

# Publications

## SECTION EDITOR



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### Editorial

In the December 2024 issue, Phil Leventhal, Danielle Drachmann, and Soren Skovlund discussed whether patients and caregivers can be authors of peer-reviewed publications. The conclusion was: yes, they can and should be! If patients and caregivers meet the International Committee of Medical Journal

Editors authorship criteria, they should be given the opportunity to be authors. People with lived experiences of a condition can provide unique perspectives about it.

In this instalment of Publications, Phil Leventhal, Danielle Drachmann, Stephen Gilliver, and Hui Zhang discuss some of the

challenges that patient authors face when working on company-sponsored publications. They suggest how medical writers can collaborate with and support patient authors.

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## How medical writers can support patient authors of company-sponsored publications

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### Patient authorship

**P**atient authorship is where patients or caregivers are listed as byline authors of peer-reviewed publications.<sup>1,2</sup> In such cases, the patients or caregivers, collectively referred to as “patient authors”, have played a meaningful role in producing and sometimes even leading the publication. This is common for publications where patient or caregiver experiences, needs, or expectations are described or where having a person with lived experience adds important perspective, such as in rare diseases, where clinicians and researchers may have limited knowledge.

Patient authorship is being encouraged by

patient advocacy groups, healthcare professionals, medical journals, academic institutions, pharmaceutical companies, and regulatory and health technology assessment agencies.<sup>1,3,4</sup> As patient authorship of publications becomes more common, medical writers are more frequently being asked to collaborate with and support patient authors.

### Who are patient and caregiver authors of company-sponsored publications and what do they need?

Increasingly, patients and caregivers are engaged in the work leading up to publication of company-sponsored research. For example, they may contribute to the design and conduct of the research<sup>5</sup> or may participate in publication steering committees.<sup>6</sup> In some cases, however, patient authors are brought in to lend their perspective only once writing starts. In the worst cases, they are added only to increase the credibility of a publication, also known as “tokenism”.<sup>7</sup>

Patient authors of company-sponsored publications are often experienced patient advocates or leaders of patient organisations; some may even be researchers or clinicians themselves. In other cases, patient authors may have little experience in and knowledge of medicine or publications. Whatever their circumstances, patient authors are emotionally invested in helping to advance knowledge about a disease or condition affecting them or someone they care for, so they want to ensure their perspective is considered.



Patient authors often face a variety of challenges when collaborating on company-sponsored publications. Some major challenges they may need support overcoming include:<sup>5,8,9</sup>

- Lack of knowledge of the publication process, author responsibilities, ethical issues, and scientific or statistical issues
- Feeling intimidated or not respected by experienced clinicians or researchers, and not knowing how to navigate power dynamics during the publication process
- Dealing with any existing relations with other members of the authoring team, for example, with a physician who cares for them or their family member
- Not knowing how to collaborate with a professional medical writer

As patient authorship of publications becomes more common, medical writers are more frequently being asked to collaborate with and support patient authors.

- Needing additional time to understand complex information or to complete work on the publication
- Needing resources to deal with physical challenges

- Not knowing where to seek advice and support

### Medical writers can support patient authors by offering training

One way that medical writers can help patient authors is by offering targeted training.<sup>11,12</sup> Because patient authors can have varying knowledge of medicine and experience contributing to publications, medical writers should first meet with them to determine their needs and the appropriate language to use.<sup>5,8,9,12</sup>

For patient authors with little to no experience, a great place to start training is a summary of the relevant parts of the **International Committee of Medical Journal Editors (ICMJE) Recommendations** (Table 1).<sup>13</sup> Of particular importance is the part about roles and responsibilities of authors, including authorship criteria.<sup>5,8,10</sup> As part of this training, Richards et al. recommend insisting “that authorship is not token and that contributions are required by all authors.”<sup>5</sup>

Guidance on the publication process, also provided in the ICMJE Recommendations, is another important aspect of training. This should include the steps in preparing and submitting a manuscript for publication, how peer review works, how to deal with reviewers’ comments, and how and why to complete conflicts of interest disclosures. This information can help demystify the publication process, reinforce understanding of authors’ responsibilities, and help patient and caregiver authors ensure that their perspective is incorporated.

