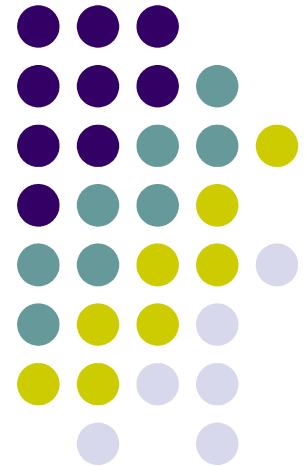


Consumers & systematic reviews

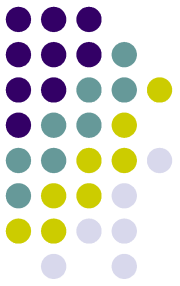
The Experience of the Cochrane Pregnancy and Childbirth Group

Dell Horey, Gill Gyte, and Carol Sakala

XIII Cochrane Colloquium Melbourne, October 2005



Why consumer participation in the Collaboration?

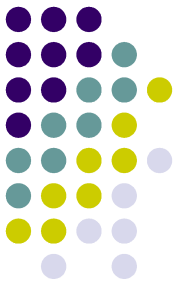


Essential to Cochrane reviews so that they :

- **target problems important to people**
- **take account of outcomes important to people**
- **are accessible to people making decisions**
- **reflect different values, conditions and healthcare across countries**

Cochrane Reviewers' Handbook

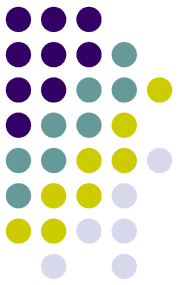
Why consumer input?



- A lack of research about what women want to know in pregnancy and childbirth

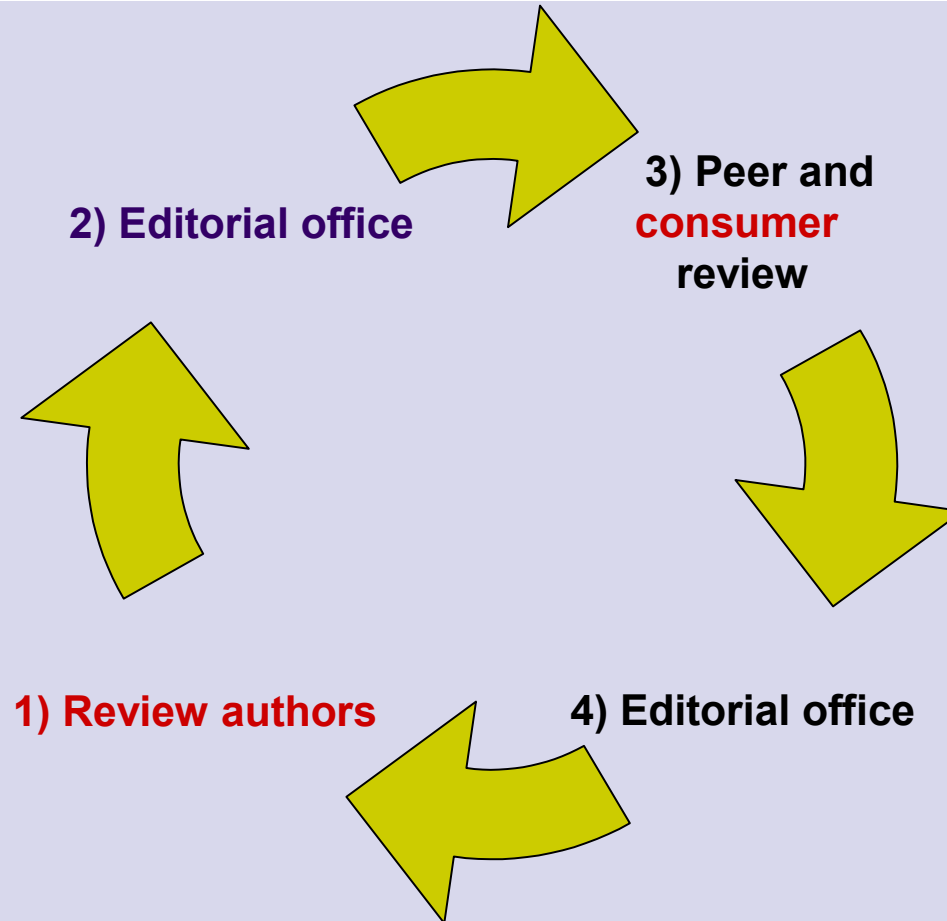
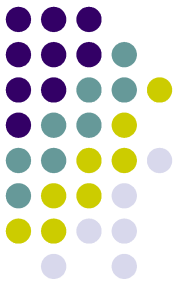


