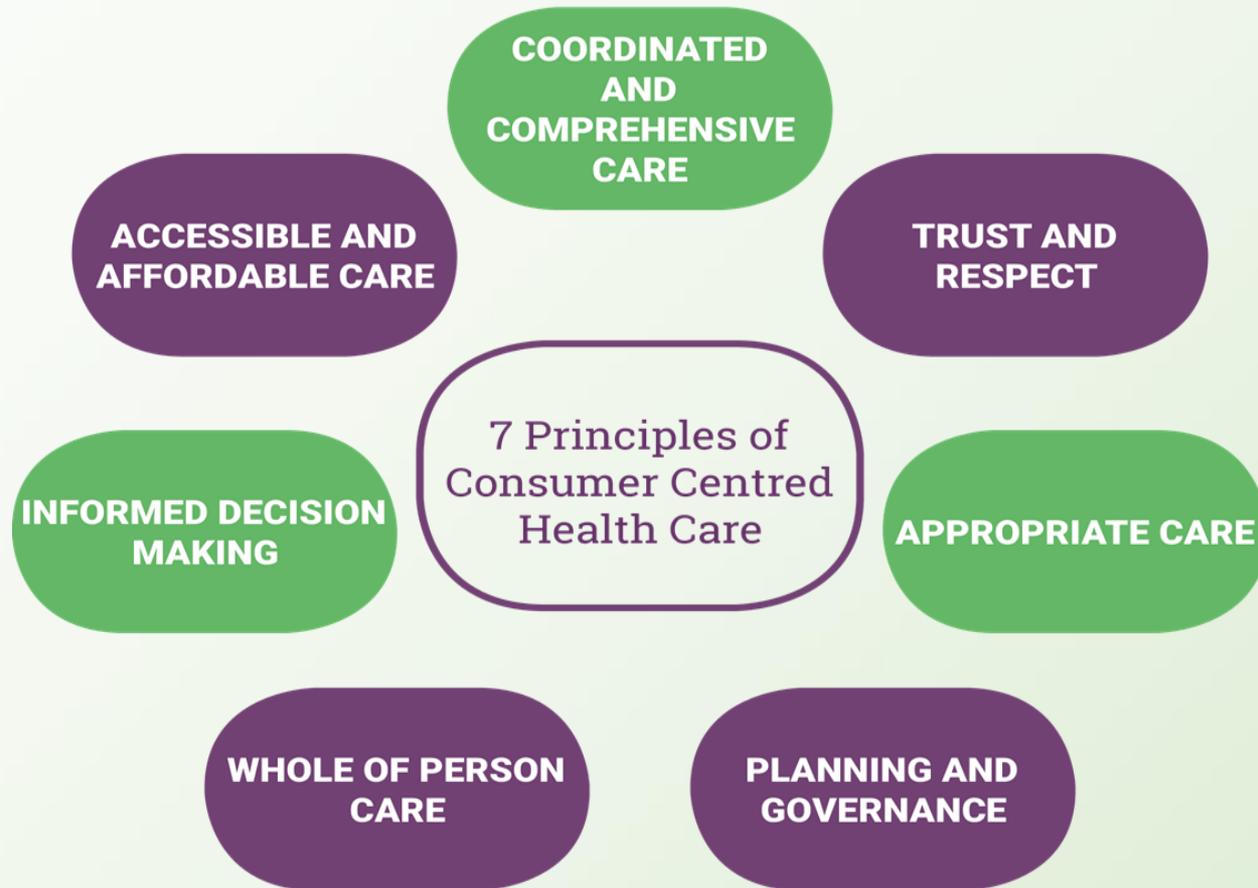


Consumer considerations

Leanne Wells

- Common language
- Involvement: more than a mantra
- Beyond the system inertia
- Frameworks
- A word on evidence
- In the real world
 - A cautionary tale
 - A promising horizon

Common language



Involvement: more than a mantra

“The evidence is clear: overall people are not as involved as they want to be in decisions about health and care, yet when they are involved, decisions are better, health and health outcomes improve and resources are allocated more efficiently”

C Foot et al (2014) *People in control of their own health and care: the state of involvement*, Kings Fund, London

Involvement: more than a mantra

- Increased level of trust and confidence in services
- Acceptability of “tough decisions”
- Services which offer personalised care and value for money
- Robust and enduring partnerships
- Compliance with treatment regimes

- Ultimately involvement helps us to better address the Triple Aims

Beyond the system inertia

- “Involvement is challenging. It challenges orthodoxies, vested interests and established ways of doing things...It requires professional communities to do things differently and to let go”
- “When things go spectacularly and publicly wrong...the instinctive policy and political response is to regulate and protect rather than liberate and empower”

Frameworks

INCREASING IMPACT ON THE DECISION 

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

NHMRC & CHF joint statement

Consumers, community members, researchers and research organisations working in partnerships, to improve the health and well-being of all Australians through health and medical research.

To guide research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research.

Forms of evidence

- Reconsider hierarchies of evidence?
- Consumers as research partners
- Understanding consumer's experiences
 - Measures of experience of care
 - Perceptions and values about experience
- Qualitative research approaches
 - Stories and experiences

In the real world: a cautionary tale

- Example of mental health policy
 - To date policy interventions have failed to change the rates of help seeking
 - Consumer involvement is a way to change this
- NewAccess as an example of trying something different but not widespread enough?

In the real world: a promising horizon

- PHN's as regional commissioners
- Consumer Advisory Councils
- Citizen juries and deliberative democracy potential
- Scope for co-design and co-production