Patient authors should also be informed about **Good Publication Practice (GPP)**, which is the principal best-practice guideline for company-sponsored biomedical research.<sup>14</sup> Relevant aspects of GPP include: the importance of reporting research in a complete, accurate, unbiased, and timely manner; the requirement to provide useful feedback at each stage of manuscript development; privacy of patient information; and confidentiality of intellectual property.<sup>15</sup>

Further, patient authors can benefit from guidance on **how to effectively navigate the power dynamics of the authoring team**, especially when they are not researchers or clinicians. Discussing the following can help:<sup>5,8-10</sup>

- Who will be on the authoring team and what their roles are
- The objective of the publication
- Who to turn to for help
- How to communicate openly and clearly
- The importance of the lived experience and how to ensure that it is incorporated in the publication
- How to avoid and deal with conflict
- Best practices for editing, reviewing, and providing comments
- The role of professional medical writers, including the difference between ghost writing and professional medical writing and the value that medical writers bring



Photo: Freepik

**Table 1. Recommended components of training for patient authors**

Topic	Key components to include <sup>5,8-10</sup>
Key guidelines	<ul style="list-style-type: none"> <li>● ICMJE Recommendations</li> <li>● GPP guidelines</li> </ul>
Structure and format of publications	<ul style="list-style-type: none"> <li>● The main sections of a publication and what is appropriate to include in each</li> <li>● Other key sections that need to be completed (e.g., acknowledgments, conflicts of interest, author contributions)</li> <li>● Formatting of publications</li> <li>● Instructions for authors</li> </ul>
Publication process	<ul style="list-style-type: none"> <li>● Overview of the steps involved in drafting and submitting a manuscript (drafts, quality checks, approvals)</li> <li>● How the journal is selected</li> <li>● The submission process and how decisions are made by the journal</li> <li>● The peer-review process and how to respond to feedback</li> </ul>
Roles and responsibilities	<ul style="list-style-type: none"> <li>● Authorship criteria</li> <li>● The patient author's role within the research and publication team</li> <li>● Expectations and responsibilities throughout the publication process, including timelines, reviews, and providing feedback</li> </ul>
Ethical responsibilities of authors	<ul style="list-style-type: none"> <li>● Confidentiality of intellectual property</li> <li>● Ensuring protection of patient privacy</li> <li>● Understanding consent and data protection regulations</li> <li>● Importance of maintaining ethical standards in research and publishing</li> <li>● Guidance on disclosing conflicts of interest and maintaining transparency</li> <li>● Plagiarism</li> <li>● Copyright, licensing, and sharing/reuse of published materials, including articles they may be an author on</li> <li>● Author rights</li> </ul>
Working with medical writers	<ul style="list-style-type: none"> <li>● Role and value of professional medical writers</li> <li>● Why medical writers are not ghost writers</li> <li>● How to collaborate effectively with a medical writer</li> </ul>
How to balance personal experience with scientific data	<ul style="list-style-type: none"> <li>● Guidance on how to effectively incorporate personal experiences and perspectives into the manuscript</li> <li>● The importance of balancing anecdotal evidence with scientific rigour</li> </ul>
Communication skills	<ul style="list-style-type: none"> <li>● How to effectively communicate with the team (e.g., active listening, providing constructive feedback, effective questioning, email etiquette)</li> <li>● Navigating power dynamics</li> <li>● How to effectively comment on and edit drafts</li> </ul>
Project-specific training	<ul style="list-style-type: none"> <li>● Familiarisation with key medical and scientific terms relevant to the research</li> <li>● Basic understanding of the study design and its objectives</li> <li>● Basic understanding of the statistics used in the study</li> </ul>
Case studies	<ul style="list-style-type: none"> <li>● Example publications where patient and caregiver authors have participated</li> </ul>

Abbreviations: ICMJE, International Committee of Medical Journal Editors; GPP, Good Publication Practice

All training, even for experienced authors, should be presented in **plain language** to help ensure understanding and encourage engagement.<sup>9</sup> This does not mean dumbing down the content but rather using words, grammar, structure, and terminology that make it easy to understand.<sup>16</sup> For more experienced patient authors, this may simply mean avoiding complicated writing, while for less experienced ones, this may mean explaining things in lay language. In all cases, both the language and content need to be appropriate; an experienced patient author may be insulted by lay language, whereas a less experienced one may not understand or be intimidated by technical language.

