Author’s response to reviews

Title: Patient and Public Involvement in reducing health and care research waste

Authors:
Virginia Minogue (vminogue@talktalk.net)
Mary Cooke (mary.cooke@manchester.ac.uk)
Anne-Laure Donskoy (al.donskoy@yahoo.co.uk)
Penny Vicary (pvicary@nhs.net)
Bill Wells (bill.wells@oxfordhealth.nhs.uk)

Version: 1 Date: 14 Dec 2017

Author’s response to reviews:

We would like to thank the reviewers for their helpful and supportive comments. We have taken their comments and amended the article to improve its clarity and readability. We hope the reviewers find the amendments acceptable.

Reviewer reports:

Reviewer #1: An interesting article, very good idea to submit the questionnaire separately to patient experts and other patients in order to appreciate the different value of their answers. Only criticism: sample size too small to be statistically significant, the survey should have included more patients.

Thank you. We appreciate and welcome your comments and would be happy to consider a much broader study in the future.

Reviewer #2: 1. I think that this paper is based on a really interesting, and ostensibly unexplored premise. I congratulate the authors for their work.

2. Page 5. Findings: I think it could be clearer whether the categories of waste were identified (which I read as 'thought up by') or chosen (i.e. from an existing list).

This has been addressed in the text.
3. I wondered if the meaning of each category could be described briefly, as has been done for 'prioritisation of research' (line 52), either in the body of the text or in an appendix - for example, people who are unfamiliar with the Lancet series on waste might wonder in what sense patient and public involvement is an area of waste.

An Appendix has been included describing each category.

4. Page 6, line 16: were the barriers to PPIE chosen from an existing list or suggested by respondents?

This has been addressed in the text.

5. Are these barriers in order of importance?

As above. Each individual respondent provided feedback and we did not weight them in terms of importance as that would have been the authors attribution not the respondents.

6. Page 6, line 17: Should this read 'NOT being taken seriously'? I think 'power imbalances' (presumably between researcher and patient rep) and 'dynamics of academic institutions' would benefit from brief explanation.

Amended in the text and the comment about academic institutions has been explained further.

7. I think the paper raises awareness of the untapped potential of PPIE to contribute to the reduction of waste in research, but I felt like it was missing a clear, practical call to action to the research community (especially those who might be sceptical or unsure about PPIE - I'm conscious that you're preaching to the converted with me). Do the authors have any recommendations for next steps, or for further investigation into this area?

This has been addressed in the discussion and conclusion.

8. Page 6, Conclusions: I agree that "PPIE representatives need to be supported to enable them to recognise and challenge wasteful practices." But do the authors have any reflections on how this can be done? Someone new to this or unsure about PPIE might just think "how?" in response to this.

This has been addressed in the text.

9. Some of the sentences are very long, I'd suggest breaking them up a bit (eg on page 6: lines 29-33, 30-37; page 7: lines 2-5, 8-10).
This has been addressed.

10. Thank you for the opportunity to comment on this paper, which I think is a useful addition to the literature on PPIE in research.

Thank you. We appreciate your comments and the helpful review.

Reviewer #3: I think that this is an interesting and topical topic and well worth researching. I think it could have been written up in a way that was more engaging and easier to follow.

I found the extent of the waste 85% shocking. Is the information available to break the 85% down into constituent parts? (failure to publish research, unclear reporting of research that is published, and the failure of new research studies to systematically review previous research in the same topic area, poor study design and conduct)

We have included a more detailed breakdown of the extent of the waste and references to texts that provide more information about the breakdown.

I found how the information was organised a little confusing - why were the findings from the R & D management group survey written up under discussion and not alongside the findings from the service user and carer survey.

We have provided more explanation of the methodology.

The surveys had different aims. The aim of the NHS R & D management survey was 'to identify their influence in ensuring research provided value and better outcomes for patients' whereas the aim of the similar survey for patient researchers was 'to assess their understanding and influence in the area of research waste'. The NHS R & D management group identified 'implementation of research in practice' as their top priority in keeping with ensuring research provided value and better outcomes for patients followed by prioritisation of research, and research taking place to time and target.

According to how I read the material the two groups were completing the same (or similar both words were used) surveys but with different aims? This jarred with me and made me question whether the research was comparing like with like?

This has been addressed to ensure consistency and clarity of purpose.

The patients researchers identified 'prioritisation of research' the most important research waste to address with the other categories being given even weight. Then in answer to the secondary question about what categories of waste that would add most value to the research process if addressed they again identified 'prioritisation of research' adding 'patient and public involvement' the rest of the waste categories being about even.
The list of barriers to involvement were all too familiar:

• Being taken seriously; tokenism;

• The low status of PPIE;

• Power imbalances;

• Lack of clarity of PPIE role;

• PPIE members' lack of knowledge of aspects of the research process and the NHS;

• Dynamics of academic institutions.

I found that there was an interesting interplay with both groups reaching out for meaningful involvement and this made me wonder what the barriers are to achieving this? It seemed like a hand and glove in search of each other and it made me wonder what was stopping them working together 'hand in glove'? I thought that the responses from the PPEI group and the R&D group in regard to PPEI and the dissatisfactions of the two groups could have been related to each other.

We have strengthened the discussion and conclusion to reflect these comments.

