

CCNet External Review of Consumers in The Cochrane Collaboration, focusing on Review Groups

Background

The findings of this Review were disseminated widely prior to and at the 2009 Cochrane Colloquium (11 to 14 October). An oral presentation was given at the Colloquium and consumers at the Colloquium had a half-day pre-colloquium session (attended by 20 people from 10 different countries). A paper was presented to the Steering Group to address how consumer involvement and CCNet are best managed within the Collaboration, with senior management commitment.

These discussions were to feed into the final report, which is a working document for CCNet to address ways of improving the value of consumer input into reviews and their dissemination; and to obtain mutual benefits for consumers and Review Groups.

CCNet thanks those who contributed to the success of the Review process - either as members of the Cochrane multi-stakeholder advisory group, part of the CCNet team that supported the process, in responding to surveys, agreeing to be interviewed by the external consultant, the Managing Editors' Executive for their comprehensive feedback on the draft document, and in the general support and feedback received. A broad communication strategy is key to everything that CCNet does.

Review of Consumers in Cochrane and the Cochrane Consumer Network: Summary report

Cochrane Consumer Network (CCNet)

Vision: Enhanced accessibility and relevance of Cochrane reviews through consumer and community participation.

Aims: To enable and support consumer participation in The Cochrane Collaboration; and continue to develop the use and usefulness of consumer participation in Cochrane groups, in particular Review Groups.

1. Introduction

This report gives a summary of a review of the position, role and management of the Cochrane Consumer Network (CCNet). The review was carried out between March and October 2009. It looked at:

- Why consumers get involved in Cochrane, and how they are recruited.
- How they are involved in Review Groups - i.e. the tasks they undertake.
- The level of impact consumers have in the Review Groups they are involved with
- The level of commitment within The Cochrane Collaboration to involving and supporting consumers
- The role of the Consumer Network in supporting consumers within the Collaboration.

2. How was the review carried out?

There were two stages to the review.

- (i) In stage one, surveys were sent by email to two target groups:
 - **Cochrane Review Groups:** This survey was directed at Managing Editors. Review Groups were asked to complete the survey whether or not they involved consumers in their work. Forty-seven responded out of a total of 52 Review Groups at the time of the survey.
 - **Cochrane consumers:** This survey was sent out to consumers who work with Cochrane Review Groups via the CCNet e-mail list. 66 people responded, of 427 people on the list.
- (ii) In stage two, interviews were carried out to gain further information specifically relating to the survey responses. The people interviewed were identified through their responses to the surveys in consultation with the Project Advisory Group; the Advisory Group also identified two consumers who had unsuccessfully tried to engage with a Review Group:
 - **Six consumers:** Four interviews were carried out by phone, with consumers based in Australia, the UK and the USA. There were email discussions with two consumers based in Bahrain and New Zealand.
 - **Four members of staff from Review Groups:** Two of these were based in the UK and two in Canada. Three are Managing Editors and one is a Consumer Coordinator.

3. Why consumers get involved in Cochrane

Consumer reasons for choosing to get involved in the Collaboration included:

- An interest in evidence based medicine.
- A desire to make health research (and Cochrane reviews in particular) more accessible.

The survey of consumers identified that the Cochrane website is important for recruiting consumers. Contact with an existing Cochrane consumer is also a prominent means of involving consumers.

4. How consumers are involved in Review Groups

The survey identified that 35 of 47 Review Groups involve consumers in their work. Eight Review Groups did not involve consumers; four did not answer this question. From the interviews, the number of consumers involved does not reflect the commitment of the Review Group, nor the attempts made by the Managing Editor or by others involved in the Group to engage consumers. Difficulties in recruitment can relate to the subject matter addressed by the Review Group, or to the complexity of the tasks required.

Both the Review Group and consumer surveys showed the principle ways in which consumers are involved are:

- Commenting on Cochrane reviews prior to publication.
- Commenting on protocols.
- Commenting on or helping to write plain language summaries.

Other roles identified by consumers but less frequently by Review Groups were:

- Raising awareness of evidence-based health care.
- Recruitment of other consumers.
- Disseminating information about reviews.

5. The impact consumers have in the Review Groups in which they are involved

Review Groups identified that they want consumers to be involved to improve the:

- Readability and/or quality of reviews (38 respondents).
- Usefulness of the plain language summaries (36 respondents).

