



‘COMET – involving the public’

Executive Summary

The Core Outcome Measures in Effectiveness Trials (COMET) Initiative hosted a meeting ‘COMET – Involving the Public’ in Spring 2014. This was a collaborative meeting between UK public involvement organisations, core outcome set developers and the COMET Initiative. The purpose of the meeting was for COMET to develop plans to facilitate, support and drive public involvement in the development of core outcome sets. A series of presentations were delivered to provide information on public involvement in core outcome sets. Group work sessions were used to generate discussion and ideas about public involvement in core outcome sets and more specifically the role that COMET could play in this.

The workshop discussions resulted in a range of suggestions about public involvement in core outcome sets and possible ways that COMET could support this work. As a result of the ‘COMET – Involving People’ meeting COMET have produced a list of recommendations for their public involvement work and are developing a PPI strategy and action plan to take these recommendations forward.

Introduction

On the 27th March 2014 the Core Outcome Measures in Effectiveness Trials (COMET) Initiative hosted a meeting ‘COMET – Involving the Public’. This was a collaborative meeting between UK public involvement organisations, core outcome set developers and the COMET Initiative (the list of people who attended is provided in Appendix 1). The aims of the meeting were to:

- Raise awareness amongst attending public involvement organisations about the work of COMET
- Identify resources that are relevant to facilitate public involvement in the work of COMET
- Discuss a strategy for engaging patient organisations in the work of COMET.

This interactive event involved a substantial amount of group work in order for COMET to learn from the experience of those attending the meeting. The three group work sessions focussed on the following:

- What are the challenges of involving patients and the public in core outcome set development?
- What should COMET’s strategy be to engage patient organisations in its work?
- What resources / research should be developed to facilitate the involvement of patients in core outcome set work?

Summary of group discussions

The notes from the group work sessions have been transcribed and are presented in Appendix 2. In the following section the key themes from the group work are summarised.

Group work session 1 - What are the challenges of involving patients and the public in core outcome set development?

Language

A key challenge in involving patients and the public in developing core outcome sets is the language used - it needs to be clear, engaging and accessible for all. It is important for core outcome set (COS) developers to involve patients in developing and designing any written information about / for the COS study from the outset.

Accessing patients/the public

It can be challenging identifying patients with relevant experience of the condition. Primary care could be utilised as well as individuals in clinics and through patient organisations. Due to their health status, getting involved in developing a core outcome set may not be a priority for patients or they may be unable to get involved if they are unwell. There were concerns that clinicians might act as gatekeepers to their patients.

There can be advantages and disadvantages to involving patient organisations and involving individuals. Patient organisations have knowledge of the condition and can support and provide access to people but there may be disadvantages in patient organisations self-selecting (they may act as gatekeepers) and they may have an advocacy agenda. Individuals may be able to offer personal commitment and long term involvement but the question about how representative they may be can arise and there was concern - will they feel under pressure to conform in a consensus building exercise? There are also challenges in involving patients from 'hard to reach' groups which may require special approaches.

There were suggestions to piggy back the work of core outcome set (COS) development onto other patient involvement activities, such as priority setting within the James Lind Alliance (JLA) priority setting partnerships.

Methods of involving patients

The challenge of available resources to support the involvement of patients in the core outcome set process was discussed. There were concerns about how resource issues might impact on the choice of methods for involvement, in terms of what is financially possible.

Bringing the views of all stakeholders together was considered essential and there were discussions around the best ways of doing this given an acknowledgement of potential balance of power issues. Two groups suggested keeping the process of involvement staged

where stakeholders' views are brought together at the end. In a consensus conference this might involve keeping the patients and other stakeholder groups separate in the mornings and then bringing them together in the afternoon.

There was a desire for evidence – what methods of involvement should people choose? There was some discussion that there may well be some existing evidence in education / social care and political areas that might inform the work of both COMET and core outcome set developers. It was suggested that it would be important to explore such potential resources for methodologies for engagement. There was discussion that, given the nature of varied health conditions and the impact on peoples' lives that there needs to be flexibility in choice of methods even within a single study – whilst short interviews might be appropriate for some patients, focus groups might be better for others.

A key issue in designing core outcome set projects (where patients are going to be stakeholders in the consensus exercise) was seen as having greater patient involvement in the design of core outcome set projects. Such involvement might help the COS developers adequately consider practicalities like the timing of the consensus meetings in order to maximise potential attendance.

