

## Write up from COMET Workshop 3

### Involving patients in core outcome set development: identifying the challenges and potential solutions

#### Question 1

What principles and practicalities are important in accessing and sampling patients/carers in core outcome set (COS) development?

#### Distinguishing features of patients

- Distinguishing patients as those with a particular, personal perspective and those that act as advocates for others
- They may be members of a support group or a charity or advocate organization
- Patients that are research partners in the COS process (e.g. co researcher, steering group member etc) or patients providing perspectives and data for COS – these are different
- If patients are going to be co researchers or on groups then please don't have just one it is not good practice – consider mentoring them as well
- They need to know about the area of the COS development for credibility, although the issue of training patients for COS development was controversial for some due to fears that it might undermine the patient voice
- Their conflicts of interest need to be transparent, as for researchers

#### Approaching patients

- Need sensitivity and awareness of the nature of the condition under COS development
- Need to check out ethics situation – if they are research partners they generally do not need ethics, if they are data providers they do especially if you are approaching them via a clinician or health service
- Consider identity and anonymity
- Some of these issues should be discussed in some sort of group/committee/steering group and if patients are represented on this all the better.
- Practical considerations could include timing and access for COS development activity
- Checking out expectations of researchers for patients and vice versa is always helpful, how do the patients see themselves and how do the researchers see them?
- Consider going through known clinical routes if you need a sample that represents your population of interest – if this is less important then social media can be a way of accessing people. However, though evidence presented at the COMET V conference pointed to how social media led to samples that lacked diversity. Importance of ethical principles of inclusivity and fairness in accessing patients.

- Consider some principles of engagement for the COS development and then what ever methods you choose need to honor these.
- Consider if it is apparent to patients why COS development matters

## Question 2

**What principles and practicalities are important in selecting a method (e.g. Delphi, qualitative interviews, focus groups) for involving patients in COS development?**

- Involvement ideally needs to be at the start and right through the process
- Think about the methods you choose and how they will suit the needs of the patients/public you are involving e.g patients who have particular needs will require a flexible approach
- Your funder may require certain methods and approaches
- Think about the numbers of patients/public you need for your COS and work backwards – allow for drop out
- By planning with patients you can potentially avoid some of the dropout and improve experience of process by making the methods suitable
- Consider methods that might help to level the playing field and address the power differentials between different stakeholders
- Need for different methods at different stages of the COS development process, may be need for methods that allow 2-way conversation at start and end of process

## Question 3

**What are the best ways of explaining the concept of a ‘core outcome set’ to patients/carers and what types of questions can we use to elicit their perspectives?**

- To explain your COS approach and purpose develop your rationale and reason for doing the COS and how this add patient benefit
- Check in with your involved patients to see how much they understand and address these gaps quickly – analogies, such as the impossibility of comparing apples and pears, can be useful
- For example they may need to learn a bit about systematic reviews or clinical trials
- Accept that different types of patients will have different perspectives and that is why their input is so valuable – also carers/parents and families may have different outcomes in mind that patients or young people for example – ensure that their voices can be heard and not conflated
- Remember it is more important to listen than talk – whether you are gathering data or working as research partners – there is no point having them involved if they are not listened to!
- Research partners do the COS development on a equal footing to the HP’s

- Consider any training and support issues
- Consider being transparent in the process of prioritization of the outcomes – it can be very difficult to let outcomes ‘go’ but if there is an explicit process that everyone is signed up to then this helps
- Consider if the involved patients need any tech support – either actual devices or access to resources also consider library membership

## Question 4

### How can we maintain the involvement of patients/carers over time?

- Remember the common courtesies of engagement they go a long way in relationships and help oil the wheels of working together this include being appreciative of contributions, reimbursing costs incurred and payment if required, 2 way communications, ensuring that there is a feedback loop for progress updates and reports that are written in plain language.
- Consider what the return on investment is for the involved patient – what do they get out of it and what will help them keep motivated and engaged?
- Consider the cultural issues at play – this may impact on the types of engagement you do and methods you use – for example in some cultures permission is required for involvement from a community or family leader
- Try to avoid the ‘horror story’ approach to engagement and using that as the starting point!

## Question 5

### Should patients/carers be brought together with other stakeholders to achieve consensus. If so, how should this be done? If not, why not, and what other ways can be used to synthesise the views of patients/carers and those of other stakeholders?

- Don’t make assumptions about what patients do and don’t know, and about their capacity to learn or to put their perspectives across given the right context and good support and facilitation. However, good support requires investment.
- There were different views in the room about whether people should work together through the process or do it separately. Those who favored a separate approach were concerned about powerful voices dominating the agenda.