# COMET IV – Patient and public Involvement workshop

## Notes from the session

## Accessing and sampling patients

- Use patient groups to network
- Diseases – cross cutting – access through clinics
- What about the possibility of patients going into clinics to explain the importance of the core outcome set work?
- Dealing with children and children's conditions – involve the young people and go to them first
- If there is no patient group and you are just accessing through clinics you may miss patients.
- There are particular challenges where the condition is short lived and not necessarily a patient group.
- Consider the administration and ethical issues of identifying patients to take part
- Importance of involving patients from the beginning
- Remember when doing PPI it's important to build a relationship and it's difficult to do PPI if the agenda is already set.
- Possibility of accessing patients through other studies, asking patients if they are happy to tick a box on a consent form to be contacted about further studies in the future.
- The SHARE project was discussed – this is a Scottish project where patients can sign up to be contacted about research studies – more information on the project can be found here: http://www.registerforshare.org/
- National and European networks do have access to patients e.g. EURODIS.

***Notes from facilitators:***

- Discussed examples of accessing patients – through patient groups for anaesthetic before surgery group, ulcers group – patients from clinics. Asking patients after finishing participating in another trial?
- All conditions –parents and children – ask children, risks and benefits – wishes and expectations.
- Children's conditions – ask children and parents about important outcomes - chronic diseases – still got choices. Lived experience.
- National CT networks. European Research Network. Encourage involvement of young people. PRIMER / EURODIS.
- Facebook / social networks
- Put a notice in the supermarket if looking for patients – in the UK there is a social class of supermarkets – Waitrose v Lidl

- Researcher wanted to know how many patients you needed to have
- Go to where your patients might be e.g. Primary Care
- Do a scoping study at the beginning with patients.
- Concern regarding how to access patients who are not actually in healthcare and their ability to contribute to a COS if not still accessing services for a health condition.
- Could there be a box on the consent form for treatment/research to be ticked if patient was interested in getting involved in COS or anything else.

## What principles and practicalities are important in selecting a method?

- Delphi is potentially problematic – make sure you do enough preparatory work to make sure the Delphi rounds and survey are well thought through.
- Delphi – concern of using the internet – has the simplification made it reductionist?
- Delphi offers anonymity and equal vote
- At the beginning ask people how the patients would want to receive information.
- It might be important to have an insight into why patients prioritise certain outcomes
- Use lay language
- Think about possible fear of speaking – may have false positive answers – can't discover what's missing for their condition.
- Make sure you detect what is important for a patient
- If use interviews these may generate a long list of domains – consensus requires few domains – how do you combine it and make is usable(not too long) but relevant?
- eDelphi – how people access them – not everyone accesses surveys on a pc – make sure software translates for use on tablets and phones.
- Importance of choosing who does the qualitative interviews - need a qualitative interviewer who understands about outcomes to enable appropriate probing.

***Notes from facilitators:***

- Need consensus meetings
- Context dependent – patient selection. Survey – lay language for both.
- Ethics – not needed for PPI – focus group. But if participants in Delphi ethical approval may be needed.
- Avoid direct questions
- A number of people were working with children – were worried that the parents might set the agenda.
- Consensus – need a mediator so as not to miss something important to patients.
- One researcher said she regretted not having involved patients from the beginning (started after one year into a 4 year project).

## How best to explain core outcomes sets to patients

- Use focus groups – talk to patients about how they feel about answering questionnaires "we know our questionnaires aren't perfect so we'd really value your input…"
- Open ended as possible – ask what matters, what's important, what do you expect from this?
- There is an issue of some people just wanting a 'cure' and so it is important to unpick what that means.
- COS difficult concept to explain.
- Maybe think about what are patients using to make a decision about a treatment?
- Small group of patients – ask how to ask others
- Exploring words expectations – words might be too positive. Survey list of outcomes – what should we measure?
- Example from education using an opposite to ask a question about outcomes – "what makes this child not ready to learn"?
- Definition of what's 'core'.

***Notes from facilitators:***

- Even colleagues need to know what COS is
- COMET website – good
- Shared decision making process – start with what matters to you – what to expect from your treatment
- James Lind Alliance – equal patients to clinicians – good practice – Research priority setting.
- Questionnaires should be designed and trialled with clinician/statistician/patients.
- Involve patients in designing a Delphi.

## Maintaining involvement of patients over time

- Depends upon the condition – is it too far down the line – how can you remember what outcomes are important?
- HOME project – importance of getting people to understand time frames involved.
- Keeping them involved – feedback at regular intervals – keeping it on the horizon
- Design of Delphi – having patients involved in the design helps researchers with the language
- Concern about stakeholders feeling disenfranchised if their outcomes aren't in the list – importance of needing to explain that outcomes might drop out.
- Young people might like an app in the context of a meeting
- Use of incentives – worked for one project described (not a COS study) , 3 prize draws, shopping vouchers and an offer to go onto a patient database – appeared to have fewer drop outs, patients knew about it from the beginning.
- Newsletters going out to the participants – patient involvement is important to determine whether the patient participants in the study might feel overburdened with newsletters.

## Bringing people together to discuss consensus

- Huge issues getting representation from all stakeholders
- Depends upon perceived power issues? Not appropriate for young people maybe.
- Consensus international – who is going to fund it?
- If you don't bring patients in you're not hearing the patient's voice
- Having an outside chair (non-clinical) at the consensus meeting – with expertise in facilitation rather than the clinical area – helps you make progress and is someone with authority that people can refer to.
- Can you weight different stakeholders?
- Need to ensure that you don't miss something that is important for patients.