Medical writers may wish to develop their own training materials, but some are already available for patient authors (Table 2). Also, providing a customised plain language glossary of technical terms may be helpful for less experienced patient authors.<sup>8</sup>

**Medical writers can help patient authors by offering mentoring and support**

Medical writers can also help patient authors by providing mentoring and support.<sup>5,8-10</sup> Patient authors may feel intimidated by or inferior to experienced clinicians and scientists on the authoring team, which can result in them not

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speaking up, not asking questions, and generally being overshadowed. In addition, even if they have received training, patient authors may need continued support during the publication process. Medical writers can help patient authors by providing:<sup>5,8-10,17</sup>

- **Confidence:** Medical writers can reassure patient authors that their lived experience is valid and valuable and that it is the reason that they have been invited to be an author on the publication.
- **A collaborative and inclusive team environment:** Medical writers can work to ensure that the authoring team understands the value of lived experience and respects the role of patient authors.
- **A “safe space”:** Patient authors may not feel comfortable asking questions or seeking advice during meetings within the full group. Medical writers can be someone patient authors can turn to, either spontaneously or in planned patient author meetings.
- **Mentorship on the publication process:** Medical writers can assist patient authors in navigating the publication process, fulfilling authorship responsibilities, and understanding technical terminology, study designs, and statistics.
- **Mentorship on effective communication:** Medical writers can advise patient authors on

how to deal with strong personalities in the team, navigate difficult discussions, provide effective and constructive feedback on manuscript drafts, and generally gain the respect of expert clinicians and scientists.

- **Advocacy:** Medical writers can help ensure that patient authors understand and actively contribute to discussions, for example by paraphrasing discussion points in plain language or by intentionally asking patient authors for input. Medical writers can also ensure the inclusion of patient authors’ feedback and contributions during the drafting and revision process.
- **Conflict resolution:** Medical writers can assist in resolving any conflicts that arise within the team, promoting a positive working environment.

**Conclusion**

Medical writers are increasingly being asked to work on company-sponsored publications that include patient authors. Patient authors, especially less experienced ones, may have difficulty understanding complex medical terminology, navigating the publication process, and effectively contributing their lived experience when working with experienced clinicians and researchers. Medical writers can provide training and support to patient authors so that their valuable perspective is respected and properly reflected in the publication.

**Table 2. Available training for patient authors**

Resource	Type	Content	URL
WECAN “Patients in Publications” course	Online, open-access course	<ul style="list-style-type: none"><li>● Module 1: Introduction</li><li>● Module 2: Publication Planning</li><li>● Module 3: Publication Writing</li><li>● Module 4: Submission, Peer Review &amp; Beyond</li></ul>	<a href="https://wecanadvocate.eu/patients-in-publications/">https://wecanadvocate.eu/patients-in-publications/</a>
Envisage the Patient “Patient Authorship” website	Downloadable files written in plain language	<ul style="list-style-type: none"><li>● Guide for Patient Authors on Meeting the International Committee of Medical Journal Editors (ICMJE) Criteria (pdf)</li><li>● Plain Language Overview of The Publications Process (pdf)</li><li>● The Basics about Conference (and Other) Abstracts (infographic)</li><li>● Guide For Patient Authors on Disclosures (pdf)</li></ul>	<a href="https://www.envisionthepatient.com/patient-authorship">https://www.envisionthepatient.com/patient-authorship</a>
Taylor & Francis “Guidance for patient authors”	Website	Basic information for patient authors	<a href="https://authorservices.taylorandfrancis.com/editorial-policies/guidance-for-patient-authors/">https://authorservices.taylorandfrancis.com/editorial-policies/guidance-for-patient-authors/</a>

Abbreviations: WECAN, Workgroup of European Cancer Patient Advocacy Networks



## Disclaimers

The opinions in this article are the authors' own and are not necessarily shared by EMWA or their employer.

## Disclosures and conflicts of interest

All authors work on patient-authored publications for their employer.

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This is called the hash, pound, or number character. A hashtag is a keyword or set of keywords that is preceded by the # character. It is used in social media to create a thread of conversations around a specific theme or topic conveyed in short texts or microblogs. It is commonly used in Twitter, Instagram, YouTube, Pinterest, etc.

A dictionary of most common hashtags can be found at <https://www.hashtags.org/definition/~h/>.

For your info, EMWA is compiling a list of standardised hashtags for our social media use.



This is called the "at" sign or symbol. The @ sign is part of email addresses and social media user names ("handles"). Our EMWA handles are as follows: @Official\_EMWA (Twitter), @EMWA (LinkedIn), and @europeanmedicalwritersassociation (Facebook)

**The two most important keys on your keyboard**