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Cochrane for Dummies: by Anna Joseph, a laywoman-turned-Cochrane enthusiast

posted on : 15 May 2012 - 17:37

Anna Joseph is the recently-appointed Communications Officer of the South Asian Cochrane Network and Centre, based in India. Anna, who holds a post-graduate degree in Mass Communication, has editorial experience in print and electronic media. As a face of the Cochrane Collaboration, she is trying to be more Communicator than the Consumer she is by default, essentially more of a Plain Language Summary Person than an Abstract Person, and if she had to go through an Abstract, more likely to look at the Risk Ratios than the [Odds Ratios](#).

Cross-posted from the [Cochrane Consumer Blog](#).



The South Asian Cochrane Network and Centre, which I joined in March, kicked off its training workshops for the year 2012 with one on 'Understanding and Using Systematic Reviews and Meta-Analyses in Informing Health Decisions'.

That's quite a few unpalatable words for a laywoman and under previous circumstances, this would have been one workshop that I would have avoided, especially if I knew it had anything to do with medicine. I'm married to a doc and I live in a medical community. So I get more than my fair share of 'medicated talk.'

But as their newly appointed communications officer, I wanted to have a clear idea of what exactly it is that I am trying to disseminate and so, sat in. I couldn't make sense of it all but here's what I did make sense of.

But before that... though this was supposed to be the report on the workshop, it has now turned into this blog-like article. How did it go from drab, professional to involved, personal? Because after the workshop, it suddenly struck me that this place, one of the 13 world-wide centres of the international, non-profit organisation known as the Cochrane Collaboration, actually has something to offer.

But don't just take it from me. Allow me to help you find out for yourself.

Let me start with something that really piqued my interest, for the simple reason that it is a woman-centric topic.





Did you know that hormone replacement therapy actually does more harm than good?

How about - that Tamiflu, into which millions are being pumped, is really not the wonder-drug that it's supposed to be?

Or that electric or powered toothbrushes are not better than manual toothbrushes?

Or that administering oxygen to a person who was having a heart attack might actually harm him?!

These are claims made by The Cochrane Collaboration and the reason they can be believed is because these guys chase after the truth like a shark that has caught the scent of blood.

Time for some shark trivia from the amazing HowStuffWorks.com:

Sharks are able to respond to one part [blood](#) for every one million parts of water; this is like being able to smell one teaspoon of something in a [swimming pool](#). What's more, sharks can smell these small amounts from hundreds of meters away.

The shark metaphor, which came to mind more as an after-thought, is actually a great one for the work of the Collaboration. Because that's what their authors, the ones who write for their on-line [Cochrane Library](#), do - go through a million parts of matter on a chosen topic and sift out that one part of matter that is The Truth (or as close to it as it gets). And their million actually covers not just the swimming pool, but all the water-bodies in the world.

In other words, why the stuff that comes out on *The Cochrane Library* can be trusted is because a conclusion is reached only after two or more people go through everything written about a particular topic. And that includes non-English data, and even stuff that has not been published.

These studies are then run through extremely stringent and scientific methods of assessment to get to the truth of the matter.

Technically, that final review that shines the light on The Truth (or as close to it as it gets!) is what is called the 'systematic review'. And in the medical community, a Cochrane systematic review is the [gold standard](#) for a systematic review.

For the curious layperson, for the scribe looking for facts to back up an interesting lead, for the anxious parent or for the patient who wants to know what his/her best [treatment](#) options are, the information that Cochrane Reviews offer is simply the best out there. And they have it all plain and simple in what is called their [plain language summaries](#). No wonder then that the Collaboration, begun in 1993, now spans over 100 countries and boasts more than 28,000 enthusiastic volunteers, which include people from all walks of life.

Now, to wind up, let me finish the job I left incomplete - what the workshop was about! I think I already dealt with the bit on understanding and using systematic reviews. The second half talks about meta-analyses and about informing health decisions.

Assuming you really want to know, a [meta-analysis](#) synthesises the analyses of various studies and informing health decisions means using the findings pro-actively to influence policy making in health care.

So that's what the workshop was about.

Ciao!

Cochrane @ PubMed Health: another audience for reviews

posted on : 18 Apr 2012 - 09:53



Hilda Bastian is a long-time contributor to The Cochrane Collaboration and currently works at the US National Library of Medicine's National Center for Biotechnology Information (NCBI) at the National Institutes of Health. She is responsible for the development of [PubMed Health](#).

PubMed Health is a US National of Library of Medicine (NLM) resource to make systematic reviews of clinical [effectiveness](#) easier to find and use. Visit it at pubmed.gov/health and follow developments



on Twitter @PubMedHealth or Google+.

A comprehensive collection of systematic reviews and their knowledge translation versions in one place: that's the basic premise of PubMed Health. The website integrates [DARE](#) (Database of Reviews of Effects), Cochrane Reviews and systematic reviews published directly by health technology assessment agencies.

With almost 20,000 systematic reviews from the last 10 years now in the collection, this goal is close to being reached. Testing and improving the quality and comprehensiveness of PubMed Health searches for systematic reviews will be critical to further development.

What's happening with Cochrane Reviews at PubMed Health? The plain language summaries (PLS) and abstracts are included, along with links to the review on The Cochrane Library and data such as when the review was last assessed as up-to-date. The plain language summary is the featured section, and it is what appears in the search results. This means that the content, readability and relevance of the PLS title may determine whether people click on a review.

Cochrane Reviews are about a quarter of those in the collection, and so are gaining a further audience as NLM provides greater accessibility. PubMed Health is an entry point for the general public looking for basic health information on the internet. We are trying, in various ways, to draw people's attention to clinical effectiveness resources, including the summaries of systematic reviews and books and articles on understanding research.

For example, people clicking on encyclopedia information will see displays linking to relevant "knowledge translation" information, such as Cochrane plain language summaries. A small feature called "Learn About" appears frequently alongside information, highlighting books like *Testing Treatments* or articles on topics like understanding the science of screening.



