

[Methods Groups]
**Cochrane Patient Reported Outcomes Methods
Group**

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What's new

The website is available at the following address: www.cochrane-pro-mg.org

See also <http://www.mapi-trust.org/>

Iliana Petkova is the MAPI support person to the PRO Methods Group.
Donald Patrick and Gordon Guyatt are co-convenors with continuing support
from the MAPI Research Trust.

General information

Cochrane Methods Groups have been established to develop methodology and
advise The Cochrane Collaboration on how the validity and precision of
systematic reviews can be improved. Methods Groups base their activities
around six core functions; these are discussed in greater detail in the 'Activities'
section.

The main objective of the Cochrane PRO MG is to advise Cochrane authors about when and how to incorporate and patient-reported outcomes, including reports on symptoms, functional status, general health, health-related quality of life, or any other health-related domain, into systematic reviews. Some Cochrane Review Groups (CRGs) have encountered difficulties when incorporating PRO data in reviews. Examples of such difficulties include pooling and interpreting data and evaluating the validity of PRO instruments. To this end, the Cochrane PRO MG has provided systematic reviews of PROs to the different Cochrane Review Groups to aid them in this task. The PRO MG will continue to update these reviews of PROs in different therapeutic areas as part of its contribution to the Collaboration. The PRO MG also conducts original research on the use of PROs in Cochrane Reviews, including how to present them in the Summary of Findings Table and other issues related to analyses and presentation of results.

Background

Over the last 20 years, Patient Reported Outcomes (PRO) assessment has become increasingly relevant in the evaluation of health care interventions, for several reasons:

1. In evaluating health care, as well as in decision-making, clinical and health services researchers have come to the conclusion that direct self-reports of how disease, illness, and treatment affects patients are the outcomes that are most significant to patients (changes PRO are one of the key factors influencing demand for care and satisfaction with treatment).
2. For some conditions, where it is not easy to make such measurements as pain, functional disorders or psychiatry, the utility of evaluating perceived outcomes is strongly suggested.
3. Health authorities, clinicians, and pharmaceutical companies seek indicators that demonstrate valid outcome differences between similar treatments, and PROs are one of these.

Cochrane authors have found that an increasing number of trials include PRO data. Because of the multi-dimensional nature of PRO and the lack of standardisation of instruments, problems when preparing systematic reviews include pooling of data, and the evaluation of the validity and meaning of observed results. This was clearly shown in a June 2000 survey of CRGs carried out by the PROMG.

Activities

Cochrane Methods Groups base their activities around the six core functions outlined by The Cochrane Collaboration. These are:

1. Providing methodological and practical advice to Cochrane entities.
2. Providing training and support.
3. Conducting methodological research.
4. Helping to monitor the quality of Cochrane Reviews.
5. Serving as a forum for discussion.
6. Ensuring that the group functions interactively within The Cochrane Collaboration.

Each Methods Group carries out its work in line with some or all of these functions, as described in more detail in this section.

The main objective of the Cochrane PROMG is to improve Cochrane reviews by advising Cochrane authors about when and how to incorporate PRO data into systematic reviews of health care interventions or participating directly in their participation as members of the Review Group.

Organisation of the Methods Group

Members of the PROMG were surveyed in 2000 and sub-groups developed according to their interests:

- Concepts and Methods Review Sub-Group
- Review Design Sub-Group
- Analysis Sub-Group

The Group and Sub-groups are managed under the control of the convenors, by a coordinator who will:

- build a research agenda for the Group; and
- take care of the flow of the CRGs' requests.

The PROMG's activities are concentrated in the following areas:

Providing methodological and practical advice

1. Advise on software development.
2. Advise the Cochrane Collaboration Steering Group upon request.
- 3 Participate in the Cochrane Methods Group

Providing training and support

1. Help prepare protocols and reviews where it has been decided to include PRO outcomes.

2. Provide advice to authors by means of written material and training workshops.
3. Convene workshops on health and patient reported outcomes issues and methods, including the validity of PRO measures, cross-cultural adaptation of PRO instruments, interpretation of scores and pooling of data, in response to the needs of the Collaboration.
4. Prepare guidelines and recommendations for the Cochrane Handbook for Systematic Reviews of Interventions.
5. Work on specific reviews, as examples.
6. Produce a glossary of PRO terms to be included in the current glossary.
7. Produce systematic reviews of the use of PROs in different therapeutic areas and distribute these reviews to the Cochrane Review Groups
8. Develop guidelines on psychometric criteria, appropriateness and cross-cultural validation of instruments for addressing PRO issues in Cochrane reviews.
9. Keep track of contacts from authors who wish to include PRO in their systematic reviews. The process should be followed closely, and the quality of advice given will be evaluated.
10. Facilitate links between Cochrane authors who need to make use of PRO observations, and members of the International Society for Quality of Life Research (ISOQOL) and others, such as the network of HRQL researchers established by Mapi Research Institute.

