Reviewer’s report

Title: The Canadian Retinoblastoma Research Advisory Board: A Framework for Patient Engagement

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Reviewer: Margaret Mary Dunham

Reviewer's report:

This is an interesting reflection on the importance of public patient engagement and generally well written. The case for engagement to promote the management of this disease is justified. The development of the PPI group is presented as a constructive and informative way to support future research and policy development related to the support of families and individuals with retinoblastoma. The use of social media and alternative ways of communicating with the population could be valuable in terms of future engagement and as a supportive measure.

The PPI group are volunteers and therefore more likely to be highly motivated and engaged with the topic, so it is interesting to discover that there is a passive subgroup, how did/does this affect their usefulness? This could be an area of future enquiry?

I'm unsure if the quantitative data, and data from the pre-test post-test questionnaires, adds much to the study. The qualitative findings are very interesting and could be further elaborated. The limitations section needs more consideration in relation to the methods, recruitment and population in the study.

The conclusion is rather bold. Suggesting that 'CRRAB is an effective vehicle…' needs rewording. Any declaration of effectiveness requires qualification with more data; however degree of engagement could be cited with possibilities for future evaluation of effectiveness.

On the whole a nice neat little study which is promoting an important supportive mechanism for good clinical and research practice for retinoblastoma.

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An article of importance in its field

Quality of written English
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Acceptable

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