Reviewer’s report

Title: Patients' and clinicians' and researchers' priorities for treatment research: a comparison

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Reviewer: Jim Elliott

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Overview – overall comment and answers to reviewer questions:

Overall: The topic of this paper is really important to patients, carers and clinicians and has significant and far reaching consequences for research on treatments in the UK. This is because PSPs challenge the long established and entrenched way research is initiated and pursued, that is, that most of it is investigator-led and the organisations and systems used to fund it are driven by the same community of investigators who are also involved in assessing the outputs (the Research Excellence Framework) and they are quite happy with the status quo. The paper’s discussion does not explore the consequences of its recommendations nor what sorts of actions might bring about the changes needed for research into treatments to be driven more by patients’ and clinicians’ research priorities. It seems like a missed opportunity not to do so. Also if more is not said in various places as suggested below there is a risk of readers thinking “so what” and missing the hugely significant implications this paper has to offer.

Answers to reviewer questions:

1. Is the question posed by the authors new and well defined? It is well defined but not new. However, it is addressing an important issue with much more data than ever before across a wider range of health conditions

2. Are the methods appropriate and well described, and are sufficient details provided to replicate the work? Yes, especially if the key reference for the Priority Setting Partnerships is cited much earlier in the paper.

3. Are the data sound and well controlled? Yes for this type of study

4. Do the figures appear to be genuine, i.e. without evidence of manipulation? Yes

5. Does the manuscript adhere to the relevant standards for reporting and data deposition? Yes in as much as I understand this and it is relevant

6. Are the discussion and conclusions well balanced and adequately supported by the data? Reasonably so but could say more (see below)

7. Do the title and abstract accurately convey what has been found? The abstract does but the title doesn’t; saying what was done rather than found

8. Is the writing acceptable? Mostly but there are some instances of less than plain English and some jargon and odd grammar
Major Compulsory Revisions

1. Plain Language Summary. The language is not as plain as it might be, e.g. “…agreed their priority research questions for treatments…” is still using jargon, how about “…agreed which questions they thought would be the most important to be asked about treatments…”? Also the summary does not give the result and conclusion. It just says what was done not what was found. That could still be done within the allowed word limit.

2. Abstract. The discussion does not reflect the main clear recommendation that funders and researchers should use PSPs to drive the research they do and fund respectively.

Minor Essential Revisions

1. Background, 2nd paragraph – I think the sentences about NHS research need to be clarified. What do the authors mean by “…commissioning mode of funding mainly operated by the NHS” and by “NHS” in this context? The NHS as such, i.e. hospital, community and primary care services and health authorities, fund very little research. So do they mean the “NHS Research and Development programme” which is funded by the Department of Health and since 2004 has been badged as the National Institute for Health Research? Either way the little research the NHS itself funds and the large amount NIHR funds is still mostly investigator-led although NIHR directly commissions more research that any other health research funder in the UK. So, does the statement mean that in as much as any commissioning of health research is done it is NIHR (the NHS) that does it, which is the case, or that NIHR (the NHS) mostly commissions research (as opposed to funding in response-mode), which is not the case?

2. Methods. In the description of PSPs it would make sense to give the reference to the JLA Guide Book (reference 4) right at the start rather than under the second sub-heading. Not sure that the tense used is consistent: “were” in the 1st sentence and “are” in the 2nd??

3. Methods. Last sentence of 1st paragraph, what does the (1) refer to?

4. Methods 3rd paragraph under second sub-heading (prioritisation) is quite hard to read and some of the terms are jargon, e.g. “classification uncertainties” rather than “uncertainties about the classification…”. Also in the sentence describing the “other” category, it would be clearer to read if the example in brackets was at the end of the sentence. The list of PSPs would be clearer in a table or as a bullet point list if the journal style allows that.

5. Methods 3rd sub heading – sampling of trials, 1st paragraph: Why clinical trials only and not other research methods? Non-drug interventions are commonly evaluated / assessed using other methods so choosing to only look for trials may under-report non-drug interventions. There may be a good reason for this but I feel it should be justified along with acknowledging the potential for under-reporting non-drug interventions.
6. Methods 3rd sub-heading - sampling of trials, not sure “de-duplicated” is a word! Better to say something plainer like “The list was checked for duplicates, which were removed”. Surely the analysis of the records and categorisation 'showed' rather than 'suggested' that 52.8% were non-commercial? Why was a sample of roughly 900 non-commercial trials wanted? Please explain.

