

# What's missing from health policy? The role of citizens

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# Currently...





# Summary

- Current status
- Concepts and practice
- AIHPS research findings
- Case examples – Australia and International
- Will the future be any different?

# NHHRC Interim Report

*Informed consumer deliberation (such as citizen's juries)* – BUT there are many techniques and approaches to citizen engagement

*Person/Patient-centred health care system* – BUT it is not just about consumers of health, health is everybody's business and responsibility

*Service delivery* – BUT its is not just about service delivery, it is about citizens being really involved with policy and decision making



*The rhetoric is there, BUT  
the real engagement with  
citizens is missing...*



A vertical strip on the left side of the slide shows a blurred, high-angle view of a large crowd of people walking, suggesting a busy public space or a large gathering.

# Why citizen participation and engagement?

- Democratic right and responsibility
- Improves policy – open dialogue, options, acceptance, accountability and implementation
- Improves health outcomes
- Makes services reflect the “real” needs of citizens and the wider community
- Improves standards and benchmarking
- Leaves a legacy

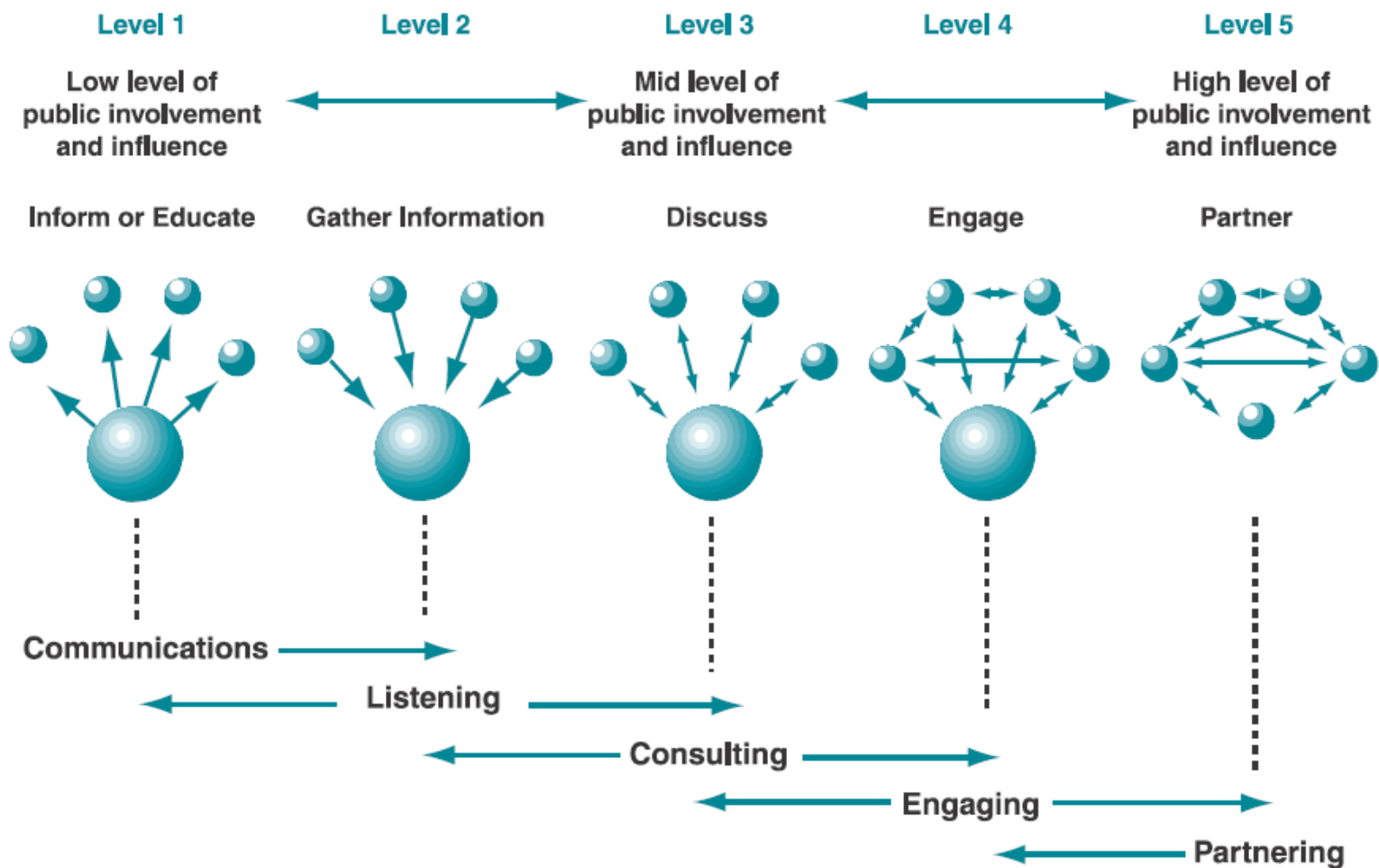


# Citizens can be:

- Drivers
- Collaborators
- Contributors

But there are many levels and instances where they can be one or take on all these roles...

- As an Individual
- Within a Program
- Within an Organisation
- As a Community



Adapted from Patterson Kirk Wallace

Source: Health Canada Policy Toolkit for Public Involvement in Decision Making



# AIHPS work – citizen engagement

- Review and assess current practices for engaging consumers
- Contribute to the development of more effective consumer engagement strategies
- Focus at the level of health policy vs delivery of health services

*Consumer engagement in Australian health policy:  
Investigating current approaches and developing new  
models for more consumer participation*

# What has been missing from citizen engagement in Australia?

- Poorly understood, inconsistently practiced, and under theorised
- Poorly defined
- A mindset, not just a technique
- Requires organisational commitment and a high-level champion
- An ongoing process, not a fixed time event
- Consumers need to be confident their input will be valued
- Consumers usually need background information
- Different approaches offer different opportunities for policy development



# Many forms of engagement...

- Active consultation and advice
- Consultation and comment
- Collecting and receiving information
- Collaborative planning structures

# Innovative examples

- Biobanking in Western Australia
  - Giving communities the opportunity to make their opinions heard about biobanks
  - Support from WA Health, Genetic Support Groups
