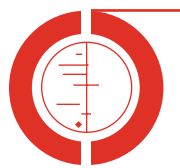


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Cochrane Consumers and Communication Review Group



THE COCHRANE
COLLABORATION®

Cochrane Consumers and Communication Review Group

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From our Coordinating Editor, Sophie Hill

In the first edition of the Cochrane Library for 2004, there are 10 reviews on communicating with consumers that have been coordinated by the editorial team of our Group. In addition, there are 12 protocols, and our Group has 16 registered titles - 'reviews in the making'. This is a great achievement for our Group and represents a growing body of high quality research that everyone should read if they are interested in improving health care and making it more responsive to people's needs.

My view is that our Group has the enormous good fortune to be associated with some of the best researchers in health care. They are an eclectic mix. We provide research support and editorial advice to many people both in Australia and around the world - public health researchers, consumer advocates, doctors, social workers, health educators, clinicians in primary care, health librarians, and students in many areas of health care. Thoughtful comment sent to reviewers by our referees improves the reviews, making them easier to read and understand, and more clinically and socially relevant.

The reviews that are coordinated by our Group are amongst the most difficult of systematic reviews being done today. There are a number of reasons for this: for instance, many new or emerging interventions; little shared understanding of the way that communication interventions

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 50 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 health care professionals, health care services and health care researchers. The interventions may relate, for example, to individual use of health care services, or to consumer participation in health planning, policy and research. The Group also carries out reviews on placebo effects.

can be categorized; and interventions embedded in complex social settings and clinical circumstances, making trialling and the interpretation of trial results a less than straightforward task. However, the reviewers and referees for our Group are not daunted by these difficulties and the outstanding body of work that is emerging is testament to their hard work and perseverance.

There is still quite a long way to go before there is a better understanding of the value of systematic reviews of communication interventions. I am frequently confronted by people who tell me that the only way to know anything of value is by reading a qualitative study. As I am a sociologist whose PhD was by qualitative method, I can say quite firmly that there is a great deal of rubbishy qualitative research around - quite as much as there is of quantitative research! The interesting issue is what we can learn from systematic reviews. Many of the reviews of trials of interventions to communicate better with consumers present us with little definitiveness in the way of a result, but along the way we can learn a great deal about what has been tried or tested, what sorts of outcomes matter to people, and for what sorts of outcomes have data been collected so far. The challenge is to make the method subservient to our purpose without stretching its capabilities.

In October in Barcelona the entire editorial team and staff of the Group met for eight hours over two days: this was Dominique Broclain, Dell Horey, Simon Lewin, Sandy Oliver, Megan Prictor, Judy Stoelwinder, Michel Wensing, and myself. Madeleine King, our Advisor on outcome measures, joined us for a short time as well. It will be a great benefit for the Group that all were able to make the time to come to Spain, and to discuss what we hope are solutions to the problems I mentioned above. As a result of our meetings we plan to expand the advice we can give reviewers (via our Resource Packs), particularly those who are reviewing emergent interventions, and those who want to incorporate qualitative research in reviews. We will soon be finalising a new list of potential review topics, a data extraction template and quality assessment guidelines. This latter work has been funded by the Health Priorities Branch of the Australian Department of Health and Ageing, in a grant lasting two years. The grant will also enable us to employ a research officer to support review teams, and allow us to explore other ways to store our register of trials. We are very grateful to receive this support from the Australian Government, in addition to the

ongoing support and funding we receive from the Office of the Chief Clinical Advisor of the Victorian Department of Human Services.

I wish to extend a very warm welcome to Dr Adrian Edwards, who is joining our editorial team. We are very privileged to have such a wonderful editorial team, all leading experts in their areas of research, and always so generous with their knowledge and expertise in support of others.

I wish you all a safe, happy and intellectually juicy 2004!

Review Group News from Megan Prictor



New Administration Officer: Jane Schleiger

The Group is very pleased to welcome Jane Schleiger who will be working with us to provide administrative support one day per week. Among her other activities, Jane will be conducting a clean-up of our membership database later in the year, so if she contacts you to confirm your address details, please assist her.

