

2010

Consumer involvement in the
Cochrane Collaboration:
BACKGROUND PAPER

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The Principles of The Cochrane Collaboration

The Cochrane Collaboration's work is based on ten key principles:

1. **Collaboration**, by internally and externally fostering good communications, open decision-making and teamwork.
2. **Building on the enthusiasm of individuals**, by involving and supporting people of different skills and backgrounds.
3. **Avoiding duplication**, by good management and co-ordination to maximise economy of effort.
4. **Minimising bias**, through a variety of approaches such as scientific rigour, ensuring broad participation, and avoiding conflicts of interest.
5. **Keeping up to date**, by a commitment to ensure that Cochrane Reviews are maintained through identification and incorporation of new evidence.
6. **Striving for relevance**, by promoting the assessment of healthcare interventions using outcomes that matter to people making choices in health care.
7. **Promoting access**, by wide dissemination of the outputs of the Collaboration, taking advantage of strategic alliances, and by promoting appropriate prices, content and media to meet the needs of users worldwide.
8. **Ensuring quality**, by being open and responsive to criticism, applying advances in methodology, and developing systems for quality improvement.
9. **Continuity**, by ensuring that responsibility for reviews, editorial processes and key functions is maintained and renewed.
10. **Enabling wide participation** in the work of the Collaboration by reducing barriers to contributing and by encouraging diversity.

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1. INTRODUCTION

The Cochrane Collaboration Steering Group (CCSG) is its decision-making body and Strategic sessions at mid-year CCSG meetings are used to focus on important issues related to the Collaboration's aims and principles. The meeting in Auckland in March 2010 will consider consumer participation in the Collaboration following presentation of the 2009 CCNet Review to the CCSG meeting in October 2009.

In preparation for this session a Consumer Involvement Advisory Group (CIAG) was established. (The history of this process and the terms of reference for the project are documented in Appendix 1, and the membership of the CIAG is listed in Appendix 2.)

The CIAG agreed that the purpose of the Consumer Session is to achieve agreement on consumer involvement in the strategic direction for the Cochrane Collaboration by:

- Achieving clarity on consumer participation in the Collaboration within the context of the 2009 Strategic Review recommendations¹ and the 2009 Consumer Network Review of Consumers in Cochrane (CCNet Review)², with particular regard to:
 - More consumer-orientated reviews across the Collaboration
 - Enhanced dissemination of the work of the Collaboration
 - Development of strong partnerships with appropriate national and international consumer organisations.

- Discussing options for the Collaboration to support sustainable consumer involvement.

2. BACKGROUND

Since its formation in 1993, the Collaboration has shown strong commitment to consumer participation and consumers have been active at all levels. Consumer involvement is part of the history of the Collaboration.

In 2009 the Strategic Review identified that the Collaboration had unconsciously adopted the structure of a 'swarm organisation', which it says "explains the behaviour of a decentralised and self-organised system ... the result of interactions of individuals acting on the basis of local information rather than 'orders from the top'".³ The Review also noted that the "majority of contributors are not employed by the Collaboration, but often have multiple responsibilities to the Collaboration and to their academic or medical institutions, and

¹ See Appendix 3 for a summary of the Strategic Review recommendations. The full report and associated documents can also be found at <http://ccreview.wikispaces.com/>

² See Appendix 4 for the detailed report of the 2009 CCNet Review, which can also be found under "Detailed report" on <http://www.cochrane.org/consumers/happenings.htm>

³ Page 2 Recommendations Report

fundings”⁴. The Strategic Review did not consider the impact of these factors on the Consumer Network, a small entity run by volunteers with no formal links to institutions and with no supporting infrastructure.

Report objective

The Strategic Review was designed to improve what was known about the Collaboration and this Background Paper set out with a similar broad task—to improve what is known about consumer participation across the Collaboration. The 2009 CCNet Review provided an important base, but this paper considers consumer involvement more broadly than the CCNet and was designed to take a wider perspective. It seeks to understand how consumer involvement in the work of the Collaboration has evolved and what would better support it.

2.1. DATA SOURCES

The sources used to inform this paper included:

- 2009 Strategic Review of the Collaboration;
- 2009 Consumer Network Review of Consumers in Cochrane (CCNet Review) which involved two online surveys and follow-up interviews. Respondents included 47 review groups (92%) and 66 consumers recruited through the CCNet email list consumers (estimated response from consumers using email list 33-44%), four CRGs and six consumers participated in interviews;
- Content analysis of all the entity modules on The Cochrane Library in December 2009;
- Content analysis of requests to the CCNet email list between September 2009 and February 2010;
- Discussions (both in person and by email) with CCNet representatives on the CCSG, people in consumer facilitator roles, members of the CIAG and Managing Editors using the CCNet email list;
- Other reports or papers prepared for the Collaboration including:
- Gillies D., Allen C. & Soares-Weiser K. (2010) Representation of people from non-English speaking background across The Cochrane Collaboration, 2009 Colloquium workshop report, distributed by email list DATE ;
- Monitoring and Registration Group (2009) Report to the Cochrane Collaboration Steering Committee, (see <http://www.cochrane.org/ccsg/agr/index.htm> MRG October 2009);
- Gillies D., Maxwell H., New K., Pennick V., van der Wouden H., Fedorowics Z., Verbeek J. & Ciapponi A. (2009) A Collaboration-wide survey of Cochrane authors;
- Deeks M (2004) Cross-cultural teams working with The Cochrane Collaboration Version 1.0 (see www.cochrane.org/docs/crossculturalteamwork.doc).
- Evaluation report of the Consumer Panel of the Pregnancy and Childbirth Review Group which operated from 1998 to 2007;
- Data from Archie (retrieved February 2010).

⁴ Ibid

3. THE PURPOSE OF CONSUMER PARTICIPATION IN THE COLLABORATION

Just as the starting point for the Strategic Review of the Collaboration was to consider its primary purpose and reflect whether this had changed, it is important when undertaking strategic planning around consumer participation to reflect on the reasons for the inclusion of consumers in the Collaboration.

Consumers get involved in the Collaboration for a variety of reasons. The 2009 CCNet Review found the most common reasons were desires 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.”*

On the other hand, the benefits sought from the surveyed Review Groups were improved readability and/or quality of reviews (81%) and improved usefulness of plain language summaries (77%). The roles for consumers identified by entities in their modules on The Cochrane Library related to: participation in decision-making, including identifying questions or topics and prioritising reviews; contribution to the preparation of reviews and associated products; dissemination of review findings and promotion of evidence-based care; influencing health professionals and the community; and encouraging others to be involved.

