

Cochrane Consumer Network

ccnet



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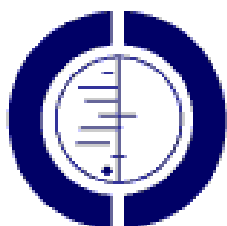
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The Magic of Madrid

By Liz Whamond

After having been in Barcelona several years ago, I was very excited about attending the Cochrane Colloquium in Madrid. Spain is a special place with wonderful architecture, the ubiquitous tapas, and extraordinarily friendly people. There wasn't much time to engage in external pursuits but the setting was indeed spectacular.

Language remains an issue for those whose first language is not English and a working group has been set up to examine possible solutions. We were delighted that 16 consumers received stipends to attend. The next Colloquium will be held in Auckland, New Zealand. It would be great to have a strong consumer turnout at that event.

One Click Access to Colloquium Presentations and Reports!

Visit the CCNet Website <http://consumers.cochrane.org>

Consumers at the Colloquium

By Gill Gyte and Catherine McIlwain

Sixteen consumers from nine countries were funded to attend the recent Cochrane Colloquium in Madrid. It was great to have so many members present. Our thanks go to the Collaboration for providing the stipends.



With all the consumers present, it seemed like a wonderful time to discuss the work of the Consumers' Executive in recent months. CCNet held *two* meetings to discuss progress and listen to member concerns. There was lively debate on these issues and we will report in more detail in the newsletter. Gill Gyte is now joining Liz Whamond as co-chair of the Consumers' Executive.

The CCNet Consumers' Transitional Executive (CTE) took this opportunity to introduce new projects and discuss work currently in progress.

[Cochrane Consumer Learning.](#)

Explore evidence-based health care.

Get more from *Cochrane Reviews*.

CCNet's Annual Meetings

By Gill Gyte and Catherine Mcllwain

The Consumers' Transitional Executive (CTE) is focusing on the process of consumer involvement in the review process. To this end, Gill Gyte is leading a team to develop:

1. **A standard checklist for consumer referees.** To help new and experience consumers alike, the checklist will include explanations of the criteria that consumers should use when commenting on protocols and reviews. This checklist will be used across review groups to support consumers involved in the review process.
2. **A standard checklist for plain language summaries.** In addition to hints for identifying jargon, this checklist will include additional tools for consumer referees, such as directions on using the original review to ensure that the key elements are accurately reported in the plain language summary.
3. **A Buddy system for consumers.** Development of a buddy system for consumer referees will be explored to improve support for consumers.

At the second CCNet meeting, Catherine Mcllwain reported on some of the projects with which she is involved:

1. **Development of the Cochrane Summaries website** (<http://summaries.cochrane.org>). The new site provides a consumer-friendly display of abstracts, plain language summaries (PLS) and related resources for individual reviews.

2. **Refining plain language titles.** Catherine Mcllwain and a team of consumer referees have examined the quality of existing titles. Nearly one-fourth of all titles were judged to need revision. In addition, a character limit of 150 characters (about 25 words) has been recommended for future titles to facilitate better display on the internet.
3. **Translation of plain language summaries.** Cochrane Summaries will include translations of plain language summaries in the six languages of the WHO (English, Spanish, French, Arabic, Russian, and Chinese). Catherine will convey consumers' concern at the possible loss of the current German translations.
4. **Improved training options.** A new training website is in development for consumers that will include the production of more interactive training tools. Tools are currently located in Cochrane Consumer Learning (<http://consumers.cochrane.org/cochrane-consumer-learning>) on CCNet's website.
5. **Standard requirements for plain language summaries.** Along with the Cochrane Editorial Unit (CEU) and the Consumers' Executive, representatives from other groups within Cochrane will be asked to join a new working group that will finalize and adopt format and style guidelines for plain language summaries and titles.

Find more at <http://consumers.cochrane.org>

Consumer Perspectives

Martha Cepeda-Hodgson, Costa Rica

I send these letters to tell you how grateful I am for your effort of the whole group of Cochrane for me as consumers first time, give me the opportunity to attend the 19th Colloquium in Madrid. I want to indicate that it was a unique experience and try to help where I can with you and especially Claudia Cattivera who was a very important support for me in that event.

I hope the proposal of the last workshop is to give more importance to the Spanish language is a reality. Although I understand some English, I lean towards my native language of Spanish. It is also my wish to extend my thanks to Mr. Brown and Mr. Xavier Jorgi Bonfil for the great effort made to bring out this great event.

