Author’s response to reviews

Title: Consumer input into research: the Australian Cancer Trials website

Authors:

Rachel F Dear (rachel.dear@sydney.edu.au)
Alexandra Barratt (alexandra.barratt@sydney.edu.au)
Sally Crossing (info@cancervoice.org.au)
Phyllis Butow (phyllis.butow@sydney.edu.au)
Susan Hanson (Susan.Hanson@canceraustralia.gov.au)
Martin HN Tattersall (martin.tattersall@sydney.edu.au)

Version: 2 Date: 26 May 2011

Author’s response to reviews: see over
Dear Dr Gonzalez Block and Dr Hanney,

RE: MS:  8218973053980245

Thank you for considering the revisions to our manuscript “Consumer input into research: the Australian Cancer Trials website.”

We have listed the concerns raised by the reviewers and given a response to each point. We have used tracked changes to highlight the changes made to the manuscript.

Reviewer 1 (Ian Olver): Discretionary revisions:
1. It would be worth articulating what made the ANZ clinical trials registry “unfriendly” to consumers which drove the need to translate the data onto a specific consumer website

   Response: We agree that we should articulate this, and have added in the “Discussion” section, on page 15:
   
   “Although they contain valuable information, trial registry websites are not always intuitive to use and are technical in nature. They do not contain related information about clinical trial participation such as a glossary and descriptive information about clinical trial participation. Subsequently, ACTO has been developed using trial registry data, to meet consumers’ demands for a comprehensive user-friendly portal of cancer clinical trials recruiting in Australia. It also provides supporting information that can assist them in the decision-making process to join a trial.”

2. Is this was a demonstration project or does it have ongoing funding?

   Response: To clarify this we have added to page 18:
   “In collaboration with CA, who is continuing to fund the website, consumers led by CVN are playing an essential role in advising about the website’s promotion and future enhancements.”

   As we state in the final sentence of the manuscript, “ACTO can serve as a model for other health conditions.” So, rather than a demonstration project, the development of the ACTO can be used as a pilot for other health conditions developing consumer-friendly clinical trial websites.

3. Although the evaluation was based on not promoting the website there is a statement that promotion of the website was planned for April. It would be useful for readers
wishing to replicate this initiative to know more details about how consumers would be
driven to the website.

Response: So readers are aware how consumers will be driven to the website we have
added to page 18:

“For example, the research team has developed a promotional plan which sets out a way to
make sure that the relevant stakeholders are aware of ACTO using print media, journal articles,
letters, advertisements, posters and bookmarks.”

Reviewer 2 (Paul Ward)

1. In my view, this manuscript does not constitute research, and therefore I can not provide
feedback on it. It is very laudable to develop a portal for consumers, but a description of
its development is not, in my view, worthy of a peer-reviewed paper. There may be other
avenues in terms of commentaries or discussion papers which are available in some
journals.

Response:
We believe detailed descriptions of interventions such as the Australian Cancer Trials website
are important for them to be effectively replicated, particularly because ACTO serves as a model
for other health conditions. It is also an important example of how consumer groups have been
involved in research that benefits consumers.

We also refer to the comments from Reviewer 1 and Reviewer 3 about the manuscript’s
importance and level of interest which support its publication:

Reviewer1: “The paper is clearly written and well referenced and provides interesting new data
on how consumer friendly clinical trials information could be provided in an attempt to improve
participation rates in trials. An article of importance in its field.”

Reviewer 3: “An article whose findings are important to those with closely
related research interests.”

Reviewer 3 (Carla Saunders): Discretionary revisions (which are recommendations for
improvement but which the author can choose to ignore)

1. Could a brief description of the critical success factors for involving consumers be
provided by the authors i.e. What would they recommend to others when it comes to
working with consumers in a technical area such as this?
Response: We agree it is useful to summarise the critical success factors and have added to page 18:

“Although the development of a website required technical input, this did not hinder consumer involvement. The research team helped liaise with technical experts so that consumers’ desire for easily accessible data about clinical trials that could inform their decision-making could be achieved. In summary, the critical success factors of this project were: (1) that the research team has worked with well-recognised consumer groups with extensive networks; (2) it was determined that a consumer-friendly cancer clinical trials website was a priority for consumer groups and their members and this was supported by the research team; (3) the research team listened to the needs of consumers’ and responded to their needs; and (4) the research team assisted consumer groups to provide input when necessary.”

Thank you for your consideration.

Yours sincerely

Rachel Dear MBBS FRACP