Appendix 3: Consumer Profiles and Experiences
HCCA Submission for Senate Inquiry into Out-of-Pocket Costs in Australian Healthcare

Consumer Experience A

Consumer: 59 year old women with a number of long term, chronic conditions.
Her Story: I am 59 year old women with a number of long term, chronic conditions a number of which will only get worse with time. (for example, Parkinson's Disease, Rheumatoid Arthritis, Osteoporosis, Migraines, PTSD and resultant chronic Depression and Anxiety, optic neuritis, brain atrophy and the list goes on!)

I have not been in paid work since January 2001 due to the impact of these conditions. This has meant I have not received a salary or contributed to superannuation for my personal future since I was 46 years old.

Some of these health conditions result in long term hospital stays.

It is not uncommon for me to have an annual gross medical bill of over $50,000, before receiving Private Health Insurance, Medicare, and PBS co-payments

I generally reach the threshold for Medicare rebates in March each year due to the number of specialists I need to visit. My pharmaceutical bill each year , taking into account current PBS rebates, is close to $4,500.

This does not take into consideration all the incidental costs associated with these health conditions.

- I see one specialist weekly and when I cannot drive, Cab Charge pays 50% of my fee, leaving me out of pocket $40 per visit.
- My husband takes carer's leave from work every few months so we can drive from Canberra to Sydney to see my Neurologist. There is no rebate for travelling costs and the resultant overnight stay in Sydney.
- My private health fund only partially covers my constant need for updated glass prescriptions, dental expenses and only a few partially covered visits to my physiotherapist and other complimentary medical services. I suffer in silence with my ongoing physical symptoms which would need large amounts of money to assist, for example, physiotherapists for bladder and constipation issues
- I attend medical conferences on my chronic conditions and

recommendations are made to do such things as extensive exercise programs for my Parkinson's. I'm put off by the costs of these programs. The irony of this is that if I could do these programs I would be less of a burden , long term on the health system.

Housing

Last year my husband and I made the decision not to leave our home which we have lived in since 1987. We are nearly finished making major ergonomic changes to this home so it will cater for my physical needs over the next 20 years or so.
There is no financial incentive from the government to do this, but it is relieving them of major long term health facility costs.

Who Pays for these Costs?

My husband has worked hard for the same employer for over 40 years. He earns a decent salary and has managed his finances well, so will have a decent superannuation when he retires.

My husband has been out of pocket for years as a result of my medical expenses. Everywhere he turns, he is over the threshold for any financial assistance from the government other than the non means tested Carer's Allowance.

His work pays him Carer's Leave when I am too sick to look after myself.

Other Issues

There are many community programs that I use that are essential in in physically and mentally helping me with management with my Parkinson's and this has been proven to benefit people like me. These programs are not supported by the government and they should be. There really needs to be a focus on primary and preventative health care in the community because that is what will keep us out of hospital.

I also used to be able to access dental care plans but this is no longer available for me.

Many of my specialists advise me to take vitamin supplements for example my rheumatologist prescribes me vitamins for my rheumatoid arthritis and my neurologist prescribes me vitamins to prevent brain atrophy. These vitamins are not on the PBS and the cost comes straight out of my pockets.

Every little bit of my life is effected by my health conditions, I have to pay more to heat and cool my house to manage my Parkinson's and I use a expensive thermo-mix tool to help cook meals as my hands shake too much. I also have a dog that in part I pay for and keep as an aid for my anxiety and stress management. I have special kitchen tools, cups with lips, cutlery, used to aid people with Parkinson's.

I feel personally responsible and discriminated against due to my health. There is also a huge time cost, a hidden cost, to my life I am left with a lower quality of life and this effects my whole family

Actions

1. I think before these blanket decisions are made to ask all people to make contributions to doctor's visits etc, no rebate for private health insurance and so on it would be great to do case studies on people in our community with multiple chronic conditions.

