Author's response to reviews

Title: Advertising and disclosure of funding on patient organisation websites: a cross-sectional survey

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Author's response to reviews: see over
Reponses to Reviewers Comments

MS: 586539211015127 - Advertising and disclosure of funding on patient organisation websites: a cross-sectional survey

Reviewer: Lisa Prof Bero

1. Add the access date for each website (in table). Although all were evaluated in the last month of 05, websites can change daily so the usual reference format included the exact access date.

The two evaluators did not necessarily view each site on the same day, and many sites had to be revisited to sort out points of contention. No changes to the information being assessed were observed during this process. A single date of access could be misleading. The date of first access (for assessment purposes) has been provided and a footnote added to the table to explain this point.

2. Include the final n in the results in the abstract; or report percentages as X% (a/ total n).

The abstract notes that 69 websites were identified and assessed in the methods. To make it clear, this has been repeated in the results.

3. Box 1 is interesting, but I'm not sure how this list of possible relationships was derived? Is this a theoretical list? I'm not sure how "Sponsoring research grants ..." fits in. Does this mean joint sponsorship by a pharmaceutical co and the patient organization? Something obvious that seems to be missing from the list is "educational pamphlets for patients" I see these around doctors' offices all the time.

This list was derived by the authors.
Some patient organisations administer research grants funded by Pharma. This point has been expanded to make this clear.
The last point has been expanded to ‘Provision of advocacy and educational material’.

4. I would not use any abbreviations in the text - I find them confusing compared to spelling out the full words.

PO has been expanded in all cases.
Pharma, USA, UK, URL have been retained as common abbreviations.
Drug company abbreviated names have been expanded with the abbreviation kept in parentheses.
The table of abbreviations has been deleted.

5. Could you justify the selection of countries where the website could be hosted? Why not just limit to English language only?

The selected countries were those most likely to have a wide range of patient organisations with websites in English. We wanted to be able to (qualitatively at least) assess whether there were any major differences between the websites and the patient groups in the various countries. Limiting to only English language could have identified a few extra patient groups from other countries which would not have permitted this. By limiting to the countries we were also able to ensure the number of websites to be assessed would be manageable. In practice, no other country sites were identified, but the selection criteria were set a priori.

6. The description of items assessed in the methods (e.g., pharmaceutical co funding, sponsorship, advertising, other does not correspond with the presentation of items in the results: structural quality, advertising, etc. I suggest describing the items assessed in the same order in the methods and results.
The description of items in the Methods has been changed to match the presentation in Results which follows the sections of the assessment tool.

7. Could you provide an example of the wording for “a website that was clear in how the organization derived all its funds”?

This is difficult since the information was usually in more than just one place and often involved lengthy description. This item was one of the weaknesses of the EU Guidelines for health-related information on the internet since it is not that clear how it should be assessed. We looked for an indication of how funds are generated and of which corporations have given funds. A statement to this effect is now included to make this clear for readers.

8. Sites based in south africa are singled out in the results quite a bit - I’m not sure of the significance of this. Under section on “annual reports and financial disclosure” comments are made by disease state (depression) and country (S.A.) Sticking to comparisons by disease state makes more sense to me.

Although not explicitly stated as an objective, comparing patient organisation websites between countries is an important part of the analysis as it can indicate the level of development of the organisation and website and how open to influence by Pharma they are and any country specific factors which may affect this. The lack of development of the SA websites and the fact they are not as ‘transparent’ as other countries (fewer annual reports available) are noteworthy and this is why they are mentioned. Other country comparisons are made e.g. advertising policies. We would prefer to keep this information as part of the text.

9. Remind readers of your baseline sample size as you present results. For example, instead of saying “only 3 sites,” say 3/69.

This has been now been included at strategic points.

10. Under ”General advertising,” para 1, I don’t understand what “we include it as a collectors piece” means.

The wording has been changed to “we mention it as an interesting example.”

11. Would it be possible to show a screen shot of the site sponsored by a local steakhouse? Great example!

Inserted as Figure 2.

12. Under para 2, section on annual reports, I don’t know what MSD means.

This drug company name acronym has been spelt out.

13. Same para - it’s not clear why a patient site is mentioning pharma donations to research fellowships .. could more context be provided?

An explanatory sentence has been added in parentheses: “(a number of patient organisations administer research grants and fellowships, the money for which comes directly from Pharma)”.

14. Could you provide a list of corporate donators who were not pharmaceutical companies? It would be useful to know what other types of interests sponsor these sites.
Corporate donors come from a wide spectrum (depending on the disease state), including banks, local businesses, pharmacy chains, computer companies. This is now mentioned when reporting on corporate donations.

15. Great quotes in para before discussion regaring why companies sponsor sites.

We recommend a visit to the website to read the text in full.

16. I suggest restructuring the discussion around the recommendations - which data from the study supported the recommendation and details of what is recommended (eg, recommendation 1 recommends standardized reporting - what should this contain? give an example of a good disclosure). This would eliminate some of the editorial comments such as “One may wonder which other POs groups owe their birth and life to Pharma.”

We welcome the suggestion of restructuring the discussion of the paper. However, the discussion is much wider than the recommendations and some aspects impinge on more than one recommendation. Inference was made to the recommendations in the discussion – this has now been made more explicit as suggested. However, we feel that a complete reworking would be difficult and not achieve the outcome desired.

None of the websites or annual reports in our sample provided an example of ‘good disclosure’; such is the scale of the problem.

17. Good discussion of limitations although the obvious one of being a cross sectional study of rapidly changing media is not mentioned.

Thank you for pointing this out. It has now been added to the limitations.

Discretionary Revisions (which the author can choose to ignore)

1. The studied websites were not compared re transparency of funding with any other type of website, so we don’t really know if their disclosure of funding is standard or not. I’m not suggesting another study, but is there any literature analyzing other types of websites that could be referenced?

We are not aware of a study of websites investigating this aspect other than that of health advocacy groups (the PatientView survey).

2. I’d like to see a copy of the assessment tool included as an appendix.

This has been done – as additional material/file.

Reviewer: David Henry

1. I think this paper may have a substantial impact in it’s likely to be circulated widely amongst patient organisations. Consequently, I think the authors should take the opportunity to spell out in detail the consequences of patient organisations becoming too close to commercial funding sources. For instance in my experience patient support groups often lobby for subsidised access to new health technologies. This is completely understandable and quite appropriate except that in a number of instances the organisations have weakened their stance by becoming very close to the organisations that sponsor the products.

A paragraph has been added to the Discussion to emphasize this.
2. The only weak part of this manuscript really is the abstract. Because the abstract is the part of a document that is guaranteed to be read they should try to put more information into it. The abstract is rather thin on data and I think it could spell out more clearly their results. In addition the authors have come up with some excellent policy recommendations and I think that these should be reproduced in the abstract in as much detail as space allows.

We have attempted to strengthen the abstract along the lines suggested while keeping to word limit restrictions.

The authors would like to thank the reviewers for their helpful comments in strengthening the manuscript.

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