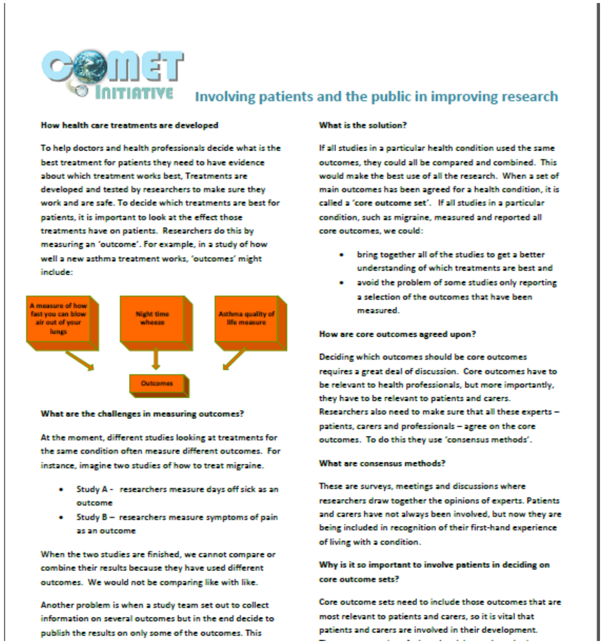
Patient and Public Involvement COMET Initiative

Heather Bagley – COMET Patient and Public Involvement Co-ordinator – heather.bagley@liv.ac.uk

Plain language resources



Involving patients and the public in improving research

How health care treatments are developed

To help doctors and health professionals decide what is the best treatment for patients they need to have evidence about which treatment works best, Treatments are developed and tested by researchers to make sure they work and are safe. To decide which treatments are best for patients, it is important to look at the effect 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

Outcomes

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

What is the solution?

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

- bring together all of the studies to get a better understanding of which treatments are best and
- avoid the problem of some studies only reporting a selection of the outcomes that have been measured.

How are core outcomes agreed upon?

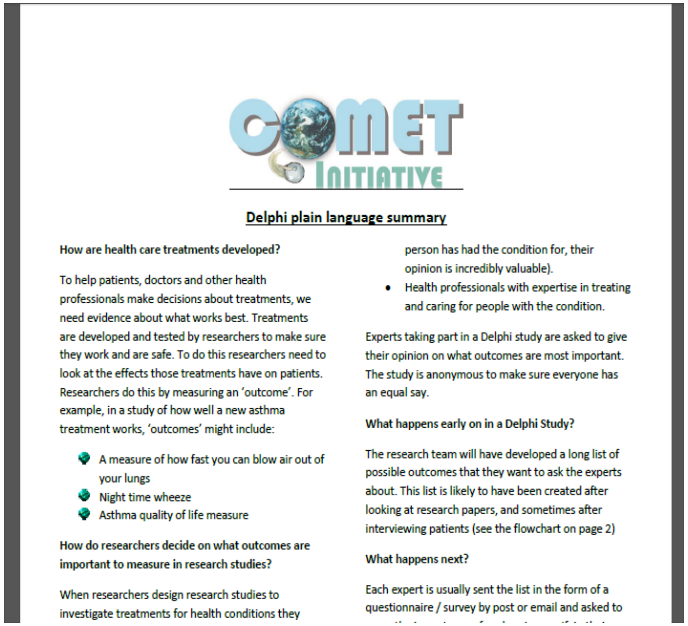
Deciding which outcomes should be core outcomes requires a great deal of discussion. Core outcomes have to be relevant to health professionals, but more importantly, they have to be relevant to patients and carers. Researchers also need to make sure that all these experts – patients, carers and professionals – agree on the core outcomes. To do this they use 'consensus methods'.

What are consensus methods?

These are surveys, meetings and discussions where researchers draw together the opinions of experts. Patients and carers have not always been involved, but now they are being included in recognition of their first-hand experience of living with a condition.

Why is it so important to involve patients in deciding on core outcome sets?

Core outcome sets need to include those outcomes that are most relevant to patients and carers, so it is vital that patients and carers are involved in their development.



Delphi plain language summary

How are health care treatments 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

How do researchers decide on what outcomes are important to measure in research studies?

