3rd COMET Network Meeting

Date and venue

17th June 2014 (11.00-15.30 BST), Oakfield House, University of Bristol, Bristol UK

Background

The aim of the meeting was to bring COS developers together to share experiences and identify best practice. The intention was that those with experience of generating COSs could educate those planning, or at the beginning, of COS development. It is also hoped that such meetings will help establish a group of individuals with experience of developing COS who can in turn help others.

The meeting was organised by Paula Williamson, Liz Gargon (Liverpool), Jane Blazeby and Sara Brookes (Bristol). Facilitation of the meeting was by Paula and Jane from the COMET Management Team.

Programme

- Welcome and workshop objectives
- Short presentations of core outcome set development from Aberdeen and Bristol (Steven Maclennan, Jane Blazeby and Sara Brookes)
- Presentation of results of survey sent to participants in advance of meeting (Liz Gargon)
- Small group discussions
- Presentation on experiences within COS development in cleft lip and palate (Nicola Harman)
- Presentation on patient and public involvement and feedback from previous COMET PPI meeting (Heather Bagley)
- Small group discussions
- Meeting summary and close

Attendees

There were 33 attendees, including representatives from the Universities of Aberdeen, Belfast, Bristol, Cambridge, Liverpool, Queen Mary London, Manchester, Newcastle, Southampton and West of England. Representatives also attended from the National Institute for health and Care Excellence (NICE), the Royal National Hospital for Rheumatic Diseases and St Mark's hospital and Academic Institute. A full list is given below:

Khalid Ashfaq	National Institute for Health and Care Excellence
Kerry Avery	University of Bristol
Augusto Azuara-Blanco	Queen's University Belfast
Heather Bagley	University of Liverpool
Jane Blazeby	University of Bristol
Sara Brookes	University of Bristol
Natalie Cooper	Queen Mary University of London
Karen Coulman	University of Bristol
Elizabeth Gargon	University of Liverpool
Katie Gillies	University of Aberdeen
Sharon Grieve	Royal National Hospital for Rheumatic Diseases
Mike Grocott	University of Southampton
Nicola Harman	University of Manchester
Noah Howes	University of Bristol
Angelos Kolias	University of Cambridge
Thomas Lam	University of Aberdeen
John Mason	University of Bristol
Steven MacLennan	University of Aberdeen
Candy McCabe	University of the West of England
Liza McCann	University of Liverpool
Helen McConachie	University of Newcastle
Shireen Meher	University of Liverpool
Alex Nicholson	University of Bristol
Jane Nixon	University of Leeds
Kevin O'Brien	University of Manchester
Elaine O'Connell Francischetto	University of Bristol
Roxanne Potgieter	University of Bristol
Carolynne Vaizey	St Mark's Hospital and Academic Institute
Tanya Walsh	University of Manchester
Paula Williamson	University of Liverpool
Katie Whale	University of Bristol
Vikki Wylde	University of Bristol
Jamie Murphy	St Marks

Presentations

A large part of the day focussed on short presentations by researchers at least part way through the development of a COS who were aware of the methodological issues involved. The presentations in the morning focussed on specific methodological issues: how to get from the long list of potential outcomes to a shorter list of 'domains' to be included in the Delphi questionnaire; and the impact on the final COS of different stakeholders responses and feedback.

Steven MacLennon described the development of a COS for localised prostate cancer – the work to date consists of the generation of a 'long list' of outcomes that will then be used within a Delphi process. Through a systematic review and semi-structured interviews with patients a total of 1512 outcomes were identified and then reduced to 77 items in 9 domains. There was much discussion around how the number of items had been reduced and the compromise between the burden of a long Delphi questionnaire and preliminary subjective reduction of items (i.e. comprehensive vs. pragmatic). Difficulties encountered were identified as the specification of the purpose of the COS (i.e. condition vs interventions); participants being able to answer all questions (e.g if looking at a whole condition with many different treatments); dealing with outcomes whose importance might vary with time; and patients' knowledge/understanding of some outcomes.