Purpose of consumer participation in the Collaboration

The Consumer Involvement Advisory Group for this project agreed that drafting a common purpose for involving consumers in the Collaboration would be useful. Health care consumers are encouraged to be involved in the Cochrane Collaboration:

- To ensure that the work of the Collaboration reflects the needs and priorities of patients, consumers and carers in health systems using the best evidence available
- To ensure the quality and relevance of Cochrane Systematic Reviews
- To promote evidence-based decision-making in healthcare.

Proposal

This purpose has been used to provide the overarching context for the research undertaken for this paper.

3.1. CONSUMERS IN THE COLLABORATION: CURRENT STATUS

Although consumers have been active throughout the history of the Collaboration, there appears to be some confusion about what is meant by the term ‘consumer’. The term itself is problematic for some, which is likely to be compounded by its different interpretations and use. I have not tried to provide a single definition of consumer but have included a detailed discussion of this issue in Appendix 4.

Problems of definitions aside, it is difficult to ascertain the number of consumers currently active in the Collaboration. The Strategic Review recognised that there is no mechanism to determine the diverse membership of the Collaboration and recommended formal membership for its contributors. The importance of this issue was apparent when trying to ascertain consumer numbers. Like other contributors to the Collaboration, consumers can register on Archie but numbers may not reflect current active participation as there can be a lag in identifying when participants become inactive.

Table 1 shows the number of consumer reviewers, consumer coordinators and handsearchers recorded in Archie overall and in the CCNet. There were 521 individuals registered as consumer reviewers, nine as consumer coordinators and 107 as handsearchers⁵ across all entities on 22 February 2010.⁶ Archie also listed 723 active members for the Consumer Network (plus 29 inactive members). This number includes both individuals and consumer organisations (although less than 10 organisations appear to be registered⁷).

Table 1: Number of consumers and CCNet members registered on Archie (February 2010).

	Number recorded in Archie	Number recorded in CCNet	Difference Archie & CCNet numbers
Consumer reviewers	521	205 ^a	316
Consumer coordinators	9	7	2 ^b
Handsearchers	107	8	99

^a This is consistent with the 2009 CCNet Review which reported that “191 people have at some stage acted as a consumer reviewer, but not all of these are on the CCNet email list.” ^b These people are also listed as entity staff.

From Table 1 it is apparent that the majority of consumer reviewers in the Collaboration are not members of the CCNet (61%). This possibly contributes to the disconnection between the CCNet and the work of the CRGs apparent in the CCNet Review, where 72 percent of Review Group respondents and 27 percent of consumers did not know if the CCNet was achieving its aims. A large proportion of the active members listed as members of the CCNet are not registered as consumer reviewers, consumer coordinators or handsearchers. Some will be review authors, but it is not possible to distinguish consumer review authors from review authors with other backgrounds.

⁵ Handsearching is a task often associated with consumers.

⁶ Content analysis of entity modules in The Cochrane Library undertaken in December 2009 found 27 CRGs named approximately 500 individuals from 34 countries, while other CRGs acknowledged consumer input but did not name individuals.

⁷ Archie does not provide categorisation for these independently.

The CCNet email list has over 400 subscribers. It was estimated in the CCNet Review that between 150 and 200 of these are consumers. If correct, subscribers to the email list would comprise less than half of all consumer reviewers recorded in Archie.

There are a number of problems with the available data that make it difficult to assess the level of consumer involvement confidently. However it appears that the majority of consumers involved in the Collaboration are not involved with the CCNet.

3.2. CURRENT MODEL OF CONSUMER INVOLVEMENT IN THE COLLABORATION

Complexity of consumer participation

The increased complexity in the structure and activities of the Collaboration that have developed over the past 17 years is mirrored by increased complexity in the involvement of consumers in the organisation. Several strategies have developed across the Collaboration which may result in duplication and create unintentional barriers to consumer involvement. It is useful to understand the ways that consumers participate in the Collaboration, the different roles they undertake, and the different types of support they need. It will help differentiate the different skills and training needed and through recognition of these differences, the Collaboration can better market consumer involvement. The involvement of a wider range of consumers is likely to increase if what consumers do within the organisation is more accurately described.

Roles

Over the history of the Collaboration, a number of reports have identified different roles for consumers and these are also described in the entity modules on The Cochrane Library. These roles can be summarised into three main areas:

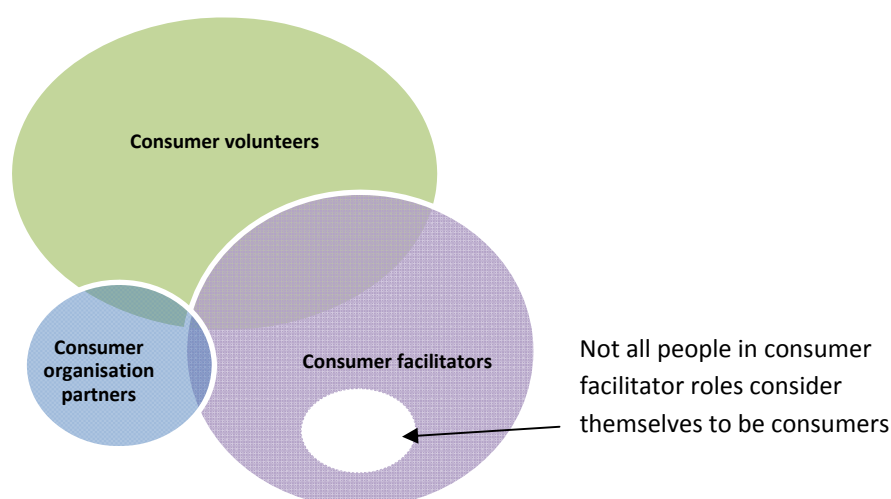
- Involvement in the decision-making processes of the Collaboration (see Section 4)
- Involvement in the choice and preparation of Cochrane Systematic Reviews (see Section 5)
- Involvement in dissemination and promotion of Cochrane Systematic Reviews and evidence-based healthcare (see Section 6).

Types of consumer roles

A useful way to think about how consumer participation is achieved in these roles is to consider who the consumers are, and the type of consumer input they provide. For example, is the input of the consumers based on their personal experience only, or do they provide a more generalised view or even a representative view? Are they required to provide a broader range of services or functions? Thinking about consumer participation this way, three fundamental groups or types of consumers can be described as participating in the Collaboration. There will be overlap between these groups, as most people rarely all fit into one type. The relationship can be represented pictorially (see Figure 1). The groups are:

- Consumer volunteers
- Consumer facilitators
- Consumer organisations partners

FIGURE 1: Model of consumer groups participating in the Collaboration



Although the presence of these three groups is evident in the Collaboration, as stated earlier is not really possible to gauge the size of each group at this stage. The size of the groups shown in Figure 1 does not represent an estimate of the actual numbers involved, but rather to show that they are different. The groups can be described in the following way:

CONSUMER VOLUNTEERS comprise the group commonly associated with consumer involvement, where their input is primarily based on their experiential knowledge as a health consumer.