2. I think it could show that this sector of the "chronic health" community is being heavily discriminated against!

3. My husband has to pay health funds to support two people but is basically taxed as an individual. Action. A fairer system would be income splitting for taxation purposes. At the moment two healthy people earning my husband's combined income pay significantly less tax then he does with a chronically ill dependant.

Consumer Experience B

Consumer profile: Older Woman who has lived with multiple chronic conditions and lived through multiple interventions.

Consumer's main out of pocket costs:

Incontinence

Incontinence Pads -3 different types needed

- Type 1 30 a packet –one month $22 Yearly $264
- Type 2 14 a packet –one month $14 Yearly $168
- Type 3 12 a packet- weekly $4 Yearly $48

Total= $480

Vitamin supplements as prescribed by doctor
Cranberry Caps 96 a bottle = $20 Yearly $120
Ural $9 3 a packet $27 per month Yearly $324
And further out of pocket cost for antibiotics and pants.
Omega 3 56$ yearly

Scripts

Uses 12 different prescribed drugs daily – cost $6 monthly or $72 Yearly

Other supplies

Dressings $10 a month Year $120
Walking sticks $75each Year $ 150
Mobility Scooter $1600

Breathing and COPD

Due to breathing difficulties and COPD the consumer finds that her heating bills are higher due to a need for a specific temperature in the home and the further cost of oxygen tanks. These cost were not quantified here but make up a large part of her bills and expenses

Story C consumer experience

My Story:

I was working part-time on a graduated return to work program following surgery as a result of a previous injury (a different one). I was a permanent full-time employee of the Commonwealth Public Service.

Then my whole life was turned upside down when I was rear-ended on my way to work by someone not paying attention. This was when John Howard was in government and all journey claims-accidents either on the way, to or from work were no longer covered by ComCare (the Commonwealth's insurer). The accident was in the 'blackhole 'time when the Commonwealth Public Sector Union has not taken out insurance for its members to be covered for journey claims. This meant that I was required to put in a third party claim through NRMA. It sounds good on paper when you receive the letter stating that the NRMA has admitted 'liability' for the accident (and subsequent motor vehicle accidents). However, they only pay a certain amount initially and then I had to pay for all my specialists, doctors, physiotherapy visits etc plus medication out of my own pocket. At the time of the first accident I had no sick leave however I was lucky in that I had been denied access to take my recreation and long service leave which initially I took at full pay and then later at half pay until it ran out and I was put on leave without pay.

As a result of the accident and subsequent accidents my medical expenses were enormous (and still are). Initially I had to use what little savings I had to pay for treatment, then adjust my lifestyle and then because we had no idea how long my medical condition would last we had to completely rearrange our whole financial situation to adjust to only one income source.

As one can imagine the loss of one's income, employment, career, work life etc and being an independent person plus dealing with the physical injuries took an emotional and psychological toil on my health as well.

Unfortunately these days I am back on the third party insurance round-about again due to inattention of another driver. As the accident happened in NSW, NRMA will only reimburse my treatment at the NSW rates which is significantly lower.

Also they are paying for physiotherapy treatments so each time I have to go I am $22.50 out of pocket personally. I have several other treatment providers who I have to see wither weekly or monthly so I can continue to remain functional, however, none of these costs are reimbursed by NRMA. Also I am not supposed to claim doctors and specialists visits back from Medicare as it is a third party injury case, however, no one seems to understand the significant costs I am faced with as I was not 'injured' enough to be taken to and treated at a public hospital and therefore able to use the public health system.

Some private health providers in the ACT won't see you/me because I am a third party injury case (they didn't want to do the extra paper work and maybe front up to court). Public hospitals refuse to see me for issues related to my third party injuries. It is like you end up in 'No Man's Land' at times when you are denied access to treatment, however, the World Health Organisation says it's everyone's 'right not to be in pain'. However the search continues to obtain the treatment that is effective for my medical condition.

My current out of pocket expenses related to medical treatment are:

- Medical treatment providers $934/month approx..
- Doctor prescribed medicine $581/month approx.
- Supplements (to support immune system, liver, migraines, joints) $352/month approx.

= $1867/month approx.