Where is medicine going? Where should it go?

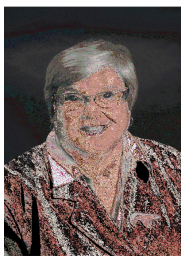
By Sara Yaron [yaron-i@bezeqint.net]



The Mario Negri Institute Symposium took place in Milan, Italy on 13 September 2011 for the 50th Anniversary of the Mario Negri Pharmacologic Institute. The issues discussed were mostly regarding pharmacological research, the global view of public health, industry attitude, regulation and European priorities and directions.

I was invited as a patients' advocate, to take part as a discussant in a Symposium: "Where is medicine going and where should it go". The speakers and discussants were some of Europe's most authoritative public health specialists, research and regulatory workers, and patients' representative. Speakers included Richard Smith speaking on 'A global view of public health needs' and Sir Iain Chalmers on 'Is academy at the service of public health?'

The fact that a patients' representative was invited to participate as a discussant in the round table panel, gave medical patients the opportunity to raise patients' voice in an important and serious forum. This is a tremendous step forward for all consumers.



CCNet's Consumers' Executive

By Liz Whamond

Mingming Zhang and I are The Collaboration's Steering Group representatives for CCNet. The Steering Group directs activities of the Collaboration and it's a real privilege to sit on this

committee as a consumer representative. Our agenda was packed with over 48 items under the general headings of products, knowledge infrastructure, external partnerships, organization and administration. Of special interest to the Consumer Network was the question of external partnerships. We will be guided by the Cochrane policy on partnerships and although not set up at this time, there will be someone who overlooks partnerships. We are anxious to get such issues sorted out.

I also attended two consumer workshops of interest for all consumers. One was lead by Gill Gyte and Shirley Manknell on plain language summaries. The second was lead by Kay Dickerson (with several facilitators) on how to ask an answerable question. Both workshops were well attended and very informative. The slides from these presentations are now on CCNet's website under Presentations

(<http://consumers.cochrane.org/presentations>).

Sandwiched between the Steering Group meetings was a very busy and well executed Colloquium with great plenary talks and many workshops, The Cochrane Collaboration's Annual General Meeting and the Cochrane Consumer Network's Annual General Meeting. The CCNet meeting was well attended with approximately 30 participants. There were great discussions on many topics and the Executive felt that a discussion format for consumers would be a useful addition at future colloquia.

Cochrane Summaries Wins Award

By Catherine McIlwain



Only recently launched, the Cochrane Summaries website (summaries.cochrane.org) has received global attention, which reached a pinnacle when The Cochrane Collaboration was awarded the runner-up trophy for the best public website by the Plain English Campaign.

Each year, a handful of the best (and worst) examples of plain language are publicly honoured by the Plain English Campaign. The organization reviews documents and websites to ensure that public information is presented in a clear fashion. Websites are judged for their content, design and layout.

A spokesperson for the Campaign indicated that Cochrane Summaries earned the 2011 runner-up award because of its unique ability to use plain language summaries to explain medical research.

Well done to all the consumer referees who contribute to plain language summaries!

The Plain English Campaign awarded the prize to The Cochrane Collaboration at a ceremony at The Cavern Club in Liverpool, UK on 9th December 2011. Catherine McIlwain and Frances Kellie accepted the award on behalf of The Collaboration.



For more information about the Plain English Campaign, visit www.plainenglish.org.

Follow CCNet 'Twitter' postings

<http://twitter.com/CochranConsumer>

What is the Cochrane Library & How to Use it

By Janet Gunderson [janetrgunderson@sasktel.net]

On August 29th I gave a presentation to nurse educators from the Prairie Health North Region (Canada). There were about twenty nurse educators at the meeting in North Battleford. This included nurse educators from North Battleford, Lloydminster and Meadow Lake.

Most had heard of the Cochrane Library and some had looked, but had found it difficult to use. I gave a power point presentation on what the Cochrane Library was and why they might want use to it. I used the story of the Cochrane logo to explain the reasons to use the library and the impact it can have. I used a handout with seven steps to use the library using the dropdown menu.