Clarity around the need for ethical approval was raised by two groups.

There were concerns that the number of outcomes to score might be off-putting to patients thereby impacting on their participation. There was discussion about the need to systematically go back through the evidence for the consensus exercise. The possibility of patients being able to text in queries whilst attending a consensus meeting was suggested in an attempt to encourage their active involvement in the process.

One group discussed the issue of keeping patients (and other stakeholders) on focus – using the survey results as evidence in the consensus meeting, keep referring back to that evidence and also the importance of repetition of the purpose of the task involved in a consensus meeting – ensuring a clear understanding as people can lose focus on the purpose.

A key factor in consensus meetings was the skill of the facilitator to ensure that patient's voices are heard along with other stakeholders.

Maintaining patient involvement in a core outcome set process

Core outcome set processes may take some time to complete due to the rounds involved in consensus exercises. It was considered important that having patient input into the design of COS projects would enable strategies for maintaining patient engagement to be identified at the outset. The importance of regular feedback and keeping patients informed was identified. There was a suggestion that in trials we invest large amounts of time in engaging

with clinicians involved in studies and that we should be planning to invest the same amount of time in engaging patients as stakeholders in core outcome set studies.

The possibility of offering an incentive to public participants in core outcome set projects was discussed. An incentive such as an ipad competition might encourage participation.

The need to give patients ownership of the studies was identified so that patients could see the relevance of the study to them and would want to be involved throughout. It would be important to document any success stories of where ownership made an impact. In addition endorsement by patient organisations might encourage continuing involvement in COS development projects (patient organisations could promote through newsletters).

There was discussion about how we can get over the importance of core outcome sets to patients and some discussion about whether patients understand why this is a detailed process. Might some patients in response to a question such as 'what would make you feel that a treatment has been effective' just think 'if I'm cured / fixed' and therefore not see the point of the exercise?

Group work session 2 - What should COMET's strategy be to engage patient organisations in its work?

Within its PPI strategy the group felt that COMET should undertake a number of activities. These have been categorised below.

Develop strong links between COMET and patient organisations

COMET should develop links with umbrella patient organisations nationally and internationally to cascade down information about COS and the COMET initiative and to act as an intermediary between patient organisations starting a project and those patient organisations that have been involved in a completed COS. Patient groups / organisations have credibility, where a patient organisation has taken part in a COS they should be encouraged to endorse the COMET Initiative. There should be an awareness that there are not patient organisations / groups for all conditions e.g. acne / indigestion There should also be awareness many patients are not part of patient organisations and the need to think about how to communicate with such patients in COS development.

A link to patient groups might come through clinicians who often have good links with patient organisations. COMET should ensure that patient groups are aware of the relevance of COS development (not just for research but for service delivery). Patient group representatives should be encouraged to present work to COMET. COMET should also consider hosting a similar event to the Involving People event for patient organisations. The links with patient organisations should help with promoting a COS when it is happening to

relevant patient communities. COMET should also develop resources for researchers to use when approaching patient organisations.

Where patient partnerships already exist and are keen functioning groups, COMET could encourage their involvement in COS.

Develop the PPI research partner activity of the COMET initiative

There should be PPI representation on the COMET management / steering groups and COMET should develop a patient research partner panel with representation from many patient groups. COMET should use patients as champions of their work and we should work towards a goal of patients expecting to be involved in COS development.

Raise awareness of the need for COS development and the role of the COMET initiative

COMET should ensure that articles about its activities are reported in newsletters such as the INVOLVE newsletter but also COMET should have a presence at PPI conferences.

A series of patient led Podcasts about patient involvement in COS should be developed. There were suggestions that COMET might be invited to speak to relevant PPI groups. Information about the need for COS, what COMET is and how COS are developed could be integrated into the research courses that are currently available for patients such as EUPATI and the Building Research Partnership.

Be a central information hub to facilitate the involvement of patients in COS development

A range of resources / guidance documents / success stories were suggested (these are discussed in more depth in the Group work Session 3 section of this report). There was enthusiasm for case studies to be developed and for the PPI co-ordinator to have a role (using these resources) in mentoring COS developers in their PPI. It was also suggested that there might be a 'do and don't section' of how to start a COS project / funding etc. including PPI. COMET should also have a role in signposting and also in providing information about resources for patient engagement.

