Guidelines for Consumers Peer-reviewing research – 2.

Ideas to help consumers peer-review Cochrane protocols and reviews.

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Guidelines Pack - 2

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This set of Guidelines (“Guidelines-2”) has been prepared for consumers who have already decided to become involved in peer-reviewing research. If you would like more information, particularly a basic introduction, please see the companion set of Guidelines (“Guidelines-1”), available from your Review Group Co-ordinator.
(1) Introduction

This document has been prepared to help consumers. It has been arranged in sections to give practical advice to consumers who have decided they want to become involved in peer-reviewing research. This document, “Guidelines-2”, is written for people who already know something about the Cochrane Collaboration and something about Cochrane reviews and protocols. If you would like more background information about the work of the Cochrane Collaboration please refer to the companion folder, ‘Guidelines-1’ (available from your Review Group Co-ordinator, see section 7).

The Cochrane Collaboration comprises a number of groups, organised according to topic e.g. a particular health condition. So, for example, there is a Cochrane “Epilepsy” group and a “Pregnancy and Childbirth” group. Each group has many members with a variety of backgrounds, experience and expertise. Members might be doctors, nurses, researchers, health advisers and, of course, consumers. The activities of each group are monitored and co-ordinated by one person known as the Review Group Co-ordinator (RGC).

A note about the term “peer-reviewing”

“Peer review is a refereeing process used to check the quality and importance of reports of research. An article submitted for publication in a peer-reviewed journal is reviewed by other experts in the area. It aims to provide a wider check on the quality and interpretation of a short report and to improve its quality” (The Cochrane Library Glossary).

There is some debate about the use of the term “peer-reviewing”. For example, some consumers have told us that they acknowledge that doctors and other health professionals (who have studied and trained for many years) have a distinctive contribution to make to research. These consumers, who feel that their own contribution is quite different, have questioned whether they are really health professionals’ “peers”. The concise Oxford dictionary defines “peer-group” as “a group of people of approximately the same age, status and/or interests”. In the context of peer-reviewing research, all reviewers have an interest in the topic and, in this context, consumers and health professionals can be considered “peers”.

After much discussion we have decided to use the term “peer-reviewing”. We discuss the term “peer-reviewing” further in section nine (see page 9 of this document).
(2) What is meant by peer-reviewing research?

Peer-reviewing aims to ensure that research is of the highest quality. Research reports are circulated to people at all stages of their preparation (from the initial proposal right up to the draft paper for publication). By sending reports to people with an interest in the research findings, suggestions can be incorporated, and improvements made, at every stage of the research.

The reviewers (authors of the review) then consider the suggestions they receive. Sometimes they will make changes. The editors of the publication in which the article will appear may also make some recommendations. When the report is published it is open to public debate. Reviewers will be able to see how the report has changed during the editorial process and readers are welcome to comment.

(3) Consumer peer-reviewers

We asked some consumers familiar with the Cochrane Collaboration to peer-review and comment on Cochrane protocols and reviews in their area of special interest. We found that when consumers peer-review they:

- **think creatively**, not only reacting to other people’s ideas, but tapping into their own experience, visualising situations that are relevant to the topic and bringing fresh ideas;
- **know their subject well**, offering suggestions from a strong knowledge base, commenting on health conditions, current practice and research questions;
- **think logically**, bringing a fresh perspective, testing the logic, commenting on the aims, rationale, flow of argument, bias and conclusions;
- **seek information**, asking personal questions as patients or carers;
- **think of consumers** applying ethical principles such as human rights and civil rights, and they comment on choice;
- **value clear communication**, seek to understand, and comment on technical language, presentation, abbreviations, readability, understandability and illustrations (or lack of them);
- **encourage the authors**, highlighting valuable aspects of a report, making practical suggestions for change and explaining the value of possible improvements;
- **prioritise**, commenting on the overall value of the research.
In all these ways consumers offer fresh perspectives and ideas for researchers to consider in their work. Individual consumers may comment on a Cochrane review or protocol in many different ways.

Sometimes they find the work a little difficult at the beginning because there are new words and ideas to learn, but they usually find it rewarding. Individual consumers need not address every aspect of the review. They can offer their consumer expertise and let other reviewers offer their specialist expertise so that a comprehensive range of comments is contributed.

