

Consumer involvement – a guide for funding applications

Richard Morley
Cochrane Consumer Engagement
Officer

Version 1 March 2022

**Trusted evidence.
Informed decisions.
Better health.**



Contents

1. Introduction
2. What is consumer involvement?
3. Why is this important?
4. What should I do?
5. Involvement in systematic reviews
6. Evidence Synthesis Groups
7. Cochrane Evidence Synthesis Units
8. Cochrane Thematic groups
9. Other activities
10. Working with consumer volunteers
11. How Cochrane can support involvement in your application

1. Introduction

Consumer involvement in Cochrane

Cochrane has a long history of consumer involvement. You can read its 2018 Statement of Principles for Consumer Involvement [here](#). Cochrane's [Knowledge Translation Framework](#) identifies consumers as a priority audience for its research, and as co-producers of its evidence.

What is the purpose of this guidance?

Most funders of Cochrane research and other activities will require you to demonstrate how you intend to involve healthcare consumers (patients, carers, and the public) in your work. This brief guide sets out issues you may wish to consider. More support is available. Please contact the Consumer Engagement Officer by emailing consumers@cochrane.org.

2. What is consumer involvement?

Consumer involvement (sometimes called patient and public involvement, engagement, co-production and other terms) is the meaningful involvement of people affected by a healthcare condition in research or the delivery of activities or services. These people can be patients, carers, family members or the public. Cochrane uses the term “consumer” to describe these people. Integrating people’s lived experience into research is key. Health professionals or people using systematic reviews to inform health policy or practice may also be involved. This may be called stakeholder involvement.

Involvement and engagement are different approaches – you need both. Within the health research sphere, public engagement (usually defined as raising awareness of research) and patient involvement (usually defined as actively involving people in research) have traditionally been seen as separate but have much to gain from working together towards a common goal of better health outcomes for all.

3. Why is this important?

Consumer involvement is important to ensure that research, knowledge translation activities, or service delivery is relevant and meaningful. The Statement of Principles for Consumer Involvement says it:

- (i) promotes transparency, accountability and trust in the way that research is produced;
- (ii) results in evidence that addresses consumers’ needs, reduces waste in research, improves the translation of research into policy and practice, and ultimately leads to improved benefits for health systems and outcomes for patients;
- (iii) is consistent with current health research approaches and is expected or mandated by our funders, partners and consumers.

4. What should I do?

If you are preparing a funding application relating to a systematic review, these are three essentials you should consider:

1. Have involvement in developing your proposal
2. Consider the application guidance
3. Review the resources described here about “how to” involve people

Consider how consumer involvement could enhance your proposed review / study. Involve relevant people in the development of your idea or proposal – this might be by having a conversation with someone with experience of a healthcare condition, or by asking someone with experience of consumer involvement to read and comment on a draft proposal.

Refer to the guidance of the funding body that you are applying for. Funders may have specific requirements for involvement, and you should refer to any guidance they offer. The guidance may be in a section of its own (e.g., a section titled ‘Patient and public involvement’ (or similar), or it could be embedded throughout the guidance for other sections. You should also make sure you are familiar with any national standards (or similar) relating to consumer involvement, e.g., the [UK standards for PPI](#).

Plan how consumers will be involved in your activity. The following types of projects and activity are covered in this guidance:

- Involvement in systematic reviews
- Evidence Synthesis Groups
- Cochrane Evidence Synthesis Units
- Cochrane Thematic groups
- Other activities

You may have many questions about issues like where do I find consumer co-applicants? When should I involve consumers? How do I recruit people? These are answered in the individual sections below, and in the linked resources.

5. Involvement in systematic reviews

There is no set formula or single method of involving people in a systematic review and limited published evidence that any one way of involving people in a review is any more or less effective, or impactful.

Cochrane funded and co-produced the ACTIVE project which systematically captured the evidence base for stakeholder involvement in evidence synthesis. The ACTIVE project led to the development of the practical learning resource [Involving People](#). This is free online learning for author teams about involving consumers in reviews. It covers all the things you need to consider when planning your involvement including:

1. General good practice when involving people
2. Planning: Your review question
3. Ethics
4. Money
5. Reporting
6. Finding people to involve
7. Methods of involving people in systematic reviews
8. When and how to involve people: learning from examples

You are strongly encouraged to consider all these issues when developing your funding application.

The Involving People learning resource is based around the ACTIVE framework. This is a conceptual framework was developed to facilitate involvement in systematic reviews, by supporting clear, transparent description of plans for, and reports of, involvement of people in systematic reviews. You can read the 2019 paper by Pollock and others “Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews” [here](#).

A number of different factors will influence the decision around the best approach for a specific piece of work or 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. “Involving consumers (patients and public) in your Cochrane review – is a brief guide for authors” and is a concise, 2-page guide, drawing on the ACTIVE framework that identifies 4 methods you could use to involve consumers:

- Involve a consumer as a co-author
- Establish an advisory group
- Select and prioritise outcomes

- A ‘top and tail’ approach

It can be downloaded [here](#).

