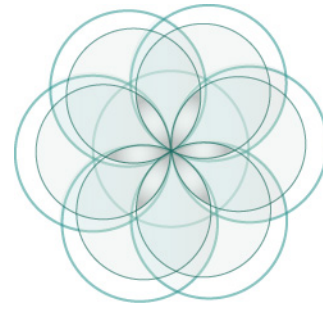


Newsletter



Cochrane Consumer Network Issue 19, June 2009

To go fast – go alone; to go far – go together (Tikki Pang, WHO, Vellore, India)

Contact e-mail: ccnet-contact@cochrane.de
E-mail discussion list: consumers@lists.cochrane.org

Web address: <http://www3.cochrane.org/consumers>
Available at: www.cochrane.org/newslett/index.htm

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Welcome to this newsletter

Just what is good management? A journalist in an Australian newspaper magazine had strong words to say about the present global economic situation.

"Almost 80 years after the Great Depression the financial world was drowning in data, the executives drowning in personal wealth, their corporations drowning in profits, governments drowning in tax revenues. Despite all the brainpower of a million *Masters of Business Administration* (MBAs) and *computers* (IBMs), a plethora of analysts and pundits and central bankers and legislators and sundry smarty-pants, the planet wobbles on its axis and the entirety of world finance and business is flushed down the toilet.

Where was wisdom when we needed it? Wise leadership demands the knowledge that comes from good information and data..... [Phillip Adams *The Weekend Australian Magazine* March 21-22 2009]

This was about the financial situation, which affects us all. Why it particularly caught my attention was because the comments seemed very relevant to other areas of our lives, including health care. The article provided good affirmation to me of the need for consumer representatives, advocates, and people like us (working within *The Cochrane Collaboration*).

Election of new Cochrane Consumer Network (CCNet) Steering Group representative

The current representatives are:

Janet Wale (Australia). Janet is about to step down from the Steering Group (October 2009), and an election for her replacement is underway - you have been invited to vote for this position.

Liz Whamond (Canada). Liz remains on the Steering Group until October 2010.

To *members of the Consumer Network*, please go to <http://www3.cochrane.org/surveys/TakeSurvey.aspx?SurveyID=m6LM9n2> to vote for your preferred candidate.

Please complete your voting by midnight (local time) on Friday 26 June 2009.

The election results will be announced on Tuesday 30 June 2009. If you have any questions or comments please let me know.

Claire Allen (e-mail: CAllen@cochrane.org)
Deputy Administrator of the Cochrane Collaboration Secretariat

See page 6 of this Newsletter for information on roles and responsibilities

External Review of the Cochrane Consumer Network

We are carrying out a review of the Cochrane Consumer Network (CCNet), funded by the Cochrane Steering Group for the appointment of an external consultant, Bec Hanley of the UK. Bec is ably assisted by Jane Nadel and Maria Belizan, Janet Wale, all CCNet members, and a Collaboration Advisory Group.

The review aims to examine how and why consumers are involved in Review Groups, what impact consumer involvement has, and how consumers are supported by the Cochrane Consumer Network (CCNet) and by Review Groups.

To do this, we're asking consumers and Review Groups to give your views.

So hurry, available a limited time only!

Please complete a short survey. The survey should take you about 10-15 minutes to complete.

We are asking all Review Groups to complete the questionnaire, even if they do not currently involve consumers.

Links to the surveys

Consumers

<http://www3.cochrane.org/surveys/TakeSurvey.aspx?SurveyID=p2LMn92>

Review groups

<http://www3.cochrane.org/surveys/TakeSurvey.aspx?SurveyID=p2LMm92>

For any enquiries or difficulties please contact Jane Nadel (e-mail: jnlw@cshore.com.au)

You can only complete the survey once and we do have the responses for the people who kindly agreed to pilot the surveys!

CCNet projects

Complementary and Alternative Medicine Field Project

Consumer summary overviews of Cochrane Reviews are now on the Complementary and Alternative Medicine Field website at http://medschool.umaryland.edu/integrative/cochrane_consumer.asp.

