Reviewer’s report

Title: Involving young people in BRIGHTLIGHT from study inception to secondary data analysis: insights from 10 years of user involvement

Version: 0 Date: 21 Oct 2018

Reviewer: Heidi Gardner

Reviewer’s report:

The authors are to be commended for taking the time to write up their experiences and learnings from a large and long-running project with substantial involvement of young people; the article has the potential to be useful to others not only in the field of oncology research, but in any field of research into diseases or conditions in which young people can be impacted. It's a generally a very easy to read article and my comments are intended just to clarify and tease out a few additional points to guide readers and hopefully improve utility of the manuscript for researchers in the future.

1. I'd like to see an additional sentence or two explaining why young people aged 13-24 were selected - this is a broad age bracket considering the physical and emotional changes that young people go through during this time, and I'd be interested to hear why the authors selected these boundaries.

2. Whilst I know it is likely to be impossible to get specific details about the young people that were involved in the early stages of the project (i.e. before the user group was formed), it would be helpful to see a general description of the group - genders/ages/cancer types/stages of the disease/type of treatment being received/socioeconomic background etc - did any of these characteristics mean that communication had to be tailored or improved, and if so, how?

3. The authors explain that challenges to the involvement of young people exist, and they are often referred to as 'hard to reach', 'hard to engage', and/or 'vulnerable' - how do these challenges differ from those encountered when working to involve other groups? Some insight into experiences here would be useful.

4. Table 1 includes lots of acronyms - I appreciate that they are listed underneath the table, but for ease of reading it would be beneficial to use full wording at least for the first mention of each acronym within the table. I found myself reading a little, then flicking the page to find out what the acronym meant, and it interrupted the flow a little.

5. The manuscript reports lots of conversations, discussions and feedback, but it lacks quotations. Whilst this is not a significant problem, it does raise questions around the authors’ interpretation of what the public partners were saying; weaving in a few quotations to demonstrate exact conversations, phrases or feedback would be useful, and it would give me confidence in the authors' interpretations throughout the rest of the manuscript.
6. Recruitment interventions and retention strategies - how was the target of 2,012 young people over 18 months calculated and agreed - who was involved in this process, and why do you think that this target was unattainable in reality? I'm also a little confused by the wording - why are recruitment ‘interventions’ used and then retention 'strategies' referred to? If these two processes really were different; i.e. recruitment interventions were singular efforts being used at once, and retention efforts were a cohesive set of interventions designed to work together, then I'd like to see some comment on why that was the case and if, in hindsight, any improvements could have been made (my PhD focussed on recruitment to trials and I'd love to see more people looking at recruitment interventions as one cohesive strategy!). Some additional detail on the interventions and/or strategies used would also be beneficial, though I suspect that would be for another paper as it would add to the non-randomised recruitment literature which is currently very thin.

7. General comment - I wonder whether the authors had thought about involving any of these young people in the dissemination of their work? It would have been lovely to have heard about additional practice that would have closed the research loop so to speak; perhaps one of the partners could have contributed to the manuscript, given their views on the language used etc. I would have also liked to have seen a short section on how the public partners felt the experience of being involved with this project impacted them; did they feel they have the amount of weight that the researchers clearly did? If so, what was it that enabled this and if not, how could that have been improved? I am very conscious that dissemination is often seen as a 'tag on' to research, and it'd be wonderful to see genuine and meaningful involvement working right through to the dissemination stage(s) too.

Overall a very well written manuscript with a fantastic thread of consistent involvement - I hope that publication of this work will encourage others to involve relevant stakeholders at every stage of their projects.

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