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HCCA Submission to the Senate Inquiry into Out-of-Pocket Costs in Australian Healthcare

Submitted 14 May 2014

"If you don't pay you are going without health care, going without health care, equals going without good health" – Consumer from HCCA out-of-pocket cost consultation.

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Background

The **Health Care Consumers' Association (HCCA) of the ACT** was incorporated in 1978 to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation
- consultations
- training in health rights and navigating the health system
- community forums
- information sessions about health services
- advocating for issues of concern to consumers

Key Findings

- It is essential that the Australian government makes a strong commitment to universal health care and provision of health services to support all Australians.
- Out-of-pocket costs disproportionately affect those with chronic conditions, families with children under 5, marginalised groups within our community, and the poor.
- The introduction of further co-payments will create a barrier for these consumers causing a negative impact on their health and causing further cost to the individual consumer and the Australian community.
- The introduction of further costs to the consumer through co-payments is a gross erosion of Medicare and the Medicare rebate system
- In four years out-of-pocket costs to the consumer for GP appointments has risen by 25% in the ACT (HCCA, 2014).
- HCCA research on consumers' experiences of general practice indicates that the costs of further medical testing and imaging are barriers to accessing appropriate and timely health care (HCCA, 2014).
- The acknowledgement of the massive workload involved in managing an individual's health is essential in establishing the true out-of-pocket costs of health care in Australia and often goes ignore by health care providers and decision makers.
- HCCA recommends that an enhanced focus on primary health care within the community could prevent inefficient costs and spending in tertiary care and create a healthier Australian community.

1. General comments

HCCA welcomes the opportunity to provide input into the Senate Inquiry into out-of-pocket costs in health care. This submission draws on extensive consultation with health care consumers in the ACT community as well as the work of the Consumers Health Forum.

- HCCA believes it is essential that the Australian government makes a strong commitment to universal health care and provision of health services to support all Australians, particularly those with young children, chronic conditions, and vulnerable groups within our communities.
- It should be emphasised that the introduction of Medicare 30 years ago was to subsidise the cost of health care to the consumer to ensure equitable access to health services.
- The introduction of further costs to the consumer through co-payments is a gross erosion of Medicare and the Medicare rebate system, which was introduced to ensure an equitable health system and a healthy Australian community.
- HCCA does not support the introduction of increased co-payments by consumers and believes that the introduction of further barriers to accessing primary health care could create negative health outcomes for consumers, and the Australian community and will increase health costs overall.
- HCCA research on consumers' experiences of general practice indicates that the costs, pharmaceuticals, and of further medical testing and imaging are barriers to accessing appropriate and timely health care (HCCA, 2014).
- HCCA recommends that an enhanced focus on primary health care within the community could prevent inefficient costs and spending in tertiary care and create a healthier Australian community.

> *" Raising the costs of GP consultations, adding a barrier, will mean poorer health for those with chronic diseases like Hepatitis, because these conditions will go unmanaged, just thinking about sustainability of the health system it doesn't make sense to block access to primary care when the consequences are this dire " –Hepatitis ACT representative.*

In a recent report from the Consumer Health Forum (CHF) on co-payments, 17% of total health care expenditure in Australia is now being funded by individual consumer co-payments, making this source of funding significantly higher than most OECD countries (2014). There is strong evidence that existing co-payments are already causing financial hardship for many consumers, particularly those with multiple chronic conditions and those on lower incomes (CHF,2014). This is certainly the experience of our membership.

In 2013 the Australian Bureau of Statistics (ABS) reported that 15 million people visited a GP in the past 12 months. Of these 5.4 per cent - or over 800,000 – people "delayed seeing or did not see" a GP at least once because of cost, indicating if a co-payment was introduced it would affect the number of patient visits. This outcome will negatively impact on the Australian community and ultimately increase costs for healthcare. Consumers and the community should be encouraged to use primary health providers more often rather than less. Primary healthcare plays a key role in preventative care and management meaning fewer people will need to be hospitalised at higher expense each year (Australian Primary Health Care Research Institute (APHCRI), 2014). Any consideration of the introduction of co-payments is not consistent with this compelling evidence.

2. HCCA Responses to the Terms of Reference

This submission addresses the following Terms of Reference;

a. The current and future trends in out-of-pocket expenditure by Australian health consumers

b. the impact of co-payments on:

   i. consumers' ability to access health care, and

   ii. health outcomes and costs

   d) the implications for the ongoing sustainability of the health system

   e) key areas of expenditure, including pharmaceuticals, primary care visits, medical devices or supplies, and dental care

   g) the appropriateness and effectiveness of safety nets and other offsets

   i) any other related matter

ToR (a) Current and future trends in out-of-pocket expenditure by Australian health consumers

In 2009 and 2013 HCCA conducted a survey on the consumer experience of general practice within the ACT region (See Appendix 1). In both years more than 600 people completed the survey. This represents a useful snapshot of consumer experience.

