



CONSUMERS SPEAKING OUT



NOTHING ABOUT US WITHOUT US:

PUTTING CONSUMERS AT THE HEART OF OUR HEALTHCARE SYSTEM

The Health Consumers Alliance (HCA) is the peak body for health consumers in South Australia. The Alliance is the independent voice of health consumers, facilitating and supporting consumer leadership through consumer networks and broad community engagement activities.

Reflecting the consumer perspective, HCA promotes a holistic and integrated approach to health and wellbeing. As a fundamental aspect of health, mental health is a key focus within HCA.

HCA believes that consumer participation in decisions about individual health care, as well as decisions related to service quality,

efficiency and equity are vital to the wellbeing and health of all South Australians.

Health care is a profoundly personal experience that has immense public consequences. The care we get – or don't get – affects our ability to lead long and healthy lives. It has ripple effects throughout our society, influencing children's ability to succeed in school, the productivity of South Australian workers, and the lifestyles of our ageing population.

Decisions have to be made now about the future of our health system and major reforms are proposed. These changes will have a significant impact

on all of us as health consumers. Effective decision making, with lasting benefits for the community, requires meaningful public engagement.

Health consumers remain the largest untapped resource, as well as the most important stakeholders, in the process of finding solutions to the issues facing our health system.

As the peak health consumer body in South Australia, HCA can assist through consumer engagement strategies that generate informed public opinion and sounder public decisions.

1: Consumer leadership

This was the theme of HCA's 2009 Conference at which the World Café session posed the question: *How do we build and strengthen consumer leadership?*

Overwhelmingly, delegates felt that the **strength of HCA as the peak body** for health consumers is critical to building and strengthening consumer leadership. HCA needs to promote and raise awareness of its role in health consumer advocacy, communicate its achievements and "gather a crowd to support its ethos". Building consumer leadership is synonymous with strengthening HCA.

Secondly, by developing and supporting consumer leadership through **networking, resourcing and capacity building**, and promoting the role of consumer leaders and advocates, HCA will strengthen the consumer voice. To be taken seriously consumer leaders must be effective advocates and representatives. HCA needs to provide structures and resources to facilitate networking, communication and connectivity between consumer leaders and between consumer leaders and decision-makers. Consumer leaders have a role in mentoring and supporting emerging leaders.

Consumers get involved because they want to change the health system for the benefit of the wider community.

Respected and influential health consumer advocacy, that contributes to transforming the culture of our health services, leads to improved safety and quality, more appropriate and responsive services, and better health outcomes for our community, will encourage and motivate consumers. By promoting consumer participation in health, providing well-informed and robust consumer perspectives and communicating the impact of the consumer voice, HCA will build and strengthen consumer leadership.

HCA IS SEEKING A COMMITMENT FROM THE NEXT STATE GOVERNMENT TO:

Support HCA with the necessary resources to promote and raise awareness of its role in health consumer advocacy and building and strengthening consumer leadership.

Support HCA to strengthen the consumer voice and consumer leadership through networking, resourcing and capacity building.



HEALTH LITERACY

Community engagement supports the promotion of health literacy. There is clear evidence of low levels of health literacy across the Australian population and it is now an acknowledged barrier to the realisation of improved safety and quality in health care.

Specific consideration needs to be given to the ways in which health care systems and professionals can and must improve their communication methods with the diverse population groups of healthcare consumers.

This necessitates a more deliberative approach to engagement with health consumers and their communities.

Health consumer engagement is essential for the development of health literacy.

There are high profile examples in South Australia of the pitfalls of not engaging early and in a planned way. For example, the strategy for planning country health services and the decision to build a new Royal Adelaide Hospital, are evidence of the dominance of the Decide – Announce – Defend (DAD) approach to community participation.

2: Community engagement

Broad and diverse community engagement that seeks to include and empower all consumers as citizens is a fundamental building block for strengthening consumer leadership. HCA needs to be able to engage the community and provide diverse opportunities for people to get involved, explore their common concerns and think through the costs and consequences of various alternatives.

