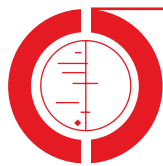


# Cochrane Consumers and Communication Review Group



THE COCHRANE  
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 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.

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## From our Coordinating Editor,

### ○ **Sophie Hill**



#### **The personal**

Eighteen years ago I left a consumer organisation I had led to have a baby. This month I will miss the Cochrane Colloquium in Keystone USA because that baby - my daughter - will be sitting her final exams. I could not imagine being anywhere but here in Melbourne but I still feel guilty for not being able to go the USA, given I am an elected member of its governing body and should be helping to represent Coordinating Editors.

Post November will be a new time for me though. How am I facing it? Well I heard the other day that Handel wrote the Messiah when he was 56 so that made me feel great. Bringing experience to bear on a problem can be a good thing I thought – and I can offer that.

The Cochrane Collaboration has deliberated a few times on the participation of women. I thought I would reflect on this in a personal way, given this milestone in my life.

I am the primary carer at home because my partner works in the film/TV industry and his standard day is 14 hours. I have worked full time for about 3 years but there were many years of part time before that. Just managing the school holidays for those years of primary school was a recurring nightmare. These experiences have made me strongly in favour of family friendly workplaces and I have tried very hard to give my team the support they needed to balance life responsibilities plus work.

One of the hidden 'dilemmas' for the Cochrane Collaboration is that much of the research we produce comes from people's voluntary labour. This is the gift of our organisation to improving health. But in societal terms, it is still the case that the majority of unpaid domestic and family work is done by women. I know that many times I have made the choice to be there in the kitchen, just in case I was needed to answer a question about homework – rather than finish that article, catch up on my emails and so on.

Do I have regrets? No. Just being able to drive my daughter to school, listen to the challenges young people face – and perhaps offer a word or two to help her keep a steady path has been its own reward.

### The political

My background is consumer advocacy. Now I am an academic and my research interest is people's experiences of health and how to improve them. I am a member of Victoria's Participation Advisory Committee and we have a consumer participation policy in this state of Victoria, titled *Doing it with us not for us*. Linked to the policy are targets and indicators, of which one is based on a Cochrane review. This is the review on decision aids led by Annette O'Connor, one of the most highly accessed reviews in *The Cochrane Library*. I am part of a team supporting Victorian health services to evaluate in the most rigorous way the effects of consumer participation interventions. I could not have imagined that this would be happening ten years ago.

When I started the job as Coordinating Editor in 2000 our group had two reviews published. In 10 years, we have helped this grow to 31 reviews, 27 protocols and 21 registered titles. I would like to thank the authors, editorial team, referees and staff who have helped to shepherd this huge body of research to fruition.

What can we dream for by 2020? Well, personally I would like to see that funding is linked in part to

services using effective ways of involving people actively in their care. Not every way of communicating is as beneficial as another.

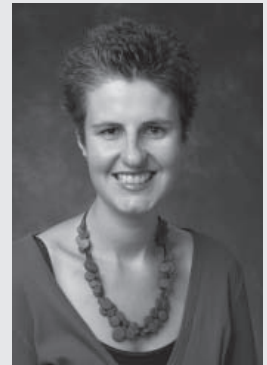
This is the link between the personal and the political. I have been able to make choices and there were benefits and costs. I made the right decision for me and the outcome is an assured and wonderful daughter who is facing the world with energy and style. Now I just have to write my own Messiah!!

## Review Group News from Megan Pricor

### Staff

Space is at a premium as the Centre for Health Communication and Participation continues to grow.

**Jessica Kaufman** has rejoined us after a stint at the Australasian Cochrane Centre. She, together with a new Research Fellow (to be appointed), will contribute to the major *Communicate to Vaccinate* project funded by the Research Council of Norway. Contact Jessica ([j.kaufman@latrobe.edu.au](mailto:j.kaufman@latrobe.edu.au)) for more information.



**Annie Synnot** joins us on the *IN-DEEP* project focusing on multiple sclerosis - 'High quality health information and decision tools to aid people with multiple sclerosis manage their health: Integrating and deriving evidence, experiences and preferences.'

