

Cochrane Consumers and Communication Review Group



Cochrane Consumers and
Communication Review Group
Australian Institute for Primary Care
La Trobe University 3086 Victoria
AUSTRALIA
Ph +61 3 9479 5779
Fax +61 3 9479 5977
www.latrobe.edu.au/cochrane/
email: cochrane@latrobe.edu.au

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 52 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.

Sophie Hill sophie.hill@latrobe.edu.au
Coordinating Editor

Megan Pricor m.pricor@latrobe.edu.au
Review Group Coordinator

John Kis-Rigo j.kis-rigo@latrobe.edu.au
Trials Search Coordinator

Rebecca Ryan r.ryan@latrobe.edu.au
Research Fellow

Helen Dilkes hkn@latrobe.edu.au
Research Officer

Dianne Lowe d.lowe@latrobe.edu.au
Research Officer

**Josip Car, Adrian Edwards, Claire Glenton,
Dell Horey, Simon Lewin, Brian McKinstry,
Sandy Oliver, Nancy Santesso, Michel Wensing**
Editors

Andrew Herxheimer
Feedback Editor

From our Coordinating Editor, Sophie Hill

Our Cochrane group has had a strong year
with some great reviews being published and interesting
protocols coming through (details inside). Many people
probably do not realise that so much of this work is done
voluntarily - by authors and certainly by our wonderful
editorial team. Worldwide interest in 'patient-centred' care
models indicates to me that this work will continue to play
an essential role in guiding and informing decisions about
improving health services for consumers and carers.

We have been experimenting with systematic
review methodology for questions other than effectiveness.
Rebecca Ryan, our Research Fellow, is the lead author of a
review that will nest a review of studies of people's
experiences within a Cochrane review of effects. The
protocol for this review will be published on *The Cochrane
Library* issue 1 2009: "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).

Another project with innovative methods is
our work for the Canadian Agency for Drugs and
Technologies in Health, Rx for Change database
www.rxforchange.ca. Staff responsible are Rebecca Ryan
and our Research Officer, Dianne Lowe. Rebecca has
developed methods for identifying the reporting of
multimorbidity in systematic reviews on interventions
directed to consumers on prescribing and medication use.

For four months this year we were very fortunate to have Carrie Kaufman work with us on the Rx for Change project. Carrie is a final year medical student from University of Massachusetts Medical School (see profile inside). Carrie also helped us prepare several papers for submission (on heart risk communication formats, on our overview methods). As we spend a lot of our time helping other people get their work published, it was wonderful to have Carrie help us get our work into publication.

For several years I have been working with the Cochrane Co-ordinating Editors' executive

group on an organisational project to develop an editorial board for the Collaboration and to establish the new position of Editor in Chief. The work came to fruition this year with the formation of the Cochrane Co-ordinating Editors' Board. Even more exciting is that Dr David Tovey will commence as Editor in Chief early in 2009. David is currently Editorial Director, BMJ Evidence Centre, in the BMJ Group.

I wish to thank our Review Group staff and editorial team for their hard work and good advice, and thank those bodies who fund our work for their continued support. I wish you all a Happy Christmas and a safe and peaceful New Year.

Review Group News from Megan Pricor

Welcome to new staff member

John Kis-Rigo joined us as our new Trials Search Coordinator in July 2008. John was previously at the University of Ballarat and before that at Charles Darwin University in the Northern Territory. John can be contacted at j.kis-rigo@latrobe.edu.au

We encourage authors who are developing their search strategies, or revising search strategies in preparation for an update of their review, to contact John for advice.

RevMan 5 and a new edition of the Cochrane Handbook

This year has seen a major and mandatory upgrade of RevMan to version 5. There's a new, more user-friendly interface that lets users work in a single document that is easily shared with co-authors and editors. Track changes functionality and a new note system facilitates the task of multiple authors working together on a review. RevMan 5 works on multiple platforms, including Windows, Macintosh and Linux.

Cochrane reviews have been expanded to include optional Summary of Findings tables and utilise a new Risk of Bias tool for assessing the methodological quality of included studies. A major upgrade of the Cochrane Handbook for Systematic Reviews of Interventions has accompanied the changes to RevMan 5.

