Consumers & systematic reviews
The Experience of the Cochrane Pregnancy and Childbirth Group

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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

1) Review authors
2) Editorial office
3) Peer and consumer review
4) Editorial office
PCG Consumer Panel

- Consumer panel coordinator (Gill Gyte)
  - Regional coordinator (Carol Sakala)
    - NORTH AMERICA (10)
  - Regional coordinator (Gill Gyte)
  - Regional coordinator (Dell Horey)
    - UK/EUROPE (45)
    - LOW/MID INCOME COUNTRIES (4)
    - AUSTRALIA/NZ (12)
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

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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 “over-loaded”
- 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.
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