We also welcome **Lidia Horvat** who is on secondment from the Department of Health Victoria, preparing a Cochrane systematic review of interventions to educate health professionals in cultural responsiveness, and then developing an education and training module for Victorian health service staff on culturally-responsive health care.

### 2010 Colloquium

Come and find our Group's table at the Meet the Entities session at this year's Colloquium, to find out more about our reviews and other activities, and meet members of our editorial team.

## Hot Tips for Review Authors

Working on a protocol or review? Here are a few important things to bear in mind:

- Don't leave the protocol or review 'checked out' when you're not working on it. Check it back into Archie after every session.
- Contact our Trials Search Coordinator for advice before any searches are run.
- Keep a copy of your search strategies, the dates they were run, and the output for each database.
- Extracted data but not sure how to present it? Talk to the Managing Editor before entering data to RevMan.
- In your review, follow the methods you had set out in your protocol. If there's a good reason for taking a different course, make this plain in the review.
- Run a spell check before you submit your work to the editorial team.

*Simon Lewin, an editor of the Group, and his colleagues report on the SURE project promoting access to and use of research evidence*

## Supporting the use of research evidence within African health systems

Authors: Susan Munabi-Babigumira, Andy Oxman and Simon Lewin for the SURE team

To provide good quality, universal and equitable health care, policymakers need to make well informed decisions about health systems. This necessitates access to and use of reliable research evidence. The SURE (Supporting the Use of Research Evidence) project aims to facilitate policymakers' access to and use of research evidence (including Cochrane reviews) that is relevant, reliable, accessible and timely. SURE is a collaborative project that builds upon and supports the African Evidence-Informed Policy Network (EVIPNet - [www.who.int/rpc/evipnet/en/](http://www.who.int/rpc/evipnet/en/)) and the Regional East African Community Health (REACH) Policy Initiative. Multiple methods are being used to develop and evaluate strategies for improving access to and use of research evidence in policy development. These methods include evidence-based policy briefs, clearing houses, rapid response mechanisms, policy dialogues, strategies for informing and engaging

stakeholders, resources for building capacity for evidence-informed health policymaking, and formative evaluations of country initiatives to help improve evidence-informed health policymaking.

A consortium of seven African partner countries supported by three European countries, Canada and the WHO has been established. Each African partner will have completed at least one policy brief and one policy dialogue by the end of 2010. Policy questions that are the focus of policy briefs under development include:

- expanding the use of health workers to deliver cost-effective interventions
- improving health district governance, and
- reducing maternal and infant mortality.

Pilot testing of a rapid response service and the first annual formative evaluation of country initiatives are now underway. The development and evaluation of guides and user-friendly formats for policy briefs, clearing houses, strategies for informing and engaging stakeholders, and resources for building capacity are ongoing.

Concerted efforts are needed to ensure that relevant evidence, including from Cochrane reviews, is accessible and used appropriately by policy makers to inform health systems decisions. This is particularly challenging in settings with severe constraints on resources and many competing priorities, such as African countries. In these contexts, every investment in the implementation of policies must be effective, safe and also promote health equity.

For more information on the SURE project, visit: [www.evipnet.org/sure](http://www.evipnet.org/sure).



## REVIEW GROUP ACTIVITIES 2010

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 at [www.thecochranelibrary.com](http://www.thecochranelibrary.com)

People without access to *The Cochrane Library* can view free abstracts (and purchase individual reviews) at <http://www.cochrane.org/reviews/index.htm>

### Titles Registered, January to September 2010

- Automated telephone communication for primary preventive healthcare (Josip Car)
- Automated telephone communication systems for disease management and care (Josip Car)
- Decision support technologies for people making decisions about participation in clinical trials (Katie Schumm)
- Extended discussion of information for informed consent for participation in clinical trials (Yoon Khee Hon)
- Goal setting in adults receiving rehabilitation for acquired disability (William Levack)
- Interventions for promoting consent to the reuse of medical data for research (Donald Nicolson)
- Interventions for supporting palliative care volunteers in community settings (Dell Horey)
- Interventions for supporting palliative care volunteers in policy, organization and service settings (Dell Horey)
- Interventions that promote informed consent for surgical and other invasive healthcare procedures in consumers (Paul Kinnersley)
- Personal financial incentives for changing habitual health behaviours (Eleni Mantzari)
- Presentation of aversive visual images for changing health behaviour (Gareth Hollands)
- Self-management for improving participation in older adults with chronic conditions (Grace Warner)

