

# Cochrane Consumers and Communication Review Group



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The Cochrane Consumers and Communication Review Group is an international collaboration of health service researchers, who as members of the Group, participate in the Cochrane Collaboration.

The mission of the Cochrane Collaboration is to help people make well-informed decisions about health care. One of the main ways it plans to achieve this is by ensuring that high-quality and up-to-date systematic reviews of the effects of health interventions are made widely available. Systematic reviews are undertaken by collaborative review groups with editorial bases situated in many different countries world-wide. Each of the 51 review groups in the Cochrane Collaboration has its own scope to identify its area of study.

The scope of the Consumers and Communication Review Group is to undertake systematic reviews of research on the effects of interventions (particularly those which focus on information and communication) which affect consumers' interactions with healthcare professionals, services and researchers. The interventions may relate, for example, to individual use of healthcare services, or to consumer participation in health planning, policy and research.

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## From our Coordinating Editor, Sophie Hill

There are some stand-out themes this year in the Group's reviews:

- Testing more active ways of involving people, e.g. shared decision making for people with mental health problems;
- Trying different ways to communicate more effectively, e.g. new communication technologies;
- Finding out how to support those who already have a major supportive role, e.g. supporting informal carers.



Communication and participation interventions are complex and can give authors and the editorial team headaches. First, I observe that the array of roles consumers and carers may (formally) occupy in the health system is expanding. Naturally this has increased the number of terms and range of meanings. There is a lot of confusion. For instance, the terms lay, volunteer, peer, carer, and user as provider may involve someone doing the same thing or vastly different things. For some newer interventions there is little consensus on what is done by whom and how.

This new language (and meanings) creates challenges because it influences the review question, from how it is framed right through to its application.

One consequence of this is that increasingly we are asking authors to extract as much useful information about an intervention as the trial report reveals. Some authors may also look for qualitative studies conducted alongside the trial and this may deepen understanding of how the intervention was actually implemented.

This work is important because a Cochrane review may be the first comprehensive catalogue of the specific interventions and therefore gives back to the wider field a solid foundation for growth in knowledge.

There is an incorrect assumption that systematic reviews are literature reviews (just a bit more thorough) and that new intellectual work is not performed. How wrong this is! Clearly those who think this have not done a review of a communication intervention. Making progress with a review may require new conceptual work, given the disparate nature of the primary studies. Doing this provides a solid and coherent rationale for the intervention types that are going to be included and for framing the comparisons and analysis. Often the conceptual work happens at several phases - the title registration and protocol phases and may be re-visited at the review analysis stage. The editors of the Consumers and Communication Group have direct input to these phases: communicating with authors, providing detailed commentary, summarising peer review, assessing and suggesting priorities for action. In addition, our editorial team provides a check on the data and analysis. This is all part of the hidden process of a Cochrane review.

Reading this newsletter I see there are a lot of generous people involved in our Review Group. I would like to thank the authors, referees, editors and staff of the Group for their original and substantial contribution to the growing research domain of evidence for communication and participation.

I would like to acknowledge the support of two health departments: the Quality, Safety & Patient Experience Branch of the Victorian Department of Health; and the Regulatory Policy and Governance Division of the Australian Department of Health and Ageing, which administers the Cochrane infrastructure funding.

We have much pride in our work for the Rx for Change interventions database. This flows from our relationship with the Cochrane Effective Practice and Organisation of Care Group in Ottawa, with the database being made available from the Canadian Agency for Drugs and Technologies in Health, through its Canadian Optimal Medication Prescribing and Utilization Service.

With best wishes for 2010 to all these people, and to you.

## Review Group News from Megan Prictor

### Staff:

From March to July 2010 we are fortunate to have Jessica Thomas joining us as acting Managing Editor during my absence on long service leave. Jessica has been Managing Editor for the Cochrane Pain, Palliative and Supportive Care Group for several years and contributes to a range of Cochrane Collaboration activities such as the Managing Editors' Executive and the Editorial Management Advisory Group. Welcome Jessica!