Drive the development/adoption of COS

COMET should be lobbying:

- For the COMET database to be consulted with before research is conducted (and that this should be part of the review process by being an item on the peer review form).
- For INVOLVE to endorse the work of the COMET Initiative and to have, as part of PPI training to undertake reviews, information about COS and the COMET database.
- COMET should seek to influence the NIHR for a themed call for COS.

There was also the question raised of how researchers can report gaps in current core outcomes to stimulate their development.

Identify patient engagement gaps in COS development

The varying amount of patient involvement in COS development was discussed and it was suggested that COMET could develop a system to identify the level of PPI in COS.

Consideration should be given to the addition of PPI to COS projects where previously none had occurred.

Group work session 3 - What resources / research should be developed to facilitate the involvement of patients in core outcome set work?

A range of resources and some possible research questions were raised during the third group work sessions.

Patient involvement in resource development

An overarching theme is the need for patient involvement in the development of COS methodology research and COMET resources. For example, consulting with patients to ask them what they would want from the COMET website. There was the suggestion that the PPI group could be an editorial board assessing whether COMET resources are fit for purpose.

Plain Language summary

The plain language summary was regarded as a good resource but some suggestions on how to improve it were made. There was a need to make the title more relevant and appealing to patients, maybe with the development of a strapline. It should be clear that patients do not think in terms of outcomes / trials / research – so the language is important. There was the need to make the resource more appealing such as incorporating some photos of patients and having graphic design input. There was a suggestion of a potential addition to the resource – a question and answer set of questions that would be relevant to a patient written and ordered in a style that would reflect a conversation about COS development. It was seen as important that the plain language summary be made available in other formats eg. video. There was a suggestion to have an explanation of the terms first e.g. ‘consensus methods’. There was a suggestion that there might need to be a pre-plain language summary with less information – if you want to know what works well / what matters to you with your eczema?

Reporting/quality assessing COS development

There should be a template for the reporting of COS studies including the PPI section of the report. A quality assessment tool should be developed for COS studies (with the involvement of patients).

Resource bank

There should be a resource bank developed that includes:

COMET information

- A clear statement about what the COMET Initiative is / is not
- FAQ section

Understanding outcomes and COS

- Repository of plain language summaries
- A video / cartoon around understanding outcomes
- Introduction for Pharma on PPI beyond Patients Reported Outcomes Measure (PROMS)

Examples of materials used in engaging patients in other COS studies

These materials should include examples of:

- Invitations to take part
- Glossaries
- Survey designs
- Survey voting forms / mechanisms etc
(These materials should be annotated with information about the pros and cons of the resources).
- Case studies of COS projects where patients have been involved in COS and what difference this has made

Designing a COS

- A list of questions around what to think about when involving patients in COS development
- Tips for good engagement
- Words to avoid list
- Guidance on the need for ethical approval
- Methodology papers

The impact of COS

- Success stories – examples of how COS has improved consistency across trials
- Personal testimonies from patients who have taken part in COS (podcasts, including the positive things that patients got out of taking part in a COS exercise)
- Testimonies from patient organisations about what they got out of the exercise and process, including how they feel they contributed to the wider field of healthcare (podcasts)
- Signpost to other (relevant) INVOLVE resources – with guidance from INVOLVE on what these resources are
- Links to other relevant resources (for patients and for researchers) including relevant engagement resources from outside health care involvement (e.g. Participation Compass) with their experience in participation in democracy

Any documents developed for the resource bank should be accessible for all (including people with sight / hearing problems) and pitched at an appropriate level for reading. The resources should take into account the need for printing and should be smartphone compatible. The PPI section should be embedded across the website with appropriate signposting to it. COMET should seek graphic design input into the materials it produces. .

Research ideas

A number of ‘methods of engagement’ questions were suggested for research / evaluation:

- How do different stakeholders interact?
- Do joint meetings work?
- What is the best way to facilitate such meetings?
- What are the information needs of patients and other stakeholders taking part in COS development?
- What is the best balance of power in consensus work – how many patients?
- What are the best methods for engagement (this was seen more as evaluation rather than research)
- Which method of COS development works best when involving patients? Why do people take part / not take part in COS studies?

Conclusions

As a result of this workshop COMET has gained invaluable input about the issue of patient involvement into core outcome sets. We are now able to make a number of recommendations.