### Protocols Published, *The Cochrane Library*, 2010 (Issue 1 - Issue 10)

- Information interventions for orienting patients and their carers to cancer care facilities (Chan R, Webster J)
- Multimedia educational interventions for consumers about prescribed and over the counter

- medications (Ciciriello S, Johnston RV, Osborne RH, Wicks I, deKroo T, Clerehan R, et al)
- Interventions to enhance adherence to dietary advice for preventing and managing chronic diseases in adults (Desroches S, Lapointe A, Ratté S, Gravel K, Légaré F, Njoya MM, et al)
- The effect of varying practitioner communication on patients' health status and treatment outcomes (Verheul W, Mistiaen P, Di Blasi Z, Kok L, van Dulmen S, Bensing J)

### Reviews Published, *The Cochrane Library*, 2010 (Issue 1 - Issue 10)

- Shared decision making interventions for people with mental health conditions (Duncan E, Best C, Hagen S)

#### Plain language summary

Mental health conditions are common and can have serious consequences for both affected individuals and society. Current clinical guidance encourages mental healthcare practitioners to involve patients in treatment decisions. This is advocated on the basis that people have a right to self-determination and also in the expectation that it will increase treatment adherence.



Eddie Duncan

The authors conducted thorough searches for randomised controlled trials (RCTs), quasi-randomised controlled trials (q-RCTs), controlled before-and-after studies (CBAs); and interrupted time series (ITS) studies of interventions to increase shared decision making in people with mental health conditions. They found two studies that met the inclusion criteria. Both studies were of good quality and made attempts to reduce potential sources of bias.

The authors examined whether interventions to increase shared decision making affected patient satisfaction with treatment or care, led to better health outcomes or to patients being less likely to be readmitted to hospital. One of the studies indicated that the intervention increased patient satisfaction in the short term. One study indicated that doctor facilitation of consumer involvement in decision making was increased by the intervention, but no effects were found on the clinical or health service outcomes in either study. Neither study reported that shared decision making for people with mental health conditions is harmful. However, no firm conclusions can be drawn from these two studies on any of the outcomes measured and further research is needed.

o **Visual feedback of individuals' medical imaging results for changing health behaviour (Hollands GJ, Hankins M, Marteau TM)**

**Plain language summary**

This review investigated whether showing (and explaining) to people their medical scan images motivates them to change their behaviour to reduce any health risks identified. This is important because getting people to change their health behaviours is generally very difficult. New techniques are needed and giving people visual evidence of how certain behaviours may be damaging their body could be an effective approach.

The authors included nine trials involving 1371 participants in the review. In general, no strong evidence was found to support the effectiveness of this approach, but it was shown to be effective in some contexts. In smoking cessation interventions the effect of showing and explaining artery scanning images (to assess the risk of cardiovascular disease) was found to be more effective than not communicating images. In other outcomes, the effects were mixed. There was no evidence of significant harmful effects of this approach, although this was not well reported.

A main limitation of the review is the small number of studies in this area and the great differences between them in terms of the precise nature of the interventions and the populations being studied. This makes drawing broad conclusions difficult.

o **Interactive computer-based interventions for sexual health promotion (Bailey JV, Murray E, Rait G, Mercer CH, Morris RW, Peacock R, et al)**

**Plain language summary**

Sexual health promotion is a major public health challenge. There is huge potential for health promotion via technology such as the Internet, but it is not known whether interventions are effective. An interactive computer-based intervention provides information, and also offers personalised feedback. The authors searched databases for studies which were randomised controlled trials (RCTs) of computer/Internet-based interventions which aimed to improve sexual health. They included trials of computer-based interventions delivered to people of any age, gender, sexual orientation, ethnicity or nationality. The review evaluated 15 RCTs involving 3917 participants.