This is ongoing work with The Cochrane Collaboration having a policy of updating reviews (ideally every two years) - so updates are now required and new consumer summaries added. If you would like to help with this project, please let us know at ccnet-contact@cochrane.de.

We thank Eric Manheimer for all he has done to make this possible. Funds have enabled us to give minimal financial support to our Administrator and Membership Secretary Jane Nadel in the US.

This project is being supported by Grant Number R24 AT001293 from the National Center for Complementary and Alternative Medicine (NCCAM). The contents of the summaries are solely the responsibility of the authors and do not necessarily represent the official views of the NCCAM, the National Institutes of Health, or The Cochrane Collaboration.

Prioritisation Project

- Prioritisation of existing Cochrane reviews for consumers and the public as a way of promoting evidence-based health care and *The Cochrane Library*

A Cochrane Collaboration Steering Group funded Prioritisation Project (2007). *Maria Belizan, Janet Wale and Sita Vij*

The CCNet Prioritised Review Titles are at www.cochrane.org/consumers/happenings.htm

[Questions that the review topics address: have a look!](#)

[A database of Cochrane review topics - prioritised by consumers](#)

<http://cochrane.org/ccnet/prioritisedgroups.html> (password - consumers)

CCNetAWARD to Maria Belizan for the huge amount of effort she has put into this project – and extending it to a Spanish version.

Sita Vij and Janet Wale enjoyed working with Maria on this project!

Cochrane Consumer Network provides a consumer, patient, carer view on protocols and reviews during their development. We have an email discussion list with over 500 people on it (not all are consumers). Often a review group, or occasionally an author, sends out a request for a consumer to work with them.

[These materials](#) are confidential until the protocol or review is published.

We compared our consumer prioritised review topics with the Wiley Blackwell & Sons list of most accessed reviews.

Of the 49 most accessed systematic reviews for 2007 (accessed December 2008) (+1 Review Group module):

- - 24 were consumer prioritised titles
- - 35 (71%) were from the Review Groups prioritised in our online survey
- The Cochrane Library contains over 3500 reviews!

In surveys carried out by Wiley to identify the main users of the Cochrane Library consumers comprise a very small section. This raises an important question as to who (or for who) the main users of The Cochrane Library are, and why.

The Prioritisation Project provides prioritised titles in the areas of: breast cancer; consumers, communication and effective practice of care; gynaecological cancers; depression and anxiety; pregnancy and childbirth; musculoskeletal and bone, joint and muscle trauma, back; heart; colorectal; HIV/AIDS; acute respiratory infection; methodologies; metabolic and endocrine disorders; tobacco addiction; and skin disorders.

Answers and information found in the Cochrane Library are important in addressing how Cochrane reviews can improve health outcomes.

Learn more about us and what we do!

www.cochrane.org/consumers/happenings.htm

We have some amazing videos - put together for us by Richard Davis and Barbara Warren in the US.



Hear Cochrane contributors and staff discuss the Collaboration's work and impact, in a series of 2006 interviews [Watch](#)



New! - A nine-minute video featuring members of the Cochrane Consumer Network describing how they work together and contribute to improve health care in communities around the world.

[Watch](#)

Consumers United for Evidence-based Health Care



A six-minute video featuring members of the Consumers United for Evidence-based Health Care (CUE), a U.S.-based coalition, which highlights the role of consumers in promoting evidence-based health care.



Some of the photographs in the second video were provided by Voices for a Malaria Free Future

Global Program on Malaria, Johns Hopkins University Center for Communication Programs, Baltimore, Maryland 21202 USA
www.MalariaFreeFuture.org

Guiding consumers and researchers on consumer involvement in Cochrane Reviews

We have the webpages on www.cochrane.org/consumers that set out to explain the role of consumers - there is also a short section for Review Groups.

