Reviewer's report

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

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Reviewer: Jack Nunn

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General comments:

There are some very important ideas in this paper and it brings together some threads very well. However, they currently remain buried within lots of other information. I feel this important paper needs focussing in this regard.

Also, while the tone of the piece reads like an opinion piece, some things discussed here are not a matter of opinion, but of scientific debate. I'm not qualified to label them all, but there is a distinction (I have tried to highlight examples of this in my detailed comments).

It is perhaps a matter of personal style, but for example, when I read someone writing in the first person - I expect it to be coming from a place of personal experience - which is highly valid in parts of this paper. At other points, (for example 'Before I go further I need to clarify two terms') it reads like a transcript of a presentation. I would rephrase it (and the many other examples where it is not coming from a place of personal experience or belief) as such 'At this point in the discussion, it is helpful to clarify two terms'.

I think the whole piece would benefit from being edited to make sure the thread of 'patient experience' is woven throughout what sometimes reads as a confusing tapestry of recent advances in cancer. For example, the 'survival/survivorship' section has central arguments which are truncated, whereas if they were integrated more into the areas discussing recent advances, it would be more clear why these advances are being included.
I am more than happy to offer more detailed feedback and support to get this paper published.

From here onwards are specific comments about particular part of the paper. Please note my line references were corrupted in the PDF so I've included original quotations followed by comments, so the original quotations can be found using a text search.

Abstract:
"The ethics of current drug adoption practices and the use of new drugs is being questioned socially and politically raising the challenge of finding the relative value of new treatments in terms of cost and benefit"

This feels like an opportunity to also mention patient and public involvement in health technology assessment (e.g. NICE in the UK). This is mentioned later in the paper but the point is fragmented.

Plain Summary:
"Science is making a difference to a few patients with metastatic disease but it has been 12 achieved at a high cost"

12: Consider adding 'Science and evidence based-medicine' to link to the next sentence.

16: "asking medical research to find the true value of new treatments" this seems to be saying that society - including medical researchers, need to redefine value in new ways.

Background

"rather than commenting on technical quality." consider adding that it is about integrating a subjective view of quality, rather than a purely objective 'technical' assessment.

"After 14 years as an involved patient in cancer research" - I think this needs defining, for example - 'a member of the NCRI Board'
"Being brutal, this analysis suggests that data are garnished to claim fancy conclusions, a few weeks added life is hyped as a significant benefit while data on the outcomes patients worry about are missing"

Consider rewording along the lines of 'The outcome measures used here do not include any quality of life measures, or other outcomes prioritised by patients'. I would also consider not using the word 'brutal' as this is a professional dissection of the research practice, not a personal attack - thus more appropriate language is 'a detached and honest appraisal' - I am also concerned 'brutal' would not make sense for some people with English as a second language.

"majority of studies included would have been industry sponsored studies"

Can we actually include data on this so we can say 'a majority WERE' as this is more powerful and can then cite other papers about systematic bias (I've linked to one later)

"Genetics is the scientific wonder of the age" - consider rewording to 'genomics' or even 'genomic medicine' as genomics is wider than humans!

"Finding the whole mutation structure of a single cancer will open up routes to treating those mutations, it does not guarantee that any mutation can be treated. But we have already seen that cancer is clever"

I'm not comfortable with the wording here at all - happy to give more detail but in summary:

1. Say genomic variations or variations of known significance - mutations is not a helpful word - although it is widely understood, it is a value judgement on a variation - saying to some people 'good or 'bad', thus coming from a 'eugenic' (meaning 'good-genes') philosophy. This is a very truncated response and something I can share more on if helpful.
2. Rather than 'treating' a mutation - the author suggests it is about understanding, thus 'molecular mapping of cancers' might be a better use of language. I refer the author to this highly relevant book chapter I wrote with colleagues which goes into much more detail: https://www.researchgate.net/publication/314636167_Involving_the_Public_in_Rare_Canc
3. Avoid 'clever' - implies intelligent design, which I really don't think this paper should tread into. I would suggest 'highly adaptive' but a qualified cancer researcher should be consulted to comment on this. It's fine for an informal conversation but not in this context.

Acronym - need explaining or this is jargon "2003 the mystery of why a GIST"

"It may also mean new side effects from the new treatment or additional side effects if the original treatment is still being taken because some tumours are still responding" - for balance mention pharmacogenomics may also lead to more targeted drug treatments or flag potential negative side effects which people are genetically predisposed to.

"A multitude of tools - I have identified 18, there are certainly more, ranging from generic to disease specific" - simply state briefly how many you found and how, and acknowledge the limitations of your method - you have essentially done this, but the reader will expect this to have been fact checked or it is not useful to illustrate this important point. In other words, if someone wanted to replicate your search, what would they do?

"Data which are cherry-picked to support a pre-determined clinical or commercial view - a concern expressed verbally to me by regulatory officer" this concern has been systematically addressed - you must cite this - this is not to be whispered - this is to be shouted!: https://www.ncbi.nlm.nih.gov/pubmed/26694022

In addition - the whole HTA process relies on this kind of evidence which has inherent bias! You should also mention All Trials here is this is central to this discussion if systematic reviews of human trials are being conducted without all the data.

"I am not aware of an incidence of this in cancer research" - this is perhaps a style point but when I read this I ask myself is the writer stating it doesn't exist or that they don't know about it. If the former, then state it as so, if the latter, then this needs to be removed or rectified.
"The idea that you can have Patient Reported Outcome Measures without patient provided inputs to inform the methods and processes used, is irrational and probably unethical" this is a crucial point and should be included in the abstract.

"Macmillan is involved" use Macmillan Cancer Support (when used for the first time, acceptable to truncate afterwards) as avoids confusion with the publisher brand.

"Birmingham University" The University of Birmingham

"Other prominent UK groups working on quality of life related projects are in Leeds, which has been using information technology to gather data at the front-line of healthcare in a number of very practical trials, and Oxford where the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU) has a programme is informing policy-makers and commissioners." Split this into two sentences.

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