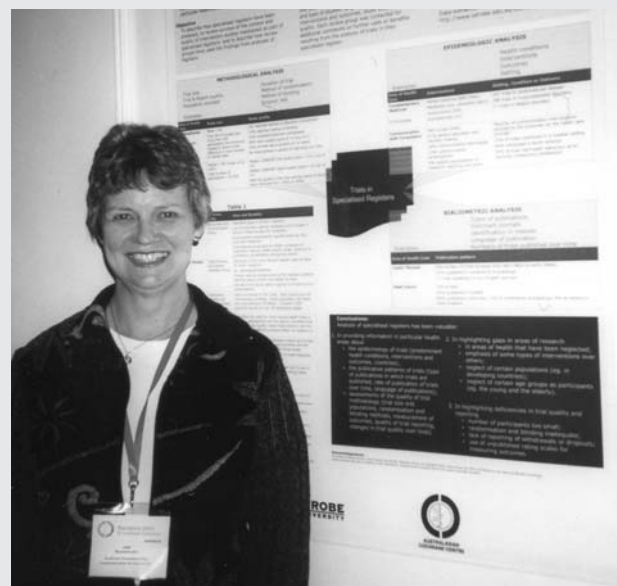
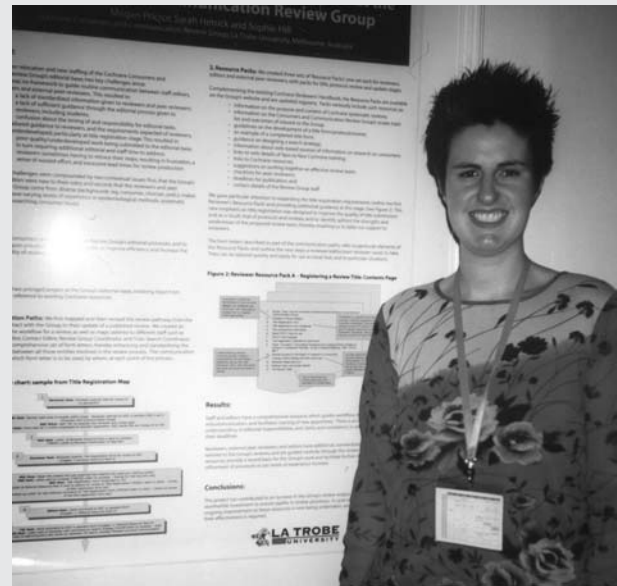
The Barcelona Cochrane Colloquium

The 11th international Cochrane Colloquium, held in the beautiful city of Barcelona in October 2003, was a landmark event for our Review Group. All of the Group's staff and editors were able to attend, enabling us to discuss in detail the Group's activities and plan its future direction. We presented two posters: "A qualitative review of studies analysing the content of Cochrane review group specialised registers" (Judy Stoelwinder and Steve McDonald) and "Ensuring review quality: New editorial processes and reviewer support at the Consumers and Communication Review Group" (Megan Prictor, Sarah Hetrick and Sophie Hill) (copies are available on our website). Sophie Hill was co-chair of the session "Consumers and sources of information for patients", and we had a fantastic attendance at our Group's open meeting, with many reviewers, peer reviewers and representatives of other Review Groups present.

On the first day, the Review Group Coordinators and Trials Search Coordinators of all fifty Review Groups met together at the beautiful Hospital de la Santa Creu i Sant Pau, home of the Iberoamerican Cochrane Centre. It is always great to meet with people you have only previously known via email. It was good to hear more about the new Information Management System to be introduced from later in 2004, and about the move to identify 'best practice' resources for Collaborative Review Groups. The workshop I attended on converting non-Cochrane reviews to Cochrane reviews (held somewhat oddly in a converted hotel bedroom!) was also stimulating.