Jessica (Jessie) Kaufman has joined us as a research assistant until May. Originally from Boston, Massachusetts, Jessie has recently moved to Melbourne after spending time in Sydney and in Wellington, New Zealand. She has a background in communications and is particularly interested in writing and editing. She is currently working on several projects with the Consumers and Communication Review Group, including writing a lay summary of a research report and preparing an article on knowledge transfer for publication. She is also contributing to an upcoming book on health communication. Jessie is very excited to be working in such an interesting field with such a respected organisation. Like her sister Carrie, who spent several months working with the Consumers and Communication Review Group in 2008, Jessie also plays roller derby with the Victorian Roller Derby League.



**New website:**

With the creation of the Centre for Health Communication and Participation earlier this year, and launch of a new website for the Centre, the Review Group's website has been entirely rebuilt. You can now see photos of our team, find information on how to participate in the work of the Group and the Centre, and find guidance on completing Cochrane reviews. We welcome your visits and your feedback:

<http://www.latrobe.edu.au/chcp/cochrane/index.html>

**Colloquium:**

Sophie, John and Rebecca attended the 2009 Cochrane Colloquium in Singapore. We also presented a poster on the pilot mentoring programme for Managing Editors in which I have been involved. (Results of the pilot mentoring programme for Managing Editors, by Jessica Thomas, Megan Pricor, Jane Cracknell, Victoria Pennick).

Multimedia from the Colloquium is available at [http://www.cochrane.org/multimedia/colloquium\\_2009/](http://www.cochrane.org/multimedia/colloquium_2009/) and posters are at [http://www.cochrane.org/colloquium/2009/virtual\\_posters/](http://www.cochrane.org/colloquium/2009/virtual_posters/)

**A change in publication frequency:**

From January 2010 the Cochrane Database of Systematic Reviews, containing all Cochrane protocols and reviews, will be published monthly instead of quarterly. We welcome this change, which will even out the workload for our authors and editors. For more information please contact the Review Group.

**Editorial group involved in publication of  
Shared Decision Making: achieving  
evidence-based patient choice – Oxford  
University Press 2009**

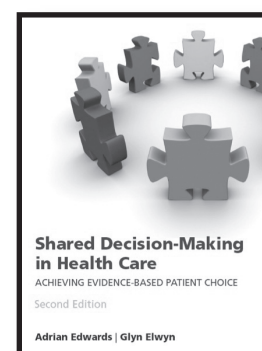
When the first edition of this book came out in 2001 (under the title *Evidence-based Patient Choice: Inevitable or Impossible?*), it examined the emerging themes of patient choice and clinical decision-making, and looked at how these might develop in the future. Since then, these issues have become even more topical. Evidence-based medicine is deeply ingrained in the practice of modern medicine, whilst patient choice is increasingly high on the political agenda. But can the two trends co-exist? 'Shared decision-making' has developed in response to the sometimes uneasy relationship between a patient's

right to have input into their treatment options, and a clinician's responsibility to provide the best evidence-based health care.

Imagine a patient with osteoarthritis of the knee. She and her doctor are considering whether she would benefit from surgery to replace her knee joint. This sort of decision is typical of many in health care where there is more than one reasonable alternative available to the patient and her doctor. These alternatives include surgery, physiotherapy, medication, complementary remedies, and more. What is right for one patient may be different from what is right for another. Clinical information (such as results of x-rays or even patient-reported symptom scores), though necessary, is not sufficient to determine the best treatment. Most importantly, each patient feels differently about the impact of the illness in their life and the importance of the potential good and bad outcomes of the treatment options. In these situations, the best treatment is the one that reflects what is most important to patients who are well-informed about the options and potential outcomes. The shared decision-making approach helps doctors and patients to decide on the appropriate treatment.