Pregnancy and Childbirth Cochrane Review Group (PCG)

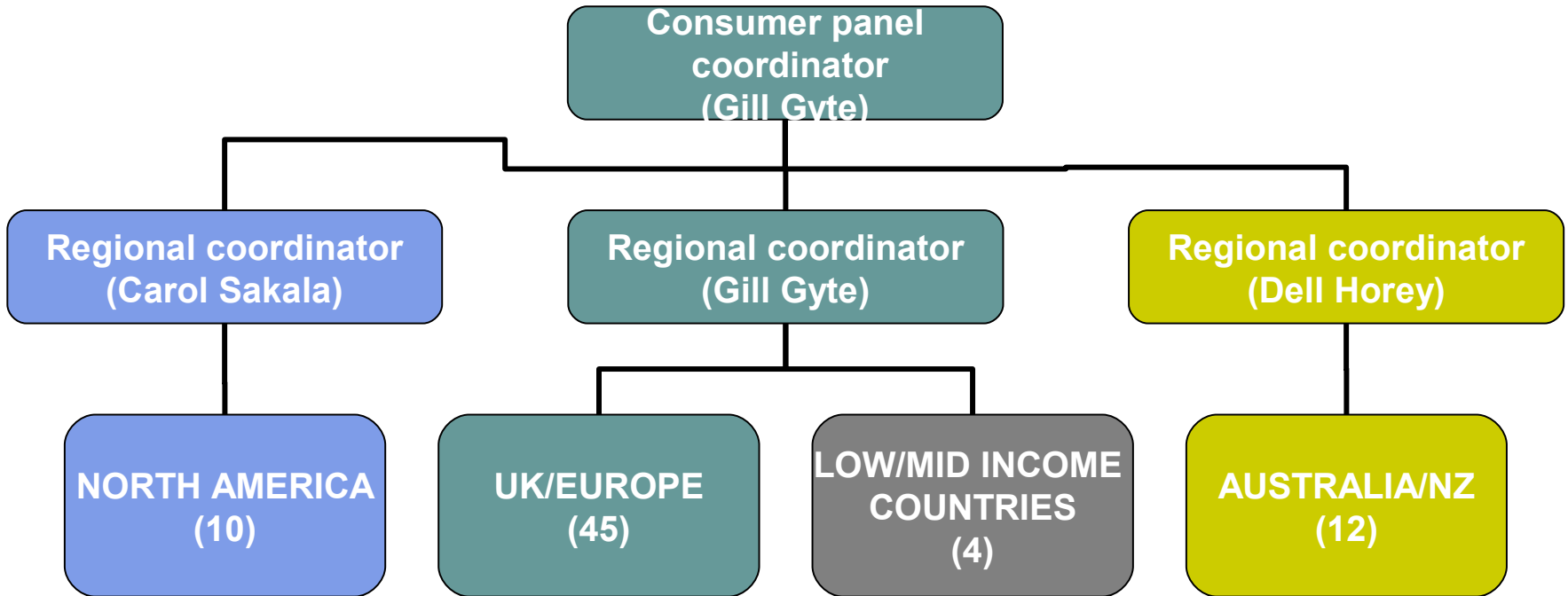
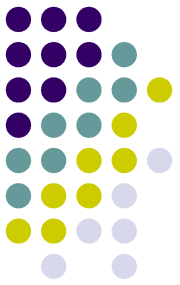


- **1992** – first review group registered
- **1998** – first consumer comments on protocols and reviews
- **1999** – Consumer Panel began (UK, Europe, Nth America, Australasia) **Consumer input on 28 protocols**
- **2001** – extended (Brazil, China, Mexico and South Africa)
- **2004** → 70 consumers in >10 countries
Consumer input on over 300 protocols, reviews and updates