Consumer volunteers undertake functions in the Collaboration such as peer reviewing Cochrane titles, protocols, and reviews; and providing personal feedback about priorities, dissemination and how to involve other consumer members.

Consumer volunteers are the primary focus of CCNet, although not all consumer volunteers active in the Collaboration are active in CCNet; some have direct relationships with Review Groups specific to their health experience.

CONSUMER FACILITATORS work to promote and support consumer involvement in the Collaboration. They may have a funded role but can also volunteer. They have direct experience as consumers but also facilitate consumer involvement in other ways. This may include actively helping other consumers be involved (some focus on particular groups of consumers, such as non-English speakers, or consumers with specific health experiences) and by acting as a bridge between consumer volunteers, health professionals and health researchers within the Collaboration.

In some cases this type of positions are held by people who have other roles and not consider themselves consumers. Facilitator positions operate under different guises across the Collaboration, for example consumer editors and consumer coordinators can be seen in this group. This type of consumer role can be funded through Cochrane Review Groups and Cochrane Centres but there are examples of consumer organisations funding positions that include a specific role working with the Collaboration.

CONSUMER ORGANISATION PARTNERS are those consumers working as representatives or in liaison roles with consumer organisations.

This group undertakes an important function that could be expanded in the Collaboration. Some Cochrane entities (e.g. CRGs and Centres) already work directly with consumer groups that contribute to decision-making within the CRG (e.g. prioritising reviews, identifying relevant outcomes, etc).

Consumer groups also provide volunteers that help with the preparation of CSRs, though this may be informal. There is also at least one example where a funded position has been established within a consumer organisation to disseminate the findings of CSRs to that membership base.

Eight CRGs and two Cochrane Centres name specific organisations on their module either as board or advisory group members, or in the development of their work.

One example of the complex way in which consumers can work in the Collaboration is provided by the Consumer Panel in the Pregnancy and Childbirth Review Group (PCG) which operated between 1998 and 2007 with three consumer coordinators. Gill Gyte, who had a funded position through PCG, was the Principal Coordinator; Carol Sakala, regional coordinator for North America, incorporated this role into her paid position with the maternity consumer organisation, Childbirth Connections; and Dell Horey, regional coordinator for Australasia, who worked in a voluntary capacity. All three had long-term connections with maternity consumer organisations in their countries and had postgraduate qualifications, making them familiar with research processes.

The role of the coordinators was to use their local networks to encourage consumer volunteers to provide feedback on PCG protocols and reviews. This feedback was largely based on experiential knowledge and personal values. During the 10-year period more than 70 consumers provided feedback on over 400 protocols and reviews. The Panel operated on an open basis; as many consumers who were interested in a particular protocol or review could comment. Contact editors were provided with the collated feedback *and* a summary of the key points, prepared by Gill Gyte (or Dell Horey) in much the same way editors collate peer review feedback. Gill ensured that there was feedback on every protocol and review. The work of the Panel was highly regarded by the editorial team and review authors. The panel ceased to function this way when Gill's position lost funding.

3.3. ISSUES RAISED BY CURRENT MODEL

Differences

This tripartite consumer structure reflects the different types of consumer involvement taking place across the Collaboration, and helps explain why there have been some difficulties transferring successful strategies of participation across entities. Conceptualising consumer involvement in the Collaboration in this way does not necessarily resolve these issues but provides a framework whereby they can be better understood and discussed.

Currently, differences in how these roles are envisaged across the Collaboration are not helped by inconsistencies in the use of some terms, especially for those in a consumer facilitator position, which itself is diverse, or the roles allocated to consumers in different CRGs (for example, some only involve consumers in development of plain language summaries; some do not have a specific policy for consumer involvement; and some have consumer input at every stage of the review development.

Information gathering

Information on current consumer involvement across the entities is routinely collected by the Monitoring and Registration Group, but this information is used only for internal reporting. There appears to be considerable potential for data about consumer involvement gathered by this group to be used more effectively.

Information about useful strategies to involve consumers is currently shared on an ad hoc basis, which means that important lessons are potentially lost and/or there is unnecessary duplication. Without a way to describe the different roles it makes it difficult to argue for ongoing funding for consumer support roles or to examine the different ways the consumer facilitator roles have developed (e.g. consumer mentors, consumer coordinators, consumer editors etc), or how the potential for consumer organisation partners may be implemented across the Collaboration.

Needs of different types of consumers

Opportunities are needed for better collaboration between people in consumer facilitator positions, so that they can share the knowledge gained from their experiences of engaging consumers. Consumer facilitator positions are likely to play an important role in encouraging consumer involvement among culturally and linguistically diverse consumers, including those from low-income countries and those with low literacy. Similarly, people representing consumer organisations within the Collaboration are likely to have issues to share and would benefit from getting together.

Thinking about the structure of consumer involvement in the Collaboration as consisting of different types of consumers helps to tease out why it is that a relatively low proportion of consumer reviewers have registered with the CCNet. Without institutional support, the CCNet is unlikely to have the personal resources to support the diverse types of consumers active in the Collaboration. Historically the focus of the CCNet has been volunteers (see Figure 2) and its important role in the decision-making processes of the Collaboration (through its two positions on the Steering Group and associated committees). Volunteers within the Collaboration remain the focus of the CCNet as shown in its submission to the CCSG meeting in Auckland (see Appendix 11).

FIGURE 2: CCNet’s relationship with consumer groups participating in the Collaboration

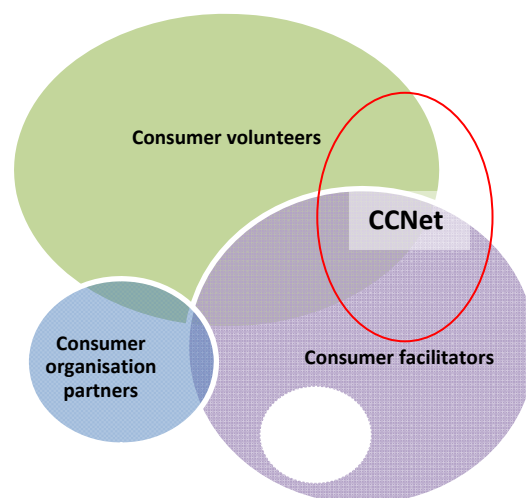


Figure 2 shows CCNet membership and consumer involvement in the Collaboration based on current data in Archie. While a large majority of respondents to the Review Group survey (81%) in the 2009 CCNet Review felt that an umbrella organisation was important, only 56 percent of the consumers surveyed felt that way, but it is not explained why they felt this way. There are concerns about what it is reasonable to expect from volunteers without any of the organisational infrastructure or institutional infrastructure available to other entities (see Appendix 11), or how such an entity might take on additional, and increasingly complex, tasks. For example, the CCNet has no formal mechanism to develop partnership arrangements with consumer organisations, nor has it the necessary resources needed to do so.

