One voice matters, many voices make a difference

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1Consumers Health Forum of Australia

The Consumers Health Forum of Australia is the national peak body representing the interests of approximately two million Australian health care consumers. CHF works to achieve safe, quality, timely health care for all Australians, supported by accessible health information and systems.

We advocate for appropriate and equitable health care, based on consumer-based research. We also work with consumers, health professionals and stakeholders to improve health literacy. CHF provides a strong national voice for health consumers and supports consumer participation in health policy and program decision making.

In short, we work to bring the consumer voice into health policy discussion, decision-making and debate.

We think that this important, because health has to be about ‘what happens to people’.

We are often asked ‘where is the evidence?’ that listening to consumers makes for better health-decision making.

Consider this (video): http://www.youtube.com/watch?v=cDDWvj_q-o8&feature=youtube_gdata_player Cleveland Clinic, February 2013

Health is about what happens to people.

The experience of every single person in this video can tell us something about health needs, health care priorities, health care delivery, health care performance and health care gaps.

If we are to improve health outcomes and the health and well-being of people in our communities, consumer experience must be at the core of health policy, planning, delivery and performance measurement. If the people who develop health policy and the people who make their livings from delivering health services don’t listen to and learn from consumer experience, then they’re really missing the point. Without that focus on the consumer, health care can just become a jumble of numbers and statistics, disconnected services and treatment options.

Consumers can be, and must be, critical contributors to health policy and partners in, and co-designers of, health care.

We have known this for decades:

The Declaration of Alma-Ata, 1978, says that ‘the people have the right and duty to participate individually and collectively in the planning and implementation of their health care.’

The National Health and Hospitals Reform Commission (NHHRC) said that, ‘the health system of the future should be organised around the integral roles of consumer voice and choice, citizen engagement and community participation,’ and that there is a need to ensure ‘that the experience and views of consumers and whole communities are incorporated into how we redesign and improve health services in the future.’

In introducing Standard 2 of the new National Safety and Quality Health Service Standards, the Australian Commission on Safety and Quality sums up the evidence for ‘Partnering with consumers’ from the around the world, saying that:

There are ‘significant benefits...

- in clinical quality and outcomes,
• the experience of care,
• and the business and operations of delivering care.4

In 2010, CHF was funded to support one of the key levers for achieving system change and better health care for all Australians identified by the NHHRC: ‘strengthened consumer engagement and voice’.5

The Our Health, Our Community Project has two key elements:
• Leadership development and support for the consumer and community members contributing at the governance and strategic level of health reform.
• Leveraging the online environment to involve consumers and support consumer advocacy at all levels.

It is the opportunity afforded by the online environment for consumers to contribute to better health care in Australia, and in particular for Australians living in rural, regional and remote Australia that I want to turn to today.

It is clear that Internet usage is now mainstream with 86 per cent of all Australians residing in a household with internet access.6

Most Australians live some portion of their life ‘online’, many doing online banking or looking for health information. Australians value the increase in accessibility and convenience. In fact 71% of Australians believe that the internet is improving our daily lives.7

Mobile phone and smartphone usage is increasingly popular. 49 per cent of Australians have a smart phone in their back-pocket and 50% of those have downloaded a mobile app for their phone.8

Naturally, teens have taken to going online as well via their phones. Teenagers spend an average of one hour a day on their mobile phones playing games, watching television and listening to music. Teens are also 50% more likely to text rather than talk on the phone.9

On the social media side of life, 62 per cent of Australian internet users access one social networking site or another.10

• 13 million Australians are on Facebook.11 If Facebook was a country, it would be the world’s third largest.12
• 1.8 million Australians use Twitter13—a place where new breaks first.

The power of social media and the internet to connect people, share ideas, news and generate momentum is increasingly evident and accepted.

Used well, the online environment is a way to reach people with information, but also a way for individuals to share their ideas, knowledge, experience and views with their family, neighbours, friends, community, networks, nation and ultimately, the world.

