



What is a core outcome set and why do we need your help?

How healthcare 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 lymphoma treatment works, 'outcomes' might include:

- Complete remission
- Overall survival
- Duration of response

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 on how to treat lymphoma.

- Study A - researchers measure overall survival as an outcome
- Study B - researchers measure progression free survival 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 sets 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 do not have full results from the study
- The information they do have might be unreliable

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 and drug developers. People working on core outcome sets need to make sure that this expertise – from patients, carers and professionals, drug developers, health authorities – is used to agree on the core outcomes. 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 all the different stakeholders in their development.

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 NHL 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.

Source: COMET Initiative | Read more at www.comet-initiative.org
Check also COMET information for, and resources relevant to patients and the public, patient organisations and researchers involving patients in their core outcome set work www.comet-initiative.org/Patients