Jane Blazeby's talk also focussed on creating a long list of outcomes (in this instance for oesophageal cancer and colorectal cancer surgery) – and reiterated the importance of defining the purpose of the COS. The research identified 701 outcomes, which were then categorised into 67 domains. It was apparent that the definitions used for a 'domain' varied across studies and that researchers needed to clearly define their approach. Professor Blazeby also reported an additional piece of work that focussed on patient-reported outcomes (PROs). Mapping PROs onto domains is further complicated by the wide range of PRO measures composed of multiple scales with differing terminology and content. She outlined a systematic approach to categorising the individual items into health domains without the loss of information.

Sara Brookes described a randomised controlled trial that had been nested into the development of three COS in surgery, looking at the impact of different stakeholder's feedback on participants' subsequent responses. Health care professionals and patients were randomised at the start of round 2 of the Delphi to receive either feedback from their own stakeholder group only or from both groups separately and differences in items rated as very important were identified. Different feedback led to differences in the final set of items but further planned work is needed to fully understand the rationale for this. Dr Brookes recommended that feedback from different stakeholder groups should be fed back separately.

Liz Gargon reported on a systematic review of methods used in the development of 198 published COSs. Only 16% included public representatives in the process. Studies primarily used mixed methods including group discussions, consensus conferences, the Delphi process or a survey, and a literature review. Dr Gargon also reported on the results of the small survey conducted in advance of the meeting, with the participants of the meeting, asking about their planned methodology. Again, this demonstrated variability in methods used and the need for guidance from COMET and other COS researchers.

The afternoon focussed on patient and participant involvement, initially with a presentation from Nicola Harman who described the COS work stream of the MOMENT study (management of otitis media with effusion in children with cleft palate). She talked about difficulties they had experienced recruiting children and parents despite targeted efforts. They also experienced a lot of difficulties recruiting parents to attend a joint consensus meeting with health professionals.

The final presentation was from Heather Bagley who talked about the need for the public's involvement in COS development. There was discussion about where to identify representatives from and suggestions included charities or condition relevant patient groups, medical institutions, or other ongoing studies. Heather described in more detail the 16% of studies identified in the systematic review that Dr Gargon reported, which had included public representatives. The extent of public involvement differed across studies with few studies involving the public in reviewing/designing study information/questionnaires. It was agreed that further work is needed to better engage the public. Heather briefly talked about the COMET PPI workshop which was held earlier in the year and attended by public involvement organisations as well as COS developers. At the meeting a COMET plain language summary had been presented, which it had been agreed may help with public understanding of the necessity of the work and subsequent engagement. The summary was again advertised and offered as a free resource. Evidence was then presented to demonstrate that patient involvement has had an impact on COS development (e.g. fatigue within OMERACT). Finally, Heather presented data from 2013/2014 from the COMET database which suggests that now over 80% include PPI activity.

Discussion

Once in the morning and once in the afternoon the group broke into small discussion groups. Each group consisted of at least one researcher with experience of developing COSs to facilitate discussion. The main objective was for participants to learn more of what each other were doing and see the variability in methods used. There was not time for each group to feed back to the whole group but pertinent issues were highlighted by Professors Blazeby and Williamson.

The morning small group discussions provided participants with the opportunity to describe the methods they had implemented or were planning to implement within their COS development. Discussion included the choice of stakeholders to include (e.g should policy makers and journal editors be included?), how to develop the full list of outcomes (discussion followed on from the morning's presentations), when it is appropriate and feasible to develop a COS on an international level, and methodological decisions relating to the Delphi process. It was acknowledged and agreed that the methods used were dependent on the condition under study and that there was not one ideal way to develop a COS.

The afternoon's discussion focussed on public involvement. There was discussion (and disagreement) about whether consensus meetings should be conducted together or separately for patients and health care professionals. It was agreed that if a consensus meeting was done with patients and health care professionals together that good facilitation was essential to its success.

It was agreed that patient and public engagement was far more difficult in certain disease areas than others (e.g. patients undergoing or having undergone treatment for cancer were more easily engaged than parents/children with cleft lip and palate). It was felt by the group that developing and sharing resources for better patient and public engagement was important and there was the request for an (unmonitored) discussion board within the COMET website.

At the end of the meeting participants were asked to feed back on the workshop – participants reported that they found the meeting very useful especially in terms of being reassured that there is no one ideal way to develop a COS and that the methods largely depend on the context and setting.