If the recognition of “Cochrane consumer organisation partners” is to be encouraged among Cochrane entities, the process may need to be monitored. In particular, there will be a need to avoid conflicted funding and procedures to assess the suitability of consumer organisations may be needed to minimise risk to the Collaboration.

3.4. OPTIONS TO SUPPORT SUSTAINABLE CONSUMER INVOLVEMENT

The Collaboration needs to consider how it might support consumer involvement across all consumer types that operate within it.

There seem to be three options available:

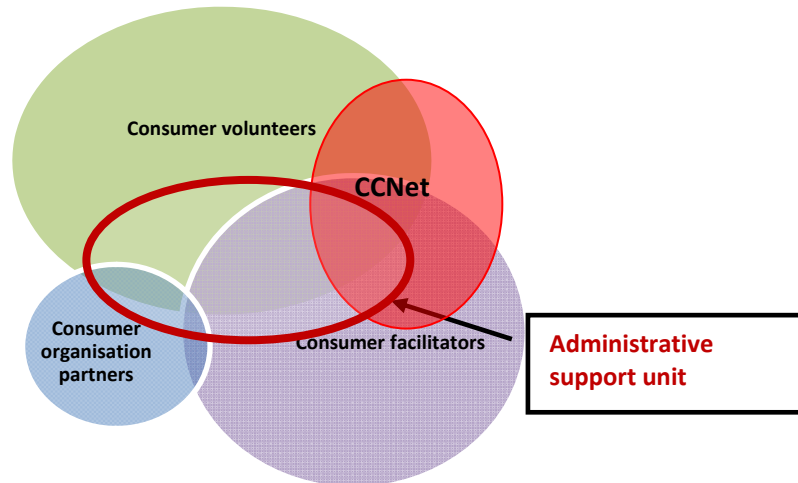
- 1) To continue the current approach including the provision of project funding to the CCNet to support consumer volunteers (see Appendix 11).
- 2) To extend the remit of the CCNet so that it assumes funded support responsibility for all consumers across the Collaboration, including consumer facilitators and consumer organisation partners. In part this is the thrust of a recommendation from the CCNet Review which was to create a dedicated position within CCNet to liaise with and support all consumers involved with the Collaboration.
- 3) To establish a new structural component within the Collaboration to support consumer participation across the Collaboration, including the provision of support to the CCNet. Figure 3 shows how such an administrative unit might relate to all consumer types in the Collaboration. In some way this extends the recommendation of administrative support to the CCNet included in the 2009 CCNet Review.

The tasks needed to ensure sustainable consumer involvement in the work of the Collaboration include: Oversight of consumer involvement across the Collaboration including the receipt of annual reports from the Monitoring and Registration Group and other relevant bodies

- Development of a database detailing how each entity in the Collaboration involves consumers which can be used to inform newcomers wanting to get involved and to investigate effective consumer involvement (this is similar to the proposal in the CCNet submission to the CCSG Auckland meeting, see Appendix 11)
- Function as a clearinghouse for resource materials for consumers across the Collaboration (in conjunction with CCNet) to minimise duplication
- Establishment of guidelines for the development of Cochrane Consumer Organisation Partners and where necessary undertake assessments of such organisations

- Work with Cochrane Centres to develop regional links for consumers, particularly in non-English speaking and low-income countries
- Assistance in the formation and operation of a network of consumer facilitators across the Collaboration.
- Development of person specifications for consumers participating in the Collaboration in conjunction with the CCNet (representing consumer volunteers) and consumers facilitators and organisation partners to ensure that the expectations about such involvement is clear and transparent (see Appendix 5 for an example).

FIGURE 3: Model for sustainable consumer involvement in the Cochrane Collaboration



4. CONSUMER INVOLVEMENT IN DECISION-MAKING IN THE COLLABORATION

Context

Consumers have been members of the Collaboration Steering Group (CCSG) since its beginning. Nine people from the Consumer Network in total have been on the CCSG since 1995, including three from low-income countries (see Appendix 6). Consumer members from the Consumer Network also have had continuing roles in the advisory groups associated with the CCSG. Consumers on the CCSG operate as either consumer volunteers, consumer facilitators or as both. While these people may be members of consumer organisations, like other CCSG members they are elected to represent their constituent base in the Collaboration and are not representatives of such organisations on the CCSG.

Leadership

The Strategic Review linked leadership, accountability and decision-making and reported that the “majority of respondents argued for greater accountability of the entities and leadership” although there were concerns that the current monitoring system was unable to effect change and that the voluntary nature of much of the work limited accountability and the impact of performance appraisals to effect improvements. These issues are also important for consumer leadership in the Collaboration.

Transparency

Transparency is an important aspect of accountability in decision-making and it is especially important for newcomers, unfamiliar with swarm organisations, to know how decisions are made and how they can contribute to them. Many Cochrane entities do not describe the role for consumers in their decision-making processes, nor is it clear how consumer organisations can be involved in the Collaboration.

Training

The Strategic Review of the Collaboration also recommended review of the membership, competencies, induction and ongoing training of the Collaboration Steering Group. This latter point, in terms of the need for training in consumer participation as a requirement for CCSG induction, was raised by consumer members of the Consumer Involvement Advisory Group, in the preparation of this paper. There was concern that non-consumer members of the CCSG do not value the contribution of consumers in the Collaboration and without the support of leadership this will be continue to be demonstrated throughout the organisation.

Consumer facilitators are likely to have the broadest consumer perspectives, and may be the type of people who would consider standing for the CCSG or be included in the editorial teams at CRG level. The skill development of this group needs to be considered (refer back to Section 3).