You can reach PubMed Health directly, or by using the dropdown box next to PubMed's search. Much of the information being gathered into PubMed Health is being fed into PubMed. And providing PubMed users with improved access to systematic reviews is another way to expand the reach of systematic reviews.

Working with Cochrane to ensure that Cochrane Reviews come up higher in results and are not disregarded as out of date because of unreported updates is an example of what can be done to increase the visibility of Cochrane Reviews^[1]. Expect to see more happening at both PubMed Health and PubMed in coming months as the resource grows and develops.

There are thousands of direct visits to The Cochrane Library every day - a great indicator of how motivated people are to find reliable information. Still, most people who see Cochrane Reviews land on them via PubMed or Medline.

Every day, PubMed gets hundreds of thousands of searches for health research. Many additional people come to PubMed Health from Google looking for basic health information. Focusing more of their attention on systematic reviews is a challenge. But it's one with great potential.

You can read more about PubMed Health and its development here
<http://www.ncbi.nlm.nih.gov/pubmedhealth/about/>

[1] Link to: <http://www.editorial-unit.cochrane.org/ceu-bulletin-december-2011>

A vision for growth

posted on : 27 Mar 2012 - 14:18

As a non-health professional, Mingming Zhang has been actively involved raising awareness on behalf of non-English speakers and members of developing countries where The Cochrane Collaboration is less recognised. She is a WHO patient safety champion in China as well as a member of a working party for the development of "WHO Patient Safety Curriculum Guide for Medical Schools". In her spare time, Mingming serves as a consumer representative on the Cochrane Collaboration [Steering Group](#) and on the Consumers' Executive.



Cross-posted from the [Cochrane Consumer Blog](#).

I am Mingming from the Chinese Cochrane Centre. I have been involved in the Collaboration since





1998 and joined [CCNet](#) in 1999. My roles in the Collaboration are varied including Cochrane author, consumer, centre coordinator and translator etc. My vision for the Cochrane Consumer Network is:

- 1) to promote wider participation in the Collaboration across the countries, particularly from non-English speaking countries;
- 2) to help more consumers get involved with different review groups;
- 3) to help promote Cochrane research substantially serve for patients.

As a non-English speaking consumer, I think my involvement is important, however it also creates many difficulties because of the language barrier and different cultures and values within The Collaboration. I understand that activities of consumers from some countries are quite different from the activities in countries where consumer involvement is well established.

With my background, I have done much work for the dissemination of Cochrane products in my country such as the translation Cochrane abstracts, CCNet information and plain language summaries to raise awareness of the Cochrane Collaboration among healthcare professionals and consumers as well since my involvement. Providing consumers' unique experiences makes the research more relevant.

In April 1999, I visited the Australasian Cochrane Centre where I met Hilda, the former convenor of CCNet who first introduced the term 'consumer' to me. She asked if I was interested in becoming involved. I did not know much about The Collaboration or consumers at that time.

As time passed, I did have a further understanding about the role of a Cochrane consumer is. I realised I can do something for The Collaboration from the perspective of a non-healthcare professional with my knowledge and experience.

I have experienced more than ten years of change within The Collaboration and CCNet, including structure reform, the appointment of a funded consumer coordinator (which could not be expected ten years ago) and much more consumer contribution within the Collaboration.

CCNet has enjoyed an increasing number of consumers coming from different countries. Their unique experiences and knowledge of different health topics have benefitted many consumers, especially through their contributions to the plain language summaries.

A reality check for systematic reviewers

posted on : 9 Mar 2012 - 20:48

Sir Iain Chalmers is one of the founding members of The Cochrane Collaboration. Since his retirement as Director of the UK Cochrane Centre in 2003, he has worked with the [James Lind](#)



[Alliance](#), based in Oxford, UK, which focuses on bringing patients, carers and clinicians together to identify and prioritise unanswered questions for directing healthcare research. Here he discusses a new book by doctor and journalist Margaret McCartney, particularly the issues it





raises about using systematic review evidence in clinical practice.

Cross-posted from the [Cochrane Editorial Unit Blog](#).

Margaret McCartney is a general practitioner and award-winning journalist. Some readers will be familiar with the regular column that she was commissioned to write for the *Financial Times* ([archived here](#)); many people will know her as a frequent contributor to the *BMJ*.

[Margaret McCartney's writings](#) are appealing. This is not only because she is an excellent writer, but also because they mix insufficiently uttered common sense with iconoclasm and challenges to mainstream thinking. Her recently published book - *The Patient Paradox: why sexed up medicine is bad for your health* (Pinter and Martin, 2012) - is packed with these things.

The 'patient paradox' in the title of the book refers to the way that political, professional and commercial promotion of screening and testing have become so pervasive that normal people are being converted into patients, and that, partly as a consequence of unwarranted diversion of limited resources to fuel this [trend](#), many real patients in need of effective professional help are losing out. The inexorable conversion of people into patients has been achieved by exaggerating the chances of important health problems developing in symptomless people (for example, by citing relative rather than absolute risks), while ignoring or downplaying the adverse psychological and sometimes physical effects of the process of 'patient creation'.

Although these are issues that Margaret McCartney and others have raised previously, her book is particularly important for people unfamiliar with the challenges resulting from these trends for doctors working in general practice. She spells out the real consequences of these trends on the use of her time as a general practitioner. Instead of using most of the limited time she has to listen to and to try to respond effectively to the variety of concerns that 'real' patients bring to her, that objective has to compete with politically imposed general risk assessment activities and the need to reassure poorly informed well people who have been worried unnecessarily.

Margaret McCartney's testimony and insights as a general practitioner are also the reason that I think the book provides 'a reality check for systematic reviewers'. A middle section of her book begins with a chapter entitled 'George Clooney and the medical certainty illusion'. This chapter contains subsections entitled 'It's all (at least) a little bit uncertain', 'Bayes, balance and humanism', and 'Binary medicine'. Although Margaret McCartney leaves her readers in no doubt about the need to take account of systematic reviews when considering how to help patients, she illustrates how complex a process this can be for general practitioners trying to take account of the varying characteristics and needs of individual patients.