*Test our new, draft training module - and comment on it - at:

<http://cochrane.clickmediapro.com/learning/>

The US Cochrane Center Consumers United for Evidence-based Healthcare (CUE)

Understanding Evidence-based Healthcare: A Foundation for Action, a free 5.5 hour online course for consumer advocates (see www.cochrane.us for the link).

Cochrane Contributors Meetings

The Canadian Cochrane Network and Centre

9th March 2009: 7th Annual Canadian Cochrane Symposium

Several consumers representing different review groups attended this meeting. Anne Lyddiatt gave an introductory session to The Cochrane Collaboration as well as presented the CCNet Prioritisation Project findings.

Training and support needs for both new and experienced consumers were discussed with the Canadian Cochrane Network and Centre and the Musculoskeletal Group. Recruitment and mentoring of new consumers as well as improved and new ways to disseminate Cochrane reviews (knowledge translation and promotion) were also discussed.

UK Cochrane Centre

The meeting of UK and Irish Contributors was in Edinburgh on the 18-19 March. UK consumers ran a Consumer workshop on two occasions that was aimed at a mix of consumers and others (e.g. researchers, Review Group Coordinators and editors). The workshop was well attended.

Things people said they wanted considered

- How to improve what I do as a consumer
- How to tackle the problem of working in isolation as a consumer
- How the role of consumers could be enhanced
- Support and feedback for new consumers
- How to find new consumers, and how to know what to do with them once we've found them

- How can consumers input more directly into reviews?
- How to move into different groups if you're a consumer
- Where and how to get consumer input
- How to ask Managing Editors's questions that they can't refuse to answer
- How to use feedback mechanisms more effectively
- How to get consumer input more quickly and more effectively
- To find out more about what consumers do and what we want from them
- The role of consumers in plain language summaries

The Director of the UK Cochrane Centre Mike Clarke gave a talk about the lack of clarity on what the Collaboration wants from consumers.

Other points raised in the discussion on the role of consumers in producing reviews

- Checklists and a lack of consistency across review groups.
 - Some review groups give good feedback to consumers, but this isn't consistent.
 - Consumers bring a wealth of life and work expertise to the Collaboration, but they aren't often asked to use it.
 - Importance of involving consumers in prioritising which reviews to do, to ensure they are the most relevant and important ones.
- Also important to involve consumers at the title registration stage, as this is when the important decisions are made.

Could review authors be encouraged to find consumers? They are more likely to have contact with consumers than review group coordinators are.

What's the best model for supporting and promoting consumer involvement; and at what level (review group, UK Cochrane Centre, CCNet)?

These questions very much reflected those discussed at the Canadian meeting and validated the need for the CCNet Review presently underway with an external consultant, bec Hanley of the UK.

Continental European Cochrane Entities meeting 10-12 June, Maastricht (The Netherlands)

The Strategic Review of The Cochrane Collaboration

In 2008, a strategic review of The Cochrane Collaboration led by Jeremy Grimshaw, Director of the Canadian Cochrane Centre and Network

The Recommendations Report is posted on the Review website. To download the report and the background documents, please go to:

<http://ccreview.wikispaces.com/Final+Report+and+Background+Documents>.

For the Review, the team had identified seven main areas:

- Purpose of The Cochrane Collaboration
- External and internal identity and perception of identity of The Cochrane Collaboration (brand)
- Environmental scan (competitors)
- Financial models
- Accountability and decision making
- Structures and processes

- Communication, advocacy and engagement with external stakeholders

From the Steering Group representatives

Janet Wale and Liz Whamond

The mid-year Cochrane Collaboration Steering Group meeting, April 2009, was preceded by a workshop on the Review of The Cochrane Collaboration recommendations. The workshop was attended by Steering Group members, a number of Review Group Coordinating Editors and Cochrane Centre staff.

