

2010

Consumer involvement in the Cochrane  
Collaboration.

BACKGROUND PAPER Volume 2: Appendices

*Strategic Session – Auckland, March 2010*

---

Dr Dell Horey

La Trobe University

## Contents

Appendix 1: Process for Background Paper .....	3
Appendix 2: Recommendations from Cochrane Collaboration Strategic Review.....	4
Appendix 3: Consumer Network Review of Consumers in Cochrane .....	5
Appendix 4: Membership of Consumer Involvement Advisory Committee .....	27
Appendix 5: Definitions of the term consumer across the Collaboration.....	28
Appendix 6: Person specification: Service user commenting on research .....	29
Appendix 7: Consumer members of the Cochrane Collaboration Steering Group 1995 to 2010.....	30
Appendix 8: Summary positive benefits and negative impacts from consumer involvement in research.....	31
Appendix 9: Managing Editors' use of CCNet email list .....	33
Appendix 10: Consensus-derived principles and indicators of successful consumer involvement in NHS research .....	37
Appendix 11: Cochrane Consumer Network: Detailed business and operational plan .....	38

## Appendix 1: Process for Background Paper

Janet Wale reported to the October 2009 Steering Group meeting on the evaluation of CCNet. A Strategic Session on consumer participation was proposed, to be held alongside the Collaboration's next Steering Group meeting, in March 2010 in Auckland. Steering Group members contributed to the draft terms of reference for the Session.

Resources for the Session were approved at its November meeting. It was agreed that the project involve the preparation of a background paper.,

Jonathan Craig asked David Tovey and Lorne Becker to chair the Project.

Executive members confirmed the Terms of Reference.

The project would:

- Examine strengths and weakness of models of consumer participation in the Cochrane Collaboration (including structure and core functions of CCNet but also at the CRG level)
- Outline opportunities for closer engagement between the Collaboration and consumers (i.e. internal and external relations)
- Outline resources, training and personnel implications of different approaches.

David Tovey offered administrative support to the Project – given the short time-frame for work to be completed.

Steering group members were asked to suggest people for the Consumer Involvement Advisory Group (CIAG).

At its first meeting, the CIAG confirmed its role.

Janet Wale proposed additional members and opportunity for consumer members to meet independently prior to next meeting. These proposals were agreed.

Consumers met in teleconference and provided minutes for this meeting (their questions arising from this meeting were integrated into the agenda of the next meeting of the CIAG), when the new members joined.

The CIAG met five times by teleconference.

## Appendix 2: Recommendations from Cochrane Collaboration Strategic Review

The Cochrane Collaboration needs:

### **Clarity of purpose, and should:**

- Reaffirm our primary purpose to be the production of systematic reviews (Dialogue 1)
- Formalise additional purposes including training, methods development and advocacy for evidence-based decision-making and identify responsibilities of entities for these purposes (Dialogue 1)
- Identify principles for developing new products or lines of activity (Dialogue 1)

### **Engagement of partners for mutual benefits, and should:**

- Develop a Marketing and Communications Strategy to promote external and internal awareness of the value arguments for and achievements of The Cochrane Collaboration (Dialogue 2)
- Improve the usability of *The Cochrane Library* and other products for diverse stakeholders (Dialogue 2)
- Develop a partnership strategy to engage other systematic review producers and knowledge packagers (Dialogue 3)
- Establish formal membership for its contributors (Dialogue 2)
- Establish an External Advisory Board (Dialogue 7)

### **New resource options for supporting strategic objectives, and should:**

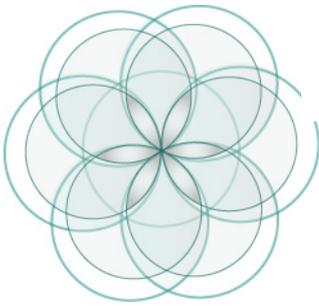
- Invest in a development function for new products or lines of activities (Dialogue 1)
- Investigate the development of a broad-based educational program (*'Cochrane Education'*) (Dialogue 1)
- Investigate the development of a responsive review program (*'Cochrane Response'*) (Dialogue 1)
- Acknowledge the reality of our current infrastructure funding model and work to maintain it (Dialogue 4)
- Explore and pursue new funding opportunities (Dialogue 4)

### **Management, accountability and effective leadership, and should:**

- Clarify the roles and responsibilities of its scientific/professional, managerial and editorial leadership (Dialogue 5)
- Develop and implement a formal succession planning mechanism for entity leadership (Dialogue 5)
- Develop and implement performance appraisal mechanisms for entity leaders (Dialogue 5)
- Enhance accountability mechanisms of entities to ensure core functions are met and Collaboration policies are implemented (Dialogue 5)
- Develop and implement policy for minimal competencies for review author teams (Dialogue 5)
- Develop and implement central decision-making processes that clearly identify communication, implementation and monitoring plans (Dialogue 5)
- Review the membership of the Cochrane Collaboration Steering Group (CCSG) and its alignment with the purposes of the Collaboration (Dialogue 6)
- Define required competencies for CCSG membership and induction and ongoing training for CCSG members (Dialogue 6)
- Review terms of reference and membership of CCSG Sub-Groups and Advisory Groups (Dialogue 6)

### **'Strategic Thinking' embedded at all levels, and at all times, in the Collaboration, and should:**

- Undertake a formal environmental scan every two to three years (Dialogue 3)
- Use uncommitted income strategically to develop new products/lines of activity (Dialogue 4)
- Review terms of reference, and number and geographic spread of Cochrane entities to ensure efficient alignment with the purposes of the Collaboration (Dialogue 6)
- Develop an ongoing and participatory approach to strategy formation (Final Reflections)



September 2009

### 1. Introduction

With Cochrane Collaboration Steering Group Discretionary funding (2009), CCNet has co-opted the services of the UK consultant Bec Hanley, working with a small project team of CCNet members (Maria Belizan, Jane Nadel, Janet Wale), to review consumer participation in Cochrane Review Groups.

We are using a best-practice model and are working closely with a multi-stakeholder Project Advisory Group internal to the Collaboration (David Tovey, Editor in Chief; Mike Clarke, UK Cochrane Centre Co-director, Sharon Parker/Kate Cahill, Managing Editors; Amanda Burls, Shirley Mankwell, Judi Strid, CCNet members) who met by teleconference (funded through CCNet funds in Australia). The Advisory Group has been vital in strengthening the external review.

*The aim of this project* is to review of the position, role and management of the Cochrane Consumer Network (CCNet). The review is looking at:

1. Why consumers get involved in Cochrane, and how they are recruited
2. How they are involved in Review Groups - i.e. the tasks they undertake
3. The level of impact consumers have in the Review Groups they are involved with.
4. The level of commitment to involving and supporting consumers, and acknowledgement of consumers' contributions to the review process
5. The role of the Consumer Network in supporting consumers within the Collaboration

### 2. Process for the Review

Two online surveys (one for Review Groups directed at Managing Editors, and one for consumers, through the appropriate email lists) were open from the 3<sup>rd</sup> June 2009 to the 6<sup>th</sup> of July 2009. Review Groups were asked to complete the survey whether or not they involved consumers in their work.

The survey addressed how consumers (patients and carers) become involved, what they do with the Review Group, the benefits gained and the barriers and requirements; as well as their awareness and knowledge about CCNet and its role and how it functions.

#### *How many people responded to the surveys?*

47 people responded to the survey for Review Groups. We were very pleased with this response rate, as there are 51 Review Groups. It is possible (but very unlikely) that more than one person completed a survey on behalf of a Review Group.

66 people responded to the survey for consumers. There are 427 people on the CCNet email list, but we know that many of them do not identify themselves as 'consumers' according to the Cochrane definition - for example they may be on the email list because they have an interest in consumer involvement. 191 people have at some stage acted as a consumer reviewer, but not all of these are on the CCNet email list. We have estimated

that between 150 and 200 consumers are involved in Review Group. We have taken this figure as our 'marker' in terms of a response rate.

We think there are a number of reasons why this response rate is lower than that from Review Groups:

- Most consumers are involved in Cochrane on a very part-time and voluntary basis, unlike managing editors.
- Many consumers will have received the request to complete the survey as part of the consumers' email digest. This means that it was harder to draw attention to the importance of the survey for CCNet

Although this response rate is not as high, we are still pleased with it.

### 3. Results of the surveys (as presented to the Advisory Group, August 2009)

#### 3.1 Involvement in Review Groups

##### *3.1.1 How many Review Groups involve consumers?*

35 respondents said that consumers were involved in their review groups, and 8 said that their Review Groups did not involve consumers. We'd like to follow up this response, as this figure is higher than that supplied to the Monitoring and Registration Group.

##### *3.1.2 How do consumers become involved in a Review Group?*

Review Groups reported the most common ways for recruiting consumers were:

- A consumer made contact direct with the Review Group (23 respondents ticked this option)
- CCNet sent contact details of an consumer interested consumer (19 respondents)
- The Review Group contacted consumer organisations (18 respondents)
- The Review Group recruited someone they knew (14 respondents)
- The Review Group put out a call for comments through the CCNet email list (12 respondents)

We were interested in what seemed to be a high number of consumers who were reported to have made direct contact with a Review Group - we wondered how they had found the Review Group, and whether this meant that they already had some knowledge of Cochrane.

Consumers had most commonly got involved through:

- The Cochrane website (16 respondents)
- Another consumer (12 respondents)
- A consumer organisation (10 respondents)
- A direct approach from a Review Group (10 respondents)

##### *3.1.3 Consumers who completed the survey*

Most consumers who responded to the survey had been involved in the Collaboration for more than one year, although encouragingly 11 consumers had been involved for less than a year - this shows we are continuing to attract consumers into the Collaboration. Many consumers who completed the survey had had recent (e.g. during 2008) contact with a Review Group. Most did not have links with their geographical centre (where they did, the UK and the USA were mentioned most).

44 respondents said that they had been involved with at least one Review Group; with 26 saying they had been involved in at least two Review Groups.

20 respondents said they had never attended a national or international Cochrane conference, and 33 had attended between one and three such events.

21 consumers said they had not attended sessions specifically for consumers at these events. This may reflect the 'type' of consumers who may have completed the survey - if they are involved in Cochrane in other ways (for example as a paid member of staff) they may understandably choose to attend other sessions.

### *3.1.4 What is the role of consumers within Review Groups?*

Not surprisingly, the most common roles reported by Review Groups and by consumers were:

- Commenting on reviews (44 consumers said they had this role, and 30 respondents to the Review Group survey said consumers had this role)
- Commenting on protocols (34 consumers and 25 Review Groups)
- Commenting on plain English summaries (19 consumers and 24 Review Groups)

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

- Raising awareness of evidence based health care (26 consumers said they had this role whereas this was only identified by 9 respondents to the Review Group survey)
- Recruiting other consumers (18 consumers, compared to 10 respondents to the Review Group survey)
- Disseminating information about reviews (17 consumers, compared to nine Review Groups)

12 respondents to the consumer survey said that they were involved in writing plain language summaries, and 10 said that they co-authored reviews.

We gave respondents to the Review Group survey a 'maybe' response option to this question, as we thought that completing this survey might encourage them to think about other possible roles for consumers. Two roles seemed to attract interest: raising awareness about the importance of evidence based health care (12 respondents ticked the maybe option) and recruiting other consumers (10 respondents). We'll aim to follow this up with some phone interviews.

### *3.1.5 More about involvement in Review Groups*

We were interested that 22 Review Group respondents felt that consumers always understand what their role is, compared with 12 who said that consumers sometimes understood what their role is. This is broadly reflected by consumer respondents.

13 respondents to the Review Group survey said that there is never enough money to enable consumers to carry out their role, and 20 said that their Review Group never runs training for consumers. 16 respondents felt that that they offered support to consumers sometimes, whilst 10 said they always did this. About one half of consumers said that they felt supported.

