Introducing the COMET People Participation Involvement and Engagement (PoPPIE) Working Group

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Bridget Young

CHALLENGES

COMET Patient and Public Involvement Involving People meeting

- Spring 2014
- UK public involvement organisations, core outcome set (COS) developers and COMET
- Plans for facilitating public involvement in developing COS

COMET PoPPIE Working Group

PoPPIE - People and Public Participation, Involvement and Engagement

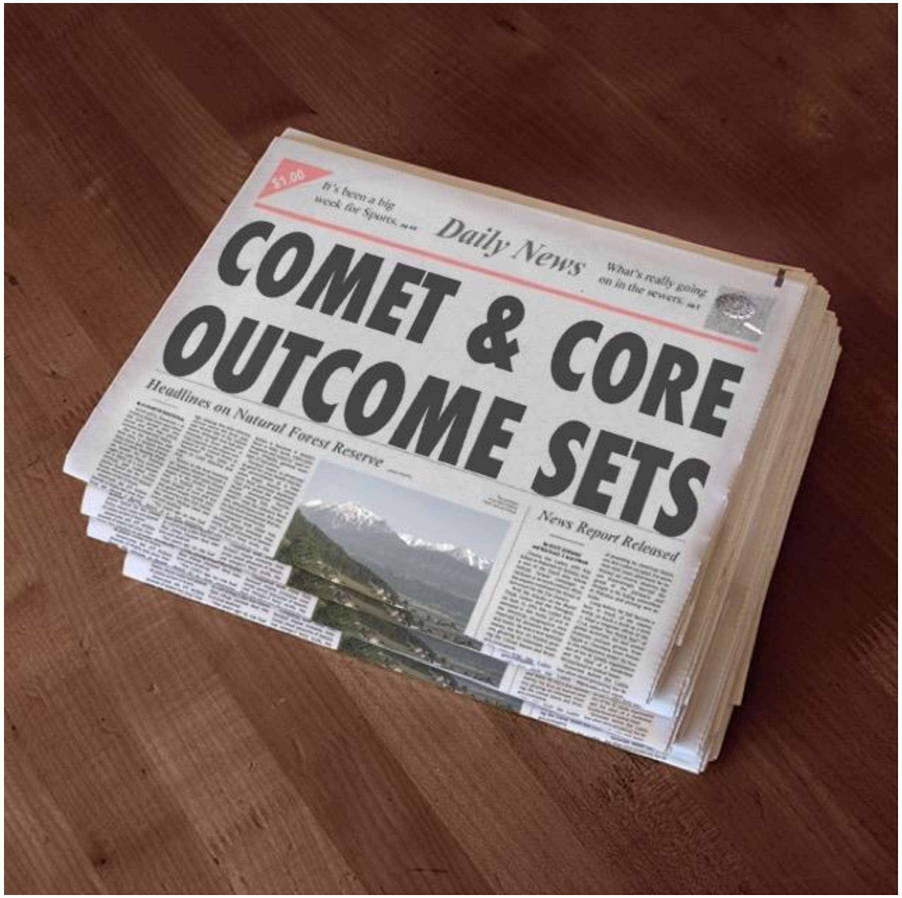
To lead the PPI and engagement work of COMET

