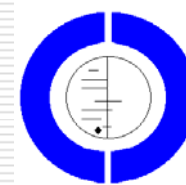


The evidence for consumer participation

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Outline

1. What is consumer participation?
 2. Questions we need to answer
 3. Why are we not asking these questions?
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1. What is consumer and carer participation?

- ... encourages consideration and debate through processes that allow people to be involved in decision making about their health care and that of the community.

 - Within a health care system different types of participation can occur across service delivery, planning and policy making.
 - DHS Consultation Paper. Participation in your health service system, 2005
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Subtle shift

- From researching issues and processes
 - To also researching effects
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Consumers and Communication

- Effective interactions with people are as important as effective clinical care.
 - We summarise the evidence on the effects of interventions to communicate with and involve consumers.
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C&C working definition of 'consumer participation' 1/2

- Interventions directed to the consumer**, eg patient education
 - Interventions from the consumer**, eg consumer participation in policy
 - Interventions for communication exchange between providers and consumer**, eg goal setting
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C&C working definition of 'consumer participation' 2/2

- ❑ **Interventions for communication between consumers**, eg self-help groups
 - ❑ **Interventions for communication to the health care provider from another source**, eg skills training of doctors
 - ❑ **Service delivery interventions**, eg appointment choices.
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Review of the effects of interventions

- 5000+ trials in our register
 - 1000+ trials of patient education
 - To manage one's health condition
 - To be prepared for surgery
 - To learn a specific health-related skill
 - To help others cope with their health issue
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Not all the evidence is positive!

- Basis of evidence-based health care
 - Examine conflicting evidence
 - Unbiased summary of sound studies
 - One input to good decision making

 - Do we apply this thinking to evidence-informed consumer participation?
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Evidence-informed decision making for consumer participation

- ❑ Definition and clear conceptual thinking
 - ❑ Greater focus on interventions in specific contexts
 - ❑ Build evidence base
 - ❑ Recognise that not everything we do works or is worth the cost.
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2. Questions we need answers to ...

□ If we are researching effects, what kinds of questions can we ask?

- Light & Pillemer: *Summing Up*, 1984

■ Illustrate questions with Cochrane reviews and protocols

www.thecochranelibrary.com

- Search by author
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Develop a sense of building

□ What have others done?

■ Nilsen and colleagues: Cochrane protocol

Investing resources: making choices

- What things work across the board, in most situations? What interventions work on average?
 - O'Connor and colleagues: Cochrane review
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Building detailed knowledge

- Do certain versions of an intervention work better or best?
 - Edwards and colleagues: Cochrane review
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Equity and diversity

- Who does it work for? Are there particular people for whom the intervention works better or best?
 - Doull and colleagues: Cochrane protocol
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It's not only about benefits: it's also about harms

- Some interventions benefit some people but may harm others
 - Capblanch & Garner: Cochrane protocol
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Effects

- What have others done?
 - What interventions work on average?
 - Who does it work for?
 - Do certain versions of an intervention work better or best?
 - What are the possible harms?
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3. Why are we not asking these questions?

- Structural reasons
 - Too much attention to consultation and representation
 - Too much research that does not build
 - Lack of infrastructural capacity building
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Why are policy makers not asking these questions?

- Acknowledge government support to evidence-informed consumer participation (eg DHS Vic, and DHA)
 - Do you see consumer participation as only consultation and representation?
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Challenges for a consumer-oriented health system 1/2

1. Evidence base of consumer participation
 2. Knowledge-building and iterative research
 3. Knowledge translation processes for consumers and policy makers
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Challenges for a consumer-oriented health system 2/2

4. Policy making on national standards around information provision and communication
 5. Structures and processes that make links across policy and service areas, and across jurisdictional policy responsibilities
 6. Debate on consumer participation issues that crosses the public/private split
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Improve the evidence base of consumer participation - to:

- Understand our world
 - Describe it to others
 - Strengthen our arguments
 - Build our knowledge and skills
 - Invest in effective methods and approaches
 - Set priorities
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Why is evidence-informed consumer participation important?

- Develop standards
 - Improve health outcomes
 - Ensure that community is involved in distributive questions
 - Improve accountability
 - Improve health policies
 - Leave a legacy
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