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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  - Louise Wiles, Susan Hillier and Julie Luker, University of South Australia
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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)

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
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)

<table>
<thead>
<tr>
<th>Review section</th>
<th>Stakeholder feedback</th>
<th>Author team solution</th>
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<tbody>
<tr>
<td>Risk of bias</td>
<td>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?</td>
<td>Assess ‘quality of engagement’ for each study, in addition to risk of bias.</td>
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# How stakeholder engagement is affecting those involved

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Authors</th>
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<tbody>
<tr>
<td><strong>Experience</strong></td>
<td>- Enjoying sense of partnership and collaboration</td>
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<td>- Finding the process genuine and respectful</td>
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<td><strong>Benefits</strong></td>
<td>- Confidence that review will be meaningful to users</td>
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<tr>
<td>- Learning about the latest research</td>
<td>- Applying consumer engagement learnings to other work</td>
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<tr>
<td>- Shaping the research</td>
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<tr>
<td>- Seeing ‘inside’ a Cochrane Review</td>
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“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.”

“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.”

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<th>Challenges</th>
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<td>- Finding the time/keeping up is difficult for both stakeholders and researchers</td>
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<td>- Cochrane ‘constraints’ (e.g. restriction to RCTs; limited flexibility with publication format) has been frustrating at times</td>
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“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 sort of stuff which is challenging.”