Consumers' comments on this issue included:

*Review Groups appear to appreciate comments but I don't know to what extent the authors take the comments into account and whether they even think consumer input is meaningful. One Review Group (I think Pain) did provide a summary including all peer review comments and the authors' reactions to the comments (which was very interesting!)*

*I don't feel that consumer input is genuinely valued. More tokenistic. I've had limited feedback or acknowledgement for the work I've done, the time frames are usually very short implying considered opinion not valued. I strongly feel that consumers should be paid for their time in participating in reviews. Believe consumers should be given a set MINIMUM time frame in which to respond that is realistic for the amount of work required. Believe it should be mandatory that consumer reviewers be formally acknowledge. I believe Cochrane will recruit and maintain more consumers world wide if these factors are put in place.*

*Many consumers are not employed; we need financial access to the annual meeting because it is there where you realize that you are part of a larger movement, learn new things, and meet other consumers (and scientists). This is an important part of our training.*

All respondents said that consumers bring different skills, knowledge or experience and make a positive difference to their Review group at least some of the time. This compares to only half of the consumer respondents who felt that their involvement makes a positive difference to their review Group. We think there may be issues about lack of feedback here - because of the way that the Collaboration works (that is mostly remotely) many consumers may not get feedback on how their contribution has (or has not) made a difference. It was clear that consumers are not always acknowledged in the acknowledgments section of a review (13 Review Groups said they sometimes do this and 3 said they never do this).

One consumer commented:

*Some of the things, like which groups use my name as a consumer reviewer, I simply don't recall. I only sometimes see the reviews after I do my part, which also means it is sometimes hard to know what effect my comments have, but that is OK. (I feel sure I could get more access to final versions if I were concerned)... But, I'm very busy, and by the time a review is finalized, I've moved on and prefer to think about the next review that appears of interest and whether I have any contribution to make from a consumer/patient point of view.*

Almost all respondents to the Review Group survey (32 of 33) said that they were aware of the skills consumers have that could help the Review Group.

### ***3.1.6 What benefits do Review Groups want to gain by involving consumers?***

The most common things Review Groups said they wanted from consumers were:

- To improve the readability and/or quality of reviews (38 respondents)
- To improve the 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, but 14 said that they were not sure about this. We'd like to follow this up in some phone interviews.

### ***3.1.7 What do consumers want to achieve through their involvement?***

Consumers gave a variety of aims. The most common related to a desire to:

- 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
- Contribute to the development of evidence based health care

Comments included:

*Involvement in medical research and who knows may be some influence in it as well. Same time acquiring the most recent data on evidence based health care available.*

*Furthering my education in and experience with the Cochrane Collaboration provides an opportunity to share information with people in my community and beyond.*

*Evidence-based information that can be disseminated to mental health service users. Making medical science less scary to those who don't have a background in it.*

*Help consumers become more involved in research and help research answer the questions that are of most importance to consumers*

*Learn and understand about how the Cochrane collaboration works and its relevance to health consumers*

*Better information on EBM for consumers worldwide*

*The best quality patient and public involvement in research; itself monitored and evaluated; awareness of what is happening in the wider Collaboration; reinforcement and promotion of the rightness and value of P&P involvement in the whole research process.*

Over half of the consumer respondents were not sure whether they were achieving these aims. We'd like to follow this up in phone interviews to understand more about why consumers gave these responses.

### ***3.1.8 What are the barriers to involvement?***

The main barrier identified by Review Groups was funding. We were interested that the following were NOT seen as barriers by the majority of respondents:

- Time (19 respondents said they disagreed that this was a barrier compared to 13 who said this was a barrier)
- An understanding of how to find consumers (21 said this was not a barrier commented to 7 who said it was) or how best to involve them (18 did not see this as a barrier, 13 did)
- Inappropriateness of reviews (27 said this was not a barrier compared to 7 who said it was)

### ***3.1.9 What would help more review groups to involve consumers?***

We asked respondents who said that their Review Group did not currently involve consumers to tell us what would help them to do so. The most common responses related to a lack of staff time and the need for more advice and guidance.

### ***3.1.10 How do consumers use reviews?***

Consumers who responded to the survey use all parts of a review to gain information for themselves, with 41 of 42 respondents saying that they used the whole review. Almost all consumers said that they told other people about Cochrane reviews (49 of 53 respondents to this question), and that they use the plain language summary to do this. This illustrates the importance of the plain language summary.

## 2 Views about CCNet

### *3.2.1 The vision and aims of CCNet*

Almost all of the respondents to the Review Group survey said that they felt that the vision and aims of CCNet are appropriate. However, consumers were less convinced, with 14 respondents saying that the vision was only 'maybe' the right one. We'd like to follow this up in the phone interviews, to ask consumers what their vision is for CCNet.

It's interesting to note that 34 respondents to the Review Group survey and 18 consumers said that they did not know whether CCNet was achieving its aims. Again this may relate to the way that the Collaboration works - it is harder to keep people up-to-date when contact is sporadic. But this is perhaps something we need to work harder at.

### *3.2.2 Views about the work of CCNet*

Most consumers who responded to the survey find the newsletter informative (44 of the 59 who responded to this question) and the website useful (39 respondents). Many consumer respondents (39 of 58 respondents) said that they had used information provided by CCNet to help them to fulfil their role, and that the CCNet email discussion list helped them to link up with consumers in other countries (41 respondents).

In contrast, most Review Groups did not have a view about the website - perhaps we need to do more to publicise it and the resources it contains.

Review Groups were also less likely to say that they had referred consumers to guidance produced by CCNet - again this suggests we could do more to tell Review Groups about the guidance we have produced.

Perhaps most interesting, a significant number of Review Groups said that they did not feel up-to-date with what CCNet is doing (20 respondents, as opposed to 9 saying they did feel up-to-date). Again this perhaps reflects on the way that the Collaboration works, where many Groups may not be aware of what other Groups are doing.

### *3.2.3 Which activities should CCNet undertake as a priority?*

In both surveys we asked respondents to list two things that CCNet should be doing as a priority. Review Groups prioritised training and support and identifying and recruiting consumers.

Comments included:

*Try to establish that in every review a special consumer page is added as part of the review in order to increase consumers' input and to make Cochrane reviews more interesting to read*

*Provide a supportive network and friendly front door\_for consumers to access the large and complex Cochrane Collaboration.*

*Ensure that consumers fulfil a role that benefits both them and the review groups that they are affiliated with.*

Consumers also prioritised training and support, but saw the promotion of effective consumer involvement across the Collaboration as the other key role for CCNet.

Comments included:

*Monitoring and ensuring meaningful consumer involvement in all Cochrane Collaboration activities.*

*Increase the understanding of Review Groups about the importance of consumer input and the consumer perspective*

*Stimulate consumers to be critical and active and to learn how to contribute usefully*

*Provide a web class on how best to use the resources available for consumers. Something that is accessible time and time again.*

*I would put communication and support at the top - with those other things can happen.*

### **3.2.4 Should an umbrella group such as CCNet exist?**

37 consumer respondents agreed that it was important too have an umbrella group such as CCNet. Two did not. It's interesting that 11 only partly agreed.

One consumer commented:

*Most consumer commenting on protocols is carried out remotely (by email). Physical contact with Review Group personnel only occurs at Colloquia or other general meetings, This can make consumer commenting a 'lonely' business and the CCNet mailing list helps to bring consumer together.*

Another said:

*I think the CCNet needs infrastructure funding but I know this is very difficult to obtain. I also think that it would help to try to develop a structure where consumers are linked together either by country and language (branches of CCNet) or by CRGs where they share a common health issue. These somehow then feed into the main CCNet team... I feel we need some structure that supports and shares experiences at the grass roots, and provides a two way communication between the grass roots and the CCNet team.*

All respondents to the review group survey felt that an umbrella organisation was important (38 respondents), or did not have a view (7 respondents).

## **4. Results of the interviews (as presented to the Advisory group, September 2009)**

This report summarises findings from the interviews which were undertaken during August and September 2009. Section 2 describes how I went about the interviews. In sections 3-7 I have grouped the findings from the interviews under the key objectives of this review, thus:

- Section 3 looks at why consumers get involved in Cochrane and how they are recruited.
- Section 4 examines how consumers are involved in review groups
- Section 5 looks at the level of impact consumers have in review groups they are involved with.

- Section 6 examines how consumers are supported to be involved in review groups, and the level of commitment to this.
- Section 7 covers the role of CCNet in supporting consumers within the Collaboration.

At the request of the Advisory Group, I asked some additional questions of interviewees about the role of the Collaboration's leadership with regard to consumer involvement. This is covered in section 8. In section 9 I look at how these interviews help us to address the key aims of the review. Finally in sections 10 and 11 I outline what we'd like to discuss with the Advisory Group and what will happen next.

## 4.2. About the interviews

Following our meeting in July I re-drafted interview schedules for consumers and for Review Group staff, in response to comments from members of the Advisory Group. Janney and I then agreed a final list of people to approach for interview.

I promised anonymity to the people I interviewed. Quotes from interviewees are in *italic text*. I have included lots of quotes, in order to give you as full a picture as possible as to the flavour of people's comments.

I interviewed members of staff from four Review Groups, two of which are based in the UK and two in Canada. I also interviewed six consumers, based in Australia, New Zealand, the UK and the USA mainly by telephone (2 consumers by email). Two of the consumers I spoke with had tried to engage with Cochrane, but not managed to get beyond the enquiry stage. One was still new, having engaged with the Consumer Network but not yet with a Review Group. The other consumers had all been involved with a Review Group. These consumers are involved in commenting on protocols and reviews (consumers A and E), and writing plain language summaries (consumer B - who is paid on a part-time basis to do this).

## 4.3. Why consumers get involved in Cochrane and how they are recruited

### 4.3.1. Motivations for getting involved in the Cochrane Collaboration

Three of the consumers I spoke with were introduced to the Collaboration by people who were already involved in it, either as a researcher or a consumer.

Some consumers were motivated by an interest in evidence based medicine:

*I was intrigued by the Cochrane Collaboration's approach to evidence based medicine... I became interested in being a referee, a consumer referee, because the science is my passion...* (Consumer A)

Three consumers wanted to make health research (and Cochrane reviews in particular) more accessible:

*I also was hoping that I could somehow take the Cochrane information and make it available to people who come on our website. We have a huge website and following... I would really like to be able to make the Cochrane Collaboration information available to the constituency that you know follows our work.* (Consumer A)

*[I wanted] to help other people understand where medical research comes from and make more of it available to people.* (Consumer B)

*My passion for reading medical reviews and pharmacology involved was what initially drew me... Refereeing Cochrane reviews and protocols allowed me to suggest layperson technology which could assist consumers when using the Cochrane Collaboration Library. (Consumer E)*

Two of the consumers I interviewed who had been involved for some time felt that they were gaining the benefits they had sought. Another consumer, who had been involved for over a year, was less sure:

*I'm kind of feeling like it's a mystery a bit. It's like I'm reaching out and I want to grab it and I want to use it, but it seems complex or complicated or cumbersome for me to do it... I have not devoted a lot of time to trying to find out for myself... I know it's a rich resource. (Consumer A)*

#### **4.3.2. What skills do Review Groups want consumers to have?**

Some of the Review Group interviewees were very clear about the skills required from consumers involved in their Review Group. Review Group Three has targeted a small group of consumers who have very specific skills that will be useful to the Group - for example journalism.

