PPI – 10 tips to make it easier

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1. Know what it is and what it is not

**Participation** = where people take part in a research study or clinical trial.

**Engagement** = where information and knowledge about research is shared with the public, with some interaction and listening to the public.

**Involvement** = where people are actively involved in research projects and in research organisations, planning what should be researched and how it should be done.
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2 Be clear with yourself about why you are doing it.

Philosophical impetus;
   a) public right as public money
   b) it will improve the research

Avoiding the tokenism cycle
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3 Understand how PPI Contributors perceive their role

<table>
<thead>
<tr>
<th>Perceived role</th>
<th>Proposed mechanism of impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>The expert in lived experience</td>
<td>Through their lived experience of a condition, PPI contributors are able to consider the acceptability and feasibility of research proposals for the target population</td>
</tr>
<tr>
<td>The creative outsider</td>
<td>PPI contributors bring a fresh perspective from outside the research system, and can help to solve problems by thinking ‘outside the box’</td>
</tr>
<tr>
<td>The free challenger</td>
<td>PPI contributors are able to challenge researchers without fear of consequences</td>
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<tr>
<td>The bridger</td>
<td>PPI contributors bridge the communication gap between researchers and patients or the public, making research more relevant and accessible</td>
</tr>
<tr>
<td>The motivator</td>
<td>PPI contributors increase researchers’ motivation/enthusiasm, for example by emphasizing how the research will benefit people.</td>
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<tr>
<td>The passive presence</td>
<td>PPI contributors can change the way that professionals think just by being present at meetings.</td>
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</tbody>
</table>
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4. Be clear about which type of involvement will work best for what you want to achieve?

- Trial steering committee
- Advisory or focus group
- Stakeholder group
- One to one interviews
- Visit to an existing group
- Virtual panel
- Social media
- Combination of any or all of the above (or others you invent!)
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5 Be clear about when to do it.
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6 Plan an adequate budget in detail

- Travel expenses
- Payment for time
- Hire of meeting rooms
- Payment to enable involvement such as respite care or personal assistance costs
- Advertising to recruit
- Training costs
- Refreshments at meetings
- Translation or interpretation
7 Recruit appropriately

It is important that both you, as a researcher, and the people you involve have a shared and clear understanding of what they are being invited to do:

✓ Explain why you want them involved
✓ Be clear about whether you need someone to have ‘lived experience’
✓ Develop a role description
✓ Be clear about the time commitment
✓ Be clear about what they can expect from you
✓ Be clear what the aims of your research are
✓ Be clear which aspects of the research have scope for people to influence and how much influence they will be able to have (including where there is no scope to change the research)
✓ Develop principles of how you will run any meetings that have the public in them
✓ Be clear about what reimbursement and payment they can expect
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8. Put time and effort into supporting your PPI Contributors and expect to have to adjust to fully include them.

Remember some of the basics:

- Meeting papers to be sent 1 – 2 weeks in advance. If necessary write summaries and present information differently.
- Phone contact before and after meetings to answer queries.
- Help with claiming expenses & payment and recording what they claim & receive.
- Tell them about any training that is available.
- Regular feedback so that they know what progress is being made on the project. Wherever possible include feedback on how their impact has made a difference to the work.
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### 9 Make use of the resources available to you

<table>
<thead>
<tr>
<th>INVOLVE</th>
<th>Briefing notes for researchers</th>
<th><a href="http://www.invo.org.uk/resource-centre/resource-for-researchers/">http://www.invo.org.uk/resource-centre/resource-for-researchers/</a></th>
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</thead>
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<tr>
<td>James Lind Alliance</td>
<td>Learn about what researchers and the public working together decide are the top research questions in your field</td>
<td><a href="http://www.jla.nihr.ac.uk/">http://www.jla.nihr.ac.uk/</a></td>
</tr>
<tr>
<td>People in Research</td>
<td>Find recruits for PPI nationally</td>
<td><a href="http://www.peopleinresearch.org/">http://www.peopleinresearch.org/</a></td>
</tr>
<tr>
<td>Research Design Service</td>
<td>Range of advice prior to grant funding including on PPI</td>
<td><a href="http://www.rds.nihr.ac.uk/">http://www.rds.nihr.ac.uk/</a> follow links to find your regional office</td>
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10 - There are specialists in each member department who can help you and many have additional resources;

<table>
<thead>
<tr>
<th>Location</th>
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</tr>
</thead>
<tbody>
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Finally, keep calm and don’t panic

Any questions?