Business Meeting—Patient Reported Outcomes Methods Group Cochrane Collaboration

## Minutes

17:15-18:30 - Friday 20 September 2013

## Attendees:

Gordon, Donald, Esther van Zuuren, Brad, Zbys Fedorowicz, Li Wang, Rikki DeVet

1) Esther presented here work coming out of a systematic review of rosacea. Generally inadequate assessment of PROs (50% of studies) but low to moderate confidence overall in these

Only 2 studies quality of life

There is hope: RosaQoL instrument validated to assess rosacea-specific quality of life

Experts are suggesting that studies should include rosacea-specific quality of life

Suggestion for Esther to make contact with Dermatology Cochrane review group and offer expertise in terms of improving use of PROs (Gordon and Donald happy to help).

- 2) We should all be aware of CONSORT extension applicable to PROs recently published in JAMA (Donald, can you provide citation)
- 3) Pooling across different instruments measuring patient-important outcomes.
- 4) Should, in a meta-analysis one use delta or just post-test in a meta-analysis. Answer to the question is that it depends on the correlation between pre- and post. If correlation between pre and post is high (greater than 0.5) one should use the delta. If correlation is low (less than 0.5) just use post-test. Example of latter is hip and knee replacement.

- 5) Asking people about frequency of pain is a patient-reported outcome.
- 6) Deciding on thresholds it is the patients' viewpoint we should use.
- 7) If people use a variety of unvalidated methods we should pool across studies and then decide to whether to rate down confidence because of confidence.
- 8) One role of the PRO methods group is to have senior people help junior people do systematic reviews. People should feel free to ask for help.
- 9) Potential workshops:
- i) use calculator that Brad is developing using excel spread sheet.
- ii) bring our own problems as examples
- 10) Patient-reported outcomes will typically differ from clinician-reported outcomes.
- 11) COMET is trying to standardize outcomes in every field what should we be measuring in every relevant trial (including PROs).
- 12) Possible systematic surveys:
- how many Cochrane reviews are using PROs and what sort of PROs are they using
- when they use PROs how are they presenting results