The opening session held in the Palau de la Música Catalana was special not just for the amazing venue but also for the mention by Mike Clarke, Co-Chair of the Cochrane Collaboration Steering Group, of one of our reviews: Anne Johnson's *Written and verbal information versus verbal information only for patients discharged from acute hospital settings to home*. Sophie and I later had a very useful meeting with our counterparts from the Effective Practice and Organisation of Care Review Group, with whom we enjoy close links.

Between all of the meeting, greeting, thinking, working and discussing, we managed to see a few of the sights, enjoy some tapas and paella, and start giving thought to the next Colloquiua, planned for Ottawa in October 2004 and Melbourne in October 2005.



(Above) Megan Prictor and Judy Stoelwinder with their posters.



(Left) The Consumers and Communication Review Group's editorial team (l-r): Megan Prictor (RGC), Michel Wensing (Editor), Judy Stoelwinder (TSC), Dell Horey (Editor), Sandy Oliver (Editor), Simon Lewin (Editor) and Dominique Broclain (Editor). The coordinating editor Sophie Hill is behind the camera!

REVIEW GROUP ACTIVITIES JUNE 2003 - JANUARY 2004

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 <http://www.update-software.com/clibng/cliblogon.htm> People without a subscription can view free abstracts (and purchase individual reviews) at <http://www.update-software.com/Cochrane/>

Titles Registered June 2003 - January 2004

Peer support strategies for people with chronic disease to enhance health and promote health equity Marion Doull (Canada), Vivian Robinson, Peter Tugwell, George Wells, Annette O'Connor

Interventions to support decision making for older people facing the possibility of long-term residential care Michelle Gravolin (Australia), Edward Reid, Katie Rowell, Roger Dunston, Jo De Groot

Patient/healthcare provider communication about the treating doctor's own performance for people considering elective surgery Amanda Henderson (UAE), Gideon Caplan, Simon Henderson, Jo Bothroyd

Protocols Published, The Cochrane Library, Issue 4 2003

Telephone follow-up, initiated by a hospital based health professional, for postdischarge problems in patients discharged from hospital to home Patriek Mistiaen (The Netherlands), Else Poot

Objectives: To determine the effects of follow-up telephone calls (TFU) in the first month post discharge, initiated by hospital-based health professionals, to patients discharged from hospital to home, with regard to physical and psychosocial outcomes in the first three months post discharge. The effects of TFU will be compared to usual care or other types of hospital follow-up (e.g. TFU initiated by primary-care-based health professionals).

Protocols Published, The Cochrane Library, Issue 1 2004

Interventions before consultations for helping patients address their information needs Paul Kinnersley (UK), Chris Butler, Phyllis Butow, Diane Owen, Fergus MacBeth
Objectives: To assess the effects of interventions directed at patients prior to their consultations, designed to help them address their information needs within consultations, on outcomes for patients (and/or representatives), their doctors and nurses and the health care system.

Interventions for promoting consumer involvement in developing health policy, clinical practice guidelines, patient information material and health research Elin Nilsen (Norway), Hilde Myrhaug, Marit Johansen, Sandy Oliver, Andy Oxman
Objectives: To determine the effects of different ways of promoting consumer involvement in collective decisions about healthcare policy, clinical practice guidelines, patient information material and healthcare research.

Interventions (non-pharmacological) for preparing children and adolescents for hospital care Megan Prictor (Australia), Sophie Hill, Angela Mackenzie, Judy Stoelwinder, Mirjam Harmsen
Objectives: To assess the effects of non-pharmacological interventions for preparing children and adolescents for hospital care, on outcomes including psychosocial and physical health, behaviour, knowledge and understanding, and satisfaction, and on relevant outcomes for parents, staff and health services.



