Thank you for agreeing to help us plan this research study. During our discussion we intend to cover some of the following topics:

- How you find out about your health condition and news about your health condition (e.g. from patient organisations)
- Contact with clinical teams about condition (frequency / hospital / clinics / community)
- Key messages that might encourage people to consider taking part in a COS study
- Best ways of explaining a COS
- Thoughts on the best methods to use in the study (surveys / interviews with researchers / focus group / decision making (consensus) meeting etc)
- Potentially sensitive topics in talking about outcomes for this condition
- If appropriate – best ways to involve children and young people
- Participant information – what information is needed / going to be understandable in this
- Reading / hearing / seeing information – any challenges for people affected by this condition (e.g. sight / hearing issues)
- Questions to be used in study – understandable?
- Layout of questionnaire – accessible?
- Timescales between surveys (if applicable) – appropriate / acceptable?
- Keeping patients interested in a survey that might have to be completed 2/3 times (if applicable)
- Best ways to run a group decision making (consensus) meeting, if applicable – joint (with clinicians) / separate?
- Logistics of meeting (if applicable) – day of week / location (hospital or in community) / accessibility issues / dress code etc
- Support before and during meeting (if applicable)
- Ethical considerations
- End of study information (for participants and for summaries of study results in newsletters etc) – what information is needed / going to be understandable
- Other issues of relevance in planning the COS