

The ACTIVE Project: key findings

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Improving health through research



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UNIVERSITY



Cochrane
Consumers and
Communication



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network



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Consumer Network



ACTIVE project

CONTINUOUS INVOLVEMENT OF STAKEHOLDERS

PROTOCOL

COMPLETE
REVIEW

DEVELOP
FRAMEWORK

CONSUMER
TESTING

FIND WHAT WAS
OUT THERE

BRING
HELPFUL
EXAMPLES
TOGETHER

CREATE
ONLINE
LEARNING

INTERVIEW KEY STAKEHOLDERS
ABOUT THEIR EXPERIENCES

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

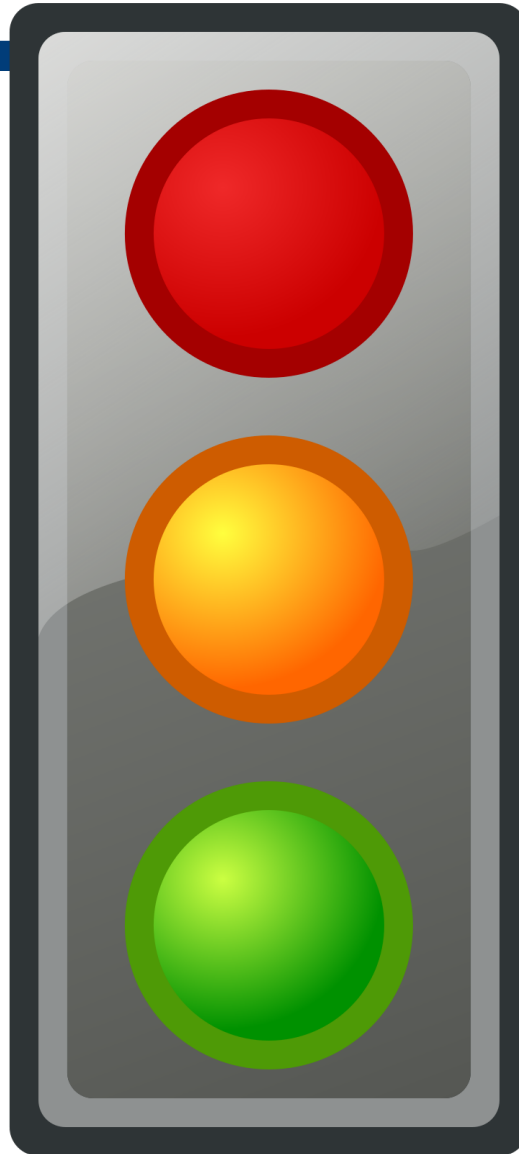
Find everything

- 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 - any paper, published or unpublished, regardless of study design, including commentaries, letters and expert opinion, which investigated, reported or discussed any aspect of involvement in a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

S
S
G

T
L



P
W

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*

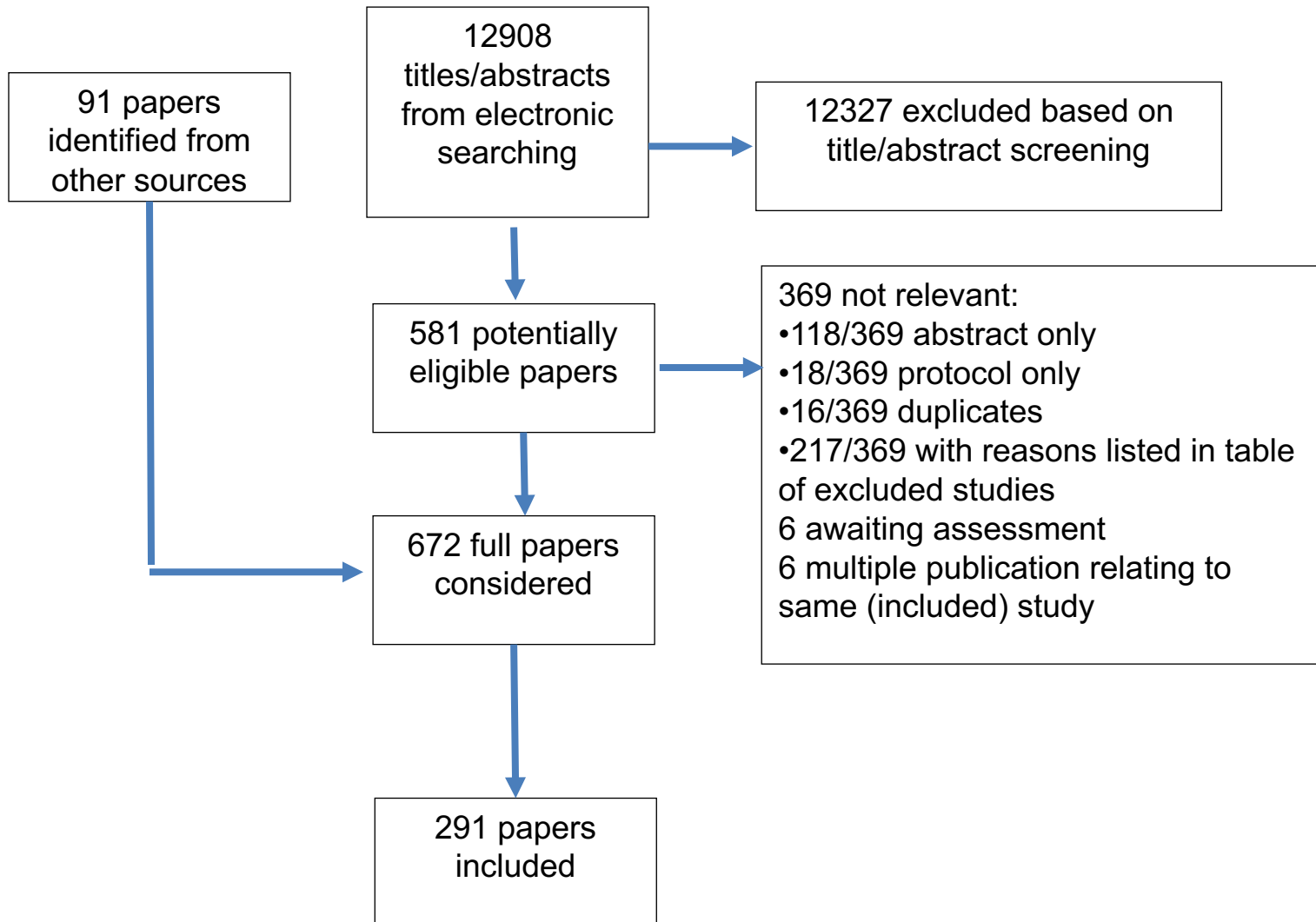
As we have seen, people can be involved at any stage of a systematic review. Sometimes people are just involved at one stage, sometimes they are involved at two or more stages, and sometimes they are involved throughout the whole review.