There was a recognition that Review Groups might recruit consumers who do not have the skills required to undertake a review:

*My worry is that [consumers] are brought in on one premise that you've had the disease, you're a caring person with time enough to devote and you buy into the Cochrane ethic and so on, but actually when it comes down to sitting and reading a paper, there are very specific skills which they may or may not have. (Review Group One)*

Review Group Two recognised that their requirement of computer literacy means that some consumers are excluded:

*We prefer that they have sort of basic word processing and computer skills because we like to do it electronically, but we also have an eye to being equitable and things like that so we have tried to engage people who maybe are in different socio economic classes or who maybe find printing the reviews expensive or find accessing a computer troublesome, so in the past I have sort of couriered reviews and done things by hand and then sort of typed in the responses but it doesn't happen very often... We don't really have the capacity to do that but we do recognise that that leaves out a segment of the population that might be really affected by these conditions and treatments. (Review Group Two)*

This Review Group offers training to build consumers' skills in reviewing

#### **4.3.3. What skills do consumers feel are needed to be involved with Cochrane?**

Two of the consumers I interviewed commented on the level of skill needed by consumers who get involved with Cochrane:

*I think you definitely have to have a rather rich in-depth understanding of your subject matter, if you're going to truly be a reviewer who can look between the lines. You can get consumers come in who have an interest in the area, who are not, who don't have sort of an in-depth understanding and they will do certainly a review that may be adequate but if you really want a review, I mean a consumer referee in a given area who is going to be useful in terms of really seeing in terms of what needs to be done then you*

*have to have someone who has some understanding both of studies, of science and has an interest in it and is willing to take the time. (Consumer A)*

*I think it does help to have a scientific or medical background, but it's not as important as it used to be because you can just Google practically everything and come up with an answer. To do what I'm doing you need to be able to write... You've got to be able to write in literate English. (Consumer B)*

#### **4.3.4. The experience of consumers who did not manage to get involved**

Two consumers talked about their experience of trying, and failing, to get involved in Cochrane:

*I'm just not quite sure what happened... Maybe there was nothing for me... [Name of consumer] got in touch with me, she emailed me... I had some kind of phone call and I sent her a CV... I thought I could maybe do some feedback... given I knew something about research... (Consumer D)*

*The guts of the story is small. [Name of consumer] nominated me. I followed all the procedures that you are supposed to follow and met a constant stone wall. I repeated the process with the same result. End of story. Either everything went "missing in the mail" or someone at the top was deliberately obstructing the involvement of someone known to hold critical views. (Consumer F)*

The consumer I interviewed who has yet to receive a response from the Review Group she had applied to join described a similar experience:

*I kind of sit on the edge of my seat thinking you know I hope something will come along soon that's of interest and I guess I haven't really received anything. (Consumer C)*

#### **4.3.5. What would make getting involved easier, as a new consumer?**

Consumers identified some things that had made their induction into Cochrane easier. Consumer B was able to attend a course on systematic reviews run by her review group. She felt this had helped enormously:

*I was really, really lucky... I got a thorough understanding of what a systematic review is, how they look for data, the statistics, we had a day on statistics, and Revman as well. So I got my head round quite a lot of complicated stuff.*

Another consumer had gained helpful information from the CCNet website:

*Well I really enjoyed you know the like Cochrane website, like the Consumer Net website and the different electronic documents that are on there like I printed those, I looked through them multiple times and I printed them out and I read them and they're really, really good. (Consumer C)*

One of the consumers who did not manage to get involved felt that a personal contact would have been helpful:

*If there was a division in Cochrane that was dealing with [my condition], I think that would have helped, if somebody from that... if someone had perhaps called or emailed... I think I could have been perhaps helpful. ... Where there's a personal contact it's always better. (Consumer D)*

## 5. How consumers are involved in review groups

### 5.1. An overview

The number of consumers involved in the Review Groups I interviewed and the extent of their involvement varied hugely. Review Group One was only involving one consumer. Review Group Two was involving 38 consumers (of whom 17 or 18 were reported to be active), and plans to recruit another 60 consumers in the coming year. Review Group Three involved a small number of consumers on an ongoing basis. Review Group Four also involves a small number of consumers on an ongoing basis, but draws in other consumers, attracted through the CCNet emails, for specific tasks:

*Initially we had a group and still do have a group of consumers who contacted the Group or who we found by various means but more recently we've used the Consumer Network and sent titles via the email system. And we have managed to get some consumers to agree to look at our reviews and sometimes not... (Review Group Four)*

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. The interviewee in Review Group One attributed difficulties in recruitment to the subject matter of her Review Group:

*We only have one consumer and it took moving heaven and earth to get her. We're one of those difficult groups... because of the subject matter... It's a real problem. And you get people like the Pregnancy and Childbirth Group, it's wonderful to be pregnant, it's easy to get people... It's much harder to get people with a sort of socially unacceptable condition... to come forward... and not only face it and help us, but face it themselves, having to keep reading about it....*

Two interviewees were concerned that the complexity of the task put people off:

*We had one guy who read one review for us, but he was, I don't think he'd ever read a scientific paper before, and he really, really struggled, and felt he was out of his league somehow, so he didn't come back and we didn't get anything that we felt was particularly useful from him. And then we had another couple of people contact us and I sent them all the support material that we routinely supply and they were just horrified at the scale of what was being asked. I think the level of expertise to be honest. We make it sound simple but I don't think it is at all simple to look at a review and comment sensibly on it, so it doesn't surprise me that consumers are few and far between. (Review Group One)*

The interviewee in Review Group Three had made a conscious choice to limit the number and 'type' of consumers involved in her Review Group:

*We don't want a cast of thousands, we really don't... The reality is, four to six consumers who are knowledgeable enough to be able to help with some of the writing and vetting issues... (Review Group Three)*

### 5.2. The role of consumers in developing plain language summaries

All of the Review Groups involved consumers in the development of plain language summaries. However, there was no consistent approach across the Groups. For example, Group One sends selected reviews to their consumer and asks her to comment on anything she wishes.

*If I give her a review I want her to look at as much of it as she can cope with, including the plain language summary... It's the hardest bit and I don't mean that to sound patronising. But I really think it's a very special skill and you know it's ironic because it's always the thing that gets left to the very end as if it was the least important part of the review, when actually we know it is the most widely read version of any review and we spend the least amount of time on it.*

Consumers may comment on some summaries because of lack of time or lack of volunteers.

Review Group Three commented:

*If I've got the luxury of two or three weeks then I'll send it [to a consumer] out but other than that I frequently do it myself. (Review Group Three)*

Review Group Four asks the same consumer to work on all of their summaries:

*We've found it better to concentrate on one person, because their understanding of our reviews increases and is more helpful... (Review Group Four)*

Consumers were clear that the plain language summaries are very important:

*They're very useful because they are nice and plain and simple really, they do bring it right back to basics and provide a nice little snapshot. I've used them a lot... (Consumer C)*

They were also clear that consumers have a key role in preparing them or commenting on them:

*I remember when I was doing refereeing I worked very, very hard to make sure that the plain language summary they had was a plain language summary and did accurately reflect what the conclusions were, what the analysis was, instead of having it be not reflective of what the analysis was... but I think it's critical because most people don't have the expertise... you have to make it accessible for them and for healthcare journalists. (Consumer A)*

*Health professionals may prefer medical jargon, hence fail to recognise when simplification is necessary for consumer purpose. Reviews which are too technical or complex would be off-putting for most consumers to wade through. (Consumer E)*

## **6. The level of impact consumers have in review groups they are involved with**

### **6.1. The perspectives of Review Groups**

I asked each of the Review Group interviewees if they could give me an example of consumer involvement which had made a difference in their Review Group. This isn't easy for people to do, as one interviewee pointed out:

*It's very often on just clarifying things where we've been too jargon-y, so we'll untangle that, particularly in the abstract or the plain language summary... So I particularly value [the consumer's] input on that, but I couldn't easily give you a before and after how [the consumer] changed anything. (Review Group One)*

However, three Review Group interviewees were able to offer examples of where consumer involvement had had an impact. In one, the involvement of consumers led to increased publicity for a review and highlighting to researchers the need for further

research in an area. This Review Group has also noted that reviewers are often positive about the feedback from consumer reviewers:

*I do ask the editors for feedback on the consumer comments and for the most part the feedback's positive. I mean it does, it is a sort of distinct fresh set of eyes, somebody who doesn't work in the field necessarily, but lives with the condition and their impression of the medications or the treatment might be different than the person who's more in the research side of things or the clinical side. (Review Group Two)*

In Review Group One, the involvement of a consumer led to the development of a glossary:

*And also we did something prompted by [the consumer]... not that [the consumer] asked for but I could see that she was struggling with some of the terms... So my colleague and I put together a glossary... And that was directly from, I don't think we would have dreamed of doing that if we hadn't, if [the consumer] hadn't struggled.... (Review Group One)*

For this Review Group, simply being able to meet Cochrane requirements had an impact:

*We were repeatedly being criticised by the Monitoring and Registration Group because we had no consumers and my colleagues said well so what, we're not interested. But I like to tick the boxes, even if they're less important. And it was nice to be able to turn around and say to the MRG, you know, we've got a consumer... (Review Group One)*

Review Group Three has two consumers on its board. This is seen to be very useful:

*The two consumers that we have on our board absolutely bring a different perspective to the wording of our policies, to the working of our procedures. They bring their expertise from their professional lives... They really give wonderful input... (Review Group Three)*

However, there are also some negative impacts, as Review Group Two pointed out:

*One of the downsides that we've noticed is that sometimes... the consumers forget that this is somebody's major project that they've worked two years on and they can be a little bit harsh in their.... So sometimes like we have even edited some consumer comments if they're a bit too hard, you know, so we kind of gently remind people you know, if it's, even if it seems ridiculous to you, don't write that it's ridiculous, offer some alternative.... In terms of negative feedback from editors, I think that's what we hear sometimes... But for the most part consumers have really enriched the reviews when they've finished. (Review Group Two)*

## **6.2. The impact of involvement, from a consumer perspective**

All of the consumers I spoke with found it very hard to comment on whether their involvement had had any impact. Only one consumer could give an example of where she knew she had made a difference:

*There was one [review] where I said what it says in the text and what it says in the forest plot doesn't agree. This went backward and forwards two or three times until in the end the author said yes you're right the statistics aren't the way I saw them they're the way you see them... If you go onto the [name of review group] website, if you go onto the list of reviews, and search [her name], all the ones I've written will come up, because it actually mentions my name and [name of voluntary organisation]. That's important. (Consumer B)*

## 7. How consumers are supported to be involved in Review Groups, and the level of commitment to this

### 7.1. Training offered to consumers

One Review Group (Review Group Two) offers face-to-face training to consumers in the country where the Review Group is based:

*Mostly we have to go right back to square one and sort of explain Cochrane, Cochrane reviews but even more than that where the information comes from so even concepts of evidence based medicine and how a clinician would make a decision and why it's important to look at evidence and things like that you know... right from the beginning. (Review Group Two)*

The other Review Groups I interviewed provide written materials to help consumers who are reviewing of protocols or reviews:

*They get the same materials as everyone else does. So they get a welcome CD and it's got... the handbook, we include our guidelines... what reviews we already have, our newsletter, that type of thing, and everybody gets that... And then we offer them a CD if they don't have access to the Library. (Review Group Three)*

*We don't really provide training... We provide any training materials that we can find in the resources. (Review Group One)*

Two of the Review Groups (Groups One and Four) I interviewed were interested in providing training, but did not feel they had the resources to do this themselves:

*I honestly don't think that we have the time or the prepared resources to offer it ourselves, but if you get someone with basic literate skills, a disciplined focussed way of reading, you know and without too much of their own agenda, then you should be able to sit them down for a half day's training and just take them through a review. (Review Group One)*

### 7.2. What training would consumers find useful?

Consumer B found a course on systematic reviews to be very useful. Consumer F felt that training on statistics would be useful. Consumer C would have welcomed more online training materials on the CCNet website. Consumer A, who leads a non governmental organisation, commented:

*What would be helpful to me is not the training to be a consumer referee because I know how to do that. What would be helpful to me as a head of major organisation that is critical of health policy... would be like coming to a half day or even a day where I would be very clearly told, informed, how can I use the Cochrane Collaboration information and infrastructure technologically and what are the costs, and does it cost me \$2,000 a year to have my constituency access the Cochrane Collaboration information? Is really the Cochrane Collaboration data only available to people who are wealthy or to organisations who are wealthy?*

### 7.3. The provision of support

Some of the Review Groups I interviewed felt they struggled to support 'their' consumers.