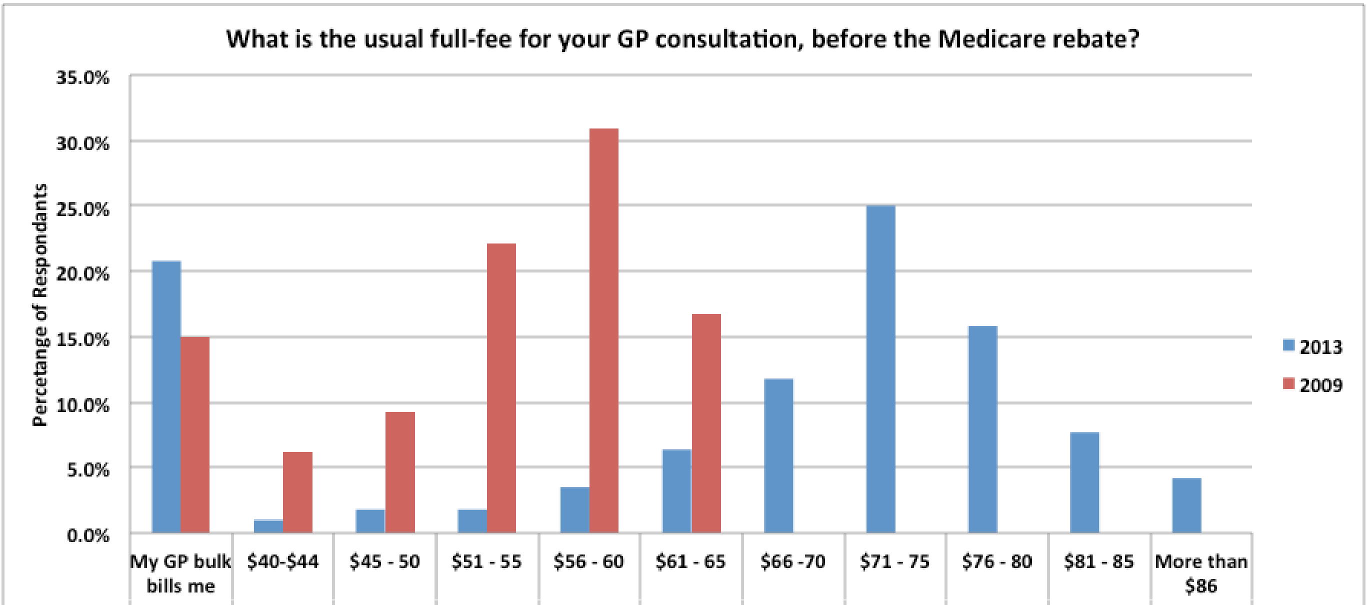

Figure 1 Costs of General Practice Consultation before Medicare Rebate in the ACT 2009 vs 2013 *HCCA survey on consumer experience of general practise. Note that 2009 data we only asked a top range of $65 or above.*

In four years the out-of-pocket cost to a consumer when visiting a GP in the ACT has gone up by 25%.

Figure 1 shows an increase in the total cost of GP consultations before Medicare rebate from 2009 to 2013.

In 2013 20% of respondents reported seeing a GP who bulk billed, a 5% increase from 2009.

The results show that, there is a large shift in the number of respondents paying $65 or more before the Medicare rebate from 2009 to 2013. In 2009 16% of respondents stated they paid more than $65 before the Medicare rebate with the average cost being between $51-60, whereas in 2013 64% of respondents reported paying over $65 dollars before Medicare rebate with an average cost of $75.50

In 2009 the average Medicare rebate after seeing a GP in the ACT was $25.63 (Australian average $21.50). For the consumers paying an average of $60, the out-of-pocket cost is $34.40.

In 2013 the average Medicare rebate for a GP consultation in the ACT was $32.50 (Australian average $28, (AGDH,2013)) indicating that if the average consumer is spending $75.50 then the out-of-pocket expenditure for consumers is $43.

This finding is supported by the CHF report on Co-payments (2014) that rising trends in out-of-pocket cost for the consumer. From 2001-2012 individual consumer payments increased by an average of 6.1% per year in real terms (cost adjusted to remove general price change over time) compared with an average of 5.4% for total funding on health expenditure (CHF, 2014). This means the out-of-pocket health cost to the consumer is rising more quickly than health costs to the Australian government. These rising costs to the Australian consumer mean that when adjusted to the cost of living, Australians pay more in direct payments for health care then most OECD countries apart from the USA and Switzerland (Squires, 2013).