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.

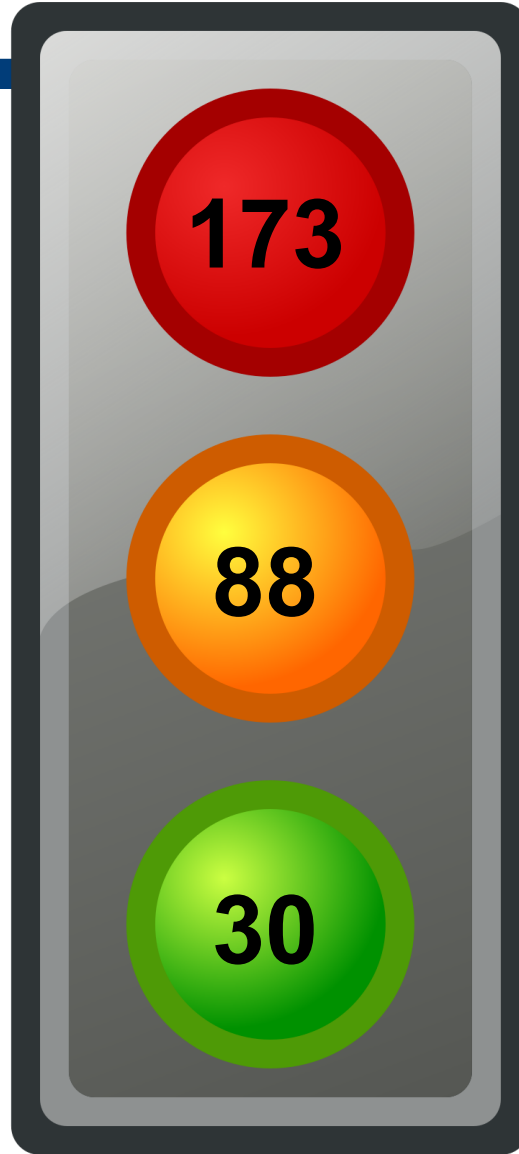


What did we find?



Find the best examples

SST
SL
G



P
W

| | | GREEN | AMBER | RED |
|------------------------------------|---|--------------|--------------|------------|
| Stage of involvement | Scope / review question | 4 | 0 | 3 |
| | Interpreting results after review completed | 7 | 30 | 25 |
| | Both (scope + interpretation) | 3 | 11 | 4 |
| | Throughout/within review process | 15 | 29 | 21 |
| | Unclear | 1 | 18 | 120 |
| Were patients/ consumers involved? | Yes | 24 | 37 | 27 |
| | No | 5 | 38 | 76 |
| | Unclear | 1 | 13 | 70 |

LEADING:

Initiating the review; lead responsibility for carrying out and completion of review.

NONE

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

CONTROLLING:

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

3 STUDIES

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

INFLUENCING

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

11 STUDIES

Tasks may include assisting with review tasks, such as screening, data extraction and analysis. May include 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.