*I don't think we're doing that very well if I'm honest... I don't know that we give enough support... We're not giving ongoing support, we give advice if they ask us questions for a*

*particular review we simply send the information we have about the form and how to fill it in... We'd welcome any advice on how we go about that... (Review Group Four)*

The key type of support offered is advice on how to complete a review:

*Telephone support for when somebody's working through the review, so they can call us whenever they want, we offer them if they are having trouble with printing something out then we will print for them, if they need other information from the review like sometimes it sparks other interests and they'd like a copy of an article or something like that, if it helps them, then we help them with that. (Review Group Two)*

One problem is how to keep consumers engaged when there may be little for them to do over long periods:

*I've only had one or two reviews in the last year that have been finished and come in... So the consumers started saying have you forgotten me? (Review Group Three)*

Review Group Two has a consumer who provides a lot of support to other consumers:

*She sends encouraging emails and she's set up a way for new consumers to team up with old, more experienced consumers to do things. So she does the bulk of keeping everybody enthusiastic and engaged.*

Two Review Groups reported using feedback to help consumers develop their skills. One commented:

*We polled our consumers last year at [a Cochrane meeting] and asked them like what do you need, what do you want, what do you like about volunteering and one thing they do want is feedback. (Review Group Two)*

There were also mixed views about how supported consumers felt by their review groups. One consumer drew her main support from the voluntary organisation for which she works - although she felt recognised and respected by her review group. Another felt she was supported by a colleague when she needed advice. Another had a very clear idea about the kind of support she would find useful from her review group:

*You know I've done my reviews and then I don't know ultimately what happens to them... I would love to have somebody send me when there's a [name of condition] review that's published, I'd love to see the fact it was published. I'd use it, I would reference that on my website I'd say to my people I'd say OK there's been a new Cochrane Collaboration review published in the BMJ or published in wherever, but I don't ever get those notices.*

Consumer C, who is new to involvement, felt that some kind of personal contact would be helpful:

*Say for instance there was another consumer near me I'd probably take the time to contact them, you know what I mean... Something I wouldn't mind from my [Review Group] is to perhaps know who the Australian members are and where they are... whether they're near me basically, I guess it does just feel like a purely online thing at the moment...*

Consumers had mixed views about whether their skills were recognised by the review groups they worked with. One consumer felt that she may be being ignored:

*At the beginning I was getting a lot of reviews... And I got very good feedback from the people who had asked for the reviews,... But I have not done one in the last year and I*

*thought to myself but I've seen no notices go out, so I don't know whether or not some people got upset... or whether I haven't got all the notices, or whether people aren't doing them...* (Consumer A)

Another felt she was treated *as an equal* by her Review Group.

#### **7.4. The level of commitment to consumer involvement from Review Groups**

The Managing Editor is key to the promotion of consumer involvement on a day-to-day basis in three of the four Review Groups I spoke with (in the fourth, a member of staff who is not the managing editor has responsibility for consumer involvement). However, the Coordinating Editor also has a key role:

*The director [of the Review Group] he values the consumer input quite a lot, and he's created this...* (Review Group 2)

*He [the Coordinating Editor] encouraged us to attract as many consumers because he knows that that's part of what the Cochrane remit is... So it's not an isolated stand I've taken.* (Review Group 4)

In some Review Groups, the Coordinating Editor does not support consumer involvement:

*Our Group generally is not interested in consumers as a point of policy if you like, but I am personally and think they have a role to play. So I've been told you get on with it if you want to but don't ask us to spend time on it... It's not quite as negative as I'm making it sound. My co-ed has the philosophical view that I think many would share in the Collaboration that the only legitimate area where consumers should participate is to comment on the plain language summary.* (Review Group One)

In Review Group Four, the motivation to involve consumers *comes from the fact that Review Groups are told that they should have consumer input in their reviews.*

### **8. The role of CCNet in supporting consumers within the Collaboration.**

#### **8.1. Views about CCNet**

All of the interviewees (Review Group staff and consumers) were positive about the vision of the Cochrane Consumer Network.

*[The vision] is probably why I thought you know I have to find out more about this and I have to see what the deal is and to try and get involved a bit.* (Consumer C)

*If you were going to ask me what did I think was the point of the Consumer Network that would pretty much sum it up, so it just seemed to me a very clear formulation of that they should be doing.* (Review Group One)

Interviewees did not feel well informed about CCNet. Some did not see this as a problem, feeling that they did not have the time and did not need more information. One interviewee did want more contact with the Network, but felt unsure who to do this with:

*I guess what makes our consumer group work is the personal relationships we have with the people, so if we knew somebody who was, we happen to know Janney, but she's involved in so many things, sort of like, who's the face of the Consumer Network, who could we talk to if we had somebody that was sort of like a personal connection we could make I guess that would make it easier for me to connect. It's just contacting them, it doesn't seem very....* (Review Group Two)

None of the people I interviewed felt able to comment on how CCNet should be managed, although one, when asked about whether CCNet could be managed by a geographical centre, felt that this was a possibility.

### **8.2. Support provided to consumers by CCNet**

I asked consumers whether they felt supported or engaged by CCNet. It was hard for most consumers I interviewed to comment, as they had not engaged with it beyond receiving CCNet emails. One consumer had found the CCNet email list very useful:

*A couple of times I sent emails to the entire group, saying is it really necessary to have the number of people total in the plain language summary, and I got answers from all over the world, I was actually dead impressed.* (Consumer B)

Another consumer, who had initially been excited by reading the information on the CCNet website, felt that the reality of involvement in CCNet was disappointing:

*Because I read all the stuff on the website and I thought gosh that's really interesting I should sign up for that and have a go and see what happens. So I did, and the actual lived experience of that if you like I... was in fact just getting a lot of emails saying would you like to review this, you know, you can review that, I guess the reality of what it seems like I was getting myself into doesn't necessarily match what the reality is... Like it's OK and I'm not saying I don't want to do it any more but I'm just thinking there's probably got to be some kind of different way to set things up so you don't just get sort of bombarded with all these emails because I sadly delete just pretty much all of them because they're not necessarily very relevant.* (Consumer C)

### **8.3. Should consumers 'belong' to CCNet or to a Review Group?**

The consumers I spoke with who had been involved in Cochrane for some time felt that their allegiance was first to their Review Group.

*I belong to the review group. I get the emails from the Cochrane consumer group but actually the majority I just delete.* (Consumer B)

But two expressed an interest in linking more closely with the Consumer Network:

*My interest however for the future is to be more involved in the consumer group in terms of networking... So I would like to get involved and network with more people.* (Consumer A)

Review Groups had different views about whether consumers should link more closely with Review Groups or with the Consumer Network.

Two interviewees felt that the primary allegiance is (or should be) with the Review Group:

*I don't think they would associate themselves as members of the whole Collaboration I think they would think that they are members [of the Review Group].* (Review Group Two)

*If you're going to be a consumer, you're going to be a consumer for all intents and purposes because you or your family or job is affected by a specific disorder... If for example I had a family member die of cancer or have heart disease or whatever, I wouldn't necessarily want to be a consumer for inflammatory bowel. I wouldn't have any real interest in it...* (Review Group Three)

But there was also recognition that if a consumer linked with one review group they should be encouraged (or at least informed about opportunities) to get involved in other review groups:

*I think some of them for sure would be wanting to be part of Cochrane in a wider way... A lot of people must have co-morbidities..* (Review Group Two)

*I think the skills are transferable between groups... It's got to be a balance between the two. But on the other hand once you've got those consumer skills and commitment it should be shared around between groups.* (Review Group One)

*I think that you get a different slant... If you get someone associated with a group, I think by and large they have one of the illnesses, conditions associated with that group or they know someone who has and the other way you're going to get people who are very review aware and... they're not going to be able I think to put the illness slant, the reality of what it's like to have (name) condition... I would have thought it's better if you have people who are suffering from, who want to know about a particular condition for their or their family benefit... Whereas the other way is going to be more interested in the review process... A mixture of the two sounds ideal.* (Review Group Four)

#### **8.4. How should CCNet work with Review Groups?**

Some of the Review Group interviewees had clear ideas about how CCNet could support them, or is already supporting them. Often this related to the resources offered on the CCNet website:

*I have found the resources that they've got there helpful to direct my consumers to. I like the fact that they've got some of the helping terms of how do you figure out a systematic review and dah-di-dah. I like that stuff and that's helpful.* (Review Group Three)

*I already use some of the resources on the Consumer Network... CCNet is the node for all of that and that would be my first port of call, so it already helps us from that point of view* (Review Group One)

*If they had training materials or other sort of information that they give to new consumers then I would like to have some kind of knowledge exchange where maybe we could compare notes and figure out what's worked for other groups, if they could be a clearing house for information that would be good..* (Review Group Two)

It also related to advice or guidance offered:

*We wanted to change the recommended structure of the plain language summary... and we emailed Janet Wale because...we wanted to change the structure of the headline... Janet emailed us back and said I think that's much, much better than the recommended format, so since then, as we re-write our plain language summaries, we've been turning them into questions, and that we wouldn't have done without CCNet's approval, because in our book they're the arbiters of this sort of thing and I trust them before I trust some handbook...* (Review Group One)

One interviewee felt that CCNet could play a role in encouraging consumers to get involved in reviews at an earlier stage in the development process:

*All Managing Editors are informed of new titles as they're registered... If someone within the Consumer Network listed all titles that were registered in a week, or a month or*

*whatever, and circulated that list to consumers, then those people who were attracted or interested or thought they could have an input or whatever, then those people could contact the review group... We'd just sort of fall down and be delighted if somebody sort of came to us... (Review Group Four)*

This interviewee also felt that the Network had a key role to play in convincing Review Groups of the value of consumer involvement:

*I would suggest that it might be slightly daunting for a consumer if they were not exactly rebuffed but not encouraged by a Review Group, that would certainly put me off... I think it's really going to have to come from Review Groups. So maybe your challenge is to involve Review Groups to get them to see the benefits. (Review Group Four)*

One interviewee was concerned that CCNet acts as a support group which encourages people to express negative views. She was concerned that she was expected to engage with this:

*If in fact the Network is giving voice to people who don't feel they have voice, for whatever reason, then fine. If it makes them feel better then I have no issue with that. But if I am required to feed into that I'm less convinced that that's my role. (Review Group Three)*

## **9. The role of the Collaboration's leadership in relation to consumer involvement**

I asked all of the interviewees about the Collaboration's leadership with regard to consumer involvement. One felt that there was a need for more guidance:

*I think compared to other organisations they do a good job of engaging consumers. They have the stipends and they encourage, there's a lot of camaraderie at the symposiums and colloquiums amongst the consumers, so I think they're on the right track really... But we don't really instruct them on what they're meant to accomplish by the end of it, or any purpose... If the Collaboration had a certain objective for how they wanted to use consumers that might be something to look at. (Review Group Two)*

There was also seen to be a need for clear leadership:

*It would be interesting to know what the editor-in chief's view of the Consumer Network, the advantages... We get directives of things we have to put into reviews... it's trickling down... you have to have that trickling down that you have to have consumer input if that's what the Collaboration wants. (Review Group Four)*

Another interviewee felt that there was already too much emphasis placed on consumer involvement:

*I think the Collaboration has to figure out whether they are producing a product or are they trying to cure the ills of the world... You cannot produce a top product when you tell everybody in the world that they have got the right to write a review... [Interviewer: Would you like that kind of message to be coming out of the Collaboration Steering Group, this is the role of consumers, it's not to write reviews?] Yes... I don't want somebody telling me that my Group isn't doing well because we're not giving enough voice. Or I'm not involving enough, or whatever, and that's part of what we're being expected to do, and that's what I take exception to. [Interviewer: And that's what it feels like, that the Collaboration leadership is pushing that?] Yes. (Review Group Three)*

The consumers I interviewed found it hard to think about how the Collaboration could change in order to promote or provide leadership about consumer involvement. For some this is because of lack of time.

