Questions regarding consensus processes

Delphi surveys / pre-consensus surveys

When preparing for the survey, public research partners (PRPs) can collaborate with the research team to consider the following:

- Who should take part i.e. the eligibility criteria for the survey?
- The design and wording of the survey and recruitment / information materials
  - What information patients might like to see on your website / newsletters?
  - How easy is it to find information on your website (if your COS has one) and is this participant information useful and easy to understand?
  - How readable and understandable your newsletters are (if these are to be used in your COS study)?
  - How readable and understandable your patient information and consent forms are for your COS study?
  - How understandable are your outcome definitions?
  - How will patients react to the outcomes?
  - What ethical issues there may be with patient participation in your COS survey?
  - How accessible is your COS survey (for example, is the font size adequate, are the colours suitable for someone with colour blindness, is the scoring system suitable for the target population, for example if children are participating etc)?
  - How understandable your COS instructions are for each round of the survey?
  - Will patients know which perspective they are to use when completing each round of the Delphi survey (for example, are they to vote from their personal perspective or considering the perspectives of the wider patient group)?
  - How understandable is the feedback that you are providing between rounds in a Delphi survey, including any graphs etc.
- The recruitment and retention strategy
  - Is there likely to be a large patient research burden in your intended patient community at the time you plan to run your COS study (e.g. large-scale, clinical trial / research prioritisation study etc. running at the same time as your COS study)
  - How will you reach a diverse range of patients to participate in your COS study?
  - Whether there are specific issues to consider when recruiting particular patient groups in your COS study e.g. patients with cognitive / additional learning needs / visual or auditory impairment.
  - How best to raise awareness about your COS study to the appropriate patient group(s)?
  - How best to maintain patient interest in the COS study over time?
  - How to address potential recruitment challenges from a patient perspective?

Consensus meetings / nominal group technique meetings

When preparing for a consensus meeting, public research partners (PRPs) can collaborate with the research team to consider:

- The design and wording of your participant information sheets, consent forms and recruitment materials

- How readable and understandable your participant information and consent forms are for your COS consensus meeting, e.g. what to expect in the meeting?
- What ethical issues there may be with patient participation in your COS meeting? E.g. in some conditions, especially in rare disease, the patient or caregiver's clinician may be in the room, have you considered with patients how this may make participants feel?
- How understandable your information is about how to get to the venue / join the meeting remotely?
- How accessible your COS meeting will be? (e.g. lifts available, prayer room, breastfeeding facilities, suitable seating, appropriate number and length of breaks, clinical room available, accessible toilets)
- How well is the information on accessibility of the COS meeting communicated to patients in the participant information sheet?
- How understandable your intended patient pre-meeting instructions are? (including for those with additional needs, as relevant)
- How best to cater for any dietary needs throughout the meeting, especially any issues relevant to the condition?
- The order in which outcomes at the meeting are presented
  - Is the order of the outcomes appropriate?
  - How can the order of the outcomes best be explained to participants?
- How best to manage situations where stakeholder groups disagree?
  - How can all stakeholders be prepared for such situations?
  - What can be done during the meeting if disagreements arise?
- What information patient participants will need after the meeting.