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**Health Care Consumers' Association Inc. Submission:
Primary Health Care Advisory Group Discussion Paper
(August 2015)**

*'Better Outcomes for People Living with Chronic and Complex
Health Conditions through Primary Health Care'*

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Health Care Consumers' Association Inc. Submission:

1. General comments

Health, and being in good health, is important to everyone and influences how we feel, function and participate in the community. As well as an individual's experience or understanding of their health, social determinants of health and cultural contexts of health and health care need to be taken into account.

Chronic disease affects 35% of all Australians, and contributes to 90% of deaths. In 2013-2014, 48% of avoidable hospital admissions were due to chronic disease¹. And yet, for many people with chronic diseases, appropriate care can allow the person to continue contributing to their community and living a good life. We welcome the establishment of the Primary Health Advisory Group. The focus on chronic and complex health condition management in primary health care is an opportunity to explore the impacts of chronic disease on consumers, carers and the health system and bring about much needed change.

HCCA sees an enhanced focus on primary health care within the community as cost effective and a way to reduce spending in tertiary care. Primary health care, health promotion and primary prevention contributes to a healthier Australian community. In Canberra we are currently living with the consequences of many years of having reduced options to access affordable primary care and as a result we have high presentations to our emergency departments. Affordability continues to be a pressing issue.

Self-management of chronic conditions is a priority area for HCCA, with many of our members interested in prevention, self-management and how primary health care services, including general practitioners, can better serve those people with chronic diseases.

This submission draws on our extensive consultation with health care consumers in the ACT community. We have also included primary research on consumer perspectives on primary care that we undertook in 2013.

¹ AIHW 2014. Australia's health 2014. Australia's health series no. 14. Cat. no. AUS 178. Canberra: AIHW

2. Response to discussion paper questions:

Theme 1 - Effective and Appropriate Patient Care

What aspects of the primary health system work well for people with chronic and complex health conditions?

We need to improve the connection between primary care and the acute health sector. This is particularly relevant to those people living with chronic conditions. Typically consumers with complex chronic disease are the heaviest users of the health system, with high emergency department use, longer hospital stays, and frequent visits to specialists and general practitioners². This is well recognised and two key strategies identified in the 2008 Garling Report³, that relate to the management of chronic disease make this very clear: *better co-ordinating the treatment of these patients within the hospital system; and where possible, treating these patients outside the hospital environment.*

A mix of engagement strategies – face-to-face, online, peer led, as well as led by health professionals – is essential to ensure that people in the community are well equipped to self-manage their conditions. We want to make sure that the health care needs of people are kept at the lowest level possible. This ensures maximum choice and agency for consumers and carers, and minimum health care costs for both the state / territory and federal health services.

In the ACT there is a self-management course for people with chronic diseases: the *Living a Healthy Life with a Long-Term Condition Program*. The course runs for 2.5 hours a week for six weeks and is taught jointly by a health professional and a person living with a long-term chronic illness. This peer-led model has been shown to improve patient outcomes and confidence to self-manage their condition⁴.

Other examples of successful peer-led programs doing valuable work in the ACT are; the ACT AIDS Action Council, Hepatitis ACT, Pain Support ACT, The Canberra Alliance for Harm Minimisation and Advocacy (CAHMA), and the ACT Self Help Organisations United Together (SHOUT).

² Garling, Peter. & New South Wales. Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals. (2008). Page 40 Volume 1, Special Commission of Inquiry into Acute Care Services in New South Wales Public Hospitals First report of the Special Commission of Inquiry : Inquiry into the circumstances of the appointment of Graeme Reeves by the former Southern Area Health Service. Sydney, N.S.W : NSW Dept. of Premier and Cabinet, <http://nla.gov.au/nla.arc-91862>

³ *Ibid*, Page 41 Volume 1.

⁴ Druss, B. G., Zhao, L., von Esenwein, S. A., Bona, J. R., Fricks, L., Jenkins-Tucker, S., ... Lorig, K. (2010). The Health and Recovery Peer (HARP) Program: A Peer-Led Intervention to Improve Medical Self-Management for Persons with Serious Mental Illness. *Schizophrenia Research*, 118(1-3), 264–270. doi:10.1016/j.schres.2010.01.026

HCCA is supportive of the *HealthPathways* program currently in use by a number of Primary Health Networks. *HealthPathways* is an online health information portal used at the point of care by GPs, specialists, nurses and allied health practitioners on how to assess, manage and refer patients in a timely manner to available services. This can help guide integrated care for consumers, standardise referral pathways for best practice and quality care. We are strong supporters of the development of a consumer portal that provides patient information about these pathways. It is only where consumers are informed of what to expect, that they can determine the appropriateness and effectiveness of what is delivered to them.

What is the most serious gap in the primary health care system currently provided to people with chronic and complex health conditions?