For others, it did not seem relevant:

*I don't really know that much about the formal structure of Cochrane above the review group. I could always go onto the net and read it but I've just never been that interested... As to how it's financed and all that kind of stuff, I haven't got a clue, and to be honest I don't really care.*

One consumer thought it would be important for the leadership within the Collaboration to engage with consumer organisations, and to support them to act as advocates for the Collaboration. In response to a comment that consumers in some countries have free access to The Cochrane Library, she commented:

*I sit here in Washington and say [name of organisation] adopts a platform of things that they want to see changed in health policy and we have one of those things be the Cochrane Collaboration database should be available to any US citizen who wants it and then we would feature it on our website and we would make sure that we advocated for the Cochrane to have a robust operation here in the United States. (Consumer A)*

#### 10. How do the interviews help us to address the aims of this review?

These interviews do not help us to answer the first aim of this review, about where CCNet should be *positioned* within the Collaboration. It's hard to address this question unless you are closely involved in the 'centre' of the Collaboration (i.e. active in the running of the Collaboration rather than of a Review Group), or are an active member of CCNet. However, these interviews do give us more information about the *role* of CCNet.

- CCNet clearly has an important role in recruiting consumers, acting as the signpost to Review Groups. With the time and resources, 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, unless there is good reason for this not to happen.
- CCNet also has a role to 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 helps Review Groups that struggle to recruit consumers.
- One Managing Editor suggested that CCNet could 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. This seems a very useful idea.
- The CCNet website and CCNet activists have a key role to play in acting as a resource for Review Groups and consumers to draw on. It would be helpful to remind consumers and Managing Editors about 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 - there is potential for development here if resources allowed.
- Again if resources allowed CCNet could do more to help Review Groups to support consumers to remain involved - perhaps by encouraging feedback to consumers - both about reviews they have undertaken and alerting them when new reviews in their area of interest have been published.
- CCNet already offers advice to some Review Groups on issues relevant to consumer involvement - this role could be strengthened and publicised to Managing Editors.
- CCNet also already offers some training, both face-to-face and online. Again there is potential for more to be done.

- CCNet could also do more work with consumer organisations to encourage the dissemination of reviews, and especially of plain language summaries.
- Finally, 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.

Although interviewees did not directly address the third aim of the review, i.e. how the Network should be **managed**, this report does suggest that CCNet needs to be centrally placed within the Collaboration.

Bec Hanley, External Consultant

### **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. 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.

## Appendix 4: Membership of Consumer Involvement Advisory Committee

NAME	COUNTRY	Role (and/or main association with Collaboration)
Lorne Becker	USA	CCSG Co-Chair Executive Group (Convenor) (2006-2010) Convenor, Publishing Policy Group
Giovanna Ceroni	UK	Business Manager, Cochrane Editorial Unit
Mike Clarke	UK	Director UK Cochrane Centre Former CCSG Member & Chair (1998-2004)
Liliana Coco	Italy	Managing Editor, Multiple Sclerosis CRG
Kay Dickersin	USA	Professor at Brown University School of Medicine Director, US Cochrane Center Member Colloquium Policy Advisory Group (CPAG) Former CCSG Member (1995-1996)
Gill Gyte	UK	Research Associate, Pregnancy & Childbirth CRG Member CCNet Former CCSG Member (1997-2000) Former member of CCNet Governing Council/Coordinating Team Former Consumer Coordinator Pregnancy & Childbirth Consumer Panel
Bec Hanley	UK	Consultant for involvement of patients, carers and the public Former Director of INVOLVE Support Unit Member CCNet Contributor to recent review of CCNet
Sophie Hill	Australia	CCSG Member (Co-ordinating Editor rep) (2009-2012) Co-ordinating Editor Consumers and Communication CRG
Dell Horey	Australia	Research Fellow, La Trobe University Editor, Consumers and Communication CRG Member CCNet Former Australasian Consumer Coordinator Pregnancy & Childbirth Consumer Panel
Lucie Jones	UK	Cochrane Collaboration Secretariat Project Support and Business Communications Officer
Tamara Rader	Canada	Knowledge Translation Specialist, Musculoskeletal CRG
Nick Royle	UK	Cochrane Collaboration Secretariat Chief Executive Officer (CEO) Member Executive Group Member Colloquium Policy Advisory Group (CPAG)
John Santa	USA	Consumers' Union Director, Health Ratings Center, Consumer Reports
Mary Ellen Schaafsma	Canada	CCSG Member (Centre rep) (2009-2012) Member Executive Group Institute of Population Health, University of Ottawa Executive Director, Canadian Cochrane Centre
Silvana Simi	Italy	Institute of Clinical Physiology, National Research Council Member CCNet Member CCNet Geographical Centres Advisory Group Former member CCNet Coordinating Team Former CCSG Member (2001-2004)
Norman Swan	Australia	Producer and broadcaster, Australian Broadcasting Commission Producer and presenter of the <i>Health Report</i> (ABC Radio) (Background in Paediatrics) Consultant World Health Organisation
Victoria Thomas	UK	Ass. Director, Patient & Public Involvement, Nat. Inst. for Health and Clinical Excellence (NICE)
David Tovey	UK	Editor in Chief, <i>The Cochrane Library</i> , Cochrane Editorial Unit Member Monitoring and Registration Group Convenor Information Management System Group (IMSG)
Janet Wale	Australia	Convenor, CCNet Consumer Editor, Bone, Joint & Muscle Trauma CRG Former CCSG Member (2003-2009)
Liz Whamond	Canada	CCSG Member (CCNet) (2007-2010) Canadian Cancer Action Network Member CCNet Member Monitoring and Registration Group Member Cochrane Library Users' Group (CLUG) Member Colloquium Policy Advisory Group (CPAG)
Mingming Zhang	China	CCSG Member (CCNet rep) (2009-2012) Member CCNet Chinese Cochrane Centre, Chinese EBM Centre Member Colloquium Policy Advisory Group (CPAG)

## Appendix 5: Definitions of the term consumer across the Collaboration

An unexpected result in the preparation of the background paper for the CCSG Strategic Session on consumer involvement was the difficulty in finding a commonly used definition for ‘consumer’ across the Collaboration. Difficulties with the term were established by the following note on the CCNet website: *“We have adopted the term consumer as it is already widely in use in The Cochrane Collaboration and because it is difficult to identify any other term that is more universally acceptable. The term ‘consumer’ may not be considered appropriate among some groups of people or in some countries. It is associated with buying or choosing a health service. Other terms may be preferred, such as user or receiver of health care, patient, a member of the public, citizen, carer/caregiver, or lay person. Each of these terms have different connotations in different environments.”*<sup>1</sup>.

It took a few inquiries before I was directed to the Collaboration glossary where I found the following definitions:

**“Consumer (healthcare consumer)**      *Someone who uses, is affected by, or who is entitled to use a health related service.”*

**Consumer advocate or representative**      *Consumer who is actively involved with other consumers and able to represent the perspectives and concerns of that broader group of people. Consumer representatives work in Cochrane **entities** to ensure that consumers’ views are taken account of when **review** questions are being decided and results presented.”*<sup>2</sup>

In my search I found that there have been some slight adjustments to this definition, The *Policy on Consumer and Developing Country Stipends* published in November 2009<sup>3</sup> includes a partial exclusion *“and who is generally not a health professional or practitioner”*.

I also found this explanation on the “Getting Involved” page of the Collaboration website<sup>4</sup> for newcomers: *“Consumers are the recipients of healthcare (patients or clients). Every Cochrane Review Group aims to have members who will represent the consumer viewpoint in deciding which reviews are done, what questions on which they focus, and how the results are presented. Consumers are the recipients of healthcare (patients or clients). Every Cochrane Review Group aims to have members who will represent the consumer viewpoint in deciding which reviews are done, what questions on which they focus, and how the results are presented.”*

Several review group modules on The Cochrane Library generally expand the definition of consumer to included carers and family, but others do further. The Public Health CRG consider consumers of public health interventions to include “general citizens as well as users of reviews from within government health agencies, non government organisations, schools, sporting organisations, transport and other sectors”; Schizophrenia CRG define consumers as “anyone reading and wishing to be informed by the reviews”; Tobacco Addiction CRG defines consumers as “individuals who smoke, and policy/public health interventions for tobacco control; Wounds CRG considers their review consumers to be those to whom the reviews are targeted, “e.g. doctors and nurses”.

---

<sup>1</sup> See <http://www.cochrane.org/consumers/cinc.htm>

<sup>2</sup> Green S, Higgins J, editors. Glossary. Cochrane Handbook for Systematic Reviews of Interventions 4.2.5 [updated May 2005]. <http://www.cochrane.org/resources/handbook/> [(accessed 22 February 2010)]. See also <http://www.cochrane.org/resources/glossary.htm>

<sup>3</sup> See <http://www.cochrane.org/colloquia/cpag/consdevcounstipends.pdf> page 3

<sup>4</sup> See <http://www.cochrane.org/docs/involve.htm>

## Appendix 6: Person specification: Service user commenting on research

SOURCE: NETSCC, HTA (2009) Why the Health Technology Assessment programme asks service users to comment on research Peer Review Guidance: Part 1. Southampton. Downloaded 14 February 2010 (See [www.hta.ac.uk](http://www.hta.ac.uk))

### Person specification: Service user commenting on research

Factor	Essential attributes	Desirable attributes
Experience	Special understanding of particular aspects of health. Representing rights and interests of service users or willingness to learn.	Having good links through service user networks/ associations/ organisations/ societies/ groups.
Special skills	Willingness to familiarise yourself with medical and research language.	To keep up to date with current service user issues via service user networks/media.
Specialist knowledge	Knowledge of service user perspectives and able to consider the questions that patients may ask.	Be research aware, i.e. understand the purpose of research within the NHS but do not necessarily have skills in research methods
Personal qualities	Good communicator. Ability to express own views in writing.	Willingness to give feedback to the NETSCC, HTA and

## Appendix 7: Consumer members of the Cochrane Collaboration Steering Group 1995 to 2010

Name	Country	Term of office	Time on CCSG
Bastian, Hilda	Australia	April 1993 to October 2001	8.5 years
Jones, Jean	Canada	February 1996 to October 1997	1.5 years
Gyte, Gill	UK	October 1997 to October 2000	3 years
Ochieng, Samuel	Kenya	October 2000 to October 2003	3 years
Simi, Silvana	Italy	October 2001 to October 2004	3 years
Wale, Janet	Australia	October 2003 to October 2009	6 years
Aja, Godwin	Nigeria	October 2004 to October 2007	3 years
Whamond, Liz	Canada	October 2007 to October 2010	3 years
Mingming Zhang	China	October 2009 to October 2012	3 years

## Appendix 8: Summary positive benefits and negative impacts from consumer involvement in research

Staley K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh.

