SPCR 2016 Annual Trainees' Event 19 -20 September 2016

PPI Handout – 10 tips to make it easier

The 10 tips in summary

1. Know what it is and what it is not
2. Be clear with yourself about why you are doing it
3. Understand how PPI Contributors perceive their role
4. Be clear about which type of involvement will work best for what you want to achieve?
5. Be clear about when to do it
6. Plan an adequate budget in detail
7. Recruit appropriately
8. Put time and effort into supporting your PPI Contributors and expect to have to adjust to fully include them
9. Make use of the resources available to you
10. There are specialists in each member department who can help you and many have additional resources

Tip 3 – understand how PPI Contributors perceive their role

Perceived role	**Proposed mechanism of impact**
The expert in lived experience	Through their lived experience of a condition, PPI contributors are able to consider the acceptability and feasibility of research proposals for the target population
The creative outsider	PPI contributors bring a fresh perspective from outside the research system, and can help to solve problems by thinking ‘outside the box’
The free challenger	PPI contributors are able to challenge researchers without fear of consequences
The bridger	PPI contributors bridge the communication gap between researchers and patients or the public, making research more relevant and accessible
The motivator	PPI contributors increase researchers’ motivation/enthusiasm, for example by emphasizing how the research will benefit people.
The passive presence	PPI contributors can change the way that professionals think just by being present at meetings.

Source

Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK-based qualitative interview study

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Tip 4 Know how you want to do your PPI

Style	Definition	Pros or details	Cons or details
Trial steering committee	Group that has overall strategic responsibility for the research throughout its funding period.	If appointing people to a either the project or steering group type of meeting it is always good practice to have more than one PPI Contributor. This means that they can; • encourage and support each other, • that you will get more than one perspective • if they are unable to make a meeting you have not lost your PPI input entirely.	May be rather technical, formal or strategic to enable PPI Contributor to easily make a contribution.
Advisory or focus group	when you get a group of PPI Contributors together just to ask them specific questions		
Stakeholder group	a focus group that contains PPI Contributors but also clinicians and researchers or others relevant to the study		
One to one interviews		means that you will get an intensive response	PPI Contributor will not be able to bounce off the ideas of others
Visit to an existing group	charitable support group or peer support group of people with a particular condition or need in their own setting at an existing meeting	Readily available group of people with keen interest in condition	They are there for their own reasons and not to further your research
Virtual panel	where you consult with PPI Contributors by email or telephone or Skype etc.	Please note that INVOLVE advice is that this work should be paid at the same rate as attending meetings in person. It is also good practice to only work with people in this way after you have already met with them and formed some sort of relationship.	Please note that INVOLVE advice is that this work should be paid at the same rate as attending meetings in person. It is also good practice to only work with people in this way after you have already met with them and formed some sort of relationship.
Social media		may be suitable for particular groups such as teenagers or the housebound. It may also be suitable in research on sensitive subjects where PPI Contributors may wish to remain anonymous e.g. pregnant women drinking alcohol or self-harmers.	If you do use this method provide quotes from respondents and actually specify the numbers of real respondents.

Tip 5
When?

Identifying & prioritising

Patients and the public can

- Through local user groups and organisations help inform research priorities
- Be consulted about research topics and priorities important to them as service users
- Collaborate with researchers to identify topics for research

Design

Patients and the public can

- Inform the design of the research study
- Clarify the research question and affirm its importance
- Ensure the methods selected are appropriate for patients
- Assist in creating a recruitment strategy

Development of the grant proposal

Patients and the public can

- Help to ensure that the research proposed and chosen methods are ethical
- Inform areas where patients and the public could be involved and provide ongoing advice on this
- Define outcome measures
- Advise on the appropriateness of the Lay Summary
- Raise awareness about costs of involvement, expenses and prompt

Undertaking/managing

Patients and the public can

- Steer the project throughout the research process
- Assist in writing the patient information and consent forms
- Aid in designing the detailed protocol

Analysing & interpreting

Patients and the public can

- Assist the research team in developing themes from data
- Be consulted to see if they understand and interpret data in the same way as the

Dissemination

Patients and the public can

- Advise of different avenues for disseminating results
- Jointly present the findings with researchers
- Write information for local patient groups/ hospitals etc.
- Assist in getting results published on charity and voluntary organisation websites
- Help distribute results within

Implementation

Patients and the public can

- Increase the likelihood that results of research are implemented by adding validity to the findings
- Develop patient information for new services/ interventions

Monitoring & evaluation

Patients and the public can

- Have continued involvement with the study to maintain focus and address issues as they arise
- Collaborate with researchers to evaluate the research process
- Reflect on their role and what

Tip 6 Plan an adequate budget in detail

http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/

This also has the ‘Budgeting for Involvement’ document which accompanies the cost calculator.

Payment for time (this does not relate to expenses which can be reimbursed without impacting on State Benefits)

It is strongly recommended that you encourage any PPI representative in receipt of State Benefits to contact the appropriate helpline to ensure that there are no adverse effects of their involvement work with you, prior to their involvement. It will help them if you tell them where the funding for your project comes from.