Good access to the internet in all rural and remote areas is challenging— but hopefully the National Broadband Network will live up to its promises and will make high-speed internet common place for 100% of all Australian homes, schools and workplace by 2021.14

The ‘Empathy’ video gave us a simple reminder about why every voice matters in designing and delivering health care. The online environment allows that voice to be shared, heard and channelled to where it can make a difference.
Online, the barrier of distance disappears. It connects people at a low cost. It can allow people to contribute at a time and in a way that suits them, and it crosses boundaries with ease.

But it also comes with challenges. For many it is an ‘unsafe’ environment where hackers, predators, liable, misinformation, bullies and those with malicious intent stalk, masquerade and hide behind mirrors.

So how can we harness the opportunities offered to connect consumers living in rural, regional and remote Australia, to share their experiences and ideas constructively to help create health solutions that improve better health and well-being for them, their families and their communities?

How can we bring that consumer knowledge, all of those individual voices, to the places where health policy, planning and decision-making happens? And how can we use it to influence decision-making once it arrives?

The approach that CHF has taken is two-fold. I mentioned earlier the leadership development aspect of the Our Health, Our Community Project. This provided professional development and knowledge sharing on consumer and community engagement and networking for consumer and community members appointed to the Boards and Governing Councils of Medicare Locals and Local Hospital Networks and for consumer representatives contributing to high level committees. Recognising that consumer participation and community engagement does not get off the ground without leadership support, we opened relevant sessions to Chairs and CEOs—with strong uptake.

The aim was to support and encourage a cultural shift in Australian health care. A shift that aims to see health organisations motivated and equipped to engage more effectively with their local communities to unlock the knowledge and potential for consumers to contribute to better health care for themselves, their families and their communities.

The second stage was to leverage the online environment to engage consumers around Australia with health reform, and to provide the means and opportunity for them to contribute their ideas, issues and experiences to improving health care.

Consumer consultation, a focus on user-design and a strategy to manage the pitfalls of the online world led to the development of the OurHealth website. Here’s how it works:

(Video) http://www.youtube.com/watch?feature=player_embedded&v=RmXUbupZctM OurHealth, Consumers Health Forum of Australia, 2012

OurHealth offers a safe, moderated, relevant online home for constructive consumer conversation to improve health care.

It allows conversation at a range of levels. Consumers can start a conversation on a local issue or specific topic and share it with their friends and network, resulting in a community conversation. Placing this conversation on a national platform allows others to learn from it, join it and take those issues, ideas and experiences across jurisdictions. It means that local information can be used to influence health policy and planning at a local, jurisdictional and national level.

OurHealth allows consumers with like interests, needs and issues to connect. Many voices can make a difference and the isolation and alienation commonly experienced by rural and remote health consumers and consumer advocates can be replaced with connection, alliance and momentum. It is an avenue for rural and remote advocacy to build a voice that can tackle the economic rationalist thinking that favours metro Australia and is so often a part of health decision-making.

OurHealth puts these conversations on a national platform: one where consumers and consumer advocates from around Australia can learn about, learn from and gain some understanding and
connection with the challenges faced by people living in the bush. Visibility is the first step to awareness, which is the first step to acknowledging issues and placing some priority on addressing them.

Finally, OurHealth is building a searchable databank of consumer knowledge that can support consumer advocates contributing to improving health care at all levels around Australia. It will offer data and support to help the issues, experiences and ideas of everyday people influence and improve health policy, planning and delivery for all Australians. It is also supported by a 1300 number to help bring the voices of ‘disconnected’ consumers to this stage.

I would like to leave you with two thoughts:

- Health consumers and their knowledge-through-experience perspective on improving health care are absolutely vital ingredients in health decision-making that will improve health and well-being around Australia

- The online environment offers great opportunity for the voice of rural, regional and remote health consumers to contribute to change. It is not a magic solution, there are some significant challenges, but it can play an important role.

References


5. Op cit


7. Ibid

8. Ibid


13. Op cit