Involving patients and the public in improving research

How health care treatments are developed

To help patients, doctors and other health professionals make decisions about treatments, we need evidence about what works best. Treatments are developed and tested by researchers to make sure they work and are safe. To do this researchers need to look at the effects those treatments have on patients. Researchers do this by measuring an 'outcome'. For example, in a study of how well a new asthma treatment works, 'outcomes' might include:

- A measure of how fast you can blow air out of your lungs
- Night time wheeze
- Asthma quality of life measure

What are the challenges in measuring outcomes?

At the moment, different studies looking at treatments for the same condition often measure different outcomes. For instance, imagine two studies of how to treat migraine.

- Study A - researchers measure days off sick as an outcome
- Study B - researchers measure symptoms of pain as an outcome

When the two studies are finished, we cannot compare or combine their results because they have used different outcomes. We would not be comparing like with like.

Another problem is when a study team set out to collect information on several outcomes but in the end decide to publish the results on only some of the outcomes. This sometimes happens when the findings for particular outcomes differ from those the team hoped for.

Why is this a problem?

Other researchers could struggle to work out exactly how effective a treatment is because:

- They don't have full results from the study
- The information they do have might be biased

How can we solve this problem?

If all studies in a particular health condition used the same outcomes, they could all be compared and combined. This would reduce waste by making best use of **all** the research. When a set of main outcomes has been agreed for a health condition, it's called a '**core outcome set**'. If all studies in a particular condition, such as migraine, then measured and reported all these core outcomes, we could:

- Bring together all the studies to get a better understanding of which treatments are best
- Avoid the problem of some studies only reporting a selection of the outcomes that were measured.

How are core outcomes agreed upon?

Deciding which outcomes should be core requires a great deal of discussion. Core outcomes have to be relevant to patients, carers and health professionals. People working on core outcome sets need to make sure that this expertise – from patients, carers and professionals – is used to agree on the core outcomes. To do this they often use 'consensus methods'.

What are consensus methods?

Consensus methods are surveys, meetings and discussions where the opinions of relevant experts are drawn together. Sadly, patients and carers have not always been involved in this type of work, but now they are being included recognising the importance of their first-hand experience of living with a condition.

Why is it so important to involve patients?

Core outcome sets need to include outcomes that are most relevant to patients and carers, and the best way to do this is to involve patients and carers in their development. There are examples of how involving patients identified an outcome that was important to them as a group but which might have been

overlooked if practitioners had done the work on their own.

How are core outcome sets used when they have been agreed?

When a core outcome set has been agreed the hope is that researchers will use it in all studies for a particular condition, adding in other outcomes if they wish. For example if every migraine study used the same core outcome set, their findings could be compared and combined correctly. In the long run, this will improve the quality of information about which treatments work and which don't and help people make better choices.

What is COMET and how is it helping?

COMET stands for the 'Core Outcome Measures in Effectiveness Trials' Initiative. It involves people from around the world and in many different areas of health and social care and was set up to help in two main ways:

- to provide the COMET database as a central point where researchers, practitioners and patients can find core outcome sets that have already been developed or are still under development.
- Provide materials to support the teams who are working on core outcome sets

COMET is funded by the UK Medical Research Council and the European Union and has links with researchers across the world.

COMET recognises the expertise and crucial contribution of patients and carers in developing core outcome sets and research more generally. It's developing resources to help patients and carers to get involved in this work.

If you would like further information about COMET or are interested in getting involved please contact Liz Gargon (COMET Project Co-ordinator, gargon01@liverpool.ac.uk) or Heather Bagley (COMET Patient and Public Involvement Co-ordinator, heather.bagley@liverpool.ac.uk). Further information on COMET can be found at www.comet-initiative.org.

COMET would like to thank the many patients, parents and carers who gave their time to comment on the development of this summary.



The COMET team

(Left to right: Mike Clarke; Liz Gargon; Paula Williamson; Doug Altman; Jane Blazeby)