



Consumers  
Health Forum  
*of Australia*

Representing consumers on national health issues

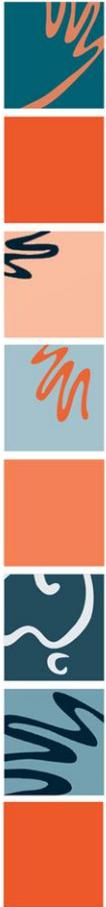
# ***Patient Engagement and Patient Experience-Consumer Perspective***

***Jo Root Policy Manager***



Consumers  
Health Forum  
of Australia

“A patient isn’t a disease with a body attached, but a life into which a disease has intruded”



## Patient Experience

“I was naked, exposed and vulnerable but I never felt embarrassed. I never felt vulnerable or exposed. I only felt strengthened and supported by their involvement

“He told me that he did not believe that my pain score was as high as I reported. He was not subtle about it, he actually said: “I don’t believe that””

“Her empathy and reassurance took away my embarrassment. I felt cared for. I felt like a person, not an inconvenience”



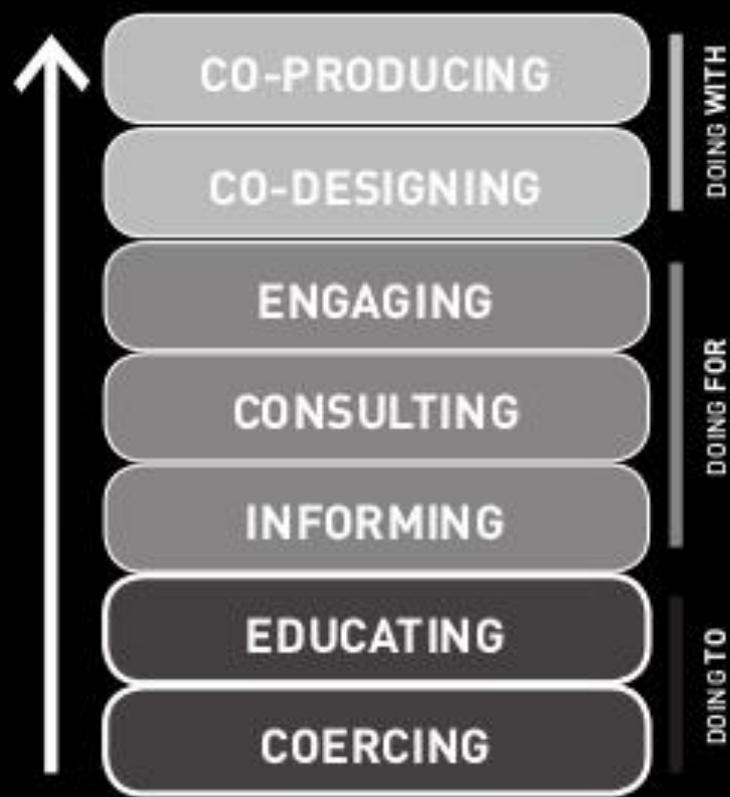
Consumers  
Health Forum  
of Australia

# What do Australian healthcare consumers want?

Digital, **paperless**,  
**accessible**, **efficient**,  
simple, **world-class**,  
**personalised**, human,  
informed, **collaborative**,  
sustainable, **affordable**,  
**connected**, provides  
better outcomes, **puts  
the patient in control**,  
*gives me what I want  
when I want it*

- Make life easier and more convenient for me
- Let me take ownership and empower me
- Include and respect me in the relationship
- Keep me informed
- Enable transparent access to my information
- Give me the best care you can
- Reduce my costs

