



Tips for Designing an Accessible Core Outcome Set Consensus Meeting

Patient & Public Involvement in the Design of your COS Study

Get public research partners* involved as early as possible to help you design your core outcome set study. Early involvement can help you plan all aspects of the study including the consensus meeting to help ensure it is as accessible and acceptable as possible for patient / public participants. Many people may never have participated in this type of meeting before, where patients and health professionals discuss and debate to reach agreement. Public research partners can help provide a perspective in planning for a consensus meeting including the areas outlined below.

** We refer to patients / the public who are involved in the design and oversight of the study as public research partners. We refer to patients / the public who take part in the consensus meeting as participants.*

Preparing for a Consensus Meeting

Plans for costing the meeting and considering who to invite

- Ensure that costs for public participants in consensus meetings are planned for. For information about costing core outcome set processes, see Section 2.13.3 of The COMET Handbook: <https://trialsjournal.biomedcentral.com/track/pdf/10.1186/s13063-017-1978-4?site=trialsjournal.biomedcentral.com>. (NOTE: If there are charges for health professional stakeholders who participate in the core outcome set process (e.g. the meeting is held during an annual conference), patients should not be charged. No public or patient participants should be out of pocket for attending / travelling to the consensus meeting).
- Consider who to invite:
 - Aim to invite a balanced range of participants (geographically, culturally, ethnically and demographically diverse).
 - Make sure patient participants have personal experience of the condition where possible and decide whether carers will also be included.
 - Consider the potential impact on a patient or carer participant if they attend with a clinician that they know – how might this impact on their responses?
 - For international consensus meetings, agree the language that the meeting will be conducted in as this may affect who can attend the meeting, unless resources are available for translation.

Plans for organising the meeting

- Consider when to host the meeting:
 - Make sure that the timing of the meeting is suitable for patients – many patients work, or have childcare or carer commitments.
 - Give stakeholders several months' notice of the meeting (we suggest a minimum of 3 months).

- Identify any potential difficulties that patients (and other stakeholders) may experience in accessing the meeting, eg. mobility/hearing issues and make plans to address these needs.
- Produce clear, plain language information describing the purpose of the meeting, why they are being invited, what their role will be, who will be there and what else to expect (along with details of the venue, date and times).
- Getting to the venue may be difficult, especially for people with physical, cognitive or mental health needs. Provide clear instructions including information on public transport / car parking etc – a photo map with pictures of various landmarks ‘en route’ might be helpful for some groups. Ensure that you have appropriate signage at the venue for people to find the meeting room and have someone available to greet your participants.
- Consider producing a glossary for participants to explain specialist terms that might be used during the meeting (you might have produced a glossary previously in your study. Numerous plain language glossaries already exist for health conditions online and may prove helpful.
- You might decide to offer a pre-meeting to patients in addition to written information. This meeting might, for example, be held immediately before the meeting starts, or, if acceptable for patients, via webinar a few days before the meeting, although not all patients are able to access webinars and some might find them daunting. In the pre-meeting you can explain what a core outcome set is, the purpose, design and format of the meeting. Ensure that patients are clear about their role and know that their contributions as people with lived experience of the condition are valued. A pre-meeting allows patients time to ask questions so helping them to feel confident and well prepared and enables them to get to know each other, potentially enhancing their feelings of support.

Plans for during the meeting

- When introducing the meeting, ensure you make it clear that every stakeholder’s contribution is equal in the meeting.
- Consider how you will support your patient and public participants during the meeting and encourage their voice:
 - It can be daunting for anyone, and particularly patients who are not used to this environment to speak in consensus meetings so you may wish to consider a buddy system in the meeting. Buddies can help to ensure that the patient understands what is going on, what they are supposed to be doing and that they understand the discussion. The buddies will need to be approachable and will also need to be clear that they must only provide clarification to facilitate understanding and must not influence or bias the patients in any way. Buddies might also help with practical issues eg. booking taxis for patients.
 - Taking part in consensus meetings can be emotional. For example, discussing which outcomes a patient feels are important can sometimes bring underlying distress to the surface and being party to discussions about the potential future impact of a condition may cause patients anxiety. It is therefore important that you plan appropriately to support patients during the meeting.
- We’d advise against videotaping of the meeting as it may inhibit contributions from participants. Audio recording with explicit consent of all present may be acceptable.
- If photographs are to be taken the consent of participants will be needed with clear information on how and why the photographs will be used.
- Provide breaks during the meeting – it can be mentally and emotionally draining taking part in a consensus meeting – so make sure that you build in enough time for breaks. This might be particularly important for certain patient groups, for example those with pain.
- If funding allows, use an independent facilitator to chair the meeting. This should be someone with experience in running consensus meetings, rather than someone involved in the clinical area. The facilitator

should clearly value patient input into the consensus process and should encourage equal participation from all stakeholders.

- There can be challenges when patients don't agree with health professionals but also when patients don't agree with other patients (each individual's personal experience of a condition can be very different and may influence their perspectives on outcomes) – so good facilitation is essential.
- Adopt a structured approach based around the consensus methodology being used.
- Use an anonymous voting system and make sure everyone knows that the voting is completely anonymous so that people feel able to express their views.

Plans for after the meeting and evaluating participant experience

- Ensure that the participants are aware how they will be updated about the study after the meeting.
- Plan to evaluate the experience of stakeholders who have participated to your consensus, an example of an evaluation form can be found here: <http://www.comet-initiative.org/ppi/researchers>
- We have heard that when it comes to publishing COS studies, some journals have asked for the team members involved in planning and running the COS project and consensus meeting (including the public research partners) to be named and brief description provided of their role in the COS development process. This is something you will want to consider when designing your consensus meeting. If the journal requires the team members to be named you will need to seek their permission.

Further information and resources

You may also find it helpful to look at some of the other resources prepared by the COMET People and Participation Involvement and Engagement (PoPPiE) Working Group, including:

- Patient and Public involvement in a core outcome set (The MOMENT study) video
- Including patients in core outcome set development: issues to consider based on three workshops with around 100 international delegates – a paper
- Making information accessible for patients and the public

These resources can be found here: <http://www.comet-initiative.org/resources/publicinvolvement>

For further information on consensus meeting in core outcome set studies see Section 2.7.6.2 of the COMET Handbook: <https://trialsjournal.biomedcentral.com/track/pdf/10.1186/s13063-017-1978-4?site=trialsjournal.biomedcentral.com>

The following paper describes the experience of patients as participants in a consensus meeting:

de Wit MP, Koelewijn-van Loon MS, Collins S, Abma TA, Kirwan J. "If I Wasn't This Robust": Patients' Expectations and Experiences at the Outcome Measures in Rheumatology Conference 2010. *The Patient - Patient-Centered Outcomes Research* 2013;6(3):179-87

This resource has been developed by the COMET PoPPiE Working Group, with additional comments from members of the PoPPiE Associate panel and from The HOME Initiative Core Outcome Set group. This is a living document; if core outcome set developers or consensus meeting stakeholders have any suggestions for improving the document please send these to PoPPiE via the COMET Patient and Public Involvement Co-ordinator whose contact details are available here: <http://www.comet-initiative.org/ppi>.