

4th International Health Care Reform Conference – Speech

A new relationship with consumers: are we going hard enough, fast enough?

Thank you for inviting me today.

You have chosen a topic which is at the heart of the mission for the Consumers Health Forum of Australia.

We are the national peak body representing the interests of Australian healthcare consumers and those with an interest in health care consumer affairs.

We advocate for a patient and person centred health and social care system and work to equip consumers and those interested in working in alliances with consumers to help shape that system.

At CHF we believe that the more choice and control consumers have over their own health and care, the better the outcomes.

If we consider what defines patient-centred care: “health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers”, then without patient input, we are left to assume that we understand what they need and value in health care. As a result, we risk perpetuating current practices.

Consumers are the only constant throughout the patient journey. They have many insights to offer that can help us think differently about how we can improve care, innovate services and ensure experiences that matter to people.

Various clinicians intervene at points in a diagnosis and treatment, various settings are accessed by people, particularly those with chronic and complex conditions, and a complex mix of social determinants are also at play.

Only the consumer has line of sight on all of this. It stands to reason that we should seek their expertise and work in collaboration with them.

Working with consumers as partners in care yields benefits right across the spectrum from the point of care delivery to the way policy is shaped.

Patients benefit through increased levels of trust and confidence in services, from services that offer personalised healthcare and value for money; and increased rates of health literacy and activation.

Health services and practitioners benefit through an increased perception of public value; robust and enduring partnerships between services, practitioners and clients; and patients who are more compliant with treatment regimes.

The benefits to the wider health system include: efficiency gains and consequently a reduction in overall healthcare costs; outcomes that patients value; improved health outcomes; and improved patient satisfaction.

So patient involvement in care, in service design and in policy setting is indeed the 'secret sauce'.

I would hope that this room doesn't need to be convinced of that.

I am just back from the UK where the NHS Five Year Forward View touts a new relationship with patients. An admirable policy goal.

And here we have the Productivity Commission – an arm of the Treasury portfolio no less - in their *Shifting the Dial* Report convinced that we need to move to a patient centred system within five years if we are to have health system sustainability.

If we accept that patient engagement is the 'secret sauce' as the evidence and more recent policy shifts would have us believe, then the opportunity we have is to spread that sauce around more liberally.

The question I would put to you is: are we going hard enough, fast enough when it comes to engaging with patients and implementing a patient-centred approach to healthcare?

In 2013 Health Workforce Australia reviewed health workforce programs and made the observation that policy and practice too regularly become too focused on the needs of practitioners and institutions, rather than those of patients and consumers.

Commentator John Menadue suggested similarly in a recent blog where he said it is too easy to lose sight of the fact that the objective is to serve the community, not providers in a complex system.

If fact, Menadue went so far as to say that the real power in health lies not with Ministers or Departments, but with providers and vested interests.

It's a power equation where consumers and community views are given cursory consideration, if they are considered at all.

While attempts have been made to change this power imbalance, the understanding of how central patient insights and experiences can be to better policy and better services is still not well practised.

But the dial is moving in the right direction.

By way of example, in 2016, CHF surveyed 55 health professional organisations to understand the extent to which they promote and practice patient centred care.

The responses told us that the organisations displayed a strong understanding of the principles behind patient centred care.

However, the translation of patient centred care into organisational policies, procedures and practices varied.

As you can see on the table, the most frequent way that patients were involved in professional associations was through survey consultations on specific issues (65% of respondents). The least

frequent way involved patients as members of a consumer advisory or critical friends group (25%).

Other ways that organisations reported involving patients were through the development of professional standards and the design and/or delivery of continuing professional development.

But what more can we do to take patient engagement to the next level? What can we do to create a system where involvement is systemic, authentic, meaningful and part of business as usual?

Some of the main barriers include lack of leadership and time, cultural and operational barriers, fear of change, power of the providers, as well as patient and doctor competencies, confidence and capacity.

In an environment where we are increasingly concerned about resource stewardship and ensuring our health system payers – both public and private – are paying for high value, evidence-based care, there are real risks if we don't mature and evolve how patients are engaged in the system.

We risk designing irrelevant pathways; poor value care and care that is not respectful of, and responsive to, the preferences, needs and values of patients and consumers.

We must also recognise that patients and service providers are likely to assess the quality and safety of a health care service in different ways.

A patient may assess quality of care against levels of dignity and respect shown by the service provider, a service provider by how well they functioned as a team. One an experiential indication of quality, the other functional.

We need to remind ourselves that one patient does not represent all patients.

This 100-year-old brain twister shows the importance of different people and different perspectives, which is at the heart of consumer engagement.

Do you see a duck or a rabbit? Different people see different things. Consumers are not homogenous. They are highly segmented with different behaviours, perceptions, needs and levels of health literacy.

Engagement and involvement strategies need to take this diversity of perspective into account.

The ideal way of involving consumers in health care program design and policy setting is 'co-design'. This is a practice where consumers serve as equal partners to work with policy makers, commissioners and service developers to review, plan and implement.

It is not simply asking patients what they want.

Another way to involve consumers more systemically in the system is to develop them as leaders.

It's about shifting our regard for consumers as 'users and choosers' to the 'makers and shapers' of services and policy.

CHF is undertaking a trial of Collaborative Pairs supported by the Australian Commission on Safety and Quality in Health Care and four Primary Health Networks in NSW and Victoria.

Developed in the UK by the Kings Fund, an independent charity that works to improve health and care, Collaborative Pairs is an initiative designed to coach and mentor clinicians, managers, patients and consumers to develop new ways of working and learning together and – most importantly – ways of relating to each other as peers.

Cultural barriers, power imbalance and information asymmetry often exist between those receiving and those delivering health care.

Collaborative Pairs aims to tackle those barriers, moving beyond a 'them and us' relationship to one where power, purpose, ambition, leadership and ownership are shared.

Through this program consumers, managers and service providers work as equals.

A patient or consumer leader is one half of the pair, the other half a clinician or health service provider looking to find new ways of working with consumers.

The initiative is designed to coach pairs from the same local PHN health area to work together on a shared challenge which serves as an anchor around which to develop and embed collaborative practice. The shared challenge could be anything from improving an aspect of governance, to a service improvement to the development of a new program.

I mention Collaborative Pairs because it is a promising example of the action we can take to take patient involvement to the next level.

So my take home messages to you today:

- We need to **close the chasm** between rhetoric and practice
- We need to **harness and act on the knowledge and expertise of consumers in its diversity**
- The ideal approach to **implementing patient centred care** is 'co-design' (of policies, programs, services) and shared decision making (around treatment plans)
- **Consumers are system assets and enablers - we need to invest** in equipping them to serve as leaders and clinicians and health administrators to work effectively with consumers
- **Collaborative Pairs** Australia is a promising tool to taking patient involvement to the next level.