Key Findings from HCCA Primary Research into cost of GP Consultation to Consumer in the ACT

- 48% increase of number of people paying over $ 65 for GP appointment from 2009 to 2013
- The average cost before Medicare rebate in 2009 was $51-60 in 2013 it is $75.50
- In 2009 the average out of pocket cost to the consumer for a GP appointment in the ACT assuming they paid an average of $ 60 was $ 34.50
- In 2013 the average out of pocket cost to the consumer for a GP appointment in the ACT assuming they paid an average of $ 75.50 was $43
- In four years out-of-pocket costs to the consumer for GP appointments has risen by 25% in the ACT

Our Survey results also indicated a 5% increase those with accessing bulk-billing in 2013. ACT has a low rate of bulk-billing compared to other jurisdictions. This increase in bulk-billing was as a result of the work of the ACT Government to support general practise following a GP taskforce. In 2009 the ACT had a shortage of 74 fulltime equivalent GPs. The number of GPs has now gone up.

The impact of GP consultation costs has a huge impact on the lived experience of health care consumers. Seven consumers from a HCCA community consultation stating:

> *"I can't go to the GP if I have no money" – Consumers from HCCA out-of-pocket cost consultation, 2014.*

The current high out-of-pocket costs of GP appointments in the ACT, coupled with the potential introduction of co-payments creates an overwhelming barrier for consumers who feel;

> *"paralysed by indecision as to where to get appropriate care, due to cost, the GP? ED? Or just try and self-manage at home?"– Consumers from HCCA out-of-pocket cost consultation, 2014.*

As many out-of-pocket expenditures are not fixed (i.e. the cost of vitamins, or how many times one person may need to see a GP) there is a differential impact on consumers, depending on their overall health and income level (CHF, 2014). The cost of direct payments falls onto the individual consumer, making co-payments less equitable then other forms of health funding, and increases the gap between socio-economic groups. **The sick and poor are more likely to pay more as a share of their income then those who are well or wealthy.** The disproportionate effect of out-of-pocket costs and co-payments on marginalized groups and those more vulnerable in our community means that should further co-payments be introduced this could have a drastic negative impact on health outcomes, leading to increased long term costs in tertiary or hospital level care.

ToR (b) The impact of co payments on consumers ability to access health care and health outcomes and costs

In developing responses on the key areas of expenditure for consumers and impact of co-payments, HCCA consulted the ACT community to identify how co-payments had impacted on their access to health care, health outcomes, lifestyle and personal finances (Appendix 2). The responses to these terms of reference are therefore shaped around key areas and impacts as identified by members of the ACT community as follows.

c. i GP visits

As mentioned above, out-of-pocket costs to the consumer in the ACT when seeing a GP have risen dramatically over the last four years. **This cost and the relative shortage of bulk-billing GPs in the ACT means that many consumers find that the cost of regularly seeing a GP is too high.** This is supported by the finding that there is a 50% higher rate, when considered across peer groups, for delay and/or deferring access to a GP in the ACT due to cost (AGO, Productivity Commission, 2014).

Cost is one of the most persistent barriers for consumers in obtaining timely access to primary health care interventions. Late last year, HCCA completed a research project for the ACT Medicare Local to support their comprehensive needs assessment (Appendix 1). While families with children under 5, older people, and people living with chronic conditions identified cost as significant issue, we also found that cost was of most acute concern to members of vulnerable populations, such as Ainslie Village residents, A Gender Agenda members.

We also spoke with a number of organisations which have contact with people on low incomes and financially disadvantaged people (West Belconnen Child and Family Centre, The Youth Coalition, Karralika ACT, Canberra Multicultural Community Forum, Hepatitis ACT). Cost was raised as an issue by all of these organisations.

The low rate of bulk-billing services is an issue even for those people who are able to access the Medicare system. While there are a number of bulk-billing hubs, such as Winnunga Nimmityjah and corporate medical centres, access to affordable services outside of these services is more difficult. Bulk-billing is at the discretion of doctors and reflects their business rules. In the ACT, very few general practise bulk-bill everyone.

Consumers in the ACT consistently point to the need for bulk-billing and the concern that the prohibitive cost of GP visits means that those with complex or multiple chronic conditions are often left trying to coordinated care on their own rather than with a regular primary care provider. This can result on people being unable to optimally manage their care, leading to unnecessary more serious illness and hospitalisation.

> *"Well, GPs are a problem. One, it's a problem to find a GP who will take you, two, it's almost impossible to find a GP who bulk bills, unless you go to one of those dreadful clinic things, where you have to sit down for 3 or 4 hours waiting. So that's the choice: you either write off a day…or you pay 70 or 80 dollars…and for most pensioners, it's a lot of money if you have to go often."-* HCCA Facilitated discussion – Lung Life ACT (Appendix 1 p.156)

In the recent HCCA report, bulk-billing GPs were acknowledged as enabling access for a number of people, especially those on low incomes, and with children under the age of 5. (Appendix 1, 2014).

