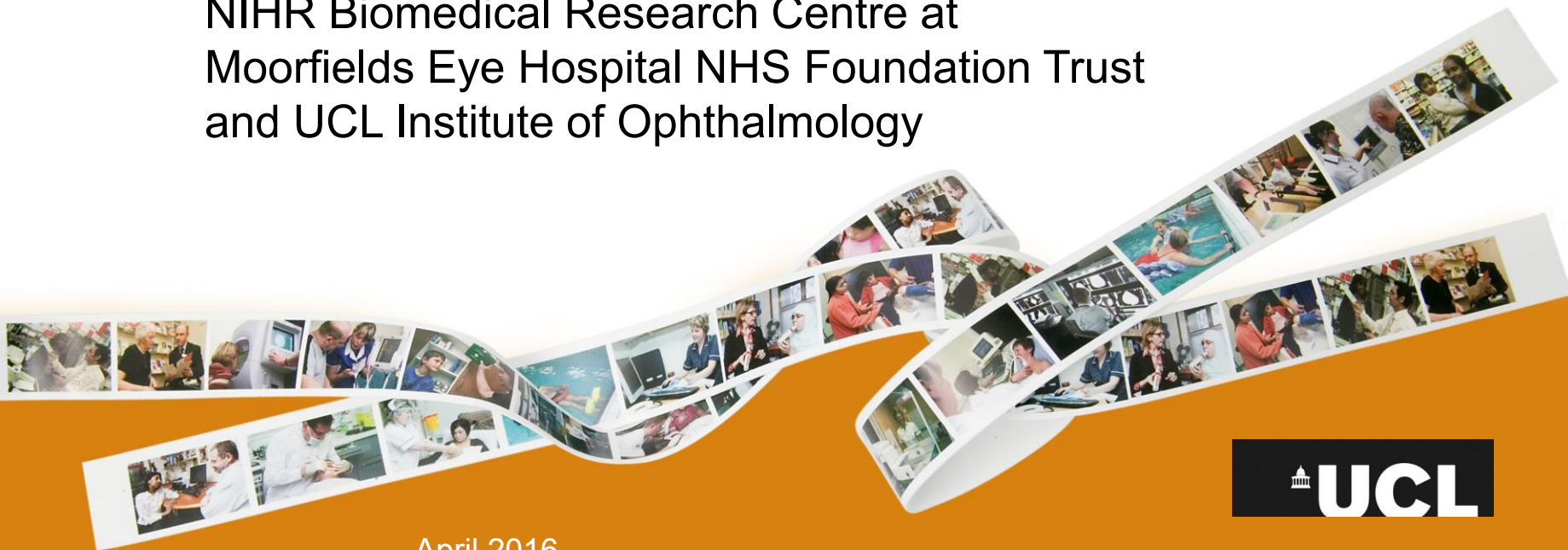


# An Introduction to PPI in Research

## Patient and Public Involvement in Ophthalmology Research

NIHR Biomedical Research Centre at  
Moorfields Eye Hospital NHS Foundation Trust  
and UCL Institute of Ophthalmology



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# 1. What is Patient and Public Involvement (PPI)?

- **When members of the public (*including patients*) are actively involved in influencing research such as:<sup>1</sup>**
  - i. through institutional committee membership (strategic and operational);
  - ii. design of a research project where research is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them;
  - iii. working with research funders to prioritise research;
  - iv. offering advice as members of a project steering group;
  - v. commenting on and developing and disseminating research materials;
  - vi. undertaking interviews with research participants.
- PPI can positively influence both clinical and basic research
  - In 2016, Parkinson’s UK released a resource for researchers which has excellent examples of the what constitutes PPI in these areas
  - [https://www.parkinsons.org.uk/sites/default/files/ppi\\_resource\\_for\\_researchers\\_pdf\\_1462kb.pdf](https://www.parkinsons.org.uk/sites/default/files/ppi_resource_for_researchers_pdf_1462kb.pdf)

1. <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

## 2. What PPI isn't...

- **PPI is not** researchers raising public awareness of research, sharing knowledge or just providing information (this is **patient & public engagement [PPE]**) **nor** is it patients and the public being recruited to be enrolled in a research study (this is **patient & public participation [PPP]**).<sup>1</sup>
  - However, PPI/E/P are often linked and can complement one another.
- **PPI is about acceptability not feasibility and sometimes this is in part about judgement:**
  - **Acceptability is experiential** - how the recipients of (and / or those delivering) the research perceive and react to it;
  - Feasibility is informed by acceptability but is about:
    - the demand (is the intervention taken up?),
    - implementation (can it be delivered as planned?),
    - practicality (can it be delivered despite constraints, e.g., of resources and time?).

