

## The Australian consumer leadership experience

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The Australian health care system includes a national organisation representing health care consumers and equivalent organisations in most states and territories. There are several disease-specific patient organisations, as well as formalised networks advocating for greater patient involvement in health technology assessment and research. This signals a system that sees a place for consumer insights: a system that is on a journey of maturing the way in which it seeks to involve consumers in decision-making.

### Patient Leadership

Patient Leadership is recognised to be the next level of patient, family and carer engagement. While it evokes a view of patients (as consumers), as leaders, on boards or in governance roles, it also places a deeper value on the experience and equal involvement of patients, families and carers in their care and quality improvement.

The Consumers Health Forum of Australia (CHF) recognises the important role of patients, families and carers in creating awareness of and promoting safe and supported health care. This position is extended to the inclusion of consumers with lived experience in committees, working groups, research and policy decision-making, providing every opportunity to expand these experiences as expertise in changing systems and processes.

Viewing patients, families and carers (consumers) as an asset is a key to transforming healthcare.

### Patient to Consumer Leadership

While patient leadership is an emerging concept in the international experience, Australia has some way to go to incorporate this thinking into practice. Some inroads can be seen in health services through the National Standards and the requirement to partner with patients, families and carers (consumers) in all levels of the organisation, particularly related to quality and safety and governance. However, there is limited systemic focus on building the capacity and expertise of consumers to serve as leaders, agents of change and service improvers despite this being recognised in the literature as an important co-creation role that they can play.

There is still a long way to go to achieve true partnership with patients, families and carers, however there is appetite for leadership roles in placing patient experience in the centre of healthcare and decision-making. There also needs to be a recognition that consumers also need to have the ability to choose to which level they want to be involved and engaged. The Consumers Health Forum of Australia (CHF) as the national consumer peak organisation, has the remit to provide opportunities to build, support and sustain consumers as leaders.

Patient leadership signals a breakthrough in healthcare that moves beyond traditional engagement and uncovers the pioneering and transformative work of patient leaders - those affected by life-changing illness, injury or disability who want to lead change in the healthcare system. Or 'those who have been through stuff, who know stuff, who want to change stuff' (Gilbert, D., n.d.)

While this work is explored further at the local level of patients being leaders, nationally, CHF is collaborating and connecting, to building capacity building opportunities and a platform whereby consumers can become leaders, if they choose to do so.

## Consumer Leadership development in Australia

CHF has undertaken several national initiatives which aim to identify and build consumer leadership in health.

In 2018, CHF released a *White Paper, Shifting Gears: Consumers Transforming Health* which set out the 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.

CHF also undertook to recognise the impact of COVID-19 through the creation of a *Consumer Commission* in 2020. The Commission demonstrated the value and power of partnering with consumer experts on significant policy and system reform. It was reflected that consumer observations and lived experience from before and during the COVID-19 pandemic are critical to understanding what worked, where the gaps are and what changes are needed to improve outcomes and experiences for the people our systems are designed to care for (CHF, 2020). The Commission made several significant recommendations.

In March 2021, CHF hosted the first virtual *Australasian Consumer Experience and Leadership Summit, Shifting Gears*, to which over 300 participants attended.

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 is engaged in the decisions about their care, outcomes improve, and experience is better (CHF, 2021).

CHF is leading the implementation of the *Collaborative Pairs Australia* program. Collaborative Pairs is a Leadership Development program that brings together a consumer, patient, or community leader to work together in pairs with a service provider, clinician, or manager to develop new ways of working together.

Developed in England, by the King's Fund, the Collaborative Pairs program objectives are to build skills in developing partnerships and to break down the cultural barriers that often exist between those providing the services and those receiving them. It is designed to re-shape consumer leadership and to position the valuable contributions and expertise of both consumers and health professionals to drive system reform (CHF, n.d.). More than 60 pairs have participated so far in 10 programs. CHF has recently developed and delivered a fully virtual Collaborative Pairs Program.

CHF is working in partnership with Macquarie University's Australian Institute for Health Innovation (AIHI) and the Australian National University, (ANU) College of Health and Medicine to advance the notion of an *Australian Consumer Leadership Academy*. An Academy was a recommendation of CHF's 2020 Consumer Commission and further endorsed by the Australasian Consumer Experience and Leadership Summit, *Shifting Gears*, in March 2021. The concept of an Academy is to provide an entity for strengthening consumer leadership opportunities and for building capacity in the health system to partner with consumers.

This activity is providing a platform for clinicians, researchers and decision-makers to recognise patients, as consumers, as full "actors" in their healthcare, own their medical information, understand the value of evidence-based medicine, be better decision makers and be fully engaged as transformational partners and leaders in their own right.

In summary, consumer insights and lived experience, supported by the right structures and policy settings as well as opportunities for skills development, can be the 'makers and shapers' of change.

## References

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