Questions regarding outcome list generation

Systematic reviews and reviews of qualitative literature

When undertaking the systematic review of outcomes or a qualitative literature review (also known as qualitative evidence syntheses), Public Research Partners (PRPs) can collaborate with the research team to consider:

- The eligibility criteria and scope for the review
    - Should the review exclude or include specific types of studies?
    - Is the scope of the review too broad or narrow?

Qualitative interviews and focus groups

When planning and analysing qualitative interviews/focus groups with patients about outcomes of importance to them, PRPs can collaborate with the research team to consider:

- The topic guides
    - What questions do you think should be used to find out what outcomes are important to patients / the public and why they are important?
    - Are the intended questions in the topic guide understandable – could anything be misinterpreted?
- The participant information sheets and consent forms for the qualitative study
    - What information needs to go into the participant information sheets to help patients understand the purpose of the study, what will happen in the study and any ethical considerations?
    - Do the participant information sheets cover everything that you think should be covered, without being overly detailed?
    - How readable and understandable are the participant information sheets and consent forms for your COS interview / focus group study? Does anything confuse you? Could anything be misinterpreted?
- Sampling strategy
    - How can we ensure the sampling strategy is appropriate and inclusive for the COS interview / focus group study?
    - What should we pay particular attention to in terms of the sampling participants for the study?
- Accessing patients / public participants
    - What are the best ways of accessing relevant patients / potential public participants for participation in the COS interview / focus group study?
    - What should the recruitment strategy be?
    - How should the study should be promoted to patients / the public?
- Ethical issues:
    - What ethical issues might there may be with patient participation in the COS interview / focus group study (for example, any risks from participation)?
    - Is there anything about the interview / focus group design that you feel could cause distress to potential patient / public participants? If so, what could be done to address this?
    - Is there anything about the interview /focus group study design that you feel could impact the confidentiality or data protection of the study participants? If so, what could be done to address this?

- Conduct of the interview / focus group
    - Consider whether the interviews/focus groups would best be held in-person, online, by telephone or hybrid?
    - If in-person, how can we ensure the venue is accessible for patients / the public?
    - What adaptations might be needed to make sure patients / the public can participate in the in-person interview / focus groups (e.g. room layout, breaks, venue accessibility, baby changing / breast feeding facilities, prayer room, timing and day of the interviews / focus group, interpreters etc)?
    - What adaptations might be needed to make sure patients / the public can participate in the online interview / focus group to ensure (e.g. instructions for joining, breaks, timing and day of the interviews / focus group, interpreters etc)?
- Analysis of the interview transcripts
    - Do you feel the intended coding and analysis of the data is appropriate from a patient perspective or are important outcomes potentially going to be missed?

Reporting and merging outcomes from different sources

When reporting and merging the outcomes from different sources (e.g. from a systematic review and an interview study), PRPs can collaborate with the research team to consider:

- Does the reporting of outcomes adequately highlight any differences found between the different sources?
- Whether the final list of outcomes for a Delphi has been appropriately merged
    - Which outcomes could be merged from the various sources?
    - Why those outcomes should / shouldn't be merged
    - Is the list of outcomes still too long – is further merging needed?
    - Are the merged outcomes appropriate from a patient perspective or have important distinct outcomes been lost in the merging?
- Does the final list of outcomes need refining?
    - Are patient important outcomes included in the final list? (For example, less frequently reported outcomes could be really important outcomes from a patient perspective)

Defining the outcomes

When defining the outcomes, PRPs can collaborate with the research team to consider:

- The list of outcomes identified by the scoping exercise and their associated plain language descriptions are understandable
    - Is the list missing any outcomes?
    - Why do you think these outcomes should be included?
    - What plain language descriptions of each outcome should be used?
    - Are the plain language descriptions understandable and do they adequately cover what the outcome is about?
- The grouped outcome headings and order
    - Are the grouped headings appropriate / do you feel they will make sense to patients/the public?
    - Would any of the groupings confuse you?
    - Is the order in which the outcomes presented important? (Typically, the groups of outcomes are randomised but there might be reasons not to do this).