1. <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

2. Brooke-Sumner *et al.* BMC Psychiatry 2015; **15**(19): <http://dx.doi.org/10.1186%2Fs12888-015-0400-6>

# 3. Why do PPI?

- **PPI improves overall research quality by helping to prioritise research and make it more relevant, acceptable and accessible to patients and the public.**
- There is a growing body of evidence that shows that PPI can also impact on research to:<sup>1,2,3</sup>
  - Improve the likelihood of securing funding through proof of greater relevancy;
  - Improve participant recruitment and retention rates on studies;
  - Improve design of study protocols including the relevancy of outcomes;
  - Support dissemination by informing how best to report findings so that they are meaningful, findable and understandable.

1. <http://www.invo.org.uk/resource-centre/examples>

2. <http://www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf>

3. Domecq et al. BMC Health Services Research 2014; 14(8): <http://www.biomedcentral.com/1472-6963/14/89>

# 3a. Why do PPI?

- **Best practice in PPI is to ensure research questions are addressing research priorities as identified by patients and the public.**
  - *James Lind Alliance Sight Loss and Vision Priority Setting Partnership (PSP)*
    - <http://www.jla.nihr.ac.uk/priority-setting-partnerships/sight-loss-and-vision>
      - Carried out in 2012 by key stakeholders in the sector, this was a national consultation which identified the research priorities for unanswered sight loss and vision research questions identified as being important by patients, the public and healthcare professionals;
      - The PSP identified 12 final priority categories of eye disease and the top 10 unanswered questions for each;
      - The survey results were incorporated into the UK Database of Uncertainties about the Effects of Treatments (UK DUETs) which publishes treatment uncertainties from patients, carers, clinicians, and from research recommendations, covering a wide variety of health problems:  
<http://www.library.nhs.uk/DUETs/Page.aspx?prv=y&pagename=SV>

## 3b. Why do PPI?

- **There may also be an important gap in the primary evidence base your research should be addressing.**
  - *Cochrane Eyes and Vision*
    - <http://eyes.cochrane.org/our-reviews>
      - This group conducts systematic reviews of the effects of interventions for prevention, treatment and rehabilitation of eye diseases / visual impairment as well as the accuracy of diagnostic tests for common ocular diseases or conditions;
      - Cochrane reviews identify the gaps in primary research that need to be addressed to improve outcomes for patients.

## 4. What does PPI achieve?

- **Patients have first-hand experience of living with a condition. They often have insights into the challenges and impacts of a disease that cannot be captured through routine clinical consultations and other reporting structures.**
- Having a mutually beneficial dialogue / partnership with patients brings their experience to bear on the key questions, outcomes, design and information for a research study and can positively shape it.



# 4a. What does PPI achieve?

Questions to think about...

*Are the research questions and outcomes relevant to patients?*

- Does the research question / purpose of the study resonate with patients as being important to address?
- How might patients' care / lives be changed or improved by the research?

*Is the design / way the research will be conducted acceptable to patients?*

- Are the intervention recovery periods/schedule of appointments manageable and compatible with daily life?
- Just because an ethics committee thinks the study is ethical, does not mean patients will be happy to take part.

*How will you enrol people to the study?*

- How will people be approached to take part?
- Will they have adequate time to consider the study and its implications before signing up?

*Is the patient information sheet useful?*

- Is the language lay accessible and is the science clearly explained?
- Have all of the questions a patient might ask been addressed, without being too long?

*How will you disseminate updates and findings about the research?*

- Have you considered how to keep people invested in the research and appraised of updates, where relevant?
- Is the language of these communications lay accessible and the science clearly explained; how will you reach broader audiences with the results?

# 5. What does PPI look like?

- There is no one size fits all formula – PPI activities must be bespoke to meet the needs of the research and those who wish to be involved if it is to add value. Some of the ways in which we commonly undertake PPI at our site are:

- **Focus groups / small group discussions**

- Group discussions / small break-out group activities (for ~3 to 30 people) can work to encourage sharing of experiences about a condition and its care; inform broader discussions around the priorities and aims of research; address the acceptability and design of a study protocol or study materials etc.

