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## HCCA Submission to the Senate Select Committee on Health

Submitted 19 September 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** is a health promotion organisation that 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
- working for the improvement of quality and safety of health services

## **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.
- Access to health services should be based on need, not ability to pay.
- An enhanced focus on primary health care within the community is cost effective and reduces spending in tertiary care and contributes to a healthier Australian community.
- Out-of-pocket costs disproportionately affect those with chronic conditions, families with children under five, and marginalised groups within our community, including those living in financial hardship.
- The introduction of further costs to consumers through proposed co-payments for GP consultations, pathology tests and medical imaging is an erosion of the Medicare Benefits Scheme and is a cause for serious concern.
- In four years out-of-pocket costs to consumers for GP appointments has risen by 25% in the ACT.
- The costs of further medical testing and imaging are barriers to accessing appropriate and timely health care.
- 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 is often overlooked by health care providers and decision makers.
- A coordinated approach across a wide range of community services is required to better meet the needs of older consumers, both in terms of preventing hospitalisation and better supporting older people following hospitalisation for an acute illness.
- Adequate staffing, training and support for all health workers is vital to ensure quality and safety of health care for consumers.
- HCCA encourages all health workforce planners to embark on a process of reform to reflect a consumer-centred approach to health care.

## 1. General comments

HCCA is very pleased that the Senate Select Committee on Health has been established. Health, or being in good health is important to everyone and influences how we feel, function and participate in the community. The concepts of 'health' and 'ill health' must be understood as complex. As well as an individual's experience or understanding of their health, social determinates of health and cultural contexts of health and health care need to be taken into account.

The establishment of this Senate Select Committee on Health is an opportunity to address complex issues within Australia's health care system to improve the health outcomes of the Australian Community and we welcomes the opportunity to provide input.

This submission draws on extensive consultation with health care consumers in the ACT community and is shaped by our Health Policy Steering Committee. We conducted a community consultation on the out-of-pocket cost of health care on the 6<sup>th</sup> of May this year and have included consumer comments from this event in this submission.

While consumer experiences are central to and inform all of the Terms of Reference (ToR) for this inquiry, however we have addressed those ToR where there is a more direct impact on consumers. Our submission will be focused mainly around **b) the impact of additional costs on access to affordable healthcare and the sustainability of Medicare**. We will address the following ToRs, however our comments can be applied to all the ToRs for the inquiry:

- **c) the impact of reduced Commonwealth funding for health promotion, prevention and early intervention,**
- **d) the interaction between elements of the health system, including between aged care and health care,**
- **f) the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners,**

**pharmaceuticals, optometry, diagnostic, dental and allied health services and;**

- **g) health workforce planning.**

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.

We want to emphasise that the introduction of Medicare 30 years ago was to subsidise the cost of health care to the consumers, to ensure equitable access to health services. Consumers value Medicare and universal health care. The introduction of further costs to the consumer through co-payments is an erosion of Medicare and the rebate system, and we remain deeply concerned at the impact this will have on the poorest and sickest members of our community.

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. ToR (b) the impact of additional costs on access to affordable healthcare and the sustainability of Medicare**

We have interpreted 'additional costs' as those that have a direct on impact the consumer, and 'sustainability' as the capacity of the community to generate the funds for Medicare and the return on this investment, i.e. improving the health and wellbeing of people in our community.

### **The impact of additional costs on access to affordable healthcare**

HCCA has conducted extensive research and consultation on these issues which can be seen in detail in our submission to the Senate Inquiry on Out-of-Pocket Costs<sup>1</sup> and in HCCA's report commissioned by ACT Medicare Local; Primary Health Care in the ACT: Consumer Experiences<sup>2</sup>. These documents capture the impact of costs in health care on consumers and the effect this has on access to affordable, high quality health care.

Key issues of cost for people in the Canberra area and the surrounding areas of NSW are; cost to see GPs, dentists, specialists, the cost of transport, the cost of complementary medicine and vitamins and the impact of these additional health costs on quality of life.

