Reviewer’s report

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

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Reviewer: Carolyn Morris

Reviewer's report:
The author's rationale is clearly expressed and the argument well made, identifying both the need for, and method of, patient led work on outcomes moving centre stage in cancer research.

In my understanding the author identifies two key issues which he argues need resolution in order to improve outcomes for cancer patients:

One- a proliferation of quality of life (qol) measures, with no coherent overview or coordination visible. Secondly, a lack of PPI in defining and designing outcome measures. Earlier, stronger signalling of these as distinct & interrelated issues would lend clarity for readers.

I did have some concerns about how the overall argument is developed: I was initially uncertain about the relevance of paras on genetics and on sarcomas, P.8. If this is to say research here may well not lead to any substantial gains in patient benefit, that point needs to be made more explicitly. I do wonder if it is necessary to the case being made, and might have the effect of muddying the overall argument?

Ethical points, p10, 12-13, are well made. As is the later link to England’s Cancer Strategy: and timely as the Strategy moves further into implementation. Imminent James Lind Alliance work to identify unanswered research questions in Cancer Survivorship will be strong on patient collaboration and adds to timeliness of this submission.
Now for something more fundamental: the author makes a compelling case for a life quality description that cancer patients and clinicians can grasp and share, and identifies possible positive outcomes for commissioners too.

"Data on the outcomes patients worry about are missing", citing a review of RCTs in 3 of the larger cancer patient groups. His own evidence however appears to draw on a narrower range of studies, viz. drug industry sponsored trials. The author's focus is then on systemic therapies only, and in area acknowledged to be low on PPI, and omits patients undergoing surgery and or radiotherapy. Patient outcomes for these groups are of equal importance— including them would make the argument both more rounded and convincing.

On P4, lines 9&10, we are told that research has been making a difference to a few of those with metastatic disease. This is unsubstantiated: no difference elsewhere? This apparent selectivity risks undermining the author's purpose. The addition of some qualifiers could help.

Elsewhere, the addition of some concrete examples could help understanding: I am familiar with this field, most readers won't be.

To be specific: "I have been told about..." P13, lines 11&12, helpful to cite one or two of these. A brief example of substantial PPI impact in proms work would help readers grasp possibilities at the level of the individual study. Recent innovative collaboration between NCRI's Consumer Forum and a large pharmaceutical co, in developing an app for patient use in trials demonstrates that such work is possible, and thence may merit mentioning.

The assertion of a "shambles" in qol measures is not backed up. Citing, e.g. the number of measures of fatigue in cancer: 20+ would surely bring the point home.

Re language, I found some inconsistencies in assumptions about what the reader will understand— especially important for a submission to this journal. P8, lines 26-P9, line 2.

And in the specific case of the new work proposed, we are told this "could be supported" by patient-led work, P14, line 18, surely the logic of the case here is that they must be?
As to the overarching case put forward for new pathways, the author does outline a method for measures better describing pathways, bringing together data from a range of clinical and research resources. The risk that too many of these resources suffer from the very lack of patient values, patient centredness or patient defined outcomes the author argues have led to the very state of play - that risk is not addressed. This reviewer would welcome acknowledgement of this risk and a suggested approach to mitigating it.

In conclusion, if the author's aim is to start a debate, then in this reviewer's assessment, he makes the case for such a debate. A debate that could resonate well beyond cancer and engage patients and clinicians in other conditions. This point is made, but in a rather low key way.

Some points where the case made would benefit from additional evidence or clarification have been identified but these are not to undermine the importance to patient benefit and to the game changing potential of PPI that this submission offers.

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