7. Methods 3rd sub-heading, sampling - 2nd paragraph, the inclusion criteria are mentioned but not described.

8. Methods 4th sub-heading, ethics, what does “through local arrangements” mean? Also that and second two sentences aren’t really relevant. Shouldn’t this section simply say that ethical approval was not needed for this study because of the type of study?

9. Discussion 1st paragraph: Is it worth including something about the fact that the expected outcome of the study would be to corroborate the findings of Tallon et al 2000 because that reflects the way research has always been prioritised and was the raison d’etre for setting up PSPs? It is hugely significant to have collected as much corroborating evidence in different areas that shows the same situation as found by Tallon et al in the management of osteoarthritis of the knee. It would be very unexpected to find that research done over the same period of time as the PSPs were conducted would reflect the same sort of balance as the PSPs themselves. A change of culture in the research community is needed for that and even if that had been put into place quickly it takes time for new work to reflect changes to the way it is set up and the timescale of the study reported clearly does not allow for that.?? The point here is that some readers might not realise this and wonder what the point of PSPs is if research isn’t reflecting the priorities identified. The answer is that there isn’t any way that the research sampled could reflect the results of the PSPs. I feel that without addressing these points directly there could be a bit of a feeling of “so what” about the paper’s findings.

10. Discussion 2nd paragraph 2nd sentence is incomplete as it is. Not sure if it was meant to be combined with the 3rd sentence, which would make some sense but I am not sure I really understand the point being made in this paragraph. I suggest it is re-written more clearly.

11. Discussion 5th paragraph, I am not in the least bit surprised at this finding because the long established culture of investigator-led research and low levels of public involvement in health research overall (see Tarpey M. 2011. Public involvement in research applications to the National Research Ethics Service, INVOLVE Eastleigh) does not encourage researchers to do this. However, it is disappointing given that there is progress in some areas as indicated by the reference to the Buckley et al. 2011 paper. It would be helpful to say what the “other initiatives (Murad et al. 2001; Boivin et al. 2014)” actually said rather than leave the reader to look them up.

12. Discussion 6th paragraph, It would be reasonable to comment here that the
success of the PSPs cited might be because they were driven by charities that are more likely to take them forward because they work as advocates for the patients with the particular condition and are well placed to commission research to address the priorities addressed rather than to hope that they are taken up through response-mode funding schemes.

13. Discussion 6th and 7th paragraphs, the references have gone askew from 24 onwards – Pollock et al. 2013 is No. 24 not 23 and the final two referenced at the end of the 7th para should be 25 and 26 not 24 and 25.

14. Discussion 7th paragraph, 1st sentence is not very clear: which “audits” and done by whom? Presumably this is referring to the overall approach presented in the paper in which case it would be helpful to say so. Also “..increase the dividends from the public’s investment in research..” is a bit of jargon really. If the first recommendation is what I think it is then it is a good recommendation as is the second. The second suggestion / recommendation could make reference to the fact that one or two charities (unfortunately can’t recall which at the moment) are now making it a condition of funding that applications should be addressing questions identified in relevant PSPs.

15. Conclusion. I think the conclusion is fine but the recommendation in the second sentence is a bit weak. I think there is enough data in the paper to provide firm enough ground to make bolder recommendations to address the mismatch. Say who should reflect the findings. They are relevant to both research funding organisations and researchers themselves. The changes needed for research to reflect the priorities of patients and clinicians needs leadership and incentives because the current research “system” and culture is not geared to do this.

Discretionary Revisions
1. Methods. A minor point, probably not for including in the paper but possibly for consideration in the PSP methods: I accept that an ‘uncertainty’ is usually defined as being the lack of a relevant and recent systematic review or one that shows uncertainty but it is possible (but not that likely I guess) that a single appropriately powered clinical trial (large sample with narrow confidence intervals) might have been done but the findings not implemented with no systematic review because of the power of the trial and uncertainty arises because patients and clinicians are unaware of it?

Level of interest: An article of outstanding merit and interest in its field

Quality of written English: Needs some language corrections before being published

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:
I am lay co-chair of the Patient and Public Involvement Reference Group of the NIHR Evaluations, Trials and Studies Coordinating Centre, which now funds and runs PSPs as one of its programmes. I receive a fee for my work as a member and co-chair of the group, of which I have been a member for three years.

I know two of the authors (SC and IC) but have not worked directly with them in the past five years.