

Online consensus meetings for COS development: issues to consider

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When developing the final list of outcomes for inclusion in a core outcome set (COS), many COS developers will hold a face-to-face consensus meeting with stakeholders. Owing to the COVID-19 pandemic, COS developers have recently had to hold their consensus meetings online. To develop guidance for COS developers, COMET convened a workshop with individuals who had been involved in the planning and delivery of such online consensus meetings.

Workshop attendees were identified as individuals who were known to COMET and had planned, facilitated, or participated in online consensus meetings. The workshop was held in February 2021, with 14 attendees joining virtually from the UK, Ireland, Amsterdam, USA, Canada, and Australia (see Appendix). In advance of the meeting, attendees were asked to complete a short email survey about their experience in organising face-to-face and online consensus meetings and the advantages and disadvantages of each. During the workshop, members of the group shared details of what they learned to inform future online consensus meetings. The key issues to consider have been summarised below, including a table of advantages and disadvantages of online consensus meetings.

Since online consensus meetings are relatively new, COS developers should collect feedback from as many participants as possible to allow continued evaluation of this guidance document.

1) Pre-meeting preparation

In advance of a COS consensus meeting, the study team prepares the meeting agenda and content. For a face-to-face meeting, this would typically involve preparing a slide set displaying the findings from the COS development process and explaining the meeting objectives. The study team may also use voting software to enable the consensus meeting attendees to vote on whether they feel an outcome being discussed should be included in the final COS. Preparation is similarly required for online consensus meetings. Below are some points that COS developers may wish to consider when preparing for their online consensus meeting.

General considerations:

- Compared to a face-to-face meeting, which can take place over a whole or even multiple days, you should plan for a shorter duration (2-4 hours, perhaps repeated if necessary), because many people find online meetings to be more tiring. It will be important to schedule appropriate breaks throughout the meeting.
- Because of the shorter duration of online meetings, substantial preparation is required to ensure a seamless meeting. This should involve preparing a detailed agenda for facilitators.
- It will be helpful to have a facilitator(s) with experience in conducting face-to-face COS consensus meetings and, ideally, online meetings. Facilitators may be recommended by other COS developers based on feedback from previous meetings they have facilitated.
- Ask Public Research Partners (PRPs) to think through any potential technical issues for patient participants that might occur on the day.

- Consider the potential impact of how the online format might exclude specific individuals from participating, such as those without internet connections and how others might best be included, e.g. individuals from low-income communities/countries, or individuals with particular disabilities (e.g., visually impaired).

Participant resources:

- In advance of the meeting, it is helpful to send relevant materials/documentation to participants. This documentation could include:
 - An introduction about what COS are, the condition for which the COS is being developed, and what has happened so far in the project;
 - Consent forms;
 - A plan for the day, including an agenda/timeline and what should be expected of participants;
 - The list of outcomes (including plain language description and definitions) that will be discussed during the consensus meeting. You may also consider sending interactive tools (e.g., cards that participants can use on the day as a visual reminder of which outcomes/domains are in/out).
- All materials/documentation should be developed with PRPs.
- Ask participants to read the documentation, ask questions and complete the consent form prior to the meeting.
- Depending on the methods that have been used before the meeting, consider asking participants to complete surveys beforehand to indicate the main points they would like to discuss.

Pre-meeting activities:

- Hold a pre-meeting introductory presentation for public participants, on a different day to the main meeting, to cover the scope, aims, objectives for the day.
 - The COMET PoPPIE Working Group has developed patient pre-meeting pilot slides, which are available from Heather Barrington (heather.barrington@liverpool.ac.uk)
 - Ensure time is included for participants to practise using the technology, including a software voting practice exercise.
- You may also find it helpful to hold a pre-meeting session for patients to informally meet and help familiarise them with the topic and the process. These can be organised/offered as group meetings and/or one-to-one sessions with the study team (depending on participant numbers and resources available).
- You could send out pre-recorded videos as an alternative to having a pre-meeting, although this may not be ideal for supporting patient participation, as it does not allow patients to familiarise themselves with the study team and other patient participants, nor does it provide the chance to clarify any misunderstandings or discuss questions that occur because of the discussion.

2) Technological issues

When planning an online consensus meeting, you will need to consider what platform and voting software you will use. The easiest option will likely be to use whatever platform you have technical support for at your institution. However, it will be worth considering whether this platform will satisfy the meeting requirements and whether it is user friendly for all participants, mainly public participants.

Other technological issues to consider:

- Think about whether the voting software you will be using can be anonymised and embedded within the video conferencing platform.
- Have a pre-prepared slide deck to copy and paste the results into after each round of voting, as this will allow you to share the results with the participants during the meeting efficiently.
- Identify dedicated, skilled helpers (at least 2) to set up voting surveys, present results, and monitor any chat. The helpers may be part of the COS study team.
- Provide dedicated technical support for participants and facilitators throughout the meeting, including providing a phone number for participants in case of technical problems.
- Ensure facilitators/helpers are aware of any technical difficulties that may arise and how they can be overcome; this will be particularly important if you will be using breakout groups.
- Have at least one (probably several) trial run(s) with the study team, facilitators, and any other helpers to practise everything.
- Ask PRPs to help think through any potential issues for patient participants that might occur during the meeting.
- Ensure participants can rename themselves so that the facilitator can see the names of all participants. It is important that participants can identify members of the study team easily in the event somebody needs help. You may want to ask participants to include their stakeholder group in their display name (e.g., Emma – Patient).