> *"Bulk-billing plays a big part…[it impacts on my ability to] see the GP as frequently. If the doctor says, 'come back in 2 weeks', and I was at another practice [that didn't bulk-bill], I wouldn't be able to do that."* (Consumer, HCCA, 2014 Appendix 1)

In one area, residents continued to see a GP with whom they were dissatisfied, as this doctor both bulk-billed and was located close to their residence. The lack of other bulk-billing services in this area impacts on the ability of people living in supported accommodation to seek appropriate care, as they do not have the resources to seek care further afield or seek alternative non-bulk-billed services close by.

Several people we spoke to also raised issues with the financial and time costs associated with the search for the "right" GP.

> *"One of the challenges is that you're basically always paying out of pocket for a GP…and so to find a GP and work out if you sort of get along well and they're the kind of GP you're looking for…that can be a bit hit and miss and it can cost you quite a bit of money if you don't find what you want*

> *straightaway…because it's not like you can have one visit with them and make a decision."* - (Consumer, HCCA, 2014 Appendix 1)

Additionally, several consumers mentioned that they have to go to the GP quite regularly when pregnant, so the consultations "*add up to quite a lot of money"*. However, one consumer states she is reluctant to go to a bulk-billing general practice as she has had poor experiences with these in Canberra. Similarly, another wants to remain with her current GP because the GP had a good understanding of her chronic condition.

The additional barrier of a consumer co-payment for GP appointments on those already coping with significant financial burden and stress will prevent adequate health care to those who need it most within our community. One consumer, a single mother of three, stated that health care costs are a huge area of stress for her.

> *"The co-payment, that 15 dollars or whatever, for each of my children…that's a lot of money, that's a meal for the week."* – Consumer from HCCA consultation

Consumers also indicated that the introduction of a co-payment would mean delay to their treatment meaning they would "*ignore our own health"* until they were too sick to do so.

> *"[I would] delay treatment because it is too expensive."*
>
> *"If I can't afford it, I can't access it."*
>
> *"We will have to delay until we are really sick, doesn't that just increase our health care costs?"*
>
> – Consumers from HCCA consultation

b) ii After hours costs

After hours GP costs in the ACT are prohibitive, causing many consumers to opt for ill health, poverty, or use an already over capacity emergency department for primary health concerns. Lack of after-hours options when seeing a GP was also an issue, with many people reporting that locum services in the ACT charge around $100 before the Medicare rebate, leaving a large financial burden for the individual consumer. One consumer stated:

> *"If I get sick after 5pm, or on weekend in the afternoon, I really have to think, do I want to choose between spending my pension money on food or seeing a GP I don't know or trust? Then I think 'Am I sick enough to go to ED?'" – Consumer from HCCA out-of-pocket cost consultation, 2014.*

b) iii Dental

The cost of dental and orthodontic care was a key issue of concern for many consumers. Even those with private health insurance failed to go to the dentist because of the high cost. One Consumer reported that a recent routine visit to the dentist for her teenage daughter cost $245 and the rebate from private health insurance was only $73 dollars.

This situation is more acute in the ACT due to the absence of No-Gap dental clinics, even with private health care providers. Others stated that long waiting periods and the limited access to public dental care meant that they often completely forgo dental care**. This is supported by a recent ABS report that states 1 in 5 people delayed or did not see a dentist due to prohibitive cost (2013). Those living with the greatest level of socio-economic disadvantage were twice as likely to not see or delay seeing a dentist then those living in areas of least socio-economic disadvantage (ABS,2013).**

The relationship between health and socioeconomic status is not new and forms a core part of knowledge when looking at the social determinants of health. A 2004 study by Ringland *et al*. demographic and socio-economic factors associated with dental health found **that better oral health among consumers is associated with a capacity to pay out-of-pocket dental expenses rather than with private dental insurance or having access to public-funded dental care (Ringland, 2004).** Several consumers at the HCCA consultation also commented on the cyclical nature and effect poor health care has on a consumer's ability to work and how they are perceived.

> *"If I can't see a dentist, if I have poor teeth, it definitely makes it harder to get a job, a perception of being well….fit for the job" – Consumer from HCCA out-of-pocket cost consultation*

Several consumers commented that the current barriers to dental care, and the consequences of that, will soon be reflected in people's access to GP care and primary health care.

