**Author’s response to reviews**

**Title:** Can a ‘consent to contact’ community help research teams overcome barriers to recruitment? The development and impact of the ‘Research for the Future’ community

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**Author’s response to reviews:**

We thank the referees for reviewing our paper and providing useful feedback. Our responses are below, and we have shaded the changes in the uploaded manuscript.

In what sense is this a ‘community’ - do they interact with each other? would this be better described as a registry or register or database?

This is an interesting comment. We have chosen ‘community’ partly as it is a friendlier term than ‘register’ or ‘database’. Labels are likely to be important, especially as the paper will be Open Access. On that basis, we would prefer to continue using that term.

Although the ‘community’ aspects could be better developed, there are relevant features that we think justify this term.

We have kept the term, but added a short paragraph to explain this on page 10.

There is also quite a lot of jargon - terms that are used in recruitment to health studies.

We have tried to reduce this where possible and to simplify the language throughout.

I am not sure how well this manuscript fits into the Intro/ Methods/ Results/ Discussion framework - I wonder if it would better as a Database article see https://bmcmedresmethodol.biomedcentral.com/submission-guidelines/preparing-your-manuscript/database-article

We agree with this in part, but as the editor has not required this, we think we would prefer to stick to the present structure, as we do not feel that an extensive rewrite would add that much value.
I think White Papers are policy documents produced by the Government that set out their proposals for future legislation - rather than actual commitments.

The reviewer is correct and we have clarified this by referring to these as proposals (page 4).

References 5 and 6 are from 2006 - suggest more recent reference to demonstrate that recruitment is still a challenge.

I am not sure there are any other, more recent empirical investigations, but we have added some references to continuing issues to try to update this.

Suggest the aims and methods are revised and written as a short narrative and the bullet points removed.

We actually quite like the structured presentation, and as the reviewer only made this as a suggestion, we have left this ‘as is’.

However, if the reviewer or editor feel strongly, we would be happy to make the change 'the ' missing on line 47.

We have edited this.

Assume people know nothing - start at the beginning and provide some context - who what when and why and how funded - did it all start with Help BEAT diabetes campaign? who led this initiative? where did it come from?

We have added a more detailed description on pages 8-9.

Line 51 page 8 - who are the project team.

We thought the optimal way of highlighting the organisations and individuals involved was through a relevant web link, as this will be updated.

Explain what NHS Spine data.

We have added an explanation on page 10.

Line 56 page 9 "with the launch of various disease areas" sounds odd.

We have rewritten this as ‘With the launch of subsequent ‘Help BEAT’ campaigns.

Page 14:

Lines 4-15 suggest revise and simplify this paragraph.
Lines 34-39 - this is not relevant to the recruitment function - maybe it should go in the discussion

We have made these changes to the revision, and moved the section on ‘other events’ into the description of the ‘community’ (see above)

Page 17 lines 34 - 51 - are you talking about recruitment to the research for the future community or to research?

We have replaced this with the term ‘attracting people to the database’

Page 18 line 4-5 I don’t understand this sentence - bias?

We have rewritten this to highlight that it is about bias among the types of patients who are registered in the Research for the Future community

Page 18 line 19- “recruitment of patients to patient and public involvement - suggest you avoid PPI jargon - and is this sentence really true? do we want the involvement of patients who are not representative of the population being under study

The reviewer raises an important point. We do not think there is consensus as to whether PPI groups should be ‘representative’ in the same way as research populations. Although it is always an issue, it may be more or less important in certain types of research.

We have used the term ‘diversity’ to reflect this debate and added a reference (page 20)

Page 19 lines 27 -37 - what sort of engagement are you referring to here?

We have clarified this to mean both providing opportunities for research, as well as wider benefits

REQUESTED REVISIONS:

In light of the authors concern on the ethics raised on page 5, line 37, I'm interested to know whether and how their model meets ethical concerns raised?

The model essentially meets ethical concerns through the ‘consent to contact’ model – patients provide overall consent to be entered onto the database, and then provide additional consent for individual studies.

For the Research for the Future community, there will be ethical issues around the protection of their information and the need to ensure that they can leave the database and that they are not burdened. We have clarified this in the revision (page 6)
Additionally, the conclusion states that the model described is feasible and useful but this conclusion cannot be deduced from the results, which merely describe the model. It would be helpful if the authors clarified how their results relate to the conclusion.

We think the data supports the conclusion that it is feasible (we have set this up in a way that is in line with current ethical and governance procedures) and useful (it has been used by researchers and patients have taken part in many studies).

We think we have been suitably cautious in terms of making strong statements about HOW useful it is, but we have added some additional comments to clarify this and highlight the additional questions that remain to be answered (pages 18 and 20)