Checklist for public research partners and Core Outcome Set (COS) study developers involved in designing a COS study

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