

Business Meeting—Patient Reported Outcomes Methods Group
Cochrane Collaboration

Minutes

17:45-19:15 - Friday 21 October 2011

In attendance: 15 persons

- 1) Minutes from the meeting in 2010 were accepted.
- 2) The workshop on interpretability was fully attended and persons on the waiting list were turned away. She shall attempt to correct this next year.
- 2) We reviewed members' experiences in reviews. Caroline Terwee reported via Gordon Guyatt on her experience with her back pain review. She found many challenges with missing and limited data and the necessity to make many assumptions to pool but felt that it was worth pooling nevertheless. She was disappointed that the review suggested the treatment was not effective so that she could not explore issues of interpretability. The data is liable to be worse in areas in which PROs are not the primary outcomes. Roy Elbers reported his work in fatigue in Parkinson's noting many different outcomes are used. Robin Christensen reported that the MSK group is working in Rheumatoid and Osteoarthritis on reviews
- 3) Getting others interested. Interest in PRO exists from consumers, qualitative methods group, adverse outcomes methods group, applicability and recommendations methods group. Uncertain how often PROs found in most reviews. Summary of Findings Tables are not mandatory in Cochrane reviews; it would be helpful if it was. If there were SoFs for all reviews it would facilitate finding out how often PROs were used. Catherine Acquadro has reviewed this number of years ago and it would be interesting to see if greater uptake. There is a need to keep repeating the importance of PRO and increase PRO profile. Variability of PROs is not greater than more "objective" outcomes.
VOLUNTEERS ASKED FOR TO UPDATE REVIEW OF COCHRANE REVIEWS FOR PROS across review groups or within them. Send e-mail to donald@uw.edu
- 4) Using continuous outcomes. Five approaches are available for presenting continuous outcomes: SMD, natural units, binary outcomes, ratio of means and MID units. Further, there is more than one statistical approach to several of these categories. One of the challenges in

applying these are that there are no minimally important differences established. Even if there is empirical information about the MID, the MID may differ across populations. Thresholds for dichotomies can either be change (is there important improvement, has your pain or disability improved by 50%) or absolute (is the patient's status acceptable). We need replications of use of these approaches to see their relative performance and qualitative studies/surveys to find out how clinicians and patients understand the measures and what they prefer. A paper will be published by Gord Guyatt and colleagues on these approaches and will be circulated to members of the PROMG

- 5) Consumers present are prepared to help disseminate awareness of the existence of the PRO working group. Ann Fonfa (annieappleseedpr@aol.com) and Anne Lyddiatt will help with this dissemination. [UNFORTUNATELY E-MAIL IS NOT ON THE FORM AND WE DID NOT GET THIS—MAYBE VIA THE COLLABORATION?—ROBIN CHRISTENSEN KINOWS ANNE LYDDIATT
- 6) One of the projects that we could all do in our reviews is to calculate all the approaches to interpretability and see how they relate and perform. Another would be to present all approaches to patients and clinicians and see what they understand and what they prefer.
- 7) Systemic reviews of PROs using the COSMIN criteria have been sent to Cochrane review groups.
- 8) The group will convene next year in Chengdu, China where the Collaboration is hoping to hold its next meeting