The nurses have full access to the Cochrane Library through the Saskatchewan Health Information Resources Partnership (SHIRP) website. After looking at the drop down menu and showing them that it took you to the Abstract, Main Results, Author's Conclusion and the Plain Language Summary, we went online to the SHIRP website and I showed them the four steps involved to see a complete Cochrane Review. The handout also included the four steps using the SHIRP website. The nurses in attendance were pleased to see that it was not difficult to use the Cochrane Library and said they would be much more inclined to use it now that they know more about it.

4th Global Patients Congress, International Alliance of Patient's Organizations

By U Hla Htay
[uhlahtay@hotmail.com]

On 24 February 2010 in Istanbul, Turkey, I gave a presentation on the works of the Cochrane Collaboration/CCNet and information on Cochrane Library followed by panel discussion in workshop format.

It was attended by patient leaders, health professionals, healthcare policy-makers, industry representatives and academics.

A few patients' organizations became aware of the CC/CCNet and one patient organization offered to distribute the CC/CCNet information leaflets at their AGM.

Resources for you:

The CCNet Brochure

<http://consumers.cochrane.org/resources>

What is a Systematic Review?

<http://consumers.cochrane.org/what-systematic-review>



Reaching Out to Consumer Organizations: An e-mail promotion project

By Marilyn Walsh [marilynwalsh@shaw.ca]

I have been involved in an individual e-mail promotional project for Cochrane during this past year. At the Canadian Cochrane Symposium in Vancouver this past February, I presented an oral presentation about an article I wrote about Cochrane for the Canadian Spondylitis Association's national newsletter. This article reached approximately 500 members. After the symposium, I was contacted by another Cochrane consumer referee who asked if she could print the article for the Consumer Advisory Board newsletter which reached another 200 of their members.

I will be presenting a poster in Madrid about how I took the project further and tried to contact as many English speaking international ankylosing spondylitis/arthritis organizations as possible in order to supply them with similar articles to be printed in newsletters/magazines and on websites in the hope that as many consumers with arthritis as possible could be reached and benefit from shared decision making and the benefits of compliance with proven treatments. As yet, not all organizations have printed the articles due to full story boards but have plans to do so in their fall/winter editions.

Consumer Perspectives of the Colloquium

Alina D. Bishop Velarde, Mexico

I am from Mexico, and have been in the Cochrane Consumer Network for 11 years. The Madrid Cochrane Colloquium has been especially significant for me. In my country at the moment, maternal care is important because the government is trying to slow down the maternal mortality rate according to the 5th goal of the Millennium, as are a lot of countries in the world. For this reason I attended health policy-centered workshops for the first time. I learned a lot and gained a new perspective of our work.

Although pregnancy and childbirth healthcare is completely free in Mexico, public hospitals in Mexico are overloaded and lack sufficient resources. This leads to poor quality health care, partly because care during childbirth is not evidence-based and hospitals since adhere to many practices not recommended by the World Health Organization (WHO). My non-governmental organization, "Parto Libre," and others have been working for many years to make a change based on evidence of beneficial childbirth practices.

Nowadays there is a very good governmental health program that is trying to improve the healthcare in childbirth based on evidence, but it is only affecting a few hospitals. In order to support this project (and resist changes to the program when the government changes in 2012), I talked with different doctors in the Health Ministry to tell them about the importance of attending a Cochrane Colloquium. No one accepted this invitation, although for different reasons.

To my surprise, a month after returning from the Madrid Colloquium, I was invited to a meeting with senior members of the Health Ministry. In January, I am invited to a working meeting with them again.

I think one of the reasons that the strange phenomena of a layperson like myself participating in such meeting is that I have more clarity and conviction in what I say for the simple reason that my work is evidence-based and supported by the Cochrane Library ...!

Lorraine Johnson, United States of America

Facebook blog from the Colloquium:

In Spain. This has been a terrific conference for me. Kay's class on PICO was fabulous. My favorite presentation? By the Mary Docherty "Using evidence to stop ineffective practice: The UK Cochrane Centre (UKCC) and NICE work together". This presentation was about how applying Cochrane recommendations that there is insufficient evidence to recommend "fill in the blank" translates (or, more importantly, does not translate) into policy recommendations.



Last day of Cochrane. Really liked the presentation by Sally Crowe, director of the James Lind Alliance. She referred us to a couple of articles. Looking forward to reading these:

- Tallon, *Relation between agendas of the research community and the research consumer*. The Lancet, Volume 355, Issue 9220, 10 June 2000, Pages 2037-2040 and
- Lloyd et al. *Democratizing clinical research*. Nature, Volume: 474, Pages: 277–278 Date published: (16 June 2011).

