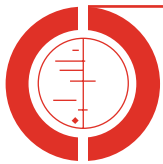


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Cochrane Consumers and Communication Review Group



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COLLABORATION®

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 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 of placebo effects.

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From our Coordinating Editor, Sophie Hill

A theme in my work this year has been to understand and talk about the relevance of Cochrane reviews. I find it is not enough just to coordinate their production with Megan Prictor and Judy Stoelwinder - their relevance needs explaining. People do not automatically see the value of reviews of interventions designed to improve people's interactions with the health system and its providers. I am not sure why this is so. Perhaps it is partly because problems with communication are not thought to lead to deterioration in health outcomes. We recognize that better communication is a legitimate aspiration of consumers and providers, but there is not a consensus on how real improvement, using 'strong' evidence of effectiveness of specific approaches or interventions, could occur, nor in what ways it could benefit us.

Given this, I read with great interest an article by Allen Fremont and colleagues, titled 'Patient-centered processes of care and long-term outcomes of myocardial infarction' published in the Journal of General Internal Medicine (2001,16:800-08). It is a report of an observational cohort study of people with acute myocardial infarction (heart attack) who live in New Hampshire, USA. The authors

were interested in whether 'non-technical aspects of care ... such as education about their condition, emotional support, and discharge about their planning', ie. patient-centred processes of care, were associated with recovery from heart attack and improvement in longer term health outcomes (p.800). Using the Picker inpatient questionnaire, they defined patient-centred care as having seven dimensions: respect for patient preferences, coordination of care, information and education, physical comfort, emotional support, involvement of family and friends, and continuity and transition. Patients reported whether specific activities had occurred associated with each of these dimensions. Their responses were used to calculate a problem score. When problem scores were in the top quartile, this was defined as 'worse care'.

In short, the findings were that patients who experienced worse care had poorer outcomes, measured over one year. Outcomes reported were overall health, mental and physical health, and odds of having chest pain or shortness of breath. The findings were not trivial. The authors write: 'patients who experienced both worse hospital and subsequent ambulatory care were nearly twice as likely to report chest pain one year after their myocardial infarction' (p.804).

I was very struck by this report, not only because of the findings but also because of a subtler message. Findings first: readers may want to look at three Cochrane reviews, authored by teams led by Anne Johnson, Simon Lewin, and Annette O'Connor, to see summaries of the effects of (respectively) written discharge information, training for doctors in patient-centered care, and decision aids.

The subtler message for me, though, was that we needed to make clearer the links between the sorts of problems that consumers have been reporting for a long time, and the rationale for, and findings of, systematic reviews. I don't think this connection is made sufficiently explicit. There are some ways we could do this. First, we have to make a series of connections: between the sorts of communication problems that consumers report, with the costs of communication failure (the consequences of the problem), with the range of interventions (solutions) that have been developed. This is what I plan to do next.

In order to get clear in our minds which interventions appear to lead to improvements in interactions, we are summarising the findings of several systematic reviews of related interventions, grouped logically into themes. For example, one theme is 'being informed and making decisions'. Our new research officer, Rebecca Ryan, has been piloting an approach to

summarising the results of several reviews. This will give us an overview that enables us to report on what we know about how people can become more informed or more involved in their care.

From this, I hope that it is easier to assist policy makers to think about, and then develop standards and performance indicators around effective approaches to interacting with consumers. I am concerned to avoid a situation where only resource-rich people/services/countries avail themselves of the benefits of the emergent evidence base of effective communication strategies. If the evidence is not transferred to practice in a system-wide approach, then the benefits will not be shared.

Review Group News from Megan Pricor

Introducing new staff:



Rebecca Ryan (above) joined the Consumers and Communication Review Group in April. Rebecca's background is in medical research, and she completed her PhD in neuropharmacology in 2002. Since then, Rebecca has been active in the field of evidence-based practice and research in Melbourne. She has worked as a research officer into clinical effectiveness at the Monash Institute for Health Services Research, and on a casual basis for the Australasian Cochrane Centre. Work as a medical writer/editor allowed her to pursue her interest in the area of effective communication of health-related information to consumers.