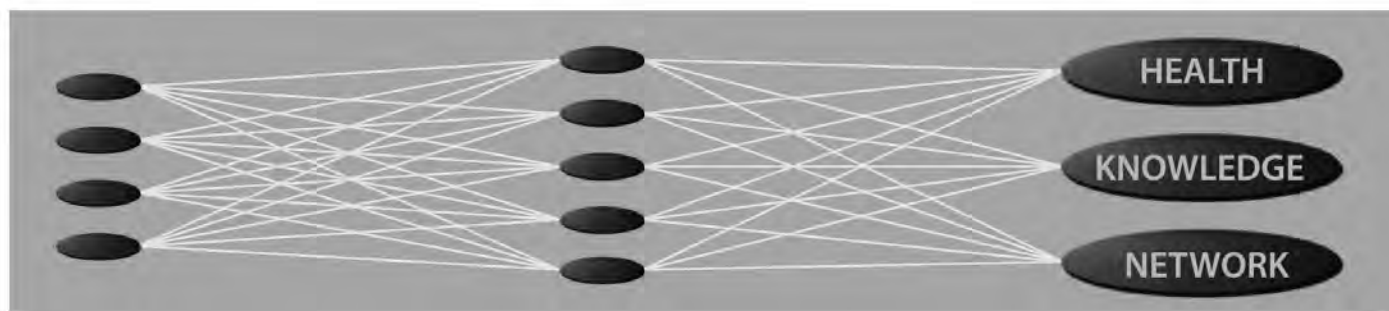
Authors should take a look at the Consumers and Communication Group's Data Extraction Template (available online) which has been updated to reflect the new Risk of Bias tool.

For more information please contact the Review Group at cochrane@latrobe.edu.au

Congratulations to our editor Josip Car on his recent marriage, and to Michel Wensing on his new house!

New Statistics Editor

We're very pleased to announce the appointment of Jo McKenzie as our new Statistics Editor. Jo will be assisted by Veronica Pitt; both are at the Australasian Cochrane Centre. Our grateful thanks to outgoing Statistics Editor Damien Jolley and assistant Kelly Allen for their wonderful work for us over the past three years.



HEALTH KNOWLEDGE NETWORK – BULLETIN SERVICE EVALUATION

By Helen Dilkes

Introduction

In June 2008 Health Knowledge Network members were invited to participate in an online questionnaire to evaluate comprehensibility, accessibility and reach of the Network's Bulletin service over the previous 12 months. In total 41 people responded to the questionnaire.

RESULTS

Comprehensibility and Accessibility

A majority of respondents read the one page summary and find it most useful—the cover page that outlines the focus of the review (review's interventions) and results (outcomes). Around half of respondents read the middle page (outlining review content and contextualising results). Around one third read all 3 sections and find them most useful—summary, middle pages and detailed technical information in the 'evidence table' on the final pages.

A large majority of respondents say Evidence Bulletins are clear and that the balance of information is right. Over half of respondents say Evidence Bulletins are not too long and technical while a quarter say they are somewhat long and technical.

All respondents receive the Bulletins from the Network via email. Most respondents know how to gain access to the source systematic review in *The Cochrane Library*.

Audience—Reach of Bulletin Service; forwarding or knowledge brokerage

Half of the 41 respondents were from hospital or university contexts and smaller numbers were from consumer groups or government departments, or from community health services, NGOs, or private health providers.

A majority of respondents forward Bulletins via email to colleagues in their organisation or to other networks; and only forward to people who are particularly interested in the topic (communication and participation) eg. researchers, consumer advocacy groups, consumers, managers, community participation team, health promotion workers, cancer advocacy workers, or policy makers.

Usefulness of Resource Bulletins

Most respondents say Resource Bulletins are useful; it "keeps issues on the agenda" or it is "very useful to know what is going on in Cochrane". Electronic links are considered a vital part of Resource Bulletins.

CONCLUSION

More people than we expected read more than the 'actionable' messages and more than expected read information from within the review. Brief summary statements in Bulletins are important but these results also suggest that some people need more detailed information from a review.

The Network's Bulletin service reaches a broad cross section of interested users, however there could be greater emphasis on reaching consumer advocacy groups in future knowledge transfer endeavours.