Just over half of the Review Group respondents said that they felt they were gaining these benefits, 14 were not sure.

The surveys of both Review Groups and consumers highlighted how important plain language summaries are in disseminating information about Cochrane reviews by consumers. The interviews showed that there was no consistent approach across Review Groups to involving consumers in the development of plain language summaries.

All of the consumers interviewed found it very hard to comment on whether their involvement had had any impact.

6. Supporting consumers

The interviews highlighted the fact that the Managing Editor is key to the promotion of consumer involvement on a day-to-day basis. However, the Coordinating Editor was seen to have a key role in supporting consumer involvement at a strategic level. Some of the Review Group responders felt they struggled to support 'their' consumers. The key type of support offered is advice on how to complete a review.

7. The role of the CCNet in supporting consumers

CCNet was identified as having a clear role in involving consumers in the work of Review Groups. Respondents to the Review Group survey felt that an umbrella organisation was important (38 respondents); seven did not have a view. Almost all respondents to the Review Group survey said that they felt that the vision and aims of CCNet were appropriate.

Both consumers and Review Groups viewed the CCNet e-mail list as a practical way of involving consumers.

Many (39 of 58 consumer respondents) said that they had used information provided by CCNet to help them to fulfil their role as a consumer.

When asked to list two things that CCNet should be doing as a priority, Review Groups and consumers identified training and support. Identifying and recruiting consumers was also important for Review Groups; and promotion of effective consumer involvement across the Collaboration for consumers.

8. Addressing the aims of this review

- CCNet clearly has an important role in recruiting consumers and acting as the signpost to Review Groups.
- It would be useful to do more to ensure that new consumers are actually contacted by and engaged in the Review Groups that interest them (if those Groups are willing).
- CCNet also has a role to tell consumers about the possibilities of getting involved in 'other' Review Groups and identifying topic areas of interest. This can help Review Groups that struggle to recruit consumers.
- CCNet could do more to help Review Groups to support consumers to remain involved - perhaps by encouraging some form of feedback to consumers.

- CCNet is a key resource for Review Groups and consumers to draw on. It would be helpful to remind consumers and Managing Editors about this, and especially the resources available on the CCNet website, on a regular basis.
- CCNet already acts as a clearing house for the sharing of information such as training materials and about involving consumers - there is potential for further development here.
- CCNet could also do more work with consumer organisations to encourage the dissemination of reviews, and especially of plain language summaries.
- CCNet has a role in convincing those within the Collaboration who may be sceptical about the value of consumer involvement. This is also an important role for the leadership of the Collaboration.
- It's clear that there is no single model for successful consumer involvement within Review Groups. Therefore at this stage it does not seem possible for the Collaboration or CCNet to issue guidance about *how* consumers should be involved in Review Groups. However, it may wish to issue guidance on the *principles* of involving consumers.

9. Recommendations

An initial report of this review was presented to the Cochrane Collaboration Steering Group in October 2009, with the following recommendations:

1. That administrative support (2 days per week) for CCNet is provided.
2. That a quality improvement process is developed for consumer input into pre-published Cochrane documents.
3. That The Cochrane Collaboration develops a Consumer Participation Plan that is endorsed by the Steering Group.

The CCNet Review Advisory Group then made a series of more detailed recommendations, which will be used to inform the development of the Consumer Participation Plan. These are:

Improve the systems that support effective involvement

1. Ensure that new consumers are actually contacted by and engaged in the Review Groups that interest them, unless there is good reason for this not to happen. This could include the development of a checklist for consumers, telling them what to expect when they contact a Review Group.
2. Ensure an effective database of consumers who are active in the Collaboration is maintained.
3. Circulate a list of new titles to consumers on a weekly basis, to encourage them to get involved at an earlier stage in the process of review development.
4. Tell consumers when reviews which are of interest to them, or that they have commented on, are published.
5. Tell consumers about the possibilities of getting involved in 'other' Review Groups (i.e. Review Groups that a consumer does not feel is their primary allegiance). This will help Review Groups that struggle to recruit consumers.
6. Look at ways of making the CCNet email more user-friendly.
7. Regularly remind Review Groups and consumers about the information and guidance CCNet can offer.