If you are bidding for work on systematic reviews specifically for the development of Guidelines, the GIN Public Working Group has a chapter in its toolkit relating to [involvement in systematic reviews](#).

Cochrane has a COVID-19 Consumer rapid response group with over 130 volunteers and dedicated resources [here](#).

6. Involvement in evidence synthesis groups

Cochrane has a long history of involving consumers in its groups: Review Groups, Fields and Geographic Centres. This [Six Step Stakeholder Engagement Framework](#) describes the different ways in which stakeholders, including consumers, have been involved in Review Groups, and ways for improving this work.

7. Evidence Synthesis Groups

Funders of evidence synthesis may well invite bids to support the production of systematic reviews. The NIHR in the UK has recently announced a bidding round to [fund Evidence Synthesis Groups](#). Patient involvement is highly recommended, and bids will be assessed on this. Opportunities to involve consumers are many, including:

- Co-applicants on funding bids
- Collaborators on funding bids
- Steering Group membership
- Support for developing an involvement plan, and implementing it
- Consumer co-ordinator role (paid) that involves a wide range of involvement activities, for example in priority setting, recruitment of and support for consumer volunteers for the co-production of reviews, knowledge translation activities, reporting and evaluation.
- The co-production of reviews

This document gives specific guidance for the involvement of consumers [Public Co-Applicants in Research – guidance on roles and responsibilities. NIHR. January 2019](#)

8. Cochrane Evidence Synthesis Units

Cochrane will create a number of multi-topic, interdisciplinary [Evidence Synthesis Units](#). Within the Units, a core team will be responsible for delivering relevant, high-quality, and timely evidence syntheses that responds to the needs of our diverse stakeholders.

There is an opportunity to involve consumers in the governance and running of these units (see above). Cochrane has recommended that the core team of each unit should include a Consumer Editor as a paid role (0.5 FTE). This is a developing process, and you may wish to take advice about this from Cochrane.

9. Cochrane Thematic groups

To maintain topic expertise and relationships with internal and external Cochrane stakeholders and provide another potential mechanism for developing Cochrane evidence syntheses, around 20 [Cochrane thematic groups](#) will be established. They will be responsible for identifying funding. Including consumers in their work will be important, and likely to be a key requirement to obtaining funding.

Activities for these groups are identified as:

- Contribute leadership and content expertise in identifying priorities in Cochrane evidence
- Synthesis production
- Recommend authors with content expertise for the development of evidence syntheses
- Provide content expertise for the Central Editorial Service
- Support dissemination of evidence syntheses within their communities
- Capacity building within their communities
- Function as the “shop window” for Cochrane’s activities in their areas of expertise
- Develop evidence syntheses and submit manuscripts directly to the Central Editorial Service

Consumers can be involved in all of these aspects of the work of Thematic Groups and can be built into funding bids. You can see how by reading Cochrane’s extensive [knowledge translation resources](#) and cases studies also in the [Six Step Stakeholder Engagement Framework](#).

10. Involvement in other activities

Consumer involvement is possible in a wide range of other activities and should be included when planning bids. Co-production offers the possibility of involvement from the very first stages including the drawing up of bids. Just a few examples of work in this area include:

Co-production of learning resources

[Evidence Essentials](#) was co-produced with consumers. That involvement included running a number of focus groups to scope the learning content of materials, a group made up of consumers, authors and others to agree a Consumer Learning and Skills Framework, consumer authors who researched and wrote significant parts of the raw content, and consumers who user tested the materials.

Involvement in the running of Events

It is possible to involve consumers in the planning and delivery of events. The Edinburgh Cochrane Colloquium in 2018 was a [Patients Included](#) conference. In this case the key involvement criteria are:

1. Patients or caregivers with experience relevant to the conference’s central theme actively participate in the design and planning of the event, including the selection of themes, topics and speakers.
2. Patients or caregivers with experience of the issues addressed by the event participate in its delivery and appear in its physical audience.

3. Travel and accommodation expenses for patients or carers participating in the advertised programme are paid in full, in advance. Scholarships are provided by the conference organisers to allow patients or carers affected by the relevant issues to attend as delegates.
4. The disability requirements of participants are accommodated. All applicable sessions, breakouts, ancillary meetings, and other programme elements are open to patient delegates.
5. Access for virtual participants is facilitated with free streaming video provided online wherever possible.

You can read how we approached involvement in the conference [here](#) and [here](#).

Research priority setting

The involvement of consumers in identifying the most important questions for future research is vital and one of the most important ways in which patients, carers and the public can be meaningfully involved. Funding applications that are committed to identifying research priorities with patient and public involvement demonstrate the importance and value of the research that will be conducted. Cochrane has produced guidance in its [Priority Setting Guidance Note for Cochrane Groups](#).

