



Engaging consumers and other stakeholders in a Cochrane Review: a mixed-methods evaluation

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- I have no actual or potential conflict of interest in relation to this presentation
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Background and context

Stakeholder engagement in SRs

- Stakeholders =
 - patients, the public, consumers, clinicians, policymakers etc
- It's happening....
 - 291 examples (Pollock, under review)
- But rarely evaluated
 - No formal evaluations of approaches and outcomes identified (Tricco 2018)

Pollock, under review, *Sys Rev*
Tricco 2018 *Impl Sci* 13:31

Priority Cochrane Review: Consumer engagement in healthcare



- Aim of stakeholder engagement in this review
 - To optimise SR currency and relevance
- Aim of concurrent evaluation
 - To document how stakeholders were involved in the SR, and explore how their engagement influenced the SR and the stakeholders and authors.

EVALUATION: Approach and progress



OBSERVATION
All 15 author-stakeholder engagement activities



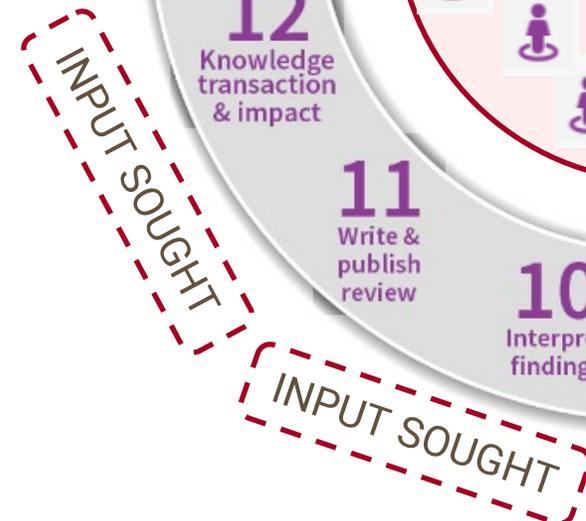
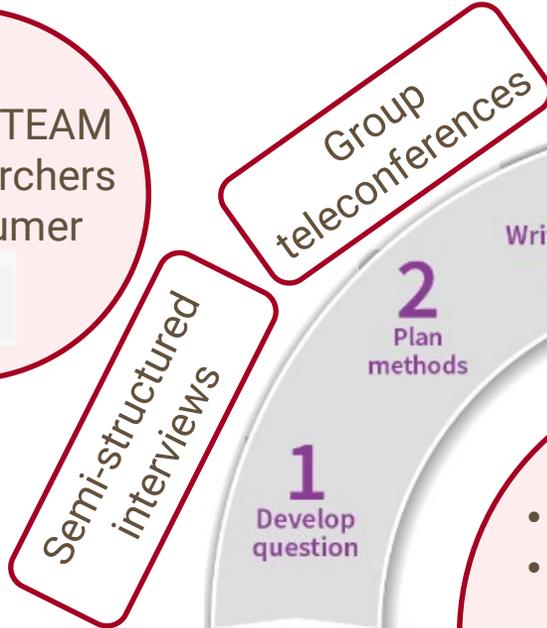
INTERVIEWS (2 rounds)
18 interviews with stakeholders;
8 interviews with authors



OTHER DATA
Project documents;
author team emails;
Research journal

STAKEHOLDER ENGAGEMENT: Approach and progress

AUTHOR TEAM
• 5 researchers
• 1 consumer



Consumer engagement in health care policy, research and services: methods and effects

Louise Wiles, Debra Kay, Anneliese Synnot, Julie Luker, Susan Hillier

Citation

Louise Wiles, Debra Kay, Anneliese Synnot, Julie Luker, Susan Hillier. Consumer engagement in health care policy, research and services: methods and effects. PROSPERO 2018 CRD42018102595 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018102595

How stakeholder engagement is affecting the research

- The research process
 - Review timeline extended
 - Authors have found creative solutions to be able to address feedback
- The Cochrane Review
 - Altered SR rationale, scope, terminology, search terms/sources, data extraction items, and planned dissemination
 - Extended/pushed the 'usual' Cochrane approach (i.e. authors planning for entire review to be in plain language)

Review section

Risk of bias

Stakeholder feedback

Other dimensions of quality are important, i.e. some studies seem 'tokenistic', perhaps should not be included?
Was consumer engagement the primary purpose of the study?

Author team solution

Assess 'quality of engagement' for each study, in addition to risk of bias.

How stakeholder engagement is affecting those involved

Stakeholders

Experience - Finding the process genuine and respectful

Benefits

- Learning about the latest research
- Shaping the research
- Seeing 'inside' a Cochrane Review

“Stakeholders are being given every opportunity to influence the review, and [while] that table was heavy going, [it shows] the reviewers are taking stakeholder feedback seriously, considering it and giving an appropriate response.”

Challenges

- Finding the time/keeping up is difficult for both stakeholders and researchers
- Cochrane 'constraints' (e.g. restriction to RCTs; limited flexibility with publication format) has been frustrating at times

“The trickiness of it all is just joining the dots (...) and keeping it front of mind because it's not everyone's real job, and it's a woolly project, it's like it's a review of a review of a review of a review sort of stuff which is challenging.”

Authors

- Enjoying sense of partnership and collaboration

- Confidence that review will be meaningful to users
- Applying consumer engagement learnings to other work

“Tailoring the review to the needs of our users – which feels really great! I feel like we are doing as much as possible to ensure this review is meaningful and relevant.”