Recommendations

COMET should:

- Raise the awareness of the need to develop core outcome sets and the work of the COMET Initiative amongst both Public Involvement organisations and amongst Patient organisations (eg. patient charities / support groups)
- Be a central information hub with guidance and resources to facilitate the involvement of patients in COS development
- Produce resources for COS developers to assist them in planning for public involvement in both the design and conduct of core outcome set studies
- Produce resources for patients interested in finding out more about core outcome sets and the COMET Initiative
- Embed public involvement in the activities of the COMET initiative
- Work with other groups to identify opportunities for developing and adopting core outcome set studies with public involvement as key
- Collate examples of the impact of public involvement on core outcome sets
- To work with others to further research into how to optimise patient involvement in COS development.

Acknowledgement

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Post-meeting note

As a result of the Involving People meeting, COMET are developing a PPI strategy and action plan to take these recommendations forward.

Appendix 1 - COMET – Involving the Public event - 27th March 2014 - Delegate List

Name	Organisation
Heather Bagley	University of Liverpool
Karen Barnes	University of Liverpool
Duncan Barron	Research Design Service South East
Sara Brookes	University of Bristol
Simon Denegri	INVOLVE & National Institute for Health Research
Bridie Evans	Swansea University
Liz Gargon	University of Liverpool
Helen Payne	NETSCC / James Lind Alliance
Gill Gyte	The University of Liverpool
Nic Harman	University of Liverpool
Rosemary Humphreys	Patient representative
Amanda Hunn	Health Research Authority
John Kirwan	University of Bristol
Delia Muir	University of Leeds and RDS Yorkshire and Humber
Sandy Oliver	University of London
Marisha Palm	INVOLVE
Jenny Preston	National Institute for Health Research Medicines for Children Research Network
Rosanna Preston	Cleft Lip and Palate Association
Victoria Thomas	National Institute for Health and Care Excellence
Heather Whitehouse	Leeds Teaching Hospital Trust
Paula Williamson	University of Liverpool
Bridget Young	University of Liverpool

Appendix 2 - Notes made by participants during group work

Group work session 1 - What are the challenges of involving patients and the public in core outcome set development?

Group 1

- Language used to communicate
 - Communicating uncertainty
 - Clear and engaging language
 - Marketing
- Challenge to identify patients / carers with experience of condition
- COS development might be a lower priority if feeling unwell, in a stressful situation etc
- Gatekeepers (wanting to protect patients eg. clinicians / patient organisations)
- Ethical approval
- Resources impacting on available methods
- Methods need to include feedback (Constant feedback – better 3 rounds with constant feedback)

Group 2

Bringing patients / carers and clinicians together

- Resources
- Jargon / language – accessible for all
- Combining all stakeholder opinion is essential
- Staged process (not necessarily brought together at beginning).

Maintaining involvement

- Condition dependent (may be unable to participate)
- Flexibility in methodology
- Piggy-back onto other things
- Time span / regular feedback
- PPI involvement from outset – ask them how we can maintain engagement

Developing questions to elicit patient views

- Language
- Involve patients in development
- Open ended vs specific

Group 3

Bringing patients / carers together

- Balance of power? / balance within clinical groups too

- JLA – Good number of patients (enough) peer support in joint meetings
- Were the survey results (evidence) used in consensus
- Systematically go back through evidence
- Keep referring back to evidence
- ? Separate groups in morning – together afternoon
- ? texting in queries
- Varying amounts of patient experience
- Skills of facilitator
- Repetition of the purpose of the exercise – real understanding – what we are trying to achieve

Keeping patients involved

- Keep patients informed
- Use an incentive to the them to come and maintain them (eg. ipad competition – big response rate)
- Feel patients own study / interested in it (patients seeing relevant to them)
- Identify major success stories where ownership of study impacts
- In trials much time invested in engaging clinicians ? same for engaging patients
- Newsletter?
- What impact does it have keeping the results for consensus (not feeding back sooner)?
- Number of outcomes to score – does it put you off?
- Endorsement from patient organisations
- How do we get over the importance of outcomes
- Do patients want a cure as an outcome?

Group 4

Accessing patients / carers

- Organisations
- Individuals in clinics
- Depends on purpose
- Depends on disease
- Primary Care

Are the organisations changing?

