Tuning Into Patients: Analysis of Patient Involvement as Authors or Contributors in Medical Research

Samantha Mei, PharmD; Elena Dang, PharmD; Pamela Sinicrope, MPH, DrPH; and Jeffrey Stumpf, PhD

Woven Health Collective, New York, NY, USA

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INTRODUCTION

- Patient involvement in research and publications provides unique perspective in the relevance of the study, yet patients remain underrecognized as authors[1,2]
- A patient author may be a patient, family member, caregiver, or advocate who contributes the perspective of the lived experience of a disease or condition to scientific publications[2]
- Recognition of the need to involve patients in research and publications continues to grow, as journals and congresses encourage researchers to include patients as authors, contributors, and peer reviewers[2]
  - GPP 2022 recognizes patients and advocates as experts: if authorship criteria are met, they may be authors, and reasonable compensation for their contributions is ethically permissible[3]
  - The *BMJ* now compensates patients and public reviewers as part of its commitment to co-producing patient-centered content[4]
  - ISMPP encourages medical communication professionals to support the evolving role of patient authorship and outlines strategies for effective inclusion of patient authors[5]
- Identifying patient-authored publications is challenging because, across publications, there is no clear method for tracking or identifying patient authors[2]

RESULTS

- Of the 170 publications identified, 41% recognized patients as authors (**Figure 1**)
- 5% (n=8) of publications included patient author or patient advocate groups in the author byline (**Figures 2** and **3**)

Figure 1. Flowchart of Search Outcomes

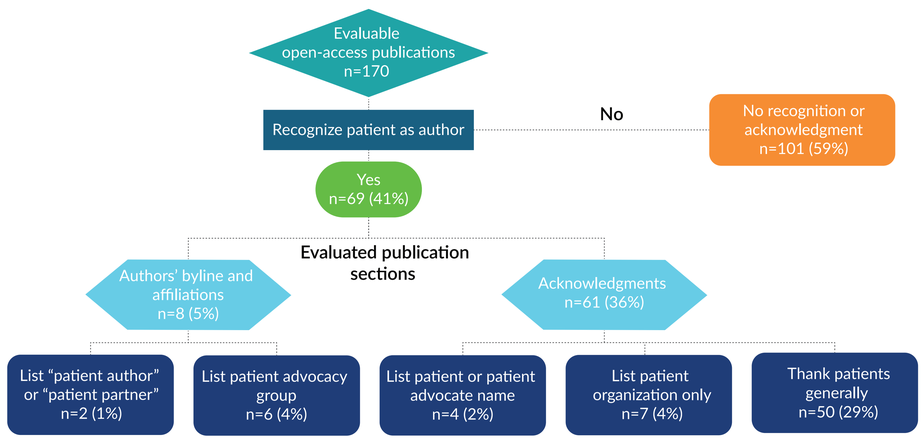


Figure 2. Patient Author Listed in the Author Byline[6]

Practices affEcting macitentan and selexipag patient persistence Rates utilizing pulmonary arterial hypertension clinical Site and patIent perSpecTives (PERSIST): a US qualitative analysis

Oksana A Shlobin[1], Gary Bruce[2], Gabriela Gomez-Rendon[3], Martha Kingman[4], Mohammhad Rahman[3], Francis Rogers[5], Sean Studer[3], Tobore Tobore[3], Colleen McEvoy[6]

Affiliations

[1]Advanced Lung Disease and Transplant Program Inova Fairfax Hospital Falls Church Virginia USA.
[2]Patient author Dallas Texas USA
[3]Actelion Pharmaceuticals US, Inc., a Johnson & Johnson company Titusville New Jersey USA.

Image was recreated from PubMed.

Figure 3. Patient Advocate Listed as a Patient Author[7]

Patient perspectives on telemedicine use in rheumatology during the COVID-19 pandemic: survey results from the COVID-19 Global Rheumatology Alliance

Mithu Maheswaranathan[1], Bruce Miller[2], Natasha Ung[3,4], Rashmi Sinha[5], Carly Harrison[6,7], Bugra Han Egeli[8], Huseyin Berk Degirmenci[9], Emily Sirotich[7,10], Jean W Liew[9], Rebecca Grainger[11], Eugenia Y Chock[12]

Affiliations

[1]Division of Rheumatology and Immunology, Department of Medicine, Duke University School of Medicine, Durham, NC, USA. mithunan.maheswaranathan@duke.edu
[2]Department of Medicine, University of California San Diego School of Medicine, La Jolla, San Diego, CA, USA.
[3]NSW Health, St Leonards, NSW, Australia
[4]University of Sydney, Caperdown, NSW, Australia.
[5]Systemic JIA Foundation, Cincinnati, OH, USA.
[6]LupusChat, New York, NY, USA.
[7]COVID-19 Global Rheumatology Alliance, New York, NY, USA.
[8]Department of Pediatrics, Children's Hospital of Los Angeles, University of Southern California, Los Angeles, CA, USA.

