

The consuming issue of health care

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Why consumers and not patients? That's the question I opened with in my presentation on Consumer-Centred Care and Consumer Leadership to the 3rd Asia Pacific Patients Congress this week. The consumer versus patient question is one we at the Consumers Health Forum have heard over the years, although not so often these days.

It was a deliberated decision to adopt 'consumers' in our name when CHF was established 34 years ago. That decision has stood the test of time.

A patient is defined as a person receiving or registered to receive medical treatment --- a status that is more passive and limited to interaction at the time care and treatment is delivered.

Consumer is a broader term, encompassing everyone who may use the health system or have a connection with now and in the future. Patients are a subset of the broader group of consumers

Consumer suggests choice, control and agency, a more active participant in health care and an 'actor' in shaping policy, research and service.

That consumer ethos has been the guide in our advocacy and policy creation.

Consumers want to be involved in all levels of decision-making, to be enabled to make informed decisions and choices about their health care and to feel trusted and respected by service providers, managers and funders.

We seek access to affordable, coordinated and quality health care which is focused on the whole person and to be engaged in collaborative and partnership approaches to service planning and improvement.

It's why CHF – and our many members and representatives - serve as the engine room for improving and innovating health and social care services.

Promoting consumer leadership is central to our mission.

In 2018 CHF published the *Shifting Gears: Consumers Transforming Health* White Paper. It was developed with consumers and informed by conversations with key stakeholders.

It looked to set the agenda, to consider shifts that are needed in the way we think about the health system. It identified eight key roles consumers can and should play into the future, including to be change agents in health care, and “expert patients” to encourage consumer-centred care.

This year we held the inaugural Australia and New Zealand Consumer Experience and Leadership in Health Summit *Shifting Gears*. It was a two-day virtual conference with multiple streams including: Consumers as researchers, consumer-based health care, consumer leadership and enablement.

The focus was on change: some of which is already underway and some of which is yet to come

Consumers owned the Summit as presenters, panelists and rapporteurs along with lively conversations on social media.

Capacity building

To be able to fulfill all the eight roles consumers can and should play, it was clear we needed to build capacity amongst consumers.

In pursuit of that goal, CHF has undertaken three key activities on this:

- *Collaborative Pairs* Australia - a consumer-clinician leadership development program based on the program pioneered by the The Kings Fund, London
- *Consumer Link* – a program to provide education and training for consumers involved in all levels of representation to empower them to effectively use their voice
- Formulating an *Australian Consumer Leadership Academy*
- CHF hosts Thought Leadership Roundtables to shape the health reform agenda. Our Roundtable on Social Prescribing sparked considerable interest among consumer, medical and research groups, and proposals for funding
- In 2020 CHF established a Consumer Commission to look at what the health system should look like beyond COVID-19. The report has shaped our advocacy and led to dialogue with key stakeholders
- In recent years we have developed Australia’s Health Panel and Australia’s Health Consumer Sentiment survey to gauge and monitor consumer attitudes on topical health issues.

CHF participates in all health reform processes with broad consultation with consumers informing our positions. Recently the focus has been on primary health care to better meet the needs of people with complex and chronic care needs; reform of the National Medicines Policy, and health technology assessment to reflect technical advances and consumer preferences.

CHF has played an active role in digital health developments, including the widespread adoption of telehealth and MyHealthRecord --- developments that have been stimulated by COVID-19.

Indeed it has been demands of COVID-19 related activity especially around ethical decision-making and consumer information and awareness that have underlined the need for a wide consumer lens that sees beyond the immediate needs of the patient to focus on the health of society.

This is an edited version of a presentation Leanne Wells, CEO of CHF, gave to the 3rd Asia Pacific Patients Congress on 16 November.