

Barriers and solutions to working with patient authors: A survey of publication professionals

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Objectives

- To identify the level of experience among agency publication professionals in working with patient authors on scientific publications.
- To gauge understanding of existing guidelines, and to identify what barriers are preventing more widespread involvement of patient authors in publications.

Methods

We distributed a confidential survey (which can be viewed via the QR code) to members of publications teams across a medical communications agency, with questions covering their recent publications practices, perceived barriers and solutions to patient authorship.

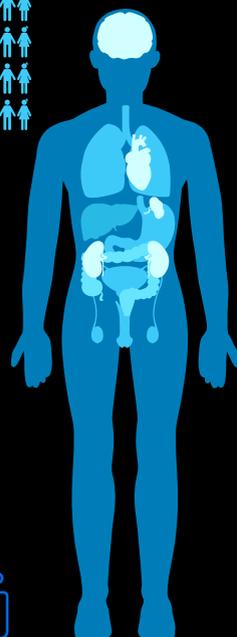
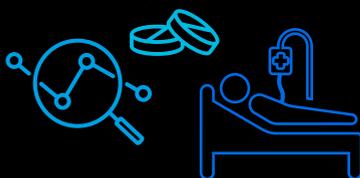
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Forty publication professionals of varying levels of experience were included

Several therapeutic areas were represented

The publication work covers various stages of the product lifecycle



Results

How many publication professionals have worked with a patient author in the last 12 months?

- Never: 85%
- Once or twice: 12.5%
- 3–10 times: 2.5%
- More than 10 times: 0%



The majority of those surveyed did not know, or were unsure about, what a patient would need to do to meet ICMJE authorship criteria.



Better awareness is needed of journals that accept or actively encourage patient authorship. Of the 40 respondents, 35 (87.5%) could not name a specific journal that actively encourages patient authorship.

Suggestions for improving rates of patient authorship included:



Five clear barriers were felt to be stopping publications teams or their clients from involving authors in scientific publications:



“Changing the perception that all patient content is emotional and poorly researched, and locating these good influential patients with an accurate and worthy voice, is key.”

“I suspect clients are wary because they’re unsure that patients will be able to follow the authorship process.”

“It’s difficult finding appropriate patient authors.”

“I think more training, and an understanding of the value, would help both us and the client.”

“An industry-wide push to recognise patient experts as legitimate subject matter experts.”

“Pharma companies need to see the value of investing in these types of publications. Agencies also need guidance on how these projects would work from a guidelines perspective if we are to recommend them to our clients.”

“Greater knowledge of what patient authors can contribute to publications ... clear guidance on what topics/types of publications patient authors can provide a meaningful contribution to...”

Conclusions

- Although patient authorship is not a completely new concept to publication professionals, it is not yet commonplace in publication practices and the level of experience in working with patient authors is low.
- There is some confusion around how a patient author could meet the existing ICMJE authorship criteria, which has led to a call for clearer guidelines to tackle the issue.
- Furthermore, practical training on how to find and work with patient authors would be welcomed.
- As well as overcoming these barriers with clearer guidelines and training, publication professionals would like to see an improved awareness of the value and importance of involving patient authors.

Limitations

These data are representative of a short survey distributed to 40 publications professionals within one medical communications group in which publications and strategic publication planning are core offerings. Additional research is needed across a greater sample size of professionals working in other agencies and within pharmaceutical companies to draw conclusions across the whole industry. Responses were anonymised and no questions were asked about level of experience/years working in publications, and we are unable to draw comparisons between experience level and level of knowledge of working with, or attitudes towards, patient authors.

Disclosures

All authors are employees of Prime Global, a medical communications agency.