To join Health Knowledge Network, contact:
Helen Dilkes, Research Officer, email
hkn@latrobe.edu.au

REVIEW GROUP ACTIVITIES 2008

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

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, January to November 2008

- Communication with and support for people with Creutzfeldt-Jakob disease (CJD) and their families and carers (Rebecca Ryan, Australia)
- Effects of varying communication in the patient-practitioner relationship (William Verheul, The Netherlands)
- Interventions for enhancing adherence to dietary recommendations (Sophie Desroches, Canada)
- Interventions for supporting informal caregivers of patients in the terminal phase of a disease (Bridget Candy, UK)
- Mass media interventions for reducing mental health-related stigma (Sarah Clement, UK)

Protocols Published, *The Cochrane Library*, 2008 (issue 1 to issue 4)

- Peer support telephone calls for improving health (Jeremy Dale, UK)
- Interventions for enhancing the skills of consumers to find, evaluate and use online health information (Anthea Colledge, UK)
- Consumer-oriented interventions for evidence-based prescribing and medicine use: an overview of Cochrane reviews (Rebecca Ryan, Australia)
- Interventions for promoting the use of advance directives for end-of-life decisions in adults (Pablo Simón-Lorda, Spain)

- Mobile phone messaging for communicating results of medical investigations (Josip Car, UK)
- Mobile phone messaging for preventive health care (Vlasta Vodopivec-Jamsek, Slovenia)
- Mobile phone messaging reminders for attendance at scheduled healthcare appointments (Josip Car, UK)
- Mobile phone messaging telemedicine for facilitating self management of long-term illnesses (Josip Car, UK)
- Visual feedback of the individual's medical imaging results for changing health behaviours in clinical and non-clinical populations (Gareth Hollands, UK)
- Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours (Theresa Marteau, UK)
- Shared decision making interventions for people with mental health conditions (Eddie Duncan, UK)

Reviews Updated, *The Cochrane Library*, 2008 (issue 1 to issue 4)

- Interventions for improving communication with children and adolescents about their cancer (Rita Ranmal, UK)
- Interventions implemented through sporting organisations for increasing participation in sport (Naomi Priest, Australia)
- Policy interventions implemented through sporting organisations for promoting healthy behaviour change (Naomi Priest, Australia)
- Recordings or summaries of consultations for people with cancer (Marie Pitkethly, UK)
- Interventions for enhancing medication adherence (Brian Haynes, Canada)

Reviews Published, *The Cochrane Library*, 2008 (issue 1 to issue 4)

- o Audio-visual presentation of information for informed consent for participation in clinical trials (Rebecca Ryan, Australia)

Plain Language Summary

Informed consent is important for people who are thinking about participating in a clinical trial. Information for informed consent could be presented on the Internet, DVD, video cassette or by other means.

We conducted thorough searches for randomised and quasi-randomised controlled trials of information about trial participation that contained some audiovisual component compared with standard information (such as written or oral information as usually provided in the particular setting). We found four relevant studies, all set in the USA and Canada. The four studies varied in terms of the design and type of the audio-visual information, its content and delivery, the people participating in the informed consent study and the different ways of measuring outcomes. While study quality was mixed, three of the studies attempted to minimise at least some sources of potential bias.

Uncertainty remains about the effects of audio-visual information for informed consent, compared with standard forms of information provision, for people thinking about participating in a clinical trial. All four studies assessed knowledge and/or understanding of the trial to which people's informed consent was being sought. Audio-visual interventions did not consistently increase participants' levels of knowledge/understanding, although one study showed better retention of knowledge amongst intervention recipients. One study showed that an audio-visual intervention could briefly increase people's willingness to participate in trials, but this was not sustained two to four weeks post-intervention. The audio-visual intervention did not affect people's views of the worth of the trial they were considering joining (one study). Another study found that an audio-visual intervention may enhance the quality of the information conveyed to participants. Many outcomes including possible harms were not measured.