In November 2009 INVOLVE, the national advisory group that promotes and supports greater public involvement in the National Health Service (NHS) in the UK published a structured review of the literature relating to the impact of public involvement on research (go to:

[http://www.invo.org.uk/All\\_Publications.asp](http://www.invo.org.uk/All_Publications.asp)).

The review used a framework to help categorise evidence of different types of impact and draw out themes. The authors found a number of factors that whether involvement makes a difference, including: long-term involvement, involvement throughout the project, and training and support for the people involved.

There are several areas in which the report has relevance to the work of the Collaboration.

First, although the literature relating to data analysis was largely concerned with qualitative data, similar benefits from public involvement are feasible in regard to systematic reviews, such as:

- Help to check the validity of researchers' conclusions,
- Correcting data misinterpretation,
- Identifying themes that might have otherwise been overlooked,
- Identifying the findings most relevant to consumers, and
- Improving the description of results in reports.

Consumer involvement in data analysis has also created greater sense of ownership of findings and researchers have found it helped to make their writing up more direct, accessible and useful to target audiences.

The literature review also found reports that public involvement in dissemination increased the likelihood of action from the findings, by changing policy and practice and by changing awareness, knowledge and attitudes.

Second, positive and negative impacts on the consumers involved were identified

Positive benefits included:

- the acquisition of new skills and knowledge, in particular, better appreciation of research and the processes involved
- personal development from increased self-confidence and self-esteem
- support and friendship
- enjoyment and satisfaction from feeling useful, being part of a team, being able to forget about themselves, and being involved in something meaningful and personally stimulating
- financial reward.

Although reports of negative impact from consumer involvement are less common, they include being:

- emotionally burdened from hearing about the hardships of their peers and being reminded of negative experiences.
- overloaded with work
- exposed through the media
- frustrated at the limitations involvement.

The third area is the impact on researchers. Again this was found to have both positive and negative impacts. Positive benefits include:

- better knowledge and understanding of the community
- enjoyment and satisfaction
- career benefits
- challenges to beliefs and attitudes.
- The reports of negative impact include:

- increased demand on resources and a slower pace of research
- loss of power
- forced changes in working practice
- challenges to values and assumptions.

## Appendix 9: Managing Editors' use of CCNet email list

### Using the CCNet email list for consumer input into Cochrane protocols, reviews and plain language summaries

The CCNet email list (the list) is increasingly used to elicit consumer feedback. Twelve review groups reporting using the list in the CCNet Review (26%) so I investigated their experiences in more detail by looking at how the list was used over the six month period between September 2009 and February 2010.

Twelve review groups used the list in this time generating 28 requests for input into more than 15 reviews and a similar number of protocols. In addition there was one request for advice on the process of developing plain language summaries (PLS) and back translations. I looked at what the requests included and emailed the 12 Managing Editors (MEs) or Assistant MEs who made the requests with some questions about their use of the list. These included: when they used the CCNet email list, others ways they got consumer input, their opinions about their requests for feedback, what they liked about the list, and what, if anything, could be better? . Seven MEs replied (58%).

### What requests include

Analysis of the requests to the list showed considerable variation in the approach used by MEs. All requests included the title of the protocol or review but other processes differed. For example, one group attached documents to their request, while the remainder asked interested people to contact them so that the material could be sent directly. Most requests related to a specific protocol or review, but on occasions the email request listed several protocols, reviews or both. Requests included either a due date for comments or a time period within which comments were due (usually 2 or 3 weeks). In one case it wasn't clear when comments were expected.

Two different review groups explained that their group had an open peer review process; one group explained what this meant. A third review group offered anonymity as an option for consumers.

Several requests included additional information about the review, such as an extract from the review or the draft PLS. (Later I was told by a ME that on one occasion a consumer had returned an edited version of a PLS included in a request. It concerned her that someone had spent time doing this when their work couldn't be used by the group as the person hadn't actually read the review.)

A range of resources were offered with some requests, including: information about the review group, checklists (either specific to consumers or standard for all peer reviewers), and advice about the availability of web-based courses for consumers.

Few review groups made any specific undertakings, but those that did offered to include acknowledgement in the published protocol or review, to send a copy of the published protocol

or review, to send a copy of all peer review comments, or to send the authors' response to comments.

### When CCNet email list is used

Five review groups reported that they use the list as part of their regular peer review process for protocols and reviews, although one of these has only just started. It is the only way one group gets consumer input. Previously this group had a voluntary consumer coordinator who worked with a small panel. The list provides input from a broader group of people.

Two review groups use the list occasionally to supplement their usual method of consumer review. Both groups have small panels of consumers that they call on regularly. One group uses the list when they have a topic of wide general interest and the other when they cannot easily allocate a submitted protocol or review to a consumer panel member, either because there are no clear links to their skills and interests, or because of recent frequent reliance on those consumers, or to broaden the pool of consumers to draw on.

### Other ways to get consumer input

Other ways that most groups found consumer input was using consumer panels associated with the review group (although the term 'panel' was not always used). Generally panels included people with an interest in the topic area or who had previously given thoughtful and high quality feedback.

Groups that are in health areas not usually associated with support organisations or charities can find it difficult to identify relevant consumers. Sometimes the nature of the health conditions can limit consumer involvement, or if a disease occurs rarely, can make it hard to find someone who knows about the specific disease.

MEs gave examples of their efforts to find suitable consumers including: contacting patient associations in several countries (sometimes searching for them on the internet); publishing short articles in patient organisations' newsletters; distributing leaflets in clinics; targeting specific people through clinical contacts; and asking friends with the condition.

One group reported that one or two people contact them each year through their website to volunteer to be involved as consumers.

### Response like to requests for feedback

All MEs described the response from the list positively. The success rate for comments for one group was about 30 percent but generally the MEs found it uncommon to have no response. Some groups regularly had two or more consumers contacting them after a request appeared on the list. One ME reported that "For 'high interest' reviews it is not uncommon to receive a dozen responses from the CC-Net list over a few days, including people of both genders and from a range of countries internationally". However, when there is a lot of interest, it can be difficult to select the most suitable consumer. Most groups appeared to operate on a "first come" basis.

Most MEs found the feedback to be generally good or excellent with one describing feedback as “comprehensive and timely”. Another said “generally their responses are of very high quality and lead to significant changes in the review.” However two MEs found feedback can be variable. One wrote “Unfortunately, it is not uncommon to receive feedback (particularly from newer consumer members of CCNet) that is of moderate to little value, because it either accepts the review quite uncritically, is extremely minimal, or goes off on a tangent/goes to matters that are beyond the review.” The ME added “This is not always the case, however, and some of the feedback received via the CCNet list is very useful and engages well with the subject matter and style of the review from a consumer perspective.”

#### What MEs like about the CCNet email list

There were several benefits from the list identified by the MEs: the diversity of the people responding, including people from developing countries; easy access to people who identify as consumers and are willing to be involved; participants usually already had knowledge of the Collaboration and Cochrane methods; the success rate with responses was considered good; and the list was seen as “an interesting and friendly forum”.

#### What MEs think could be better about the CCNet email list

Some concerns were raised by MEs in response to the question about where things could be improved. The most important related to concerns about confidentiality. At least two draft reviews were sent to people from the list for comment who did not respond and were subsequently identified with an industry link, specifically working for/or advising a pharmaceutical company.

Another concern, raised by two groups, related to the issue of what a 'consumer' means. One ME said that “often the consumer turns out to be a researcher or other health worker with good health/content knowledge. Not sure that this is the whole point of getting a consumer to referee the publications.” Another also had offers from people who were obviously specialists in the area, so instead of getting feedback from a layperson they found that they were getting comments from “yet another medically qualified person”.

A couple of MEs disliked the format of the list or the volume of emails generated by it and another identified occasional problems with understanding the issues raised by consumers without good English. The ME wasn't sure how to address this issue as she wanted to encourage involvement.

#### Suggestions for improvements

The MEs suggested three ways the list could be improved:

- 1) Develop a web-based form that would generate an email to the list and standardise the information included. The form could ask for information such as: group name; ME name & email address; review title; author names; date comments were due and whether it was

protocol or review. The form could include provision for a brief description or objective for protocols and either draft PLS or brief description for reviews, and space for other information.

2) Include standard information from respondents such as a brief description about their interest in the topic (e.g. because of personal experience, membership of a patient organisation, or general interest) to give a more objective way to select from a range of consumer referees who respond to a request.

3) Create a second list so that there is one for discussion between members and another to recruit consumer referees.

## Summary

The CCNet email list is an easy and effective way for review groups to get consumer input into protocols and reviews. Concerns about possible problems were identified that need to be addressed. These relate to confidentiality, the background of the consumer reviewer and understanding when English literacy is low.

**Dell Horey**

## Appendix 10: Consensus-derived principles and indicators of successful consumer involvement in NHS research

Principle	Indicator(s)
1. The roles of consumers are agreed between the researchers and consumers involved in the research	<ul style="list-style-type: none"> <li>The roles of consumers in the research were documented</li> </ul>
2. Researchers budget appropriately for the costs of consumer involvement in research	<ul style="list-style-type: none"> <li>Researchers applied for funding to involve consumers in the research</li> <li>Consumers were reimbursed for their travel costs</li> <li>Consumers were reimbursed for their indirect costs (e.g. carer costs)</li> </ul>
3. Researchers respect the differing skills, knowledge and experience of consumers	<ul style="list-style-type: none"> <li>The contribution of consumers' skills, knowledge and experience was included in research reports and papers</li> </ul>
4. Consumers are offered training and personal support, to enable them to be involved in research	<ul style="list-style-type: none"> <li>Consumers' training needs related to their involvement in the research were agreed between consumers and researchers</li> <li>Consumers had access to training to facilitate their involvement in the research</li> <li>Mentors were available to provide personal and technical support to consumers</li> </ul>
5. Researchers ensure that they have the necessary skills to involve consumers in the research process	<ul style="list-style-type: none"> <li>Researchers ensured that their own training needs were met in relation to involving consumers in the research</li> </ul>
6. Consumers are involved in decisions about how participants are both recruited and kept informed about the progress of the research	<ul style="list-style-type: none"> <li>Consumers gave advice to researchers on how to recruit participants to the research</li> <li>Consumers gave advice to researchers on how to keep participants informed about the progress of the research</li> </ul>
7. Consumer involvement is described in research reports	<ul style="list-style-type: none"> <li>The involvement of consumers in the research reports and publications was acknowledged</li> <li>Details were given in the research reports and publications of how consumers were involved in the research process</li> </ul>
8. Research findings are available to consumers, in formats and in language they can easily understand	<ul style="list-style-type: none"> <li>Research findings were disseminated to consumers involved in the research in appropriate formats (e.g. large print, translations, audio, Braille)</li> <li>The distribution of the research findings to relevant consumer groups was in appropriate formats and easily understandable language</li> <li>Consumers involved in the research gave their advice on the choice of methods used to distribute the research findings</li> </ul>

Telford R, Boote JD, Cooper CL. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations* 2004;7:209–20.

## Appendix 11: Cochrane Consumer Network: Detailed business and operational plan

---

Prepared by Janet Wale, Convenor of the Cochrane Consumer Network (CCNet) with input from the CCNet Advisory Group, February 2010.

Submitted: 22 February 2010

Purpose: For information in moving forward

Access: Open

### Detailed business plan: Cochrane Consumer Network

Evidence-based practice (EBP) is<sup>1</sup>:

- "the integration of best research evidence
- with clinical experience and
- patient values and circumstances"

Each component is essential<sup>2</sup>. Yet the evidence to support evidence-based health care remains unconvincing to the public and the media, policy makers and decision makers.

### Executive summary

*The purpose* of this document is to engage entities within The Cochrane Collaboration in partnering to develop communication strategies and improved, coordinated processes for involving consumers as end users of health care in the Mission of The Cochrane Collaboration.