Each experience of peer-reviewing a protocol or a review is a learning experience and, if you get involved, we hope you will enjoy it.

(4) Bringing consumer perspectives to research

We have worked with experienced UK contributors to the Cochrane Collaboration to find out how they use their insights to comment on Cochrane protocols and reviews. Their comments regularly draw on their special understanding of particular aspects of health and of their ability to represent the rights and interests of consumers. They think through a problem logically to check the authors’ arguments and think creatively to consider the problem from different angles. They consider the questions that patients may ask. Lastly, but importantly, they encourage authors in their work. We describe these ways of working below, and suggest how consumers may develop their skills.

Tapping your own experience

People who think creatively not only react to other people’s ideas, but tap into their own experience (and that of their family, friends, colleagues). They are also informed by their personal reading. They visualise situations that are relevant to the topic and bring fresh ideas.

As a consumer you are bringing an important perspective to a Cochrane review. You do not want to let other people’s perspectives overwhelm your particular expertise. You could try bringing to mind what you already know about a topic, before thinking about how the reviewers have tackled the question they are addressing.

For instance: When reading a review about neonatal care a consumer explained “I picture the mother and baby, and apply what’s written to her. Does it make sense? How does the intervention affect everything else that’s happening?”

Another consumer imagined some sight screening tests and wondered whether a difference in where the tests were done might have an effect upon the results. For example, “Patients may be less relaxed in a clinic.”
To build your own skills: Take every opportunity to extend your expertise as a consumer. Listen carefully to people talking about their experiences. Notice what they are talking about, and how they are talking about it. When accepting health care for yourself or your family, notice how you react to situations.

When peer reviewing: Try reading the title of the protocol or review first, then stop to think about it. Jot down your own ideas about the topic. What do you think is the problem? Can you visualise people experiencing this problem? Where might they be? Who with? How might they be affected by the problem? What questions might they have? In what ways might people be different? What personal experience do you have? What have you heard from other consumers? Do you have books on your shelf addressing this topic by consumers? What issues concern them? What terms do they use? What questions do they ask? What treatments might they be considering? What outcomes might they be hoping for?

Asking yourself particular questions may help: What does the title mean to you? What information do you expect in the background? What is the theoretical reason for trying an intervention? What might you expect to happen, for better or for worse? What aspects of the experience might be particularly important to patients?

Using your expertise

People who know the topic well comment on research reports from a strong knowledge base. They can comment on health conditions, current practice and research questions. Some people are concerned that the more knowledgeable consumers become, the more like professionals they grow. However, consumers who become more knowledgeable but continue to be influenced by other consumers, are able to challenge clinicians’ and researchers’ perspectives in greater detail.

For example, when reading a review of iron supplementation, a consumer with personal experience wrote “All the information is about the problems of anaemia (and the benefits of iron therapy) but nothing about the problems of iron therapy which I believe can be considerable…”

To build your own skills, continue to learn from consumers, patients, carers, lay writers and bring their views to bear when you are considering technical reports. Read popular media reports on your subject of interest as well as technical reports.

When peer reviewing, remember the authors are writing from their perspective. You bring another perspective that is valuable and important.
Speaking for consumers

People who apply consumerist principles bear in mind public protection and rights to information and choice. They can comment on choice and ethics.

For instance, one consumer felt “… what is being said here is fine, but the way it is expressed implies that once the benefits and risks can be estimated with greater certainty then [patients’] choice should be removed.”

To build you own skills, when reading newspaper editorials or listening to the news on the television or radio, compare how the stories are reported according to which service you are listening to or which newspaper you are reading. Notice how journalists and lawyers give very partial reports depending on whose perspective they are representing. In bringing a consumer perspective you need to be aware of your own principles and biases and to notice other people’s principles and biases too.

When peer-reviewing: Every Cochrane review includes a conflict of interest statement pertaining to the authors. You may find other potential conflicts of interest such as sponsorship of the included trials or commercial interests in the products being tested. Are all potential conflicts of interest openly acknowledged? Do authors use emotive language? Of course everyone, including consumers, has particular interests and we must be vigilant to the many possible sources of bias.