Results showed that computer-based interventions have a moderate effect in improving people's knowledge



*Julia Bailey*

about sexual health in comparison to minimal interventions such as 'usual practice' or a leaflet. The authors also found a small effect on safer sex self-efficacy (a person's belief in their capacity to carry out a specific action), a small effect on safer-sex intentions, and also an effect on sexual behaviour (such as condom use for sexual intercourse). They found that computer-based interventions seem better than face-to-face interventions at improving sexual health knowledge, but there were insufficient data to analyse other outcomes. No studies measured potential harms (apart from reporting any deterioration in outcomes).

Interactive computer-based interventions for sexual health promotion are feasible in a variety of settings. They are effective tools for learning about sexual health, and they also improve self-efficacy, intention and sexual behaviour, but more research is needed to establish whether computer-based interventions can change outcomes such as sexually transmitted infections and pregnancy, to understand how interventions might work, and to assess whether they are cost-effective.

o **Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours (Marteau TM, French DP, Griffin SJ, Prevost AT, Sutton S, Watkinson C, et al)**

**Plain language summary**

Tests can now be conducted in which DNA is analysed to estimate the chance of developing diseases such as heart disease or lung cancer in smokers. It was thought that risk estimates derived from these genetic tests may motivate people to change their behaviour in order to reduce the identified risks. In this review, the authors assessed the effect of communicating disease risk estimates from genetic tests on risk-reducing behaviours and motivation to undertake such behaviours.



*Theresa Marteau*

A systematic search located 14 papers reporting the results of 13 eligible studies: seven clinical studies and six analogue studies (studies in which participants are given hypothetical scenarios asking them to imagine receiving genetic test based disease risk estimates).

Five clinical studies assessed smoking cessation, with statistical combination of the results revealing no statistically significant effects on smoking cessation in either the short-term (< six months) or long term (> six months). Two clinical studies assessed dietary behaviour and showed that communicating genetic test-based risk estimates did change people's behaviour. The two studies assessing physical activity and the one study assessing medication or vitamin use aimed at reducing disease risks

did not show that communicating DNA-based disease risk estimates had an effect on behaviour.

For the six analogue studies, statistical combination of the results revealed a statistically significant effect of genetic test based disease risk estimates on intention to change behaviour only. There was no evidence of any unintended detrimental effects on motivation or mood.

In summary, the limited amount and quality of evidence currently available suggests that communicating genetic test based disease risk estimates may have little or no effect on behaviour, but may have a small effect on intentions to change behaviour. Larger and better quality trials are needed.

## NEW REVIEWS IN THE PIPELINE

Reviews we expect to publish in 2011 include:

- Consumer-oriented interventions for evidence-based prescribing and medicines use: an overview of systematic reviews (led by Rebecca Ryan)
- Interventions for enhancing consumers' online health literacy (led by Josip Car)
- Interventions for supporting informal caregivers of patients in the terminal phase of a disease (led by Bridget Candy)
- Provision of a surgeon's performance data for people considering elective surgery (led by Amanda Henderson) - published November 2010

## Increasing the accessibility of Cochrane reviews

The Cochrane Collaboration is constantly working to increase the accessibility of Cochrane reviews. Several staff members and editors in the Consumers and Communication Group have been involved in this work.

Two papers recently published by Rosenbaum et al (2010) describe efforts to develop and evaluate Summaries of Findings tables for Cochrane reviews. The tables were developed in collaboration with Cochrane Collaboration stakeholders and were tested, revised and re-tested among health professionals in UK and Norway.

Resolving the tension between achieving precision and simplicity was a main focus of this work. Evaluations of the table in two small randomised trials suggested that inclusion of the table improved understanding and rapid retrieval of key findings compared with reviews with no table.