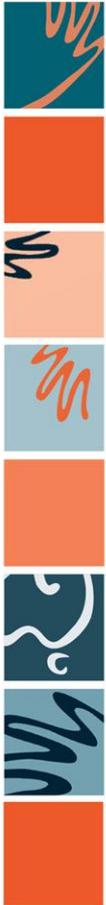
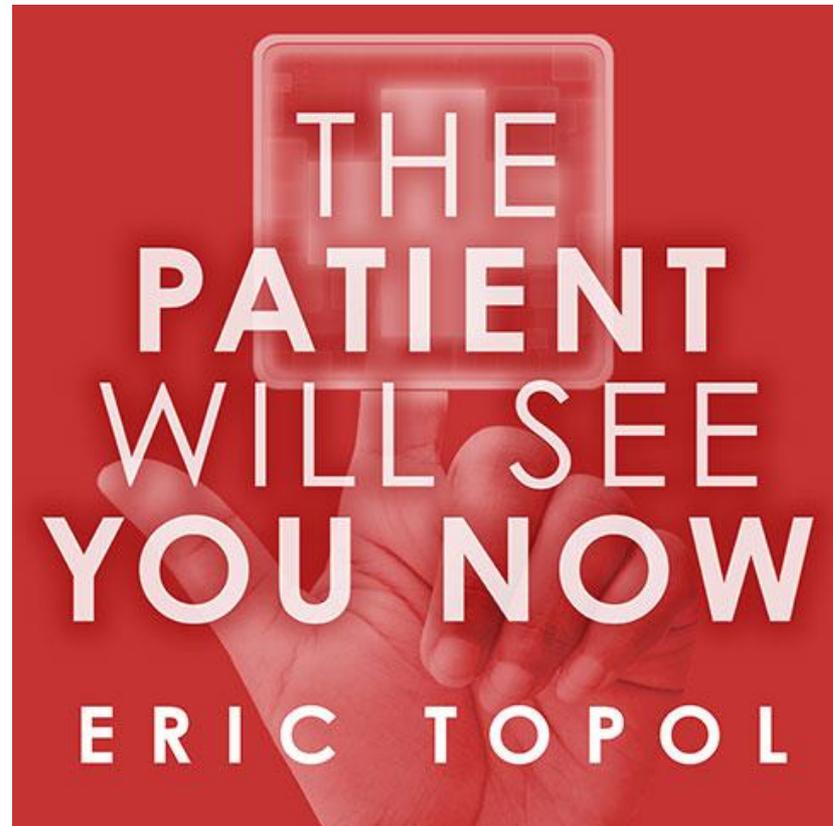
# LADDER OF PARTICIPATION





Consumers  
Health Forum  
of Australia

# Why does consumer participation and empowerment matter?





Consumers  
Health Forum  
of Australia

**Accessible and Affordable Care**  
Timely access to care based on need  
*Well organised, without organisational or systemic barriers*  
Affordable for consumers  
*Equitable access*

**Coordinated and Comprehensive Care**  
Linked care with good referral and feedback  
*Integrated with supported transitions across the system*  
Availability of a range of services to multidisciplinary care  
*Complete personally controlled health record*

**Trust and Respect**  
Provider asks about and understands concerns  
*Transparent*  
*Accountable*  
*Timely and effective complaint resolution process*  
Shared responsibility and decision making

**Principles of Consumer – Centred Health care**

**Informed Decision Making**  
Access to right information at right time  
*Information is clear and understandable*  
Costs are clear  
*Personal choice and right to refuse respected*  
Informed and timely consent  
*Consider carers and supporters*

**Whole of person care**  
Take account of consumers lives and personal values  
*Emotional*  
*Physical*  
*Cultural, spiritual and social factors*  
Consider carers and support  
*Address risk factors and all health problems*