- o Peer support telephone calls for improving health (Jeremy Dale, UK)

Plain Language Summary

Telephone peer support is widely available through helplines but its impact on health outcomes and health-related behaviours is largely unknown. We examined the effects of peer support telephone calls on physical and psychological health and on health behaviours. Seven randomised controlled trials conducted in the USA, UK, Canada and Australia related to a range of conditions and target populations. They provided some evidence of efficacy. Peer support telephone calls may increase mammography screening in women over 40 years, may help patients change their diet and cease smoking after a heart attack; and may help reduce depressive symptoms among mothers with postnatal depression. Findings need to be interpreted cautiously. There is a need for well designed randomised controlled studies to clarify which elements of peer telephone interventions work best to improve health and health-related behaviour.

NEW REVIEWS IN THE PIPELINE

Reviews we expect to publish in 2009 include:

- o Interactive computer-based interventions for sexual health promotion (Julia Bailey, UK)
- o Interventions for improving understanding and minimising the psychological impact of screening (Jenny Doust, Australia)
- o Negative versus positive framing of health information (Elie Akl, USA)
- o Using different statistical formats for presenting health information (Elie Akl, USA)
- o Written information about individual medicines for consumers (Donald Nicolson and Peter Knapp, UK)
- o An update of Hróbjartsson and Gøtzsche's review of Placebo interventions for all clinical conditions
- o An update of O'Connor's Decision Aids review (Issue 1 2009)

Making better use of Cochrane reviews

By Dell Horey

The primary goal of a Cochrane review is to ask whether an intervention is effective and, rightly, this aspect of a review gets the most attention. Yet while Cochrane reviews can't always answer the question of effectiveness that has been asked (need more research!) they can usually offer a lot more than many expect. But you need to look past the 'bottom line' as the importance of Cochrane reviews as a resource for academics, evaluators, policy-makers and students is often overlooked. The enormous value of Cochrane reviews, particularly those looking at complex interventions need to be given more attention. There is a lot of meat on those bones!

Each protocol and review presents systematic thinking in a topic area. There are now more than 5500 peer-reviewed bodies of work that cover a broad range of topics. An enormous amount of thinking has built up this collection and the strengths of Cochrane reviews make this thinking a particularly valuable resource. Cochrane reviews are:

- Transparent—so you can understand what has happened,
- Dynamic—so that they change over time as new knowledge is added
- Methodologically cutting-edge—as better ways to make the best use of data are introduced.

Some of the useful contributions that Cochrane reviews can add to your own thinking include:

- Frameworks for approaching new topics or conceptualising issues.
- Access to the decisions that others have taken such as:
 - Who to include and exclude as participants
 - Definitions used
 - How interventions and outcomes might be categorized
 - What outcomes and comparisons to use.

The completed reviews demonstrate the success of these decisions in interpreting the available research evidence and delivering meaningful outcomes.

In addition, Cochrane reviews give an assessment of the quality of current research and identify gaps. In some areas you can compare different reviews for comparison of different approaches that can be used.

The wealth of information in Cochrane reviews is particularly important in those areas of research that involve complex interventions. Often these are new areas of study and there may be no established consensus. A systematic approach to these issues is an important step and become a reference point for future work.

We just need to look at what is sitting under our noses!

DID YOU KNOW...

...that the Consumers and Communication Group handsearches each issue of *The Cochrane Library* for systematic reviews that are relevant to our work, but published by other Review Groups. These are incorporated in our online Resource Bank, which is hyperlinked to *The Cochrane Library*. Recent examples of relevant reviews that have been listed in our Resource Bank include:

- Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups (Hawthorne K, Robles Y, et al).
- Information provision for stroke patients and their caregivers (updated) (Smith J, Forster A, et al.)
- Strategies for communicating contraceptive effectiveness (Lopez LM, Steiner M, et al)

Short course at Master's level: Evidence for policy, practice and personal decisions

Led by Sandy Oliver and Ruth Stewart

This course is designed for people in public or voluntary sector organisations that are, or aspire to become, research informed.

On successful completion participants are able to conduct and use research collaboratively in order to promote change for better health, education or social well-being.

The course is built on a thriving programme about diverse perspectives and participation in research and policy. Public involvement in research, practitioners' action research and evidence-informed policy-making have different histories, different styles and different supporters. Yet they are all facets of stakeholder involvement in the whole research cycle and there are lessons to be shared between them. We have drawn on them all, and more, to examine the perspectives of users and potential users of research, and their participation in decisions about policy, practice and research.