Cultural diversity

The recent report of a workshop at the 2009 Colloquium identified that lack of strong English skills often precludes participation of such people in the Collaboration. The CCNet has been successful in encouraging people whose first language isn't English into decision-making roles, but more support is needed in terms of resources, effective communication strategies and training to get the most from this involvement. For example, there were no strategies in place to assist people without first language English to facilitate on the CIAG teleconferences. Some procedures were implemented, such as the list of CIAG members (see Appendix 3) and clear, detailed agendas to overcome issues related to the large number of participants and the

involvement of people without English as their first language. Also follow up by phone, email discussion to allow people time to read and reply

Access

Consumers involved in the Collaboration through CRGs but who are not in the CCNet will only have the CRG at large position available to them on the CCSG, which is unlikely to be seen as relevant to consumers by other voters in that category. This means that these consumers would not currently be offered the opportunity to vote for the consumer positions.

4.1. OPTIONS TO SUPPORT SUSTAINABLE CONSUMER INVOLVEMENT IN DECISION-MAKING

To support sustainable consumer involvement in decision-making in the Collaboration, the organisation could develop a policy on consumer involvement that clearly outlines the principles of the organisation's approach, opportunities for involvement, and the support available to consumers, including their role in decision-making.

All newcomers to the Collaboration would be helped if all Cochrane entities clearly described their governance structures including any role that consumers may have.

People from non-English speaking backgrounds, including consumers, could participate in the decision-making of the Collaboration if appropriate guidelines and support mechanisms were developed.

Steering Group

Effective consumer involvement in the main decision-making body of the Collaboration, the Steering Group would be enhanced by:

- Training for all CCSG members on the role of consumer involvement in the organisation.
- Role descriptions for consumer members on the CCSG that include the specific skills required and expectations of the role. These could be developed by past and current consumer members of the CCSG.

Similar strategies are likely to benefit other decision-making bodies throughout the Collaboration.

5. CONSUMER INVOLVEMENT IN THE CHOICE AND PREPARATION OF SYSTEMATIC REVIEWS

Context

Involving consumers in the preparation of reviews is considered one of the main features of Cochrane reviews and the most commonly shared goal between consumers and other Collaboration contributors. Almost all review groups involve consumers in the preparation of their reviews or protocols. Consumers comprised two percent of Cochrane authors in the recent Collaboration-wide survey (Gillies 2009) in which no particular issues relating to consumers were raised.

The most recent report of the Monitoring and Registration Group found almost one third of CRGs always involve consumers (31%), the same proportion mostly involve them (31%), a smaller number involve consumers only sometimes (27%) and a minority never involve them (10%); the latter equate to five review groups.⁸

Similarly, content analysis of the entity modules found five review groups without a consumer involvement policy, and most were largely under-developed. The modules of about half of the review groups included requests for consumers to contact them if they wanted to become involved; about one quarter acknowledged the Consumer Network in their policy and a similar proportion were either involved with, or sought involvement from consumers associated with consumer organisations, which suggests that some review groups want consumer input that is broader than an individual's experiential knowledge.

Goals of consumer involvement

The CCNet Review found the vast majority of review groups wanted consumer involvement to improve the quality or accessibility of reviews and plain language summaries: however a significant minority of review groups (30%) were not sure they are gaining these benefits. Among the consumers surveyed, there was also uncertainty about whether their aims of involvement were being met, but as it is not clear whether this applied to the specific aim of helping make health information more relevant and accessible to consumers.

Not surprisingly, the CCNet Review found three common tasks between the review groups and consumers: commenting on reviews (94% of CRGs and 45% of consumers); commenting on protocols (53% and 52%); commenting on plain language summaries (51% and 29%). It is not clear why there is such a significant difference between the views of review groups and consumers in relation to commenting on reviews and plain language summaries, but it may be because a high proportion of consumer reviewers are not associated with the CCNet and this may have affected the survey population.

Appendix 7 summarises the findings in relation to potential benefits and harms to consumers and researchers identified in a recent literature review undertaken for INVOLVE UK on the impact of public involvement on NHS, public health and social care research. Although the literature review does not specifically address the impact of consumer involvement on systematic reviews, it does provide one case study that shows how a systematic review of the literature on HIV health promotion was reframed to a more

⁸ Monitoring and Registration Group report to the CCSG in October 2009. The report raised concerns about "possible damage to the image of The Cochrane Collaboration Steering" because 5 CRGs reported that they never have consumer involvement in their work.

acceptable message for end-users.⁹ Like many adverse outcomes, the potential for negative impact from consumer involvement are less commonly reported and are often overlooked but it is important that efforts are made to minimise them. The review identified four such impacts: being emotionally burdened; being overloaded with work; being exposed through the media; and being frustrated at the limitations involvement.

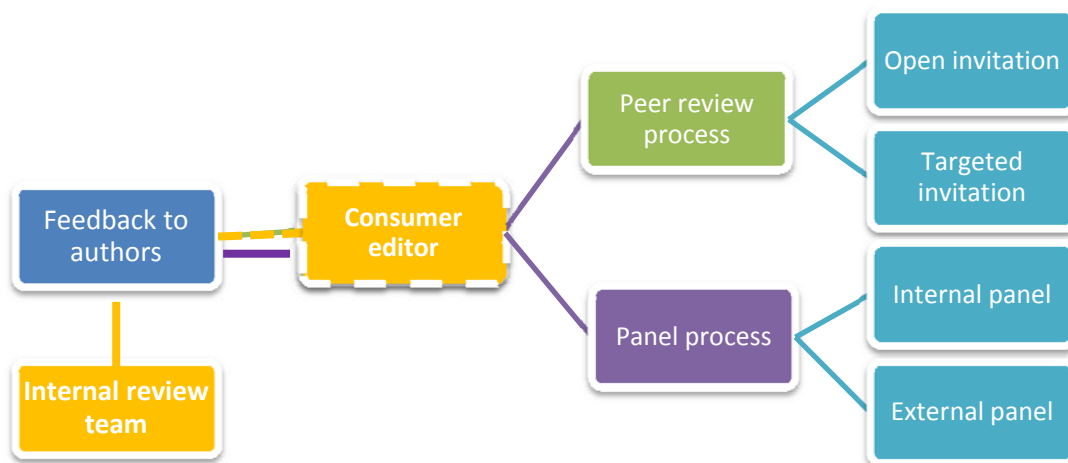
Roles and tasks for consumers

The entity modules identified a number of potential roles and tasks for consumers related to review development. There were three roles identified: consumer reviewer (18 CRGs), review author (14), and consumer coordinator (2). General tasks included: helping to identify questions or topics (11), handsearching journals (10), supporting the involvement of other consumers (by finding consumers or consulting in the community around specific issues [5]) and helping to prioritise reviews (2). Activities related to specific reviews included: helping with plain language summaries (15); interpreting for common usage (and to other languages [9]); identifying appropriate outcomes (5); advising on applicability (5); reading abstracts (1); and, for one review group, helping to address potential conflict of interest by participating in the editorial group when a review group editor is also the author of a review. These roles and tasks vary across review groups.