INVOLVE which will offer personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state Benefits.

It is available to:

- members of the public involved in studies **funded by the NIHR**

The process is:

- The PPI Contributor contacts INVOLVE on benefits@invo.org.uk or 023 8059 5628, what the research project is and which NIHR funding it has.
- They are then given an email address (or telephone number) to contact the Benefits advice service directly, together with a unique code that will need to be quoted. E-mail is preferred for the first contact. The service will then arrange a time to call.

NHS England has also arranged for a helpline to be available to patients and staff who have queries about being involved with NHS England’s work. Bedford Citizens Advice Bureau provides a telephone helpline service to help resolve any benefit concerns that arise from payment of fees and expenses for public involvement. The service should be contacted via email involve@bedfordcab.org.uk with a brief summary of the query, or by calling 01234 330604.

Tip 8

Reporting your PPI is now a requirement of the BMJ and other journals are sure to follow;

All authors are now asked to include the following:

- How was the development of the research question and outcome measures informed by patients' priorities, experience, and preferences?
- How did you involve patients in the design of this study?
- Were patients involved in the recruitment to and conduct of the study?
- How will the results be disseminated to study participants?
- For randomised controlled trials, was the burden of the intervention assessed by patients themselves?
- Patient advisers should also be thanked in the contributorship statement or acknowledgements.
- If patients were not involved please state this.

If this information is not in the submitted manuscript we will ask you to provide it during the peer review process.

Please also note also note that The BMJ now sends randomised controlled trials and other relevant studies for peer review by patients.

http://www.bmj.com/about-bmj/resources-authors/article-types/research

Tip 9 Make the most of the resources available to you

INVOLVE	Briefing notes for researchers	http://www.invo.org.uk/resource-centre/resource-for-researchers/
Healthtalk	Range of interviews of patients and researchers on all aspects of PPI	http://www.healthtalk.org/peoples-experiences/medical-research/patient-and-public-involvement-research/topics http://www.healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/topics
James Lind Alliance	Learn about what researchers and the public working together decide are the top research questions in your field	http://www.jla.nihr.ac.uk/
People in Research	Find recruits for PPI nationally	http://www.peopleinresearch.org/
Research Design Service	Range of advice prior to grant funding including on PPI	http://www.rds.nihr.ac.uk/ follow links to find your regional office

Tip 10 Get the help of the specialists in your department

Bristol Catherine Jameson cdzclc@bristol.ac.uk

People in Health West of England - http://www.phwe.org.uk/

Events, training, resources, signposting, finding participants

Rosie Davies, Research Fellow (PPI)

Cambridge Stephen Barclay sigb2@medschl.cam.ac.uk

INsPIRE (patIeNt & Public Involvement in Research – Bedfordshire and Cambridgeshire)

Paula Waddingham at paula.waddingham@ccs.nhs.uk.

Keele Krysia Dziedzic k.s.dziedzic@keele.ac.uk

Research User Group

Aim to recruit at least two members of the RUG to each Project Group.

Adele Higginbottom co-ordinates the PPIE within research projects.

Oxford me!

We have a pool of over 130 PPI Contributors – contact through me.

Manchester Claire Planner Claire.planner@manchester.ac.uk

http://www.population-health.manchester.ac.uk/primer

PRIMER stands for "Primary Care Research in Manchester Engagement Resource". The group is part of the Centre for Primary Care, and works with researchers at the University of Manchester and across the NIHR School for Primary Care Research (NIHR SPCR), to help promote the involvement of the public in shaping research.

The Group meets every 6-8 weeks and has two slots available at each meeting for researchers to present their emerging ideas for research and to gain advice on how to develop a project specific strategy for involving the public in their work

Every Friday we run our regular clinic which is hosted by one of our Centre PPI leads.

Training – see the website for a range of courses

Financial support for developing PPI activities - £350 bursary

Newcastle Richard Thomson richard.Thomson@Newcastle.ac.uk

http://www.ncl.ac.uk/ageing/partners/voicenorth/#about

VOICENorth (Valuing Our Intellectual Capital and Experience) was established at Newcastle University and aims to harness the mental capital and immense experience of the public in addressing the challenges and opportunities of ageing and demographic change.

For any enqueries regarding VOICENorth, please contact Dr Lynne Corner at: voicenorth@newcastle.ac.uk or 0191 208 1288

Nottingham Christina Brindley Christina.Brindley@nottingham

http://www.nottingham.ac.uk/medicine/research/get-involved.aspx

Southampton Clare McDermott crm20@soton.ac.uk

appointing person to do one day per week in Sept

UCL Fiona Stevenson f.Stevenson@ucl.ac.uk

http://uclpartners.com/our-work/patient-insight-and-involvement/

Has a community of engagement which runs virtually on yammer and meets occasionally to brainstorm and consider issues. It's user led.