Thinking logically

People who test the logic of a report do not necessarily share the same assumptions as the authors. Rather they may bring a fresh perspective and comment on the aims, rationale, flow of argument, bias and conclusions.

For instance, one consumer wrote “I did like the review and protocol which said what hypotheses they would be testing. This would have helped to focus the eventual analysis, but in the full review, the discussion did not return to the hypotheses! So, although the review was very interesting and educative, I would have benefited from… discussion in the same order as set out in the objectives. In fact, I think the information is there, but it is difficult to unpick.”

To build your own skills, look for opportunities to exercise your logic. Does a film plot make sense? What does an advertisement actually claim (compared to what it wants you to believe)?

When peer reviewing: At first sight research may look puzzling. When you think you understand it, you could try rewriting the ideas in plain language, or drawing a diagram to illustrate the work done, or imagine trying to explain it to a friend over a cup of coffee. Does it still make sense?
Asking patients’ questions

People who seek information ask personal questions as if they were patients or carers.

For example, “consumers would like to know whether they will be in pain, is the surgery done under local/general anaesthetic, will they have to stay in hospital (if so, for how long?)”. The information might be found in the list of outcomes, or in a detailed description of the intervention.

To build your own skills: When you read technical reports, get into the habit of putting yourself in the place of the patient. Would you know what to expect? What would you ask about? What might worry you? If this topic is new to you, do you have any pre-conceptions?

When peer-reviewing: When asking questions about health problems and their treatment, patients typically want to know: What would happen if nothing were done about it? What is the likely course, outcome, prognosis and danger? What options are there for treating the condition? All these issues could be considered in a review of effectiveness.

Checking the clarity of the message

People who communicate well seek to understand, comment on technical language, presentation, abbreviations, readability, understandability and illustrations (or lack of them) and make practical suggestions.

Some confusion has existed about who the readership is for Cochrane Reviews, so the Cochrane Collaboration Steering Group has deliberated carefully, consulted widely, and produced a policy statement:

Clear communication is essential. The target audience of Cochrane Reviews is people making decisions about health care. This includes health care professionals, consumers, policy makers with a basic understanding of the underlying disease or problem.

It is part of the mission and a basic principle of the Cochrane Collaboration to promote the accessibility of systematic reviews of the effects of health care interventions to anyone wanting to make a decision about health care. However, this does not mean that Cochrane Reviews must be understandable to anyone regardless of their background. This is not possible, any more than it would be possible for Cochrane Reviews to be written in a single language that is understandable to everyone in the world.

Cochrane Reviews should be written so that they are easy to understand by someone with a basic sense of the topic who may not necessarily be an expert in the area. Some explanations of terms and concepts is likely to be helpful, and perhaps essential. However, too much explanation can detract from the readability of a review. Simplicity and clarity are also vital to readability. The readability of Cochrane Reviews should be comparable to that of a well-written article in a general medical journal.
So how can consumers help? When reviewing and commenting on protocols or reviews, it may help to think of the primary readership as individual health professionals about to embark on a discussion with a patient about treatment options. These readers will find it easiest to assimilate facts and ideas if the report uses technical language with which they are familiar, but they will need to discuss these facts and ideas with their patients largely in plain language. If lay terms or simple explanations are added (possibly in brackets) alongside the technical language, the clinician is introduced to phrases suitable for a patient discussion at the same time as accessing the information about effectiveness they are seeking from *The Cochrane Library*. Consumers as peer reviewers can highlight those terms which clinicians would need to explain to patients during a consultation, and suggest lay alternatives if possible which can be incorporated into the text of the review and into a glossary of terms.

**For instance:** A consumer may ask “How well does the review explain the words and scientific terms it uses? I thought the[y] worked hard to explain terms, but scientific terms crept in which could have done with a mini dictionary somewhere in the text. So in [the review] which was admirably explained for the most part, words such as ‘papular’, ‘vesicular’, ‘coagulate-positive’ crept in unexplained. As a general point, I believe all reviews and protocols should have mini-dictionaries explaining the terms they use; and I have suggested that review groups should develop and maintain a common dictionary as a resource so their reviewers are not constantly having to re-define meanings”.