Rebecca is involved in a number of projects within the Review Group. She is a co-author on two reviews currently in preparation ('Interventions for preparing children and adolescents for hospital care' and 'Informational video for potential participants of clinical studies used in the process of seeking informed consent'). She also assists in a support role for other reviewers associated with the Group. Rebecca is currently involved in the construction of a database of "communication-type" interventions, based on the work of the Consumers and Communication Group and others. She will also take a supportive research role in the Victorian Quality Council project being coordinated and implemented by the Review Group.

While this seems to keep her relatively occupied, Rebecca has just moved from Melbourne and is currently in the process of adjusting to life in wine-growing country. In her spare time she enjoys reading, etching, painting, yoga and travel.



Angela Melder (*above*) joined the Consumers and Communication Review Group in May. Angela has a medical research background and worked in Melbourne and Darwin before moving to public health research. She completed a Master of Public Health based at the Menzies School of Health Research in Darwin and was involved in Indigenous health research for a number of years. She has worked with Indigenous communities across the Top End of the Northern Territory with a specific focus on child health. Following this work, Angela was involved with a project that examined the epistemological debates associated with research methods.

Angela has now commenced work on a new project with the Consumers and Communication Review Group which has consolidated her strong interest in research dissemination, and making connections with community members and health practitioners. This project, supported by the Victorian Quality Council, focuses on the communication issues in three Victorian health services. The three sites are: the Royal Women's Hospital, Broadmeadows Health Service, and Southern Health. The project aims to develop a systematic approach to incorporating into quality improvement activities, the evidence of effectiveness of interventions that address communication issues. A further project objective is to develop a decision making manual for hospitals, which documents models of an evidence-based approach to addressing communication issues, and therefore provides hospital staff with knowledge and skills to identify evaluated interventions to address these issues in the hospital setting. It is planned that this exercise will put in place strategies that can aid in addressing communication problems in hospitals and health services, which could bring about improved and positive outcomes.

Dr. Sandy Oliver to visit Melbourne

We are thrilled that Dr. Sandy Oliver, an editor for the Group, has been awarded an Associate Fellowship from La Trobe University's Institute for Advanced Study, for 2005. Dr. Oliver will be visiting the University for two months (mid-October to mid-December 2005), coinciding with the Melbourne Cochrane Colloquium.

During her visit she will be focusing on a project to advance methods for studying public involvement in research. This is designed to improve the way we undertake democratic and participative means to involve members of the public in researching health care and health treatments. The project will be undertaken by systematically reviewing evaluations of public involvement in research, drawing from specialised databases of reports of Australian and international research and projects. It will provide information on the benefits and harms associated with past activities, and inform future evaluation and research. Sandy will also speak at several seminars in Melbourne during her visit.

Local Presentations

Over the past few months, Sophie and Megan have presented information about the Cochrane Collaboration, the Cochrane Library and the Consumers and Communication Review Group to a range of local audiences including the School of Public Health, La Trobe University - both Bundoora and Bendigo campuses - and the Department of Human Services, Melbourne. If you think a presentation on some aspects of the Group's work would benefit your organisation, please let Megan know.

New Cochrane Contact Database

The Consumers & Communication Review Group has changed the way in which it stores members' contact details. These used to be held in a MS Access database in the Group's editorial office. The entire Cochrane Collaboration is in the process of transferring the contact details of people active in the Collaboration to a single, password-protected web-based Contact Database: www.cochrane-net.org/contact Among the benefits of this change is that people active across a number of entities now only have to inform one entity of a change in their details.

The Database contains contact and membership information for individuals and groups involved with the Cochrane Collaboration. The data for entities and their members are maintained by the entities themselves. Since the Database runs on a central server, whenever an update is made, it is instantly available for other users. The Cochrane Collaboration is committed to handling contact information responsibly, and aims to respect all privacy concerns. The Cochrane Collaboration will never transfer or sell members' details to third parties.