Improve the CCNet support available to Review Groups to involve consumers effectively

8. Help Review Groups to recruit consumers, and act as the signpost to Review Groups.

9. Develop the existing CCNet role of acting as a clearing house for the sharing of information such as training materials between Review Groups.
10. Offer advice to Review Groups on issues relevant to consumer involvement.
11. Be clear that the number of consumers involved in a Review Group does not reflect the level of commitment to involvement within the Review Group.
12. Work to convince those within the Collaboration who may be sceptical about the value of consumer involvement. (This is also an important role for the leadership of the Collaboration)
13. Recognising that there is no single model for successful consumer involvement within Review Groups, explore the possibility of developing guidance on the *principles* of involving consumers.
14. Promote and support the effective involvement of consumers in the development of all plain language summaries.

Improve support for consumers to be actively involved

15. Develop more face-to-face and online training and ensure consumers know about these opportunities.
16. Explore the possibility of offering consumer ‘buddies’ to new consumers.
17. Work with consumer organisations to encourage the dissemination of reviews, and especially of plain language summaries.
18. Create a dedicated position within CCNet to liaise with and support all consumers involved with Cochrane.

Further information:

Full reports of the surveys and of the interviews are available on the CCNet website (www.cochrane.org/consumers/happenings.htm).

This review was carried out by between March and October 2009 by Bec Hanley (a consultant in consumer involvement in research) and three members of CCNet: Janet Wale, Maria Belizan and Jane Nadel. An Advisory Group, drawn from consumers and people who work for the Collaboration, helped to guide the development of the review. Members were Amanda Burls, Mike Clarke, Shirley Manknell, Sharon Parker/Kate Cahill, Judi Strid, David Tovey, and the Managing Editors Executive.

About the CCNet Project Team:

Maria Belizan: Maria’s background is in Social Communications Sciences (National University of Rosario, Argentina), Master in Social Sciences and Health (FLACSO-CEDES, Buenos Aires, Argentina, 1997-1999), and a post-graduate degree in Health Promotion (National School of Public Health, Instituto de Salud Carlos III, Madrid, Spain, 2001). Maria contacted CCNet in 2004 and started to collaborate as consumer peer review with the Pregnancy and Childbirth Group Consumer Panel and later with Complementary and Alternative Medicine, and Consumers and Communication Review Groups. She was the Project Officer of the Project “Prioritisation of Cochrane reviews for consumers and the public in low and high-income countries as a way of promoting evidence-based health care” funded by the Cochrane Collaboration Steering Group. She is involved in different qualitative and quantitative epidemiological research projects in maternal and child health and quality of care improvement.

Jane Nadel: Jane has held various positions in community and labor organizations as an advocate, lobbyist, and organiser. Her focus is on empowering workers and consumers to collectively and individually address issues affecting their lives and welfare. She became involved in health advocacy out of concern that profiteering instead of evidence was dictating health care practices (in the States). As Consumer Coalition Coordinator at the USCC in 2004, she became familiar with The Cochrane Collaboration and affiliated with the Cochrane Consumer Network. She holds degrees in law and health advocacy.

Janet Wale: Janet has a PhD in Pharmacology with years of experience in industry (UK), university and research institute environments (Australia). She managed her husband's country dental practices in Western Australia while bringing into the world and raising four daughters. Her work in research came to a halt for health reasons and that was when she became involved in The Cochrane Collaboration and health consumer advocacy. She is a senior consumer representative on a number of national medical and health technology committees in Australia.

The CCNet project team, as a result of their own experiences, are committed to helping consumers to be informed and to participate in shared decision making at all levels of health care. This is a recognised, shared driving force for most active consumer representatives and advocates.

Framework for Consumer and User of Health Care Involvement in The Cochrane Collaboration

The final report of the CCNet External Review of Consumers in The Cochrane Collaboration is an important document for further developing and evaluating consumer involvement in the Collaboration, if that is what the Collaboration wants. Active consumer involvement is important at the Steering Group or management level and at the Review Group, Field and Centre level with involvement in the development of systematic reviews of best evidence and dissemination of information. From discussions within and external to the Collaboration, the following Framework has been developed as a working document to provide context and to open discussion on the tasks and activities. The Consumers United for Evidence arm of the US Cochrane Center is a vital, integral part of the Cochrane Consumer Network and has been strongly involved in its development.