Pros and cons to be aware of

	Pros	Cons
Organisations	Know about it	Self-selected
	Have people	Advocacy agenda
	Have responses	Not 'fresh'
	Can offer support	
Individuals	Personal commitment	Social pressures to conform (with ways)

	Long term involvement	Representative?
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- Difference between participants in research and collaboration (partners)
- Some question of ethics approval
- Special challenge in hard to reach sectors, special approaches
- Need to consider advocacy when considering where to identify patients.
- Need to match task to skills / abilities for each purpose
- Evidence about to do this
- May get evidence from elsewhere

Further discussion

Method – in relation to purpose of engaging - surveys v discussion groups.

Work out from research protocol which bit we are involving.

Evidence – which methods to choose?

Evidence in education and social care (politics) – what methods have they used in similar types of work?

Might depend upon setting (e.g. primary care).

Methods need to be specific to each project. In some situations interviews / others focus groups in the same project.

Having to have flexibility in methodology – methods appropriate.

Greater patient involvement as research partners in the design – what would be the best way to take forward?

Consensus process for certain groups.

Stages process – keep people’s opinions separate and then together at the end.

Piggy back the project onto existing projects as you have an audience that’s already listening eg. JLA.

Need strong facilitation skills

Give patients more ownership

Consider timing of the meeting – patient involvement may help.

Do patients think that the question that we are asking in COS development is relevant or do they think it is a ‘silly’ question to ask – maybe they believe that an effective treatment is just a cure and that puts them off getting involved?

Group work session 2 - What should COMET's strategy be to engage patient organisations in its work?

Group 1

- COMET produce guidance for specific research groups to then utilise when work about to commence
- Patient group reps presenting work at COMET
- Need to get across why COS relevant to a patient group including service delivery
- Lobbying on behalf of COMET
- Umbrella patient organisations – cascade down
- INVOLVE newsletter
- Membership of PPI representation on COME management group
- Patient panel with representation from lots of groups
- Signposting between COMET and patient groups
- Podcast – patient led
- Need to remember that there aren't patient organisations for everybody
- Many health care professionals have good links with patient groups

Group 2

- COMET help groups access a wider range of patients
- Have a member of a patient organisation as part of the steering group
- COMET PPI co-ordinator mentor COS groups – keep information on how COS developers do this (case studies)
- COMET – awareness raising ordinary patient support groups when a COS is happening – or lobby researchers.
- JLA partnerships – clinicians and patients well placed for further work – a next step doing COS after the JLA PSP (linking with existing projects as stakeholders already interested)
- Have patients as champions
- Should be lobbying for the COMET database to be consulted with before research is conducted (part of review process) part of peer review form
- NIHR themed call for core outcome sets
- Through INVOLVE – Training the patients that undertake review to include looking at COMET database
- ? Charter for patient organisations – clear how they can be involved eg. here are things that you can help us with or here is your potential for involvement
- ? Raise awareness of COMET through NICE 'Patients Involved in NICE' group – invitation to present about COMET received.
- Some existing COS datasets have not had PPI – Can PPI be added retrospectively – validation process?
- Could be a rallying call for change
- Could be a traffic light system to flag gaps in PPI
- Could there be a set of criteria by which to accredit / judge core outcome sets?

- There should be reporting standards for COS including about the PPI that they have had as they are publishing
- Is there a process for researchers to report gaps in core outcomes?

What would good engagement look like?

- Evaluative, reflective, case studies – key questions
- Need to include areas which don't have patient organisations but would benefit from a core outcome set eg. dyspepsia
- However patient organisations do have credibility

Group 3

- Channel of communication – not all patients members of organisation
- COS developers should engage patients, not COMET
- COMET could provide information leaflets for research developers and patient groups
- Act as central information place
- Need endorsement list to raise awareness
- Case studies and success stories
- Need to raise COMET profile to confirm validity
- ? Patient steering group
- Do and Don't section of how to start project / funding etc
- Intermediary between patient organisation starting project and those that have completed them
- Clear message about what COMET's role is and what COS are:
 - Central hub for resources
 - Signpost
 - Resources about engagement
- Patient organisations could better publicise COMET – integrating multiple studies 'piggy back'
- Integrate COMET into research courses already available to the public eg. EUPATI, free to patients and Building Research Partnership
- D/W Clinical Studies groups
- Continuity – follow up on projects
- Neutral place to get feedback from patients

Group 4

- To develop the strategy for patient organisation engagement we need > 2 active contributors

Further discussion

Peer reviewers to look at core outcome set

Signpost database

All NIHR – should be a question about COS on their forms

Build on studies that have had PPI in design

One line commentary which have / haven't had PPI in COS

Resources for researchers to use to approach patient organisations

Any communication – why COS is relevant to that group

Use umbrella organisations – nationally and internationally

INVOLVE endorse / raising awareness

Changing system so patients expected to be involved

NICE uses traffic light system for PPI

Systems on research grants to prompt applications / peer reviewers

Are patient partnerships ready for more? What next after JLA? What next when you have an established functional performing group?