The COMET PoPPIE Working Group

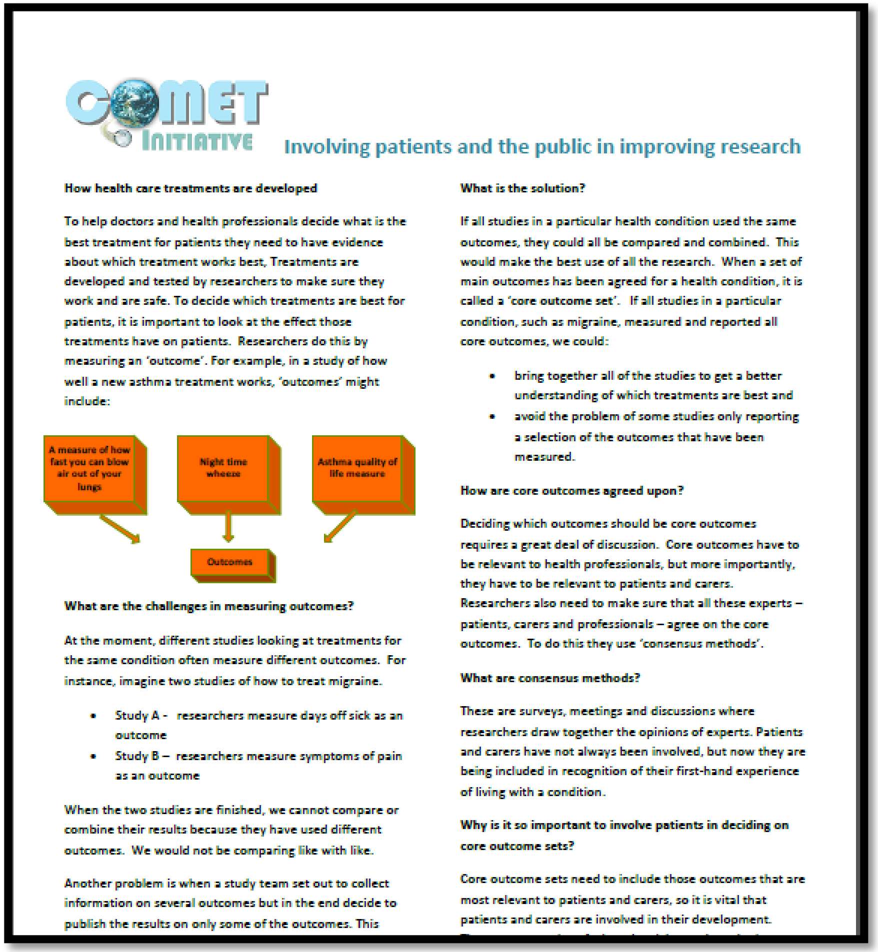
- Rosemary Humphreys
- Bridget Young
- Simon Denegri
- Jean Slutsky
- Maarten de Witt
- Heather Bagley

Raising awareness

- Association of Medical Research Councils presentation
- Cochrane UK Symposium
- EURORDIS (Voice of Rare Disease patients)
- Slide set developed



Resources



COMET INITIATIVE

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.

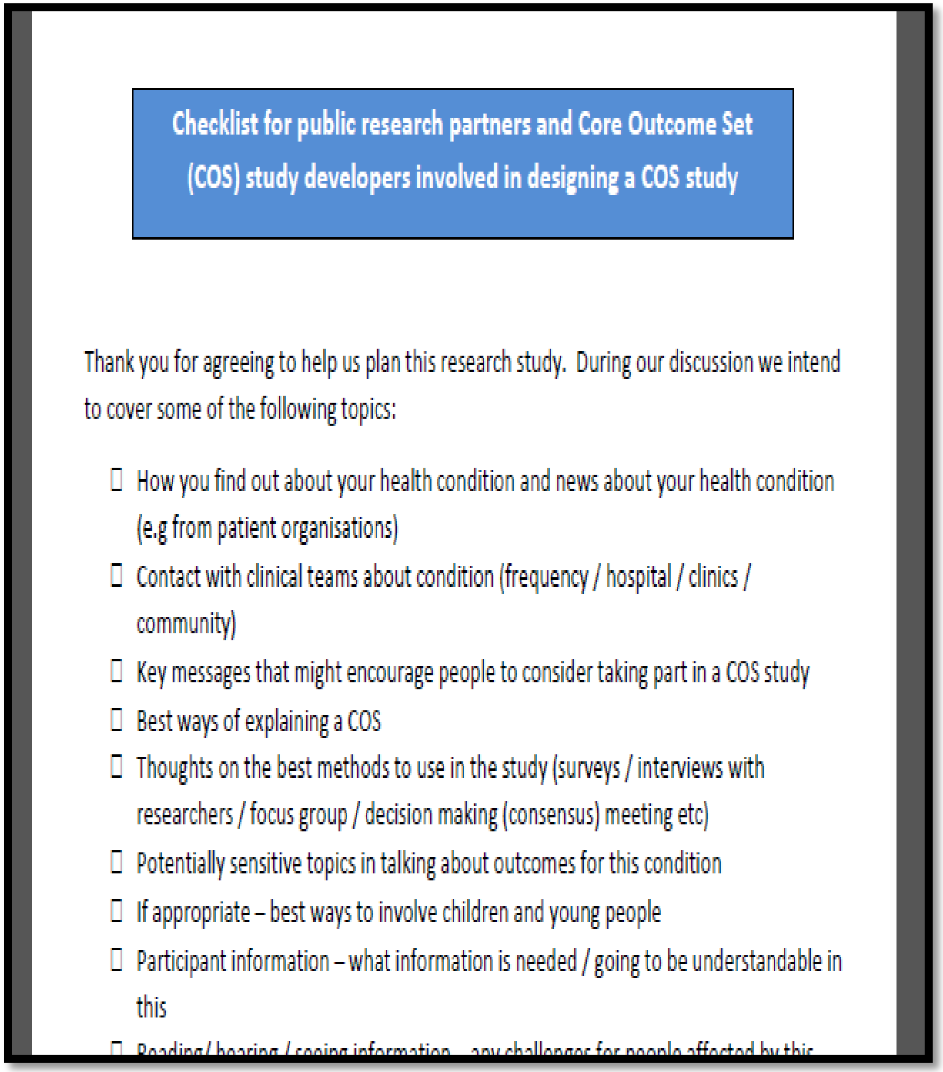
Why is it so important to involve patients in deciding on core outcome sets?