SA Health's Consumer and Community Participation Policy and Guidelines promote the adoption of the International Association of Public Participation's (IAP2) model of consumer engagement. A key principle of the IAP2 approach is that effective consumer engagement activities must be well resourced, planned and purposeful.

Some argue that consumers are not informed enough about issues to be able to make real contributions but this becomes a self-fulfilling prophecy if adequate investment of time and resources is not prioritised.

HCA IS SEEKING A COMMITMENT FROM THE NEXT STATE GOVERNMENT TO:

Support HCA to conduct effective consumer engagement activities which must be well resourced, planned and purposeful and be supplemented by effective communication, for example, through the use of new social media.

IAP2 Core Values for the Practice of Public Participation

Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.

Public participation includes the promise that the public's contribution will influence the decision.

Public participation promotes sustainable decisions by recognizing and communicating the needs and interests of all participants, including decision makers.

Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.

Public participation seeks input from participants in designing how they participate.

Public participation provides participants with the information they need to participate in a meaningful way.

Public participation communicates to participants how their input affected the decision.

3: Individual health consumer advocacy

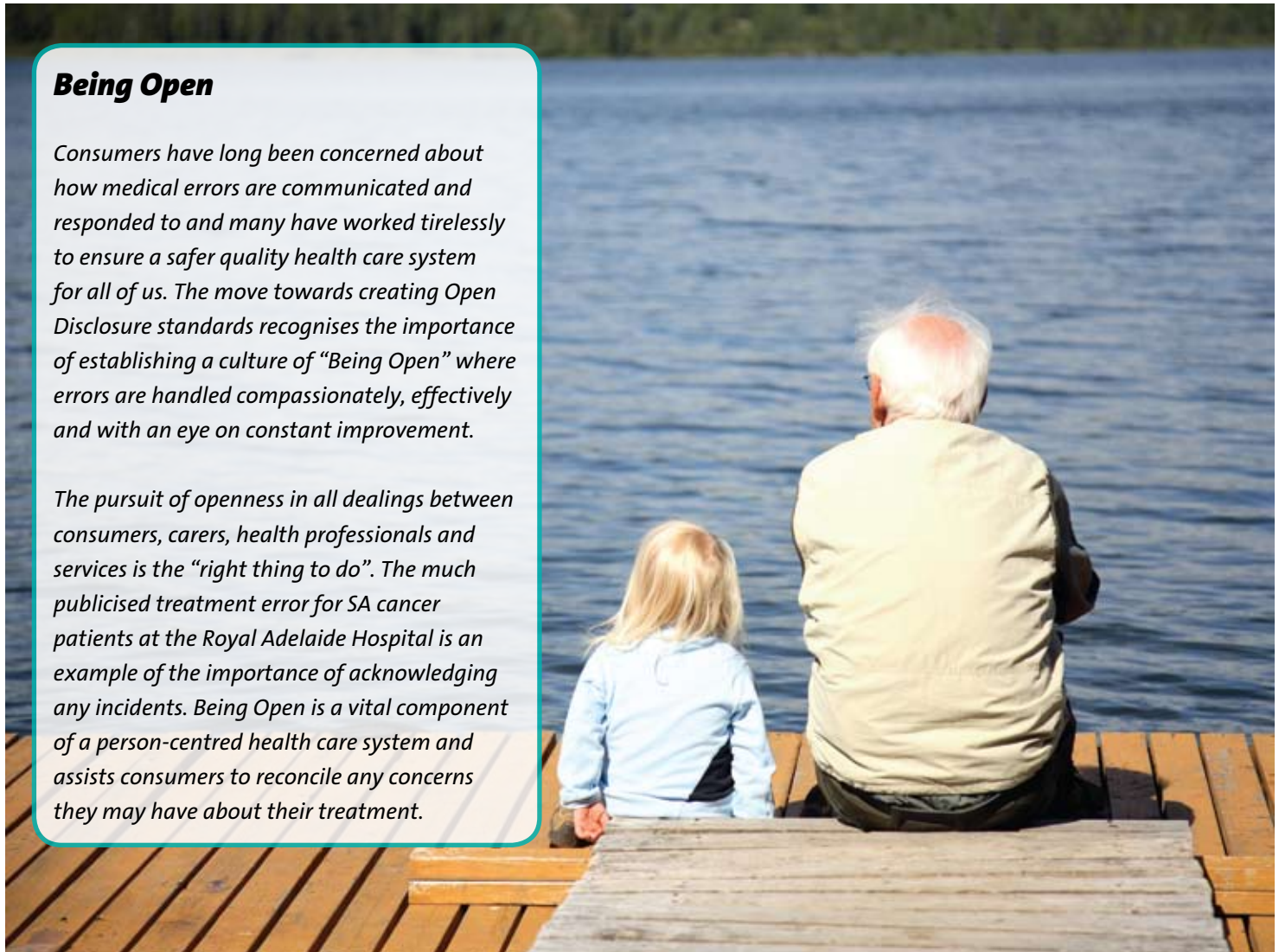
It is generally appreciated that consumers may require "someone to walk alongside of them" when they are receiving medical treatment. For many consumers this support is provided by a loved one, a family member, a pastoral worker or a volunteer. However, when a difficulty arises in patient care, or the safety and quality of treatment is questioned, this type of support may no longer be adequate for the task.