Endorsements from patients' organisations already worked with COMET

Endorsements tab – increase organisations on that tab

Patient organisations that have been through COS to act as a mentor for other patient organisations

Of the 31 COS with patients already done how many have involved patient organisations? What about ongoing COS?

Tap into existing PPI groups and questions who decided on outcomes.

More than one patient involved in the steering committee.

Group work session 3 - What resources / research should be developed to facilitate the involvement of patients in core outcome set work?

Group 1

Plain Language summary

- Title of 'Plain language summary' – Introduction to COMET
- Research focused – need for Q&A questions to come from patients
- Graphic design
- Photograph – ideally have a patient / less formal
- Accessibility – other formats – all documents
- Ordering of Q&A reflect on a conversation about COS
- Have explanation of terms first – example consensus methods

Resources

- Links to general PPI
- Template for reporting to patients
- Examples of invitations to take part
- Survey designs / voting forms etc.
- Annotations of resources pros / cons of each depending on COS
- List of questions – what to think about
- Example of how COS has improved consistency across trials – OMERACT
- Glossary of terms – useful for patients and clinicians
- Examples of work already done and how patients were involved- format needs consideration
- Any documents – colours used – printing, smartphone compatible, accessible to all

Research

- How do different stakeholders interact?
- Do joint meetings work?
- How should they be facilitated?
- What information do people need?

Group 2

- Quality assessment tool – to include patients
- Identification of methodology papers
- Identify what patients / public might want from the website
- Consider approach to drawing patients in – base around health conditions rather than ‘core outcome set’
- Personal testimonies / case studies / videos (cf NICE committees)
- Link to existing relevant resources

Group 3

- Plain language summary – could be more focussed about what patients think
 - A summary that doesn’t include ‘effectiveness’ (a patient friendly strapline or title)
 - Patients don’t think in terms of outcomes / trials / research
- Glossary
- FAQ
- Clear about what COMET is / is not
- Story / narrative to parallel plain language summary – could be tailored to make relevant to groups using it
- Case studies (bad as well as good)
- Toolkit – eg. what’s a Delphi / qualitative work guidelines (some form of flow chart / decision tree)

- Repository of plain language summaries / resources etc. so people / groups aren't re-inventing the wheel
- Ethics approval (where is this needed?) guidance

PPI section

- Intro for pharma on PPI beyond PROMS
- Involving your PPI contacts in other ways eg study design
- Info suited to different audience needs (patients, researchers, pharma)
- Point to other INVOLVE resources
- Whole website – readable to anyone

Group 4

Resources

- Pod casts patients+ quotes from patients on COMET website (to include what else you get out of taking part in a COS)
- Examples of glossaries
- Case studies
- Tips for good engagement (prepare patients, running things in different ways, new to everyone)
- Pre plain language with less information – if you want to know what works well / what matters to you with your eczema?
- What did patient organisations get out of it (blog / video) – what did they feel they contributed to the wider field of healthcare.
- Links to specific areas on the INVOLVE website (Get INVOLVE involved in directing this)
- Cartoon film – what are outcomes? (Like on ECRAN site) Available on DVD in case don't have internet access. Make sure that audio reflects content for people with sight problems.
- Links to relevant engagement resources outside health care involvement eg. Participation compass (not just INVOLVE) experience of participation in democracy
- How do we get PPI into our resources so we know are they fit for purpose (? Editorial board)
- Another event like today for patient organisations (charities etc.)

Research

- What is the best balance of power in consensus work – how many patients?
- Best methods for engagement – evaluations rather than research
- RCT of two methods of COS development
- Why do / don't people take part in COS?

Further discussion

PPI section – embedded across website & signposts to that

Documents – what format could documents be in – black and white – can you read from smartphone

Having a design element improves first impressions

Words to avoid list

Before do more advertising – need to show COS make a difference