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.

- Plain Language Summaries:
  - COS (accessed by >1100 people from 45 countries)
  - Delphi
- Video – PPI in a core outcome set (MOMENT study)
- Webinar for EURORDIS

Resources

- PPI checklist for COS developers
- Making information accessible for patients and the public
- End of study information
- Social media guidance
- Consensus meeting evaluation form example
- Commentary article - issues to consider when including patients



Checklist for public research partners and Core Outcome Set (COS) study developers involved in designing a COS study

Thank you for agreeing to help us plan this research study. During our discussion we intend to cover some of the following topics:

- ☐ How you find out about your health condition and news about your health condition (e.g from patient organisations)
- ☐ Contact with clinical teams about condition (frequency / hospital / clinics / community)
- ☐ Key messages that might encourage people to consider taking part in a COS study
- ☐ Best ways of explaining a COS
- ☐ Thoughts on the best methods to use in the study (surveys / interviews with researchers / focus group / decision making (consensus) meeting etc)
- ☐ Potentially sensitive topics in talking about outcomes for this condition
- ☐ If appropriate – best ways to involve children and young people
- ☐ Participant information – what information is needed / going to be understandable in this
- ☐ Reading/ hearing / seeing information – any challenges for people affected by this

Associate Panel

- Advise on resources for patients, patient organisations and researchers
- Learn from patient communities in a diversity of countries and geographical areas
- Identify gaps where further resources are needed