> *"Having no rebate on dental care means that we don't go to the dentist, we suffer because of it, it's a perfect example of what this co-payment is going to do, cause suffering." - Consumer from HCCA consultation*

b) iv Specialists

The availability, access to and cost of specialist care is a key issue in the ACT. The HCCA GP surveys from 2009 and 2013 show that there has been a 25% increase in the number of respondents being referred to specialists from their GP. Most respondents 95.7% said they did follow up on the referral. Of the 5% of respondents who stated they did not follow up on their specialist referral, cost and waiting time where the major reasons given for not seeking care. From 2009 to 2013 there was a 53% increase in respondents stating cost was a barrier in seeking specialist care.

When asked at the consultation why people were prepared to pay so much for specialist care one response was:

> *"If you don't pay you are going without health care, going without health care, equals going without good health" – Consumer from HCCA out-of-pocket cost consultation*.

Transport costs to specialist appointments was also raised as an issue.

b) v Transport

For many with chronic conditions or multiple chronic conditions appointments are a part of everyday life, however all those consulted stated that costs not supported by Medicare rebate include travel costs, parking costs and the costs to carers of leave and work hours. These costs are further explored in Appendix 3 (Consumer profiles and stories).

> *"I see one specialist weekly and when I cannot drive, Cab Charge [taxi subsidy scheme] 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."* – Consumer with multiple chronic conditions (Consumer story A Appendix 3)

For many even the process of claiming Medicare rebates is costly with inadequate parking while visiting the Centrelink offices in the ACT. This includes limited disabled parking spots.

Not all general practises have an electronic payment system in place that enables the medical rebate to be claimed at the time of consultation, this means a trip to the Medicare office to consumers. While online claims are possible, not all consumers are comfortable with this technology, or have access to it. Similarly some consumers prefer face-to-face transactions rather than relying on Australia Post. Even fewer specialists offer this electronic billing and processing. While the federal government have continued to provide incentives for practises to move to electronic billing, there is still a considerable lag. This puts financial pressure on consumers as we pay the fee in full, and then have to seek out Medicare to claim the rebate. We really need doctors to do better in this regard.

Such expenses and inconveniences may seem insignificant, but place further burden on those living with multiple conditions and / or with lower incomes. Within the area of transport consumers also mentioned the high out-of-pocket cost of medical transport such as ambulances.

b) vi Alternative and complementary medicine

A recent Australian National Audit (ANAO) report on complementary medicine found that around two thirds of the Australian population regularly use complementary medicine such as chiropractic, acupuncture, herbal supplements and vitamins. The report also stated that consumption of these treatments has continued to rise over the years with an increase between 3 % and 12 % a year (ANAO, 2013). Use of these treatments were also substantially higher in those managing chronic conditions (Adams, The Conversation 2014). With such a high use of complementary medicine within the Australian community and little funding for research into efficacy of treatments, consumers are often left bearing most of the cost of these treatments as they are not seen as suitable for the PBS or Medicare. Many consumers reported that they are asked by their specialists (i.e rheumatologists and neurologists) to take vitamins and supplements as part of their treatment which are not eligible for the PBS or Medicare rebate (see Appendix 3 story A and B, C for examples).

> *"My doctors also 'prescribe' or advise that I take supplements (to support immune system, liver, migraines, joints) [this costs me] $352/month approx."- Consumer experience C, Appendix 3.*

For many consumers the use of complementary therapy is not optional but rather an essential part of their overall management of their chronic conditions and general wellbeing.

b) vii Other Costs

Other key areas of expenditure as identified by consumers include; private health insurance, allied health, pharmaceuticals, medical appliances and supplies and the cost to carers.

A number of people we spoke to, especially people with chronic conditions or complex needs, found that the cost of medicines contributed substantially to their healthcare related financial burden, particularly if these medications were not subsidised through the PBS.

> *"If you have to buy medicine…if you don't have a health care card, you have to pay so much."* (Participant, Pain Support ACT session, 22 October 2013)
>
> *"I've found the cost of one of my medications, which has been the most effective for me, was extraordinarily high. It wasn't on the PBS list. There's been a battle and I think it's now on."* (Participant, Pain Support ACT session, 22 October 2013)

Medication costs also became a concern for people when they developed a new condition, which they had not had to previously manage. One consumer noted that while cost is not usually an issue for her, using an array of services and treatments (especially medications not subsidised by the PBS) can "add up".

> *"Sometimes, you weigh things up…whether to pursue treatment or not."* – Consumer Interview Appendix 1

One consumer who suffers from *hyperemesis gravidarum*, noted that the cost medication she requires to maintain her quality of life is substantial, especially over the course of a pregnancy. The high cost of this medication is due to its listing for specific management of nausea related to cancer, rather than for *hyperemesis.*

"My ondansetron costs $200 per fortnight."- Consumer Interview Appendix 1

When discussing the impact of the cost of pharmaceuticals several consumers reported they;

> *"miss out on medication or, go without medication and our health suffers." – Consumer from HCCA out-of-pocket cost consultation*.