Reviews Published, The Cochrane Library, Issue 4 2003

Interventions for improving communication with children and adolescents about a family member's cancer Tim Scott (US/UK), Megan Pricor, Vikki Entwistle, Amanda Sowden, Ian Watt, Mirjam Harmsen, Alex Broom

Communicating well with children and adolescents about a sibling's cancer can improve their knowledge and understanding as well as their coping, adjustment and wellbeing. It has not been common for families and health practitioners to share information with children or adolescents about a family member's cancer. Interventions to try to help young people cope with cancer in the family include printed information materials, counseling, education and support programs, sibling group programs and art, play and music therapy. The review found limited evidence of some interventions for children and adolescents about a sibling's cancer only. Structured group interventions and camping programs for healthy siblings improved knowledge and understanding about their sibling's cancer, and improved coping, adjustment and wellbeing. There was no evidence of harm.

Written and verbal information versus verbal information only for patients discharged from acute hospital settings to home Anne Johnson (Australia), Jayne Sandford, Jessica Tyndall

When children are discharged from hospital, parents' understanding of how to continue care at home is better if they receive both written and verbal information

When people are discharged from hospital, they and/or their carers are given information on how to manage care effectively at home. Hospital staff usually explain what is required verbally and may also give written, or even video-taped, information. The review of hospital discharge information found only studies looking at parents caring for their children. Parents had a better understanding of the care needed when given both written and verbal instructions, rather than verbal instructions alone. Further research is needed to determine if this leads to better health outcomes and faster recovery times, and on discharge information for other hospital patients.

Reviews Published, The Cochrane Library, Issue 1 2004

Information for pregnant women about caesarean birth Dell Horey (Australia), Jane Weaver, Hilary Russell

Information to encourage pregnant women to attempt vaginal birth has not been shown to change caesarean birth rates. Caesarean births have become more common in many countries. Women need information to know what to expect after surgery and to help them make decisions. Women's choices are thought to contribute to the rise in caesarean births. Information given to pregnant women may affect their choices. Shortcomings in the included studies mean the evidence is inconclusive, although the trials found that information to encourage women to attempt vaginal birth did not affect caesarean birth rates. More research is urgently needed.

Protocols in the Editorial Process (January 2004)

Contracts for increasing patient adherence to case management activities Xavier Bosch-Capblanch (UK), Paul Garner

Family-centred care for children in hospital Linda Shields (Ireland), Vikki Flenady, Judith Hunter, Jan Pratt

Group visits as part of longitudinal care for improving health John Epling (UK), Eugene Bailey, Martha Bonney, Thomas Dennison, Jennifer Schultz, John Smucny

Involving service users in providing mental health services for adults;

Involving service users as trainers for mental health professionals; and

Involving service users as researchers for the evaluation of adult mental health services Emma Simpson (UK), Allan House, Michael Barkham, Simon Gilbody

Interventions organised by sporting organisations for increasing participation in sport; and

Policy interventions implemented through sporting organisations for promoting healthy behaviour change Faline Howes (Australia), Jodie Doyle, Elizabeth Waters, Nicki Jackson

Review Updates in the Editorial Process (January 2004)

Placebo interventions for all clinical conditions (former title: Placebo intervention versus no treatment) Asbjørn Hróbjartsson (Denmark), Peter Gøtzsche



Review Group welcomes new editor: Dr. Adrian Edwards

Dr Adrian Edwards is Reader in Primary Care and part-time general practitioner in Cwmbran Gwent, Wales. His main research interests are in risk communication and shared decision making. Further interest areas include quality improvement in primary care, and the diagnosis of childhood urinary tract infections. His methodological interests have centred on systematic reviews. The first major review was on the effectiveness of risk communication interventions in one-to-one health care encounters, and employed a meta-regression analysis to assess a range of interventions and from a range of study objectives, designs, and contexts. It was a section of this review - focusing on personalised risk communication in screening programmes - that led to Adrian's involvement with the Cochrane world. Initially this was via the Effective Practice and Organisation of Care (EPOC) Review Group, but then the Consumers and Communication Review Group was born, and became the natural home for this review. Adrian has also been involved the Breast Cancer Review Group, but as the Consumers and Communication Group is where his principal interests lie, he was delighted to be invited recently to join our editorial committee.