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Next Steps

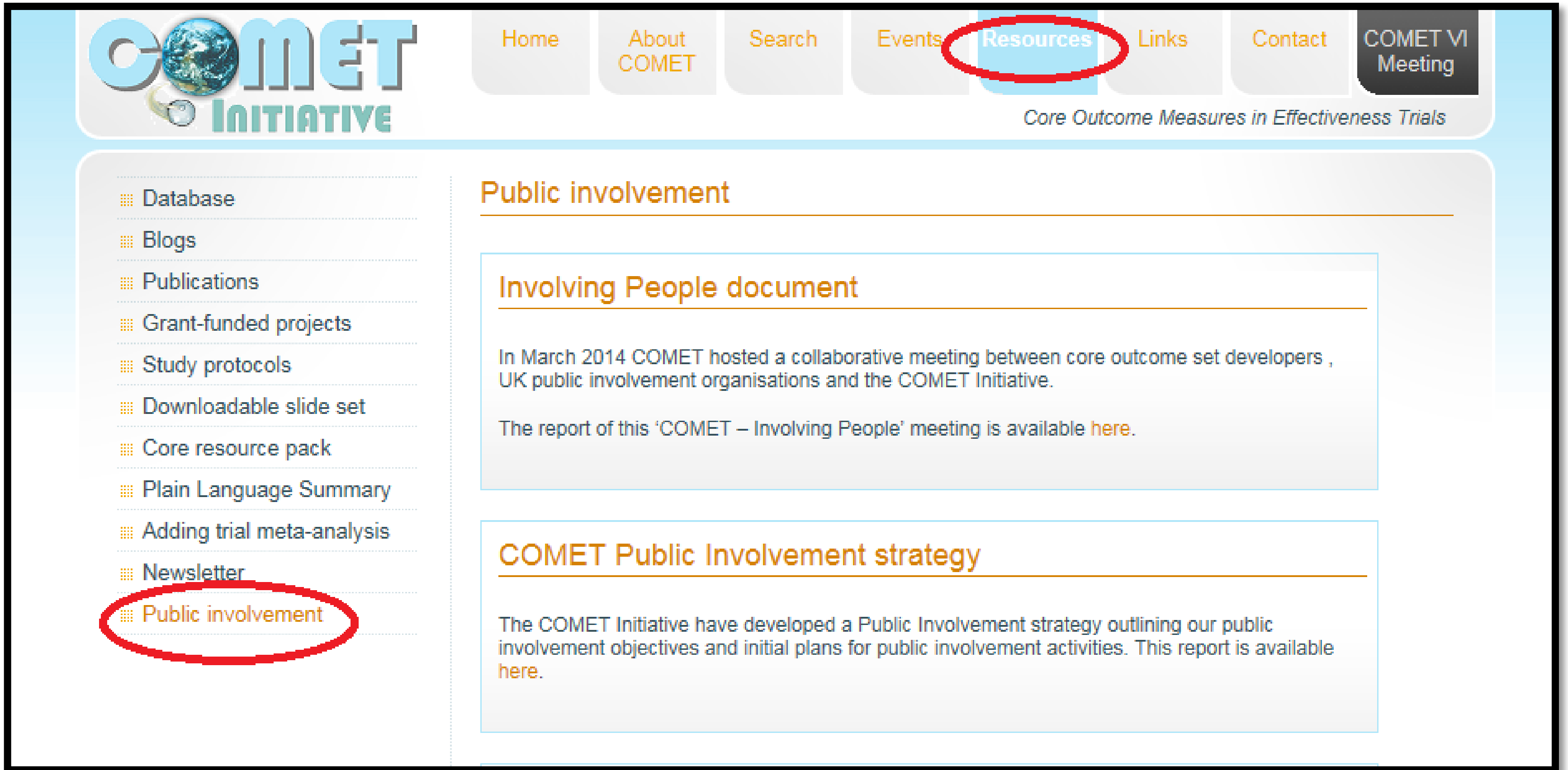
Develop:

- COMET website public involvement pages – new resources and re-organisation
- PPI toolkit (to use during the 'life course' of a COS study)
- International PPI Network on COS
- COMET PoPPIE Associate Panel

Where to find the resources

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

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



Public involvement

Involving People document

In March 2014 COMET hosted a collaborative meeting between core outcome set developers , UK public involvement organisations and the COMET Initiative.

The report of this 'COMET – Involving People' meeting is available here.

COMET Public Involvement strategy

The COMET Initiative have developed a Public Involvement strategy outlining our public involvement objectives and initial plans for public involvement activities. This report is available here.

Study of patient and public involvement in design and conduct of COS studies

Investigate experiences of patients/public with PPI roles in COS

Phase 1: Telephone interviews with patients/public involved in COS development as partners, co-investigators, advisors or members of study teams.

Aims to inform the development of guidelines and resources to facilitate improved engagement with patients as key partners in COS development.

Interesting in taking part?

Lucy Brading
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Any questions?

What resources would you find helpful?

Interested in the Associate Panel? Email Heather: heather.bagley@liverpool.ac.uk