- With a mind to social capacity, the 'glue' of the Collaboration

Review Recommendations are grouped around:

Clarity of purpose

- Reaffirm our primary purpose is the production of high quality (up to date) systematic reviews (seen internally and externally)
- Formalise additional purposes including training, methods development, and advocacy for evidence-based decision making
- Identify principles for developing lines of activity and new products

Engagement of partners for mutual benefits

- Develop a 'marketing and communication' strategy to promote internal and external awareness of the value arguments for and achievements of The Cochrane Collaboration
- Improve the useability of The Cochrane Library (and other products) for diverse stakeholders (CCNet/Fields)
- Develop a partnership strategy to engage other systematic review producers and knowledge packagers
- Establish formal membership for its contributors
- Establish an external advisory board

New resource options for supporting strategic objectives

- Invest in a development function for lines of activity or new products
- Investigate the development of a broad-based educational program
- Investigate the development of a responsive review program
- Acknowledge the reality of our current infrastructure funding model and 'work to maintain it'
- Explore and pursue new funding opportunities

Management, accountability, effective leadership

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

'Strategic thinking/framework' embedded at all levels and at all times

- Undertake a formal environment(al) scan every 2-3 years
- Use uncommitted income strategically (to develop lines of activity, new products)
- Review terms of reference, number and spread of Cochrane entities to ensure 'efficient' alignment with the purposes of the Collaboration

Working Groups are being set up, for example on:

Cochrane training
 Cochrane response (team for carrying out prioritised reviews)
 Cochrane products
 Cochrane education
 Cochrane advocacy
 Cochrane marketing and communication
 Cochrane funding models
 Cochrane external advisory board

International Clinical Trials Day

The 20th May was International Clinical Trials Day for 2009. Learn more about it on

www.cochrane.org/news/articles/ICT_day_2009/ICT_2009.html

The AccessCR 2009 Clinical Trials Honour Roll was released on May 20th in celebration of International Clinical Trials Day. The Cochrane Consumer Network was registered and obtained a certificate of acknowledgement.

Thanks for your participation in this event and your contribution to Australasian Clinical Trials. www.accesscr.com.au

Cochrane Consumer Network was listed as an Organisation on the

AccessCR 2009 Clinical Trials Honour Roll

International Clinical Trials Day, 20 May 2009

Their contribution to / support of clinical trials in 2008-9, helped advance Medical Knowledge & Care for all Australasians.

[Health Action International, an independent, global network working to increase access to essential medicines and improve their rational use through research excellence and evidence-based advocacy](http://www.haiweb.org) (www.haiweb.org)

Andrew Herxheimer also informed us about a joint letter to nine EU health ministers on International Clinical Trials' Day 2009: <http://www.wemos.nl/en-GB/Content.aspx?type=news&id=3152>

He wrote: this is about an issue that concerns us all, in poor and in rich countries. It's worth checking your own national policies.

Wednesday 20 May marks International Clinical Trials' Day 2009. A group of European organizations led by Wemos (The Netherlands) sends letters to nine European health ministers.

On 20 May, International Clinical Trials' Day 2009, we would like to draw your attention to the position of trial subjects in developing countries. We are sending this letter to health ministers in the Netherlands, Belgium, Germany, France, United Kingdom, Italy, Sweden, Spain and Denmark.

Clinical trials are increasingly being carried out in low-income and developing countries. Several studies have shown that the rights of trial subjects in these countries are not sufficiently protected

due to inadequate oversight. These studies have also shown that unethically tested drugs are finding their way onto the European market unhindered.

A recent study (March 2009) commissioned by the European Parliament and carried out by the Centre for Research on Multinational Corporations (SOMO) shows that with the information the European registration authorities currently have at their disposal, it is almost impossible for them to ascertain whether or not clinical trials have been conducted ethically. In its recent strategy paper, the European Medicines Agency (EMA) states that it will give greater priority to ethics when granting marketing authorization to medicines that have been tested outside Europe.³ More specifically, the EMA states that it will consider the practical application of ethical standards for clinical trials, such as the Declaration of Helsinki, particularly in the context of developing countries.

