Author’s response to reviews

Title: Open to the Public: Paywalls and the Public Rationale for Open Access Medical Research Publishing

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Author’s response to reviews:

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Dear Editors of Research Involvement and Engagement,

Thank you for your helpful comments and for the opportunity to revise our paper. We believe we have made edits that strengthen the paper based on your feedback. Please find below our point-by-point responses and description of the changes we have made.

Best wishes,

Suzanne Day on behalf of the authors
Reviewer #1

Comment: “From a European perspective, I would suggest to mention the Clinical Trial Regulation EU 536/2014 which will come into effect in the second half of 2020. It requires the dissemination of a Lay Summary within 12 months after the end of the study and within 6 months in paediatric trials. I believe it shows the willingness of the European Commission to share the results of research to patients and general public on an appropriate format.”

Response: We thank the reviewer for this suggestion and have added a reference to EU CTR 536/2014 in the revised manuscript.

Comment: “Maybe, you could mention that sometimes, patients involved in clinical trials do not have access to the results. After few years, they can discover information regarding "their" clinical trial on internet which is very frustrating and jeopardize their trust in research... Giving them access to information it is a way to respect their involvement into research. A mindset change is required on the issue to attract more patients to clinical trials. Research is financially supported by patients (through donation to NGO), so showing them what is it done with their money is a way to recognize their contribution. It will have a positive impact on their next donation. Having a large access to research will give an overview to the patients/general public of all the ongoing research and it will give them hope.”

Response: This is a very good point raised by the reviewer, and we have added additional text to the section on Obligations to Research Participants acknowledging that paywalls restrict participants from learning about the results of studies made possible only through their efforts.

Comment: “To me the practical suggestions (page 3, line 26) were not clear.”

Response: Our practical strategies are presented, albeit briefly, in the Conclusion of the manuscript. We have added additional text in this section to better emphasize these strategies.
Reviewer #2

Comment: “Making useful information, such as research findings, part of the commons has obvious and substantial benefits and like the authors and most of the scientific community I see open-access publishing as an important contributor to this. As I read this paper, the main focus is on arguing for this importance of open access. I do am not convinced of a primary or even substantial focus on the public and patient voice. Open access to research is an important foundation to support aspects of patient and public involvement, but for me, the focus of the paper is certainly not primarily focussed on that as an end.”

Response: We thank the reviewer for these concerns. The focus of our manuscript is on advancing open access, however we do so from the belief that patients and the public are primary beneficiaries of these efforts who are often overlooked. We have revised the introduction of the manuscript to clarify our argument that open access is an important aspect of patient and public involvement in research.

Comment: “Although open access is a step "to correct historical practices of exploitation and communication failures because many of the patient partners came from marginalized indigenous, rural and remote communities” identified as the insight and motivation leading to this piece it is far from the obvious first or most important step in addressing that problem. As noted in the pre review comments from editors, accessibility, in particular for these groups, goes far beyond open access of technical papers.”

Response: We appreciate and agree with the reviewer’s point that there are additional accessibility issues beyond open access that should be considered in the efforts to advance inclusion of patient involvement. We have acknowledged this in the first paragraph of our section, Caveats and Counterpoints to Open Access for the Public (i.e. noting that open access should not be considered a total panacea), and have added additional text in the revised manuscript to note that indeed this should be considered the most important caveat to our arguments in favor of expanded open access from a public perspective.
Comment: “The excellent example of open access supporting advocacy (in the text box identified as Figure 1) is a case of substantial community organisation-researcher collaboration than just an open access publication. The similar really strong example of the Melanoma Patient Network Europe on page 10 is presented highlighting the central role of open-access to this initiative. Linking through identifies their engagement with open access but also identifies and promotes arrangements with mainstream publishers through "patientACCESS" to make papers from behind a paywall accessible to patients. This group is thus assuring access for their stakeholders in the existing imperfect world and mixed economy of publishing rather than being particularly founded on open access. These two examples are where the material is most relevant to the journal, although I would argue that it would be better with this emphasis on assuring advocate and patient accessibility rather than the specifically open access focus.”

Response: The reviewer raises a good point that the successful example of a community-based organization’s advocacy presented in Figure 1 is not attributable to open access alone. We have added additional text to the first paragraph in our Caveats section to acknowledge that efforts to advance researcher-community collaboration will also be needed alongside expanded open access to advance public advocacy and innovation.

Comment: “For the most part this piece casts open access publication in opposition to for-profit publishing. Open access certainly undermines the traditional monetisation model of publishers that has been founded on restricted access. However the same major publishers are generating for-profit open access models with the costs largely borne by the same institutions and researchers funding the profits under the pay-wall model. There has also been an explosion of entities entering for-profit publishing of research under the open access - researcher pays model. Both systems can justifiably be critiqued as broken markets, and one where individuals (researchers, research institutions, members of the public or others) are not served by the market model. I would judge the thinking behind initiatives such as plan S to move away from this market imbalance and would see that as more central to a well-founded argument than the approach here where that work is mentioned in the "Caveats and counterpoints to open access for the public" section. In an atomised market the wider implications of this open access expansion on the average quality of published science, and approaches to assessing this quality, may well have profoundly negative impacts on efficient and beneficial direct public access to useful research. That the authors don't see this as a main issue is evidenced by their return to their main argument in closing such as the statement "Research scientists should reflect on how their contributions to for-profit journals inadvertently hide results from study participants and the wider public." again conflating for-profit with subscription models and ignoring the for-profit open access issues.”
Response: The reviewer raises an excellent point, and we agree that at times throughout the manuscript we have conflated ‘for-profit’ with ‘paywalled’ publishing. As noted in our Caveats section, there is certainly many problems with for-profit publishers offering open access options for a hefty fee, essentially pushing costs onto individual researchers. We have revised our phrasing throughout the manuscript to make it more clear as to when our critique is focused on paywalls specifically vs. for-profit models. We believe this helps to clarify that our primary concern is with paywalls, while acknowledging the problems of for-profit models as well.