The Review Group is particularly pleased to see this publication promoting shared decision making, involving as it does several editors and authors affiliated with our Group. Our editor Adrian Edwards led the editing of this book. Sophie Hill contributes a chapter on health literacy, Hilda Bastian (former Coordinating Editor) writes about on making information available to the public, and Vikki Entwistle (former editor) contributes on consumer involvement. Other Review Group authors appearing in the book include: Lyndal Trevena on MMR vaccination, Annette O'Connor, Dawn Stacey and other members of the Ottawa group on decision aids, France Legare on healthcare teams and roles of professionals, Theresa Marteau on informed choice, and Elizabeth Murray on internet-delivered interventions.

For more information, or to order via OUP, visit <http://ukcatalogue.oup.com/>



## REVIEW GROUP ACTIVITIES 2009

The Group's main task is to coordinate the preparation and publication of systematic reviews. Details of our recent work in this area are given below. Completed reviews and protocols are published on The Cochrane Library which can be accessed by subscribers at [www.thecochranelibrary.com](http://www.thecochranelibrary.com)

People without a subscription (or national access) can view free abstracts (and purchase individual reviews) at <http://www.cochrane.org/reviews/index.htm>

## Titles Registered 2009

- Consumer-oriented interventions for evidence-based prescribing and medicine use: an overview of systematic reviews (Rebecca Ryan, Australia)
- Interventions for enhancing medicine use by older adults prescribed multiple medicines (Johnson George, Australia)
- Non-pharmacological interventions preparing children and adolescents for an acute/single episode of hospital care (Paula Strong, Wales)
- Psychosocial interventions for informal caregivers of people living with cancer (Olinda Santin, Ireland)

## Protocols Published, The Cochrane Library, 2009 (issue 1 to issue 4)

- Consumer-oriented interventions for evidence-based prescribing and medicine use: an overview of systematic reviews (Ryan R, Santesso N, Hill S, Kaufman C, Lowe D, Grimshaw J)
- Email for clinical communication between healthcare professionals (Atherton H, Car J, Meyer B, Majeed A)
- Email for clinical communication between patients/caregivers and healthcare professionals (Atherton H, Car J, Meyer B)
- Email for communicating results of diagnostic medical investigations to patients (Meyer B, Car J, Atherton H, McKinstry B)

- Email for the management of healthcare appointments and attendance reminders (Atherton H, Car J, Meyer B)
- Email for the provision of information on disease prevention and health promotion (Atherton H, Car J, Meyer B)
- Interventions for supporting informal caregivers of patients in the terminal phase of a disease (Candy B, Jones L, Drake R, Tookman A, King M)
- Notification and support for people exposed to the risk of Creutzfeldt-Jakob disease (CJD) through medical treatment (iatrogenically) (Ryan R, Allen K, Hill S, Lowe D)

## Reviews Published, The Cochrane Library, 2009 (issue 1 to issue 4)

Written information about individual medicines for consumers (Nicolson D, Knapp P, Raynor DK (Theo), Spoor P)

### Plain Language Summary

Medicines are the most common intervention in most health services. People taking medicines need good quality information: to enable them to take and use the medicines effectively, to understand the potential harms and benefits, and to allow them to make an informed decision about taking them. Written medicines information is provided in some countries as a leaflet accompanying medicines, and is available via the Internet. Our review examined if written information about individual medicines can improve knowledge or attitudes, or change behaviours relating to taking a medicine.



Lead author, Donald Nicolson

The findings of this review were inconclusive for a number of reasons. First, because the included trials measured different outcomes in different ways, we were unable to combine their results. Second, these trials presented the written information for patients in different ways, and most did not design the leaflets in a way that made them easy to read. Third, in many cases trials were not clearly reported, so we do not know if they were carried out correctly.

Despite these limitations several trials, while using different types of information and different measures, found written information improved knowledge. This is encouraging for people who want to learn about their medicines from leaflets. None of the studies showed that written information was harmful.

Future research needs to use improved methods, and needs to examine the same measures on many occasions. It is important that medicines information be well written and designed to maximise the possibility of improving knowledge. Consumers are increasingly seeking out health information, including information about medicines, on the internet, but we found no trials examining whether internet-based medicines information changed people's knowledge, attitudes, or behaviour.