CONTRIBUTING

Providing views, thoughts, feedback, opinions or data. 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).

19 STUDIES

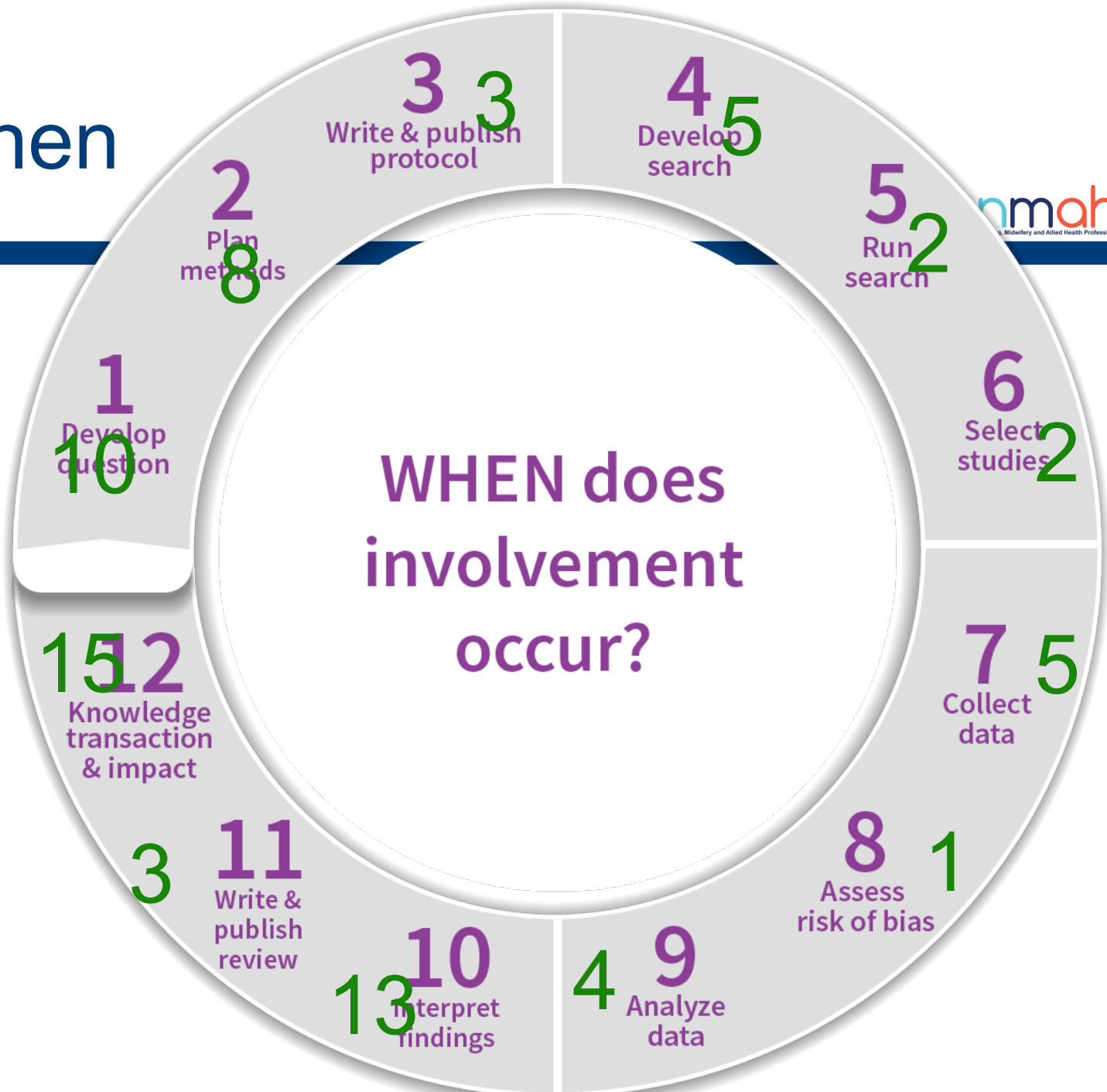
Tasks may include sharing views or opinions, for example through a focus group or interview. May include ranking, voting or prioritising as participants in a research study (e.g. Delphi study).

RECEIVING

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

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



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

INVOLVING PEOPLE RESOURCE

- Cochrane Training website:
[https://training.cochrane.org/involving-people.](https://training.cochrane.org/involving-people)
- Directly to the resource:
<https://cochranetraining.gomocentral.com/content/883f3b44-f1df-400f-8ea3-5d1e11f59b8e/web>
- Short cut: <http://bit.ly/2wglIEh>

Reference

- Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, Goodare H, Watts C, Morley R (2017) Stakeholder involvement in systematic reviews: a protocol for a systematic review of methods, outcomes and effects. Research Involvement and Engagement. 3, 9. <http://rdcu.be/rv9L>