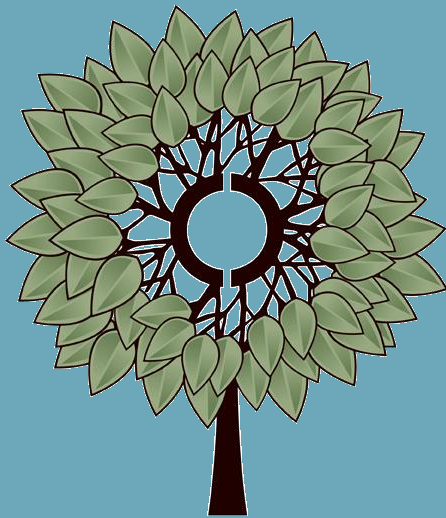


Including the patient perspective at Cochrane

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Knowledge Broker
Canadian Cochrane Centre

Patient Involvement Forum
Edmonton
February 5, 2010



Outline

- Introduction
- CCNet
- Roles
- Training & support



Consumers – a natural fit

Mission statement

The Cochrane Collaboration is a unique worldwide organization that aims to *help people make well informed decisions about health care* by preparing, maintaining and promoting the *accessibility* of *systematic reviews of the effects of health care interventions*.



Cochrane principles

1. ***Collaboration***
2. ***Building on the enthusiasm of individuals***
3. ***Avoiding duplication***
4. ***Minimising bias***
5. ***Keeping up to date***
6. ***Striving for relevance***
7. ***Promoting access***
8. ***Ensuring quality***
9. ***Continuity***
10. ***Enabling wide participation***



Cochrane Consumer Network (CCNet)

October 1995 Cochrane Consumer Network
registered as part of Cochrane

www.cochrane.org/consumers



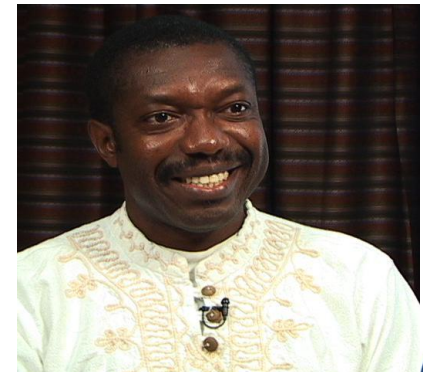
Vision:

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



CCNet role:

- Support the role of consumers within Cochrane
- Provide information and a forum for networking among consumers
- Help disseminate review results to patients, caregivers & families



Communications from CCNet

- Consumers listserv
- Newsletter
- Colloquium meetings
- CCNet website



-



How are consumer involved in Cochrane?

- a. Comment on Cochrane protocols & reviews
- b. Write or review plain language summaries
- c. Raise awareness of EB health care & disseminate info about reviews
- d. Recruit other consumers



a. Peer review – main activity

- Link directly with Cochrane Review Groups
- Provide consumer viewpoint & concerns on protocols & reviews
 - Feedback on research question and relevance to patients
 - Identify relevant outcomes but also outcomes of concern to consumers (often differ from those of researchers)
 - Presentation of results in form easily understood by lay person



Checklist provided – tailored to RG

Screen 1 of 5

View Options X Close

Checklist for Consumer Review of Cochrane ENT Group Protocols

How to use this checklist

The checklist attached is a reminder and quick guide only. Feel free to comment on as few or as many aspects of the protocol as you like, or to raise any thoughts about the topic. Some of the points mentioned might be irrelevant for the protocol you have been asked to referee (for example, if the data reviewed were not of sufficient quality for doing a meta-analysis). Please mention any points you feel need improving, anything you feel is missing - and anything you want to stress as being particularly good.

How to reply

We would prefer to receive your comments in writing (paper, fax, electronically) but if it is more convenient for you, you can also comment by phone. Please give details of why certain aspects of the document were inadequate and suggest improvements if possible.

If you have any questions, please do not hesitate to contact the Review Group Co-ordinator, who will be pleased to help. The *Cochrane Consumer Network* also provides some excellent resources for consumers commenting on Cochrane reviews, including glossaries of medical and technical terms. These can be found on the Internet at www.cochraneconsumer.com. 'Understanding Health Research'.

Title of review:	
Name of referee:	
Please return to Editorial Base by:	
Please return your comments to:	<p><i>Jenny Bellorini</i> <i>Cochrane Ear, Nose & Throat Disorders Group</i> <i>Department of Otolaryngology</i> <i>West Wing - John Radcliffe Hospital</i> <i>Headley Way</i> <i>Oxford OX3 9DU</i> <i>UNITED KINGDOM</i> jbellorini@cochrane-ent.org http://www.cochrane-ent.org</p>

1. TITLE

<input type="checkbox"/> Does the title reflect the subject of the protocol? Is it understandable?

11

Microsoft Office... Patient Involvement... The Cochrane Collaboration... ENTconsumerche...