In a related piece of work, Glenton et al (2010), describe the development of a Plain Language Summary format of a Cochrane Review. The paper describes how different Plain Language Summary formats were developed, tested, revised and re-tested among members of the public in Norway, Argentina, Canada and Australia. While this process allowed the researchers to identify and address a number of problems, they also point to challenges that still remain, including how best to present confidence intervals and continuous outcomes.

### References:

Rosenbaum SE, Glenton C, Oxman AD. Summary-of-findings tables in Cochrane reviews improved understanding and rapid retrieval of key information. *Journal of Clinical Epidemiology*, 2010 Jun;63(6):620-6.

Rosenbaum SE, Glenton C, Nylund HK, Oxman AD. User testing and stakeholder feedback contributed to the development of understandable and useful Summary of Findings tables for Cochrane reviews. *Journal of Clinical Epidemiology*, 2010 Jun;63(6):607-19.

Glenton C, Santesso N, Rosenbaum S, Nilsen ES, Rader T, Ciapponi A, Dilkes H. Presenting the results of Cochrane systematic reviews to a consumer audience: A qualitative study. *Medical Decision Making*, 2010. Published online before print July 19, 2010, doi: 10.1177/0272989X10375853.

*A report on a project to develop tools to support evidence informed policy-making, from editor Simon Lewin*

## Facilitating evidence-informed health policymaking: the SUPPORT tools

Simon Lewin<sup>1,2</sup>, John N Lavis<sup>3</sup>, Andrew D Oxman<sup>1</sup>, Atle Fretheim<sup>1</sup>

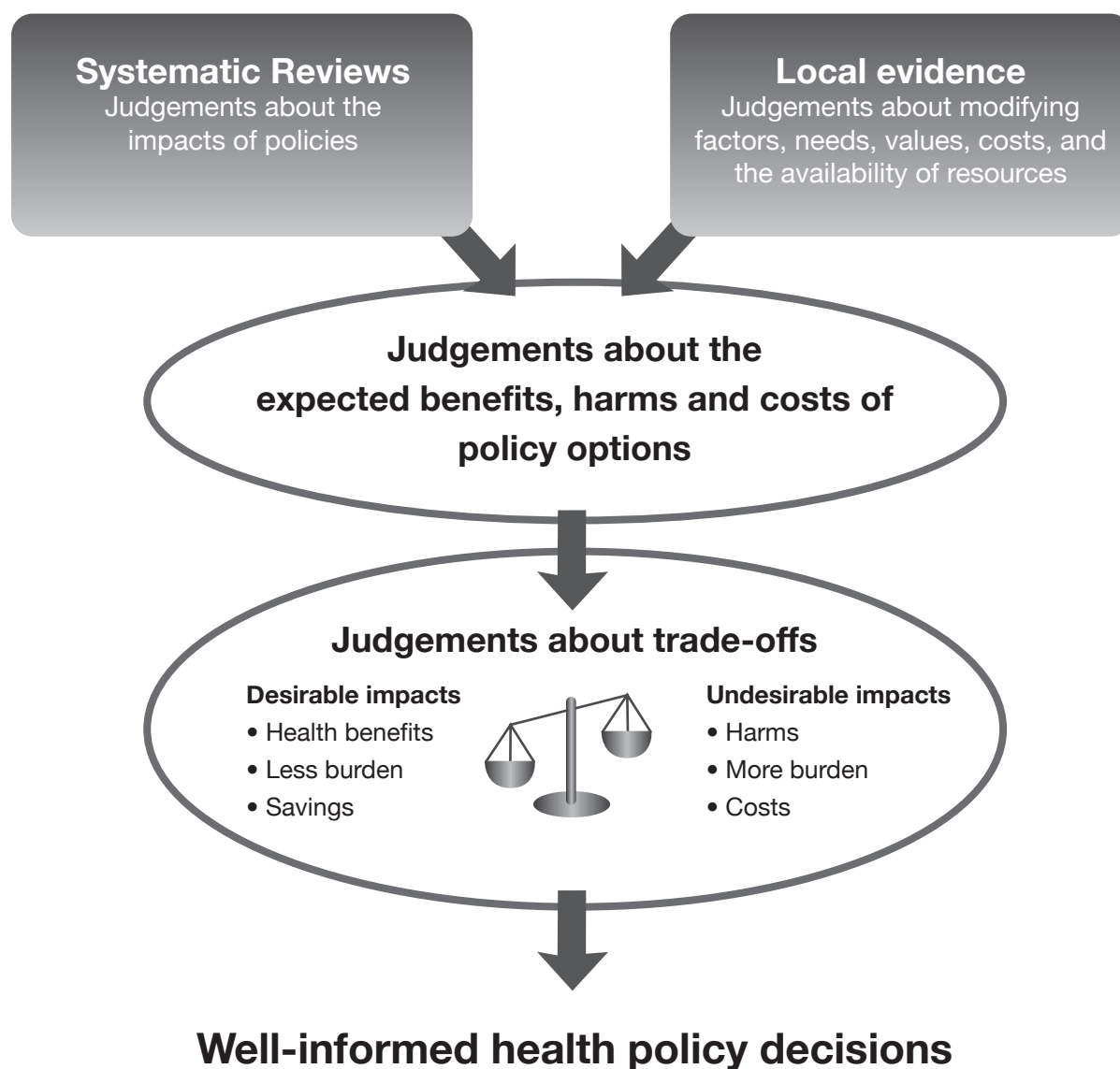
<sup>1</sup> Norwegian Knowledge Centre for the Health Services, Oslo, Norway;