A Gender Agenda members experience similar difficulties with accessing subsidised medicines, especially when the drug was only subsidised for use by a particular gender or for a particular reason.

> *"It costs $150 per testosterone injection, which is difficult when you're unemployed. It wasn't covered by Medicare because I was still a female on my parent's card."* (Participant, A Gender Agenda young people session, 10 October 2013)

In another example, a person undergoing a transition was prescribed an expensive anti-androgen prior to gender reassignment surgery. In order to have the medication covered under the PBS, this person had to be classified as a sexual deviant.

Other costs are further explored in Appendix 1, and the consumer profiles, stories and out-of-pocket cost breakdowns in Appendix 3.

ToR d) Implications for the on-going sustainability of the healthcare system

If cost and access barriers are created for those seeking primary health care and support for management and treatment of ongoing chronic conditions, the health care costs to the individual consumer, to tax payers, and to the federal, state, and local government will dramatically increase. This has implications for the on-going sustainability of the health care system, as tertiary care, and acute hospital care is highly costly and often at, or over capacity.

Health is one of the chief determinants of well-being and with an ageing population and increasing chronic health problems, the maintenance of the quality of life requires increased health spending. **If Australia does not provide support for primary**

health care and prevention which is proven to reduce health care costs and be highly cost effective (APHCRI, 2014), then the provision of health care to an ageing population with rising levels of non-communicable disease and chronic health conditions will become an unmanageable budget expenditure in the longer term and lead to higher levels of poor health in the Australian community.

ToR g) The appropriateness and effectiveness of safety nets and other offsets

For many consumers who manage chronic health conditions current Medicare safety nets are inadequate to cover extensive out-of-pocket costs. Consumers reported that safety nets often only come into effect after a high out-of-pocket costs (~$2000). Those with lifelong conditions felt that the safety nets and offsets should be immediately and consistently available for those who are known to have higher out-of-pockets costs rather than after initial significant spending by the individual. One woman we spoke to raised concerns about the PBS Safety Net thresholds, and disadvantages for a single person.

> *"[Before my husband died] when we were two of us, you know you get up to 58 scripts a year, and then you go onto the Safety Net…but now, he's not here, I still have to reach that same amount of scripts for only one person."*
> (Participant, Lung Life ACT session, 26 September 2013)

Tax offsets and the use of Healthcare Cards for those whose partners and / or carers earning just above, or above the threshold was raised as a significant issue. Many consumers stated that managing chronic conditions without a health care card meant high costs on pharmaceuticals and medical supplies (See Consumer experience A and D Appendix 3)

> *"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 D, Appendix 3*

T o R i) Other related matter: The impact of co-payments on consumers health outcomes, quality of life and personal finances

Consumers reported that the stress of out-of pocket health costs, and the time costs due to health conditions put a large strain on relationships with friends, family and the community. Several consumers at our consultation described higher levels of social isolation, and poor mental health due to the impact of these health costs. Consumers reported:

> *"…always concerned about affordability"*
>
> *" it causes us huge amounts of stress and anxiety."*
>
> *"Money for health care means sacrifice we can no longer go to social activities that require money."*
>
> – *Consumers from HCCA out-of-pocket cost consultation*.

Consumers described the effects of out-of-pocket health care costs on their life as broad and far reaching, making it difficult to separate effects on health, quality of life and personal finances. The impacts of out-of-pocket costs are not always financial with consumers stating the time costs, and stress levels that accompany managing a chronic condition or ongoing health issues are huge.

> *"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."- Consumer experience A, Appendix 3*

This issue is largely invisible to institutional health care providers and health care policy makers. In Jowsy *et al.*'s review on time spent managing chronic illness, several findings suggest that consumers who have a chronic condition or care for someone who has a chronic condition, suffer from high levels of stress reporting that they have; *"a constant sense of having to juggle the commitments in their lives",* largely due to the time cost of health-related activity (Jowsy *et al.* 2012). **The acknowledgement of the massive workload involved in managing an individual’s health is essential in establishing the true out-of-pocket costs of health care in Australia.**

A study by Corbin and Strauss (1985) established the notion of ‘illness work’ being carried out by those with chronic conditions and carers of those with chronic conditions. They identified three areas of ‘illness work’; 1) management, prevention, diagnostic and crisis prevention, 2) everyday life work –keeping household going, 3) biographical tasks by the individual and the family need to reconceptualise their life and life story with a chronic condition (Corbin and Strauss, 1985). For all of the consumers who contributed to this submission the main areas of work, time, or costs, were key to their lived experience of managing their health. Monetary burdens and barriers effect all aspects of this and cause inequity for those managing long term illnesses or conditions and /or are from vulnerable groups such as those from lower socio-economic backgrounds.