These reflections will confirm what many - perhaps most - of Margaret MacCartney's clinician readers know already; but then her book is not aimed principally at them, but at the general public. However, the book should help people preparing and publishing systematic reviews who remain insufficiently familiar with the realities of clinical care. It illustrates how the process of using the important evidence they are producing to inform decisions in health care is often far from straightforward.

This reality was reflected in the brochures and articles introducing the first Cochrane Centre and The Cochrane Collaboration. These made clear that systematic reviews are essential, but not sufficient for informing decisions in health care. Needs, resources and priorities also have to be taken into account. I have sometimes been left with the impression that these complexities have been insufficiently appreciated by those unfamiliar with the realities of clinical care.

It comes as a surprise to many people that I have never accepted invitations to speak or write on the





topic of 'evidence-based medicine'. As a clinician who has not practised clinically since 1973, I don't think my opinions on this important topic should have any credibility. One of the characteristics of experienced and effective clinicians is that they draw on wisdom to judge how best to use reliable research evidence in the service of their patients. [Ben Djulbegovic and Paul Ash](#) have suggested that "Wisdom is the ability to distinguish between reducible and irreducible uncertainty". On the basis of what she has written, Margaret McCartney is a wise clinician who helps us to appreciate what this means in practice. If I lived in Glasgow, I hope she would accept me as her patient.

"Consumers - an ever more significant resource for The Cochrane Collaboration"

posted on : 24 Feb 2012 - 21:09

***Silvana Simi** is a long-time and active Cochrane contributor, in addition to her work for the National Research Council in her native Italy. Here she discusses what brought her into The Cochrane Collaboration initially, and the importance of making healthcare information widely available.*

Cross-posted from the [Cochrane Consumer Blog](#) as part of the Consumer Network's focus on Wise Consumer Month.



Why did you join [CCNet](#)?

I have been involved in The Cochrane Collaboration (CC) since 1999, when my eldest daughter was diagnosed with multiple sclerosis (MS). I joined the MS group, and from the beginning I have taken an active role, both as Editor and consumer representative.

Anyway, I have felt myself essentially a consumer, so, since then, I also joined the Consumer Network (CCNet), working as a member of its Governing Committee since the network revamping in 2002, and currently as a member of the CCNet Executive.

While, at the beginning, to work for the CC was simply a way to fight my private war against MS, being in CCNet made me more and more aware about the centrality of patients/citizens/consumers in all the steps of healthcare. So, my two guide concepts have been evidence-based medicine (EBM), which emphasises the importance of basing care on valid evidence rather than consolidated opinions, and, mostly, patient-centred medicine (PCM), because it focuses on patients' views and values and highlights the potential for patients to become lead actors in health, rather than passive recipients of authoritarian advices. During these years, I have run workshops, given talks to





congresses, master's, and continuing medical education courses to stress the pivotal role of patients both in healthcare and in research.

Cochrane consumers are a fantastic, multifaceted but like-minded community of good will persons wishing and acting to make patients to become able to speak up for themselves. Consumers/patients are important entities for the CC, both as reviewers of systematic reviews and as champions of disseminating to other lay people the results of the reviews, and I have personally experienced their increasing importance mostly in the last years.

I consider Plain Language Summaries (PLS) of the reviews the Cochrane product that fit best for consumers/patients/citizens information and "formation", offering good, evidence-based information and Cochrane consumers can help a lot to make PLS more and more available and understandable to the average member of the public.

For these reasons I have been committed to act as consumer [referee](#) for systematic reviews and to write or comment on PLS for my group (besides being co-author of two reviews), and also for several other CRGs. Furthermore, living in a non-English-speaking country, I am very aware of the difficulties non-English people have to face, so I am working to translate into Italian the PLS and other documents, so contributing to make them available to a greater number of persons.

At the moment, to improve the quality and consistency of PLS is one crucial engagement of the CC, being that the PLS is the most read section of a review, not only by consumers, who have been the "natural" target since the beginning, but also by professionals, policy-makers, and journalists. So PLS is assumed as a stand-alone document, and consumers can help a lot to make it clear, complete, transparent, really in plain language, and available and acceptable in all the different social/cultural settings.

The challenge is, therefore, to foster a greater collaboration between CRGs and consumers and to provide effective methods of communication between consumers and the whole CC. Consumers will be up to the task, and will go on being an ever more significant resource for the whole Collaboration.

Silvana Simi

Pisa 15 January 2012

Engagement . . . education . . . empowerment . . . action: The ALOIS Community: Involving caregiver volunteers in research and evidence in dementia

posted on : 24 Aug 2011 - 20:31

Engagement

The Cochrane Dementia and Cognitive improvement [Review Group](#) is running a year-long public engagement project, funded by the National Institute of Health Research. The grant was awarded to test the innovative idea of recruiting carers (and former carers) of people with dementia to volunteer with our group, helping us update and maintain our unique online register of dementia studies, ALOIS - named after Alois Alzheimer: <http://www.medicine.ox.ac.uk/alois/>.

"All you need to volunteer with ALOIS is an interest and an internet connection" . . . well almost. We are asking our volunteers to read reports of dementia trials, and extract key pieces of information from the reports such as the number of participants, the [treatment](#) being tested, the outcomes being measured, and to populate the database directly online. This form of online volunteering is very flexible, and uniquely engaging. We offer a high level of feedback, encouragement and personal support, combined with the opportunity to make a real contribution to dementia research virtually





instantly.

The task has proved to be surprisingly attractive to a wide range of people - not just to our initial target group of carers and former carers. As well as carers, our volunteers now include doctors and other healthcare professionals, social workers, school students, university graduates, teachers, and researchers. We are constantly striving to reinforce the value and accessibility of the ALOIS study register as a resource, and how increasingly important the contribution of our volunteers is becoming. To date, over 100 of the study records published on ALOIS have been coded by volunteers.

