The COMET People Participation Involvement and Engagement (PoPPIE) Working Group – An update

Rosemary Humphreys & Heather Bagley
The COMET PoPPIE Working Group

- Rosemary Humphreys (Co-chair)
- Professor Bridget Young (Co-chair)
- Simon Denegri OBE
- Jean Slutsky
- Maarten de Witt
- Jan Geissler
- Heather Bagley
The COMET COS Video

http://www.comet-initiative.org/resources/PlainLanguageSummary
Raising awareness of the Video

- NIHR
- Involving People
- Cochrane
- University of Western Australia
- EURORDIS
- NICE
- iCAN
Evaluation of the Video

• 460 views
• Evaluation question
35 responses:
  – Extremely well: 25
  – Reasonably well: 10
POPPIE RESOURCES
### Resources

<table>
<thead>
<tr>
<th>New</th>
<th>Developing</th>
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<tbody>
<tr>
<td>• Tips for Designing an Accessible Core Outcome Set Consensus Meeting</td>
<td>• Nominal Group Technique plain language summary</td>
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<td>• What are the research ethics considerations for core outcome set studies with patients?</td>
<td>• Resource for public research partners co-producing participant information sheets for COS studies</td>
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<td>• What’s it like taking part in a consensus meeting?</td>
<td>• Remit document for public research partners</td>
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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
- Research article - issues to consider when involving patients
Working with young people

- iCAN Edinburgh Summit 2018
- COSMIC group
Headlines from our involvement work

**Likes**
- Videos
- Clarity on how COS will help
- Hover over Delphi question and its spoken
- Try to give consensus meeting a social, fun, friendly vibe
- Nice food!

**Dislikes**
- Boring presentation of Delphi
- Long lists of outcomes to score

**Mixed feelings**
- Games
- Seeing others scores
- The 1-9 scale
Cochrane Colloquium Workshop

Discussion points

• Positive about COS as a way of ensuring the voice of patients in selecting outcomes for reviews
• Lack of awareness of COS amongst Cochrane review authors
• Use of the Cochrane Task Exchange to promote COS
The International PPI Network

• Why important for COMET and useful for COS developers?
• Progress to date
PoPPIE Associate Panel

• Advise on resources for patients, patient organisations and researchers
• Insights on patient communities in particular geographical areas
• Identify gaps where further resources are needed

Any COS developers interested in joining please contact: Heather.bagley@livepool.ac.uk
Next Steps for PoPPIE

Further development of:

- PPI toolkit (to use during the life course of a COS study)
- Public pages on COMET website - additional resources and re-organisation
- Our awareness raising activities (especially within the International PPI Network)
- Involvement with Alice Biggane (PhD student) – Delphi video
- COMET PoPPIE Associate Panel
Where to find the resources

http://www.comet-initiative.org/ppi

http://www.comet-initiative.org/resources/PlainLanguageSummary
Any questions?

What resources would you find helpful?

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