Author’s response to reviews

Title: Meet the Researchers: an alternative method of engaging patients with research in mesothelioma.

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Author’s response to reviews:

We thank all the reviewers for their constructive and insightful comments, and for the assistance they have rendered us to improve our manuscript. We have carefully revised and restructured the paper in response. Changes are detailed below and highlighted in yellow throughout the manuscript text. We have also updated the paper with evaluation data from our latest event which took place on 6 July 2018.

Reviewer #1:
The authors are to be commended for taking the time to write up their observations of a method which has the potential to be useful to others. It's a generally a very easy to read article and my comments are intended just to tease out that 'demonstrable advance on current practice' and guide the reader.

1. Title: I recommend tempering the title given the nature of the current evaluation and placement of the article. Consider 'an alternative method of engaging ...'

Response: Title changed Line 3 and Line 94

2. Language: Watch the use of adjectives and make sure you substantiate claims with references, e.g. p5 ln 108 'good step' - reference?

Response: The use of adjectives throughout the paper has been reviewed and revised accordingly. Specifically the example above (see lines 139 to 141).

3. Guideposts: Most journal articles are research articles or commentary, so readers may value some extra guideposts. For example, in the introduction it can be useful to tell the reader that this is a methodological article and then clearly write the aim of the article and the approach you will be taking (e.g. are you describing the practice based on x no. of sessions, comparing to past practice and reflecting on its value using feedback surveys. Then use that to keep the rest of the article in line.
Response: Two new paragraphs have been added to the introduction to clarify the focus of the paper on patient engagement (lines 105 to 119) and its aims and objectives (lines 143 to 150). Sub-headings have also been added and new references included.

4. I really like the links to further data, but please explain the data sets and don't use vague descriptions like 'over a number of years'. If you use quantitative data, please give us the numbers.

Response: Results section in abstract amended to give more accurate timeline for the data (Lines 76-79)

5. Your first paragraph in background is useful for explaining the issue of work with this group of patients, but then it becomes a bit of a general review of things happening in this space. What I really want to know is what are the specific outcomes you seek to achieve by bringing patients (referencing the lit that supports this sort of work) and researchers together given you've just made it clear how valuable the patients' time is. Is it that researchers use it to scope better questions, inform outcome measures or patients to make contact with trials or whatever?. Then when you look at the results, the reader will have a better sense of if it is achieving these outcomes and where further work is required or how they might build on it. 6. Consider looking at Kristina Staley's recent papers which may add support or point of comparison to background and discussion. 7. p. 14 In 305 - how is engagement different from PPI? I would be inclined just to say PPI rather than getting into an explanation of a difference which may not be widely shared.

Response: We agree that the distinction between PPI and engagement is blurred and that consensus on the definition of each can be contentious. This is now acknowledged in the introduction to the paper (lines 106 to 119) and the discussion has been revised to clarify the focus on the method of engagement and its evaluation. The reference to other involvement activities has been removed as we concluded that this was confusing for the reader. Sub-headings have been used to structure the discussion and additional references included.

I look forward to seeing the revised article as I believe it will be very useful for people working in this field because you have clearly gained a lot of insight into your method. I just need a few more specifics to see what you have seen.

Reviewer #2: This is an interesting and well written piece of work that reports on patient and public engagement activities in the field of mesothelioma research. The authors premise their account on the assertion that sustained patient involvement is problematic given the typical mesothelioma disease trajectory.

Their practice has elaborated an engagement methodology (the populations that they have engaged are not specified clearly but appear to be lay and mixed and include patients) based on informality and the simplification of complex research information.

Much of what they describe and advocate by way of methodological tips for running groups that provide for an improved quality of interaction between lay populations appears excellent.

The problem with the paper lies with an ambiguity revolving around the practices of 'engagement' and 'involvement'. Much of the paper is concerned with effecting engagement and finding more effective ways for researchers to communicate with interested lay populations in a process of information transfer. On a couple of occasions there is reference to partnership and the benefits of patient and public engagement.
perspectives informing research. The authors attempt to subsume these elements within their proposition without providing evidence of this being attempted or of it having occurred. This sleight of hand is compounded when they draw comparisons between their approach and that of the NCRI Dragons' Den model where the emphasis is placed upon partnership, problem solving and co-production.

This problem is not insurmountable. It does require that the authors provide a clear differentiation between 'engagement' and 'involvement' and clarify the boundaries of their work in this respect and be more precise in their nomenclature.

Response: The introduction and discussion sections have been revised and restructured to reduce ambiguity around the focus and aims of the paper. The comparison with the NCRI Dragon’s Den and the different aim of the “Meet the Researchers” event specifically has been clarified (lines 367 to 379).

They should also provide a clearer description of the populations that they have engaged.

Response: A sentence has been added to the methods (Line 172 to 175) to describe the participants and a new table has been created, see Table 1: Participants’ profile 2016-2018 (Line 177)

The very many successful techniques that they describe are transferable. There is room for the authors to speculate on the ways in which their methods could be applied when pursuing the objectives of involvement and co-production as distinct from those of engagement and information transfer.

Response: A section has been included in the discussion (lines 389 to 398) about other involvement activities for which “Meet the Researchers” could be adapted, and examples provided.

Reviewer #3: Thank you for your paper which I enjoyed reading. It is well written and easy to read. The Meet the Researchers approach is one that will be of interest to the journal's readership and I agree that not enough is written about feedback on events. I think it will be useful within and beyond your area of work. I think it could be strengthened by more use of literature and reference to the evidence base about public engagement and engagement in science/science communication, in addition to the web site links you provide. I think it needs this to make it publishable as currently somewhat descriptive. I do hope you agree as it would make a stronger paper. Thank you for sharing your insights.

Response: Unfortunately the evidence base for these type of events is limited. Reports of events are mainly found on the websites to which we have provided links. However, five new references have been added to support the restructured background and discussion so hopefully they will go some way to addressing this important point.

Reviewer #4: This is an interesting study and article, and the authors are to be commended for their innovation.

A few issues of clarification would further enhance the manuscript:

1) An indication of whether or not the patients were paid for their time, and the reason for this decision.

Response: This has been clarified in the methods (lines 168 to 175).
2) Practical suggestions with regards to the problem of the noise level and whether, for example, would having lots of rooms be a help or cause other problems.

Response: This has been addressed in the evaluation sections (lines 270 to 274) and in the discussion (lines 401 to 403).

3) Would a combination of the traditional formal format together with the innovative informal format, be better than either format alone.

Response: This point has been raised in the restructured discussion (lines 422 to 424) but unfortunately we do not have evidence on which to base an assessment of which format is best.