The document does this by addressing work to date and how it can be measured and moved forward.

*Background:* The role of and issues for CCNet have been clarified through the recent reviews of The Cochrane Collaboration (2008)<sup>3</sup> and the Cochrane Consumer Network (CCNet) and Consumers in Cochrane (2009)<sup>4</sup>. CCNet is now in a position to strengthen its business planning. This document has been developed to better define the required planning and input by all key stakeholders in The Cochrane Collaboration to further end-user involvement. As such it does not provide the solutions.

The reference materials are contained within the accompanying document.

*The desired outcomes* include greater adherence to the Principles of The Cochrane Collaboration, particularly those related to building on the enthusiasm of individuals, avoiding duplication of effort, fostering collaboration, ensuring relevance of the work of the Collaboration, keeping up to date, and enabling wide participation within the Collaboration. The practical experience gained by CCNet to date puts it in a position where it can fulfill a supportive and advisory role for stakeholders in the Collaboration who wish to involve end users of health care in their work.

Through a coordinated partnership model we are able to extend our already existing role in demonstrating to others that involving consumers, patients and the public in the development of evidence-based materials can be measured and does have a positive impact.

*Desired process outcomes could address the following issues:*

Consumers link mainly with Managing Editors of Review Groups: to determine processes for entire Editorial and author teams to be clear about (and committed to) consumer participation.

CCNet has a geographically based Advisory Group of consumers: to determine the support roles Centres and Branches can play for CCNet and its members, including participation in local contributor meetings.

CCNet has, in the last two months, piloted the collection of materials that could form the basis of two databases: the first monitoring the effectiveness of consumer involvement; and the second measuring the support offered to consumers and identifying ways to build on that support. It is envisaged that these databases are centrally resourced to foster collaboration and enable wide participation.

*Benefits* to be gained by The Cochrane Collaboration include increased relevance and usage of The Cochrane Library, its flag ship; and harnessing of the experience and opportunities provided by consumer representatives, advocates and their organisations through their acknowledged commitment to furthering evidence-based practice in health care.

*Next Steps:* The application of this plan requires partnering between key stakeholders representing the various roles and responsibilities with Cochrane entities. CCNet is the registered Cochrane entity responsible for consumers internationally, across the Collaboration. CCNet proposes the formation of a CCNet-led Working Group that has the clear aims set out in the 'Purpose of this document'.

An underlying pre-requisite for the implementation of this plan is commitment by The Cochrane Collaboration to centrally coordinated consumer involvement and for the provision of additional funding and resources.

## **Background information**

The role of the Cochrane Consumer Network (CCNet) is to support and coordinate international consumers working across the Collaboration by enabling effective input into the development and dissemination of Cochrane reviews; open communication, training and support and advisory role opportunities. Consumers work across entities of the Collaboration in a voluntary capacity (Figure 1).

For an organisation such as The Cochrane Collaboration, the contributions made through voluntary input are huge<sup>3</sup>. It is very important that this voluntary effort is shown to be valued – through knowledge about, feedback on, and recognition of that effort.

Consumers have commitment and passion either through personal experience or from the groups we work with. This in itself can present problems to researchers<sup>5</sup>.

The Consumer Network has been formally registered within the Collaboration since 1996. CCNet has a Convenor, Administrator, an international Geographical Centres Advisory Group and Chair; membership of CCNet is as individuals (Table 1). Many of the members have strong links or are part of consumer and patient organisations. Overall, the aims of the members are to contribute to the development of evidence and the practice of evidence-based health care<sup>4</sup>.

The Review of The Cochrane Collaboration<sup>1</sup> and CCNet External Review of Consumers in Cochrane<sup>2</sup> identified that communication about the different components of the Collaboration is lacking.

**The first goal** of the processes defined in this ‘Detailed Plan’ is to increase awareness within The Cochrane Collaboration of the roles and function of CCNet and to have central mechanisms in place for it to more effectively achieve its Vision and Aims:

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

**CCNet Aims:** To enable and support consumer participation in The Cochrane Collaboration; and continue to develop the use and usefulness of consumer participation in The Cochrane Collaboration.

**A second goal** is to engage entities and key stakeholders in a sustainable process for coordinated international consumer engagement within the Collaboration; and ownership of that engagement.

Review authors and consumers/end users of Cochrane reviews are unique in that they form a large part of the voluntary workforce of The Cochrane Collaboration. For CCNet its leadership and management also work in a largely voluntary capacity (Table 1).

See ‘CCNet External Review of Consumers in Cochrane’ for information on consumers working with Review Groups<sup>4</sup>. The recommendations from the Review resulted in the development of a draft ‘Framework for Consumer and User of Health Care Involvement in The Cochrane Collaboration (January 2010)’<sup>6</sup>. [Part of appendix to CCNET Jan 2010 newsletter](#)

**Responses to the CCNet Review** raised key issues around the need to identify and clearly express:

- What The Cochrane Collaboration offers for consumers participating in its activities
- How the Collaboration supports consumers and healthcare user activities overall
- The ways in which the leadership of The Cochrane Collaboration can demonstrate value for healthcare user involvement, particularly as part of the voluntary workforce

The involvement of consumers, patients and the public in health research is recognised as being challenging to researchers<sup>7,8</sup>. This means that raising the profile of consumer and the end-user voice in the researcher/research-based environment of The Cochrane Collaboration is potentially threatening for some. Furthermore, it opens up the issue of

control of the role that patients and the public can have; and of management of funding for that consumer involvement. Indeed national research funding bodies are well aware that researchers define funding for consumer and community involvement with little say by those stakeholders as to how the funding is both spent and accounted for<sup>5</sup>. The declaration of confounding issues by researchers and other stakeholders, including funding for research and projects involving consumers, is a prerequisite for transparency and accountability.

The government level fiscal control of not-for-profit and non-government organisations has led to the professionalism of those organizations. The agenda of many patient and consumer support organisations has in some cases moved away from the individual needs of groups of patients, consumers and communities.

The Cochrane Collaboration is a not-for-profit organisation registered as a Charity in the UK. Its primary purpose is to produce systematic reviews of best evidence on healthcare interventions to inform health care and to work internationally to promote evidence-based practice. These form *The Cochrane Library* ([www.thecochranelibrary.com](http://www.thecochranelibrary.com)).

The fragmented organisational structure of The Cochrane Collaboration<sup>3</sup> makes internal communication particularly challenging. The different parts of the Collaboration are often not fully aware of the activities of others. This was demonstrated clearly in the formal Reviews of the Steering Group (2006)<sup>9</sup>, The Cochrane Collaboration (2008)<sup>3</sup>, and Cochrane Consumer Network (2009)<sup>4</sup>. Yet effective communication and the willingness to listen are key to the success of the Mission of the Collaboration to produce systematic reviews that inform evidence-based health care. Funding of Cochrane entities is generally around the production of systematic reviews, such that within the present culture Cochrane Review Groups are in a position of strength. The Collaboration, therefore, has a need to think carefully about how it can strengthen the supporting, contributing and substance-building roles of other entities.

### **Benefits CCNet activities bring to The Cochrane Collaboration**

Consumers contribute to the readability and relevance of Cochrane reviews by commenting on prepublished reviews and their plain language summaries<sup>4</sup>. ‘Consumers’ bring the user and receiver of health care, consumer, family and carer perspectives<sup>10</sup>. Early input by consumers into the review process is desirable: assisting with setting review topics and prioritising reviews so that the most relevant review questions are approached in a timely manner. Procedural justice is in this way achieved as the process involves the people to whom reviews ultimately apply.

CCNet provides a formal support system within The Cochrane Collaboration for preparation of plain language summaries of Cochrane reviews (Table 1) as a way of communicating the evidence held within *The Cochrane Library*.

It is important that consumers involved within The Cochrane Collaboration are empowered to inform other consumers of the value of systematic reviews and evidence-based health care as part of informed decision making in health care<sup>4</sup>. The Network uses its website and e-mail discussion list to disseminate information from systematic reviews and to keep its members informed. Newsletters, the website and e-mail discussion list are also used to identify consumers to work with Cochrane review groups and in other capacities within the Collaboration. Facebook has been added to the armory to start to address some of the language barriers that are inevitable within an international organization.

CCNet regularly evaluates the input of consumers and their relationships within The Cochrane Collaboration<sup>8</sup>.

### *Identified priority areas for CCNet, from the CCNet External Review<sup>4</sup>:*

- ✚ Provide support, guidance and central resources on participation (for consumers/healthcare users and for staff and other involved stakeholders).
- ✚ Provide training on communication with and involvement of consumers.
- ✚ Encourage feedback and monitoring of consumer involvement.
- ✚ Advocate for closer consumer/CCNet collaboration within The Cochrane Collaboration as compared with the present consultation and communication of information (Figure 2<sup>11</sup>).

### **Measureable outcomes for the ‘Detailed business plan’**

#### Internally

- Clarification of the role of volunteers within the Collaboration and how knowledge about, feedback to, and recognition of consumer involvement is communicated
- Overall acknowledgement of a level of end-user involvement that fits most comfortably within The Cochrane Collaboration
- Development of a quality improvement process between consumers, as represented by CCNet, and Cochrane entities\*
- An identified, accountable mechanism for enabling consumers in the dissemination of information from Cochrane reviews\*\*

\*Such a quality improvement process would work most effectively if all consumers involved within the Collaboration being registered with CCNet.

\*\*Possible mechanisms identified in the CCNet Review<sup>4</sup> were: a ‘Page for healthcare users’ to accompany each Cochrane review; greater healthcare user involvement in the preparation of plain language summaries; distribution of information on newly registered titles in a way that healthcare users can express their interest in assisting with development of a review; being part of the wider dissemination strategies by the Review Groups and the Collaboration.

#### External to The Cochrane Collaboration

- Further formal development of working relationships with the:
  - Health Technology Assessment International (HTAi) Patient and Citizen Special Interest Group,
  - Guidelines International Network (G-I-N) Patient and Public Involvement Working Group, and
  - World Health Organization (through Patients for Patient Safety program).
- Continuing development of the CCNet website to present ‘a face’ of The Cochrane Collaboration for consumers and consumer organisations and the promotion of consumer and public involvement in the processes of evidence-based health care

### **Identifying measurable outcomes**

Desired process outcomes could address the following issues.

Consumers link mainly with Managing Editors of Review Groups: to determine processes for entire Editorial and author teams to be clear about (and committed to) consumer participation.

CCNet has a geographically based Advisory Group of consumers: to determine the support roles Centres and Branches can play for CCNet and its members, including participation in local contributors meetings.

### **Next steps for measurable outcomes**

- Set up a CCNet-led database to monitor the effectiveness of consumer involvement (eg checklists); and 'who' the consumers are\*
- Set up a CCNet-led database to measure the support offered to consumers and Cochrane entities and to build on that support\*
- Demonstrate Collaboration support of consumer involvement by developing these databases centrally through funded positions
- Apply the Principles of The Cochrane Collaboration\*

\*CCNet has, in the last two months, piloted the collection of materials that could form the basis of these databases. Reports on these are contained in the CCNet Monitoring and Registration Report for 2010. It is envisaged that databases be centrally resourced.

\*\*Building on the enthusiasm of individuals, avoiding duplication of effort, fostering collaboration, ensuring relevance of the work of the Collaboration, keeping up to date, and enabling wide participation within the Collaboration.

### **How the outcomes outlined in this document support the objectives of CCNet as a whole**

The process outcomes outlined in this Plan have the potential to do the following.