Education

To assist with recruitment, and to support our growing volunteer community, we are also developing an interactive online course, Making Sense of the evidence in dementia. The course will consist of a series of short units using topical dementia examples to illustrate general research and evidence principles.

We intend to launch the course with around six units in the early Autumn, covering topics such as fair tests, publication and [reporting bias](#), outcomes, levels of evidence, statistical methods, diagnostic tests, and NICE. Each unit will be built around a recent dementia “news” story.

Click on the link below to play the “pilot” unit, **A study suggests . . . the real research behind the headlines.**

http://aloiscommunity.org/dev/sites/default/files/articulates/Unit1_2/player.html

This initiative is bold and innovative in that it embraces the fact that members of patient and carer groups are much more likely to engage with and act on information directly relevant to their own situation. Currently, consumer contributors to Cochrane will be affiliated to one or two review groups or fields reflecting their experience as a patient, carer or advocate. It makes sense that outreach activities to encourage wider consumer participation should be tailored to address the unique concerns and information needs of different disease “constituencies” in the same way.

Empowerment . . . and action

Through encouraging people to volunteer with ALOIS or to take the online course, we would like to create a virtual community of well-informed and enthusiastic citizen scientists making a real and acknowledged contribution to the work of The Cochrane Collaboration. Particularly for the carers who participate, we envisage that their involvement with the project will arm them the knowledge and confidence to advocate both for themselves and their loved ones at all levels within the NHS. We also want to encourage greater public involvement in research-related activities, including direct participation in primary research studies.

Caroline Struthers
Project Manager, ALOIS Community Volunteer Project
Cochrane Dementia and Cognitive Improvement Group
caroline.struthers@ndm.ox.ac.uk

Improvements in abstracts and plain language summaries needed

posted on : 28 Nov 2011 - 20:23

Maryann Napoli, Associate Director of the [Center for Medical Consumers](#) (New York City), is a member of CCNet’s Geographic Advisory Group as well as the US Cochrane Center’s consumer coalition, [Consumers United for Evidence-Based Healthcare](#). A regular Cochrane contributor, she reflects on an opportunity for growth within The Collaboration’s plain language summaries.





Cross-posted from the [Cochrane Consumer Blog](#).

The reality is that many who read Cochrane reviews (including clinicians, policymakers, medical reporters) do not read beyond the plain language summary and the abstract. Inclusion of the following information in the abstract and PLS of Cochrane drug and device reviews is key when relevant:

- 1) State when all or most of included trials are funded and/or conducted by drug or device makers;
- 2) State when the authors have requested harms data but this has been refused or the request not answered, as well as selective reporting of harms data;
- 3) Avoid expressing results in relative risk reduction terms (see the new Cochrane statistical formats review for alternatives that are not as confusing to consumers and health professionals); and
- 4) State the magnitude of the benefit whenever a benefit is identified.

To leave out this crucial information from the abstract and the PLS would deprive a significant portion of the Cochrane review “audience” of crucial information needed to make an informed decision whether they are deciding to prescribe a drug, take a drug or make reimbursement policy for a drug.

It would also be helpful to include a section in the abstract and PLS entitled, “Caveats,” where industry funding is noted when relevant. Here is an example of such a format from an excellent, physician-run website (www.TheNNT.com), which, by the way, uses Cochrane reviews frequently as a source:

“Caveats: Virtually all of the major statin studies were paid for and conducted by their respective pharmaceutical company. A long history of misrepresentation of data and occasionally fraudulent reporting of data suggests that these results are often much more optimistic than subsequent data produced by researchers and parties that do not have a financial stake in the results.”

It is difficult to separate the science from the marketing now that industry has taken over the lion’s share of drug/device research. Contributors give time to The Cochrane Collaboration because we see it as the rare independent evaluator of research findings.

Mammography screening ten years on: reflections on a decade since the 2001 review

posted on : 27 Oct 2011 - 13:05

Peter Gøtzsche, Director of the Nordic Cochrane Centre, is one of the authors of the landmark 2001 Cochrane systematic review ‘[Screening for breast cancer with mammography](#)’. Ten years on from first publication, he reflects on the review’s impact on healthcare policy and practice.

See also: [Cochrane in the News report on planned review of UK breast cancer screening policy](#) and [t](#)





[The Cochrane Library Special Collection on breast cancer detection.](#)

It created a lot of stir when we published our systematic review of mammography screening in *The Lancet* and in *The Cochrane Library* in October 2001. We showed that - because of substantial overdiagnosis - women who are screened have higher rates of aggressive [treatment](#), including increased mastectomies. We also raised concerns about the reported benefits of screening based on our analysis of the methods used in several of the trials. In fact, we concluded in the Cochrane review that "The currently available reliable evidence has not shown a survival benefit of mass screening for breast cancer."

Our finding of increased mastectomies has consistently been ignored by screening advocates for 10 years, and information from many cancer charities and governmental agencies continues to state the opposite - that screening decreases mastectomies - despite having no reliable data to support this claim. We recently confirmed that screening increases mastectomies, using data from both the Danish and Norwegian screening programmes (1, 2). We have also shown that many screening-detected cancers would have regressed spontaneously if they had been left alone, without treatment (3). By our estimates, the level of overdiagnosis in countries with organised screening programmes is about 50% (1).

Studies published in the last couple of years have failed to find an effect of screening in Europe, and have also failed to find a decrease in the occurrence of advanced cancers. When screening doesn't decrease advanced cancers, it cannot work. We summarised the most important of this research in September 2011 (1).

There are likely three main reasons why screening is no longer effective. Adjuvant therapy, such as tamoxifen and chemotherapy, is highly effective (even when the cancer has metastasised), but was used very little in the old randomised trials. Increased breast cancer awareness has likely also been important, as women attend a doctor much earlier today if they have found anything unusual (1). Finally, diagnosis and treatment have been centralised in many countries, so that experts are available in all disciplines required for optimal processes.

Therefore, what was considered so controversial in 2001 is now increasingly being recognised to be true, even by people who advocated the introduction of screening in the first place. The tides are plainly turning for mammography screening, and it is now essential that women be provided with information that allows them to make an informed choice about mammographic screening, rather than being pushed toward mammography as routine, while being told it is an unambiguously beneficial test.

