Reviewer’s report

Title: Public involvement could usefully inform ethical review, but rarely does: what are the implications?

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Reviewer: Jacqui Gath

Reviewer's report:
I enjoyed reading this paper.

In the last 5 years, the situation re PPI has improved enormously, particularly since PPI was mandated by the HRA and many funding bodies as being a desirable aspect of any study. There are excellent examples of close and fruitful cooperation between researchers and the public as trust has grown, and the benefits discovered. There are still pockets of uncertainty, and this paper points up areas for discussion and improvement.

A timely paper paving the way to a better understanding and implementation of PPI by researchers.

Well written, in terms and style easy to understand and follow, the paper centres around section A14-1 in the IRAS submission. The examples given all resonate with the reviewer, who, as a member of an Ethics Committee, has suffered all the examples given in Tables 3 'The range of approaches used to consult the public during the design of a study' and 4: 'Applicants' justification for not involving the public in their research'.

My comments are as follows:
Researchers need education about the meaning of participation as opposed to involvement. There is a lot of confusion about this. (Is some of it deliberate?)
Researchers can help a lot by outlining what changes they have made to their work in response to PPI.
It would help if researchers took a PPI representative with them to the Ethics Committee as support and to outline how differences were resolved, if any.

Section A14-1 needs rewriting.

We should be asking that INVOLVE guidelines have been followed.

Practical implications for the Ethics service too, in researchers needing to submit amendments (Page 8 line 46)

Confidentiality: Is this such a big worry? As long as data is anonymised, the subject cannot be identified, and lay people know that confidentiality is of prime importance, the risk should be very low. Suggest that whatever rules are decided upon is part of A14-1 (Page 10 line 80)

Page 11 re results to participants (and sometimes the PPI team!)
All too often, researchers are happy to make some vague reference to a website, where interested participants may go to find the results. This is not adequate. Sometimes even the PPI team do not get the results.

Section 14-1 in the IRAS submission is not completed to the satisfaction of the Committee: If the answer is obviously not as it should be, why isn't the submission delayed until the applicant provided a reasonable response? (Page 11)

Reasons for not including lay PPI in the research - Yes, I'm tired of the explanation/excuse, when the applicant is questioned, that the subject is 'too technical for lay people to understand'. An intelligent lay person (many of whom have degrees and professional qualifications!) can understand difficult concepts especially when explained in easy to understand terms. Researchers should be reminded of this.( Page 12). Any researcher should be able to explain their work to anybody. The comment that lay people cannot understand is patronising, and can be quite insulting. (Page 12)
Researchers do not seem to want to acknowledge that PPI is a team effort, a partnership. Is it that they don't want to share the glory, ie being an author on resulting papers? Being acknowledged in publications? Being thanked for their efforts? The PPI team should be credited with all the effort they have put in, whether paid or not. (After all, the researcher is paid. (Page 12 line 48)

A pleasure to read, and more important than might be thought.
Jacqui Gath

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An exceptional article

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