- **Surveys / questionnaires**

- Can gather broader views, experiences and opinions about research from disparate and / or larger groups of people when there are limited opportunities to bring people together. The questions require careful wording to ensure a survey is useful and stand alone. Findings can help provide a framework to direct further / future discussions with patients and the public.

# 5a. What does PPI look like?

- There is no one size fits all formula – PPI activities must be bespoke to meet the needs of the research and those who wish to be involved if it is to add value. Some of the ways in which we commonly undertake PPI at our site are:

- **Interviews**

- Face-to-face, telephone or on-camera interviews can work well to bring to life case studies around living with a condition and allow us to go deeper into one person's insights. They enable us to have an interactive discussion when a group meeting is not possible or appropriate.

- **Research Days**

- Provide an opportunity to bring together larger groups of people (~100) and discuss / feedback on a number of research projects relevant to the audience. These can be effective in breaking new ground and prioritising research in traditionally under-supported/under-recognised conditions, as well as bringing to bear broader, multidisciplinary support, charity and community perspectives on research.

## 5b. What does PPI look like?

- There is no one size fits all formula – PPI activities must be bespoke to meet the needs of the research and those who wish to be involved if it is to add value. Some of the ways in which we commonly undertake PPI at our site are:

- ***Patient Advisory Groups / Trial Steering Committees***

- A PPI group can provide important additional perspectives to help navigate unexpected challenges and comment on findings and the dissemination of data through the life of the study
- Provide patient perspective on procedures within the research programme to ensure the priorities and needs of patients are considered throughout

- ***Charities and patient organisations***

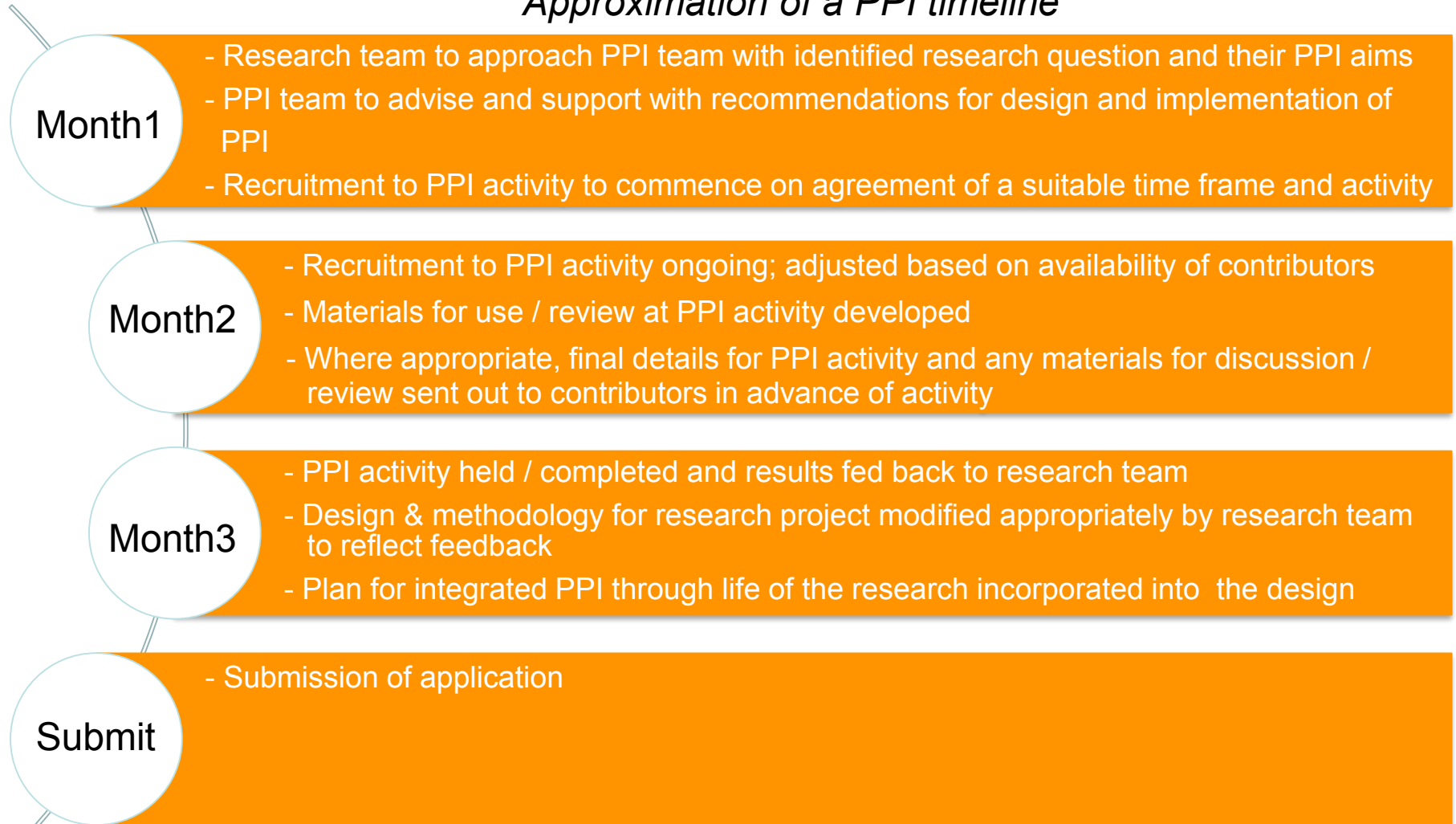
- We work very closely with a number of charities and organisations who have a very good understanding of the needs of their members and can provide invaluable insight into the priorities and needs of their members as well as provide opportunities to speak with patients who may hope to benefit from one's research