If you wish to know if data about you are stored in the system, you can contact Megan Pricor (m.pricor@latrobe.edu.au). You can also request a report on the data stored about you.

New arrival

Congratulations to our editor Dr. Michel Wensing and his partner Carla on the birth of their son Bas, on 21 April 2004.

REVIEW GROUP ACTIVITIES FEBRUARY 2004 - AUGUST 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 (or national access) can view free abstracts (and purchase individual reviews) at <http://www.update-software.com/Cochrane/>

Titles Registered

February 2004 - August 2004

Calendar packaging aids for patients to improve adherence to self-administered long-term medications
Heneghan C (UK), Glasziou P, Perera R

Educational interventions for general practice trainees to improve their communication skills in the clinical consultation

Van Nuland M (Belgium), Hannes K, Goedhuys J, Aertgeerts B

Educational programs on organ donation for high school students

Piccoli G (Italy), Mezza E, Soragna S

Interventions utilizing marketing strategies for promoting healthy eating behaviours in young people
Duxbury H (UK), Pit S, van Binsbergen JJ, Yanagi M

Protocols Published, The Cochrane Library, Issues 2 - 4 2004

Calendar packaging aids for patients to improve adherence to self-administered long-term medications (Issue 4 2004)

Heneghan C (UK), Glasziou P, Perera R

Objectives: To determine the effects of calendar packaging aids as used to enhance patient adherence to self-administered long-term medication/s.

Additional objectives are: (1) to assess effects on clinical outcomes; (2) to assess cost of interventions; and (3) to assess any harms, barriers to use, and errors associated with packaging devices.

Contracts between patients and healthcare practitioners for improving patients' adherence to treatment, prevention and health promotion activities (Issue 2 2004)

Bosch-Capblanch X (UK), Garner P

Objectives: To assess the effects of contracts between patients and healthcare practitioners on: (1) patients' adherence to treatment, prevention and health promotion activities; and (2) patients' health status.

Family-centred care for children in hospital (Issue 2 2004)

Shields L (UK), Davis L, Flenady V, Hunter J, Pratt J

Objectives: The primary objective of this review is to assess the effects of family-centred models of care for hospitalised children when compared to standard or professionally-centred models of care, on child, family and health service outcomes.

A secondary objective of this review is to assess whether the effects of family-centred models of care for hospitalised children, when compared to standard or professionally-centred models, differ according to: (1) degree of family-centredness; and (2) population of children.

Group visits as part of ongoing care for improving health (Issue 3 2004)

Epling J (USA), Smucny J, Bailey E, Schultz J

Objectives: To evaluate the effectiveness of group visits with a clinician as compared to traditional, one-to-one clinician visits for chronic disease management and/or clinical preventive services.

Interventions organised by sporting organisations for increasing participation in sport (Issue 2 2004)

Howes F (Australia), Doyle J, Waters E, Jackson N

Primary objectives: To determine the effects of interventions implemented through sporting organisations for increasing (active and non-active) participation in organised sport.

Involving service users as researchers for the evaluation of adult statutory mental health services (Issue 2 2004)

Simpson E (UK), House A, Barkham M, Gilbody S

Objectives: We aim to find existing evidence regarding any positive or negative effects of user involvement in mental

health service evaluation research, on the research conducted. These will include data on design and conduct of research, as well as research results such as response rates and also research findings.

Involving service users as service providers for adult statutory mental health services (Issue 2 2004)

Simpson E (UK), House A, Barkham M, Gilbody S

Objectives: We aim to find existing evidence regarding any positive or negative effects of user employment as providers of mental health services. Evidence is sought on the outcomes of involvement for clients (those receiving services). These effects comprise health effects and psychosocial outcomes. Service provision outcomes, such as time spent by employees on various tasks, or times and locations of meetings with clients will be sought, as will data regarding service use such as drop-out rates.