**To build your own skills** you can get into the habit of using technical and lay language interchangeably. This is particularly helpful when discussing health care in a mixed group where some terms may not be familiar to everyone. Look out for phrases you regularly use amongst friends and colleagues. Such phrases often hide layers of assumptions and invoke different ways of thinking. For instance, ‘informed consent’ and ‘informed choice’ tend to be used by different groups of people who visualise completely different scenarios. If other people use phrases you tend not to use yourself, explore the different meanings they may have and the assumptions behind them.

**When peer-reviewing:** Are there words which need explaining, perhaps in brackets? Are sentences long and unwieldy? Can you work out the likelihood of a patient benefitting or suffering from the intervention being tested? Mark technical words and phrases which could be usefully included in the glossary and offer lay translations. Pay particular attention to the abstract because this is most widely available and most widely read.

Suggest plain, non-technical wording to help consumers and to help clinicians explain evidence to patients.

Even if you can’t suggest an improvement, it is still helpful to highlight sections that are difficult to read or understand.

You could offer to help the review group prepare glossaries for individual reviews or for the group as a whole.
Encouraging authors

People who encourage others highlight valuable aspects of a report, make practical suggestions for change and explain the value of possible improvements. Review authors have worked hard to prepare a draft protocol or review, and they have had to be brave to let their work out for comment for the first time. No one expects their work to be received without suggestions for improvement, but criticism is easier to accept if it is accompanied by an appreciation of the better points of a piece of work.

For example: “This is a good, well-written protocol. It’s easy to understand, concise and to the point.”

“This is wonderful stuff! The patient is obviously on the reviewer’s mind; not only is quality of life mentioned, but reference is made to patient satisfaction, which is vitally important. When patients are treated as people, rather than a pair of eyes, the surgical procedures become easier to bear on an emotional level. The psychological well-being does much to promote the healing process. Seems to present a holistic approach for treatment.”

To build your own skills you can get into the habit of noticing and commenting on the positive aspects of any experience, as well as the disappointments.

When peer-reviewing: What can you find in the authors’ work which pleases you? The explanation of the problem, or choice of outcomes? The language used? Or a particular turn of phrase?

Give positive feedback first, give it as often as possible, and give it even if you have been asked to fill in a standard checklist which doesn’t request positive feedback.

(5) Peer-reviewing step-by-step

Step 1 Gathering your own ideas

To begin, you might try reading only the title of the protocol or review, and jot down your own ideas about the topic. You may prefer to flick through to get a general idea of the whole document first. Whichever method you prefer, notice what thoughts and questions you have.

What do you think is the problem? Can you visualise people experiencing this problem? Where might they be? Who with? How might they be affected by the problem? What questions might they have? How different might people be? What personal experience do you have? What have you heard from other consumers? Do you have books addressing this topic by consumers? What issues concern them? What terms do they use? What questions do they ask? What treatments might they be considering? What outcomes might they be hoping for? What side-effects might they be hoping for?
Then ask yourself some questions about what you might expect in the review. What does the title mean to you? What information do you expect in the background? Why is the intervention used? What might you expect to happen, for better or for worse? What about the experience might be particularly important to patients? Who might want to know about the effects of this intervention?

When you read the report you may find it is very different from the ideas you had from the title alone. Is this because you are learning a lot from the authors, because you have other relevant ideas you can share with the authors or because the title could be improved?

Step 2  Thinking about the research

Read the report carefully and consider it in the light of your own experience and expertise. You may scribble notes on the report itself, or on a separate sheet of paper. Notice how you react as you read through the report. Are there some sections that you particularly like or particularly don’t like? What do you think is good and what do you think is bad? Can you explain how and why you think this? Who might want to use the findings of this work, and when?

Might the report be biased? Are any sources of influence disclosed? Such as commercial interests in the interventions or research? Might other sources of influence be hidden? Is the language emotive?

Are you disappointed by the findings of the review? Some reviews are unable to provide a clear answer because there is very little relevant high quality research. Other reviews may have found relevant trials, but not trials answering questions that you consider particularly important. This is an opportunity for you to list questions that still need answering. You can make some suggestions for the concluding section on ‘Implications for Research’.