An effective healthcare user voice can best be achieved with overall endorsement and core funding of the overarching Consumer Network (CCNet), a funded CCNet Coordinator position, and a multi-stakeholder group to design and implement the CCNet infrastructure and work plan. For these processes to be successful, it is important that healthcare users are strongly represented, work in partnership and have an equal voice.

Any feedback and comments are welcome and can be submitted via ccnet-contact@cochrane.de or through the CCNet email discussion list.

This draft Framework sets out:

To address how the broad community of healthcare users can be best represented at all levels within the Collaboration and resourced on an ongoing basis.

- a) **Monitoring:** A process for formal registration of all consumers/users of health care in Cochrane through CCNet;
- b) **Management and Training:** Provision of an orientation to the Collaboration structure, work and opportunities for consumer involvement,
 - a. A process that helps to assess existing skills and skill-building needs for involving consumers in Cochrane,
 - b. A variety of opportunities and mechanisms to access that training and support,
 - c. A connection to Cochrane entities for healthcare users to participate meaningfully on a number of levels and in different capacities depending upon interest, experience, time and skills,
 - d. Connectivity between Cochrane entities and CCNet in a mutually beneficial manner,
- c) **Evaluation:** Ongoing evaluation of impact and outcomes of consumer participation processes at all levels.

Background:

- ✚ This Framework is based on the findings of the External Review of the Cochrane Consumer Network (Bec Hanley 2009) and the Internal Review of The Cochrane Collaboration (Jeremy Grimshaw, Mary Ellen, Lucy Jones, 2008/09).
- ✚ At its Meeting on 10th October 2009, following the presentation of the draft findings of the CCNet External Review of the Consumers in The Cochrane Collaboration (Hanley 2009), the Cochrane Collaboration Steering Group affirmed that consumer involvement is valued.
- ✚ The Review has shown that within Cochrane Review Groups, consumers have the capacity to improve Cochrane protocols, systematic reviews, plain language summaries, and their dissemination (Hanley 2009);
- ✚ the Review also endorses the benefits of having the Consumer Network.

The Vision and Aims of CCNet were affirmed in the 2009 External Review:

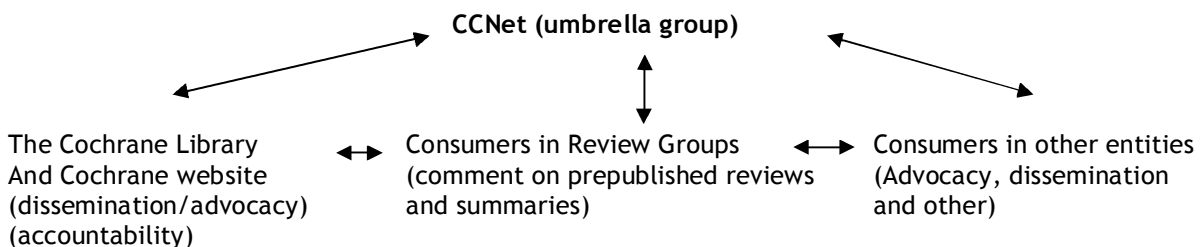
CCNet Vision:

Enhanced accessibility and relevance of Cochrane reviews through consumer and community participation.

Aims:

To enable and support consumer participation in The Cochrane Collaboration; and continue to develop the use and usefulness of consumer participation in Cochrane groups, in particular review Groups.

Present Map



Framework to address:

The need for best practice strategies for consumer and user of health care participation in The Cochrane Collaboration.

Objectives:

- To build on and strengthen consumer involvement in the work of the Collaboration using continuous quality improvement strategies such that the involvement is consistently meaningful and of mutual benefit.
- To move from a model of participation that aligns most closely with consultation to a more collaborative model, at least in some settings within the Collaboration.
- To improve communication, feedback and acknowledgement between consumers/CCNet and other Cochrane groups.
- To build capacity within the Collaboration in involving consumers.
- To learn from our experiences, evaluate and develop an evidence base, and
- To ensure that actions on consumer participation in the Collaboration are implemented using ‘Consumer, patient, and community participation’ measures against standards.