We have worked 'upstream' with research managers, patients, families, carers and their advocates to develop ways of supporting public input into decisions about what research is commissioned. 'Downstream', we have worked with health clinicians, laboratory scientists, NHS managers and people who use health services to develop evidence-informed policy. All this work is informed by systematic reviews and primary research about how to involve service-users in research and about their perspectives on policy developments.

We are now using our experience, and the wider literatures by and for academics, health services and service users, to offer a short course on doing and using research that includes multiple perspectives and maximum participation. Participants critically engage with the latest theories and debates about the relevance and application of research findings for policy, practice and personal decisions. They also develop practical skills for working together in mixed teams to apply their learning to their own interests.

Teaching is centred on four one-day workshops and aims to:

- appraise the research literature about bridging the gaps between research and policy, practice or personal decisions
- consider the research needs of policy makers, practitioners and personal decision-makers
- explore mechanisms for encouraging research based policy, practice and personal decisions
- explore mechanisms for supporting policy maker, practitioner and public service user involvement in research

It can also be taken as part of MSc Evidence for Public Policy and Practice. The next start date is March 2009 when there are four one-day workshops (fee: £654)

For more information please contact:

Kim Reynolds
+44 (0)20 7612 6280
K.Reynolds@ioe.ac.uk
<http://eppi.ioe.ac.uk/MSc/eppp>

Profile: Carrie Kaufman

Carrie Kaufman is a medical student from the University of Massachusetts in the United States. She recently spent several months working with the Consumers and Communication Review Group in Melbourne on a variety of projects. These included compiling primary literature investigating interventions directed toward consumers of prescription



medications as well as analyzing and writing up focus group data looking at different formats for presenting cardiovascular risk to patients. Carrie is going into the field of Obstetrics and Gynecology, a specialty where the ability to communicate effectively with patients is of tantamount importance. She was very excited to work within the Cochrane system, as she frequently relies on Cochrane reviews during her day-to-day practice of medicine. In addition to her contributions to the Consumers and Communication Group's work, Carrie also introduced the Group to the sport of roller derby, which is alive and well internationally, as evidenced by the Victorian Roller Derby League right here in Melbourne.

Cochrane Colloquium 2008

Five of our staff and several editors attended this year's Cochrane Colloquium in Freiburg, Germany. The Group had a strong presence, presenting a workshop on reviews of complex interventions, four posters (see below), and holding an open meeting for interested parties. We also held editorial meetings, participated in meetings with a cross-Collaboration focus such as the RGC, TSC, Co-Eds and various committee/advisory group meetings, and enjoyed the social activities. Here's the evidence:



Rebecca Ryan discussing her poster on mixed-method reviews.



Simon Lewin, Sophie Hill, Rebecca Ryan, Helen Dilkes, Megan Prictor (left to right)

The posters we presented in Freiburg are available on our website:

- Pilot induction and mentoring programme for new RGCs.
- Linking a qualitative review and a Cochrane intervention review.
- Education and support for improving the evaluation of consumer participation in hospitals.
- Evaluation of Evidence Bulletin knowledge transfer.

Upcoming Conferences

5th International Shared Decision Making Conference

14 to 17 June 2009

Boston, USA

<http://www.informedmedicaldecisions.org/isdm2009/>

The 4th International Conference on Patient- and Family-Centered Care

17 to 19 August, 2009

Philadelphia, USA

<http://www.familycenteredcare.org/events/index.html>

International Conference on Communication in Healthcare

4 to 7 October 2009

Miami Beach, USA

<http://www.aachonline.org/programs/internationalconference/>

Cochrane Colloquium 2009

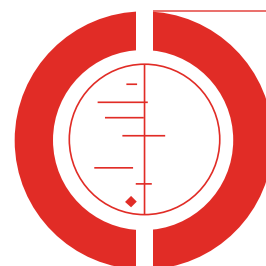
11 to 14 October 2009

Singapore

<http://www.cochrane.org.au/colloquium2009/singapore.htm>

To join the Review Group or update your address details, please contact Megan Prictor at cochrane@latrobe.edu.au or visit www.latrobe.edu.au/cochrane/

If you receive the newsletter by post and would prefer to receive it by email, please let us know.



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