## Reviews Updated, The Cochrane Library, 2009 (issue 1 to issue 4)

- Interventions for improving communication with children and adolescents about their cancer (Rita Ranmal, Megan Pictor, J. Tim Scott)
- Interventions implemented through sporting organisations for increasing participation in sport (Naomi Priest, Rebecca Armstrong, Jodie Doyle, Elizabeth Waters)
- Policy interventions implemented through sporting organisations for promoting healthy behaviour change (Naomi Priest, Rebecca Armstrong, Jodie Doyle, Elizabeth Waters)
- Recordings or summaries of consultations for people with cancer (Marie Pitkethly, Stephen MacGillivray, Rebecca Ryan)
- Interventions for enhancing medication adherence (Brian Haynes, Elizabeth Ackloo, Navdeep Sahota, Heather Pauline McDonald, Xiaomei Yao).

## Looking forward – a profile of new and updated reviews on issue 1 2010:

### New protocol

- Information interventions for orienting patients and their carers to cancer care facilities, Raymond Chan (Australia).

### New reviews

- Shared decision making interventions for people with mental health conditions, Edward Duncan (UK)
- Visual feedback of individuals' medical imaging results for changing health behaviour, Gareth J Hollands (UK).

### Updated reviews

- Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material, Elin Nilsen (Norway)
- Placebo interventions for all clinical conditions, Asbjørn Hróbjartsson (Denmark)

## New Reviews in the Pipeline

Reviews we expect to publish in 2010 include:

- Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours (Theresa Marteau, UK)
- Interactive computer-based interventions for sexual health promotion (Julia Bailey, UK)
- Interventions for improving understanding and minimising the psychological impact of screening (Jenny Doust, Australia)
- Negative versus positive framing of health information (Elie Akl, USA)
- Using different statistical formats for presenting health information (Elie Akl, USA)

## A note from an author: Gareth Hollands



Gareth published “Visual feedback of individuals’ medical imaging results for changing health behaviour” on issue 1 2010 of The Cochrane Library, released in January 2010. At the conclusion of the publication process for his review he wrote:

“Many thanks for all your help and great attention to detail in the long process. It's been hard work but an absolutely brilliant learning experience for me. I think the rigorous, systematic process of doing a Cochrane review is very much a good thing and I felt very supported when that was needed. Just for your general feedback at Cochrane, I'd also like to say that I went on a several-day long course at the UK centre where we essentially sat in a room and tried to progress our reviews, with an available statistician and other advisors. That was excellent and really helped in getting to the point of first submission of the final review, and I like the way that such courses give you contact with other people doing reviews, so that you can all share experiences, expertise and struggles!

I'm definitely keen to do another review once the dust settles, and I would hope the next one would benefit from my experience with this one. “

## Potential Review Topics

Would you like to undertake a Cochrane systematic review about communicating with people about health care? The following broad topic areas are in need of new authors to refine them and prepare a formal review proposal, Cochrane protocol and finally the full review. Each of the topics below could potentially be broken down into several reviews. If you have an interest in any of these areas and feel you have the time to commit to a review, please contact Megan Pictor.

- Librarians / information specialists providing targeted health information to consumers...  
Patient information prescriptions...
- Interventions for improving informed-decision making during and shortly after childbirth.

We are always keen to hear from people wanting to undertake a review in any area of our scope – not just those listed above.

## Consumer participation policy developments in Australia: building on Cochrane reviews

*Sophie Hill*

In the State of Victoria we have entered the 2nd phase of a state-wide consumer participation policy, brought in by the Victorian Department of Health. The updated policy is titled 'Doing it with us not for us: Strategic Direction 2010-2013'. You can get a copy of both current and new policy documents here:

<http://www.health.vic.gov.au/consumer/participate.htm>.

Consumer participation is valued not only because it is an aid to improving health outcomes and the quality of care but also because it is a democratic right and an accountability mechanism.

