

## Involving consumers (patients and public) in your Cochrane review - a brief guide for authors.

### What is patient and public involvement?

Patient and public involvement is the meaningful involvement of people affected by a healthcare condition in research. These people can be patients, carers or family members. Cochrane uses the term “consumer” to describe these people. Health professionals or people using systematic reviews to inform health policy or practice may also be involved.

### Why is this important?

Patient and public involvement in systematic reviews is important to ensure that the review is relevant and meaningful. Cochrane is committed to having consumer involvement in all aspects of their work.

### Doesn't the Cochrane review group do this for my review?

No, not necessarily. Cochrane and Cochrane review groups do always work in partnership with consumers. However, most Cochrane review groups have limited time and resources and it is likely that their consumer involvement activities relating to your individual review will be limited to (some or all of):

- Checking that a new topic or title for a review addresses a question which is of known importance (a priority) to people affected by the healthcare condition
- Getting one or more Cochrane consumers to peer review the submitted protocol
- Getting one or more Cochrane consumers to peer review the submitted review, specifically asking for feedback on the plain language summary
- Involving consumers in the dissemination of the completed review

### What should I do?

There is no set formula or single method of involving people in a systematic review and no evidence that any one way of involving people in a review is any more or less effective, or impactful. A number of different factors will influence the decision around the best approach for a specific systematic review, including (but not limited to) the aim of involvement, the people who are being involved, and the resources and time available for this. This guide provides some examples of what you could do, and signposts you to various resources that may help you.

### At the planning stage, authors should consider:

Does your protocol/review address a question which matters to patients/carers, with outcomes which are important?

In what specific ways could patient and public involvement potentially benefit the clinical relevance and/or impact of your review?

Think about:

- The AIM of involving people. What do you want to achieve?
- WHO you are going to involve
- WHEN in the review process you are going to involve them
- WHAT level of control you will give to them
- HOW you will involve them

What resources (including time, finance and access to expertise) do you have which could support patient and public involvement?

All reviews should report patient and public involvement, reporting WHO was involved, WHEN in the review and WHAT control they had over the review. The ACTIVE Framework is a template that could be used to describe involvement; this could be an appendix in the published review.

### Resources & further information

**Involving People:** A resource for systematic review editors and authors to support them in getting people involved in the production of reviews. Open access with a free Cochrane account

<https://training.cochrane.org/involving-people>

**Stakeholder Engagement in Evidence Synthesis:**

Open access resources related to engaging with stakeholders during the planning, conduct, and communication of evidence syntheses.

<https://stakeholdersandsynthesis.github.io>

**Cochrane Consumer Training:** A collection of resources for those who want to involve consumers in the production of systematic reviews.

<https://training.cochrane.org/online-learning/consumer-involvement>

**Webinars from the International Network for Patient and Public Involvement:** A series of open access recordings of webinars about engagement and involvement in an international context, including Stakeholder Involvement in Evidence Synthesis.

<https://training.cochrane.org/international-ppi-network-learning-live-webinar-series>

**Cochrane Consumer Statement of principles:** outlines Cochrane's guiding principles relating to consumer involvement, which include equity, inclusiveness and partnership.

<https://consumers.cochrane.org/news/statement-principles-consumer-involvement-cochrane>

**ACTIVE Framework:** A journal paper reporting a framework for describing patient and public involvement in reviews.

<https://journals.sagepub.com/doi/abs/10.1177/1355819619841647>

**GIN Handbook:** This handbook includes a chapter on how to involve patient and public in systematic reviews.

<https://g-i-n.net/>

**Top and tail example:** A journal paper describing involvement in a Cochrane review.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4407304/>

**Further examples:** A scoping review which identified examples of involvement in systematic reviews.

<https://systematicreviewsjournal.biomedcentral.com/articles/10.1186/s13643-018-0852-0>

## What could Cochrane authors do? Here are some examples to consider.

### Involve a consumer as a co-author

**What does this mean?** Someone with lived experience of the healthcare condition, as a patient or carer, is a member of the author team, and makes a substantial contribution to the conception or design of the work or the acquisition, analysis, or interpretation of data for the work.

