



# Involving Consumers in Guideline Development – How and Why?

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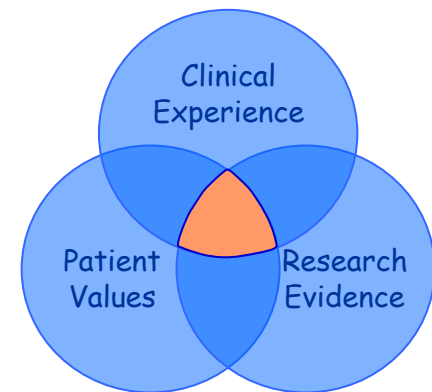
HEALTH for KIDS  
in the South East

# Health for Kids in the South East

- Victorian Government funded 'Hospital Admission Risk Program' project at Southern Health
- Aims to improve health for children in S-E Melbourne
  - evidence-based best practice
  - partnerships between acute and community providers
- Consumer involvement in decision-making
- Evidence-based guidelines
  - asthma, bronchiolitis, croup and gastroenteritis

# Involving Consumers – Why?

- Evidence-based process
  - best available research evidence
  - clinical expertise
  - **consumer preferences and values**
- Theory
  - Guidelines should be developed by a multidisciplinary group that includes at least 2 consumers
- But little explanation of why to include consumers
- And even less explanation of how to actually do it



# Involving Consumers – Our Process

- Recruit
  - Advertise, inform, interview, select
- Educate
  - Explain role, train, manage expectations
- Support
  - Champion role to others, meet practical needs
- Involve
  - Ask for input on everything, in many different ways
- Value
  - Consumer perspective overtly valued as equal to others
- Review
  - Ask for feedback on the process, and the role

# Involving Consumers - How

- “Patient tour”
- Surveys
- Focus groups
- Feedback on patient information material
- Representation on guideline development group
- Feedback on guideline and clinical path drafts

# Involving Consumers - Experience

## *'The hard bits'*

- Time
  - identifying consumers, communicating, finding meeting times, avoiding school holidays
- Practicalities
  - parking, reimbursing expenses
- Sustainability
  - ensuring consumer participation plan becomes part of 'the system'

# Involving Consumers - Experience

## *'The good bits'*

- Enthusiasm
  - we worried about burdening them
  - they wanted more
- Variety of opportunities
  - increased their ability to be involved
  - enriched our process
- Belonging
  - being part of a group was important

# Involving Consumers - Learnings

- Consumer input is hugely valuable, but also hugely challenging to organise
- Don't underestimate the amount of information about or involvement in the process consumers will want to have
- Spending time with consumers preparing and supporting them individually and as a group is time well spent