We welcome the fact that the EMA is prioritizing ethics within the marketing authorization procedure, but regret that this process is not open to public scrutiny. We urge you to take swift steps to guarantee that the process initiated by the EMA is implemented to ensure that the rights of trial subjects in developing countries are adequately protected. For this, it is vital that experts from developing countries and non-governmental organizations are involved in the discussions which will define the framework for implementation of ethical criteria in the marketing authorization procedure.

Furthermore, it is essential that ethical guidelines are integrated in a harmonized way in the marketing authorization procedures of the national registration authorities in Europe. We therefore urge you to take action to ensure that your national registration authority also prioritizes ethics in its drugs marketing authorization procedure. As members of the European Union and consumers of drugs tested in developing countries, we all have a responsibility towards the subjects on whom these drugs are tested.

Last February, FairDrugs.org, a worldwide coalition of health and human rights organizations led by Wemos launched the *Call for Ethical Clinical Trials in Developing Countries* in Europe. This launch was the starting point for the FairDrugs.org campaign, which aims to promote the support for "fair" drugs. Please find attached a copy of the *Call for Ethical Clinical Trials in Developing Countries*, as well as a list of organizations and individuals who have already pledged their support. Over the next few months, we will be gathering as many additional pledges of support as possible.

In India, The Draft National Health Bill, 2009 is at <http://www.karmayog.org/redirect/stred.asp?docId=23282>

This is a "Bill to provide for protection and fulfilment of rights in relation to health and wellbeing, health equity and justice, including those related to all the underlying determinants of health as well as health care; and for achieving the goal of health for all; and for matters connected therewith or incidental thereto." This working draft has been prepared by the Ministry of Health and Family Welfare, Government of India (<http://mohfw.nic.in/>)

Cochrane groups

In order to give organisations outside the Collaboration a better understanding of the role of a Cochrane Review Group Co-ordinator (RGC), the Collaboration's Steering Group, following approval by Co-ordinating Editors, agreed at their mid-year

meeting (24 to 26 April) to the request from RGCs to change their title to Managing Editor (ME) with immediate effect. Adrian Grant and Lorne Becker, Co-Chairs, Cochrane Collaboration Steering Group

Cochrane Schizophrenia Group

Beth York is now the Managing Editor (formerly Review Group Co-ordinator)
e-mail: Bethany.York@nottingham.ac.uk
Website address: <http://szg.cochrane.org>

Lung Cancer Cochrane Review Group

José Ángel Expósito has replaced Jordi Pardo as Review Group Co-ordinator of the Group. The Group wishes to thank Jordi for all his hard work and effort during all these years, and to wish him the best in his new endeavours.

Fields

The Nursing Care Network was officially registered with The Collaboration on 25 February, 2009. The Network Co-ordinator/Convenor is Professor Alan Pearson, operating from South Australia.
E-mail: alan.pearson@adelaide.edu.au

Spanish speaking consumers

Read the latest newsletters from the Iberoamerican Cochrane Center (CCIB) in Spanish. Visit: <http://www.cochrane.es/newsletters>

Happenings - within The Cochrane Collaboration

We now have an Editor-in-Chief for *The Cochrane Library*. This opens up the way for major developments of the Collaboration's editorial processes, including quality improvement and management, prioritisation of review topics, and progressing *The Cochrane Library* and its ability to change health outcomes.

Formed over a period of time, a Coordinating Editors Board, led by an executive group of coordinating editors; a Coordinating Editors and Methods group; and a Review Group Coordinators (now Managing Editors) Board are now operational. These have been formed as part of a drive for better communication and improvement of Cochrane processes. The Trials Search Coordinators are working as a team to develop a new CENTRAL (the database of clinical trials on *The Cochrane Library*). Centre Directors have always met regularly and discussed common issues and position statements. It seems likely that Fields and Networks will also form a 'Board' as a means of developing consensus views and representing them in key decision making at a whole of Collaboration level.