5.1. APPROACHES TO CONSUMER INVOLVEMENT IN THE PREPARATION OF CSRs

Review groups also use different approaches to gather consumer feedback for review authors. The most common of these are summarised in Figure 4.

FIGURE 4: Approaches to providing review authors with consumer feedback



Internal review team

A small number of review groups encourage consumer input as an *internal review team process*, in addition to other consumer review processes. While 14 review groups suggest that consumers have roles as review authors, it is actively encouraged by two groups, and another two groups encourage review author teams to seek consumer input while planning and working on their review.

⁹ See Case Study 6 p32 Staley K (2009) http://www.invo.org.uk/All_Publications.asp

Peer review process

There appear to be two styles of consumer review processes used across the Collaboration. The first follows a similar pattern to other *peer review processes* with one or two consumers providing feedback. However, two different methods are used to select the consumer peer reviewer who does this. One way uses an *open invitation method* by making use of the CCNet's email list while the other uses *targeted invitations* to selected individuals, who are usually connected to relevant consumer organisations (this seems to be the least common approach in the Collaboration). Peer review processes may be more suitable for people able to take on a consumer facilitator role, as they are able to reflect on issues beyond their personal experiences.

Panel process

The second style of consumer review makes use of a *panel process*, whereby an already established panel is asked to comment on the protocol or review. These can be groups with strong consumer advocacy populations outside the Collaboration - such as breast cancer and HIV/AIDs or can be groups with a specific chronic illness which tend to be not common, or which may have some type of stigma attached such as tobacco addiction, sexually transmitted diseases, colorectal cancer etc. Panels can be *internal*, where all members are active within the Collaboration, and can be quite small – some are comprised of only one person but more often they have 6 or more people, and operate as a list upon which the Managing Editor can call. (In this, they are similar to the targeted peer review process above but the selection is an internal one). Panel members usually have a particular health experience or interest in the topic of the review group. Single-person panels can provide feedback on all reviews and/or protocols. External panels make use of networks outside the Collaboration, just like the Pregnancy and Childbirth Group Consumer Panel described earlier or community consultation activities. A panel process differs from a peer-review process in that the panel is associated with the review group, where the peer review process uses consumers who may be external to the review group. A panel process may also elicit a greater number of consumer responses, depending on the size of the panel and these may need to be summarised to be useful to review authors. This process may be more relevant for consumer volunteers so that the feedback to authors is more diverse.

Review groups can use a mix of these strategies, such as an open invitation peer review process through the CCNet if there is no one available on the internal peer review panel.

Consumer editors

Some groups use a consumer editor, although it is not clear that this role is the same across the Collaboration. Eight review groups refer to consumer editors in their module on The Cochrane Library with two others mentioning them in historical terms. Some have one consumer editor while others have up to three. There is considerable variability in the work of a consumer editor when it is described. For example, in the Musculoskeletal review group, the consumer editor (along with the biostatistician) reviews all protocols and reviews prior to submission to The Cochrane Library. In the HIV/AIDS CRG the role of the two consumer editors is to “to represent consumers internationally, offer guidance on prioritisation of reviews, and referee all abstracts”. The Renal Group appoints a consumer editor and two external editors when one of their editors is an author of a review to address potential conflict of interest issues. And the Dementia and Cognitive Improvement CRG appears to use the term consumer editor in a different way again; a list of consumer editors is kept by the group in case a review author is

“unable to find” one. The group acknowledges 89 previous consumer editors who have contributed to protocols and reviews. This appears to be another type of internal review team process.

5.2. ISSUES RAISED BY CONSUMER INVOLVEMENT IN THE CHOICE & PREPARATION OF CSRs

Perceptions of consumer involvement

There are different perceptions of what is meant by consumer involvement. The most common notion is that consumer involvement is direct consumer input into an individual review or protocol, or in some CRGs, plain language summaries, in much the same way that peer referees operate. However, relatively few consumers will have the skills or interest in such tasks. In interviews with MEs in the CCNet Review there was concern that the complexity of the task could overwhelm some people, one review group said *“We make it sound simple but I don’t think it is all that simple to look at a review and comment sensibly on it, so it doesn’t surprise me that consumers are few and far between.”*

Interviews with staff from review groups in the CCNet Review were also clear that having the experience of a disease or condition was not sufficient to contribute effectively to the review process. Consumers need to understand the purpose of a Cochrane Systematic Review and how it is produced. They also need to be prepared to be critical, without being offensive.

Training is an obvious response and should be encouraged but relatively few consumers want, or are able, to participate in this way particularly those who are disadvantaged. The Collaboration may need to consider how it can extend its understanding of consumer involvement to be more inclusive and less demanding on individuals. With the current ratio of consumers to review authors of 1:40 to 50, this will become increasingly necessary if the Collaboration wants to maintain consumer involvement in its work.

A useful starting place is to recognise that consumer involvement has many levels, and consumers can contribute to the development of systematic reviews in many ways, from taking on a role as a lead author, to indirect contributions. The Cochrane review on consumer involvement found *“moderate quality evidence from two trials that involving consumers in the development of patient information material results in material that is more relevant, readable and understandable, without affecting anxiety. This ‘consumer-informed’ material can also improve knowledge.”*¹⁰ In the included trials consumers did not write the patient information material, rather they gave feedback on it terms of their understanding of what it meant to them, and what they felt was missing.

As there is no central resource to identify indirect examples of consumer input, I need to refer to my own experience where I have analysed the collated feedback from consumers over a topic area,

¹⁰ Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD004563. DOI: 10.1002/14651858.CD004563.pub2.

identified common themes from which we were able to produce advice to review authors about the sorts of things important to consumers related to that topic.¹¹

It is clear that such initiatives are not shared between review groups. In preparation of this paper one review group told me *“Recently one of our consumers told us he was making near identical remarks for two separate PLSs. This made it seem like we don't listen to him, but actually we only pass on comments specific to each author. We hope to include some general guidelines for review authors in the above mentioned guide.”* It is likely that similar guidelines for authors have been developed in other review groups.

In terms of the quality of consumer feedback the CCNet Review found that just over half of the Review Group respondents felt they were gaining the benefits they wanted from consumer involvement; 14 (30%) were not sure.

Managing Editors using the CCNet email list were generally very positive about the quality of the feedback and the range of consumers contributing to their reviews using this mechanism to contact consumers. However, a number of potential problems, particularly relating to confidentiality were raised that need to be addressed (see Appendix 7).

Variation in practices

There seems to be considerable need to improve consumer involvement in the preparation of CSRs across the Collaboration if the organisation wishes to retain this aspect of its history as one of its strengths. In particular it should be noted that more than a third of all review groups only sometimes or never involve consumers in their work.