The policy covers acute and sub-acute services, mental health services, residential aged care and free-standing community health services. It conceives consumer participation broadly and is informed by evidence. Priority actions cover four levels:

1. Individual level, e.g. communicating treatment information;
2. Program or department level, e.g. training staff in communication skills;
3. Health service organisation level, e.g. consumer participation in quality programs;
4. Department of Health level, e.g. providing training to staff on evidence-based participation.

The policy retains its focus from previous years but heralds a new direction. It proposes standards for consumer participation, with indicators, and targets. In two cases, Cochrane systematic reviews published by our Group were used to set standards. These were the review of decision aids led by Annette O'Connor and the reviews of methods of consumer involvement led by Elin Nilsen [go to [www.thecochranelibrary.com](http://www.thecochranelibrary.com) for full text and search by author. If your country or institution does not have subscription, go to [www.cochrane.org](http://www.cochrane.org) and search 'Cochrane reviews' by topic (Consumers and Communication)].

It is very exciting to see broad-based Cochrane reviews from our Group supporting change in health policy and supporting the development of new standards.

The policy promotes and supports evaluation of consumer participation interventions. It has enabled the Department of Health to provide funding for a series of demonstration projects: Evaluating the Effectiveness of Participation (EEP) projects in 2007-08 and a second round of funding has been offered in 2009-10. Health services are expected to conduct a controlled evaluation of a consumer participation intervention. The Consumers and Communication Review Group will be providing support in the application process and to the successful applicants.

## Launch of Centre for Health Communication and Participation

Eagle-eyed readers may have noticed that the Consumers and Communication Review Group has a new website and a slightly different mailing address. That's because in April this year we became a constituent arm of the new Centre for Health Communication and Participation within the Australian Institute for Primary Care at La Trobe University.

### CENTRE FOR HEALTH COMMUNICATION AND PARTICIPATION

The Centre has sprung from the work of the Cochrane Consumers and Communication Review Group and is directed by the Group's Coordinating Editor Sophie Hill. The Centre's mission is to improve communication with and participation by consumers and carers, through evidence-informed policy and decision making.

The Centre has focussed on these key themes in 2009:

- Evidence for different modes of consumer participation
- Communication in circumstances involving a rare disease
- Communication and participation with regard to use of medicines
- Communication in situations of healthcare complexity, such as multimorbidity
- Understanding and communicating the science of evidence-based health care.

The Centre comprises the Cochrane Group, the Health Knowledge Network led by Helen Dilkes, and an Effectiveness Research arm led by Rebecca Ryan. The latter produces systematic reviews in Victorian priority areas, as well as developing innovative tools and resources for research and implementation of interventions for communication and participation. The Centre model helps to raise the profile of the Cochrane Consumers and Communication Review Group and facilitate research stimulated by the Group's systematic reviews. Please take a moment to visit our new site at <http://www.latrobe.edu.au/chcp/>

## Upcoming Conferences

### International Forum on Quality and Safety in Health Care

20 to 23 April 2010

Nice, France

<http://internationalforum.bmj.com/>

### Inaugural International Advance Care Planning Conference

22 to 24 April 2010

Melbourne, Australia

<http://www.internationalacp2010.com/index.php>

### EACH International Conference on Communication in Healthcare

5 to 8 September 2010

Verona, Italy

<http://www.each-conference.com/>

### 8th Australian Conference on Safety and Quality in Health Care

6 to 8 September 2010

Perth, Australia

<http://www.aaqhc.org.au/>

### Joint Colloquium of the Cochrane and Campbell Collaborations

'Bringing evidence-based decision-making to new heights.'

18 to 22 October 2010

Keystone, Colorado, USA

<http://www.regonline.com/builder/site/Default.aspx?eventid=766689>

Review Group staff and editors will be attending the Keystone Colloquium, please come and say hello!

**To join the Review Group or update your address details, please contact Megan Prictor at [cochrane@latrobe.edu.au](mailto:cochrane@latrobe.edu.au) or visit <http://www.latrobe.edu.au/chcp/cochrane/>**

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