The Cochrane Library

Everyone who has access to the internet can read the plain language summaries and abstracts of Cochrane reviews at: <http://www.cochrane.org/reviews/>
Click on a review and you will be able to see the plain language summary.

You can also listen to podcasts of some of the new and updated reviews, often involving the authors at:

www.cochrane.org/podcasts/index.html

Issue 45 of Cochrane News had the results of the Cochrane Strategic Review, as well as details on the success of *The Cochrane Library* podcasts. Cochrane newsletters are found at www.cochrane.org/newslett/index.htm

The Canadian Cochrane Network and Centre, in partnership with the Canadian Health Libraries Association, has successfully secured a pilot for a national licence to The Cochrane Library in Canada. Until the end of 2009, all Canadians with Internet access will be able to download full reviews from the Library. Sustainable funding will be sought to make the access permanent for all Canadians. Visit

www.ccn.cochrane.org/Files/Website%20documents/Other/Press%20release_EN%203_.pdf to read more. Contact j.douce2@uottawa.ca for further details.

Hearing the patient's voice

The Royal Society of Medicine is organising a conference on Saturday 11th July - Medicine and Me: ME and CFS www.rsm.ac.uk/academ/x2g106.php

'Medicine and Me' conferences, initiated and developed by the Royal Society of Medicine, are specifically designed for patients. These meetings bring together patients, their families, carers, advocates, patient support groups, clinicians and researchers to discuss care and research issues in a particular condition.

'Medicine and Me' meetings aim to provide a forum in which patients' concerns about their illness are given top priority. The meetings provide an opportunity for patients and their families to share experiences, to hear about the latest research and treatment, to discuss treatment choices and access to treatment, and to question the experts on a wide range of issues.

This meeting will focus on the difficulties and delays in diagnosis, ME and CFS in children and adolescents, the existing range of treatments, and the latest research and its impact on the development of new, disease-modifying treatments.

The audience at 'Medicine and Me' meetings typically comprises patients, their families, carers and advocates, representing at least 70% of those present; and clinicians and researchers, representing not more than 30%. Clinicians will include doctors, specialist nurses and all other health professionals involved in the treatment and care of patients with ME and CFS.

Cochrane Consumer Network (CCNet)

Works under the Cochrane principles of:

- Avoiding duplication of effort
- International collaboration (across populations at all income levels)

Its role is to:

- Support consumer involvement with The Cochrane Collaboration
- Link consumers (and consumer or patient organisations)
- Train in commenting on Cochrane protocols and reviews
 - Mentoring by fellow consumers;
 - General support in commenting on Cochrane reviews, disseminating Cochrane information and contributing to evidence-based health care

- Dissemination (knowledge transfer) of information from Cochrane reviews to other consumers of health care
- Increase awareness of evidence-based health care, in practice
- Keeping consumers informed (website, newsletters).

Administration as a registered Cochrane entity includes:

- Responsible reporting (Steering Group, Monitoring and registration Group)
- Provision of two steering group consumer representatives
- Keeping members strategically informed
- - Undertaking funded projects, such as prioritisation of existing Cochrane reviews from a consumer perspective
- - Governance for consumers within the Collaboration

Key roles (basically voluntary positions)

Convenor

Membership Administrator/Administrator

Chair of CCNet GC Advisory Group

Governance is through:

CCNet Geographical Centres (GC) Advisory Group

Set up to:

- Provide governance of the Network by the members themselves
- Be internationally inclusive
- Enable liaison with Cochrane Centres

The first two, within our own 'capacity', are ongoing.

The third, which we see as very important, has 'not happened' at this time and efforts continue. For many of the Centres, Cochrane work is only part of their reasons for being and their funding.

At present the CCNet GC Advisory Group has 23 members and corresponds by e-mail.

Role of Chair:

- Signatory for CCNet (re governance, projects, funding etc)
- Endorse, or otherwise, the actions of the Convenor/CCNet
- Special powers to report direct to Steering Group and Monitoring and Registration Group, if required.