> *“Prioritising bills can become really stressful, you sacrifice money that could go to the home, your car maintenance, basics!”*
>
> *“It’s Health costs vs food and electricity, and leaves no money for recreational activities eg. Holidays” - Consumers from HCCA out-of-pocket cost consultation*.

The erosion for Medicare and Medicare rebates causes a huge amount of inequity in our health system with a disproportionate effect on vulnerable or marginalised groups in our community, ultimately leading to poor health for the consumer and high health costs to the Australian community.

One such vulnerable group is prisoners and those returning to the community after time in dentition or remand. People from this group, have been found to have greater health needs and worse health outcomes than the majority of the general population (AIHWb,2013). These people are vulnerable. There is a need for prisoners to access quality health care once they are released into the community. This is particularly important given the high risk of morbidity in the first few weeks post-release for prisoners due to health complications (such as overdose, suicide or other injury)(2013b). Given most prisoners will be exiting into unemployment, and potentially unstable housing or homelessness, and there are often delays in restarting Centrelink payments and accessing bank accounts, most recently released prisoners struggle to find spare money to contribute to health care visits (ACTCOSS, 2014).

People we spoke to who were thinking about or undergoing gender transitions also spoke about how difficult it was to find an appropriate GP and the impacts of barriers in primary health care. While this is a small cohort of people in the Canberra community (thought to be around 250), they have clear needs of their health professionals in primary health care. For transgender people, the GP is the gatekeeper to the very first elements of their transition, usually access to hormone therapy. A Gender Agenda members we spoke to generally found their experiences with GPs uncomfortable, frustrating and judgemental.

> *"You're often on the receiving end of a GP's moral view. I badly wanted chest surgery, but I was told I could not have chest surgery until I'd had a hysterectomy. I did not need that. It affected my energy levels and took me a long time to recover enough to be able to return to work. It was all born out of ignorance and discrimination."* (Participant, A Gender Agenda younger members session, 10 October 2013)
>
> *"The only issue is that the GP still uses my PTSD to question whether I am genuine about transitioning. It's very invalidating."* (Participant, A Gender Agenda younger members session, 10 October 2013)
>
> *"It took me two years to access hormones at the same GP [because] I was under 18. She had worked with trans people before, but thought she could decide what was best for me. She said I needed a note from a psychiatrist or specialist. I had to go through four psychiatrists before I found one that would help me. My GP also ignored several letters from psychiatrists, so I had to find one she would accept."* (Participant, A Gender Agenda younger members session, 10 October 2013)

> *"There is often a lack of information about transitioning even though GPs are the gatekeepers. When there's a lack of knowledge, a consultation becomes a voyeuristic experience."* (Participant, A Gender Agenda younger members session, 10 October 2013)

Another vulnerable group are those Australians with Hepatitis. Hepatitis B and C mainly effect marginalized groups including, IV drug users, Aboriginal and or Torres Strait Islander peoples, and those engaging in male-to-male sex. Hepatitis has also been found effect those to effect those from lower socio-economic backgrounds. Therefore the introduction of co-payments may prevent much needed care for those with Hepatitis. In Hepatitis C, 80% of current cases come from blood products shared in IV-drug use. Around 300000 Australians have been exposed to the Hepatitis C virus and for three-quarters of these people exposed to the virus their infection will be long-term or chronic. Hepatitis C is now the leading cause of liver transplant in Australia as chronic Hepatitis C can cause liver damage or liver cancer.

Of those with Hepatitis B one in three will develop liver cancer if they go untreated and this is predicted to cause a doubling of liver cancer due to Hepatitis by 2020. Hepatitis C costs the Australian Government $252 million each year due to the consequences of untreated and unmanaged Hepatitis C. By treating and curing people of Hepatitis C these significant costs would drastically reduce. For every $1 spent to treat Hepatitis C, $4 is spend combating the consequences of not treating it. These conditions affect a person's ability to work and study and can further isolate people due to their health conditions.

A focus on diagnosis and management of Hepatitis in primary care is essential in preventing higher tertiary costs if treatment is not available. By further training the GP workforce to manage and coordinate care for those with Hepatitis, we can provide better health outcomes, diagnosis and treat early to prevent liver damage and cancer and safe huge amounts of spending on the consequences of unmanaged care.

> *" Raising the costs of GP consultations, adding a barrier, will mean poorer health for those with chronic diseases like Hepatitis, because these conditions will go unmanaged, just thinking about sustainability of the health system it*

> *doesn't make sense to block access to primary care when the consequences are this dire " –Hepatitis ACT representative.*

Many consumers were confused as to what the proposed co-payment achieves other than to cause further stress and burden on those with chronic conditions and those vulnerable in our community. Others were confused by the administration arrangements of such co-payments.