  - First forum was held August 2008

<http://www.health.wa.gov.au/biobanks/home/>



# Innovative examples

- Department of Planning and Infrastructure (WA)

*Community engagement is critical in the successful development of acceptable policies and decisions in government, the private sector and the community...*

This saw the use of innovative techniques such as deliberative forums, citizens juries, consensus forums etc.



# International examples – UK

- In the UK, consumer engagement has been formalised into the policy making process through the *Modernising Government White Paper*. Policy makers are expected to consider how the policy will involve consumers at all stages of policy making.
- Extensive research is ongoing by the Cochrane Collaboration and the National Institute of Clinical Excellence (NICE)



# International examples – Canada

- Consumer engagement is a recognised element of the health system
- In 1994, through the National Forum on Health the Canadian government committed to examining the health system, with a mandate to involve citizens in the process.



# Is it a new era in Australia?

- A new-ish government... new action, new thinking
- Formation of the NHHRC
- Formation of the National Preventive Health Taskforce
- Announcement of the National Preventive Health Strategy
- Announcement of the Primary Healthcare Strategy

**Will anything really change?**

# What is missing?

- There is great interest in citizen engagement in health – but the approach is ad hoc and little agreement about what constitutes “true” engagement
- The successes and failures in engagement are generally not reported on – so there is little evaluation or comparison
- Most interest lies at the service and organisational level – what is missing is a focus on how citizens contribute to health policy and decision making

# Ways forward...

- Build a culture of commitment to engagement within organisations
- Demonstrate the success of engagement and the valuable return on investment that it offers
- Build engagement into all aspects of planning and policy work, rather than leaving it until the end
- Develop the skills needed to make decisions about the best engagement approach for each issue and to implement new approaches



- We have some comparative case examples of techniques used in other sectors from Australia and overseas
- We need to move past the traditional tokenistic approaches and use the voice of citizens in other ways – where it is a joint and informed learning experience
- We need to move towards a whole-of-health emphasis rather than just a focus on health services

# Informing the future... AIHPS

- Listening to citizens' views about chronic disease prevention and health promotion (2009)
- Citizen engagement: Listening to citizens' views about Australia's health system and prevention (2009-2011)
- Active and informed citizen engagement in health – how can this be achieved? (2009)

[www.aihps.org](http://www.aihps.org)