**How could I do this?** You need to: identify a person with relevant experience (e.g. personal experience of a specific intervention); have a discussion with them about what would be involved, their interests, and what their roles and responsibility would be. You would include them as an equal member of the author team.

**Advantages?** Co-production of a review in this way should make your review relevant and accessible.

**Things to consider?** What are the needs of the person that you are involving – do they need any training; do they have access to necessary IT and software; are you planning to pay for their expenses and/or time (have you got the finances? Have you discussed and agreed this with them?)

**Example:** Bernd Arents was a “consumer author” for this review:

<https://doi.org/10.1002/14651858.CD012119.pub2>

### Establish an advisory group

**What does this mean?** A group of people act in an advisory capacity to the review. This group could include patients, carers, health professionals, or other people relevant to the review topic.

**How could I do this?** You could form a group that is going to meet face-to-face, or you could form a group that is going to communicate electronically (e.g. by email or videoconferencing). You could approach an existing group of people (e.g. a patient support group), or you could advertise for members and form a new group.

**Advantages?** An advisory group can provide oversight and input throughout the whole review process. The authors can turn to them for advice or input when specific issues arise during the review process. Having a group of people means that a variety of viewpoints can help form elements of the review.

**Things to consider?** The aims, roles and remit of the group are important. Will the group members have any control over decisions made during the review process? Are the group members clear about what their roles and responsibilities are?

**Example:** An international advisory group contributed to this review:

<https://doi.org/10.1002/14651858.CD013779>

They provided detailed feedback on the protocol and written drafts of the review. Some members also helped with screening search results, and searching online to find full papers.

### Select and prioritise outcomes

**What does this mean?** Deciding on the critical and important outcomes is an essential part of a review. You want these to be outcomes which matter to people affected by the condition of interest. You could hand over the decision-making on outcomes to a group of consumers.

**How could I do this?** You could hold focus groups and ask people what outcomes are important to them. You could use the results from the focus groups to form a long list of outcomes, and then use consensus methods (e.g. a Delphi approach, or voting) to agree the most important outcomes for the review.

**Advantages?** This ensures that the outcomes in your review are the ones that matter most to people. This makes your review relevant.

**Things to consider?** Have there been other consensus projects relating to outcomes in your field (e.g. is there a core outcome set, generated with input from consumers)? If there is, then you would want to build on this established work.

**Example:** Stakeholders are being involved in a major update of this review, and the updated review will have outcomes which are determined using the methods described above: (update due for completion May 2021)

<https://doi.org/10.1002/14651858.CD007039.pub2>

### A ‘top and tail’ approach

**What does this mean?** This means that there is consumer involvement during the initial stages of the review (e.g. planning the question and protocol) and during the final stages (e.g. interpreting the review findings and drafting/disseminating findings). This is a common approach that review authors have used to involve people.

**How could I do this?** You could involve a small carefully selected group of people and have a series of meetings, or you could hold a large open event to which interested people are invited.

**Advantages?** This lets you plan really meaningful involvement at stages in the review which seem to be of importance to consumers (i.e. contributing to deciding on the question – including the outcomes of interest; and contributing to the interpretation of the findings from the review).

**Things to consider?** You need to decide the AIM of your involvement at either end of the review, and how much control you want to hand to the people that you involve. For example, if the aim is to ensure a meaningful review question, will you let the consumers that you involve decide on the final wording of the question to be addressed?

**Example:** For this review, a group of stroke survivors, carers and health professionals met twice at the beginning of the review to clarify the question – and structure – of the review, and once at the end to agree key implications arising from the review results:

<https://doi.org/10.1002/14651858.CD001920.pub3>

### For further help and advice, contact:

Cochrane Consumer Network - [consumers@cochrane.org](mailto:consumers@cochrane.org) or your Cochrane Review Group - <https://www.cochrane.org/about-us/our-global-community/review-groups>