Comment: “My overall impression of the arguments advanced are that they use the patient and public dimension as a means to advance an argument for open-access, rather than being focused on effective patient and public access and involvement as an end.”

Response: Our purpose in writing the paper is indeed to advance an argument for open access, but we do so from a patient and public perspective and ultimately as a means to achieve greater inclusion of patient and public involvement in research. Although it is certainly not the only strategy needed, we believe that having greater access to medical research via open access can play a vital role in patient and public engagement.

Reviewer #3

Comment: “I find this article challenging, not because of the content but because the authors promote and support one business model for publishing over another based on their own agenda and without considering other issues. To be fair, their title implies that this is what they would do. Their argument is built on social values, which I fully subscribe to, but they do not give consideration to alternative models which might offer value which is assessed in a different way. They assume that profit is the only outcome from a 'capitalist' model and they do not consider whether there may be other outcomes of non-monetary value or methods of mitigating the impact they describe. Open access to published research results is a crucial topic for all the reasons the authors put forward. Their case that paywalls are a barrier to the wider understanding of science is a slightly simplistic claim. One important challenge is whether they also protect science from the 'fake news' movement. Do they? By cultivating their exclusivity do they also ensure that the most significant science gets the widest exposure to those of influence?”
Response: It is true that paywalls prevent the dissemination of science not only by those who would seek to use it for social good (i.e. informing the public) but also those who would seek to mislead (i.e. ‘fake news’ that misconstrues research findings for the sake of sensationalism or to promote a political agenda). We have added this point to our Caveats section. However, by the same token paywalls make it harder for members of the public to identify and challenge ‘fake news’ generated in and perpetuated by non-academic information sources (e.g. news media, social media, political leaders). Hence, we include a call for greater efforts to enhance the navigability of scientific writing among the general public.

Comment: “The medical publishing world is a very tight market, dominated by just five large companies. Their ability to raise prices for institutions is already causing some significant institutions to reconsider their subscriptions and to promote open access routes to their researchers. Some of these publishers also operate open access journals. This may not be a sustainable market model in the longer term quite apart from the 'open access' movement.”

Response: The reviewer raises a good point regarding the open access options provided by for-profit journals. As noted above in response to Reviewer #3, we realize that throughout the manuscript we may have conflated the terms ‘for-profit’ with ‘paywalled’, and have revised to more clearly specify when our critique is aimed at the profit-driven publishing model vs. a lack of freely accessible research.

Reviewer #4

Comment: “Overall the paper provides a strong argument for the increasing use of open access, however there are two areas I think the paper could make small improvements. First, the introduction could make greater reference to the wider debate in academia, beyond the discipline of medical research, perhaps referencing the Finch report in 2012 and subsequent changes in government policy regarding publicly funded research. This appears to be a significant development contributing to the disruption of the status quo in academic publishing.”

Response: We agree that including the Finch Report would be an excellent way to note broader efforts to advance open access publishing for public benefit, and have included additional text referring to this in the Introduction.
Comment: “Second, the authors could provide a more balanced discussion on the argument of 'who will pay' for open access. The authors acknowledge the potential for creating a two-tier system in which publishing decisions are made on the basis of who can afford to pay. They suggest that shifting the financial burden to funders is one way of addressing this problem without discussing some of the potential problems. Here the relevance of acknowledging the wider academic debate becomes significant. While, the percentage of publically funded research in medical sciences may be high, this is not the case across all disciplines for example education and the social sciences. It may also negatively affect students who wish to publish from dissertations, as well as independent researchers. Finally, funders themselves will need to identify extra resources or limit research activities to accommodate this approach. In this vein, the authors could acknowledge that the entire academic publishing sector has been disrupted by the growth of open access publishing. While this a positive step in terms of addressing inequality in access, systems and processes to mitigate against some of the potential negative consequences, such as exacerbating the existing inequality between publically funded and independent research, are still emerging during this period of flux.”

Response: We thank the reviewer for raising these points. It is certainly the case that a strategy of requiring funders to cover open access publishing fees does not necessarily present a universally beneficial solution for expanding open access as a public good. We have added a discussion of this to the Caveats section to provide a more balanced assessment as recommended.

From the Editors

Comment: “Clearly your paper is one that intends to stimulate discussion and debate, and equally clearly - judging by the responses of our reviewers - it will do so. However Reviewers 2 and 3 have raised some important questions about the various models for publication that are available, and we feel that your paper does need some significant adjusting to address these, and perhaps to state more clearly your position (which may also suggest a more pointed title too).”

Response: We thank the editors for the opportunity to submit a revised manuscript. It is our hope that our clarifications and additions – particularly based on the feedback of Reviewers 2 and 3 – will help to provide a more nuanced exploration of the public perspective on open access. We have also edited the title to better fit the manuscript’s content.