### **i) Cost to see General Practitioners, Specialists and Dentists**

In 2009 and 2013 HCCA conducted a survey on the consumer experience of general practice within the ACT region (See Submission for Senate Inquiry into Out-of Pocket Costs in health care in Australia<sup>1</sup>). In both years more than 600 people completed the survey. This represents a useful snapshot of consumer experience. Key findings can be seen below:

- 48% increase of number of people paying over \$ 65 for a standard 15 minute GP appointment from 2009 to 2013;
- The average cost of GP consultation in 2009 was \$51-60 in 2013 it is was \$75.50 before Medicare rebate;
- In four years out-of-pocket costs to the consumer for GP appointments has risen by 25%. In the ACT In 2009 the average out of pocket cost to the consumer for a GP appointment in the ACT was \$34.50 assuming they paid \$60 before Medicare rebate. In 2013 the average out of pocket

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<sup>1</sup> Health Care Consumers Association of the ACT, (2014) Submission for Senate Inquiry into Out-of Pocket Costs in health care in Australia. Accessed on 17 August 2014 ;  
<http://www.hcca.org.au/component/rsfiles/download?path=Out%20of%20Pocket%20Costs/Health%20Care%20Consumers%20Association%20-Senate%20Submission%20into%20out%20of%20pocket%20cost%20May%202014.pdf>

<sup>2</sup> Health Care Consumers Association of the ACT (2014), Primary Health Care in the ACT: Consumer experiences. Accessed on 17 August 2014;  
<http://www.hcca.org.au/component/rsfiles/download?path=Out%20of%20Pocket%20Costs/Appendix%201%20HCCA%20Submission-%20Senate%20Inquiry%20into%20out-of-pocket%20health%20costs%20May%202014.pdf>

cost to the consumer for a GP appointment in the ACT was \$43 assuming they paid an average of \$ 75.50 before Medicare rebate.

In the ACT 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<sup>3</sup>.

Bulk-billing GPs were acknowledged as key to enabling access to primary health care for a number of people, especially those on low incomes, and with children under the age of 5<sup>1</sup>.

*“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 )

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.

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<sup>3</sup> SCRGSP (Steering Committee for the Review of Government Service Provision) 2014, Report on Government Services 2014, Productivity Commission, Canberra.

*“[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

## **ii) Specialists**

Costs to see specialists are prohibitive. The business arrangements of many specialists are inconsistent making it hard for consumers to understand the substantial out-of-pocket costs. 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 96% said they did follow up on the referral. Of the 4% of respondents who stated they did not follow up on their specialist referral, cost and waiting time were the major reasons given for not seeking care. Anecdotally consumers talk to us about rising cost as a barrier to following up specialist referrals.

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.*

## **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 out-of-pocket cost.



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<sup>4</sup>. Those living with the greatest level of socio-economic disadvantage were twice as likely to not see or delay seeing a dentist than those living in areas of least socio-economic disadvantage<sup>4</sup>.

Several consumers at the HCCA consultation also commented on the cyclical nature and effect that poor health care has on a consumer's ability to work, their productivity 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*

#### **iv) Transport**

For many with chronic conditions appointments are a part of everyday life. Costs are not supported by Medicare rebate include travel costs, parking costs and the costs to carers of leave and work hours.

*“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*

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<sup>4</sup> Australian Bureau of Statistics 4839.0 - Patient Experiences in Australia: Summary of Findings, 2012-13 2013

*Canberra to Sydney to see my Neurologist.” – Consumer with multiple chronic conditions (Consumer experience -HCCA submission to the Senate Inquiry on out-of-pocket costs<sup>1</sup>)*

Consumers in the ACT and southern NSW regularly have to travel interstate to receive medical treatment that is not available in their areas. The Australian Interstate Travel Allowance granted to those in regional and rural areas rarely covers the true costs of make trips to metropolitan areas for treatment or specialist care. HCCA advocates for increased support for consumers from these regional and rural areas to access, timely and quality health care.

#### **v) Alternative and complementary medicine**

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.

*“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*

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.

#### **iv) 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,*

HCCA submission to the Senate Inquiry on out-of-pocket costs<sup>1</sup>

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<sup>5</sup>. **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.**

*“Prioritising bills can become really stressful, you sacrifice money that could go to the home, your car maintenance, basics!”*

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<sup>5</sup> 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

*“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 of Medicare will amplify existing 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.**

### **Implications for the on-going sustainability of the healthcare system and Medicare**

Allocation of funds to health care is always a matter of balance and depends on how important the Australian community thinks health care is relative to other spending alternatives of government. We are firmly of the view that expenditure on health care needs to be viewed as an investment, not just a cost. An investment in appropriate health care results in the avoidance of higher downstream health costs and also increased workforce participation and national productivity.

Any consideration of the sustainability of Medicare must be made within a conceptual framework that includes the social determinates of health. The social determinants of health are the societal and economic factors which effect how people are born, grow, live, work and age. People’s experiences are shaped by the distribution of money, power and resources at global, national and local levels. Many of these factors can be modified to some extent by interventions, focused actions and health care<sup>6</sup>.

