



Crowdfunding for respiratory research: a new frontier for patient and public engagement?

To the Editor:

The rapid expansion of social media has broadened the number of crowdfunding platforms available today. This phenomenon should be seen in the context of a long tradition of appealing to the public for financial support. Modern crowdfunding initiatives have developed into a significant source of funding, garnering an estimated US \$5 billion annually, with proceeds projected to expand to an annual \$100 billion by 2020 [1]. Websites such as Kickstarter.com allow users to pool the resources of many contributors, funding predefined initiatives [2] with incentives ranging from merchandise or symbolic gifts, to acknowledgement of project contribution [1]. Furthermore, there has been an interest in research-specific platforms to act as an adjunct to or replacement of traditional funding sources [3]. Entities such as Experiment.com offer a platform to seek crowdfunding support ranging from basic science initiatives [3] to clinical trials. A recent systematic search identified 20 clinical trials funded *via* crowdfunding, with eight out of 13 completed campaigns reaching their funding goals, the largest funding allocation reaching a total of \$3 113 000 [4], underscoring the financial implications of crowdfunding.

In the realm of study design, patient-oriented research is a growing initiative internationally [5] and is defined as a “continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes” [6]. These ideals emphasise patient experiential knowledge; support allowing public involvement, and mutual respect between researchers, practitioners and participants; and facilitate problem solving between these groups [6]. While input into the design process could foreseeably impact the direction of individual projects, control over funding allocation through crowdfunding has the potential to shape research direction, a mechanism for patient involvement not addressed in these guidelines.

Chronic conditions require significant patient involvement to self-manage over time. Moreover, self-efficacy has been associated with a decreased disease burden in chronic respiratory disease [7], and crowdfunding has the potential to act as the funding mechanism to encourage patient engagement and self-efficacy by linking the public and patient to research funding allocation. Furthermore, the increasing prevalence of chronic respiratory disease [8] has the potential to provide a large population of contributors, from the design stage to funding allocation, and into the completion and dissemination of study results.

Patient-funded research has been described in trials in Parkinson disease, multiple sclerosis and use of human tissue products, referred to as a “pay-to-participate” model. Ethical concerns have been voiced with regard to this approach, including the potential for misconception of therapeutic intent as well as equipoise, with bias towards subjects’ entry into treatment arms as funding contributors [9]. Research crowdfunding prompts further ethical issues. This funding modality, executed in an unregulated manner, has potential to subvert the established process of peer review in funding allocation, which acts as a barrier to ensure only worthy projects are initiated and successfully completed. Recipient accountability for ethical and academically acceptable use of funding following this process is not assured, especially considering the marked diffusion of sources. Given the extensive use of public advertising to garner popular mainstream public interest, there is a concerning potential for appeal to emotion to act as a bias in funding selection [9].



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Crowdfunding is a novel mechanism of public involvement that has profound implications on respiratory research <http://ow.ly/2CsV30eEiVi>

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Given the tumultuous political climate with regard to research funding [10], alternative monetary sources are becoming a relevant priority for researchers. Lack of regulation and a standardised peer review process in crowdfunding campaigns could result in the loss of the major selection mechanism for quality projects in the increasingly competitive field of respiratory research. We see an opportunity for established research bodies to provide leadership in upholding the high standards of project selection demonstrated to date. Crowdfunding platforms managed or established by international respiratory societies could provide accountability, anonymous peer review and expertise lacking in generalised crowdfunding platforms. Alternatively, collaboration with established crowdfunding platforms would combine already established software with the aforementioned benefits. Initiatives identified as relevant by an anonymous peer review panel could be presented to the public for funding consideration, with greater assurance of recipient accountability and project integrity.

Crowdfunding provides a platform to bring members of the public to become engaged in respiratory research from a funding and allocation standpoint, in keeping with the ideals of patient-oriented research initiatives. Caution, however, must be exercised, given the lack of current regulation and peer review, evolving the evidence base, and potential for bias. Maintenance of a robust anonymous peer review process and a mechanism to ensure selection of not only quality initiatives, but also the ongoing ethical and academically sound use of funding throughout the life of a project should be of high priority. Crowdfunding already has evidence of significant enterprise and we advocate not only further study of the use, regulation and relevance of crowdfunding to patient-oriented research, but also of early intervention and leadership by established international respiratory bodies in the incorporation of this funding modality to best preserve ethical and academic integrity in respiratory research as a whole.

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