Proposed Standards:

For consumer, patient, carer, community participation in The Cochrane Collaboration - through the Cochrane Consumer Network (CCNet)

1. The organisation demonstrates a commitment to diverse consumer, patient, carer, community and user of health care participation, where:
 - ✓ The organisation contributes to the development, implementation and monitoring of healthcare user participation in collaboration with CCNet
 - ✓ The organisation ensures that collaboration meets the needs of participating consumers/users of health care, CCNet and Cochrane Groups
 - ✓ The organisation has systems, processes and structures in place to support CCNet in involving consumers and users of health care (through resources, training, feedback, dissemination materials, decision making and policies in the Collaboration)
 - ✓ The organisation builds the capacity of staff to support CCNet and consumer and community involvement
 - ✓ Involvement is demonstrated to be valued including through a democratic process for a diversity of consumers to attend Cochrane events.
2. The organisation actively contributes to building the capacity of the Cochrane Consumer Network so that users of health care can participate fully and effectively:
 - ✓ The Collaboration actively engages in and supports CCNet activities - new initiatives and ongoing
 - ✓ CCNet, healthcare users and communities can identify that changes have taken place within the Collaboration because of their involvement
 - ✓ The roles of CCNet, users of health care and community participation are clearly defined and communicated widely within the Collaboration.

Priority Actions:

1. From the CCNet External Review, the immediate key areas are to:

- ✚ Provide support, guidance and resources on participation (for consumers/healthcare users and for staff and stakeholders/others involved).
- ✚ Provide training on communication and involving consumers and CCNet.
- ✚ Encourage feedback and monitoring of consumer and CCNet involvement.
- ✚ Advocate for closer consumer and CCNet collaboration within The Cochrane Collaboration (compared with consultation and communication of information).

2. From the 2008 Internal Review of The Cochrane Collaboration:

- ✚ Address sustainability of consumers in the Collaboration.
- ✚ Address commitment to and sustainability of CCNet.
- ✚ Identify leadership requirements and succession.
- ✚ Build on the advocacy role of consumers/CCNet.

3. Development of knowledge and skills

What a person gains from being involved

How to become involved

Mapping of 'training' needs

1. About the organisation (The Cochrane Collaboration and Cochrane Consumer Network) - and
2. What you can do as a consumer or user of health care (Cochrane.org)
3. Peer education (consumers e-mail discussion list)
4. Communication and assertion/advocacy skills
5. About evidence-based health care (www.cochrane.org/consumers) - and evidence-based health care in different countries (WHO)
6. Calling for consumers to consumer referee Cochrane protocols and reviews
7. About commenting on Cochrane protocols and reviews (www.cochrane.org/consumers)
8. About plain language summaries and user of health care pages
9. Critical Appraisal (CASP, Oxford)
10. Scientific methods (CUE, US Cochrane Center)
11. Asking Answerable Questions (our workshop in Singapore - US Cochrane Center, CCNet); titles of reviews
12. About plain language summaries - guide to writing (www.cochrane.org/consumers)
13. Support:
 - a. Mentoring
 - b. Teaching others
 - c. Availability of information (Cochrane.org)
 - d. Communication
 - e. Attendance at meetings
14. About the different levels of involvement - assessing consumer participation models
15. Dissemination (Wiley, Fields, other)
16. Training of Cochrane staff; authors of reviews (on request)

Questions to address at a strategic level:

1. A requirement that consumers, carers and community members who participate within The Cochrane Collaboration are formally registered as members of the Cochrane Consumer Network (CCNet)
2. The Consumer Network presently operates as an internet community based network. Is there a preferable more empowering and effective formal structure and placement of CCNet
3. Development of a consumer/user of healthcare page for Cochrane reviews - and with plain language summaries for planned dissemination of information from Cochrane Reviews
4. Training of consumers/users of health care in increasing awareness about evidence-based health care
5. Increased use of consumers/users of health care in the above roles
6. That CCNet works collaboratively with the Colloquium Policy Advisory Group on the management of Consumer stipends
7. It is envisaged that in the immediate future consumers/users of health care continue to work on a voluntary basis - how could the Collaboration assist in obtaining funding to build on

resources, opportunities for face to face training etc? This includes getting sufficient consumers to these events to have a significant presence and voice in decision making as well as an opportunity to engage face-to-face.