Involving service users as trainers for professionals working in adult statutory mental health services (Issue 2 2004)

Simpson E (UK), House A, Barkham M, Gilbody S

Objectives: We aim to find existing evidence regarding any positive or negative effects of user involvement in mental health service delivery as trainers of mental health professionals. Evidence is sought of the outcomes of involvement for those trained by user-trainers, such as skills developed.

Policy interventions implemented through sporting organisations for promoting healthy behaviour change (Issue 2 2004)

Howes F (Australia), Doyle J, Waters E, Jackson N

Primary objectives: To determine if policy interventions implemented through sporting organisations instigate and sustain healthy behaviour change within the sport setting. To determine if policy interventions implemented through sporting organisations instigate and sustain changes in attitudes, knowledge or awareness of healthy behaviour or intention to change behaviour within the sport setting.

Reviews Published, The Cochrane Library, Issues 2 - 4 2004



Disclosing to parents newborn carrier status identified by routine blood spot screening (Issue 4 2004)

Oliver S (UK), Dezateux C, Kavanagh J, Lempert T, Stewart R

No guidance is available on the best approach to disclosing to parents newborn carrier status inadvertently identified by routine newborn blood spot screening.

Newborn screening programs may inadvertently identify infants who are unaffected by serious in-born errors such as sickle cell disorders or cystic fibrosis, but who are genetic carriers. This will not affect the health of the child but may have important health, social and/emotional effects on the family. No trials were found about the impact or effects of disclosing newborn carrier status. There is an urgent need to develop clear guidance as how best to communicate this information effectively.

Interactive Health Communication Applications for people with chronic disease (Issue 4 2004)

Murray E (UK), Nazari I, Lai R, Tai S

Interactive Health Communication Applications for people with chronic disease have benefits and harms.

People with chronic disease have multiple needs, including information about their illness and the various treatment options; social support; support with making decisions; and help with achieving behaviour change, for example changes in diet or exercise. Computer-based programmes which combine information with on-line peer support, decision support, or help with behaviour change may be one way of meeting these needs, and helping people achieve better health. This review sought to determine the effects of such computer programmes, known as Interactive Health Communication Applications (IHCAs), for people with chronic disease. The authors found that IHCAs improved users' knowledge and perceived social support. IHCAs had no effect on users' self-efficacy or health behaviours, and users of IHCAs had worse clinical outcomes than non-users.

Placebo interventions for all clinical conditions (former title: Placebo intervention versus no treatment) (Review Update, Issue 3 2004)

Hróbjartsson A (Denmark), Gøtzsche P

No evidence that placebo treatments in general have important effects, although they may have small effects on patient-reported outcomes, for example pain.

It has been widely believed that placebo (dummy) treatments (for example sugar tablets) are associated with substantial effects on a wide range of health problems. However, this belief is not based on evidence from randomised trials that use a placebo treatment for one group of people, while another group receives no treatment. The effect of placebo treatments was studied by reviewing more than 150 such trials covering many types of health care problems. Placebo treatments caused no major health benefits, although they possibly had a small effect on outcomes reported by patients, for example pain.

Interactive Health Communication Applications the story of a Cochrane review



By Elizabeth Murray (elizabeth.murray@pcps.ucl.ac.uk)

Dr. Elizabeth Murray's review of Interactive Health Communication Applications will be published on Issue 4 2004 of the Cochrane Library. Elizabeth is based at the Department of Primary Care and Population Sciences, Royal Free and University College Medical School, University College, London (UCL).

This was my first systematic review, and I was delighted to be able to do it under the auspices of the Consumers and Communication Review Group. Everyone I had contact with in the editorial group was very generous with their time and support. This didn't mean there weren't occasional hiccups - RevMan software has a mind of its own and I don't think I could have managed it without our very own IT whizzkid, in the person of Jo Burns, the lead research fellow on the review.

