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HCCA Submission to Standing Committee on Health on Chronic Disease Prevention and Management in Primary Health Care

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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.
- 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 acknowledgement of the significant workload involved in self-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 consumers with chronic conditions, both in terms of preventing hospitalisation and better supporting people with chronic conditions following hospitalisation for an acute illness.

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, contributes to 90% of deaths. In 2013-2014, 48% of avoidable hospital admissions were due to chronic disease[1]. 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. The Inquiry on Chronic Disease Prevention and Management in Primary Health Care is an opportunity to explore the impacts of chronic disease on consumers, carers and the health system.

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.

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

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.

While consumer experiences are central to and inform all of the Terms of Reference (ToR) for this inquiry, we have addressed those ToR where there is a more direct impact on consumers. Our submission will be focused mainly around;

2.1 Examples of best practice in chronic disease prevention and management, both in Australia and internationally;

2.3 Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care

2.4 The role of private health insurers in chronic disease prevention and management;

2.5 The role of State and Territory Governments in chronic disease prevention and management;

2.8 Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

2. Response to Terms of reference

2.1) ToR 1: Examples of best practice in chronic disease prevention and management, both in Australia and internationally;

In the ACT there is a self-management course for people with chronic diseases called 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 condition[2].

[2] 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

Further gaps identified by our members in information for self-management of chronic disease are:

- How to manage health 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 your medical information. This could include keeping your 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.
- Managing your employment. For example do you have to disclose your condition? Where to go for support in the work place and if you are having trouble and your legal rights.
- Pain management has also been suggested as chronic pain or pain is often associated with chronic conditions
- Information for young people with chronic conditions, particularly those with chronic pain. Preliminary work from Women's Centre for Health Matters suggests there is a gap for young women and women of a child baring age in receiving information, and peer-led support for living life with a chronic condition.
- In-home support and residential aged care facilities and support for carers.

Women's Centre for Health Matters a member of HCCA, recognises the newly emerged Canberra Endometriosis Network as an example of best practice in peer-led chronic disease management support group. This group works to provide support to women through the journey of living with endometriosis and pelvic pain in the ACT region. This is done through online forums and social media all hours of the day, online videos and webinars and regular information sessions and meetings. Their closed group website is very active and has experienced massive growth in the last 12 months - a link to the public page can be found here: https://www.facebook.com/EndometriosisCanberra

One of the areas this group highlighted as a difficulty they face gaining skills and resources to help establish, incorporate and lead a growing peer–led support group.

> *"Personal cost to individuals to start these groups are high, who helps us start these networks? Do I personally fund courses around this? Or the Network? Who shoulders the cost to do this? The grants are only for established groups, public liability insurance and legal issues start to arise as your membership grows"* – Katie Williams, Canberra Endometriosis Network

Other examples of successful peer-led programs do 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).

Sustainable funding models and infrastructure are essential to support greater reach into the community and expansion of the services provided. Any best-practice program must be able to function in the continuum of health services between public/private hospital care, primary care and allied health care.

A mix of engagement strategies both face-to-face, online, peer lead, and professionally led is essential to ensure that people in the community are well equipped to self-manage their conditions, and so 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.

2.3) Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;

Primary Health Networks (PHNs) play an important role in showing that primary health care is more than just general practice through a partnership approach to the development and delivery of services to the community. We believe they are identifying the needs of the community and developing programs to meet these needs.

PHNs provide the opportunity to engage with important stakeholders who have traditionally not had a seat at the table. Nursing, for example, has long played an important role in primary care. The place of nursing in our health care system continues to expand and other health care providers are also strengthening their position within the system. We need an integrated approach to the governance and operation of PHNs, involving a wide range of clinicians from varied disciplines. In addition to the wider inclusion of clinicians, the involvement of consumers and community is important in the development and operation of PHNs.

We strongly support the following principles which, we believe, underpin the overarching objectives of PHNs:

- A holistic understanding and recognition of the social determinants of health
- Equity in health care
- Community participation and control over planning and provision of health services, including corporate and clinical governance
- A focus on health promotion, chronic disease prevention and reduction in impairment from chronic conditions

- A balance between health promotion, preventive care and illness treatment
- Reflecting local needs with a basis of evidence and research
- An understanding of health as including wellbeing, not just the absence of disease
- Services which are be locally based, affordable, acceptable, well integrated and offer a multi-disciplinary range of care from health promotion to rehabilitation
- Continuity of care for people through all levels of the health care system

The PHN Community Advisory Committees include community members who understand the health and social needs of their communities. It is imperative to remember the value of lived experience in providing an insightful and meaningful consumer perspective. We believe consumer membership of the governing bodies of PHNs provides a blend of diverse working abilities and skills, concentrating on the "big picture", rather than only engaging in the finer operational details.

We support the strong connection between primary care and the acute health sector to ease the transition between the acute setting and community based care. This is particularly relevant to those 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 practitioners.[3] This is well recognised and two key strategies identified in the 2008 Garling Report[4], 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.*

Primary Health Networks can play a greater role in prevention of chronic disease, through early identification and intervention programs. This would include interventions targeting a population or group prior to them presenting at a general practice. A number of services currently not fully covered by Medicare but are increasingly being used by people living with chronic disease, including; diabetes educators, osteopaths, occupational therapists and fitness coaches.