Mixing qualitative and quantitative methods in complex health service and public health RCTs

by Simon Lewin (Simon.Lewin@lshtm.ac.uk)

*London School of Hygiene and Tropical Medicine and Medical
Research Council of South Africa*

A significant proportion of health service and public health interventions target health care provider or consumer behaviours or the organisation of care. It is increasingly recognised that qualitative methods are important in evaluating these complex interventions, particularly in eliciting the views of consumers and providers on the effects of these interventions and their satisfaction with them. However, little research has examined how qualitative methods are currently used in RCTs and how they should optimally be used to improve the usefulness and policy relevance of trial findings.

We have just received funding from the UK Medical Research Council to explore these questions. The four year study aims to develop knowledge of appropriate methodological approaches for the integration of qualitative and quantitative methods and findings in the context of RCTs of complex health service and public health interventions. The research will involve several components. Firstly, RCTs included in the Cochrane Effective Practice and Organisation of Care (EPOC) Review Group register will be systematically reviewed. For studies including qualitative components, data will be extracted on how the qualitative and quantitative findings were combined. A narrative overview of current practice in this area will then be produced.

Secondly, qualitative case studies will be developed of ongoing or recently completed RCTs that included qualitative components. For each study, the investigators will be interviewed to explore the development of the study; the reasons for mixing methods; and the facilitators and barriers to integrating qualitative approaches. Thematic and discourse analysis will be used to identify key issues from these case studies. Drawing on this data, a typology for mixing both methodological approaches and data collection methods in RCTs will then be developed. Finally, draft guidelines for mixing methods in complex RCTs will be compiled. These will be refined using formal consensus development methods.

We believe that this research will contribute to improving the quality of evaluations of health service and public health interventions and, in particular, their relevance to policy makers, consumers and health care providers. To aid the dissemination of the project findings, we hope to incorporate the guidelines on mixing methods into an online tool being developed to support developing country researchers with the design, conduct and analysis of pragmatic RCTs. This online protocol support tool is being developed through Practihc (Pragmatic Randomised Trials in Health Care) - a European Union funded network based in the Department of Health Services Research, Oslo (www.practihc.org).

Work on the mixing methods project will start early this year. For further information please email Simon.Lewin@lshtm.ac.uk.

Information at hospital discharge: the story of one Cochrane review

by Anne Johnson and Jayne Sandford

Anne Johnson and Jayne Sandford's review

Written and verbal information versus verbal information only for patients discharged from acute hospital settings to home was published on Issue 4 2003 of the Cochrane Library. This was notable for being the first review completed for our Group by an Australian team. For our newsletter, Anne and Jayne describe their experience of undertaking this review.

We were working on a hospital project which was related to the provision of written health information to consumers being discharged from hospital. We wanted to ensure what we were planning was based on current evidence, but couldn't find a systematic review that provided the evidence as to whether providing written health information and verbal information to consumers made a difference at all. At the time of these deliberations we received the May-June 2001 newsletter from the Cochrane Consumers and Communication Review Group. There was a call for people to adopt an orphan review, one of which was "supplying care advice and instructions for consumers when leaving hospital". We decided to adopt this orphan review and began an incredible journey of learning the "Cochrane way".

It has been a great experience for us both. We were keen to learn more about doing a systematic review and critiquing the trials that came up through that review. We attended one training program (run by the Australasian Cochrane Centre) when we were writing up the protocol. This was extremely helpful. We would have liked to attend further training when we were writing up the review, but work commitments prevented that from occurring. We found the support of the review group coordinators and the comments by the peer-reviewers really helpful.

Despite a very thorough systematic review of the literature we only found two trials that met our inclusion criteria, and both related to providing information to parents of children being discharged from hospital. Hence our conclusions are guarded, but we found that providing consumers with written and verbal information on discharge from hospital to home does improve satisfaction and knowledge when compared to

verbal information only. We found it interesting that the measures of both trials related to what professionals wanted to measure, not what consumers would consider important as well. This area really is a greenfield for further research.

Having just published the review, we aren't sure whether we will do a second review or not. Time will tell! We can highly recommend doing a review - it is a great experience and you learn a lot.