Consumer Network Steering Group representatives (2)

- To represent consumers and CCNet on the Steering Group
 - Give the consumer and CCNet perspective
 - Identify and work at every opportunity to involve consumers in working groups, committees and strategic sessions ie decision making and work of the Collaboration – where consumers can be most useful
 - Provide transparency and accountability as 'a member of the public' (not to gain professionally through The Cochrane Collaboration)
 - Work to increase the role of consumers within the Collaboration

Responsibilities

- Are to CCNet, which is a Field within the structure of the Collaboration (so also support work re strengthening the voice of Fields and their input into the recommendations [and action upon] from Strategic Review of the Collaboration)
- Consumers are users of evidence to inform decision making in health care
- Report to GC Advisory Group
- Reports in CCNet Newsletters

- Raise issues relevant to consumers to the Steering Group (recent papers have been dropped from the agenda eg funding of trials in plain language summaries, issues that the CCNet prioritisation project raised)
- Report strategic issues back to CCNet, in particular Convenor and GC Advisory Group.

Why two CCNet consumer members on the Steering Group?

Consumers are representatives of users of Cochrane reviews and shared decision making in health care. It is this that makes CCNet strongly aligned to other Fields. Research into consumer and community participation in healthcare policy and research strongly recommends more than one consumer - so that they are not a lone 'non-professional' voice.

Consumer representatives also have an important role with regard to transparency and accountability around decision making (for example on policy, spending, organization). The Cochrane Collaboration is a not-for-profit organization registered as a charity in the UK and 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.

The Representatives are given the opportunity to report on what they see as their role and hope to achieve through reports in the CCNet Newsletter.

CCNet members

Andrew Herxheimer: I'd like to suggest as a firm rule that all Cochrane Review Groups soliciting comments/refereeing from consumers through the e-mail discussion list should automatically attach the protocol, or if a review, the plain language summary. It is not possible to decide from the title alone whether the topic 'is of interest'....

Including the funding of trials, where appropriate, and harms in plain language summaries

Maryann Napoli voices the CCNet very clearly: it's time for the plain language summary (and the abstract) of reviews to include the bias most crucial to consumers, such as who funded the trials and what percentage of them withheld harms data... particularly for drugs that people are expected to take for years



**Singapore Colloquium 11-14
October 2009**

www.colloquium09.com

The consumer stipends application deadline was 1 June 09

The Cochrane Collaboration is committed to the active involvement of consumers and consumer advocates in the preparation and dissemination of systematic reviews and in furthering the aims of the Cochrane Collaboration.

A limited number of stipends each year help consumers from both developed and developing countries to attend.

The Cochrane Collaboration defines a health consumer as someone who is affected by a health condition, or who uses or is entitled to use a health related service, and who is generally not a health professional or practitioner. A consumer advocate or representative is a consumer who is actively involved with other consumers and is able to represent the perspectives and concerns of that broader group of people.

The Cochrane Consumer Network considers its members to be people who contribute as consumers to the Cochrane Collaboration, particularly in giving their views on the relevance and readability of Cochrane reviews, and who support the aims of the Consumer Network.

A program of meetings, workshops, posters and oral presentations, some specifically for consumers, are being organised. The plenary sessions are always relevant and stimulating; as are the out-of-session discussions.





People can join the Cochrane Consumer Network by sending an e-mail to ccnet-contact@cochrane.de

YOUR CONTACT DETAILS

We would appreciate you completing the following form

Please return completed form to: ccnet-contact@cochrane.de

Name:

Contact Address:

Postcode:

Phone Number:

E-mail Address:

Area of work (Parent, Carer, Nurse, Teacher, Librarian, Advocate etc):

Healthcare area(s) that most concern you:

Any consumer or patient support groups that you are associated with:

I wish to be put into contact with the appropriate disease-based Cochrane group: Yes/No

I would like to be part of the moderated e-mail discussion list: Yes/No

Any personal information collected is kept strictly under Privacy Regulations and is used solely for consumer participation activities of The Cochrane Collaboration.