In 2009, we published an information leaflet on mammography screening in *BMJ* and on our website, www.cochrane.dk, which volunteers have translated into 11 languages. We clearly need to update the leaflet, which starts thus: "It may be reasonable to attend for breast cancer screening with mammography, but it may also be reasonable not to attend, as screening has both benefits and harms." It is getting more and more difficult to argue that it is reasonable to attend for breast screening.

Peter C. Gøtzsche
Director, The Nordic Cochrane Centre
pcg@cochrane.dk
October 2011

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Enabling remote participation at Cochrane meetings: some reflections

posted on : 29 Jul 2011 - 02:22

Lucie Jones is Project Support and Business Communications Officer at the Collaboration's Secretariat, and is based at the German Cochrane Centre in Freiburg, Germany

Over the past couple of years, as part of my business communications role, I have been asked to provide and run remote conferencing, and in particular, web-based audio-visual conferencing, at various Cochrane meetings and Colloquia. I've also arranged for the recording of many of these sessions, which are subsequently posted on cochrane.org.

The idea has been to enable participation in real time at meetings and sessions that are of interest to contributors Collaboration-wide who are not attending in person. In the long term, it is hoped remote conferencing might lessen the environmental impact of our meetings by reducing the need for some participants to travel to them in person.

I was running these remote sessions as experiments at first – on my own, with one laptop, microphone and webcam, with either WIFI Internet access or a hard-wired connection if I could arrange it. As you can imagine, the quality was variable (!), but I have a few loyal participants who have continued to attend sessions and provide positive feedback (incidentally, particularly those participating from lower income countries and those whose first language is not English).

As demand has grown and I have become more aware of the requirements and challenges of providing remote conferencing at meetings, the 'team' and workload for providing these facilities have grown too.

At the meetings of the Collaboration's management committees this year in Split, Croatia, in addition to the independent technical consultant who had been engaged to conduct the remote conferencing, there was a team of ten Cochrane contributors and venue staff helping run the sessions, some located far from the venue itself and giving up their free time to help. During one of the sessions, a remote participant in Canada even started to provide simultaneous Spanish translation of proceedings to a colleague in Argentina. It's this kind of enthusiasm and commitment that is so indicative of the Cochrane spirit – we just make things happen.

Whilst the nature of our organisation, our contributors and our meetings make remote conferencing very suitable for us, they also bring a specific set of technical and process-based challenges:

1) Our meetings are always in different places:

This means there are always different local organisers and different facilities, which makes things more difficult to plan in advance. We can't be sure what the internet connection, telephone facilities, acoustics or the size of the rooms will be like.

2) Our remote participants are in different places too:

This means we're dealing with many different internet connections, computer speeds, web know-how, etc. Even though one participant might be hearing and seeing everything very well, another might not – we cannot control this from the presenter's end.

3) We run lots of different kinds of meetings and presentations:





It's always easiest to broadcast presentations where you have one speaker and everyone else is listening. However, the sessions that we run range from meetings of five to ten people, to strategic sessions of more than 50 participants, all discussing and contributing. From a technical perspective this makes things more difficult (think lots of microphones, cameras and a really stable internet connection!). It also means there needs to be someone constantly monitoring the broadcast, answering remote participants' questions, etc.

So, is this a message of doom? No, I don't think so. The Collaboration's Operations and Finance Committee recently made a statement of its support for remote conferencing. In response, the Secretariat and Cochrane Editorial Unit will be working together to address the challenges and plan how best we can work with local organisers to provide cost-effective, simple and reliable remote conferencing at key Cochrane meetings throughout the year for the Collaboration's dedicated contributors.

Lucie Jones
The Cochrane Collaboration Secretariat
ljones@cochrane.org

Does Cochrane have a plan for consumer participation?

posted on : 22 Jul 2011 - 19:22

As part of its funding for a consumer co-ordinator, The Cochrane Collaboration requested that [CCNet](#) design a plan for consumer participation in Cochrane Reviews. The Collaboration and CCNet hired consultants who interviewed consumers, editors and authors to identify any gaps in the current process and to determine the best solutions to support consumers within Cochrane.

The Consumers' Executive has been working with the Consumer Co-ordinator, the CCNet Geographical Advisory Group, and members of CCNet and Cochrane to develop these solutions into a new support structure that will improve consumer integration within the Collaboration. **All consumers and Cochrane Collaboration members are invited to comment.**

Since the needs of consumers within Cochrane and CCNet are too broad for all issues to be addressed concurrently, key activities have been prioritized for the purpose of developing the Consumer Co-ordinator's work plan. To support consumer participation and address current challenges, these projects are planned:

- A new induction process for new consumers
- A framework connecting consumer participants
- The provision of accessible Cochrane products
- Formalized management agreements for CCNet and its Executive

Induction process for new consumers

Issue: Communication void facing new consumers. Many consumers join the Consumer Network (as many as 15 every week), but activities and options for consumer involvement are limited. Unless new consumers extensively browse the web for information about Cochrane, they are likely to be unaware of how consumers can improve the quality of Cochrane Reviews. Instead, consumers receive notifications about commenting on reviews without receiving a comprehensive introduction to Cochrane.

Solution: The new induction process will integrate new consumers within Cochrane. A new process for membership is in progress which more accurately collects consumer demographics to track consumer involvement. A 'Welcome Packet' will explain the opportunities available to consumers





and explain the work of Cochrane. New members will later receive training materials that introduce them to The Cochrane Collaboration, Understanding evidence-based healthcare and Using *The Cochrane Library*. Those interested in becoming consumer referees will be offered incremental training in the Cochrane Review process, the Role of the Consumer Referee, and a series of Guidelines on commenting. Additional roles within Cochrane will also be developed for consumers.