Our members have highlighted specific issues below:

- “The need for coordination of care, access and choice”
- Finding a GP you can work with, who understands your social context and works with you to achieve your health goals.
- Primary Health Networks can play a greater role in prevention of chronic disease, through early identification.
- Recognition that many people access services currently not fully covered by Medicare including; diabetes educators, osteopaths, chiropractors, naturopaths, occupational therapists and fitness coaches.
- The consumer experience of fragmented health care is all too common
- Managing our own health related finances, including affording medications, appointments and treatments through subsidised or free health programs and initiatives, e.g. community care programs, seeking financial advice, free legal services, and health clinics. Most support measures cost money, so financial education is important.
- Managing and organising our medical information. This could include keeping scripts and paperwork together and ensuring you know when your appointments are, knowing your legal rights around privacy and records, considering a Personally Controlled eHealth Record. Also medication information; when your scripts expire, when your medication is about to run out and knowing what medications you are taking and their strengths.
- Support in managing to maintain employment through diagnosis and live with chronic conditions.
- Knowledge and capacity of health professionals. For example, chronic pain or pain is often associated with chronic conditions. Many of our members talk about the need to increase the skills of general practitioners and other health providers in this area.
- The gap between health and community services is significant, presenting problems for consumers, particularly when trying to access In-home support and residential aged care and support for carers.

Do you support patient enrolment with a health care home for people with chronic and complex health conditions?

In principle, HCCA supports patient enrolment, however choice and control is central to meeting our needs. We must be able to move or change general practices easily if the services do not meet our needs.

We need any enrolment system to be based on control and choice for consumers, ensure continuity of care and have strong financial and clinical accountability built in. The 2009 Primary Health Care Research & Information Service report on patient enrolment is clear in describing both international best practice models of patient enrolment and highlighting weaknesses with these models⁵ and we found this to be of value.

What are the key aspects of effective coordinated patient care?

Care coordination and supporting people to self-manage their chronic condition is key to make certain that we meet the health care needs of people at the lowest level possible. Chronic disease management seems to be largely service and system focused rather on improving care for consumers and carers. Service and planning documents need to be driven with consumers, families and carers at the centre of care. We would like to see policy indicators, actions and outputs reflect the tenets of consumer and family centred care in all chronic disease management models.

Navigating the health system is a difficult task for many consumers. This can be particularly challenging when people have multiple chronic conditions or comorbidities. Patient navigators can help address this. Patient navigators have been shown to facilitate improved health care access and quality for underserved populations through advocacy and care coordination⁶. Patient navigators also help address many of the disparities associated with language and cultural differences, fostering trust and empowerment within the communities they serve⁷.

⁵ Kalucy L, Katterl R, Jackson-Bowers E, Hordacre A-L. (2009). Models of patient enrolment. PHCRIS Policy Issue Review. Adelaide: Primary Health Care Research & Information Service.

⁶ Natale-Pereira, A., Enard, K. R., Nevarez, L. and Jones, L. A. (2011), The role of patient navigators in eliminating health disparities. *Cancer*, 117: 3541–3550. doi: 10.1002/cncr.2626

⁷ *Ibid*

Theme 2 - Increased use of Technology

How might the technology described in Theme 2 improve the way patients engage in and manage their own health care?

Information technology and the need for integrated electronic medical records in hospitals, general practice and community health is also key to successful models of chronic disease prevention and management in primary health care⁵.

A common experience of consumers is the frustration of having to repeat key information about themselves, their medical history, and current medications to multiple clinicians. Information must follow the consumer as we move from service to service.

There has been a fair degree of frustration at the pace of eHealth work to date. The Consumers E-Health Alliance (CEHA) published a paper in December 2014 that expressed their concern about the progress made, given the amount of time and money expended so far. Many of our members share this view. We are very keen to see the eHealth agenda realise the benefits that have been long promised and are interested in contributing to this.

We support the implementation of a consistent eHealth record system for all Australians. This is a missing element of our health system if we are to achieve an integrated system that will optimise our health outcomes.

What enablers are needed to support an increased use of the technology described in Theme 2 of the Discussion Paper to improve team based care for people with chronic and complex health conditions?

The information needs to follow consumers so that it is available when we need it.

Ensuring there are mechanisms for transfer of accurate and timely consumer health information between these providers remains a concern for consumers. Ehealth and technology such as the MyHealth Record must be further developed with consumers and all stakeholders to make sure there is enough functionality, and the correct elements included to support integrated health care. As stated above it is essential that information follows us as consumers as we access multiple services to manage our health.

Chronic disease and ill-health impacts on consumers' ability to participate in the workforce. Consumers struggle with the ongoing tasks of balancing their lives with the increasing demands and intrusion of chronic illness. We need to provide models of

care and infrastructure that enable patients and their family carers to balance life and illness, and aligning patient-centred care not only within health services but also with community and social support services⁸.