#### **Within The Cochrane Collaboration**

- ✚ Strengthen CCNet as a central international resource providing and supporting effective consumer participation in the preparation and dissemination of Cochrane reviews
- ✚ Bridge the communication gaps between Cochrane entities, individual consumers and health consumer and patient support organisations through a partnership approach
- ✚ Develop the role of consumers in positively contributing to the function of Cochrane Reviews Groups, Fields, Methods Groups, Cochrane Centres and The Cochrane Collaboration as a whole
- ✚ Further the promotion of patient-centred health care and shared decision making in health care through the provision of relevant, applicable information and a knowledge base for evidence-based practice

#### **External to The Cochrane Collaboration**

- ✚ Increase awareness the benefits of working in partnership with consumers and with an understanding of the issues that are important for the end users of health care in the development of materials to inform evidence-based health care
- ✚ Strengthen links with other groups working with consumers, patients and the public
- ✚ Broaden links with a wider group of consumers, consumer and patient support organisations and users of health care

### **Outcome targets**

The outcomes of this CCNet 'Detailed business plan' are targeted at the fulfillment of evidence-based practice<sup>1</sup> and the provision of evidence that is within the reach of practical application.

### **Reference Documents**

1. Straus S, Richardson SR, Glasziou P, Haynes BR. Evidence-Based Medicine. How to practice and teach EBM. 3rd ed. Elsevier Churchill Livingstone. 2005

2. Greenberg P, Physician Melbourne University Australia. Personal communication
3. Internal review of The Cochrane Collaboration 2008  
www.cochrane.org/ccsg/StrategicreviewofTheCochraneCollaboration.doc - 2008-12-15
4. CCNet External Review of Consumers in The Cochrane Collaboration, focusing on Review Groups (January 2010) at [www.cochrane.org/consumers/happenings.htm](http://www.cochrane.org/consumers/happenings.htm)
5. Involving people in research: A National symposium on consumer and community participation in health and medical research: Perth, March 2008.
6. Draft 'Framework for Consumer and User of Health Care Involvement in The Cochrane Collaboration (January 2010): Appendix to CCNet Newsletter January 2010 at [www.cochrane.org/consumers/resources.htm](http://www.cochrane.org/consumers/resources.htm)
7. Oliver S et al. Involving consumers in research and development agenda setting for the NHS: developing an evidence-based approach. Health Technology Assessment 2004;8:15; Ref 4.
8. Wale JL et al. International Health Consumers in The Cochrane Collaboration: 15 years on. Journal of Ambulatory Care 2010; special edition.
9. Review of the Cochrane Steering Group 2006  
www.cochrane.org/docs/2006\_Review\_of\_CCSCG\_Recommendations\_and\_Response.pdf - 2007-12-12
10. Prioritisation project, criteria for prioritising existing review topics  
[www.cochrane.org/consumers/happenings.htm](http://www.cochrane.org/consumers/happenings.htm); Wale JL et al. The Cochrane Library review titles that are important to users of health care, a Cochrane Consumer Network project
11. Rowe G, Frewer LJ. (2005). A Typology of Public Engagement Mechanisms. Science, Technology and Human Values, 30(2), 251.

### Other links and information

Structure of The CC [www.cochrane.org/resources/leaflet2of5structure.htm](http://www.cochrane.org/resources/leaflet2of5structure.htm)

Cochrane Policy Manual [www.cochrane.org/admin/manual.htm](http://www.cochrane.org/admin/manual.htm)

CCNet reference materials: [www.cochrane.org/consumers/resources.htm](http://www.cochrane.org/consumers/resources.htm)

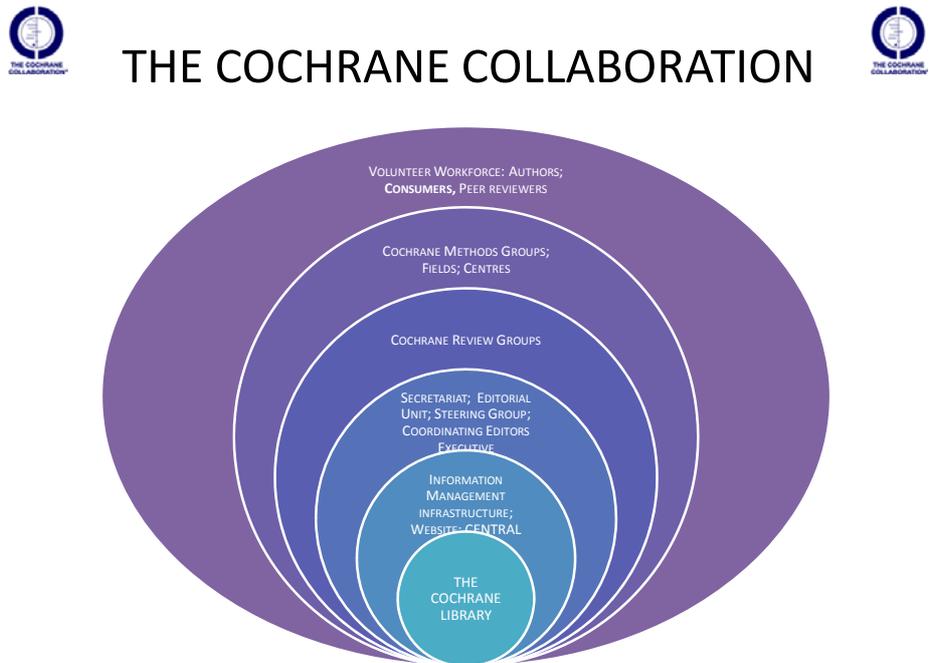
(5) Involving people in research: A National symposium on consumer and community participation in health and medical research: Perth, March 2008. In involving civil society as a part of social inclusion/governance and a source of 'quality assurance':

*Enablers:* Operational capacity (funding and infrastructure/governance); Both consumer and researcher training – to work together effectively; Mutual respect; A standard of/for consumer participation is set at senior leadership level; Concentrate on the common ground (what put in is what get out); Set underpinning principles; Acknowledge and support consumers, as partners; Start being involved at the front end of research; Involve in priority setting (including re funding projects); Evaluate or review (externally) at organisational and not individual level.

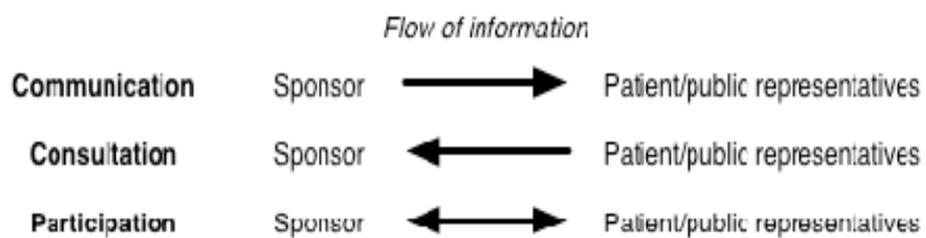
*Barriers:* Lots of people are voluntary, not just consumers; Researchers have concerns about the 'emotions and underlying fears' of consumers; Consumers treated as a resource and do not 'get anything' out of participating; Burnout – as many are patients.

## Figures

### 1. Schematic structure of The Cochrane Collaboration



### 2. Levels of patient and public involvement<sup>11</sup>



## 1. Operational plan of the existing Cochrane Consumer Network (CCNet)

OPERATIONAL PLAN: Cochrane Consumer Network (CCNet)				
	Title/Description	Who is responsible	Region(s) covered	Details
<i>These positions are for CCNet and are separate to roles at a local level, as a Steering Group (SG) member or other</i>				
Convenor		<b>Janet Wale</b>	International	Full time, largely unpaid (if paid: AUD 75,000 plus)
	Management			Day to day; strategic
	Spokesperson			
	CCNet-Contact			External to Collaboration:
	Relations			Internal: links to other Cochrane entities, member of Fields Executive: External: member of HTAi Patients and Citizens Working Group; G-I-N Public
	Publicity			Newsletters, regular articles in Cochrane News; Website content, papers and publications
	Funding			Cochrane Steering Group: Discretionary, Prioritisation
	Monitoring and Registration/Cochrane requirements			MRG; Papers for SG; Funding applications and reports; Module
	Colloquia			re consumers attending, meetings, evaluation/follow up; workshops, presentations meetings
Administrator		<b>Jane Nadel</b>	International	Two to three days per week voluntary (if paid AUD 60,000 pro rata)
	Archie			Entering and maintaining information; making information available as required

	Membership management			Day to day management, enquiries, follow up; reports
	Liaison Officer			with Secretariat, Review Groups, other entities etc
General management	E-mail list management	Maryann Napoli	International	Content management
	Stipends (Colloquium Policy Advisory Group)	Barbara Warren; Liz Whamond		
	Stipend committees	Maryann Napoli		
	CRG Plain language summaries service	Janet Wale		
		Maryann Napoli		
		Silvana Simi		
	Website	Sally Lakeman		Web manager
		Janet Wale		Content manager; development Web 2.0 training
	Facebook	Claudia Cattivera		Management
Project officers	Principal project officer/researcher	Janet Wale		Australian Department of Health and Ageing, Regular evaluations of CCNet, SG/CAM summaries, Prioritisation Project, CCNet External Review
		Jane Nadel		CAM summaries, Prioritisation Project, CCNet External Review
	Qualitative researcher	Maria Belizan		Prioritisation Project, CCNet External Review; Spanish/Portuguese projects eg prioritisation, website
		Sita Vij		Prioritisation project; other

	CAM Plain language summaries	Libby Lissiman		Complementary and Alternative Medicine overviews
		Jane Nadel		
		Anne Peticolas		
		others as required		
Governance	<b>CCNet Geographical Centres Advisory Group</b>			
Centre area:	UK	U Hla Htay	UK	National Dementia; UK Cochrane Centre, IAPO
		Shirley Mankwell		Consumer rep on CCNet Review Adv Group
<b>Chair</b>	Canadian	Liz Whamond	Canada	Canadian Cancer Action Network
		Anne Lyddiatt		National Musculoskeletal; liaison with Canadian CC; Consumer rep to CMSG edit board
	US	Barbara Warren	US (CUE)	Consumers United for Evidence; educational/promotional videos
		Maryann Napoli		Consumer reports on Cochrane reviews; liaison with authors
	Iberoamerican	Claudia Cattivera	South America (Argentina)	Patientes Online Argentina; WHO Patients for Patient Safety
		Raphael de Souza	Brazil	
		Kathie Godfrey	Spain	
	Italian	Silvana Simi	Italy	WHO Patients for Patient Safety; MS
	German	Britta Lang	Germany	Science and society; media coverage
	Dutch	Jacqueline Limpens	Netherlands	Health blog

	Nordic	Helja Balmer	Finland	
		Vassily Vlassov	Russia	
	Bahrain Branch	Mona Nasser	Iran/Germany	
		Sarah Yaron	Israel	National Breast Cancer; WHO Patients for Patient Safety
	South African	Godwin Aja	Nigeria	Working with communities
		Clare Jeffrey	South Africa	Co-author CCNet papers
	South-East Asian	Shobha Iyer	India	Media
	Thai Branch	Chanpen Choprapawon	Thailand, South East Asia	
	Australasian	Janet Wale	Australia	National HTA, diagnostics
		Steph Newell		National Safety & Quality, WHO Patients for Patient Safety
		Judi Strid	New Zealand	Consumer rep on CCNet Review Adv Group
	Chinese	Mingming Zhang	China	WHO Patients for Patient Safety
	SG representatives	Liz Whamond		Elected representatives: Conferring with and reporting back to CCNet Advisory Group and its Officers
		Mingming Zhang		
Healthcare user members				members of specific entities as consumers/patients
				comment on and contribute to prepublished Cochrane protocols, reviews and summaries
				are consumer editors, members of advisory groups within Cochrane

				disseminate information from reviews
				participate in discussions in and outside of Cochrane
				promote evidence-based health care