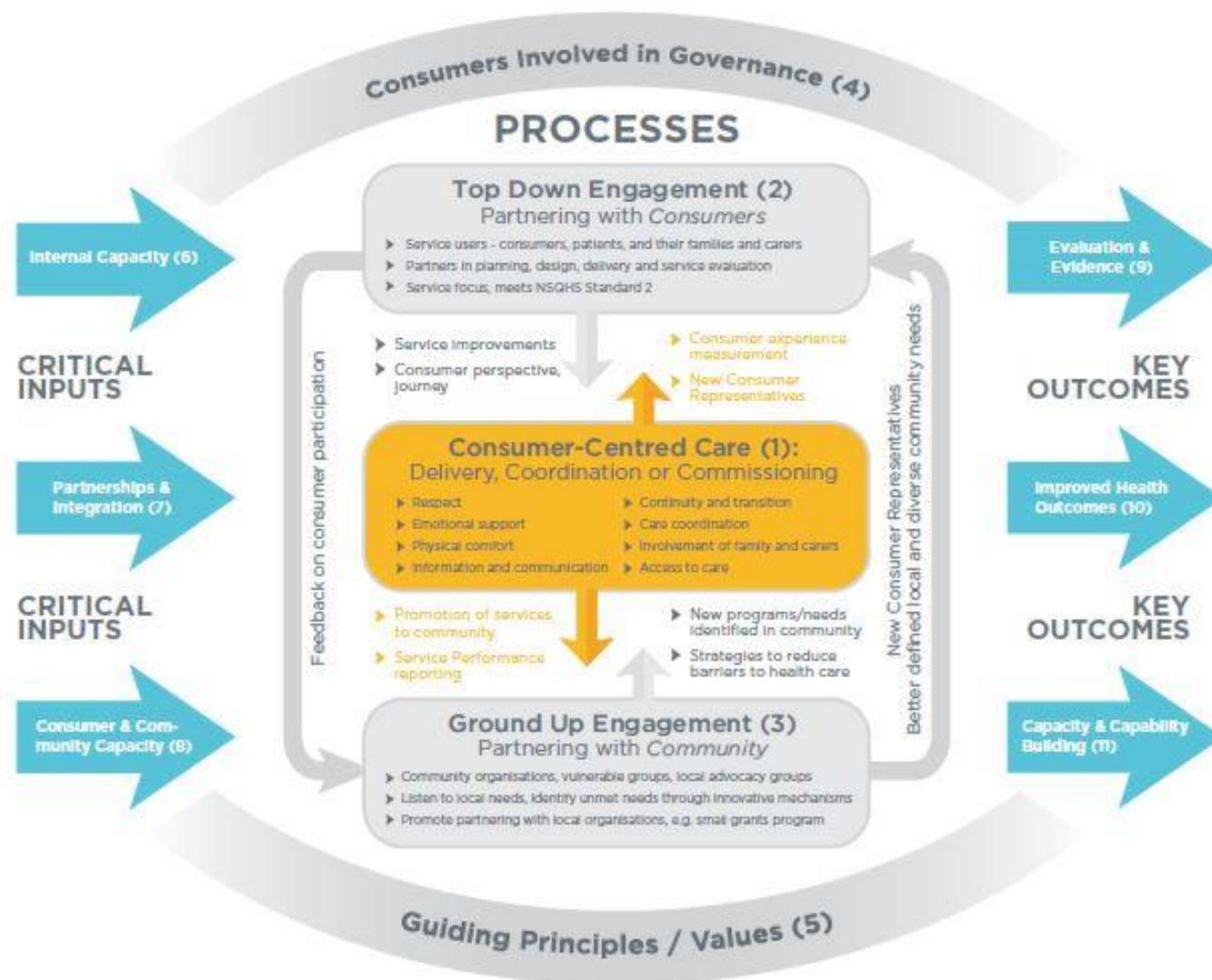
**Appropriate Care**  
Meet the needs and preferences of individuals  
*Evidence based with consumers engaged in research*  
Treatment options, risks and benefits identified  
*Safe and technically proficient with risks minimised*  
Practitioner engages with consumers, families and carers to ensure understanding

**Planning and Governance**  
Partnership with consumers to ensure sustainability  
*Consumers involved at all levels of planning, system design and service development*  
Consumers involved in key governance structures



Consumers  
Health Forum  
of Australia

# The Health Consumers NSW/ WentWest Consumer and Community Engagement Model



## KEY

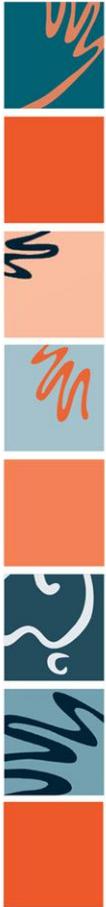
- Consumer-Centred Care**  
Improving the experience and outcomes of consumer-centred care is central to engagement. It applies to service delivery, coordination and commissioning.
- Top Down Engagement - Partnering with Consumers**  
is planned engagement with consumers that supports the design, delivery and evaluation of health services provided or coordinated by the organisation.
- Ground Up Engagement - Partnering with Community**  
is broader engagement with communities to explore, understand and determine together how to better meet diverse health care needs.
- Consumers Involved in Governance**  
involving consumers in clearly defined governance roles ensures that the consumer perspective is always considered in decision making and engagement is a priority.
- Guiding Principles / Values**  
provide a frame of reference for the way in which consumers and health services (and their staff and management) will engage with each other.
- Internal Capacity**  
is a major factor in engagement success. It includes governance and accountability, resources such as a 'champion' and a facilitator, plus training for staff.
- Partnerships & Integration**  
improving the experience and outcomes for consumers requires working across services and integrating care with partners.
- Consumer & Community Capacity**  
to engage is critical. Consumers need resources, training and support. Communities can be supported to increase their capacity to engage.
- Evaluation & Evidence**  
includes monitoring and improving processes, evaluating engagement and outcomes, and contributing to the small but growing body of evidence.
- Improved Health Outcomes**  
includes improved experience and health outcomes for consumers, and better community outcomes through new services or improved access to care.
- Capacity & Capability Building**  
With engagement experience, staff and consumers grow in capability, while organisations and communities increase their capacity to engage.

