

**Effective consumer voice
and participation for
New Zealand:
a systematic review
of the evidence**

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GIN Conference
1 November 2004**

Purpose

- Strengthen the consumer sector in New Zealand
- Improve consumer participation in decision-making

Method

- Literature review of NZ & international participation
- Scoping report of current consumer participation in NZ
- International models of consumer participation activities and consumer networks

Results

- Huge diverse literature, no agreed methodology
- Mostly case studies
- 2 systematic reviews
- Australian Consumer & Provider Partnerships in Health (CAPPS) trials
- UK Commission for Health Improvement

Limitations

- Few studies of high-level involvement
- Few reports of independent advocacy
- Mostly of involvement in health sector
- Social science agendas
- Lack of consumer involvement in research
- Lack of study of private sector/NGO

Genesis

- Social movements
- Community development approach
- Social inequalities
- Inquiries into medical failures
- Reaction to market approach
- New frameworks for participation
- Rationing
- Evidence-based health care and quality movement

Types of participation

- Independent consumer advocacy
- Participation within the health sector

Rationale for participation

- Redistribution of power & intrinsic benefit
- Legitimation and compliance
- Better decisions and service/policy improvements

Consumer rationale

- Consumer motivations (voluntary groups)
 - Help others
 - Social activism
 - Support collective action
 - Change attitudes
- Non-aligned consumers
 - Lack motivation
 - Prefer passive methods
 - Support consumer groups

Outcomes of participation

- Focus on process
- Change timeframe can be long
- Contested settings, powerful opposition
- Australian CAPPs projects
 - ✓ Positive long-lasting impact
 - ✓ Joint agenda setting, willingness to change direction
 - ✓ Partnership approach
 - ✓ Additional unexpected benefits

Systematic reviews

- Few studies have shown participation improves
 - ✓ Quality of care
 - ✓ Acceptability & accessibility of services
 - ✓ Improvements in health or quality of life
- Most common benefits
 - ✓ New services established
 - ✓ New consumer information, minor changes
 - ✓ Abandonment of proposals, eg close hospital
- Improved organisational attitudes, further initiatives

CHI inspections

- Patient & public involvement lowest priority
- Few brought about change
 - ✓ Few examples where PPI entered the 'corporate bloodstream'
 - ✓ A 'brick wall' between activities and changes on the ground

Limitations of participation

- Limited to marginal and 'safe' issues
- Insider control
- Unequal interests
- Few examples of redistribution of power
- Decrease in focus on organised collective consumer action

Enablers and barriers

Key enablers:

- Government support, policy and funding
- 'Champions' to act as catalysts for change
- Strengthen consumer sector
- Power-sharing from the beginning
- Commitment to act on results
- Organisational culture that values participation

Enablers and barriers

- Key barriers:
- Lack of government support
- Consumers' previous tokenistic experiences
- Attitudes of health professionals and managers

Representativeness

- Consumer representatives challenged by those in the system
- Advantages are:
 - ✓ Accountability
 - ✓ Expertise & access range of consumers
 - ✓ Provided with support
 - ✓ Greater effectiveness
 - ✓ 'work things out'

New Zealand situation

- Long tradition of community action on health
- Elected health boards
- Concept of consumer network explored in 1980s
- Striking differences between health, mental health & disability

Health

- Weak strategic framework
- Little government support/funding
- Based on devolution
- Consumer sector fragmented and uncoordinated
- Consumer participation haphazard and varying practices

Mental health

- Support from Mental Health Commission
- Pattern of paid mental health advisors
- Weak consumer sector

Disability

- Support from Office for Disability Issues
- National disability consumer organisations &
- Large NGO service providers
- Moves towards a national disability body.

Overseas

- Different experiences in different countries
- UK highly proscriptive top-down programme
Citizenship framework
- USA more organic, driven from consumer organisations
- Canada - govt support for major consumer health networks
- Australia - only country with a 'peak' consumer body

Consumers' Health Forum

- Formed 1986 after lobbying by consumer, community and medical groups
- Supported by Minister of Health
- Govt support for community-based model of health
- Govt wanted ally for reform of health care
- Also Consumer Focus Collaboration 1997-2001
- National Resource Centre for Consumer Participation in Health

Consumers' Health Forum

- Initially funding for research/development
- Major activity now representation programme
- Quality Use of Medicines Program
- Organisation imbalanced by representation programme
- Loss of organised collective action to influence whole health system

Benefits of a national network

- Bridge between govt and health consumers
- Regular communication keeps consumer issues on agenda
- Clear route for consumers to participate in decision-making
- Govt can simply communicate to a wide constituency
- Built capacity of consumer movement

Where to next?

- Report to NZGG Board
- Summary discussion document to consumer groups
- National hui to discuss options, seek support
- ? funding

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