Is the language clear, accurate and not too technical? Are there words which need explaining? Are sentences long and unwieldy? Are there any unnecessary or obscure abbreviations? Can you work out the likelihood of a patient benefitting or suffering from the intervention being tested? Mark technical words and phrases which could be usefully included in a glossary and offer lay translations. Pay particular attention to the abstract because this is most widely available and most widely read.

What can you find in the authors’ work which pleases you? The explanation of the problem, or choice of outcomes? The language used? Or a particular turn of phrase?

Step 3:  Ordering your thoughts

Look back at the notes you made in step 1. Are all the questions that arose from your initial thinking answered? Might you suggest changes in how the research is done or how it is reported?

Look at the notes you made in step 2. Would your suggestions allow the authors to keep those sections you liked and change the sections you did not like?
Using a checklist after you have had ideas of your own may help you see if there is anything else you could think about. You may like to read through the report again in light of the checklist. But reading the checklist first to provoke your thinking may not help you work more efficiently. Instead it may restrict your thinking and stifle your imagination.

Step 4: Making your comments

If you are given a checklist or form for feedback, using this will help the editors and authors. But some forms do not help collate the ideas that commentators have, and you may wish to write more freely.

Give positive feedback first, give it as often as often as possible, and give it even if the standard checklist you are invited to use doesn’t request positive feedback.

List your suggested changes. Explain why you recommend doing it differently and how important it is. List who might find the findings from this work useful and in what circumstances. You might like to work together with other people or you might like to work alone.

You may wish to send a copy of the protocol or review back to the Review Group with your comments written on it. Don’t worry if you would like to rewrite them or tidy them up first – just ask your Review Group Co-ordinator to send you a new copy.

(6) Looking after yourself

Contributing to research as a consumer means thinking hard about issues that are personally very important. You might be taken by surprise by the strength of your emotional reactions, as was found by members of staff at a national charity who were reviewing a research report:

“[The research topic] is an extremely important but sensitive issue for each of these users. They found reading the report an emotional experience and have each taken time to think through their comments which are presented here in a reasoned form. The strength of feeling aroused by this report amongst users should not be underestimated”.

Before you start, please be aware that it’s not unusual to get upset when the work touches on issues that are important to you personally. Ask yourself how you will make time to talk about your feelings and who you can turn for help. Can you call on a personal support network of family, friends, other people contributing to the Cochrane Collaboration, self-help groups, colleagues or specialist health help lines?

This is particularly important for consumers working in isolation. Indeed you may prefer to work in a team if this is possible, or develop a system of mutual support with other consumers.
If other consumers hear of your involvement in research, they may turn to you for help and support with their personal health concerns. Beware of trying to deal with complex enquiries from other consumers. It is a great responsibility. There is a big difference between befriending and peer support, and a trained counselling service with structured supervision sessions. Perhaps you know of a counselling service, either as part of the NHS or as part of a consumer group, that could help.

Take seriously your potential need for support when undertaking peer review in areas which can touch you personally, and consider how you can encourage others to be similarly gentle with themselves.

(7) Getting more help

We hope that this document has been a useful introduction to commenting on and reviewing research in the Cochrane Collaboration. You may have some further questions and you might like to talk about the work with your Review Group Co-ordinator or with the Cochrane Consumer Network.

If you have decided that you would like to become involved in the work of the Cochrane Collaboration, please contact your Review Group Co-ordinator (see Section 1, page 3). If you are unclear who your Review Group Co-ordinator is, the person who helped you obtain these Guidelines might be able to help.

A companion document “Guidelines-1” is also available. It gives more general background information. It can be obtained through your Review Group Co-ordinator.

To help us try to assist consumers commenting on and reviewing research, please send us your comments on this document and tell us about your experiences as a consumer peer-reviewer (see last page).

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(8) Your ideas…

We have learnt about consumers commenting on and reviewing research from consumers themselves. We would like to learn more. So this space is for your ideas. Please tell us what you think of this document, what you think about consumers peer-reviewing research and whether you have any advice for us or for other consumers.

Please get in touch to tell us

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