# 6. Planning for PPI

- **PPI is most effective when it is undertaken before research begins.<sup>1</sup> If you want your research to genuinely benefit from PPI then make it part of the overall planning process, not an afterthought:**
  - NIHR applications require the application itself to be informed by PPI;
  - Increasingly, funders require a PPI plan as part of an application;
  - Increasingly, ethics committees want to see that the public / patients have been involved in the design of the research and its materials;
  - PPI does not have to be expensive but it should be included in the project budget. Guidance on PPI budgeting can be found on the INVOLVE website:
    - <http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>
  - The Research Design Service can advise on incorporating PPI into your research and may be able to provide financial support for PPI from their Enabling Involvement Fund if you are conducting PPI before you have secured funding:
    - <http://www.rds-london.nihr.ac.uk/Patient-Public-Involvement/Enabling-Involvement-Fund.aspx>
- 1. Domecq et al. BMC Health Services Research 2014; **14**(8): <http://www.biomedcentral.com/1472-6963/14/89>

# 6a. Planning for PPI

## *Approximation of a PPI timeline*



# 7. How to do PPI

- **One-off PPI activities can be useful but most research will benefit from an ongoing process of PPI throughout the life of the project; this could, for example, be through an advisory group or lay membership of a steering group:**
  - As the needs of the research change or as problems arise, having access to a PPI group can provide important additional perspectives to help navigate unexpected challenges;
  - Managing expectations and keeping people informed throughout the research is critical to maintain people's commitment and interest in supporting the research;
  - Being flexible in your interactions is important - people need to fit your PPI around their lives. Let them decide on the commitment they are able to make - having a core group with other 'floating' members can allow for consistency whilst bringing in new perspectives;
  - Ensure all PPI members are supported and provided with training, clear role descriptions and adequate remuneration where necessary.

# 7a. How to do PPI

- **PPI requires you to bring people together which takes time. Conducting PPI a *minimum* of three months before planned submission of an application is recommended:**
  - For PPI to be effective, people need time to consider the research in a relaxed and informal way. It often requires experienced facilitation to ask the right questions to get meaningful feedback OR the opportunity to go home and consider things in a more relaxed setting;
  - Asking patients in a clinical appointment to review your research proposal and materials is not good PPI practice;
  - Asking someone in the organisation to review your research and check that they think it is accessible and acceptable may not capture the same insights and perspectives as speaking with patients.



## 7b. How to do PPI

- **Don't wait until the study has been approved and is active before your consider conducting PPI:**
  - Not considering PPI at the beginning can pose challenges for ethical approval processes and for recruitment and retention of participants later on when it is more difficult to make changes;
  - Informing a study design with PPI from the outset can help to identify these potential challenges for future participants and find more acceptable alternatives;
  - Certain PPI activities or recommendations from patients which, if they arise after a trial is ethically approved and is active, may in the eyes of the HRA constitute a major change to the trial protocol requiring additional ethical approval and revision of the protocol.