Available training

- Videos at www.cochrane.org/consumers/happenings.htm
- Cochrane Consumer Learning at: www.cochrane.org/consumers/resources.htm
The Cochrane Collaboration and evidence-based health care
Commenting on Cochrane protocols and reviews
- Consumers United for Evidence-based Healthcare and the US Cochrane Center: online course "Understanding Evidence-based Healthcare: A Foundation for Action."
<http://distance.jhsph.edu/trams/index.cfm?event=training.launch&trainingID=130>
- About Modern Medicine An easy to read description of evidence-based health care and why it is important.
http://cochrane.clickmediapro.com/ebi/evidence_based_healthcare/Modern_Medicine_Leaflet.pdf
Healthwise: accessing quality health information on the internet - for Australians in particular.
- How to ask an answerable question for health care and health research:
Consumers United for Evidence-based Healthcare and the US Cochrane Center online course "Understanding Evidence-based Healthcare: A Foundation for Action."
<http://distance.jhsph.edu/trams/index.cfm?event=training.launch&trainingID=130> Module 2 in the online course is called "Ask" and is all about how to ask an answerable question.

Annual monitoring of healthcare user involvement in Cochrane Review Groups:

An annual 'inventory' of healthcare user involvement in Cochrane Review Groups is needed as a basic marker of the level of commitment of the Collaboration to consumer involvement. This process was begun in December 2009 as a voluntary exercise.

It is recognized that some Review Groups, such as Public Health, consider their 'consumers' to be policy makers rather than individual users of health care. With the Methodology Review Group health consumers are the 'consumers' for only some of the reviews. While the Effective Practice and Organization of Care Group do not see individual health consumers as the people to whom their reviews are directed, individual consumers are interested in their review topics to the point that this was a prioritised area of health in the CCNet Prioritisation Project (2008). Not all Review Groups presently have published reviews. Only two other Groups stated that they do not involve consumers. Four stated that they had limited involvement. Six Groups stated they would not use the CCNet e-mail list to identify consumers. The use may be limited or a possibility only; one group would to identify consumers for its Group, which has happened with at least one other Group previously. Of note, since this survey of Managing Editors at least two groups have asked for consumers to comment on a pre-published protocol or review in this way for the first time. The Groups were generally happy for CCNet to send them the details of healthcare users who were interested in their area of health, although further work needs to be done in determining beforehand if these people are interested in commenting on the pre-published reviews.

Conclusion: Overall this was a valuable exercise that we can learn from.

Draft checklist for monitoring and improving healthcare user input:

In the CCNet Review (2009), healthcare users said they wanted to contribute to the development of evidence-based health care AND

- Make information about evidence-based health care more accessible
- Learn and keep up to date, either with research about a specific condition or with evidence-based health care
- Tell other people about Cochrane reviews - using the plain language summary.

Many consumers do not get feedback on how their contribution has (or has not) made a difference and whether they were could do things differently, or not.

If you have any suggestions for making this Checklist better, please email ccnet-contact@cochrane.de

TO BE COMPLETED BY HEALTHCARE USERS

This checklist is to be used by the Cochrane Consumer Network (CCNet) in conjunction with Cochrane Review Groups to help us with improving what we do - and in working out what differences we can make.

HEALTHCARE USER CHECKLIST

Title
Review or
Protocol
Review
Group
Your name
 (optional)

We would like to know:

Response:

Commenting

- Have you commented on a review before?
- Do you understand the review process?
- what a systematic review is?

Do you have health user experience (direct or indirect) with the issues raised by the review topic

Your comments

- Were you able to raise issues of relevance &/or concern to users of health care?
- Could you easily express them on the checklist provided by Review Groups?
 - If not, why not?

For decision making

- Did the plain language summary give the information you thought useful from the review?
- What would improve the plain language summary and make it more useful?
- Could you use this review to help you make a healthcare decision?
- Could you use this review as it is to inform others?
- Is there anything that would make the review more useful?

Feedback & support

- To improve the process:**
- Is there anything that would help you in providing comments?

support from other consumers

feedback

training

What feedback or acknowledgement did you

get back from the review group?

Other

Any other comments
