The ACTIVE Project: key findings

Pauline Campbell on behalf of the ACTIVE team

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ACTIVE project

CONTINUOUS INVOLVEMENT OF STAKEHOLDERS

- Protocol
- Complete Review
- Develop Framework
- Consumer Testing
- Interview key stakeholders about their experiences
- Bring helpful examples together
- Create online learning

Find what was out there
Background – why this review?

• Good practice to involve stakeholders in systematic reviews

• Limited practical evidence about how to do this

• Definition of stakeholder
  – “any person involved in research who would be a knowledge user of research but whose primary role is not directly in research”
Getting the right team

The ACTIVE TEAM:
Dr Alex Pollock, Dr Pauline Campbell, Dr Jacqui Morris – NMAHP RU, Glasgow Caledonian University

Caroline Struthers, EQUATOR Network, University of Oxford, UK
Heather Goodare, Edinburgh, UK

Anneliese Synnot, Cochrane Consumers and Communication, La Trobe University, AND Cochrane Australia, Monash University, Australia
Sophie Hill, Cochrane Consumers and Communication, La Trobe University, Australia
Jack Nunn, Centre for Health Communication and Participation, La Trobe University, Australia

Chris Watts, Cochrane Learning and Support Department, Cochrane Central Executive, London
Richard Morley, Cochrane Consumer Network, London
Finding out what is out there

Aim: to synthesise evidence relating to stakeholder involvement in systematic reviews and use this evidence to describe methods and approaches to involvement used within systematic reviews.
Find everything (methods)

- Find everything
  - Comprehensive database searching (from 2010)
  - Pre-defined hand searching
  - Contacted experts
  - Citation searching

- 2 reviewers applied inclusion criteria
Find everything

• What were we looking for?
  – any paper, published or unpublished, regardless of study design, including commentaries, letters and expert opinion, which investigated, reported or discussed any aspect of involvement in a systematic review.
  – Excluded:
    • Research prioritisation
    • Guidelines development
    • Involvement in primary research
    • Reviews only stating “contacts with experts” at search stage
    • Protocols
    • Titles with no abstracts
Bringing helpful examples together
Finding helpful examples

- In order to determine which study we would look at in more detail, we employed a traffic light system:

- GREEN = comprehensive description of one or more specific method or approach to the involvement in systematic reviews. Description sufficient to enable replication of methods.
- AMBER = brief or partial description of one (or more) specific methods or approach to the involvement in SRs. Description sufficient to enable partial replication of methods.
- RED = few details provided and/or inadequate description of the method or approach of involvement. Description insufficient to enable replication of methods.
- Data extracted by one reviewer and a sample randomly compared by an independent consumer reviewer.
When and how to involve people:
Learning from examples

As we have seen, people can be involved at any stage of a systematic review. Sometimes people are just involved at one stage, sometimes they are involved at two or more stages, and sometimes they are involved throughout the whole review.

This section brings together when and how people are involved in systematic reviews into an interactive map. The map is based on detailed descriptions from the ACTIVE project, which examined detailed descriptions 32 examples of systematic reviews that involved people in their development.

Click on the Stage numbers to explore the detailed findings of the ACTIVE project at each stage of the review process. You can use this to see examples of different roles, approaches and levels of involvement against each of the 12 review stages.
What did we find?

91 papers identified from other sources

12908 titles/abstracts from electronic searching

12327 excluded based on title/abstract screening

581 potentially eligible papers

369 not relevant:
- 118/369 abstract only
- 18/369 protocol only
- 16/369 duplicates
- 217/369 with reasons listed in table of excluded studies

6 awaiting assessment

6 multiple publication relating to same (included) study

672 full papers considered

291 papers included
Find the best examples
<table>
<thead>
<tr>
<th>Stage of involvement</th>
<th>GREEN</th>
<th>AMBER</th>
<th>RED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope / review question</td>
<td>4</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Interpreting results after review completed</td>
<td>7</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>Both (scope + interpretation)</td>
<td>3</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Throughout/within review process</td>
<td>15</td>
<td>29</td>
<td>21</td>
</tr>
<tr>
<td>Unclear</td>
<td>1</td>
<td>18</td>
<td>120</td>
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</table>

<table>
<thead>
<tr>
<th>Were patients/consumers involved?</th>
<th>GREEN</th>
<th>AMBER</th>
<th>RED</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>24</td>
<td>37</td>
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<td>No</td>
<td>5</td>
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<td>76</td>
</tr>
<tr>
<td>Unclear</td>
<td>1</td>
<td>13</td>
<td>70</td>
</tr>
</tbody>
</table>
LEADING:
Initiating the review; lead responsibility for carrying out and completion of review.

CONTROLLING:
Working in partnership with researchers, with varying degrees of control or influence over the review process. Make decisions and/or controlling one or more aspects of the review process, in collaboration with or under the guidance of the review authors.

INFLUENCING
Stating, commenting, advising, ranking, voting, prioritising, reaching consensus. Providing data or information which may influence the review process, but without direct control over decisions or aspects of the review process.

CONTRIBUTING
Providing views, thoughts, feedback, opinions on a review. Providing data or information which may indirectly influence the review process. People may be participants in a research study (e.g. focus groups or interviews).

RECEIVING
Receiving information about the systematic review, or results of the review.

Tasks will include authorship of a review, and may include activities associated with review completion, making key decisions relating to the methods and execution of the review.

Tasks may include defining outcomes of interest, inclusion criteria, key messages arising from review findings and writing a plain language summary. In completing tasks may have control over final decisions, such as application of inclusion criteria, categorisation of interventions, or recommendations for clinical practice.

Tasks may include assisting with review tasks, such as title and abstract screening, data extraction and assessment of risk of bias, possibly in a co-reviewer role. Tasks may include peer review, such as commenting on a protocol, systematic review or plain language summary.

Tasks may involve sharing views or opinions, for example this may be a group of interview. May include ranking, voting or prioritising as participants in a research study (e.g. Delphi study).

Tasks may include attending events, or reading or listening to information about the review. While the results of a review may be discussed, these discussions do not influence the review process in any way.
WHEN does involvement occur?
Approach

Continuous involvement

One-time involvement

Combined involvement

“Top and tail” approach
Conclusion

• Wide body of evidence about how people have been involved in systematic reviews

• One size does not fit all – no evidence that one approach was better than another

• Planning is critical - consider resources (time, money and expertise)

• High quality training materials will be a useful resource for reviewers planning stakeholder involvement in reviews
IN Volving People Resource

- Cochrane Training website: https://training.cochrane.org/involving-people.
- Directly to the resource: https://cochraneltraining.gomocentral.com/content/883f3b44-f1df-400f-8ea3-5d1e11f59b8e/web
Reference