Involving Consumers in Guideline Development – How and Why?

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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.