PCG Editorial process

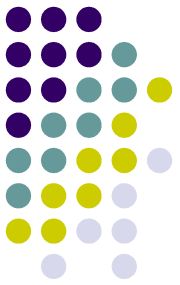


PCG Consumer Panel

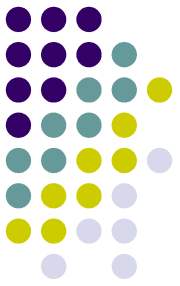


In practice there is:

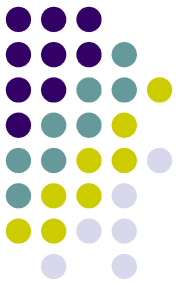
- A large workload
- Significant investment of time and effort by consumer panel members
- Uncertainty about the best way to use consumer input to improve reviews
- Uncertainty about how best to support consumers



Phase 1 evaluation: interviews

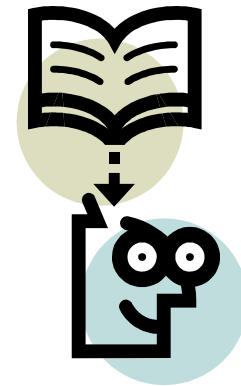


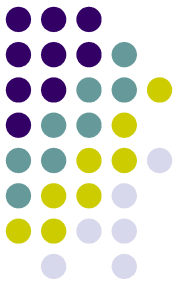
4 Editors 1 Review Group Coordinator	3 Consumer Coordinators
5 Review Authors	5 Consumers



Phase 1 interviews

- Does consumer input improve the quality of PCG reviews?
- What could be done better?





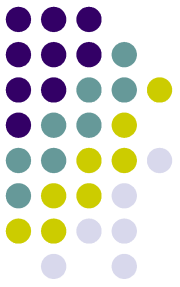
Editors and authors said:

Editor: *“The input in general is fantastic. It’s the highest quality we get”*

Editor: *“As an editor, well there’s no doubt some of the best, most constructive comments about the review come from the Consumer Panel”*

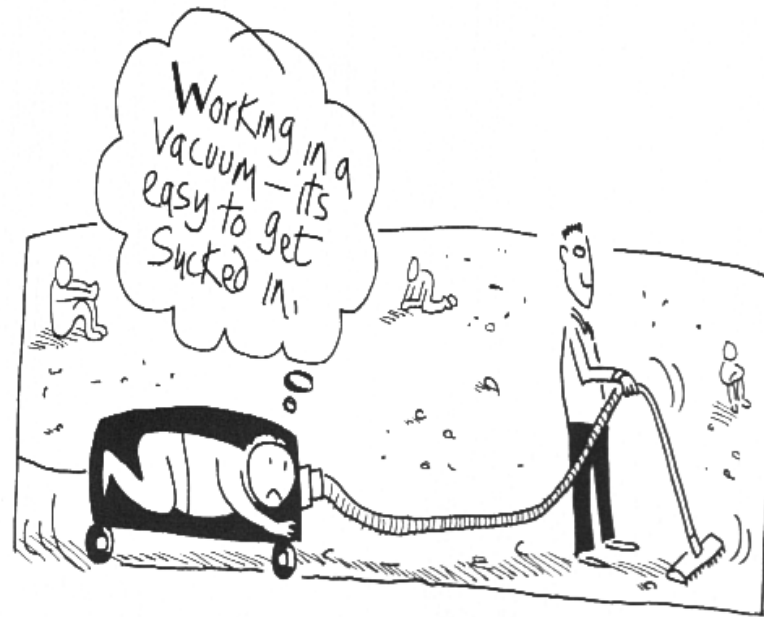
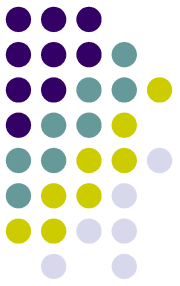
Author: *“I think we get excellent constructive feedback on the reviews”*

Summary of editors' and authors' views

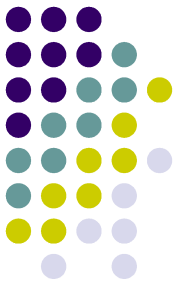


- Consumer input makes positive contribution
- Consumer coordinator skills important to success. Provide useful summaries of consumer feedback and work well with variety of people
- Large volume of feedback both helpful and a challenge to editors and authors
- Need to broaden input from low- and middle-income countries

So what did the consumers say?