A framework connecting consumer participants

Issue: Isolation experienced by contributing consumers. Many consumers report that they feel alone in the review process. When questioned further, they ask for feedback on their comments. Some suggest the possibility of having discussions with reviewers via Skype. Consumers also find they are not part of a community of consumers, because they have no mechanism for communicating with other consumers or building their skills as a peer reviewer.

Solution: A framework connecting consumer participants will be implemented. Consumers will soon have several models for participation in reviews and the opportunity to share concerns with other members of the CCNet community. A new consumer discussion board is in development for the external website that will allow consumers to meet other referees for a particular [review group](#) and discuss the experience of a consumer referee. Consumers will have the option of adding comments to the online blog on the CCNet website. Tweets will provide consumers with notifications about consumer important reviews, events and Cochrane announcements. Also, a new guide for Review Groups (to be released in Madrid) provides helpful hints for reviewers to encourage repeat consumer participation by improving awareness of consumers needs. New opportunities for involvement, beyond the role of a consumer referee, will be explored to expand the impact of consumers within the Collaboration.

The provision of accessible Cochrane products

Issue: Inaccessible/incomprehensible review content. In many countries, CCNet consumers are invited to comment on reviews which, once published, they will never be able to access, since they participate in organizations unable to fund individual memberships to *The Cochrane Library*, and live in countries without general public access. Many consumers find that the *Library* does not provide information in their first language. Furthermore, those lucky enough to have access find that *Library* search terms and review titles are often unintelligible. Plain language summaries (PLS) are meant to help, but the present quality of the PLS is not monitored and standards for the PLS are vague.

Solution: CCNet is developing a strategy for the provision of accessible Cochrane products. CCNet has formed partnerships with Cochrane entities to collaborate on PLS improvements and ensure consumer participation. Several initiatives within CCNet and the Collaboration are in progress to develop the standards and guidelines for the PLS and consumer referee checklists. In addition, a new website, dedicated to consumers, will be developed to provide the information within *The Cochrane Library* that is of most interest to consumers. It will present plain language summaries in multiple languages. The new consumer library will have new search criteria for easy access to information.

Formalized management agreements for CCNet and the Consumers' Executive

Problem: Transitional management structure. The Consumers Transitional Executive (CTE) was established for a period of 18 months to put systems in place that would support the management of CCNet activities. The CCNet organizational structure has adapted to include a paid Consumer Co-ordinator and a transitional executive. New lines of accountability need to be determined and existing CCNet policies updated.

Solution: Formalized management agreements are in development with the Consumers' Transitional Executive (CTE) and CCNet's Geographic Advisory Group (CCNetAdvisory). A CCNet work plan and objectives will be drafted for a multi-year period and the roles and responsibilities of the Consumers' Executive will be clarified. Elections for a permanent Consumers' Executive will begin after the 2011 Colloquium. A new organizational chart, which diagrams the management and accountability of CCNet, has been approved by both groups and has been submitted to CCNet and





the Collaboration's Monitoring and Registration Committee ([MaRC](#)) for comment. Accordingly, the CTE and CCNetAdvisory have approved a revised remit and core functions for CCNet and updated its module (available online). The CTE has also proposed a governance plan to the CCNetAdvisory which will be submitted to CCNet and the MaRC for comment.

These ideas will be used to generate a work plan for CCNet over the next five years. If you have ideas or suggestions on this plan, please let us know. **Submit your comments at the bottom of this blog.**

Catherine McIlwain
Cochrane Consumer Network
CMcIlwain@cochrane.org

What about the outcomes? A consumer point of view.

posted on : 22 Jul 2011 - 19:02

I have to admit that I have always had problems with outcomes. *Death* is sometimes listed as a [primary outcome](#), sometimes a [secondary outcome](#); *quality of life* wanders likewise between the two, as does *pain* and *days in hospital*.

As a consumer, I expect the outcomes to answer the question, 'Does . . . affect . . .?' , but it seems to me that current review statements of outcomes and measures do not always reflect awareness of this consumer need. I know that 'we have to live in the real world' and not every desired outcome may be measurable, but I would value help in identifying and ranking these.

I now know that primary and secondary outcomes are chosen based on the specific review topic. Death may be considered a primary outcome when it is common for the condition and there is potential to reduce it. Alternatively, it may be secondary if it is very rare for the condition and unlikely to be affected by the [intervention](#). As an author, I believe that there needs to be a sound rationale for each outcome chosen for a review.

There is some research being undertaken now to try to set 'core outcomes' for a topic for both clinical trials and systematic reviews. In time, we may have a set list of core outcomes that would need to be measured in all trials for that topic, although additional outcomes could be added if desired, such as the possible side effects of a drug under investigation.

Until then, is there a need for Cochrane Collaboration consumers to have some training input regarding the use of outcomes? It may be that other consumers would welcome this kind of training, too.

Shirley Mankell
[CCNet](#) member
manknell@btinternet.com

Gill Gyte
CCNet Consumers' Executive Member
ggyte@cochrane.co.uk

What if there is no clear evidence one way or the other of the intervention under review?





posted on : 22 Jul 2011 - 18:57

I would like to run past Consumers a problem I have had with comments that have turned up on the Internet that have been taken out of context. I personally have never put anything on the net. Also I have never seen the following subject raised in discussion in Consumer circles when review results are not clear-cut.

I am the lead person of the review Speleotherapy for Asthma, Cochrane Collaboration Review, Beamon, S., Falkenbach, A., Fainburg, G., Linde, K., published on CD Rom, Cochrane Library, 1999. Updated regularly. I questioned this matter with Airways Entity years ago and below are the relevant comments.

'When referring to speleotherapy reviews where there is no clear evidence to support the use of an [intervention](#). It is a complex methodological issue - just because a review does not provide evidence to support the use of an intervention readers should not conclude that the intervention is necessarily unhelpful. One can make fairly strong conclusions from a [meta-analysis](#) that demonstrates a clear [treatment effect](#), but we can never draw conclusions (in favour of either direction) from a meta-analysis that demonstrates no clear [treatment](#) effect.'

The history of evidence based medicine is littered with examples of people wrongly concluding that an absence of evidence is evidence of no benefit . . .'