On top of that amount I have to pay for taxis to attend doctors appointments/ medical appointments as I am still unable to drive due to ongoing medical conditions as a result of the initial motor vehicle accident that caused me to lose my employment. Depending on when my appointments are scheduled and when my other commitments are these can range from a minimum of $450.00.

Consumer experience D

I think this is a big issue for two main groups of people – older people who are developing age related conditions and those of us with chronic conditions.

I am 67 and a part age pensioner and in the past five years have had to spend more money on dentists (I grew up without fluoride) than in the past – crowns I thought would last me a lifetime are now breaking and needing to be replaced. I have had one cataract operation and expect to have another within the next 12 months, each cataract operation requires at least two new pairs of glasses and since mine are multifocal I am looking at a minimum of $1000 a pair. Most of my friends, even if otherwise healthy, have remarked on the same things.

There is also the high cost of seeing a GP in Canberra. Last time my GP retired I had to try over 25 surgeries before I could find someone to take me on. I am very happy with the GP I now have but she charges $80 a visit or $70 for pensioners. This seems to be around the going rate and I don't know anyone who has a bulk billing doctor. Jo Hockey's electorate might be the third highest bulk billing electorate in the country but Canberra must be one of the worst

I have had major back and hip problems for years but it is only in the last few years that a GP has diagnosed this as Ankylosing Spondylitis. A form of arthritis which is genetic and crippling. Apart from the drugs which are generally covered by the PBS system, I have one which is not and which costs me $100 a packet. I take 7 other drugs covered by PBS. My doctor also expects me to take Vitamin D because one of the drugs drains it from my system, Vitamin B for the same reason, additional folate, over the counter pain killers, and over the counter hayfever pills. I have just been to the pharmacy to get this month's drugs - $165 and that is not everything. Because of the Ankylosing Spondylitis I also have to frequently visit physiotherapists and podiatrists – they charge around $90 a visit and if you are lucky you get under $30 back from private health insurance. These refunds are subject to limits each year. The pain and stiffness from the arthritis also means I need to employ a cleaning lady and someone to do the gardening. Because ankylosing spondylitis affects my feet badly I also have to purchase orthotics and heel cushions which are not cheap

I do have private health insurance and extras and it is expensive and always going up and does not actually cover that much of the cost.

I thought I would spend my retirement years travelling and enjoying myself, not staying home because I need to cover my medical costs and as from next year will not even be able to claim them off my tax. I think excess medical costs should at the very least be tax deductible.

Consumer Experience E

This consumer contacted us to discuss the experience of a delayed cancer diagnosis at the effect of this on their health and personal finances.

> *"My GP failed to diagnose my cancer from 2003 until January 2011.*
>
> *I had difficulty get access to a biopsy and was put on a 12 month waiting list/ My GP informed me that it was specialists tactic to extort a fee for a private biopsy."*

The consumer stated that after political pressure was put on his local public hospital he was given a biopsy June 2011.

> *"The result was that my cancer had bilateral carcinomas and was aggressive.*
>
> *Then I was unable to get access to suitable surgery under Medicare. All but one risked loss of my eyesight due to operating method, the other was unsuitable for different reasons. I spent 5 months searching for surgeon and was just about to book surgery in Istanbul when I found a private surgeon that I could afford in Ipswich. I had to borrow the money to pay for surgery.*
>
> *The pathology of excised organs indicated that my cancer was aggressive T4 and had metastasised (spread outside the original organ site.)*
>
> *To survive I then had to have radiation, but was hypersensitive and developed permanent side effects after only 3 of the 33 treatments.*
>
> *I now have permanent negative consequences from both surgery and radiation."*

Due to this late diagnosis, and the need to seek private cancer services, the consumer incurred over $10,000 cost in providing radiation and follow up therapies.

> *"In not diagnosing my condition initiating early (timely) intervention that costs*

> *me: expense, pain suffering, stress, depression, negative life consequences and ultimately my livelihood."*

This experience is consistent with other consumer experiences and stories that have been reported to HCCA regarding the cost of private cancer services.