Author’s response to reviews

Title: Finding and engaging patients and the public to work collaboratively on an acute infection microbiology research public panel

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Author’s response to reviews:

Reviewer 1:

Overall - the style in which the article is written is quite informal and at times verbose. If the text could be written in a more formal, succinct manner, (in the third person) it would read better for academic publication.

We have edited the text to make it more succinct. We are mindful that European colleagues will read this and want the language to be accessible.

Abstract: line 114 - results. This section reads as if this was the order you contacted the different groups/panels as opposed to the recruitment rate.

This has been reworded to make it clearer.
Methods: It would be helpful for the reader if the methods section was broken down with further headings such as 'recruitment' etc. The way it reads at present it is quite difficult to follow the order of the process.

Three section headings have been added. Planning, recruitment and panel selection.

Line 235 - the wording of the advertisement should be described/labelled as a 'figure' or a 'box' and referred to as such in the text.

This change has been made.

Results: Again, it is helpful for the reader if the text is divided by headings and follows the flow of the methods section. The order of the results would benefit from restructuring. E.g. Have the description of the members and the final panel before the quotes.

We have added in headings and moved the description of the panel to before the quotes and have improved the introduction to the quotes.

It would be useful to know exactly how the final panel was chosen, what was the criteria? How was this fulfilled?

We have added a paragraph into the Methods section.

Discuss the quotes first before presenting them as you have done so in line 405, then have a few to illustrate points/themes (some quotes too long as they stand) divide them into themes.

We have done this. We have, however, left the two lengthier quotes because we feel they add the perspective of the patient panel members more adequately than we can.

The table needs to be labelled and referred to in the text.

This change has been made.
The discussion is quite speculative in places and needs to be backed up with references.

We have added in some more references to address this.

Also, be aware of bringing in new information into the discussion that has not previously been mentioned. For example on line 485 the plan to use local press and GP surgeries is mentioned but this was not discussed in the original methods plan.

We have added this in to the Methods section.

Thank you for your comments.

Reviewer 2

I wondered whether you had a Patient Representative on your Advisory Group and Management Group for the project overall? If so, was this person/s also on the PPI Panel?

The project is composed of a large consortium of 5 pharmaceutical companies and 30 academic partners across 10 European countries. PPI in Europe is less advanced than in the UK thus no PPI is included in the management group. We were not in a position to influence this. Our aim and belief in PPI is that we can raise its profile within the project and try to get our European colleagues to engage with it. We have added a couple of sentences into the background to explain this.

Thank you for your comment.

Reviewer 3

One weakness of the paper is the omission of any discussion of the reported ethnic make-up of their panel, whom they describe as "100% White British." As a participant in a similar panel in another multi-ethnic nation, I understand the difficulties in recruiting participants from a variety of ethnic groups and socioeconomic circumstances. However the paper would be strengthened by a discussion of how this limitation may affect their deliberations. For example, some ethnic
groups may perceive infections differently than mainstream citizens do, which in turn may require alternative approaches to patient consent and participation.

We agree on the importance of this point and have expanded on this in the discussion section.

Thank you for your comment.

Reviewer 4

It would be beneficial to explain more fully how the team remained motivated in the face of nil responses to mail-outs and advertising to 1700+ people.

We have explained this more in the discussion section.

Also there is no mention of the use of social media in the recruitment process. As the use of social media platforms i.e. FaceBook is widespread in the community and a very effective communication tool, it would be useful to understand why this was not used?

The involvement opportunity was advertised on the hospital trust’s Facebook page – although this yielded no response. Had our recruitment problems continued we would have investigated other social media means of advertising.

Methods:

I query why the team did not seek advice from patients and members of the public about how to recruit members for the panel. For me it was an important and missing piece of information that requires comment about why this was not done

Thank you for raising this valid point. We have included this in the discussion section.
Discussion:

I think more could be discussed about the value and importance of building and maintaining relationships with patients and the public. This is highlighted by the difference in responses when personal connections were made to people who had either been involved previously with the researchers or they had a personal interest as a patient with an infection. There is an opportunity to explore how the relationships contributed to the ultimate success of establishing the panel. Given there is little published on this topic for people who may only have a on-off interaction with a health service i.e. with an acute infection, sharing the experiences of the researchers in this endeavour is important.

Building a good relationship with the panel has been of huge importance to the team. We have addressed your comments further in the discussion.

Conclusion

In this section it states seeking advice was paramount and yet there is nowhere that the researchers sort advice from patients and members of the public about the best way to recruit to a panel. This seems to be a glaring omission and I feel it should be at least explained why this was not considered of done.

We have commented on this in the Discussion section.

Thank you for your comments.

Editors' Comments

We would also ask that the authors rewrite the Plain English summary, which is written largely in the passive mood rather than the active one, and we would ask the authors to consider very carefully the language in some points. Is it necessary or helpful for an academic research paper to state that "careful planning was vital"?
The Plain English Summary has been rewritten.

Lastly we would hope to see a separate statement about why there is no patient author for the paper. Is it another example of patients not engaging or was there no attempt to find someone?

There are two patient authors on the paper: R Campbell and V Kenny. Both were former patients and are members of the PPI Panel. Both contributed lengthy comments in the text and also reviewed and commented on drafts of the manuscript. We apologise for not making this clearer and have clarified by amending the author list.

Similar questions should also be asked and answered for the initial planning of the project. Were any experienced patient representatives (eg from microbiological research in cancer, for example) approached to advise or to join the initial (academic) panel?

The project was planned by a large consortium of academics from across Europe, pharmaceutical partners, overseen by representatives of the Innovative Medicines Initiative (IMI - a European public funding initiative). We were not in a position to influence the original planning. PPI is much less evident in other parts of Europe, but the IMI have shown commitment to its development and supported the inclusion of some funding within our Work Package. Our work aims to raise the profile of PPI in the consortium, introduce it to our European colleagues, and demonstrate the benefits.

Thank you for your comments.