



ccnet
CONSUMERS IN COCHRANE

Draft Strategic Overview

2004

COCHRANE CONSUMER NETWORK

The World Health Organization (1978) states: *The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.*

Background

The Cochrane Consumer Network (CCNet) was registered as an entity within *The Cochrane Collaboration*, in October 1995, as part of the Collaboration's goal to achieve broad consumer participation in Cochrane activities. The membership has grown from just a handful to some 300 consumers who contribute to the review process. Consumers represent many countries across the globe, including lower economic status countries.

The Cochrane Collaboration is an international not-for-profit organisation, established as a company, limited by guarantee, and registered as a charity in the UK (number 1045921). Its mission is *to help people make well-informed decisions about health care by preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions.*

Healthcare decision-making throughout the world will be informed by high quality, timely research evidence. The Cochrane Collaboration will play a pivotal role in the production and dissemination of this evidence across all areas of health care (Vision Statement).



Background

To achieve its goals and objectives, *The Cochrane Collaboration* comprises entities charged with developing or supporting the development of systematic reviews; these are made available electronically on *The Cochrane Library*. Of vital importance is that reviews are consistently of high quality, relevant and that steps are taken to minimise bias.

The Cochrane Consumer Network's role is very clear, to support and coordinate consumers working within The Collaboration, enabling effective, open communication, training and mentoring opportunities. Consumers comment on Cochrane reviews to ensure the readability and relevance of the reviews for users and receivers of health care, consumers, parents and carers. Early input by consumers into the review process is desirable, assisting with setting review topics and prioritizing reviews so that the most relevant review questions are approached with some degree of urgency; and developing protocols, the wording and setting of the review question and outcomes considered. Procedural justice is, in this way, achieved as the process involves the people to whom reviews will ultimately apply.

Consumers generally contribute their time and effort to *The Cochrane Collaboration* on a voluntary basis and are not in a work environment where they can claim expenses or the experience gained adds to their curriculum vitae and work prospects. It is important that consumers involved within *The Cochrane Collaboration* are empowered to inform other consumers of the value of systematic reviews and the processes for giving consumer input into medical research as well as communicating the evidence held within *The Cochrane Library*.

Role statement for a Consumer in Cochrane

- A Cochrane consumer is an individual who has unique personal experiences that allow him or her to provide an effective healthcare user/receiver perspective to a systematic review question.
- A consumer may be an individual or representative of a community health support organization or group without specialist medical knowledge
- A Cochrane consumer brings an impartial, strong and realistic attitude to the current state of healthcare knowledge and is dedicated to the development of evidence-based health care and information.
- They are able to identify gaps in our knowledge from a consumer perspective and accept an intellectual long-term approach to improving health care.
- A Cochrane consumer seeks information from a wider audience of consumers and may also communicate with and support consumers in providing input into a review question, while maintaining the confidentiality of the review team.

Role statement for the Cochrane Consumer Network

- The Cochrane Consumer Network is a clearly identified and independent Cochrane entity that links and coordinates a valuable resource of consumers to participate in the work of *The Cochrane Collaboration*.
- It empowers consumers by providing training, support, and multilevel communication to develop best practice for providing a consumer perspective to the systematic review process.
- The Cochrane Consumer Network provides an efficient and valuable global resource of consumers who are active in their own right and who are able to link with other consumers and health support organizations or groups to provide a consumer perspective.

The Network encourages evidence-based practice and a long term approach to improving health care, on a global level.

Opportunity

1. The policy of *The Cochrane Collaboration* is to involve consumers in the preparation of systematic reviews of best evidence for health care and communicating information held within *The Cochrane Library*. The Cochrane Consumer Network sets out to access consumers from a diversity of backgrounds, across the globe, and train and support them in a way that they can provide well-balanced, representative and effective consumer input into the preparation of meaningful reviews.
2. The disease-based and geographically located Cochrane entities and supporting infrastructure that is global
3. More and more countries are rationalising healthcare expenses by introducing an evidence-based approach to health care that aims to be cost effective and politically relevant
4. Relevance to ‘users/consumer’ needs is best achieved by the inclusion of consumer representation in preparing materials that inform health care and in decision-making processes
5. A market exists for provision and training of consumer representatives who are well-versed in evidence-based healthcare strategies and have access to good evidence-based information
6. Procedural justice and consumer relevance in a climate where more people are taking part in shared decision making with regard to their own health care.
- 7.