<sup>2</sup> Medical Research Council of South Africa, Cape Town, South Africa;

<sup>3</sup> Centre for Health Economics and Policy Analysis, Department of Clinical Epidemiology and Biostatistics, and Department of Political Science, McMaster University, Hamilton, Canada.

Knowing how to find and use research evidence can help policymakers and those who support them to do their jobs better and more efficiently. More systematic processes and tools are needed to support such evidence-informed policymaking. A series of tools has been developed by the Supporting Policy relevant Reviews and Trials (SUPPORT) project to help ensure that health policies are informed by the best available research evidence (Figure 1).

Figure 1: *The role of evidence in health policymaking*

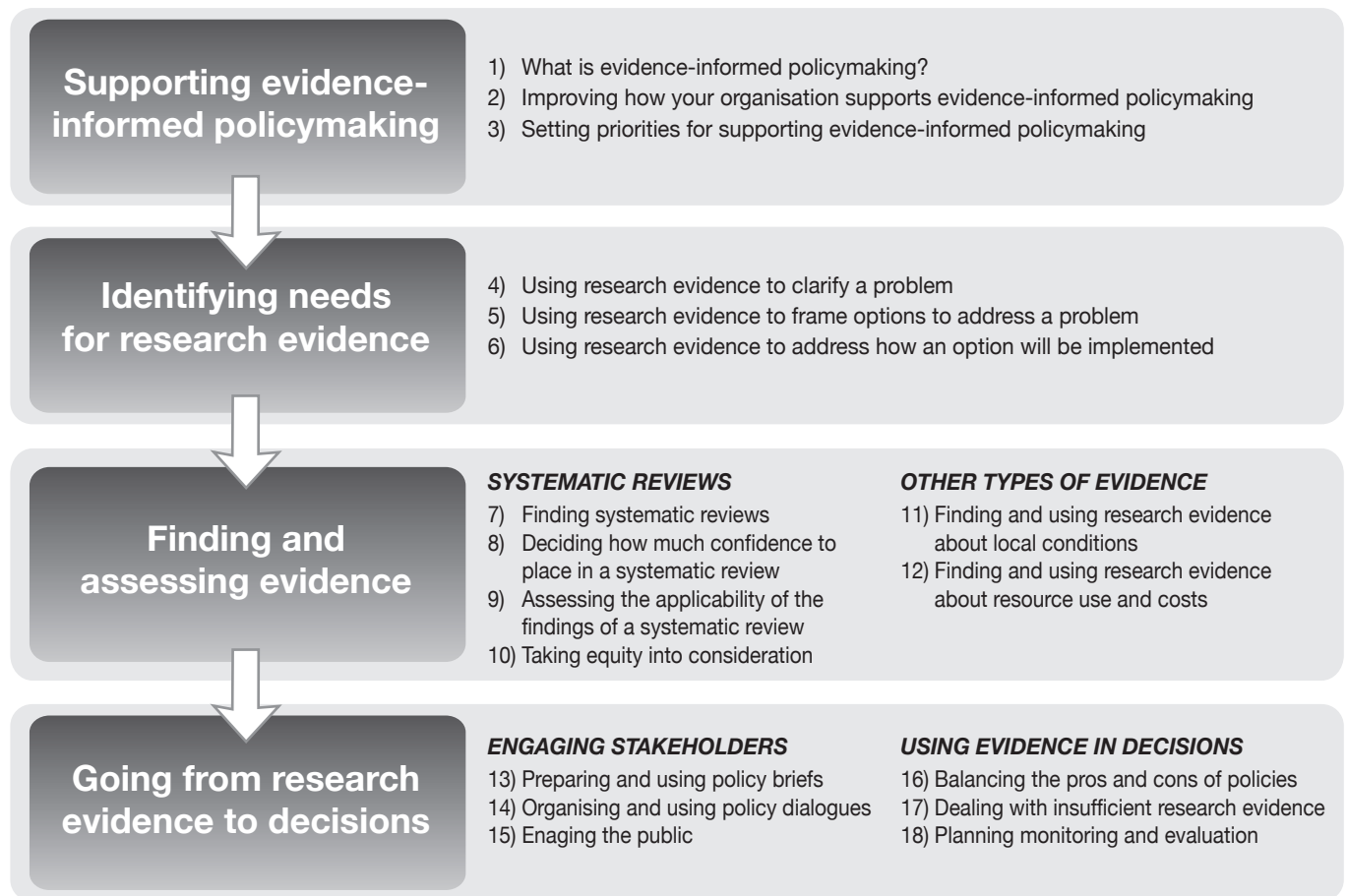


The tools are based on experience from workshops for policymakers on evidence-informed health policy. The materials were adapted from these workshops as well as from other evidence-based healthcare resources and resources identified through searches of relevant databases (primarily PubMed), websites and through personal contacts. The tools were revised based on feedback from policymakers and researchers.

The SUPPORT tools address four areas (Figure 2): (1) Supporting evidence-informed policymaking; (2) Identifying needs for research evidence; (3) Finding and assessing research evidence, and; (4) Going from

research evidence to decisions. Each tool is structured using a set of questions that guide readers through the tools and indicate how to undertake activities to support evidence-informed policymaking effectively and efficiently. These activities include, for example, using research evidence to clarify problems; assessing the applicability