IDEAS FOR IMPROVING THE RELEVANCE OF YOUR REVIEW TO CONSUMER ISSUES

Introduction

<u>Cochrane</u> is an international organisation that aims to help people make well-informed decisions about health care by preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions.

Consumers, as patients, carers, or interested members of the public, have a strong interest in making good decisions about health, after weighing up the available evidence, and taking into account their own values and perspectives.

Systematic reviews should ideally, therefore, consider issues and outcomes of importance to consumers, as one way of ensuring the relevance and quality of the review. Potential users of a review should be involved in the key stages of the review process (Oliver 1997). For example, involvement can ensure that key questions that policy makers and practitioners consider important are addressed. Secondly, research by consumer and patient groups often identifies outcomes of importance to patients that have not been considered by conventional research. Finally findings and recommendations can be presented in a more accessible way. Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) research with various user groups suggests that it is more likely that policy and practice will be informed by the results of systematic reviews when these factors are addressed in the preparation of a review (Peersman 1997).

Cochrane Consumers and Communication encourages authors to consider a number of ways to ensure that their review is relevant and responsive to consumer issues. Internally, we have a structure and processes that reflect our commitment and interest in these matters.

- We have an editorial team of people with experience in researching issues of relevance to consumers and involving consumers in research.
- All protocols and reviews are externally peer reviewed by at least three people: one of these has identified themselves as an expert in consumer issues (as compared to a methodological expert, or health science expert)

Ensuring the relevance of your review

There are a number of ways that we encourage authors to consider improving the quality of their review, in terms of its relevance to issues and outcomes for consumers. We strongly recommend you use <u>Involving</u> <u>People</u>, Cochrane's own web-based resource about involving consumers in your review. In addition, we list a number of different ways to involve consumers below and ask you to consider whether any of these approaches would be useful for your team.

a. Background reading

Many consumer and patient groups research issues of relevance to their members. These reports provide a valuable source of information on problems as people experience them. However, they are often difficult to trace via conventional library and computer-based databases.

In many countries, there are consumer organisations that can inform you of who are relevant consumer groups that you could contact for information on the available literature.

b. Consumer involvement

You could invite members of a consumer group to be part of your review team, to contribute ideas, comment on drafts or to analyse and report on the data. The consumer member would then become one of your authors.

Some review teams establish a small panel of consumer advisors, drawing on their contacts and ours. Panel members advise on issues of relevance and comment on drafts. Their comments are dealt with similarly to peer reviewers' comments. Panel members are not authors but should be acknowledged appropriately within the protocol and/or the review.

c. Additional research and consultation

Some review teams undertake additional research (subject to available resources) to support their analysis. This may be because so little research has been done that a good understanding of the problems is not available.

Research could involve:

- focus groups
- questionnaires
- personal interviews

Note: these types of research are likely to require ethics approval.

Alternatively, some teams may wish to provide an exhaustive summary of published research (not just a review of trials) in the Background section of the review.

You might also wish to contact consumer groups to seek their views by email, by phone, mail or in person.

d. Special needs groups

As a review team you might wish to focus on people with special needs, for example, people from low socioeconomic backgrounds who experience poorer health. To do this you might want to employ several of the methods outlined in steps a. to c. or you might wish to ask the editorial base for assistance.

If relevant, we ask you to incorporate a section on consumer participation at the end of the methodology section of your protocol, outlining the methods you are using to incorporate consumers' perspectives in your protocol and review.

We ask you to acknowledge consumers' contribution to the review, and include consumers as authors where appropriate.

References

Oliver S. Exploring lay perspectives on questions of effectiveness. In: Maynard A, Chalmers I, editor (s). *Non-random reflections on health services research*. London: BMJ Publishing Group, 1997: 272–291.

Peersman G, Oliver S, Oakley A. *Review guidelines: data collection for the EPIC database*. London: EPPI-Centre, Social Science Research Unit, 1997.

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E Coren (ed.) (2007) Collection of Examples of Service User and Carer Participation in Systematic Reviews. London. Social Care Institute for Excellence. Available at: <u>www.scie.org.uk/publications/details.asp?publD=125</u> (accessed 29th June 2012).