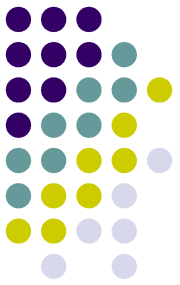


Consumer reviewers



- Are highly motivated
- Grow in confidence with experience
- Opt to comment on reviews of interest to them or *“if there wasn’t anyone else to do it”*
- Find two weeks sufficient time to comment
- Feel comfortable saying no if they have other commitments

Consumer reviewers



- Not always sure that their comments incorporated by review authors
- Want to know if they make a difference
- Want opportunities for training and to meet others doing the same work
- Want simple language especially those whose first language is not English

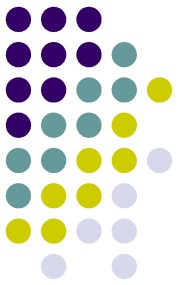
Consumer coordinators said:



Consumers

- look carefully at the reviews *“picking up a lot of issues the reviewers haven’t thought about”*
- ask questions and challenge assumptions
- offer perspectives from different countries and different health care systems





Consumer coordinators:

Differentiated between

“grassroots” consumers

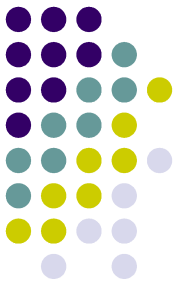
- bring personal experiences

“consumer reps”

- have broader perspective of maternity issues and research

Both make useful contribution.

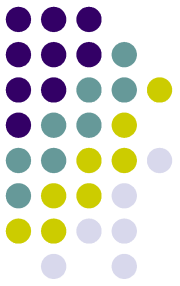
Lack of feedback



Led to:

- feelings of inadequacy
- cynicism about “window dressing”

Lack of feedback

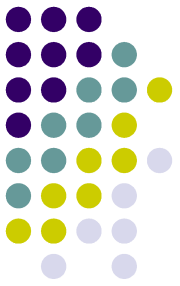


“I don’t know whether the ones that I did do, I did really, really badly and nobody’s telling me, and that’s why I’m not getting any to do”

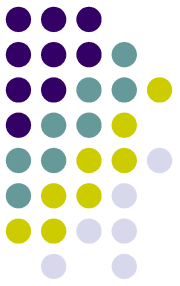
“just trying to make Cochrane look good”

Challenges

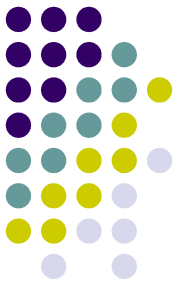
- Lack of resources
- Coordinators can feel “stressed” and “overloaded”
- Reliance on volunteers
- Uncertainty about future



Challenges

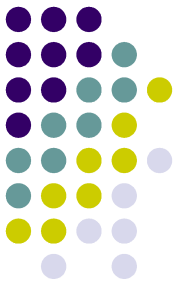


“I think that there are too many demands on a small group of people, so that we’re too dependent on them, and at some point they’re just going to move on, or find it too overwhelming, or whatever. I think there are possibilities for burnout”



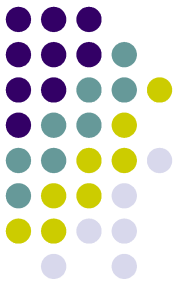
Possible solutions

- Involve more consumers
- Remuneration for tasks
- Training
 - include explanation of role and development of critical appraisal
- Improve communication
 - eg newsletters, copies of relevant protocols and reviews
- Targeted support
 - possible access to mentors



Phase 1 evaluation

- identified key issues related to consumer involvement in Cochrane reviews.
- contributed to the development of guidelines for consumer involvement in the Cochrane systematic review process.



- **Thanks to Carol Grant-Pearce, Cathy Neale, Sandy Oliver, and Jane Taylor for their help with the evaluation and the Cochrane Collaboration Steering Group Discretionary Fund for financial support.**