Vision

The Cochrane Consumer Network supports and coordinates the consumer perspective for systematic reviews of best available evidence on health care, as produced by *The Cochrane Collaboration*, with a view to enable and support partnership in health care.

Mission

To act as a relevant international resource for timely and effective consumer participation in the preparation and dissemination of Cochrane reviews, and bridging the gap between medical research, Cochrane entities, individual consumers and health support organisations through a partnership approach.

To create an environment that will support and sustain effective and international consumer participation in The Cochrane Collaboration that is effective and rewarding for all.

Goals

To take a lead role in ensuring that the consumers involved have the knowledge, skills and support to provide influence.

Inform and empower individuals re their role in health and medical research including best practice principles.

Aims

1. To enable and support consumers to contribute to the function of Collaborative Reviews Groups, Fields, Cochrane Centres and *The Cochrane Collaboration* as a whole. This function is seen as the development of high quality systematic reviews that inform evidence-based practice in health care.
2. To increase the awareness of *The Cochrane Collaboration* of the value and benefits of working in partnership with consumers and with an awareness of issues that are important for the users and receivers of health care
3. To inform a wider community of the work of *The Cochrane Collaboration* and to act as a means of contacting other consumers and health support organisations
4. To establish a sound, effective governance and management system that enables a valuable resource and provides business, consumer and Cochrane accountability.

Objectives

- To develop and support consumer roles within *The Cochrane Collaboration* and to provide effective representation in the Steering Group and sub-committees
- To develop a pool of consumers who are available to participate in the review process and who come from a geographical and socioeconomic diversity
- To work toward ongoing education and training of consumers with regard to methodologies, evidence-based practice and critical appraisal of healthcare evidence
- To tap into the competencies and associations of members to further the work of the Consumer Network and to communicate information obtained from systematic reviews
- To mould a flexible, dynamic system that can achieve these aims using democratic and transparent processes, accountability, and the strengths that are contained within the Network
- To evaluate consumer participation within The Collaboration
- To maximize the opportunities at annual colloquia and regional meetings to provide relevant and useful meetings and workshops and to encourage local consumers to be in attendance
- To support the use of evidence-based practice by health support organisations and agencies.

Strategic tactics

- An international database of consumers
- Communication and support through a moderated e-mail address, newsletters and a reliable contact person
- Guides on working with consumers to obtain a consumer perspective (entities and reviewers)
- An effective mentoring system
- On-going education and training
- An interactive, informative web site.

Requirements

- A flexible and dynamic structure and management that works from a principle of teamwork and shared decision-making
- Effective communication
- A dynamic website that promotes the function of the Network as a valuable resource for consumer participation and dissemination of Cochrane information relevant to its consumers
- Funding through the process of grant applications and alliances

Actions

- Design of a web site to enable the running of educational programs, monitoring of consumer participation and discussion of pertinent issues
- Data collection to identify the background and experiences of Cochrane consumers
- Develop the structural framework that enables consumers to be actively involved
- Development of Cochrane discussion papers and educational programs to inform the practice of evidence-based practice relevant to consumers
- Workshops at a regional level and at colloquia – development of training packages that can be adapted to local needs
- Ongoing evaluation processes
- Encouragement of consumers in review groups to collate the evidence from reviews in a way that is most pertinent to consumers and different healthcare situations

Management

An administrative position that is answerable to an elected coordinating team and The Cochrane Collaboration Steering Group.

Coordinating Team

Elected from the membership in accordance with the Constitution and have geographical diversity

Financial considerations

Sources of funding

Expenditure

Performance indicators

Completion of targets as set out in detail under goal tables

Quality standards

The Cochrane Consumer Network agrees to comply with the principles of *The Cochrane Collaboration* and all appropriate legislation, statutory and health standards.