One tool that can aid consumers in managing their chronic disease and work-life balance is to develop booking systems, where consumers can choose their appointment times for health appointments. A web-based booking system could provide consumers and carers with greater capacity to co-ordinate these appointments with the rest of their lives.

ACT consumers also have access to an online database of services called, Find a Health Service: <http://findahealthservice.act.gov.au>. This is based on the National Health Service Directory, an important piece of infrastructure in our health system. This allows consumers to identify the service provider that can best assist them in their care. This currently doesn't include peer-led support groups, or community organisations that as acknowledged throughout this submission actively support many people living with chronic conditions. We have been advocating for the inclusion of this data.

Theme 3 - How do we know we are Achieving Outcomes?

Reflecting on Theme 3, is it important to measure and report patient health outcomes?

Yes. Measuring and reporting on outcomes is really important and challenging for any clinical care, research and quality improvement activities. Let us not forget Ernest Amory Codman!

Transparency and greater reporting around both patient outcomes and quality and safety in primary care is essential to creating solutions that meet the needs of our community. We are dragging our heels on this. Providers need to be more transparent and enable better sharing of data, including outcomes data.

To what extent should patients be responsible for their own health outcomes?

As consumers we live with the outcomes of our health every day. Chronic disease and ill-health impacts on our ability to participate in the workforce, to socialise or be as active as we need to be.

We are not supportive of punitive approaches that shame and blame people based on their social circumstances. We need to have a social approach.

⁸ Jeon Y., Jowsey T., Yen L., Glasgow N.J., Essue B., Kljakovic M., Pearce-Brown C., Mirzaei M., Usherwood T., Jan S., Kraus S.G., Aspin C. (2010) Achieving a balanced life in the face of chronic illness. Australian Journal of Primary Health 16, 66–74. <http://dx.doi.org/10.1071/PY09039>

Consumers struggle with the ongoing tasks of balancing their lives with the increasing demands and intrusion of chronic illness. Many of our members feel that the work involved by individuals to self-manage chronic conditions is often under recognised and not well supported in current chronic disease management models.

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 HCCA Out-of-Pocket Submission (2014)

This issue is largely invisible to institutional health care providers and health care policy makers. In Jowsy *et al.*'s⁹ 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 activity¹⁰.

It is essential that the potentially massive workload involved in managing an individual's health is acknowledged to establish the true out-of-pocket costs of health care in Australia. A study by Corbin and Strauss (1985)¹¹ 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 and,
- 3) biographical tasks by the individual and the family need to reconceptualise their life and life story with a chronic condition¹².

For consumers living with chronic conditions the work, time, or costs associated with their chronic conditions were key to their lived experience of managing their health.

⁹ Tanisha Jowsey, Laurann Yen and Paul Mathews W, Time spent on health related activities associated with chronic illness: a scoping literature review *BioMed Central Public Health* 2012, (12) 12:1044

¹⁰ *Ibid.*

¹¹ Corbin J, Strauss A: Managing chronic illness: three lines of work. *Qual Soc* 1985, 8(3):224–247.
<http://www.publish.csiro.au/media/share/blank.gif>¹² *Ibid.*

Theme 4 – How do we establish suitable payment mechanisms to support a better Primary Health Care System?

How should primary health care payment models support a connected care system?

We believe that blended payments and innovative payment models are needed to support in primary health care. Fee for service models have not been effective in providing care for people with chronic and complex medical issues. Whatever models we develop we need to ensure that they do not further disadvantage consumers or compound the health inequity in our community.

What role could Private Health Insurance have in managing people with chronic and complex health conditions in primary health care?

We have not come to a decision within our membership about our position on this. It is fair to say that we have concerns about ensuring access to services of a high quality and with low out-of-pocket costs.

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 other vulnerable groups within our communities.

We note that Medibank is piloting a program called CarePoint providing doctors with extra resources, including social services, to treat the chronically ill¹³. The trials include patient initial assessments, GP-led care planning, clear referral pathways, service delivery and shared e-records across the acute and primary care sector¹⁴.

At a recent event at the Consumer Health Forum, Dr Linda Swan from Medibank Private spoke about the success of this model. We would like to see the public system embrace the principles of this work and improve the way in which health care is delivered. We want good health and good health are for everyone, regardless of their ability to pay.

We are also aware of the IPN trials in Queensland. It would be in the community's best interests if Medibank Private was to make the evaluation of this trial public.

¹³ Mcdonald K, Carepoint Trial Looks To Reduce Hospital Admissions, (April 2015), Accessed 4/8/2015
http://www.pulseitmagazine.com.au/index.php?option=com_content&view=article&id=2371:carepoint-trial-looks-to-reduce-hospital-admissions&catid=16:australian-ehealth&Itemid=327

¹⁴ VIC Health, CarePoint integrates services for Victorians (March 2015) Accessed 4/8/2015:
<http://www.health.vic.gov.au/news/carepoint-update-mar15.htm>

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