Health Consumers are people who use, have used, or are potential users, of health services - including their family and carers.

Engagement describes a range of activities that involve consumers or communities participating in health service decision-making, policy development, service design, delivery and evaluation.

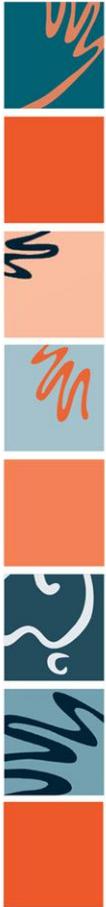
# National Safety and Quality Health Service Standards

- Care aligned with expressed preferences and health care needs
- Partnership with consumers
- Version 2 greater emphasis on partnerships with consumers
- Good consumer experience → safe and quality health care



# Finding out about patient experience

- Collecting stories using Real People Real Data
- Video stories
- Feedback mechanisms e.g Patient Opinion
- Patient experience websites





## “Real People Real Data

Consumers  
Health Forum  
of Australia

**The aim** is to equip consumer health advocates, health services and health policy makers with a relevant and practical tool that can assist them to gather, analyse and present consumer stories, and **use this often overlooked evidence base to shape health decision-making.”**

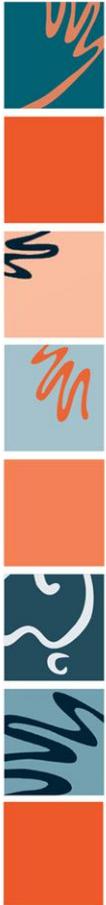




Consumers  
Health Forum  
of Australia

# Why gather stories?

- Help build understanding and empathy for the consumer experience;
- Document impact of the program – document gaps and issues in service delivery, barriers to better health outcomes;
- A different kind of information to complement other evaluation methods – explain the ‘why’ behind the stats
- Understand what matters to program users *from their perspectives*
- Support participation and engagement of your service users in program development, advocacy and evaluation
- Consumer stories tell your service’s story too
- It can be empowering for people to tell their story... (but there are risks!)





# Health Forum of Australia

'I really didn't have the support to cope with it all.' **Lack of medical and non-medical support available**

'I believe a lot of the DBS success is your mindset immediately after, and I was in a really bad place' **For like lack of consideration for emotional wellbeing impacted success of treatment**

'people had spent a lot of money and research and I needed to get on with my life' **Neurologist used guilt to try to motivate**

'a lot of people come through and have this operation and I don't see it working very often' **Nurse gave negative observations which impacted emotionally**

'I had some wonderful nurses in hospital during treatment.' **Wonderful nurses in hospital during treatment**

'the whole operation cost \$80-100,000 and I was out of pocket \$21,000' **High out of pocket costs for treatment**

'I couldn't get through it if someone had guided me a little bit, but it got too hard to manage and I got too sick, and I just, panic set in' **Lack of personal assistance through the whole process**

'if something is a bit private, they'll take me aside somewhere quiet.' **Good respect and care from pharmacist**

'most monitoring that I get, and I'm really pleased, is from my pharmacist.' **Good medication support from pharmacist**

'every medication they put you on, they don't ring you back to ask how you're going' **Lack of follow-up when put on new medications**

'no place for me to go to get managed with that medication.' **Lack of support for managing medication**

'I went to an early onset conference in NSW and they didn't advocate DBS.' **Different treatment strategies in different states**

'one other specialist who was the person you went to see if you have Parkinsons in QLD. But its impossible to get in to see him.' **Lack of options for specialists**

'go an have your MRI and come back in a week and we'll talk about what you have to do.' **Delayed discussing diagnosis and treatments**

'websites are very good, but look we won't talk about that now. Neurologist did not support information seeking.