At the same time there are multiple models of consumer involvement across the Collaboration, some reflecting the different contexts of review group topics. A lack of appropriate conceptual frameworks to describe consumer participation and its processes within the Collaboration contributes to problems that have developed, such as the inconsistent use of terms and approaches to participation. These differences create variable expectations and processes for consumer involvement across the Collaboration, which can be difficult for consumers whose interests may cross review groups. Some review groups involve consumers in all stages of a review production, whereas others only want consumers to comment on their plain language summaries. These variations in practices can be confusing for consumers, particularly for those who are newcomers to the organisation or those whose first language is not English.

The choice of the processes used by review groups is dependent on a range of factors including, the prevalence of the topic of interest and its importance to consumers, the availability of resources to review groups and knowledge of alternative approaches that can be used.

Review groups also have different practices in terms of acknowledging consumer input in a review. The CCNet Review found that 13 review groups sometimes acknowledge consumers, whereas three never do. Consumers generally want feedback on their contributions, but workloads within review groups

¹¹ Horey D., Gyte G., Sakala C. & Henderson S (2004) [P058] What do you mean? Collated consumer feedback on Cochrane reviews and protocols on topics in pregnancy See <http://www.imbi.uni-freiburg.de/OJS/cca/index.php/cca/article/view/2670>

prevent most review groups taking on this additional task. However, it has been suggested that when this does happen it appears to help consumers understand more about the review process and what was expected of them. Before any action is taken to implement such a strategy it should be evaluated to determine its benefits, if any, or to find acceptable alternatives.

Resources

At least six review groups have developed specific guidelines and/or checklists to help consumers reviewing protocols and reviews, suggesting that there has been considerable duplication across the Collaboration. However, there is still no guidance on consumer participation in the Cochrane handbook.

Consumer orientated reviews

Many people have ideas about what is meant by consumer-orientated reviews. They can be about the questions that reviews ask, in terms of the specific topic or how it is framed. Some people think consumer-orientated reviews are about the types of outcomes chosen or the comparisons used. For others consumer-orientated reviews are more about the type of products that reviews generate or how the information is presented. There appears to be no shared understanding across the Collaboration about what is meant by consumer-orientated reviews.

Funding

Financial support to enable consumer involvement has occurred at two levels in the Collaboration; support for system-wide consumer involvement through funding to the CCNet; and support for specific CRG consumer involvement.

The Consumer Network was initially funded through the Australian Cochrane Centre and provided with office space. When this support ended, the then convenor of the Consumer Network gained external funding to produce a website containing consumer friendly evidence summaries based on Cochrane reviews. This initiative folded when the convenor resigned and her skill-set was lost. Since then the CCNet, as it now known, has relied on project funding from government departments and internal Collaboration projects (see Appendix 11).

Some review groups have used funding to employ people in consumer facilitator roles, almost always on a part-time basis. Not all people in these roles identify as consumers themselves and in some groups this role is undertaken on a voluntary capacity. The earlier example from the Pregnancy and Childbirth Review Group shows that a funded position can embed consumer input into editorial processes and ensures input into all protocols and reviews.

5.3. OPTIONS FOR SUSTAINABLE CONSUMER INVOLVEMENT IN CHOICE & PREPARATION OF CSRs

Sustainable consumer involvement in the production of Cochrane reviews across the Collaboration is likely to require commitment from its leadership that demonstrates the value placed on such involvement.

The Collaboration will need to consider whether it continues to provide financial support to consumer involvement in review preparation on an ad hoc basis through review groups and other entities and

project funding to the CCNet, or whether this activity should be primarily supported through core funding. This decision will affect the strategies undertaken by the Collaboration to maintain consumer involvement in its work and will potentially impact accountability mechanisms, for example if CCNet were given core funding for specific positions, who would be responsible for their selection and performance monitoring? What consequences may be anticipated if other entities are accountable for their practices to the CCNet? Provision of core funding outside the UK will also be influenced by fluctuations in exchange rates.

The Collaboration should also consider independently of funding issues, if it wants consumer involvement across all review groups, how this might be monitored. It would be useful to involve relevant methodology groups in these decisions, however one option would be to develop principles and indicators for consumer involvement (see Appendix 8 for an example) and require review groups to report against these. Ideally, this would not be used in a punitive sense but to identify where further support may be required. The CCNet proposal to the Auckland CCSG meeting offers another option to monitor activity which involves the development of two databases (see Appendix 11).

More effective use of consumer facilitators could be made across the Collaboration, to elicit consumer input into Cochrane reviews. In particular consumer facilitators could be used to ensure input from a wider range of consumers, particularly those who are economically disadvantaged or have low literacy. The inclusion of younger people in the work of the Collaboration is also apparent and there may also be a role for consumer facilitators in this area. Extending involvement in the Collaboration to these groups may require broader interpretation of consumer input than that currently used, which tends to focus on the direct involvement of individuals in the production of reviews or their products. For example, engagement with consumer groups about a topic area could elicit their views on outcomes of importance that would be relevant to a range of reviews, not just one.

Similarly, review groups could consider how they might make better use of consumer input, for example, feedback across reviews on similar topics could be collated and analysed to see if there are similar themes or issues being raised that could be used to form general advice for future review authors in that area. It may be useful to evaluate existing review author guidelines in use across review groups to determine if there is guidance that could be available to all review authors.

The Collaboration could consider developing a central resource or library to house all resources developed for consumers to avoid unnecessary duplication. Such a clearing house could also collect information on strategies involving the different types of consumers. This would provide useful data for skilled analysis that may identify issues associated with effective consumer involvement. Such a proposal is also included in the CCNet submission to the Auckland CCSG meeting (see Appendix 11)

Training for consumers entering the Collaboration is likely to be needed on an ongoing basis. Consumers need to understand the purpose of the organisation and have clear expectations of their possible roles. Similarly training for those working with consumers would increase the Collaboration's capacity to support consumer involvement.

The Collaboration should consider how it could best develop existing mechanisms to overcome identified problems related to consumer involvement. For example, evaluation trials could assess

whether possible solutions achieve their goals without creating unforeseen new problems. Trialling a dedicated email list for registered consumer reviewers, who have signed declarations of interest, to alert potential consumer reviewers to Cochrane reviews and protocols looking for consumer input may find that it is not acceptable to consumers. However, if successful, Archie could be used to send automated emails when new consumer reviewers are registered. This approach would address some of the recommendations raised in the CCNet review relating to communication issues.