There is a growing body of evidence that recognises that partnerships between health care providers, health care professionals, patients, family members, carers and communities have a significant impact on patient outcomes and safety<sup>7</sup>. The importance of such partnerships is reflected in the Australian Safety and Quality

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<sup>6</sup> World Health Organisation,(2012) *Social Determinates of Health Report*, 132 Session of Executive Board Provisional Item 7.2,

<sup>7</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011), National Safety and Quality Health Service Standards. ACSQHC, Sydney

Framework for Health Care<sup>8</sup>. By acknowledging and investigating the role the relationships of health care providers and professionals, patients, family members, carers and communities in ensuring patient safety, we deepen our knowledge of what constitutes appropriate patient care in the 21st century.

There are three tiers of consumer engagement in decisions about our health care. Firstly, individual health professionals can engage with patients to ensure they are delivering patient-centred care. Secondly, health services can partner with users of their services to ensure they are meeting their needs. Thirdly, government can engage with the community to ensure the public dollar is being spent appropriately and they are accountable for the decisions being made about our health. This move towards active consumer engagement is the most cost effective way to design, change and deliver health care as it is responsive to the needs of the ultimate end users.

**A strong commitment to universal health care and provision of health services is needed to support all Australians. Medicare plays a critical role in supporting people to access timely and appropriate health care. Primary health care is an important foundation to a strong health system that actively supports consumers to manage their own health needs and stay healthy for as long as possible<sup>9</sup>.**

In the 2013 OECD Health Indicator Report it was stated that countries with strong primary health care systems have lower avoidable admissions tertiary care, which is not only preferable to the patient, but also saves large unnecessary costs to the health care system<sup>10</sup>.

If Medicare is eroded then this has implications for the on-going maintenance of the health care system, as tertiary care, and acute hospital care is highly costly and often at, or over capacity.

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<sup>8</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC). Australian Charter for Health care rights. Sydney :ACSQHC, 2008

<sup>9</sup> SCoH (Standing Council on Health) 2013. National Primary Health Care Strategic Framework, Canberra: Commonwealth of Australia

<sup>10</sup> OECD (2013), Health at a Glance 2013: OECD Indicators, OECD Publishing.  
[http://dx.doi.org/10.1787/health\\_glance-2013-en](http://dx.doi.org/10.1787/health_glance-2013-en)

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 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.

It is critical that barriers to access for those seeking primary health care and support for management and treatment of ongoing chronic conditions to be identified and removed. A strong Medicare system is core to this.

## **2. ToR c) the impact of reduced Commonwealth funding for health promotion, prevention and early intervention**

When discussing the impacts of out-of-pocket cost on health, many consumers stated that preventative health care, early intervention and management programs 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.

HCCA advocates for increasing or at least maintaining funding for community health promotion, prevention and early intervention programs. HCCA regularly conducts information sessions with members of the multicultural community in the ACT about how to navigate the ACT health system and the appropriate use of services. This is part of our health literacy program. Many people from the multicultural community feel at a loss as to where to go within the health care system for care and stated that sessions like those run by HCCA were essential in their ability to successfully access the health care system.

*“there are new migrants arriving all the time in Canberra and there is no one providing this sort of information to new arrivals”. - Father from Multicultural Play Group HCCA information session on After-Hours options*

Health literacy is a focus of HCCA, and our work in this area is based on the understanding that health outcomes are better when consumers have good health literacy and when health services, activities and support groups have inclusive policies and practises<sup>11</sup>. The Health Literacy program enables disadvantaged and marginalised health consumers to build skills and knowledge to improve their use, understanding, awareness and confidence engaging with their own health, their families health and with support services, community services and with the health system. The link between health literacy and better health outcomes is well established<sup>12</sup>. Developing strategies to reduce the effects of low health literacy on health outcomes warrants the attention of policymakers, clinicians, and the community.

### **3. The interaction between elements of the health system, including between aged care and health care.**

One of HCCA’s policy priorities is aged care and this is a significant focus for our members. In light of this HCCA formed the ACT Aged Care Consumer Reference Group in 2013 whose purpose is to;

- Inform the ACT Government about the needs of older health care consumers in the ACT region and to foster relationships between consumer and aged health service delivery providers
- To ensure consistent consumer representative input on related issues across aged health care services in the ACT and region
- To provide a reference point for the development of patient centred care within health and community services regarding aged care and rehabilitation

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<sup>11</sup> Australian Primary Health Care Research Institute (APHCRI) Video Interview *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](http://www.youtube.com/watch?v=FHAwMo_8Q5E)

<sup>12</sup> Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Ann Intern Med.* 2011;155:97-107.