COLLABORATION NEWS IN BRIEF

CCInfo

Anyone with an interest in the Cochrane Collaboration's activities is encouraged to subscribe to CCInfo. CCInfo is the primary email list for The Cochrane Collaboration. It offers an excellent means of keeping members of the Collaboration well informed about the activities and policies of the Collaboration. The goal is that every Cochrane participant with access to email will be a subscriber.

The list is now moderated (all items will be checked for suitability before being distributed to subscribers). This means you can subscribe with the confidence that you will not waste time with irrelevant material. The list will be used for announcements and discussion of matters relevant to the Collaboration as a whole.

To subscribe, send an email (from the address you normally use) to ccinfo-list-request@mailman.mcmaster.ca. The content of your message is simply: "subscribe". That's it. Don't fill in the subject or add a signature. Send it. Subscription is free.

AusInfo

AusInfo is run by the Australasian Cochrane Centre and is the main list for news of Cochrane activities in Australasia and South East Asia. Like CCIInfo, AusInfo is a moderated list. It contains announcements of training events, meetings, national or regional initiatives, funding opportunities, and local stories about Cochrane. This list has a web interface which is the preferred means of subscribing, unsubscribing, accessing the list archive, and setting options:

<http://cochrane.de/mailman/listinfo/ausinfo>

Proposed Childhood Cancer Review Group (ChCRG)

An exploratory meeting for the proposed Childhood Cancer Review Group is being held in Amsterdam in February 2004. Interested parties should contact the proposed Coordinating Editor, Leontien Kremer, at l.c.kremer@amc.uva.nl

European Cochrane Contributors' Meeting 2004

The Dutch Cochrane Centre will host the next annual meeting of continental European contributors to the Cochrane Collaboration, from 12-14 May 2004. Please contact the Dutch Cochrane Centre (cochrane@amc.uva.nl) for further information.

12th Cochrane Colloquium 'Bridging the Gaps', Ottawa, Canada

The next Cochrane Colloquium will be held from 2-6 October 2004 in Ottawa. Early bird registrations close on 14 June. Staff from the Consumers and Communication Review Group will be in attendance and we are particularly looking forward to meeting our many Canadian members. For further information see www.colloquium.info

2nd International Conference on Shared Decision Making, Swansea: Conference Report

by Adrian Edwards (Adriangedwards@btinternet.com)

The Swansea Department of Primary Care can probably claim to have just had its first birthday. Many of you will know Glyn Elwyn. He started up the Department in Autumn 2002, and we have had various new members join over the past year. As would be expected in starting afresh, there has been much to learn, plenty of good times to enjoy, a few challenges, and some significant events. Probably the main event was the 2nd International Conference on Shared Decision Making, held in Swansea in September 2003. We were delighted with the turnout, approximately 200 delegates from around the world. No doubt they were attracted in equal measure by the opportunity to hear keynote addresses from Annette O'Connor and Al Mulley (each leading lights in the field from North America) and the prospects for informal networking whilst walking the beach outside the conference venue (and our offices!). Of course, with this theme of research being closely allied to the interests of the Consumers and Communication Review Group, other editors from the Group were there as well.

A number of topic areas remain inadequately addressed and provide opportunities for further work including systematic reviews - ask the editors for advice if you are interested. But the other outcome that has emerged from the conference, and which involves many people from around the world including several other members of the Review Group, is a collaborative Delphi consensus process towards the establishment of quality criteria for decision aids. Many groups are examining different elements of decision aids with a view to proposing quality criteria for consideration by an international group of stakeholders. If you want to be involved, or think you should be a stakeholder as you have an interest in this area of communication support in health care, then please contact Dawn Stacey at Ottawa (dstacey@ohri.ca)



If you would like to become a member of the Cochrane Consumers and Communication Review Group (free of charge!) please contact Megan Pictor (m.pictor@latrobe.edu.au) at the address on the front of this newsletter, or go to www.latrobe.edu.au/cochrane/ Please remember to let us know if you are changing address!