given the proportional bias toward participants from major cities, it is reasonable to assume that some consumers may have had difficulty accessing the survey.
References