4:31 PM

b. Plain language summaries

- Improve readability & usefulness of PLS
- Don't need to be an expert in the topic
- Working towards consistent, useful, understandable template for PLS
 - 2 versions tested with consumers internationally
 - small controlled trial with consumers: does new format improve understanding of a review?



c. Raising awareness: reviews

● Patient organizations post Cochrane review PLS on websites

rethink

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Research looking at treatment

What is the Cochrane Collaboration?

The Collaboration is an international, independent and not-for-profit organization which examines research trials to find what the best practice should be in medicine. A central administration team supports the Schizophrenia Review Group in developing systematic reviews on interventions for schizophrenia and psychosis. There are review groups in all health and disease conditions and they are spread across the world, generally based at universities and teaching hospitals.



What is a systematic review and how is it written?

A systematic review summarises the results of available carefully designed healthcare studies (randomised controlled trials – RCTs) and provides a high level of evidence on the effectiveness of healthcare interventions.

To write a review, a small group of people look critically at RCTs that have appeared in the medical or health literature on a particular topic ('reviewing the literature'). For example they may look at a drug treatment for schizophrenia compared to having no medication (placebo). The reviewers set about their task very methodically following, step by step, an advance plan (protocol) that covers:

- the way existing studies are found;
- how the relevant studies are judged in terms of their usefulness in answering the review question;
- how the results of the separate studies are brought together to give an overall measure of effectiveness (benefits and harms) – statistical techniques used to combine the results are called meta-analysis.

Living with mental illness

- Treatment and therapy
 - Research looking at treatment
 - Contents of summaries
- Recovery and self management
- Everyday living
- Money, debt & mental health problems
- Coping in a crisis
- Rights and laws
- Caring



[Read Jane's blog on the Cochrane reviews she produces in plain English.](#)

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• Osteoporosis

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• Raynaud's Phenomenon

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• Scleroderma

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Other Categories:

Select an option.

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The Cochrane Musculoskeletal Review Group (MSG) is a specialized group of researchers and consumer representatives that belong to the Cochrane Collaboration, an international not-for-profit organization that encourages informed decisions about health care by preparing, maintaining and promoting reviews of the effects of various health care treatments.

MSG members review the best available literature to determine the best evidence to support specific arthritis treatments. They explore the evidence for and against the effectiveness and appropriateness of treatments (medications, surgery, education, etc) in specific circumstances. The results are medical reviews that are then included in The Cochrane Library and made available to health professionals around the world.

For members of the public who also want to be informed about the evidence concerning health care practices and decisions in their lives, the Cochrane Musculoskeletal Review Group have summarized their reviews into consumer fact sheets. They've agreed to try their best to use nonmedical language and to post them on this page as soon as they become available. You can learn more about the Cochrane Collaboration and the Cochrane Musculoskeletal Review Group by visiting the [MSG Web site](#).

This page was last reviewed/updated on : 02/09/2009



c. cont'd Knowledge transfer

- Partnership with CIHR Institute (IMHA) *and* Cochrane Musculoskeletal Group
 - Team of consumers, allied health professional & knowledge translation specialist
 - KT derivative product based on Cochrane review
 - Identified research gaps
 - Publication in Physiotherapy Journal

GUEST EDITORIAL

Partnership in Action: An Innovative Knowledge Translation Approach to Improve Outcomes for Persons with Fibromyalgia

Mary Brachaniec, Vince DePaul, Margaret Elliott, Lynn Moore, and Pamela Sherwin



d. Recruitment

- Word of mouth – friends
- Disease organizations, patient support groups
- Consumer coordinator – part of role to recruit new consumers
- Satellite workshops at s



Training and support

- Mentoring and support
- Online self-learning resources:
 - Introductory course in modules (US)
 - Videos
 - Online info learning kit
 - Cochrane Library tutorials & webinars
- Workshops
 - Introductory, skill building

- CCNet listserv discussions



Priorities for Canadian consumers

- More training and mentoring
- Guideline and tools to help guide role in communicating to peers about CCNet, Cochrane and reviews
- Recruitment of more consumers



Reflection and review

- Currently, undergoing review of consumer involvement in Cochrane

Goal:

- Increase value of consumer input into reviews and their dissemination
- Improve mutual benefits for consumers and Review Groups



Issues

- Not all Review Groups open / ready to involve consumers at this time (most do)
- Challenges in recruiting consumers, eg. reviews in english; consumers afraid not "smart" enough
- Lack of process for direct feedback to consumers on usefulness of input
- More formalized processes to integrate & train consumers into Cochrane



Acknowledgements

Anne Lyddiatt – consumer coordinator, MSRG

Janet Wale – coordinated survey and external review of consumer network

Tamara Rader – recruitment, PLS testing, KTE project

Gill Gyte – Pregnancy & Childbirth group – supporting consumers in UK



Thank you!

Questions?

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