

## INVOLVING MEMBERS OF THE PUBLIC IN APPLIED HEALTH RESEARCH; *Introduction to PPIE for researchers*

### **The CLAHRC Wessex view:**

CLAHRC Wessex supports applied health research aimed specifically at '*improving the health of the people of Wessex, and the quality and cost-effectiveness of health care*'. Patient and Public Involvement Engagement (PPIE) is central to everything we do - a compulsory element of our research that ensures our work remains relevant to the people it is designed to serve.

Ensuring that our registered PPI members know how to make an effective contribution to our research is important. Their views can add so much value to our research; knowing how to optimise our gains from their opinions and insight is of critical importance to our researchers.

This brief digital '*Introduction to PPIE for researchers*' is designed to support new researchers joining CLAHRC Wessex. It does not 'reinvent the wheel'; rather it signposts to existing external resources to this end.

### **Resources:**

[INVOLVE](#) have published a number of guidance documents and resources online, designed to help researchers understand how to involve members of the public in their health research.

As an example, '*Information for researchers*' provides a very good series of [briefing notes for researchers](#), aimed at providing practical information towards helping them facilitate and optimise the benefits of PPIE in their research:

<http://www.invo.org.uk/find-out-more/how-to-involve-people/information-for-researchers/>.

As a new researcher to CLAHRC Wessex, and especially if PPIE is unfamiliar to you, we would strongly advise that you schedule some time to review these documents ahead of direct engagement with PPI contributors for your study.

The following table (overleaf) summarises the '10 briefing notes' associated with the web address detailed above:

**The INVOLVE Briefing notes for researchers:**

1	'Introduction'	<a href="http://www.invo.org.uk/posttyperesource/introduction-to-the-briefing-notes/">http://www.invo.org.uk/posttyperesource/introduction-to-the-briefing-notes/</a>
2a	'What is public involvement in research?'	<a href="http://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/">http://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/</a>
2b	'Public Involvement in Research' video	<a href="http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/what-is-public-involvement-in-research/">http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/what-is-public-involvement-in-research/</a>
3	'Why involve members of the public in research?'	<a href="http://www.invo.org.uk/posttyperesource/why-should-members-of-the-public-be-involved-in-research/">http://www.invo.org.uk/posttyperesource/why-should-members-of-the-public-be-involved-in-research/</a>
4	'Why members of the public get involved in research'	<a href="http://www.invo.org.uk/posttyperesource/briefing-note-four-why-members-of-the-public-get-involved-in-research/">http://www.invo.org.uk/posttyperesource/briefing-note-four-why-members-of-the-public-get-involved-in-research/</a>
5	'How to involve members of the public in research'	<a href="http://www.invo.org.uk/posttyperesource/before-you-start-involving-people/">http://www.invo.org.uk/posttyperesource/before-you-start-involving-people/</a>
6	'Who should I involve and how do I find people'	<a href="http://www.invo.org.uk/posttyperesource/how-to-find-people-to-involve/">http://www.invo.org.uk/posttyperesource/how-to-find-people-to-involve/</a>  <i>* CLAHRC Wessex maintains its own database of contributors, making it quite straightforward to find people to involve in your research. Always contact <a href="#">Martin Simpson-Scott</a> before exploring other options.</i>
7	'Approaches to public involvement in research'	<a href="http://www.invo.org.uk/posttyperesource/approaches-to-public-involvement/">http://www.invo.org.uk/posttyperesource/approaches-to-public-involvement/</a>
8	'Ways that people can be involved in the research cycle'	<a href="http://www.invo.org.uk/posttyperesource/where-and-how-to-involve-in-the-research-cycle/">http://www.invo.org.uk/posttyperesource/where-and-how-to-involve-in-the-research-cycle/</a>
9	'What to do if things go wrong'	<a href="http://www.invo.org.uk/posttyperesource/what-to-do-when-things-go-wrong/">http://www.invo.org.uk/posttyperesource/what-to-do-when-things-go-wrong/</a>
10	'Where to go for more information'	<a href="http://www.invo.org.uk/posttyperesource/briefing-note-ten-where-to-go-for-further-information/">http://www.invo.org.uk/posttyperesource/briefing-note-ten-where-to-go-for-further-information/</a>

In November 2017, CLAHRC Wessex also produced a visualisation of 'How to Involve People in Research', focussing on how we've approached the various 'bumps in the road' along the way. Access this here: <http://bit.ly/2j0y7f0>.

### ***New 'National Standards for Public Involvement (PI)' published***

In March 2018, a new set of PI standard were published by a collaboration of the Public Health Agency, the Chief Scientist Office, Health and Care Research Wales and the NIHR.

The new 'national standards' were a culmination of 18 months of endeavour, building on previous work in this area. They aim to provide people with a clear, concise understanding of what constitutes effective PPI, alongside benchmarks and associated indicators against which improvement can be monitored.

Intended to encourage approaches and behaviours that will support 'gold standard' PPIE, the standards can be accessed here: <https://bit.ly/2uaKfPc>

### ***Involving children and young people in research***

INVOLVE also provide a suite of resources to help researchers understand critical facets of involving young people in their work. CLAHRC Wessex would like to recruit more younger people to the contacts database - something which would make our registered PPI community more representative of the population of Wessex. Whilst this ambition remains unfulfilled at present, understanding some of the critical facets of involving younger people in applied health research remains relevant:

<http://www.invo.org.uk/find-out-more/getting-involved/involving-children-and-young-people/resources-for-involving-children-and-young-people/>

### ***Providing feedback for involved PPI contributors***

A point of consternation repeatedly raised by PPI contributors working within health research programmes, is that they have no idea whether their contributions have been useful, impactful or resulted in beneficial outcomes. Typically, PPI contributors care deeply about the work to which they are volunteering their time, energy and efforts - whether they are remunerated or not. As such, understanding the value of their inputs also matter deeply.

It is generally accepted that more than just a common courtesy, affording involved patients and members of the public feedback on the outcomes of their endeavours will facilitate further engagement with not only the project in question, but the health programme in general.

In 2018 [CRiPACC](#) published guidance on the importance of PPI feedback - why it is important, who should do it and how, when etc. Endorsed by Wessex PIN, you can access this guidance document here: <https://bit.ly/2ubgZaV>

***Other sources of support, to help CLAHRC Wessex researchers enable PPI contributors to ‘hit the ground running’:***

Established over 20 years ago (1996), INVOLVE are funded by the NIHR, and the national authority on PPIE. The organisation has collated a comprehensive information set with respect to ‘where to go for further information’. To access this:

<http://www.invo.org.uk/posttypesource/briefing-note-ten-where-to-go-for-further-information/>

***Inclusivity in Public Involvement***

INVOLVE’s Diversity & Inclusion Monitoring Group published fresh guidance in February 2019, towards understanding some of the things that should be considered in developing a more representative, diverse PPI community, and thus becoming more inclusive with public involvement in health research. A short 2-page guidance document, it can be found via this link:

<https://www.invo.org.uk/wp-content/uploads/2019/02/Being-Inclusive-Health-Research.pdf>

***THIS IS A WORKING DOCUMENT - Reporting omissions and amendments***

If you would like to suggest that any material is added to this induction document please contact the NIHR CLAHRC Wessex Central Office by email ([CLAHRC-WessexPPI@soton.ac.uk](mailto:CLAHRC-WessexPPI@soton.ac.uk)) or by telephone (02380 598211) - this is viewed as an evolving document, and recommendations towards ongoing improvement(s) are most welcome.