One of the most common methods for identifying research priorities is the James Lind Alliance method, used by multiple Cochrane groups, and you can read more [here](#). The JLA Guidebook is free to download [here](#).

Outcomes identification

Identifying important outcomes for research is vitally important and consumers can play a key role in identifying patient-important outcomes. This is a discrete activity, and separate from identifying important research questions, and other involvement activities. Core Outcome Set development is one method and you can read more about the involvement of consumers [here](#).

Knowledge Translation activities

There is a range of ways that consumers can be involved more widely, and in activities that can be broadly described as Knowledge Translation, from advocating for evidence, disseminating evidence, and forming partnerships with patient led organisations. You can find out more [here](#).

Cochrane UK formed its Consumer Champions Network in 2020. The Consumer Champions role involves advocating for evidence-based health care and Cochrane amongst organisations and patient groups in the UK. You can read more [here](#).

11. Working with consumer volunteers

The importance of investing in relationships between consumers and other members of author and project teams is vital for successful involvement. Your funding application should refer to your plans and should be budgeted for.

Good practice in involvement

Healthy relationships mean mutual respect, sharing of information, and learning and flexibility in working together. You are strongly recommended to read the section “Essentials for Good Practice” in

Cochrane's Involving People resource. You can access this [here](#). Module 5 of Cochrane Evidence Essentials, whilst aimed at Cochrane consumer volunteers, contains useful information and you can access this [here](#).

Standards for Public Involvement have been developed by a UK-wide partnership, the standards are a description of what good public involvement looks like and encourage approaches and behaviours that are the hallmark of good public involvement such as flexibility, sharing and learning and respect for each other. You can find the standards [here](#). There may be other standards in your own country.

Budgeting for involvement

This document "Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies" Involve, June 2013 is extremely useful when it comes to budgeting for involvement although the document is not recent. "Budgeting for Public & Patient Engagement in Health Research" (2017) by Carolyn Shimmin is another useful document.

["Payment guidance for researchers and professionals"](#) is an important UK NIHR document.

For bids outside the UK, you should refer to the funder's guidance to identify what things are eligible or ineligible within the grant funding

Payment for involvement

Cochrane itself has no policy on payment for involvement, though all expenses should be met. It is regarded however as good practice by funders of research. It is not without its issues however, and there may be implications for taxation and social welfare benefits.

You can read guidance from the UK NIHR about payment [here](#). Canadian CIHR guidance is [here](#). Cochrane is a global organisation, and you should seek advice locally.

Payment is not the only form of recognition of consumer involvement. Within your funding application you should state how consumers will be recognised, or thanked, for their contributions.

Reporting of involvement

Reporting the involvement in your work is a vital part of improving the quality, transparency, and consistency of the international patient and public involvement (PPI) evidence base, to ensure that PPI practice is based on the best evidence. Involvement in evidence synthesis is under-reported. Please think about how you might do this in individual systematic reviews, but also consider budgeting for reporting your involvement in peer reviewed journals, so that others may learn about your work. Consumers can be involved in this process, and this may be included in your plans and budgeting.

12. How Cochrane can support involvement in your application

There is a range of support that may be available to support grant applications that are relevant to Cochrane.

The Cochrane Consumer Engagement Officer

Cochrane's Consumer Engagement Officer can offer guidance, link you to resources and consumer volunteers and for high priority activities be an active co-applicant or collaborator. Inclusion as a co-applicant may require to be costed into applications, typically at 5% FTE. Contact Cochrane's Consumer Engagement Officer for more information by emailing consumers@cochrane.org

Cochrane Consumer Network

The [Consumer Network](#) made up of just under 2,000 volunteers across the globe is a unique feature of Cochrane's work, and from which we may be able to recruit volunteers for the activities described above, and for consumer peer review.

TaskExchange

[TaskExchange](#) is Cochrane's platform for recruiting collaborators for research.

Learning and other resources

Cochrane has developed [conceptual frameworks](#) to support co-production in the form of the ACTIVE framework [here](#) and the [Six-Step Stakeholder Engagement Framework](#) for stakeholder engagement in groups.

There are extensive [resources and high-quality learning](#) for both researchers and consumers, notably [Involving People: A learning resource for systematic review authors](#) and [Evidence Essentials](#) for your consumer volunteers.

Cochrane has produced a [range of recordings of webinars](#), many in partnership with the Learning Live programme, and the International PPI Network. These range from an introduction to PPI, involvement in evidence synthesis, reporting and evaluation of PPI.

There is a range of high quality learning and practical resources that relate to KT activities that relate to consumers [here](#).

13. Acknowledgments

I would like to thank the following groups and people for providing feedback on draft versions of this document: the Consumer Network Executive, Alex Todhunter-Brown.