When researchers design research studies to investigate treatments for health conditions they

person has had the condition for, their opinion is incredibly valuable).

- Health professionals with expertise in treating and caring for people with the condition.

Experts taking part in a Delphi study are asked to give their opinion on what outcomes are most important. The study is anonymous to make sure everyone has an equal say.

What happens early on in a Delphi Study?

The research team will have developed a long list of possible outcomes that they want to ask the experts about. This list is likely to have been created after looking at research papers, and sometimes after interviewing patients (see the flowchart on page 2)

What happens next?

Each expert is usually sent the list in the form of a questionnaire / survey by post or email and asked to

http://www.comet-initiative.org/resources/PlainLanguageSummary

Patient Information Sheets

Awareness raising

Within Cochrane

News from and for the Cochrane community


ECRAN


TTi

INVOLVE


EUPATI

Involving patient research partners in study design

Patient
Involvement
In
COS Study
design

Involving People

Working group discussions

www.comet-initiative.org/resources/publicinvolvement

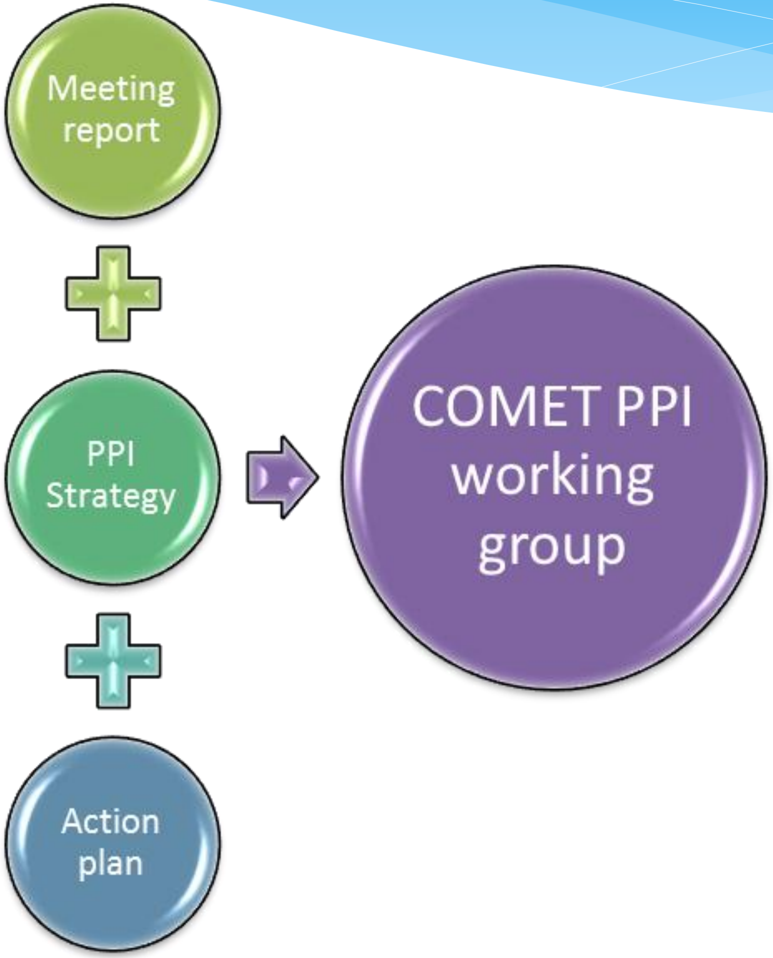
COMET Initial PPI Strategy

Examples of some of our public involvement objectives

- To raise awareness of the need to develop core outcome sets and of the work of the COMET Initiative amongst Public Involvement organisations (e.g. INVOLVE and EUPATI) and Patient organisations (e.g. patient charities / support groups)
- To be a central information hub with guidance and resources to facilitate the involvement of patients in COS development
- To produce resources for COS developers to assist them in planning for public involvement in both the design and conduct of core outcome set studies
- To work with others to further research into how to optimise patient involvement in COS development.

www.comet-initiative.org/resources/publicinvolvement

Next steps



Meeting report

+

PPI Strategy

+

Action plan

COMET PPI working group

Source: www.sign.ac.uk/patients/joining.html

heather.bagley@liverpool.ac.uk