



HCCA Submission on 'Consumers, the health system and health literacy: Taking action to improve patient safety and quality.'

Submitted 11 September, 2013

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

In 2008, State and Territory Health Ministers endorsed the Australian Charter of Healthcare Rights. The Charter was developed by the Australian Commission for Safety and Quality in Health Care and applies to all people receiving, seeking or delivering health care in all settings in Australia. The Charter was launched in the ACT in December 2009 by the Health Minister, Ms Katy Gallagher MLA. HCCA believes that a shared commitment to the Charter will improve the safety and quality of health care for all consumers.

The Australian Charter of Healthcare Rights states that all consumers have the right to:

- **Access** – to have timely access to health services that address our needs
- **Safety** – to receive safe and high quality care
- **Respect** - to be shown respect, dignity and consideration

- **Communication** – to be informed about services, treatments, options and costs in a clear and open way
- **Participation** – to be included in decisions and choices about our care as well as health service planning
- **Privacy** – to have our privacy maintained and proper handling of our personal health information assured
- **Comment** – to comment on or complain about our care and have our concerns addressed properly and promptly

It is with reference to these rights that HCCA works with its members to shape health policy and engage in systemic advocacy on behalf of all health consumers in the ACT community.

HCCA welcomes the opportunity to provide input to the Australian Commission on Safety and Quality in Health Care (ACSQHC) consultation on improving health literacy. We strongly support the recognition that health literacy should be a national health priority and can empower consumers to engage in healthier lifestyles and access the care they need.

Comments on the Consultation Paper

Overall, we were impressed with the quality of the consultation paper. The document has a clear layout and is well researched. The examples of initiatives already being implemented to improve health literacy were very encouraging and we see value in investigating how they could be adapted for use in other areas and facilities. We also agree with many of the definitions of health literacy and related concepts. Our main concern is that health literacy should be seen as a tool for empowering consumers to take action and become involved in their own health. Rather than bombarding consumers with health information, we need to equip consumers with the skills to seek out the information that is relevant to their situation.

Health literacy is not only the key to improving the health of individual consumers; it enables consumers groups to engage in decision making at all levels of health service planning and delivery. This in turn ensures that health systems are able to provide the best possible care for consumers.

The social determinants of health

We would like to see the social determinants of health included as a separate related concept. There is an increasing recognition that the health and wellbeing of an individual is largely determined by the socioeconomic context in which they live.¹ It is

¹ World Health Organisation (WHO), 'The social determinants of health'.
http://www.who.int/social_determinants/sdh_definition/en/index.html - last updated May 2013.

not enough simply to provide consumers with information about staying healthy; we also need to be empowered to take action.

Social isolation is another factor that can be detrimental to an individual's capacity to access health information. Often it is our peer groups who are able to provide relevant advice based on their own experiences with the health system or simply provide assistance seeking out information and services. Community self-help groups such as those encompassed by Self Help Organisations Uniting Together (SHOUT) in the ACT are an invaluable resource for people living with chronic conditions who want to connect with others having similar experiences for advice and support.

Rather than 'involving' consumers in decision making processes, health literacy needs to be about actively enabling consumers to make informed decisions about our own health care. The term 'involved' is vague and somewhat passive.

Improving communication between consumers and health professionals

It is essential to address the power imbalance between clinicians and consumers during clinician/patient consultations. In a more supportive environment, consumers can have the confidence to ask questions and speak up when they do not understand something or even disagree with the clinician. We see this as a cultural issue that needs to be addressed within the health system.

Critical literacy skills

We also believe that critical literacy skills are important for consumers to be able to assess the value and relevance of health information to their own situations. There has been some consideration of including critical literacy skills in school curricula. This could also form part of the strategy to improve health literacy across Australia.

Measuring health literacy

Measurement of health literacy also needs to take into account the information needs of individual consumers, which are likely to vary. For instance, what is it that the individual wants to know and what outcome are they looking for? The resulting data is then able to indicate whether consumers are satisfied with their own level of health literacy.

Our approach to Health Literacy

The HCCA consumer-led approach to health literacy is underpinned by democratic values that position health care consumers, patients and their families and carers as equal partners in all health decision making processes.

In 2011, HCCA was funded under a Health Promotions Grant by the ACT Government to develop the Health literacy Project (HLP). The aim of the HLP is to develop the expertise of health consumers to actively engage with their health care

systems and health professionals in order to make informed decisions about their own and their family's health. We seek to work with those who will benefit the most from building confidence and skills around health literacy and advocacy, including people with a chronic illness, people with a high use of the health system, and people at risk of social exclusion.

The HLP, along with free Consumer Representative Training (CRT) provided three times a year, is also assisting to fulfill HCCA's objective of empowering health consumers to be involved in policy initiatives and represented at all decision-making points throughout the health system.

Since 2012, HCCA's Health Infrastructure Program (HIP) Team has been raising the awareness of ACT Health's HIP in the ACT community and making contact with marginalised community groups. Our information sessions aim to deliver information, but also to collect comments, concerns and suggestions so that we can feed this back to the ACT Health.

Our Multicultural Liaison Officer (MLO), who is currently funded as part of the HIP team, works with culturally and linguistically diverse (CALD) groups to provide information and collect feedback from this often overlooked section of the community. Through this work, we have discovered a real need for more effective engagement with CALD communities, who are often left out of the consultation process and have great difficulty navigating the health system.

Future Directions

New technologies and online resources

Governments will need to consider how new technologies can be utilised to improve health literacy. Australia has an incredibly high uptake of new technologies, and the use of smartphones has become ubiquitous across all demographics. Health Apps can provide a valuable and readily accessible source of reliable information and assist consumers with locating the services they need when they need them. There are already a number of Apps available relating to healthy lifestyles and health services that have been well received by our membership, such as the 'Find A Health Service' App launched in April 2013 by ACT Health.

We also see great potential for improving health literacy through the use of social media. Often, consumers rely on online resources when seeking information about particular health issues. With the advent of social media, this is the case now more than ever. Social media is accessed by millions of consumers each day is an easy and cost effective means of disseminating information about healthy lifestyle strategies and disease prevention methods. Health professionals may also be able to direct consumers to reputable sources of information on the internet, which is far more preferable to the increasingly common practice of 'Ask Dr Google'.

Consulting with consumers

In developing and implementing strategies, health organisations and departments will need to ensure that they close the feedback loop with the consumers involved in consultation processes. Our members give up a lot of their time to read through documents and provide feedback based on their experiences within the health system, yet often receive no indication of whether their feedback has been taken on board. This can lead to consumers becoming disengaged out of frustration; leading to the loss of consumer insight in to what is working and what needs to change.

Siloed health services

Many of our members are living with multiple chronic conditions and find it virtually impossible to find answers to questions regarding how the treatment of one condition may impact on another. Health professionals working in silos inevitably means that the burden is on the consumer to attempt to integrate the information they receive from multiple specialists who don't fully understand their situation. Consumers would greatly value enhanced communication across health specialties and the opportunity for joint consultations. With the number of people living with chronic conditions on the rise, this will continue to represent a significant challenge to improving health literacy.

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

The Health Care Consumers' Association of the ACT