6. CONSUMER INVOLVEMENT IN THE DISSEMINATION AND PROMOTION OF SYSTEMATIC REVIEWS & EVIDENCE-BASED HEALTHCARE

While a role for consumers in the dissemination and promotion of systematic reviews is recognised by some in the Collaboration, this appears to be an undeveloped area in the Collaboration. Less than half of all respondents to the surveys in the CCNet Review, and even fewer review group modules, identified roles in these areas for consumers (see Table 2).

There is evidence of some activity at the regional level, led by CRG engagement with consumer organisation partners, albeit with no particular strategic overview or guidance from the Collaboration. The CCNet Review also encouraged the Collaboration to work with consumer organisations to help with the dissemination of reviews and plain language summaries.

The Strategic Review acknowledged the need for external engagement with the users of Cochrane reviews but its recommendation did not include consumer organisations rather the proposal to develop a formal partnership strategy, was directed at engaging “other systematic review producers and knowledge packagers”.

Table 2: Proportion of consumers, review groups & review group modules identifying roles for consumers in dissemination and promotion

Role for consumer	Consumers (N=66) %	Review groups (N=47) %	CRG Modules on Cochrane Library (N=51) %
Raising awareness of evidence-based health care	39	45*	10
Disseminating information about reviews	29	19	20

* Includes 9 who answered yes and 12 who indicated that this *maybe* a role for consumers.

On the other hand, a proposal to develop a Cochrane UK Consumer Coordinator at the UK Cochrane Centre includes a target to develop a presentation about The Cochrane Collaboration to be used to raise the profile of the Collaboration’s within existing consumer groups in that country.

However, there are other examples where Cochrane entities and consumer organisations have worked together to promote evidence-based health care and the Collaboration within their organisation.¹² There is no apparent mechanism to monitor or assess these developments. It does not appear to be included in the CCNet proposal to the Auckland CCSG meeting but this would need further clarification (see Appendix 11).

¹² Carol Sakala, who was one of the international consumer coordinators for the Consumer Panel of the Pregnancy and Childbirth Review Group works for Childbirth Connection in the USA, which promotes evidence-based maternity care and links to the Cochrane Collaboration.

The Musculoskeletal Review Group actively engages with consumer organisations in Canada and Australia (<http://www.cochranemsk.org/consumer/default.asp?s=1>), which publish plain language summaries of relevant reviews.

6.1. OPTIONS FOR SUSTAINABLE CONSUMER INVOLVEMENT IN DISSEMINATION AND PROMOTION

The Collaboration needs to consider its relationship with external consumer organisations in regard to the dissemination and promotion of its work. There may be opportunity to extend the remit of the working group established from the Strategic Review with responsibility to develop a partnership strategy with external organisations to include the option of Cochrane consumer organisation partners with a role in the dissemination of the work of the Collaboration and involvement in the prioritisation of reviews.

The development of dissemination strategies through consumer participation should be monitored centrally, particularly through the engagement of consumer organisation partners, across entities in the Collaboration and report regularly to the CCSG about progress.

7. SUMMARY

In considering the strategic direction for consumer involvement in the Collaboration, a question asked during the Strategic Review could be rephrased, “What would be lost to The Cochrane Collaboration if consumer involvement ceased to exist?”

Consumer involvement has been a part of the Collaboration from its beginnings. It has built on the enthusiasm of many individuals, particularly those in the Consumer Network. However, the growth in the size and complexity of the Collaboration, means that a more sophisticated response is needed to support consumer involvement to ensure its sustainability, to better reflect the types of consumer involvement that have evolved within the organisation, and to ensure a proficient response. It is no longer feasible to rely on the effort of volunteers and their personal resources. Strategies are needed that build on the strength of the CCNet and provide infrastructure to support consumer participation across all relevant facets of the Collaboration’s work.

Table 3 compares the different options raised in section 3.4 and identifies *some* potential issues for each in terms of the roles for consumers in the Collaboration.

Other strategies that could be considered to support consumer participation in the Collaboration include:

Development of policy on consumer involvement

The Collaboration could develop a policy that clearly outlines the principles of the organisation’s approach, opportunities for involvement, and the support available to consumers, including their role in decision-making. The policy could also address training, position descriptions and principles and indicators for consumer involvement.

Development of Cochrane consumer organisation partners

The remit of the working group established following from the Strategic Review with responsibility to develop a partnership strategy with external organisations should be extended to include Cochrane consumer organisation partners and their role in the dissemination of the work of the Collaboration and involvement in the prioritisation of reviews.

Development of guidelines to support the involvement of people from non-English speaking backgrounds and low literacy

It is imperative that an international organisation that seeks to involve consumers from diverse backgrounds develop guidelines to facilitate the involvement of people with low literacy in English.

Training in consumer participation for all members of the CCSG.

Areas where further attention may be warranted:

- Investigation of consumer facilitator roles and how they can be better supported
- Better use of information and data systems
- Trial of dedicated email list for registered consumer reviewers.

Table 3: Funding options for consumer involvement in the Collaboration and their potential impact on consumer roles

	OPTION	INVOLVEMENT IN DECISION-MAKING	INVOLVEMENT IN CHOICE & PREPARATION OF SYSTEMATIC REVIEWS	INVOLVEMENT IN DISSEMINATION & PROMOTION
1.	Current approach including the provision of project funding to the CCNet to support consumer volunteers	No change	No change No development of consumer facilitator role or consumer organisation partners (in formal sense).	Links to consumer organisations based on individual relationships
2.	Extend remit of the CCNet to assume funded support responsibility for all consumers across the Collaboration, including consumer facilitators and consumer organisation partners.	Possible concern about the independence of CCNet in decision-making if core-funding provided. Possible issues related to selection of personnel and their line of accountability.	Databases to monitor effectiveness of consumer involvement (not clear how defined), people involved, and support offered to consumers. Status of data ownership will need to be clarified. Requirement for all consumers to register with CCNet may be unacceptable to some. Consumer time spent on administrative tasks rather than participation in review development. Training for consumers further developed in line with current plans.	Not clear if any change but through partnership approach with individuals and consumer organisations.
3.	Establish administrative support unit to support CCNet, other volunteers, consumer facilitators and consumer organisation partners.	No change	Extends current arrangement to provide administrative support to CCNet to other consumers across the Collaboration. Mechanism to monitor consumer involvement without any change to registration preferences. All administrative systems consistent with current processes in the organisation and data ownership not an issue. Support for consumer involvement embedded in Collaboration infrastructure and not dependent on availability of volunteer workforce and people with administrative expertise.	Partnership strategy consistent with other with external organisations linked to Collaboration. Mechanism and resources to assess and monitor dissemination strategies including those involving consumer organisation partners.