3) Conduct on the day

General:

- The slides should only include key information, as people may be viewing them on a small screen.
- Plan to get through less, as it is more tiring to meet online than face-to-face.
- Look into the camera when speaking to give the impression that you are making 'eye contact'.
- The facilitator must be strict with timings, as you are likely to have a tight schedule.
- Allow time at the beginning of the meeting for all participants to introduce themselves.
- Allow time at the end to agree the main points to be fed back Find ways to avoid individuals dominating conversations, e.g., ask others for their thoughts.
- A chat function will allow more participants to input during the meeting, but it could also be distracting. *Note: If using a chat function this needs to be monitored by a person separate from the facilitator.*
- Identify dedicated helpers for timekeeping, monitoring chat and emails.
- Consider having a visual demonstration of outcomes linked to interactive cards or other materials, which will have been sent out to participants beforehand. However, this needs to be easily accessible/well-referenced, as there is no way of knowing precisely what participants are looking at.

Housekeeping:

- Remind all participants to mute their microphones when not speaking to avoid any background noise.
- Depending on the software you are using, encourage participants to use the 'raise hand' function when they would like to speak (or define/clarify alternatives if no "raise hand" function available). This will be particularly helpful if the number of participants means their faces cannot all be seen on the screen by the facilitator at the same time.

Support:

- Ask participants to use the chat function if they have any queries or questions that they would like the facilitator to address. If no chat function is available, consider providing a phone number for participants to text in their queries/questions.
- Have an experienced clinician or trained helper on hand to clarify the outcome descriptions or provide additional information.
- Have a clinician or trained helper available for a 1:1 chat to discuss issues with a patient participant if an outcome triggers an emotional response.

Study team:

- If allowed, have the core study team together in the same room to discuss things and tweak materials. However, you will need to consider whether microphones will be needed to capture voices if more than one person in the room will be speaking.
- If study team members will be in separate locations, plan breakout rooms for use during breaks to discuss how to address possible challenges and the need to deviate from the meeting agenda/plan.
- You will need to have a communication channel, external to the meeting, for the core study team, e.g., a WhatsApp® group.

Use of sub-groups/breakout rooms:

- One approach is to keep the whole group together, which has advantages in terms of time and logistics. However, there may be reason to use sub-groups or breakout rooms instead. If you decide to use sub-groups or breakout rooms:
 - Consider how you will bring together the discussions from the separate groups.
 - Ensure experienced facilitators run them.
 - A note-taker will be required for each group to provide feedback regarding main points.
 - Consider holding a facilitator/note taker training session beforehand to brief them on specific issues around feeding back online.
 - Allow time for participants to introduce themselves.
 - Allow time at the end to agree on the main points to be fed back to the main group.
 - Breakout rooms may need to be recorded separately, which may help for decisions/clarifications following the meeting.

4) After the event

- Send out thank you emails and allow participants to ask questions about discussions during the day or plans.
- Prepare feedback forms (with PRP input) to collect views on:
 - pre-meeting preparation,
 - the process of facilitated discussions and voting,
 - ability to contribute, and
 - perceived fairness of the final results of the meeting.
- Consider meeting after the consensus meeting (whilst ensuring confidentiality is maintained) to celebrate agreeing on the COS. However, be mindful that this may run the risk of reopening debates.

- Hold a study team/facilitator catch up session to:
 - learn from the experience,
 - make suggestions on immediate next steps, and
 - send COMET any additional issues to consider.

5) Other issues

- You may have to hold multiple meetings to cover different time zones or enable patients to attend outside working hours. If so, you would need to be clear with participants beforehand that they will not see the results in real-time, as would happen in a face-to-face meeting.
- If holding multiple meetings, it may be useful to have pre-recorded presentations so that all meetings receive the same information in the same manner. However, you may need to make revisions if something is not understood.
- May have to prompt participants to speak more than you would have to during a face-to-face meeting.
- Bear in mind that it can be more difficult for a facilitator to see when participants are disengaged in an online rather than face to face meeting, as they are not always able to see everybody on the screen.
- Consider logistical complexities of reimbursing participants and public research partners.
- A hybrid meeting style (some participants in a room and some online) is much more challenging and is not recommended:
 - You are likely to encounter technological difficulties and so may have to hire an audio-visual company at your expense, e.g., to ensure you have sufficient microphones in the room.
 - Will require facilitators experienced in delivering hybrid meetings.