This is not true as not proved either way.

' . . . A review can give you a clear answer only if there are high quality clinical trials that present us with that evidence.'

There was, and still is, a PAUCITY of speleotherapy systematic randomised controlled trials.

I don't think these problems are raised enough or explained and I would be interested in what other Consumers think.

* Speaking as a former chronic asthmatic I personally believe in speleotherapy treatment. I undertook such therapy in both Romania (1995) and Poland (1997), then was completely free of asthma for five years and only experience mild symptoms occasionally since (2011). I realise, of course, I am prejudiced!

Sylvia P. Beamon
Airways Group
sylvia@salisburyvillas.freerve.co.uk

How Well Do Meta-Analyses Disclose Conflicts of Interests in Underlying Research Studies

posted on : 22 Jul 2011 - 18:38

A recent study published in JAMA reviewed 29 meta-analyses from high impact journals and found that conflicts of interests in the studies underlying the meta-analyses were rarely disclosed. The 29 meta-analyses included 11 from general medicine journals; 15 from specialty medicine journals, and three from the Cochrane Database of Systematic Reviews. The 29 meta-analyses reviewed an aggregate of 509 randomized controlled trials (RCTs). Of these, 318 RCTs reported funding sources with 219 (69%) industry funded. One hundred and thirty-two of the 509 RCTs reported author conflict of interest disclosures, with 91 studies (69%) disclosing industry financial ties with one or more authors.





However, very rarely was this information reflected in the meta-analyses. Only two (7%) reported RCT funding sources and none reported RCT author-industry ties. The authors conclude, “without acknowledgment of COI due to industry funding or author industry financial ties from RCTs included in meta-analyses, readers’ understanding and appraisal of the evidence from the [meta-analysis](#) may be compromised.”

The authors noted that most assessment tools for meta-analysis do not include a domain for study funding source and state: “Currently, The Cochrane Collaboration’s Risk of [Bias](#) tool includes an optional 'other sources of bias' domain, which meta-analysts could use to include information on COIs. We recommend that The Cochrane Collaboration consider formalizing the requirement to assess potential bias from COIs.”

Roseman M, Milette K, Bero LA, Coyne JC, Lexchin J, Turner EH, et al. Reporting of Conflicts of Interest in Meta-analyses of Trials of Pharmacological Treatments. JAMA: The Journal of the American Medical Association. 2011 March 9, 2011;305(10):1008-17.

Lorraine Johnson, JD, MBA
[CCNET](#) member
johnson.lorraineb@gmail.com

Article about Cochrane contributors published in the Journal of Evidence-Based Medicine

posted on : 22 Jun 2011 - 22:42

Claire Allen and Kiley Richmond recently (March 2011) published an article in the Journal of Evidence-Based Medicine about contributors to Cochrane Review Groups. The abstract is as follows:

The Cochrane Collaboration (<http://www.cochrane.org>) is the world's largest organisation dedicated to preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions. It is an international organisation with participants in more than 100 countries, principally focused around the Cochrane Review Groups that are responsible for the preparation and maintenance of Cochrane Reviews. Since 2000, a periodic audit has been done to count the number of active members in the Cochrane Review Groups, subdivided by the countries in which these people are based. At the beginning of 2010, there were almost 28,000 people involved, an increase from about 5,500 in 2000. The growth of activity has been dramatic, and especially large for authors of Cochrane Reviews and protocols. In the year 2000, 2,840 people were listed as authors by the Cochrane Review Groups. At the beginning of 2010, this had risen to over 21,000 people.

You can access the full article at:

<http://onlinelibrary.wiley.com/doi/10.1111/j.1756-5391.2011.01109.x/full> should you wish to read it.

Claire Allen
The Cochrane Collaboration [Secretariat](#)
CAllen@cochrane.org

Topic list for Cochrane Complementary Medicine Field related reviews on Cochrane.org

posted on : 6 Jun 2011 - 19:55





The Cochrane Complementary Medicine (CAM) Field published a paper in the Mar/Apr 2011 issue of *Alternative Therapies in Health and Medicine*, describing the development and classification of an operational definition of CAM for The Cochrane Collaboration (i.e. a CAM Field “topics list”). This paper discusses the challenges in developing the topics list, including developing a detailed, explicit, and [reproducible](#) operational definition of what is CAM, applying the operational definition to identify relevant Cochrane Reviews, developing the structured list of CAM therapy-specific topic categories, and determining where the Cochrane Reviews should be placed in the topic list categories. The development of the CAM Field topics list has been valuable in allowing the CAM Field to reproducibly and consistently classify Cochrane Reviews as CAM/not CAM, and thereby reliably track the number of CAM-related Cochrane Reviews.

The placement of this list on the Cochrane.org website (<http://www2.cochrane.org/reviews/en/subtopics/22.html>), and the multiple options for viewing the list of reviews, are designed to allow persons interested in Cochrane evidence on CAM to identify and access the evidence that is of interest to them. The CAM Field is pleased to note that the 'Research' webpage (<http://nccam.nih.gov/research/>) as well as the 'Resources for Health Care Providers' webpage (<http://nccam.nih.gov/health/providers/>) of the NIH National Center for Complementary and Alternative Medicine website both link to the CAM Field topics list, and the CAM Field topics list is the first resource listed on the NCCAM 'Research Results' webpage (<http://www.nccam.nih.gov/research/results/>), as this further facilitates CAM researchers and providers accessing the findings from CAM-related Cochrane Reviews. We have found the CAM Field topics list to be very valuable, particularly in promoting and marketing Cochrane CAM-related Reviews, and facilitating the accessibility of these reviews. For more information on the CAM Field topics list or the paper describing the development of the CAM Field topics list, please contact Susan Wieland at swieland@compmed.umm.edu.

Susan Wieland
Complementary Medicine Field
[lswieland@gmail.com](mailto:swieland@gmail.com)

Eric Manheimer
Complementary Medicine Field
emanheimer@compmed.umm.edu

What about the outcomes? A consumer point of view.

posted on : 6 Jun 2011 - 19:25

I have to admit that I have always had problems with outcomes. *Death* is sometimes listed as a [primary outcome](#), sometimes a [secondary outcome](#); *quality of life* wanders likewise between the two, as does *pain* and *days in hospital*.