of the findings of a systematic review about the effects of options to address problems; and organising and using policy dialogues to support evidence informed policymaking. The SUPPORT tools include examples and resources from disparate settings and are relevant to low-, middle- and high-income countries.

Figure 2: Areas covered by the SUPPORT tools



The SUPPORT tools can aid the use of the best research evidence available to inform health policy decisions. They are available as a series of open access articles

([www.health-policy-systems.com/supplements/7/S1](http://www.health-policy-systems.com/supplements/7/S1)), and have been translated into Chinese, French, Portuguese and Spanish. The translations will be available soon on the SUPPORT website ([www.support-collaboration.org](http://www.support-collaboration.org)).

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

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

## Upcoming Conferences

### Joint Colloquium of the Cochrane and Campbell Collaborations

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

18 to 22 October 2010, Keystone, Colorado, USA

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

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

5 to 8 April 2011, Amsterdam, The Netherlands

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

### 6th International Shared Decision Making Conference

19-22 June 2011, Maastricht, The Netherlands

See <http://www.isdm2011.org/>

### Consumers Reforming Health conference

18 to 20 July 2011, Melbourne, Australia

See <http://consumersreformhealth.asnevents.com.au/>

### Cochrane Colloquium 2011

19 to 22 October 2011, Madrid, Spain

More information available on [www.cochrane.org](http://www.cochrane.org) soon