

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

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**CHALLENGES**

# 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

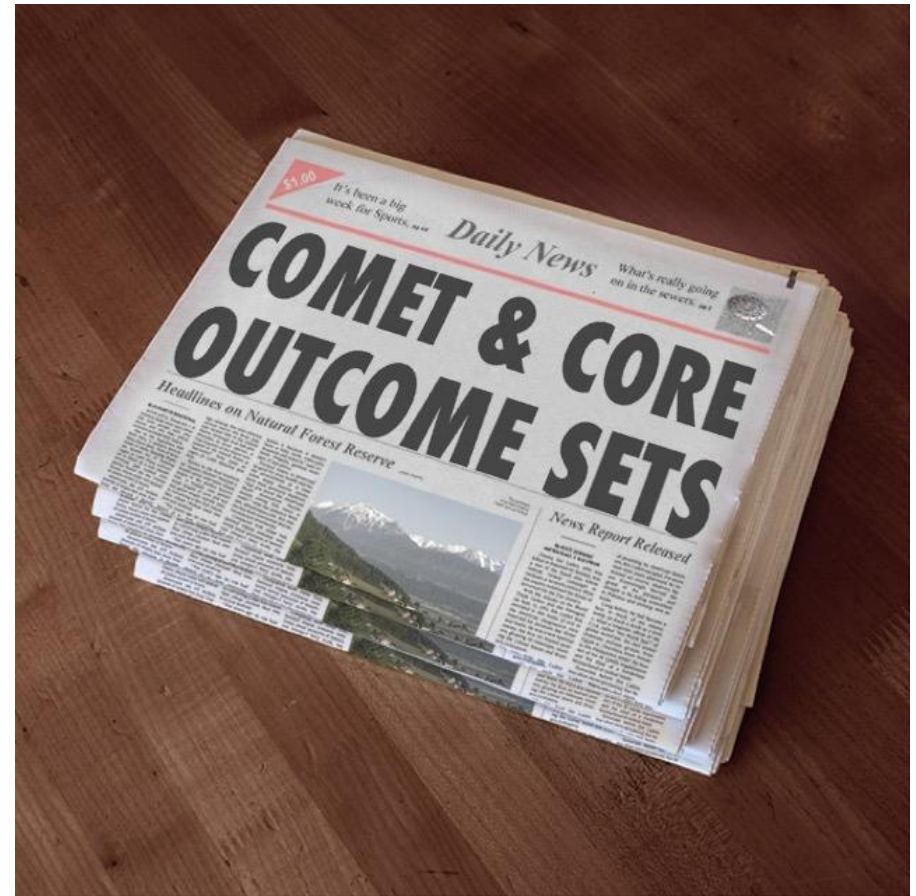
# The COMET COS Video



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

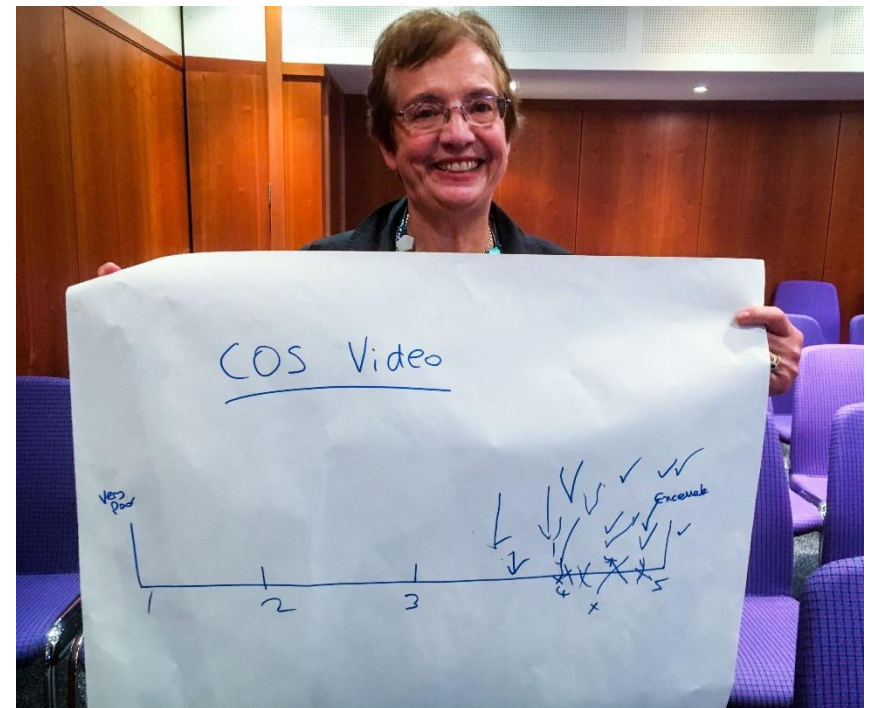
# Raising awareness of the Video

- 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





# Resources

## New

- Tips for Designing an Accessible Core Outcome Set Consensus Meeting
- What are the research ethics considerations for core outcome set studies with patients?
- What's it like taking part in a consensus meeting?

## Developing

- Nominal Group Technique plain language summary
- Resource for public research partners co-producing participant information sheets for COS studies
- Remit document for public research partners

# 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@liverpool.ac.uk](mailto:Heather.bagley@liverpool.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](mailto:heather.bagley@liverpool.ac.uk)