

2010

Consumer involvement in the  
Cochrane Collaboration:  
Executive summary

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## EXECUTIVE SUMMARY

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.

It is difficult to ascertain the number of consumers currently active in 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. Across all entities in February 2010 Archie recorded 521 individuals registered as consumer reviewers (consumer referees), nine as consumer coordinators and 107 as handsearchers. Archie also listed 723 active members for the Consumer Network. The majority of consumer reviewers in the Collaboration were not members of the CCNet (61%).

Consumer roles in the Collaboration can be summarised into three main areas:

- Involvement in the decision-making processes of the Collaboration.
- Involvement in the choice and preparation of Cochrane Systematic Reviews.
- Involvement in dissemination and promotion of Cochrane Systematic Reviews and evidence-based healthcare.

Three fundamental groups or types of consumers can be described as participating in the Collaboration. These overlap as most people rarely all fit into one type (see Figure 1).

**FIGURE 1: Model of consumer groups participating in the Collaboration**



The groups are:

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

**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, for example, actively helping other consumers be involved. Facilitator positions operate under different guises across the Collaboration (e.g. consumer editors and consumer coordinators). The role can be funded through CRGs or Centres but there are examples of consumer organisations funding positions that include 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 already work directly with consumer groups that contribute to prioritising reviews, identifying relevant outcomes, etc.

Figure 2 shows CCNet membership and consumer involvement in the Collaboration based on current data in Archie. 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, 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.

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

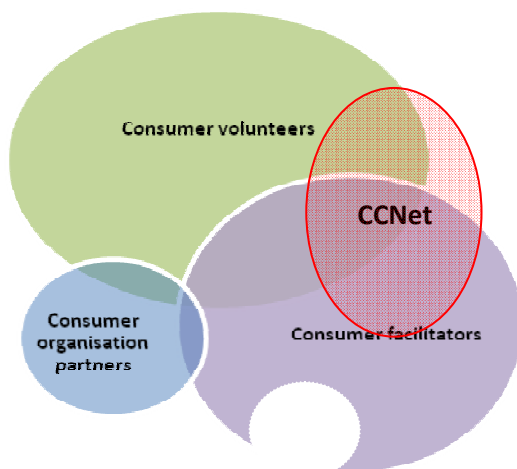
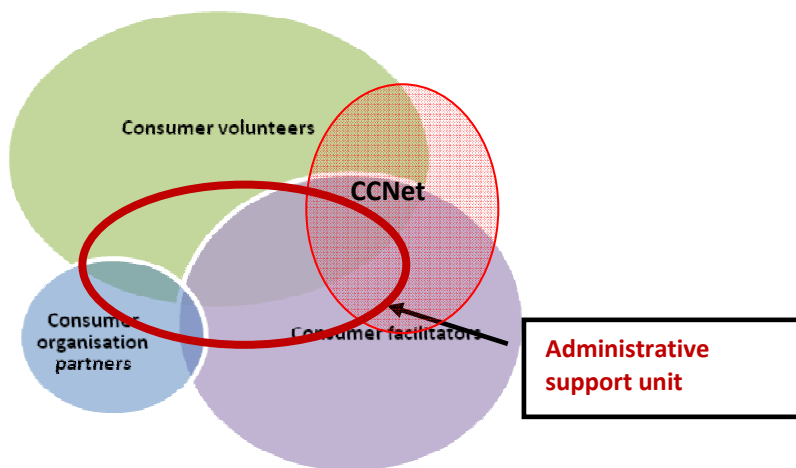


Figure 3 shows one option, the provision of an administrative unit within the Secretariat, which would support consumer involvement across all consumer types and assist the CCNet.

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



The following table compares three different options and identifies *some* potential issues for each in terms of the roles for consumers in the Collaboration.

	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 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. People with administrative expertise.	Partnership strategy consistent with other external organisations linked to Collaboration. Mechanism and resources to assess and monitor dissemination strategies including those involving consumer organisation partners.