The role of patient advisers within SA Health services is to assist consumers with their concerns, predominantly within a hospital setting. In addition, a well supported volunteer scheme may also offer invaluable support and low level advocacy.

Being Open

Consumers have long been concerned about how medical errors are communicated and responded to and many have worked tirelessly to ensure a safer quality health care system for all of us. The move towards creating Open Disclosure standards recognises the importance of establishing a culture of “Being Open” where errors are handled compassionately, effectively and with an eye on constant improvement.

The pursuit of openness in all dealings between consumers, carers, health professionals and services is the “right thing to do”. The much publicised treatment error for SA cancer patients at the Royal Adelaide Hospital is an example of the importance of acknowledging any incidents. Being Open is a vital component of a person-centred health care system and assists consumers to reconcile any concerns they may have about their treatment.



The role of the Health and Community Services Complaints Commissioner (HCSCC) becomes significant when no resolution is achieved, to the consumer’s satisfaction, at the service level.

However, these services do not provide independent professional support and advocacy to the individual consumer or carer. The result is that at the time of potentially greatest need for some consumers’ there is “no-one to walk alongside of them”. It is this service gap that an independent, professional advocacy program can fill.

The need for the establishment of an independent advocacy service was identified in the review of the Health and Community Services Complaints Act 2004. The concept is informally supported by the HCSCC and the Medical Board of SA. These bodies recognise the limitations of their services to support consumers. They have indicated that such a program would complement and enhance their capacity to ensure that safe, quality health care standards are upheld.

An independent individual advocacy program will bring benefits to consumers, carers, providers and the health system and fill the acknowledged gap in services to consumers and carers in a cost effective, professional manner.

Establishment of a scheme would also enhance the capacity of HCA to hear and respond to consumers, promote awareness of consumer rights and identify potential consumer advocates and representatives who are reconciled to the health system.

HCA IS SEEKING A COMMITMENT FROM THE NEXT STATE GOVERNMENT TO:

Support the funding of a pilot independent advocacy program to be auspiced by the Health Consumers Alliance modelled on the Advocacy Program of the WA Health Consumers Council (HCC), including appropriate funding to conduct an independent evaluation of the pilot.

Health Consumers Alliance of SA Inc.

Level 3, 45 Flinders Street
Adelaide SA 5000

Ph: (08) 8223 1374 Fx: (08) 8232 6260

Email: info@hcasas.asn.au

Twitter: www.twitter.com/HealthConsumers

Facebook: Health Consumers Alliance