One final note is that the presentation of John Ioannides. Great talk, raising several challenges to Cochrane members regarding the type of research being done that is funded by pharma and the holes left in that research as a result of their motivation and FDA placebo oriented framework for trials. Essentially he proposed creating a prospective research agenda that is responsive to the needs of patients and fills in the research gaps. I think he is raising the bar for EBM. Here's one of his older articles: <http://www.theatlantic.com/magazine/archive/2010/11/lies-damned-lies-and-medical-science/8269/>

Consumer Perspectives of the Colloquium



Maryann Napoli, United States of America

The highpoint of my attendance at the Madrid colloquium was talking with John Ioannides ("[Lies, damned lies, and medical science](#)" Nov 2011). I was standing by my (and Silvana Simi's) poster thinking to myself that probably no one will stop by, hardly anyone ever does, and that's why they put the coffee near the posters. My reverie was broken first with a nice chat with Lorraine Johnson who was looking forward to her turn at the poster session the next day. As we were talking, I read the badge of a man standing near me (but not looking at my poster). I think he was just passing through on the way to the coffee, but there was John Ioannides. I introduced myself as someone who works with CCNet and someone who writes about systematic reviews for the general public. I told him how discouraged I was to read his 2005 Public Library of Science article entitled, "Why most published research findings are false" (<http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0020124>). If medical writers like me can't trust most of the *published* studies, then that leaves us little to report to our readers.

He was surprisingly optimistic, saying that we must keep at it; we must make sure that the studies we select for reviews are unbiased. When I showed him our poster, I drew his attention to one aspect of it - the bias involved when all RCTs in a Cochrane drug review were paid for and conducted by the pharmaceutical industry. Here too, he was surprisingly optimistic. He said that many drug-industry conducted RCTs are very well-designed, but the industry-sponsored studies do not ask the questions doctors and patients want answered. For example: is this new expensive drug better and safer than the old drug for same condition? This was the gist of his excellent presentation at the next morning's plenary session. Actually his response didn't make me optimistic, but it cheered me to know that he was.

CCNet on Facebook

Information that matters to you:

<https://www.facebook.com/groups/188375461224285/>



Shirley Mankell, United Kingdom

My thoughts regarding the Madrid Colloquium, 2011:

PLS s - the challenges presented by 2 very different approaches to evaluating these

Rewards - meeting & working with so many 'old' & also new friends

Opportunities - to contribute to the development of CCNet, possibly in new ways

Venue - sad that the convention centre management could have been more cooperative.

Encouragement - that CCNet is getting its co-operative act together!

Internet - sadness that Maxine had hers hacked.

Thanks - very many, to Marga, of local secretariat, for help when my wallet was pinched, and, of course, to Cochrane for enabling me to be in Madrid.

Once again I am sad that the very best & valuable opportunities of meeting & working with other consumers are at the most expensive & erudite events - the Colloquia-wherein the Consumer input is necessarily a relatively small part. I did not manage to get to the Denver Consumer day in 2010, but other entities manage their 'add-ons' - could this work for CCNet? I wonder if this could make better use of stipend monies, without causing an unhelpful separation of consumers from the whole colloquium.

Marilyn Walsh, Canada

When Catherine McIlwain first asked consumers attending the Madrid Colloquium to present our thoughts, my first inclination was to discuss all the presentations and workshops I had attended. After attending, I realize that the most memorable component about the whole experience for me was not the technical information (although extremely helpful) but rather the people. Cochrane is truly like a family. Fellow consumers, whom I had never met before, became fast friends.

Being my first colloquium, I was a little nervous at first but I needn't have been. Experienced consumers were quick to welcome someone new to the fold and make them feel extremely welcome. They were very eager to share their knowledge and experience and several lead very informative and valuable workshops which were presented in a manner that was comprehensible to everyone in attendance. The Newcomer's Session was particularly helpful and was presented with humour and a component of fun that made the session fly by. The consumer workshops gave me the groundwork to expand my involvement with Cochrane in a way which feels most comfortable for me.

