**Author’s response to reviews**

**Title:** ADAPTING THE JAMES LIND ALLIANCE PRIORITY SETTING PROCESS TO BETTER SUPPORT PATIENT PARTICIPATION: AN EXAMPLE FROM CYSTIC FIBROSION

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Response to reviewers comments

**REVIEWER 1 COMMENT**

1. The particular issue of infection risk for people with cystic fibrosis led to adaptations of the James Lind Alliance (JLA) standard approach, but as noted in the article the use of effects were to also support attendance of those unable to attend in person for other reasons, which may then be important for other conditions. I think that the discussion might consider this general point more fully, including whether standard methodology may exclude voices in the JLA process. Although the initial justification to vary the approach was very situation specific- it does read to me that once the question of "is this the best way" is raised it is difficult to put it back in the box and not look more broadly at the advantages and disadvantages of modified approaches both generally and for specific contexts.
ACTION

We have added a paragraph about how our methods could be used in other conditions. We have also added information on the Digital technology for mental health PSP where they adapted methodology to increase participation in their particular patient community.

We have added more detail about more general applications of our adapted methodology.

REVIEWER 1 COMMENT

2. The mixed video-conference / face to face meeting difference from standard JLA process are explicit but as non-expert in the JLA method I am not sure on the JLA standard process equivalent of he online surveys used to elicit and provide the initial prioritisation of questions. It would be useful to have a figure that is a flow chart of the standard JLA process and the process adopted to give an overview of the standard approach and the differences. We have added a short section at the beginning of the methods to describe the usual methodology and added a figure (figure 1) to show the usual method and where we had adapted it.

ACTION

We have added a short section at the beginning of the methods to describe the usual methodology and added a figure (figure 1) to show the usual method and where we had adapted it.

REVIEWER 1 COMMENT

3. The use of a "room buddy" to represent those joining remotely sounds innovative, and highlights the difficulties in gaining full participation for both people on line and in a room for mixed video (/tele) and in person meetings. The authors also report an online version of the physical sorting or priorities to facilitate full participation by those not in the room. This raises the question of whether a fully on-line facilitated discussion, supported by the right tools might be a generally applicable approach. If emphasising the general aspects of supporting people who are geographically remote, rail or otherwise unable to travel as well as those with an infection risk this fuller challenge to standard methodology is worth raising, including any defence of the current standard approaches.

Might there be an argument for an evaluation of a fully on-line vs standard process being applied to some areas to test the two?
ACTION

We think we have covered this in response to the above comments.

We have added in a sentence about the possibility of doing a trial to compare different methodologies.

REVIEWER 1 COMMENT

4. As it is such a central driver of team considering alternative approaches it may be worth specifying that particular types of infection are problematic for patients with cystic fibrosis as the basis of advice to not mix socially. If it were any respiratory infection then the risk of picking infections up from people without cystic fibrosis would be more important with a different advice than the current advice targeting infections (substantially) restricted to people with cystic fibrosis.

ACTION

Thank you for raising this. We have added in “risk of cross infection with particular bacteria that people with CF are more susceptible from with potentially devastating consequences”.

REVIEWER 1 COMMENT

5. There is no referenced discussion of others who have adapted the JLA methodology. This should be included or explicitly identified as absent if this is the first report of a modification.

ACTION

We have added in a small section in the discussion about how the digital technology for mental health PSP and others adapted their uncertainty gathering process.

REVIEWER 1 COMMENT

6. Although having read the paper the affection for the "Question CF" wording echoing the hash tag and twitter names used it gives a confusing title in terms of this being the first thing that people see. I think that the title would lead to greater impact if were more informative. e.g. Adapting the James Lind Alliance priority setting process to better support patient participation: an example from cystic fibrosis.
ACTION
Amended, thank you for the suggestion

REVIEWER 2 COMMENT
A succinct summary of the JLA PSP is necessary

ACTION
See above

REVIEWER 2 COMMENT
A table describing the comparative between the "original" and the "adaptive" JLA PSP is recommended. The reference to a "toolkit" in the title should have a reality in the paper!

ACTION
We have added a flow chart (figure 1) to show the standard JLA methodology and how we adapted it.

REVIEWER 2 COMMENT
There is no "Results" section in the paper. The results are mixed in the "Methods" section. For example, a remark like "through twitter conversations with US counterparts we forged a collaboration with researchers from the CF Foundation", in the Methods section, is a bit disturbing. The whole paragraph on "Further development of the Top ten research priorities in CF" seems a bit out of purpose in a Method section as well; these are perspectives.

ACTION
We have moved the results into a separate results section and the discussion about further development into the discussion.
REVIEWER 2 COMMENT

The discussion could be a bit more elaborated (more reflection on the "lone" questions management, the participants' experiences ... and less on your future work related to the priorities identified - not the purpose of the article, I think...)

ACTION

We have elaborated on the lone question issue.

We feel that it is important to mention the future work as we feel strongly that the exercise should not just stop with the release of the top ten, it’s a first step in co-production of research.

We have added a sentence explain this to the discussion

REVIEWER 2 COMMENT

The reference to "clinical trials" as THE form of Research is a bit reductive. Many research questions that matter and can benefit CF patients can also be answered from epidemiological or prospective studies, and not only "clinical trials".

ACTION

The focus of the JLA is on clinical trials

We have added “Although the focus of the JLA is to further the evidence base through clinical trials of treatment interventions, it is increasingly apparent that other research methodologies such as registry studies may be key in aiding understanding of what is happening at present to enable us to move forward to answer our research priorities.”

REVIEWER 2 COMMENT

Twitter jargon, like "impressions" and "engagements", should be explained and discussed...

ACTION

We have added in definitions in brackets that follow these to explain what they mean, added explanations to the figure legend and added more in the discussion around the use of twitter
REVIEWER 2 COMMENT

Is it necessary to mention the BlueJean brand more than once (in the Methods section)? Does BlueJean own very specific features that no other videoconferencing platforms possess? (publicity...)

ACTION

We have removed the references to BlueJeans beyond the mention in methods.