I wondered who the audience for this research was? In trying to understand the issues and background I used Google and landed on this website: http://www.futurefocusedfinance.nhs.uk/close-partnering/reducingwaste

The Following is an extract: "The aim of this work stream is to facilitate and engender clinical, finance and citizen engagement in reducing waste and delivering high value care by:

Actively working with professional groups to build awareness, mobilise knowledge and to identify specific areas of focus.

Engaging in discussions with those delivering the efficiency programme, Right Care, the new nursing strategy, Choosing Wisely, the NIHR, and identifying and taking up opportunities for shared working.

Learning from national and international experience and developing a directory or manual of good practice examples.

Harnessing the value maker community to share messages and good practice in the finance community.

Building a culture of responsibility amongst professional staff groups by including information about adding value and reducing waste in finance and clinical educator training."
Building citizen awareness.

Working with the NIHR and the NHS RD Forum in the reduction of waste in research and the delivery of the Adding Value Project. I pleased when I found this web page because it contextualised the research for me and helped me grasp its importance and significance.

Thank you for this reference back to the starting point for our work. We have added some additional commentary to the footnote on page 3 to add some further context.

Reviewer #4: This is an important area for discussion, but I was somewhat disappointed both in the presentation (I had to read it a number of times to make sense of it) and in the detail provided. To be able to critically appraise this work (ie make a judgement about how likely the presented findings are to represent ground truth) I (as the reader) need to see the questionnaire, and to know the number of persons invited to contribute. Does this represent a 100% response, or 10%, or 1%? Further, it is in my view no longer sufficient to say that data are available "on reasonable request" - they should be published in full in supplementary material or made available in a public repository.

Thank you for your comment. We hope the additional information in the paper will provide further clarity. The questionnaire has now been included as an Appendix.

Coming to interpretation, I wonder if the authors might reflect that the importance attributed by the participants to the various sources of waste might reflect their experiences and accumulated biases - that is, you are probably more likely to get involved with such activities if you think patient and user involvement is important and if you think current research prioritisation is wrong.

This is a very important point and is equally an issue for the R & D managers who will be influenced by the nature of their role. We have included a comment on the fact the participants were likely to have experience of research and PPIE.

To be clear, there is nothing in this that I think is wrong; but I think I need to hold the people with whom I agree to the same standards to which I hold others.

Reviewer #5: This is an interesting and important topic. Thanks to the research team and others involved in the project. I enjoyed reading the paper but I am left somewhat confused as to what the key messages are.

Thank you for your helpful review and comments. We have clarified a number of issues with the aim of making the messages clearer.

p2 line 48. (and echoed p7 line 10) I don't understand how 'Being mindful of the potential for wasteful practices is part of the conduct and operation of research studies' can be concluded from the survey results. The aims of the survey are expressed twice and slightly differently. Firstly
The aim of the similar survey for patient researchers was to assess their understanding and influence in the area of research waste. And secondly (p5 118) as - 'The purpose of the survey was to discover the main areas of waste identified by representatives of the PPIE community.’ Surely the conclusions of the study need to draw from the findings? As currently written all the statements in the conclusion are true but they don't appear to come from or directly connect with the survey findings. Apols if I am missing the point here!

The term ‘being mindful’ has been changed and clarified.

The aims have been checked and clarified to ensure consistency and clarity.

The conclusions have been amended to ensure consistency with the findings.

p3 l23-27. A couple of reflections on what doesn't seem to be included here or elsewhere in the article in relation to how patients and the public are currently involved in avoiding waste in research. Might it be helpful to state if the survey is only focussed on roles as co-applicants, study advisory groups and co-researchers? Patients/public already play in role in research topic identification (such as through James Lind Alliance Priority Setting Partnerships) where there is a process for systematically excluding potential waste and the premise of the partnership between patients/carers and clinicians is to focus on patient/carer benefit. Also the routine involvement by many public and voluntary sector research funders of patients/public in assessing funding applications. Deciding what does and doesn't get funded as a function of avoiding waste. Is the research being proposed needed and likely to be of genuine patient/carer benefit - from the perspective of patients/carers?

This is very helpful and we have included a reference to the work of the JLA and PPIE representatives on funding panels.

p4 l60 and p5 11-9 Would be helpful to have greater clarity here about a few things. How large (numbers of people) are the 3 groups that were surveyed? How many people were surveyed in total? Would be good to know what the response rate was. Looking at Figure 1 it has no numbers or percentages on it. Which I think would be helpful to include. It is also not clear to me if only the patient/carer members of the 3 groups were invited to respond to the survey or all members of those groups (if they include others). Elsewhere - e.g. in aims the survey it talks about 'patient researchers' and the 'PPIE community'.

We have addressed this in the text.

p6 l26 - Discussion - somewhere in here I would like to see some reflection on the nature of the groups involved - all relatively research and PPI savvy - and the small number surveyed. What does that mean then in relation to the aims of the survey and the findings? Would also be interested to know the numbers from the management community survey by comparison.

We have addressed this in the text.
p6 l29-32 - Perhaps relevant to acknowledge the work that research charities and voluntary sector organisations do and have done to raise public awareness of research - mass communication / marketing with reach well beyond publications cited.

A reference to the work of research charities has been included.

p7 l4 - says - 'main areas of waste identified by both respondents in the PPIE and R & D community surveys were prioritisation of research and PPI' but this seems to be contradicted by statement of p6 l46-47 'They identified implementation of research in practice, prioritisation of research, and research taking place to time and target as the most important and valuable areas of waste to address.'

This is not intended to be contradictory and simply points to differences in the two surveys as the latter statement refers only to the manager community not to the PPIE representatives.