Author’s response to reviews

Title: PATIENT LED PROMs MUST TAKE CENTRE STAGE IN CANCER RESEARCH

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Version: 4 Date: 13 Dec 2017

Author’s response to reviews:

Dear Roger,

Thank-you for your continued and prolonged patience while we have been considering the most recent iteration of your paper. In particular we recognise and appreciate the efforts you have made to reflect the comments and suggestions of the reviewers, although having seen the paper in all its submissions, we wonder if you have a colleague (ie an experienced patient) who could read the paper through for you and advise you on (a) whether or not it still flows logically and coherently following all the rewriting, and (b) whether or not there may still be some sideshows that may detract from the main issues that you flag?

You have submitted the paper as a Review but in the light of the various changes made thus far, we wondered if your wished to submit it as a Commentary? Several of the reviewers have suggested that as a Review it is incomplete, and as it is clearly an opinion piece, it is better suited to be a Commentary. As another option, you may also wish to consider if your paper is a Letter to the Editors, a vehicle tailor-made for personal views and for starting up debates and discussions? We have not yet published a Letter in RIE and so if you chose this route, you would be breaking new ground.

Although it is usual for the Editors to decide the category of papers received, as we believe in involving our authors in our decisions where we can, we thought we would raise these choices with you. If you need it, there is a little more information at
Are the researchers who are mentioned by name in your paper, for example Ian Tannock and Charlie Swanton, aware of your views and/or of your paper? Most of the reviewers of the various drafts of the paper have considered it to be potentially a good addition to the journal, and several commented that they hope and/or expect that it will be good at what it intends to do, namely to start a debate. One idea we might consider as Editors would be to invite some key players to respond to this article via another submission (a Commentary or Letter) to start a discussion within RIE, for example Tannock and/or Swanton - the latter perhaps especially, given his new role as Cancer Research UK's Chief Clinician. What are your views on this approach?

Whatever your views on all these points may be, it is worth nothing that because of the Christmas/New Year break and the existing pipeline of papers for the journal, even if we accept your paper today, it will not be published until the end of January at the earliest, and so there is no long-term harm in tasking a few more days to consider these issues and perhaps, if wished, to make one final set of improvements and to decide the publication format, as the paper has evidently changed substantially from the original submission (and is much better for it).

Please also note that all the queries we have are linked together, but all affect what we are seeking to achieve, which is to publish your paper and start an informed and rational debate around the principles you outline, the challenges you identify and the suggestions you make. So we are seeking your views and - if you wish - a modified manuscript. If you would prefer that we make our own decisions on these matters, that is a more than reasonable request, especially after so much time has elapsed.

Yours sincerely,
Richard Stephens and Sophie Staniszewska
RESPONSE

The Springer BMC notes suggest that a Commentary is a short, narrowly focused article of contemporary interest. I suspect that short is the only criterion my piece does not meet so if you are happy to ignore that fact I am more than happy to change the submission category and have done so on the resubmission screen. I agree with the comments that as a Review it is not comprehensive. I do not think that it is appropriate as a Letter.

Addressing your two questions:

a) whether or not it still flows logically and coherently following all the rewriting,

b) whether or not there may still be some sideshows that may detract from the main issues that you flag?

I have had one well informed reader (a science journalist – in confidence) and one not informed on the subject but a scientist who did a quick read. Summarising comments:

The argument is that while research focuses on improving survival, with varying degrees of success, the greatest potential benefit for the majority of patients that there is today, whether they are survivors or not, is through addressing quality of life. Keep that clearly in mind and it might be worth re-iterating it.

Patients are involved in research in various ways but not as much in the development of qol tools as they should be. So strengthen the message that the purpose and practice of qol in research should lead to greater patient benefit if involvement could be effectively unlocked.

The sections leading up to The Role of PROMS are fairly brief, quite strong, well articulated and heavily referenced. They are nonetheless arguable and some readers might very actively disagree. The Survival section is a bit thin but the planned NCRI research is important in context.
When the paper moves to The Role of Proms you need to keep the focus on the original question, avoid being diverted.

As a result I have added to the introduction to make the agenda quite clear at the outset to any reader, not just those informed on the subject. There were minor comments on the paragraphs on QoL which have been changed accordingly. There were also several suggested deletions, mostly my side comments, in response to the sideshow question - which I have made.

This has taken out about 500 words. It has tightened the paper and the resulting stronger focus helps the stream of the logic and the coherence.

With regard to starting the debate within RI&E I am very supportive of the idea of getting significant ‘players’ to comment. Among current researchers Tannock and Swanton would be a good start, although neither of them has had any notice of this paper. Professor Mari Lloyd-Williams at Liverpool is an end of life clinician and researcher with strong views on cancer treatments. Prof Michael Sharpe (Oxford) is a psychiatrist and comes at cancer from a psychology direction. Someone like Peter Selby could give a more strategic view, given that he is now (slowly) stepping back from clinical research. He is well aware of my interest in QoL and his championing of the European Patient Bill of Rights is an important background too. I would also suggest Prof Sheila Payne at Lancaster (a psychologist and end-of-life researcher) and Prof Jane Seymour at Nottingham – a cancer nurse by background.

Others you might like to consider are Dan O’Connor at MHRA, Francesco Pignatti at EMA, or Carole Longson at NICE for a regulatory view. They all know me slightly. Jan Geissler, Kathy Oliver or Bettina Rhyll – all prominent European patient advocates (they know me well) and of course you know the QoL world better than me.

Another possibility would be Dr Janet Woodcock, director of human drug approvals at the FDA, who openly stated at a (very) recent conference that the clinical trials system is “broken” but I suspect she may just be too busy!
Overall you are both now so familiar with this paper and its intent that if you can see ways of strengthening the argument or its presentation I would be happy to discuss them.

Kind regards

Roger