Table 1. Advantages and disadvantages of online consensus meetings

Advantages	Disadvantages
<ul style="list-style-type: none"> - Facilitates wider geographical representation - Involvement of more diverse stakeholders - Opportunity for people to attend regardless of geography/ability to travel - Lower cost, as no travel/catering expenses - Better for the environment - Less administration (travel booking, room booking, catering etc) - Easier to find a suitable date and time, due to absence of travel - Easy to record the meeting, particularly useful if there is a challenging discussion - Many platforms allow for easy use of anonymous voting tools - Access to chat function - Ability to use ‘live captions’ depending on software used, e.g., for accessibility - People can attend if they have a computer or a tablet and internet connection - Can be less daunting for participants to contribute to discussions (as opposed to take the floor in a large meeting room) 	<ul style="list-style-type: none"> - Need significant pre-meeting time investment for preparation - Technical issues (e.g., internet connection problems) - Excluding participants who do not have access to technology or struggle to express themselves in these kinds of settings - Participants may be based in different time zones during the meeting, as opposed to being in the same room at a face-to-face meeting - Easier for participants to cancel at short notice - Difficult for the core study team and facilitators to communicate with each other if in separate locations - Requires additional support to monitor chat, etc - Likely to need more expert facilitators/ dedicated helpers - Difficult to keep track of who is in the meeting, as people can come and go - Some participants may dial in twice (e.g., one for audio, one for visual) – difficult to know who is online - Participant engagement is a little more challenging - Significantly harder to read visual cues - Greater attention needed to ensure all individual participant voices are heard - Turn taking can be challenging for participants - Plenary discussion can be more challenging - People tend to lose concentration quicker online than they would face-to-face, therefore need a shorter meeting or planned breaks - Less time for questions/discussion or perhaps need for repeat meetings - Less opportunity for participants to chat to each other (including informal catch-ups and building connections), which is often an important aspect for participants - Miss out on social events/networking before and after the meeting

Appendix 1. Author details and experience in online consensus meetings

Sarah L Gorst, University of Liverpool, UK: FSR-SCOUT (pulmonary sarcoidosis) online meeting.

Heather Barrington University of Liverpool, UK: Patient participant in online consensus meeting and attended online patient pre-meeting prior to an online consensus meeting.

Sara T Brookes, University of Birmingham, UK: Facilitator for the following online consensus meetings: FSR-SCOUT (pulmonary sarcoidosis), COS-AECOPD (acute exacerbations of COPD).

Joanne R Chalmers, University of Nottingham, UK: HOME online meetings.

Declan Devane, HRB-Trials Methodology Research Network, National University of Ireland Galway, Ireland: pregestational diabetes COS online meeting, RE.CURRENT (recurrent miscarriage) guideline recommendation consensus meetings.

Anne C Fledderus, University of Amsterdam, the Netherlands: OCOMEN (congenital melanocytic naevi) online meeting.

Shawna Grosskleg, Outcome Measures in Rheumatology (OMERACT), Canada: OMERACT online meetings.

Deborah A Hall, University of Nottingham, UK: COMiT (tinnitus) online discussion forum; CROSSSD (single-sided deafness) online meeting.

Nicola L Harman, University of Liverpool, UK: FSR-SCOUT (pulmonary sarcoidosis) online meeting.

Christin Hoffmann, University of Bristol, UK: preparatory work for improving PPI experience in consensus meetings.

Roulla Katiri, University of Nottingham, UK: CROSSSD (single-sided deafness) online meeting.

Rebecca Maeso, University of Southampton, UK: James Lind Alliance online priority setting workshops.

Ian J Saldanha, Brown University School of Public Health, USA: Participant in COVID-19-COS online meeting.

Allison Tong - The University of Sydney, Australia: COVID-19-COS online meeting, SONG Initiative (nephrology) online meetings.

Paula R Williamson, University of Liverpool, UK: FSR-SCOUT (pulmonary sarcoidosis) online meeting, COVID-19-COS online meeting, GASTROS (gastric cancer) hybrid meeting.

Appendix 2. Further resources relating to online consensus meetings

James Lind Alliance (JLA) Development of online priority setting workshop – Lessons Learned Report
<https://www.jla.nihr.ac.uk/jla-lab/Report-on-JLA-PSP-online-priority-setting-workshops.pdf>

JLA Guidebook – The JLA priority setting workshop online
<https://www.jla.nihr.ac.uk/jla-guidebook/chapter-8/the-jla-priority-setting-workshop-online.htm>

Blog post from patient with hearing loss who participated in online consensus meeting
<https://myhearinglossstory.com/2021/03/22/meeting-in-an-online-environment-with-hearing-loss/>

The Big Hack: Best video conferencing apps and software for accessibility
<https://bighack.org/best-videoconferencing-apps-and-software-for-accessibility/>

Public engagement in the digital environment: Opportunities and challenges for Arts and Humanities Researchers
<https://www.kcl.ac.uk/ahri/assets/working-paper-dr-anna-khlusova.pdf>

Focus groups and PPI: working with patients and the public in a virtual world
<https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:24ac23d4-4572-4df9-b830-2dfc43296346>