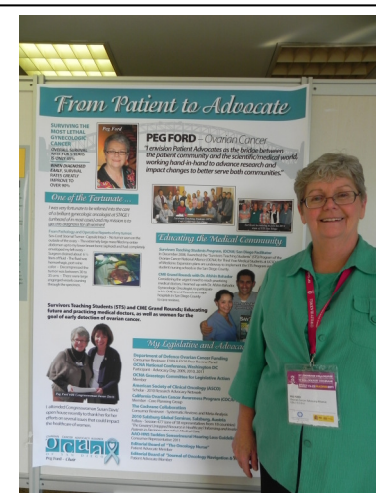
Aside from consumer sessions, I believe listening to perspectives from top policy-makers in the healthcare field was not only a privilege but also very enlightening. I can't think of another forum where a consumer could be a "fly on the wall" and be party to such an honest exchange of ideas regarding healthcare. On the last day of the colloquium, I had the opportunity to present a poster I had worked on. Mine was only one of several consumer related posters among many technical ones. It was impressive and gratifying to see that the work of consumers was respected enough to be included amongst that of professionals.

I believe that the thing that was impressed upon me the most during this colloquium was that the opinion of everyone involved with Cochrane is respected, whether they are policy-maker, healthcare professional or consumer. We all have our value. My sincere thanks to the stipend committee for giving me the opportunity to attend the Madrid Colloquium. It was truly an experience that I will never forget.

**Peg Ford, United States of America**

My attending the Colloquium in Madrid Spain not only strengthened the connection with the Cochrane Gynaecological Cancer Review Group who I participate as a consumer reviewer, but also presenting my Poster "From Patient to Advocate," afforded me the opportunity to share my journey to the delegates. Two contacts could very well bring an opportunity to collaborate Advocacy and the "Survivors Teaching Students" Programs to India and Turkey!!

The sessions added depth to my understanding of the mission and efforts of The Cochrane Colloquium and confirmed my commitment to support those efforts in many ways; one being receiving a request to write an article of my experience for a national oncology magazine. Attending "Making Sense of the evidence --a workshop for consumers" was outstanding and one important aspect dear to my heart of Shared Decision-Making, was the Cochrane Musculoskeletal Group's Decision Aid (DA) Style Guide session. To be present to hear the questions, concerns and participate from a consumer/patient advocate was invaluable. To attend the US contributors session to hear the up-to-date efforts including the newly established "The Cochrane Collaboration College for Policy" at George Mason University for advocacy legislative action shows the potential where advocates and scientists can work together to focus on legislative issues. Without question, attending the Colloquium is something I recommend to any of Cochrane Collaboration Consumers to attend.



Katie LeBlanc, Canada

It was truly an honor to attend the XIX Cochrane Colloquium! Indeed, arriving in Madrid October 17th after an overnight flight from Canada was incredibly exciting. Prior to the journey I had registered in workshops that corresponded with my requirements for expanding knowledge and developing new skills for the benefit of Cochrane and particularly the consumers who read our reviews. The Colloquium's schedule of workshops, presentations, and meetings sounded both inspiring and motivating. The opportunity to join others who assist with the development and transfer of knowledge while continually aspiring to increase quality of life for humankind is both a privilege and a joy! Hats off to all those industriously wonderful people who developed and generated this marvelous event! The following is a summary of some of the XIX Cochrane Colloquium highlights.

Initially I participated in a workshop that was presented as a Consumer event, "Making sense of the evidence." The inclusive environment contributed to maximal interactive learning. In fact the active collaboration between facilitators and audience initiated and optimized an excellent educational program. It is my hope that the facilitators of this event will receive due recognition for both their excellence in identifying ongoing effective learning material and for presenting their educational tools with the utmost of precision. The well designed workshops I attended contributed towards enhancing my skills as a consumer, peer reviewer and review author. It is exciting to hear about the development of new courses for consumer-advocate training, and the courses which are presently evolving and undergoing modification.

The Newcomers' Session was a highly important positive exchange between seasoned Cochranites and new attendees. This meeting, intended to welcome and engage newcomers to the multi faceted and appealing challenges of Cochrane work, through the many introductions, was of vital interest to participants and our small space was actually overflowing with enthusiasts. Also, on Oct. 19th, the World Health Organization and the Pan American Health Organization presenters discussed the fact that they are in the process of assisting consumers towards a more panoramic view of educated choices. A global strategy and plan of action on innovation and intellectual property rights was exceptionally well presented.