'they really don't want to deal with the emotion; feel like they want to escape the whole situation.' **Neurologist showed no empathy or emotion**

'I became sick again.. said, I just need a referral for an MRI and he said you don't need MRI. I know what you've got, you've got Parkinson Disease.' **Abrupt and non-empathetic delivery of diagnosis**

'practical considerations like you should perhaps find out if your super covers you' **No advice for checking super/insurance cover**

'that's about 5% of what you've got to worry about. The 95% is the financial, the social, the relationships, this other whole big circle' **Insufficient support for overwhelming personal impacts**

'nobody really to tell you what to do and you don't know where to go' **No support to navigate the processes**

'maybe your specialists won't give you a copy of information but they'll send it to your GP and say to your GP, do you want to be my advocate?' **Lack of coordination of care between GPs and specialists**

'I need you to collect copies of everything from specialists and give them to me. Keep a file of everything from the word go.' **Took own initiative to create care coordination**

Never really been sick' **No history of illness until this experience**

'I sort of thought he would take me and say, wow, you've always been so healthy and I never see you, let's make sure we cancel everything out.' **GP didn't do any thorough checks**

'Instead he said, I think you're being very anxious. You're at a stage in your life when that can happen, just go home and relax and you'll get over it.' **GP didn't take seriously**

'I progressively got sicker to the point I couldn't drive.'

'a doctor across the road who has fibromyalgia herself and I hear she's very understanding.' **Found more understanding GP**

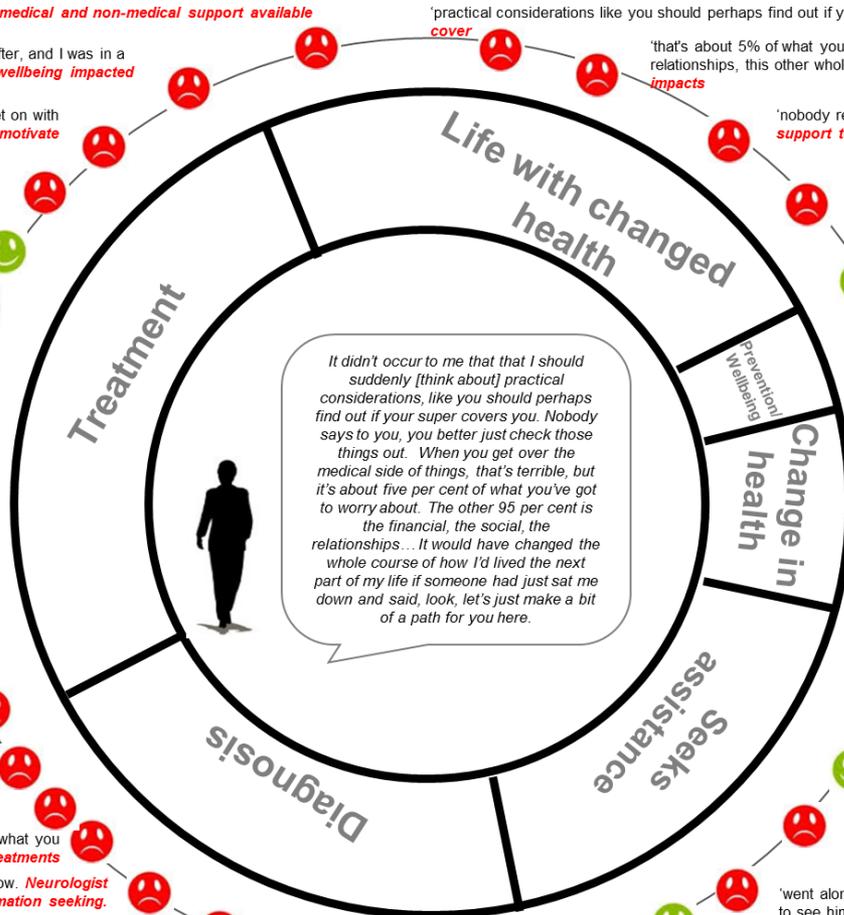
'she said, well if it was stress, or coffee the tremor would be in both hands.' **Taken more seriously by next GP**

'the only neurologist I could get into was one particular person.' **Lack of options for specialists to see**

'went along to the neurologist, and the thing was that nobody really wanted to see him.' **Only available neurologist had a poor reputation**

'you just have to take best care of yourself that you can, and we'll deal with pain relief.' **GP supportive and caring**

'so I managed it. Together with that doctor I managed it.' **Undertook shared management with GP**



# Conclusion

- On the right track
- The patient is a person and is the centre of care

