Reviewer’s report

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

Version: 1 Date: 31 Jul 2017

Reviewer: Begonya Nafria Escalera

Reviewer's report:
- The topic of this paper is important and it's required more practical evidence from the perspective of patients about how design and implement PROMs in the field of cancer research. At the present moment we have a lot of theoretical background about that it's important to include in research these types of measures that become directly from patients, but the practice in the real world is limited.

PLAIN SUMMARY

(Second paragraph)
When the author speaks about ethics of current drug adoption practices, I prefer detail this information with a comment that not reinforces a 100 % of evidence that patients with metastatic disease are taking their last chemotherapy few days before they dy.
In the field in what I have experience, related to paediatric cancer, children are not receiving treatment close to the time that they pass away. When doctors know that no treatment is working they are transferred to the palliative care unit and at this moment is most important the quality of life of patients and families than the research that can be behind the innovative drug that they could have been taking before. I suggest to rephrase the second paragraph of this section with the aim to be less forceful. Thank you.

(Last paragraph)
A deeper definition about PROMs would make more easy to understand the focus of the paper, at least from the perspective of patients. We know that patients read scientific papers every time
more, and a short definition about what means PROMs would ensure a better understand of the content of the paper from the very beginning. Thank you.

ABSTRACT (Section)
I agree the content of the last paragraph, when the author suggests that patients can contribute to design the pathways related to QoL and PROMs measures. This point of view is realistic and ensures items that can measure areas of interest for patients. Thank you.

RESEARCH (Section)
(First paragraph)
The stark findings of a paper in what Dr. Ian Tannock is one of the authors were published on 1975. These findings are radical and the author needs to be sure that are valid on 2017 at least in the European scope. When we check the bibliographic reference of the conference on 2014 we can understand that perhaps are valid, but I recommend to rephrase this paragraph with the aim to ensure that we are speaking about evidence that were on 1975 and in the present moment are working in the same way. Thank you.

I appreciate the comments in the paper about the new ways of treat cancer: immunology, genetics and personalised medicine. This approach open new topics for discussion related to the PROMs and they are related to the evolution of innovative drugs for oncology diseases. Thank you

In general, when you speak about personalised medicine the main conclusion after read the text is that it isn't working properly. Perhaps will be nice improve the content of this section with a general comment that can emphasises the need of more research. These types of treatments are very innovative and more evidence is needed to discover diseases or status of the diseases where it can work. For this reason I suggest to be less strict in the text. Thank you

DELIVERY TREATMENT (Section)
First paragraph
When you refer to DGH would be nice if you contextualize it in UK, this is important for the reader and helps to understand about the reality are you speaking.

SURVIVAL (Section)
It's positive to include in the paper the reference about the experience of James Lind Alliance about the priorities for research. Thank you.

THE ROLE OF PROMs (Section)
I agree with the fact that QoL methods are really scarce in the real world of innovative treatments under study. There is an important gap between theory and practice. The author lists different comments about tools and criteria; I think that it's possible to improve the description of this listed items. For example, when you explain that you have identified 18 tools I propose to add a general description about the field (area of disease) in what they can be applied.

It's positive the reference to the EMA and FDA guidance about Quality of Life endpoints. Thank you

BUILDING NEW PURPOSE FOR PROMs (Section)
Also it's a positive reference and very well described the expertise that has CPROR in the field of PROMs, and the other experiences that you detail in this section.

CONCLUSION (Section)
I agree with the content of the first and second paragraph of this section. At the centre of any development of PROMs always we need to put the patients and at the same time we need to define items that patients can understand. We need to know that the level of health literacy can be different between the patients that perhaps are going to be involved in the process to design this metrics and the huge pool of patients that can provide feedback about PROMs.
The implementation of pathways to provide frameworks for developing research ideas would be an interesting way to standardize this important contribution of patient involvement. Would be nice a more wide description about what the author consider a pathway (we can understand between lines) in order to offer more detailed information to the readers and perhaps would be interesting to include an example at this point.

Many thanks for inviting me to review this paper that is the outcome of the experience of the author as a patient advocate in the field of oncology. It can be a powerful paper to promote improvements in this field. I trust on it.
I hope that my comments would be useful.

Good work. Congratulations.
Warm regards

**Level of interest**
Please indicate how interesting you found the manuscript:
An article whose findings are important to those with closely related research interests

**Quality of written English**
Please indicate the quality of language in the manuscript:
Acceptable

**Declaration of competing interests**
Please complete a declaration of competing interests, considering the following questions:
1. Have you in the past five years received reimbursements, fees, funding, or salary from an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?
2. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?
3. Do you hold or are you currently applying for any patents relating to the content of the manuscript?
4. Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript?
5. Do you have any other financial competing interests?

6. Do you have any non-financial competing interests in relation to this paper?
If you can answer no to all of the above, write 'I declare that I have no competing interests' below. If your reply is yes to any, please give details below.

I declare that I have no competing interests

I agree to the open peer review policy of the journal. I understand that my name will be included on my report to the authors and, if the manuscript is accepted for publication, my named report including any attachments I upload will be posted on the website along with the authors' responses. I agree for my report to be made available under an Open Access Creative Commons CC-BY license (http://creativecommons.org/licenses/by/4.0/). I understand that any comments which I do not wish to be included in my named report can be included as confidential comments to the editors, which will not be published.

I agree to the open peer review policy of the journal.