The plenary sessions with their distinguished speakers were thought-provoking as they provided excellent updates regarding healthcare quality and patient safety; and in general, evidence-based healthcare research, current challenges being faced, and initiatives planned for the future. The joint presentation on Thursday, October 20, was an excellent example of the efforts Cochrane has effected in helping to deal with the crisis of serious adverse events. The Oct. 21st plenary session agenda included discussion regarding the World Health Organization's contribution to Cochrane's visibility and as well, future directions for Cochrane data and the possibilities of expansion and data-linking.

"Together we can ..." Although we are increasing patient education resources as we translate evidence from Cochrane reviews, practical methods and techniques for physicians to commence/continue to engage patients interaction in making treatment decisions appears to remain an unconquered challenge in many areas. The following question remains to be answered "Are all physicians prepared to accept patient choices of treatment?" Have we as yet reached this point? I would like to hear more regarding effective strategies to assist with enhancing individual physician/patient interaction.

'Critical Appraisal Skills - Making sense of evidence about clinical effectiveness' was well-attended and extremely relevant for consumers. There was positive feedback within the attending group regarding the exercise we participated in and its benefits. From my perspective, I found the methodology most valuable for organizing my work and the instruction was excellent and highly useful for peer reviewing.

These are just a few of the highlights of the many experiences I shared with other attendees at the XIX Cochrane Colloquium. Participation in the Colloquium was a highly unique and most valuable learning experience for me and an excellent opportunity for renewing acquaintances, developing new networks, sharing experiences and generally gaining the knowledge to develop and refine my skills. Currently I am preparing a presentation on the healthcare initiatives, patient safety and Cochrane contribution based on the Colloquium, for a local healthcare group. The illness of diffuse systemic sclerosis has contributed to a more intimate understanding for me, and affiliation with multiple consumers' medical concerns and challenges. Education through the Colloquium has fostered my ability to keep current with new technologies, and our evolving healthcare system, while I embrace the joy of learning and cultivating new avenues and methods of facilitating consumers' healthcare knowledge.

In summary I feel that the Colloquium was highly successful in fulfilling so many of our goals and objectives. I would like to take this opportunity to thank everyone involved in the Colloquium. It was such an immense surprise to learn I would be attending the event and I am most grateful for being selected as a stipend recipient by the C.C.Net Committee and for the enormous support and kind encouragement of our Cochrane IBD/FBD Group's Managing Editor, John MacDonald. I applaud the facilitators of the XIX Cochrane Colloquium in Madrid, and all those involved in producing such a magnificent and successful event.

Anne Lyddiatt, Canada

I thought this was a great Colloquium. I found every session I attended informative and came back with useful pointers for KT, recruiting consumers, and commenting on reviews and protocols. I was able to take in all plenary sessions and found them interesting and informative – I have been a WHO Patient Safety Champion for several years and am involved with the Canadian group so it was great to hear what is going on elsewhere and the progress that has been made – and that the challenges we face are similar!

The opportunity to network and renew acquaintances was great – as was being able to put faces to the names I knew only through email. The consumer meetings were great – I feel that we are really moving forward. There is a great sense of community within the group and I think that sure came through with the dinner. The changes were unexpected and unavoidable and yet I think everyone who planned to attend persevered until they got there – including me which was a real miracle considering my total absence of a sense a direction and the inability to speak Spanish!

My one disappointment was `Mee(a)t the Entities – I think it was a good idea but it was frustrating for all – the space was too tight, the signs needed to be high and in alphabetical order and the poor catering staff needed to be pre-warned. I think they were totally frustrated with all of us. I really appreciated the opportunity to attend and to expand my knowledge of Cochrane in many areas.

Kathie Godfrey, Spain

As a resident in Spain, I was delighted to receive a consumer stipend to attend the 19th Colloquium in Madrid last month. I have been a Cochrane consumer since becoming involved in hand searching in 1997 and this was the fifth Colloquium I have attended during that time. Over the years, the Collaboration has evolved into the authoritative and professional body that it has become today and the consumer network has developed within it.

My first engagement was to attend the annual meeting of the Skin Group which was, as always, informative and an excellent forum for debate among group members. A very enjoyable dinner followed that evening. A bi-lingual consumer workshop run by Gill Gyte and Amanda Burls was most interesting and deserved more time devoted to it. I had to leave before the afternoon's practical session to assist with the "Newcomers Session" which was extremely well attended. Gill Gyte is as indefatigable as ever on behalf of consumers and her work on Plain Language Summaries is a boon to consumer referees and patients alike.