HCCA is also supportive of the *HealthPathways* program currently in use by an number of PHNs. *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

[3] 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

[4] *Ibid,* Page 41 Volume 1.

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.

2.4) The role of private health insurers in chronic disease prevention and management;

This issue is one that is of great interest to our members. We note that Medibank is piloting a program called CarePoint providing doctors with extra resources, including social services, to treat the chronically ill[5]. In the CarePoint trials Medibank Private is partnering with the Victorian Government, and the Queensland Government - to trial a two year integrated care program for insured and uninsured with chronic and complex conditions and a history of multiple hospitalisations. The trails include patient initial assessments, GP-led care planning, clear referral pathways, service delivery and shared e-records across the acute and primary care sector[6]. We will continue to watch the development of these models of care and programs as they may potentially lead to greater choice, and better outcomes for consumers with private health insurance.

We recognise that increasing costs for services and limiting access to public services can 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 premiums and copayments.

2.5) The role of State and Territory Governments in chronic disease prevention and management;

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.

There is a critical role for state and territory governments in chronic disease management and prevention. State and territory governments must ensure that all service planning, workforce planning and infrastructure spending on health looks at chronic disease management and prevention as an ongoing and increasing investment.

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[5] 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

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

Both federal and state and territory governments are uniquely able to influence the architecture of the health system and therefore have a responsibility to lead and engage the community, service providers and other stakeholders in health service reform[7]. Actions taken by taken by state and territory governments, such as new funding models for health services directly influence service delivery and models of care. Governments also have an important role to play in engaging consumers and community groups. This can be done through investing in health literacy and strengthening consumer engagement mechanisms in the management of health services[8]. The increase in the number of people living with chronic conditions are a growing health need and so provide a call to action for federal and state and territory governments, health services, community groups and consumers, carers and families.

Many consumers struggle with continuity of care and fragmentation of services, including the coordination of care for those required to travel interstate for chronic disease management. For many consumers of chronic disease management services in the Capital region the experience of fragmented health care is all too common. It is essential that chronic disease management strategies clearly outline how the state and territory governments intend to coordinate care and support these consumers and their families as they move between local and interstate services and how we can be assured that consumers have seamless holistic care, with coordination of both treating teams and services.

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.

2.8) Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

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 than focusing on improving care for users of these services. 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.

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[7] National Health and Hospitals Reform Commission. ***A Healthier Future For All Australians – Final Report of the National Health and Hospitals Reform Commission – June 2009.*** Canberra: NHHRC; 2009 Jun Available from: http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/nhhrc-report

[8] *Ibid*

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 care[5].

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. 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 because the information does not follow the patient but rather gets caught up in provider repositories.

Whilst self-management is essential to providing people choice and control in their life with a chronic condition and in preventing acute health events, 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.*'s[9] 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[10].

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 condition[12].

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[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 Soc1985, 8(3):224–247. http://www.publish.csiro.au/media/share/blank.gif[12] *Ibid.*

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. Financial 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.

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 services[13].

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.

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 coordination[14]. Patient navigators also help address many of the disparities associated with language and cultural differences, fostering trust and empowerment within the communities they serve[15].

Dedicated Care Navigators and Case Coordinators for people living with complex chronic conditions is also a promising and innovative model to assist those with chronic conditions self-manage and prevent unneeded hospitalisations and presentations to the emergency department. Consumer health care needs are coordinated by a single person such as a general practitioner or care coordinator / navigator. That person ensures that as many services as possible take place outside of the acute care hospital, and that admission to an acute care hospital, unless clinically necessary, happen through the emergency department. These programs can be managed State and territory governmentsand administered locally by that area health service. The programs should reflect the needs of the consumers, carers and families in the area, the

[13] 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

[14] 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

[15] *Ibid*

availability of services in the community and in hospitals[16]. We note that the 2015-2016 Queensland Government Budget a promise to employ 400 Nurse Navigators in Hospital and Health Services across Queensland. The additional nurses will, improve patient safety and assist patients to navigate from their referring GP or other primary care providers, through hospital based care[17]. We are in favour of this model of care and believe it is more person-centred then current chronic disease management programs in place.

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.

Concluding remarks

HCCA welcomes the opportunity provide input into this inquiry and looks forward to continued involvement in the work of this committee.

Chronic conditions are a fact of life in a society with a long life expectancy. The story so often told in our community is that people with chronic diseases are a burden on our society, and yet for the vast majority of people, much of their lives lived with chronic conditions can remain full and satisfying.

Our health system should be focussed on facilitating the empowerment of consumers and their families to self-manage their conditions as much as possible. This fundamental change in the relationship between consumer and health providers can be challenging, but this negotiation as a new more equal partnership is central to any effective reform in this area.

[16] Garling, Peter. & New South Wales. Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals. (2008). Page 40 Volume 2, Section C, 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

[17] Queensland Government, 2015-2016 Budget, Budget Highlights (2015), Accessed 6/8/2015 : http://www.budget.qld.gov.au/budget-highlights/health.php

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