Help to revise the Cochrane Handbook for Systematic Reviews of Interventions (formerly the Reviewers' Handbook): points 4 and 7 could form part of a special new section dedicated to PRO.

Conducting methodological research

1. Refine literature search on and for meta-analyses of PRO studies.
2. Develop methods for systematically reviewing PRO studies.
4. Refine methods for meta-analysis of PRO studies (in collaboration with the Statistical MG).

5. Refine methods for use of PRO measures in economic evaluations in collaboration with the Campbell-Cochrane Health Economics MG.
6. Collect examples of clinical trials that incorporate poor and good quality PRO assessment.
7. Develop and assess search strategies, i.e. produce a list of relevant key words to be used by researchers from CRGs to assist information searching and retrieval.
8. Develop and assess a checklist to evaluate the quality of PRO outcomes included in RCTs and retrieved by Cochrane authors. This checklist provides criteria that enable authors to include or exclude PRO studies.
9. Develop and validate methods for pooling PRO data in the context of a meta-analysis.
10. Develop guidelines for the interpretation of PRO results [i.e. effect sizes (ES), minimally important difference (MID), cumulative distribution curve, responder definition, and number of patients needed to treat (NNT)].
11. Develop methods for the inclusion of data into RevMan software (non-numeric data, as for MID, SMD, for each domain or with a summary score).

Helping to monitor the quality of Cochrane Reviews

1. Develop and assess checklists for quality assessment of systematic reviews including PRO.

Serving as a forum for discussion

The PRO MG mailing list serves as a forum for discussion, primarily focusing on the following topics:

1. Methods to aggregate patient-reported outcomes.
2. Methods of interpretation of PRO results.
3. Methods for using PRO instruments in global clinical trials (cultural adaptation).
4. Methods for reporting results of meta-analyses and systematic reviews of PROs.
5. Reporting of PRO validation and results in clinical trials.

Ensuring that the group functions interactively within The Cochrane Collaboration

1. Manage overlap with the work of several other MGs, especially those concerning statistics and health economics. Representatives from the PROMG will participate in these MGs when appropriate to identify where and when such overlap may occur, and to plan joint work.
2. Participate in Cochrane Review Groups.

To help manage the Group's work effectively, the PROMG's website (www.cochrane-pro-mg.org) includes information about its organization and structure, as well as contact details and updates on recent activities. Other information is contained on the website maintained by MAPI Research Trust, <http://www.mapi-trust.org/>

Management of requests from CRGs

The coordinator chooses the appropriate group for the request and sets the deadline for response.

- Requests specific to the areas of health listed below will be dealt with by the Pathology-specific PRO experts sub-group: CNS, diabetes, gerontology, gastrointestinal, HIV, musculoskeletal, oncology/palliative care, ophthalmology, psychiatry and urology.
- All other requests will be forwarded to and processed by the relevant working group.

Ongoing activities

- Production of a glossary of PRO terms (Concepts and Methods Review Sub-Group).
- Collaboration on specific reviews.
- Production of chapter for the Cochrane Handbook for Systematic Reviews of Interventions (Review Design Sub-Group).

Future activities

- Produce guidelines on the interpretation of PRO scores.
- Collect examples of clinical trials that incorporate poor and good quality PRO assessments.
- Produce guidelines on how to pool data.
- Help in the development of RevMan.

Contributors

Members of the Group have published work on methods of PRO assessment in clinical trials, and have also been involved in the development of guidelines for reviews of PRO evaluation studies.

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Diary

October 2008: 16th Cochrane Colloquium, Freiburg, Germany

- General meeting with members of the Cochrane PRO MG
- Workshops delivered by convenors and members of the PRO MG: more information is available online (www.cochrane-pro-mg.org/Documents.html)

October 2007: 15th Cochrane Colloquium, São Paulo, Brazil

- General meeting with members of the Cochrane PRO MG
- Workshops and plenary presentations organized and delivered by Convenors and members of the PRO MG: more information is available online (www.cochrane-pro-mg.org/Documents.html)

Reports and publications

Minutes from the exploratory, business and strategic meetings are available at the PRO Methods group website (www.cochrane-pro-mg.org). Interim reports will be prepared for dissemination and discussion throughout The Cochrane Collaboration. We do not plan to create a bulletin board for the moment. Nevertheless, if people are interested in such a discussion list, the PRO MG will consider the request.