The CCNET AGM raised lots of interesting new approaches and I look forward to hearing of progress and joining in the ensuing discussions re the ongoing development of the consumer network. On the social side, it was lovely to catch up with old friends and enjoy their company. Thank you for offering me this opportunity.

U Hay Htay, United Kingdom

It was an interesting colloquium to attend with catching up the developments at various review groups and intense networking during breaks. Plenary Sessions dealt with future plans and issues. Making Sense of Evidence workshop helped to update the process. At two CCNet meetings met with new consumers and as a UK CCNet Representative at the IAPO, I have presented a paper on "Benefits or no benefits for CCNet membership with the International Alliance of Patients Associations (IAPO)" as some members raised issues and concerns. It was decided to leave it for discussion at the next Consumers Transitional Executive Meeting in the light of the Collaboration's new policy on partnership resented at the Colloquium.

Ann Fonfa, United States of America

Of course it was a lot of fun to be with the advocates, many of whom I had not seen since 2007 when I was in Sao Paulo. We had many lively discussions, as always, about our role in Cochrane, and how we can best serve. The thing that stood out the most for me had to do with the many studies that spoke to the problems in gathering evidence about the evidence. Many solutions were proposed – adoption will be the issue, won't it?

Here are some of the poster titles that caught my attention:

- P1A15 The sensitivity and precision of adverse effects search filters in MEDLINE, EMBASE and Science Citation Index (SCI).
- P1416 The usefulness of different information sources for retrieving adverse effects data for a systematic review ("In order to identify all the relevant references for this case study a number of different sources needed to be searched. The minimum combination of sources required to identify all the relevant references did not include MEDLINE").
- A603 An investigation into the assessment and reporting of harms in clinical studies (only 3 of 101 studies included data on causality, predictability and avoidability).
- A604 What is a rapid review? (wherein I discover that "there is no agreed and tested methodology and it is unclear how RRs differ from SRs").
- B203 Primary outcomes reported in abstracts and ClinicalTrials.gov – do they agree? ("Our data suggest that investigators may not be updating ClinicalTrials.gov trial information")
- C304 Do Cochrane systematic reviews report patient-important outcomes? ("Strategies to integrate patient priorities for....outcomes in clinical trials and systematic reviews are needed")
- P1S34 Where and how to find data on safety: What do systematic reviews of complementary therapies tell us? ("The finding also indicated that there is a potential to improve safety-related search strategies")
- P1A37 Accuracy of the MeSH term 'Breast Neoplasms': Ten years on
- ("Our analysis shows that the term ...is not always accurately assigned")
- P1A48 Geographical and language distribution of trials in Cochrane Systematic Reviews related to acupuncture ("...the reviews are from very few countries. It reminds us there might not (be) enough diversity to show the real world:.)
- P2A190 Systematic reviews of adverse events. Is screening by title and abstract enough? ("...the partial data suggests that clinical trials do not consistently report the presence or absence of adverse events. Systematic reviews of harms may need to screen studies based on full text in order to capture all the applicable studies and reduce type II error".)

As you can see from the above, and I saw many more of interest to consumers particularly, much needs to be done to make our evidence gathering and sharing the best it can be. I urge all consumers to attend at least one Colloquium to meet and greet our Cochrane people.

Sandy Walsh, Canada

I found that there were four ways that the Madrid Colloquium was helpful. The first was the programs to benefit consumers. The workshops specifically to help consumers understand the scientific information and the workshop to know how to read and write plain language summaries fill a necessary need in having new consumer reviewers be well prepared to provide the consumer point of view to authors and to translate the information in a way that patients can understand.

The second practical type of workshops presented information that provided an understanding of the editorial issues in providing the most accurate reviews possible. I was impressed with the efforts to improve the methods used and the workshops that allowed the input of the authors in considering new or approaches or improvements in the existing procedures. The third type of presentations was the plenary sessions that presented overviews of information on particular topics. These were interesting and informative presentations. I especially appreciated the final plenary on economics and healthcare and the presentation by Kay Dickersin on comparative effectiveness.

Finally, meeting and getting to spend time with other consumers was great. The dinner the first night and the CCNet meetings provided times to get to know some of the other consumers and hear what they are doing. Overall, the Colloquium was an outstanding experience for me from all of these points of view.