I undertook this systematic review as part of a five year programme looking at the effects of Interactive Health Communication Applications (IHCAs) for patients with chronic disease on health status, health service utilisation and the doctor-patient relationship. IHCAs are computer-based, usually web-based, interactive programmes which combine health information with at least one of peer support (usually in the form of on-line chat rooms), decision support, or behaviour change support. There are numerous claims for the benefits of IHCAs in the literature: they are expected to be an effective way of informing patients about their health problems, and hence help patients to play a more active role in their health care, help with decision-making, and help promote healthy behaviours. The knock-on effects are expected to include more rational use of health service resources and better clinical outcomes. Although the e-health literature is full of claims for these potential benefits, the evidence seemed less positive, so I decided to undertake a systematic review, and was fortunate to work with an excellent and experienced team from UCL.

We searched all the major electronic bibliographic databases for published work, the grey literature for conference presentations and other unpublished work, research registers for on-going research, and contacted authors of included studies personally. We included all randomised controlled trials which had an IHCA as an intervention, for patients of all ages, with any type of chronic disease. All titles and abstracts were screened by one reviewer, two reviewers independently screened candidate studies. Included studies were assessed for quality by two independent reviewers and data were extracted by two independent reviewers. Data were synthesised using a random effects model and standardised mean differences were calculated to provide net effect sizes for the outcomes of interest.

We identified 24,757 unique citations and retrieved 958 papers for further assessment, yielding 28 RCTs involving 4042 participants. Meta-analyses revealed that IHCA improved user knowledge (SMD 0.49; 95% CI 0.14 to 0.84) and improved users' self-rated social support (SMD 0.47; 95% CI 0.28 to 0.66). IHCAs had no effect on self-efficacy or behaviour change, and had a negative effect on users' clinical outcomes (SMD -0.32; 95% CI -0.63 to -0.02).

We concluded that although the number and range of IHCAs is increasing rapidly, there is a shortage of high quality evaluative data. In the meantime, consumers who wish to improve their knowledge about their health problem, or increase their social support amongst others with a similar problem are likely to benefit

from using an IHCA. The negative effect on clinical outcomes was unexpected and is concerning. There was substantial heterogeneity in these data, suggesting that some IHCAs are helpful while others were harmful. Further research is needed to determine whether there are specific patient features (such as motivation), specific disease factors (such as the relative importance of self care), and/or specific IHCA features (eg. enhancing self-efficacy) which determine the effect of an IHCA on clinical outcomes. I hope to answer these and other questions raised by the review in my ongoing programme of research, and would be glad to discuss this work with other researchers in the field.

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 to CCInfo, 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 CCInfo, 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>

New Information Management System (IMS)



In 2005, the Cochrane Collaboration will gradually introduce a new Information Management System (IMS) to improve the process of publishing your reviews. The new IMS is an internet-based system that, among other things, will support Cochrane Collaborative Review Groups (CRGs) in preparing, maintaining and publishing Cochrane reviews. It will require small changes in the way review authors work, but will provide big benefits.

The main changes to the way Cochrane protocols and reviews are to be managed will be dealt with at the CRG level. As a review author, you will basically continue to prepare and maintain protocols and reviews as you do now. To facilitate a smooth transition, the necessary training and support will be available in the form of workshops and manuals.

The new IMS is Internet-based, and there will be a central check in/check out system, leading to easier sharing of your reviews. You will be able to send reviews directly from RevMan without having to locate the correct file and attach it to an e-mail. Central archiving and backup will protect you from data loss. There will be improved functionality for tracking changes within your review.

If you would like to find out more about the plans for the IMS, an introduction paper is available from www.cc-ims.net/download/imsg/newims.pdf.

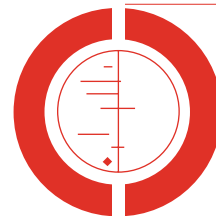
12th Cochrane Colloquium 'Bridging the Gaps', Ottawa, Canada



The next Cochrane Colloquium will be held from 2 to 6 October 2004 in Ottawa. The Group's open meeting will be held on Monday 4 October at 12.30pm. Megan and Judy will be presenting about the Group and several of our editors will be in attendance. We hope to see you there! For further information see www.colloquium.info

If you would like to become a member of the Cochrane Consumers and Communication Review Group (free of charge!) please contact Megan Prictor (m.prictor@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 your address!



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