This group brings to the fore examples of the unmet needs of the ageing population in ACT community in both acute and health care.

We have identified the following key issues:

- There is strong correlation between inadequate health care in community and primary care settings and increased hospitalisations and mortality rates in older patients<sup>13</sup>;
- The significant costs and consequences associated with urgent Emergency Department presentations mean that reducing the demand for ED and acute care services needs to be a top priority for the primary care system;
- a coordinated approach across a wide range of community services is required to better meet the needs of these people, both in terms of preventing hospitalisation and better supporting older consumers following hospitalisation for an acute illness<sup>14</sup>.
- By improving the quality of and access to primary health care for older consumers, the number of older people admitted to hospital could be greatly reduced. This has the potential to significantly reduce the health costs for our ageing population and to improve the quality of life for a large proportion of our community;
- Without adequate support from community and primary health care services, the caregiver burden can increase to the point where the carer is no longer able to care for their family member. This in turn can result in the older person having to be admitted to a residential aged care facility (RACF) prematurely or to receive inadequate care that often leads to hospitalisation and more serious health issues;
- Older people are highly likely to have ongoing contact with particular primary health professionals, providing them with the unique opportunity to work with the consumer to monitor and maintain their overall health and prevent health problems from deteriorating to the extent that they require an escalation in care beyond the capacity of the primary care system;

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<sup>13</sup> Bradshaw, et al., (2013). Six-month outcomes following an emergency hospital admission for older adults with co-morbid mental health problems indicate complexity of care needs. *Age and Ageing*, 42, 582-588.

<sup>14</sup> Imison, et al., (2012). *Older people and emergency bed use: exploring variation*. The Kinds Fund.



- Older people living with a number of chronic conditions have commented that they often found it frustrating when trying to access the care they need. They feel that GPs don't always have a good understanding of complex chronic conditions such as chronic pain or mental health issues, which means they are less able to provide useful advice on how to self-manage and refer to appropriate services;
- The experience of some older people is that GPs were often reluctant to continue caring for older people, and that many refuse to make home visits or go to RACFs. This can result in older consumers ultimately becoming cut off from quality primary care services and the practitioners they know and trust;
- Unregulated aged care workers in RACFs providing care out of their scope of practice; and
- Workforce issues in RACF in terms of adequate staff numbers and quality of care provided.

#### **4. g) health workforce planning**

Many national workforce planning documents have a focus on empowering and engaging with consumers to facilitate workforce reform<sup>15</sup>. As a consumer organisation, we welcome this approach and encourage all health workforce planners to embark on a process of reform to reflect a consumer-centred approach to health care. We hope this committee continues to seek input from consumers and consumer organisations as the committee progresses, because the consumer perspective offers a uniquely holistic perspective on how workforce issues can effect care and consumer journeys through the health care system.

Adequate staffing, training and support for all health workers is vital to ensure quality and safety of health care for consumers. This is a key issue particularly in aged care, with a growing ageing population and staffing issues in this area. Many consumers in

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<sup>15</sup> Health Care Consumers Association of the ACT, Submission to the Draft National Cancer Workforce Strategy(2012) Accessed on September 17 2014 ;  
<http://www.hcca.org.au/component/rsfiles/download?path=HCCA%20Submissions%202012/HCCA%20Submission%20to%20the%20National%20Cancer%20Workforce%20Strategy.pdf>

our membership have expressed concerns over the lack of regulation of personal care workers in aged care facilities and low staffing numbers meaning that workers are often working beyond their scopes of practice.

There had been rapid changes to roles in health workforce in Australia, including the introduction of multidisciplinary roles and shifts in the scopes of practice for health workers particularly in primary and aged care. These changes may offer more choices to consumers as to where and when to get care. However it is essential that consumers are involved in shaping these roles and that the community is made aware of what each worker can and cannot do within their scope of practice. This means that consumers have clear expectations of the care they will receive.

### **Concluding remarks**

HCCA welcomes the establishment of this Senate Select Committee on Health. It is an opportunity to address complex issues within Australia's health care system to improve the health outcomes of the Australian community. We look forward to continued involvement in the work of this committee.

The Health Care Consumers' Association of the ACT

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## HCCA SUBMISSION TO SENATE SELECT COMMITTEE INTO HEALTH

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