## Health consumers of today, partners of tomorrow

Jennifer Doggett in @CroakeyNews writes that the recent *Shifting Gears* Summit hosted by the Consumers Health Forum of Australia highlighted the changing role of consumers in health care, moving from a tokenistic "charity and volunteer" model to one of co-design and co-creation.

The Trans-Tasman conference involved leading consumer advocates from Australia and New Zealand, as well as keynote speakers from Canada and the UK. It showcased the many and varied ways in which consumers are working at all levels of the health system to drive changes which support the delivery of consumer-centred care.

Here CHF CEO, Leanne Wells, draws on CHF's work in areas such as the <u>Collaborative Pairs Australia</u> program, and the presentations and discussions at the Summit, to explore strategies for strengthening the role of consumers to ensure they continue to shape the health system of the future.

**Leanne Wells writes:** COVID-19 has shown that more than ever, our health depends on us and how we respond to messages like pandemic precautions and getting vaccinated.

The COVID era has accentuated the trend towards more assertive health consumers. Rising use of 'Dr Google' and digital health generally has fueled a more questioning attitude from consumers about their health and treatment options.

Australasia's first health consumers conference involving over 820 delegates from Australia and around the world recently displayed the growing momentum of consumer influence in health care.

The Consumers Health Forum conference was titled *Shifting Gears* and consumer leaders and delegates attending the virtual conference have stepped up a gear. With consumer representatives and advocates now so much an active part of the health system, it is time for their place to receive more formal support, recognition and pay.

A health consumers' academy to support research, education and training would provide the intellectual and organisational leadership

entity for more strategic development of health consumer leaders, advocates and their organisations as an integral part of the health system. This should include the establishment of a bespoke mentoring program for consumer advocates the value of consumer advocates. Consumer leaders would benefit from mentors in the same way leaders in the business and clinical worlds do.

Their insights and advice must be recognised with appropriate remuneration. Leadership and education in collaborative practice and better ways to work together and share power are already underway through leading-edge programs such as CHF's *Collaborative Pairs Australia*.

We are moving from the traditional volunteer and charity-based tradition of consumer advocates. The demand for consumer advocates and their insights in an era of chronic diseases such as diabetes and mental illness where effective therapies can depend very heavily on non-medical services as much as clinical interventions, is placing heavier and more complex demands on a relatively small pool of competent people.

And as we heard at the conference, patient groups and organisations like CHF are reporting that demand for consumer advisors is outstripping supply.

The lay consumer's experience and perspective can play a pivotal role in areas like tailoring hospital and primary care to an individual patient's needs, advising hospitals on consumer-friendly services and ensuring patients can be partners in care – rather than the subjects of care - by getting the best information on treatment options.

The place of the consumer representative or advocate in health organisations is now widely accepted. The pity has been that too often it seems the "consumer" may be seen as more of public relations gesture or compliance exercise than a genuine attempt to have them serve as a strategic and irreplaceable functionary who may attend board and committee meetings but be excluded from crunch decisions. This practice is changing but is far removed from the ethos of the business world where the consumer is sovereign.

It is worth remembering that the consumer is often the only individual in the care setting to have complete experience and knowledge about all aspects of their care. The best health care professionals and organisations learn from listening to the lived experience of consumer advocates in improving health policy and practice.

The qualitative evidence available from lived experience and consumer insights is equally valid to quantitative data in research.

A central driver in the changing attitudes to effective health care has been the move away from provider-centric care practices to more individually focused consumer-centred, personalised care.

The advantages of consumer-centred care in both health and economic terms have been highlighted in landmark reports by both the Productivity Commission in its *Shifting the Dial* Report and the CSIRO in its <u>Future of Health</u> report.

In 2018 CHF released a White Paper called <u>Shifting Gears: Consumers</u> <u>Transforming Health</u> which set out the transformational policy shifts needed to make the health system more person-centred, and described varied roles consumers can play in shaping better policy, programs, research and services.

The central messages of the conference sought to re-imagine health towards a future where the focus is on consumers as partners in health and social care. As contemporary practice and research around the world is showing, where the consumer or patient is engaged in the decisions about their care, outcomes improve, and experience is better.

The consumer of tomorrow will be recognised as a full "actor" of care, own their medical information, understand the value of evidence-based medicine, be better decision makers and be fully engaged as transformational partners.

There was strong recognition of the need for health systems to embrace the community-controlled ethos of indigenous healthcare, and a call for strengthening indigenous voices in consumer advocacy. The success of Aboriginal community-controlled health centres in countering COVID offers insights of benefit to the rest of Australia.

That experience demonstrates that health and social care organisations need to be 'engagement capable', that is actively creating environments where consumer-centred services can flourish. Culture, strategy and practices all need to work to deliver consumer-centred programs and services.

We are at risk of a growing shadow of inequity as a consequence of widening wealth disparities. The development of ever more varied and expensive treatments and the advent of digital health has increased the risk of the well-off having care not available to others who are often the 'unheard yet most vulnerable'.

Health consumer advocates play a vital role in pressing for quality health care to be available to all and for reforms to the system not only to make the most of medical advances but to promote wellness through preventive health measures.

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