Author’s response to reviews

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

Authors:
Suzanne Day (suzanne.day@med.unc.edu)
Stuart Rennie (stuart_rennie@med.unc.edu)
Danyang Luo (ryan.luo5@gmail.com)
Joseph Tucker (jdtucker@med.unc.edu)

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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

COMMENT: “We would ask you to clarify why a paper representing a patient/public viewpoint does not have a patient/public co-author, and whether or not you have sought/obtained any input from patients (or the public) who are engaged or involved in open access publication.”
Response: We are grateful to the editors for pointing out this omission. We work with a number of community-based organizations (CBOs) in the context of our research, particularly regarding social and bioethical aspects of HIV research and community engagement for HIV clinical trials. We have approached a colleague of ours from one such CBO (Danyang Luo of Zhitong Guangzhou LGBT Center) to review and provide feedback on the manuscript and contribute to our arguments for the importance of open access from the perspective of a community-based advocate. His substantial contributions to the revised manuscript warrant co-authorship, and we have added him accordingly.

COMMENT: “Have you explored what patient advocates or groups are already doing in this area (for example around clinical trials in Europe), or what some research teams/organisations are doing, for example the Envision group, or is that a piece of future research (for you or for others)?”

Response: While there is a need for the open access movement to engage more closely with patient advocacy groups, there are some excellent international examples of patient advocacy groups for whom increased open access is a core goal. We have revised the manuscript to include some concrete examples of these efforts.

COMMENT: “On a more theoretical level, we wondered if you wished to begin a wider debate around what can open access do for the public generally? Open access is a fine principle of course, but how people access knowledge raises issues of how they understand and/or (mis)use it. Our journal is open access but we insist on plain language summaries too. What do patients and the public want from open access, and how do you (or we) know? Is there a genuine tangible patient/public demand for Open Access or is it simply a principle of idealistic researches and a campaigning point for patient advocates and activists? Why do patients co-author academic papers (again, especially in clinical research) but are happy for them to be published behind paywalls? Do they then obtain access themselves and send pdfs or photocopies to friends?”
Response: One area where greater research is needed is on the topic of how the general public finds and makes use of open access medical research. We have included some examples of the few studies that have taken up this question; it would appear that there is indeed public demand for open access (particularly for the purpose of health decision-making), but under certain conditions to enhance navigability (e.g. inclusion of lay summaries, improvements to discoverability). We have revised the manuscript to acknowledge that more research is needed to better understand how laypersons use and/or share open access articles and what suggestions they have for how to enhance uptake of open access information among members of the public.