> *"How do I plan for this in an emergency? Do I have to have $15 by the door just in case?" - Consumer from HCCA out-of-pocket cost consultation*.

When discussing the impacts of out-of-pocket cost on health, consumers stated that preventative care and management such as exercise programs and dietary requirements are highly costly to the individual meaning that maintenance of these conditions goes down, or health care needs are often ignored due to cost. This again indicates the need to support consumers to manage conditions in the community to prevent further health decline and cost to the consumer and the community at large.

Areas for Action

Listed below are areas for action from the HCCA community consultation on out-of-pocket health care costs:

- Patient centred, coordinated, holistic care in the community focusing on primary health care
- Focus money and spending on preventive health care and primary health care
- Increase the number of bulk-billing clinics in the ACT
- A financial assessment to determine bulk-billing status for vulnerable individuals or groups or an increase in Medicare rebates on a sliding scale
- Improve access to more public dental services with a wider scope of practise and private dental subsides
- Introduce legislation of fixed specialist fees to avoid higher than necessary cost to the consumer

- Coordination of NDIS services and information to form a coherent and consistent service for consumers
- More training and support for Allied Health in the community
- Increase the numbers of Nurse Practitioners and encourage the use of nurses and community nurses in leading management of chronic conditions.
- Return of free medical clinics to the ACT and increase the number of Walk-in Centres
- Making the Health Care Card application more equitable for those with multiple chronic conditions.
- No introduction of further co-payments

Concluding remarks

HCCA does not support the introduction of co-payments as this will result in poorer health outcomes for those vulnerable within the community and cause a higher burden to those with chronic conditions. People will not access the care they need when they need it, and this may result in more hospitalisations.

The proposed co-payments are an ill-founded and poorly researched idea that will cause drastic negative impacts on consumers who already pay a large amount for their health system, whether it be through existing co-payments and costs, taxes or private health insurance.

These rebates pose a risk to a Medicare system put in place to provide easier access to universal health care for the consumer and better health outcomes for the Australian community.

The burden of out-of-pocket costs disproportionately effects those with chronic conditions, families with children under the age of 5, those from marginalised groups within our community and the poor (HCCA, 2014). Introduction of further cost barriers will make these consumers re-think use of primary health care resulting in poor health and high cost to the individual consumer and Australia as a whole.

HCCA recommends a higher focus of funding and resources to support primary health care as a means to prevention of further higher health costs and to better the health of the Australian community.

Please do not hesitate to contact us if you wish to discuss our submission further.

The Health Care Consumers' Association of the ACT

References

ACTCOSS, *Personal communication with Nadia McGuire –prisoners as vulnerable group, 2014*

Australian Bureau of Statistics *4839.0 - Patient Experiences in Australia: Summary of Findings, 2012-13* 2013

Australian Department for Health *Quarterly Medicare Statistics-data relating to Medicare from March Quarter 2007 to March Quarter 2014, 2014*

Australian Institute of Health and Welfare *Australia's Health* 2012

Australian Institute of Health and Welfare *Health Expenditure Australia 2011/12* 2013 AIHW 2013a

Australian Institute of Health and Welfare 2013. The health of Australia's prisoners 2012, AIJW2013b

Australian National Audit Office *Audit Report No.3 2011–12 Therapeutic Goods Regulation: Complementary Medicines 2011*

Australian Primary Health Care Research Institute (APHCRI) Video Interveiw *The role of primary health care in the context of the larger health system Dr Dr Hernan Montenegro, Health Systems Advisor at World Health Organization* accessed May 2014- http://www.youtube.com/watch?v=FHAwMo_8Q5E

Consumers Health Forum of Australia, Jennifer Doggett, *Empty Pockets: Why Co-payments are not the solution, 2014*

The Conversation, Adams, J, *Here's why we should research alternative therapies,* 2014

Corbin J, Strauss A: Managing chronic illness: three lines of work. *Qual Soc*
1985, 8(3):224–247.

Health Care Consumers Association of the ACT, *Primary health care in the ACT: Consumer experiences*, 2014

Jowsey *et al*. Time spent on health related activities associated with chronic illness: a scoping literature review *BioMed Central Public Health* 2012, (12) 12:1044

Ringland, C., Taylor, L., Bell, J., & Lim, K. (2004). Demographic and socio-economic factors associated with dental health among older people in NSW.*Australian and New Zealand journal of public health*, *28*(1), 53-61.

SCRGSP (Steering Committee for the Review of Government Service Provision) 2014, Report on Government Services 2014, Productivity Commission, Canberra.

Squires, David *Multinational Comparisons of Health Systems Data, 2013* Commonwealth Fund 2013