1. Survey of Collaborative Review Groups (CRGs)

This initial step enabled the Cochrane PROMG to determine which groups include PRO in their reviews (and how they do this), and why others do not, and also to identify appropriate criteria for including PRO evaluation in their reviews. This survey was launched on June 6, 2000 and the results were disseminated to all CRGs on December 20, 2000.

2. Survey of The Cochrane Library: systematic reviews and CRGs

A review of systematic reviews produced by Collaborative Review Groups (CRGs) within The Cochrane Collaboration was conducted in order to:

- identify those CRGs already including PRO data in their reviews; and
- study how PRO outcomes are currently included in the reviews.

In addition, an exploration of CRG modules published on *The Cochrane Library* has been undertaken to identify CRGs intending or planning to include PRO data in their reviews.

The results of surveys 1 and 2 are expected to enable the Cochrane PROMG to contribute to the work of CRGs in the most relevant way:

- by defining a research agenda with those CRGs most interested in PRO evaluation, especially in chronic disorders; and
- by drawing up a list of Frequently Asked Questions.

Archive

October 1997: 5th International Cochrane Colloquium, Amsterdam: Pre-exploratory discussion with Andy Oxman to prepare the application to form a Cochrane PRO MG and organise a meeting.

November 1997 - June 1998: First draft of the application form and organisation of the exploratory meeting, in collaboration with the French Cochrane Center (Margaret Haugh).

July 6th, 1998: Exploratory meeting (French Cochrane Center and contributors to the possible PROMG).

October 1998: 6th International Cochrane Colloquium, Baltimore:

- internal meeting of some members of the possible PROMG;
- presentation to the CC of the objectives and topics of the possible PROMG; and
- participation in the MGs convenor meeting.

January 1999: First contribution to the Cochrane Review Methodology Database in Issue 1, 1999 of *The Cochrane Library*.

February 1999: Submission to Jean-Pierre Boissel and Mike Clarke for comments.

October 1999: 7th International Cochrane Colloquium, Rome:

- training workshop; and
- business meeting.

February 2000 Lyon: strategic meeting.

April/May 2000: Review of *The Cochrane Library* (reviews and CRG module information).

June 6, 2000: CRG survey initiated.

December 20, 2000: Results of the survey disseminated to all CRGs.

October 2001: 9th Cochrane Colloquium, Lyon, France:

- Internal meeting with members of the Cochrane PROMG.

- Participation in 'Meet the entities' session.
- Participation in the MG convenors' meeting.

August 2002: 10th Cochrane Colloquium, Stavanger, Norway:

- 2nd internal meeting with members of the PROMG.
- Sub-group meetings.
- Participation in 'Meet the entities' session.
- Satellite event: An Introductory Programme on Health-Related Quality of Life (HRQL) for 10 Cochrane reviewers: 9 participants.
- Workshop: Advanced Programme on Health-Related Quality of Life (HRQL) for 10 Cochrane reviewers: 11 participants.

November 2002: ISOQOL, Orlando, USA:

Two sub-groups met:

- Analysis sub-group chaired by Jeff Sloan.
- Concept and Methods Review sub-group chaired by Elaine McColl.

October 2003: 11th Cochrane Colloquium, Barcelona, Spain

- A general meeting with members of the Cochrane PRO MG.
- 3 workshops - 'Educational program on Health-Related Quality of Life for Cochrane Reviewers'.

October 2004: 12th Cochrane Colloquium, Ottawa, Canada

- A general meeting with members of the Cochrane PRO MG.
- 2 workshops - 'Educational program on Health-Related Quality of Life for Cochrane Reviewers'.

On 31 January 2005, the Monitoring and Registration Group (a sub-group of the Cochrane Collaboration Steering Group) approved the change of name the group to 'Patient Reported Outcomes Methods Group', and the change of scope to include all outcomes reported by RCT participants.

October 2005: 13th Cochrane Colloquium, Melbourne, Australia

- A general meeting with members of the Cochrane PRO MG.
- 2 workshops - 'Educational program on Health-Related Quality of Life for Cochrane Reviewers'.

References

Revisions to the PRO MG's chapter in the *Cochrane Handbook for Systematic Reviews of Interventions* are anticipated for 2007, working to a schedule set by the Handbook's editors. The revised chapter is also scheduled for publication in the *Journal of Clinical Epidemiology*.

Acknowledgements

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