Author's response to reviews

Title: Patients', clinicians' and the research communities' priorities for treatment research: there is an important mismatch.

Authors:

   Sally Crowe (sally@crowe-associates.co.uk)
   Mark Fenton (mark.fenton@nice.org.uk)
   Matthew Hall (mdhall272@gmail.com)
   Katherine Cowan (katherine@katherinecowan.net)
   Iain Chalmers (IChalmers@jameslindlibrary.org)

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Author's response to reviews: see over
19th March 2015

Sophie Staniszewska

Editorial Team: Research Involvement and Engagement, BioMed Central

Dear Sophie

Re: Manuscript revision 1943865140157854 - Patients' and clinicians' and researchers' priorities for treatment research: a comparison

We thank the reviewers for their positive and constructive comments, which we have used to improve our manuscript. These are addressed as follows:

General editorial comments

We have reviewed the language used in this article and agree that it isn't always easy to read and understand and may not appeal to a wide range of readers. We have addressed this throughout the article, shortening sentences and replacing research jargon with more accessible words.

Reviewer 1

Comments addressed in general editorial comments

Reviewer 2

Comment 1 "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. 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".

We agree with this and have added into the discussion some more robust statements and challenges to the research community and funders. We have also added in a sentence about the research communities response to the formation of the JLA, i.e. many were sceptical and challenged by this new model.

Comment 2 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"

We agree and have changed the title to reflect the main finding.

Comment 3 Is the writing acceptable? "Mostly but there are some instances of less than plain English and some jargon and odd grammar"

Addressed throughout the whole paper, as per reviewer 1.
Comment 4 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”.

We have added to the Plain Language Summary and hope that it now reflects the whole study and is easier to understand.

Comment 5 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?"

We have rewritten this section to be much more explicit about the different funding agencies and mechanisms for funding research, describing 'responsive funding' and 'commissioned research'. We have suggested that there have been consequences of these models of research funding and that these findings were responsible for the initiation of the JLA.

Comment 6 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".

We agree and have changed the order of this citation

Comment 7 2 Methods. "Not sure that the tense used is consistent: “were” in the 1st sentence and “are” in the 2nd??"

Thank you for spotting this - the majority of the paper has been rewritten in present tense as much of the JLA methods are being used now.

Comment 8 3. Methods. "Last sentence of 1st paragraph, what does the (1) refer to?"

This has been removed and was an error.

Comment 9 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".

We agree and we have tried to simplify this as much as we can, we have moved the example to the end of the sentence.

Comment 10 4. Methods "The list of PSPs would be clearer in a table or as a bullet point list if the journal style allows that".

We agree it was unwieldy. If the journal allows we have created a list of PSPs with their respective citations.

Comment 11 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."

This is a good challenge, we have explained why we only used the WHO database and acknowledged that other sources of other types of research and that this is a possible limitation of this study.

**Comment 12** Methods 3rd sub-heading "sampling of trials, not sure "de-duplicated" is a word!"
"Surely the analysis of the records and categorisation 'showed' rather than 'suggested' that 52.8% were non-commercial?"

We agree and have replaced this with a more accessible statement, and have replaced showed with suggested.

**Comment 13** "Why was a sample of roughly 900 non-commercial trials wanted? Please explain".

We have taken a decision to remove this methods point from the text as we felt that it doesn't add anything to the article. We wanted a large random sample to inspect - and we achieved that.

**Comment 14** Methods 3rd sub-heading, "sampling - 2nd paragraph, the inclusion criteria are mentioned but not described".

We have explicitly stated our inclusion criteria.

**Comment 15** 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?"

We agree! It is not an issue with this work so we have removed it, and replaced with a simple statement as to why.

**Comment 16** 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'être 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."

Yes we have strengthened the discussion section in this regard, we have been more robust about our findings generally in the discussion section, and challenged the research community to be more reflective about the culture of prioritizing research and being aware of how these decisions are made.

**Comment 17** 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."

Thank you for spotting this, we have amended these sentences as part of the rewrite of parts of the discussion section.
Comment 18. "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.

We agree and have described the Boivin trial, and removed the Murad citation as on balance it didn't address the point being made strongly enough.

Comment 19. 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”.

Thank you for this comment, we thought about and discussed at some length what sort of paper we have submitted. This suggestion takes us much more into a commentary article and this paper is an account of some research that leads us to some commentary about research funding mismatches. This we felt was taking the commentary too far so have declined to take up this suggestion.

Comment 20. 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”.

Thank you - these have been sorted.

Comment 21. 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”

We have decided to go with the phrase To increase the returns on their investments, we suggest that research funders assess the extent to which the treatment research in their portfolios reflects the priorities identified by the future users and beneficiaries of the research they fund. We hope that this explains audit more fully.

"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”.

Again this is really helpful feedback but would require further work to establish the exact nature of this statement to we won’t include it as a suggestion. However we know that there are plans afoot to do an audit of what happens to PSP priorities in all forms and if funders are using PSP priorities as a criteria for funding we would hope that it will be reported on!

Comment 22. 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".
We agree and have adjusted the conclusion to this effect - thank you.

**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?"

This is a really interesting point - however we cannot change the definition of uncertainty as defined by NICE and UK DUETs.

Thank you once again for your very good spirited and thorough review of our article, we feel it has benefited greatly from this feedback. We have added both of your names to the acknowledgement section if that is permissible.

Sally Crowe on behalf of all the authors