# 8. What support is available for PPI?

- **ACTIVE (Applied Clinical Trials Centre Investigating Vision & Eyes) at Moorfields is a collaborative ophthalmology resource for the design, conduct, analysis and reporting of randomised controlled clinical trials addressing important questions for eye health and vision, that are applying for / funded by the NIHR:**
  - <http://www.brcophthalmology.org/applied-clinical-trials-centre-investigating-vision-eyes-active>
    - Applications to ACTIVE can be made directly via the homepage (link above);
    - Supports studies received via Moorfields R&D:  
<http://www.moorfields.nhs.uk/content/our-vision>
    - Supports studies received from UCL IoO via Moorfields' R&D or via the Comprehensive Clinical Trials Unit (CCTU) at UCL:  
<https://www.ucl.ac.uk/cctu>
    - ACTIVE is linked with the Ophthalmic Stats Group and Cochrane Eyes and Vision;
    - ACTIVE members have experience in: clinical ophthalmology; statistics; PPI; clinical trial management; research and development.

# 8a. What support is available for PPI?

- **The PPI/E team at NIHR Moorfields BRC works with ACTIVE but can also provide guidance and support with planning and conducting PPI activities for non-NIHR studies that are being conducted at Moorfields Eye Hospital or the UCL IoO:**
  - <http://www.brcophthalmology.org/patient-and-public-involvement>
    - We can only support with PPI for research being conducted at / with Moorfields or UCL IoO ;
    - We can only provide support to non-animal research studies:  
<http://www.nihr.ac.uk/policy-and-standards/use-of-animals-in-research.htm>
- **The PPI/E team membership is made up of:**
  - Moorfields and UCL staff; patients and family members;
  - With expertise in: qualitative and quantitative research methodology; applied medical statistics; communications, content development and education; filming and photography.

# 8b. What support is available for PPI?

- **Since 2010, NIHR Moorfields BRC has been delivering Public Engagement and PPI activities with researchers and clinicians across the NIHR Moorfields BRC**
  - Since 2010 we have delivered:
    - **18 research days** for patients and the public designed to educate on ophthalmic disease and research and introduce PPI to patients and researchers;
    - **25 separate PPI activities** including focus groups; surveys and interviews and advisory/steering group meetings to inform the design and progress of research studies.
- We can advise on, and have experience with implementing, activities to meet the needs of people with visual impairment and considerable experience working with the third-sector.

# 8c. What support is available for PPI?

- **The NIHR Moorfields BRC have been building a “Research Community” – a database of patients and others who wish to help shape ophthalmic research:**
  - Consists of nearly 500 members representing experience in around 45 different conditions and with differing experience in PPI;
  - Is the BRC’s first port of call to recruit for PPI activities although we supplement it with recruitment through clinics and charities, where appropriate;
  - Is not a tool to recruit people as participants in research studies;
  - Membership does not yet represent all eye conditions but is continuing to grow.
- We recognise that there can sometimes be challenges to conducting PPI for a study. The PPI/E team can advise and work with the research team to explore PPI needs to address areas such as:
  - Potential challenges and difficulties;
  - Language and accessibility of patient facing materials;
  - Identification and long-term involvement of patients on committees.

# 9. What other resources are there for PPI?

- **INVOLVE** – national advisory group funded by the NIHR to support PPI in NHS, public health and social care research
  - <http://www.invo.org.uk>
- **Research Design Service** – supporting researchers at the initial stages of designing their study
  - <http://www.rds-london.nihr.ac.uk/Patient-Public-Involvement/Resources.aspx>
- **PiiAF**– Public Involvement Impact Assessment Framework
  - <http://piiaf.org.uk>
- **GRIPP Checklist** – Guidance for Reporting Involvement of Patients and Public
  - <http://www.ncbi.nlm.nih.gov/pubmed/22004782>
- **PPEET** – Public and Patient Engagement Evaluation Tool
  - <http://fhs.mcmaster.ca/publicandpatientengagement/ppeet.html>
- **A Resource for Researchers** – A Parkinson’s UK publication on PPI in research
  - [https://www.parkinsons.org.uk/sites/default/files/ppi\\_resource\\_for\\_researchers\\_pdf\\_1462kb.pdf](https://www.parkinsons.org.uk/sites/default/files/ppi_resource_for_researchers_pdf_1462kb.pdf)
- **Staff / students at UCL IoO** can find advice / resources on the UCL SLMS website and can join the UCL SLMS Community of Engagers and from UCL Public and Cultural Engagement
  - <https://www.ucl.ac.uk/slms/engagement>
  - <https://www.yammer.com> (sign up with UCL email and search for ‘UCL SLMS “Community of Engagers”’)
  - <https://www.ucl.ac.uk/public-engagement>

# 10. What if I have questions about PPI?

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