As a consumer, I expect the outcomes to answer the question 'Does . . . affect . . . ?' , but it seems to me that current review statements of outcomes and measures do not always reflect awareness of this consumer need. I know 'we have to live in the real world' and not every desired outcome may be measurable, but I would value help in identifying and ranking these.

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Shirley Mankell
CCNet member
manknell@btinternet.com

Gill Gyte
CCNet Consumers' Executive Member
ggyte@cochrane.co.uk

Cochrane Canada Builds Capacity for Webinars and Conducting Reviews

posted on : 6 Jun 2011 - 19:11

In April 2011, the Canadian Cochrane Centre conducted their first capacity building event for staff with several Cochrane Canada groups, PAHO/WHO, and the Iberoamerican Cochrane Centre for conducting webinars. Attendees learned the webinar platform's functionality, tips and tricks for conducting webinars, and, for Cochrane Canada groups, how to coordinate efforts. Be on the lookout for more Cochrane Canada Live webinars as they are advertised on CCInfo!

In May 2011, the Canadian Cochrane Centre hosted their first Review Completion Course. Five Canadian review authors from different review groups (Airways, Injuries, Hepato-Biliary, Hypertension, Pregnancy and Childbirth) attended this week-long course that was scheduled concurrent to the Ottawa Tulip Festival. Attendees outlined goals in advance and returned



home with individual action plans for completion and submission of their reviews. Each review author was paired with a mentor; Adrienne Stevens, Alain Mayhew, Erin Ueffing, and Dr. Vivian Welch served as mentors and provided daily guidance. Lucy Turner provided statistical advice and Nancy Santesso supported authors on GRADE and developing Summary of Findings tables. Dr. Yoon Loke was available on-call during the week to address questions regarding adverse effects. Thank you to all course faculty! We look forward to seeing those reviews published on *The Cochrane Library*!

Adrienne Stevens
Education Coordinator
Canadian Cochrane Centre
astevens@uottawa.ca





How Well Do Meta-Analyses Disclose Conflicts of Interests in Underlying Research Studies

posted on : 6 Jun 2011 - 19:18

A recent study published in JAMA reviewed 29 meta-analyses from high impact journals and found that conflicts of interests in the studies underlying the meta-analyses were rarely disclosed. The 29 meta-analyses included 11 from general medicine journals; 15 from specialty medicine journals, and 3 from the Cochrane Database of Systematic Reviews. The 29 meta-analyses reviewed an aggregate of 509 randomized controlled trials (RCTs). Of these, 318 RCTs reported funding sources with 219 (69%) industry funded. One hundred and thirty-two of the 509 RCTs reported author conflict of interest disclosures, with 91 studies (69%) disclosing industry financial ties with one or more authors.

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The authors noted that most assessment tools for meta-analysis do not include a domain for study funding source and state: “Currently, The Cochrane Collaboration’s Risk of [Bias](#) tool includes an optional 'other sources of bias' domain, which meta-analysts could use to include information on COIs. We recommend that The Cochrane Collaboration consider formalizing the requirement to assess potential bias from COIs.”

Roseman M, Milette K, Bero LA, Coyne JC, Lexchin J, Turner EH, et al. Reporting of Conflicts of Interest in Meta-analyses of Trials of Pharmacological Treatments. JAMA: The Journal of the American Medical Association. 2011 March 9, 2011;305(10):1008-17.

Lorraine Johnson, JD, MBA
[CCNET](#) member
johnson.lorraine@gmail.com

Health Evidence - information service for public health decision makers

posted on : 3 May 2011 - 19:55

Health Evidence is a Canadian service and research organization located at McMaster University, Hamilton, aimed at assisting public health decision makers in using research evidence. Health Evidence offers a suite of services to support the development of knowledge, skill and culture for evidence-informed decision making. Launched in 2005, a key resource, the <http://www.health-evidence.ca/> registry of systematic reviews, is a free, user-friendly searchable database of public health relevant, quality-appraised reviews. Tailored capacity assessments for evidence-informed decision making, workshops and presentations on evidence-informed decision making 'how to', and Knowledge Broker mentoring services are available to support incorporation of evidence into practice.

Lori Greco
Knowledge Broker
Cochrane Canada Policy Liaison Office (McMaster University)
lgreco@health-evidence.ca





New Deputy Coordinating Editor for Cochrane IBD/FBD review group

posted on : 27 Apr 2011 - 16:46

We are pleased to announce that Dr Nilesh Chande (The University of Western Ontario, London, Ontario, Canada) will be serving as Deputy Coordinating Editor for the Cochrane IBD/FBD group. Dr Chande has been working with the IBD/FBD group as an author since 2001 and as an editor since 2008. We would like to take this opportunity to welcome Nilesh in his new role as Deputy Coordinating Editor and we look forward to working with him in this capacity.

John MacDonald
IBD/FBD [Review Group](#)
jmacdonald@robarts.ca

Entity name change: IPD Meta-analysis Methods Group

posted on : 18 Apr 2011 - 16:35

The Individual Participant Data (IPD) [Meta-analysis](#) Methods Group has 74 members from 17 countries, with interests spanning prevention, diagnosis, [treatment](#), rehabilitation and prognosis in a wide range of health care, including cancer, epilepsy, stroke, perinatal care and malaria. With this diversity in mind, The Cochrane Collaboration has agreed with our change of the name of the Group, replacing “patient” with “participant” to become “Individual Participant Data”, retaining the “IPD” abbreviation and the name change is effective immediately.

Larysa Rydzewska, on behalf of the Individual Participant Data Meta-analysis Methods Group
Convenors
Individual Participant Data Meta-analysis Methods Group
IPD@ctu.mrc.ac.uk

Source URL: <http://www.cochrane.org/taxonomy/term/549/all/pdf>