Image was recreated from PubMed.

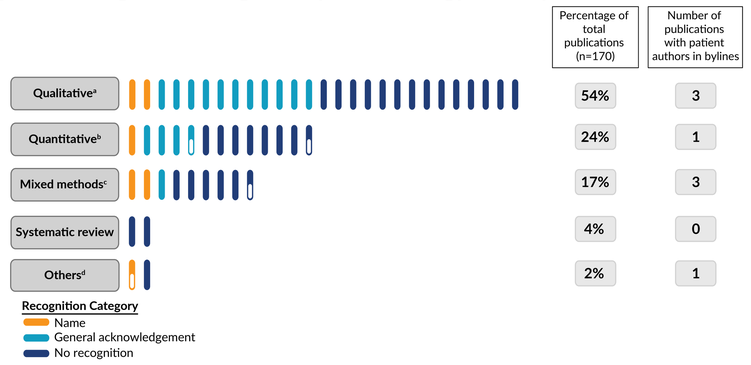
- In total, 2% (4/170) of publications recognized patients or patient advocates in the acknowledgment section, for example (bolding added):

> We would like to thank the members of **Hope for HS, HS Connect, and HS Warriors** for participating in our survey. Special thank you to the following **patient advocates** who provided feedback about the survey: **Athena Mammis-Gierbolini, Brindley Brooks, and Denise Panter-Fixsen.**
>
> Arroyave Caicedo et al.[8]

> We **gratefully acknowledge** the participants for sharing their stories, sometimes at **great cost to their daily functioning.** We thank **K. Hartley and P. Garner** for providing feedback on the study design, interview guide, and results based on their **lived experience with ME/CFS.** We also thank Recovery Norway for their recruitment assistance.
>
> Hasan et al.[9]

- Of the 16 industry-funded publications, 13% (n=2) of publications acknowledged patient authors in the author's list, and 44% (n=7) of publications had general acknowledgment statements that included patient authors
- 80% (136/170) of publications addressed a wide variety of therapeutic areas vs nontherapeutic areas
- Recognition of patients as authors or patient advocates by study methodology are described in **Figure 4**

Figure 4. Recognition Categories by Methodology in Analyzed Publications



Each full bar represents approximately 2%. [a]Qualitative methods included interviews, focus groups, and roundtable discussions. [b]Quantitative methods included surveys and questionnaires. [c]Mixed methods combined both qualitative and quantitative approaches. [d]Other methods consisted of a letter, a report, a social media analysis, and an observational study.

OBJECTIVE

To evaluate the frequency of patient perspective publications that document patient involvement, individually or collectively, through authorship or acknowledgments

METHODS

- A PubMed literature search identified publications from 2023 to 2024 that included "patient" and "perspectives" in the title
- Of the publications identified from the search, articles that were not freely available were excluded
- Two reviewers screened the remaining publications to identify patients as authors:
  - "Patient author" or "Patient partner" in the author bylines
  - Patient organizations in the affiliations or acknowledgments sections
  - General patient acknowledgments
- Publications were assessed for industry funding, then further stratified by therapeutic area and study methodology

CONCLUSIONS

- Despite patient experience being central to many patient perspective studies, patients are rarely invited as authors, highlighting gaps in author representation and inclusion
- When patient authors were listed in the acknowledgments section, their contributions to the publication were often unclear
- The increase in the inclusion of patients as authors in publications highlights the need for clear and consistent practices for patient author recognition
- We recommend the following approaches to ensure that patient authors receive meaningful acknowledgment when they meet ICMJE authorship criteria:
  1. List "Patient Author" in the affiliation, along with their associated organization
  2. Acknowledge the affiliated patient organization in the acknowledgments section
  3. Clearly define each author's role and contribution in the author contributions section
  4. Consider reimbursement for patients' time and unique perspectives of the disease state
  5. Demonstrate industry-wide leadership by expanding GPP and ICMJE guidelines to include clear, practical standards for recognizing and implementing patient authorship
- This study underscores the need to systematically acknowledge patients' contributions to enhance the transparency, relevance, and impact of research

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