

Diversity in Patient Authors: A Randomized Bibliographic Analysis

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Background

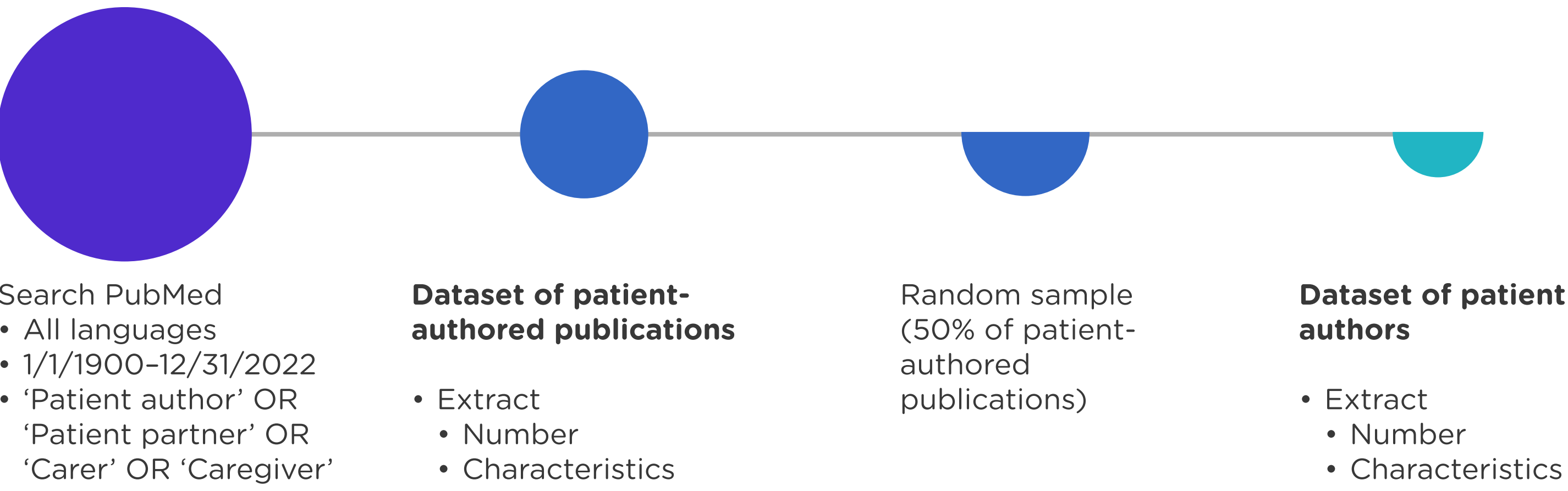
- There is an urgent and passionate call to increase diversity, equity, and inclusion in scientific publishing
- Consistent with these principles,¹ patients are (co)authoring publications.^{2,3} However, little is known about patient-authored publications and patient authors
- Specifically, it is not known whether academic publication biases are reproduced with patient authorship.¹ If so, most patient authors would be men from high-income countries publishing in English^{1,4-7}

“...teams that are diverse in terms of gender, ethnicity, and social background produce better health science, are more highly cited, generate a broader range of ideas and innovations, and better represent society.”
— The Lancet Group, 2019¹

Objective

- To conduct the first study on patient authors to inform evidence-based authorship practices that promote diversity, equity, and inclusiveness

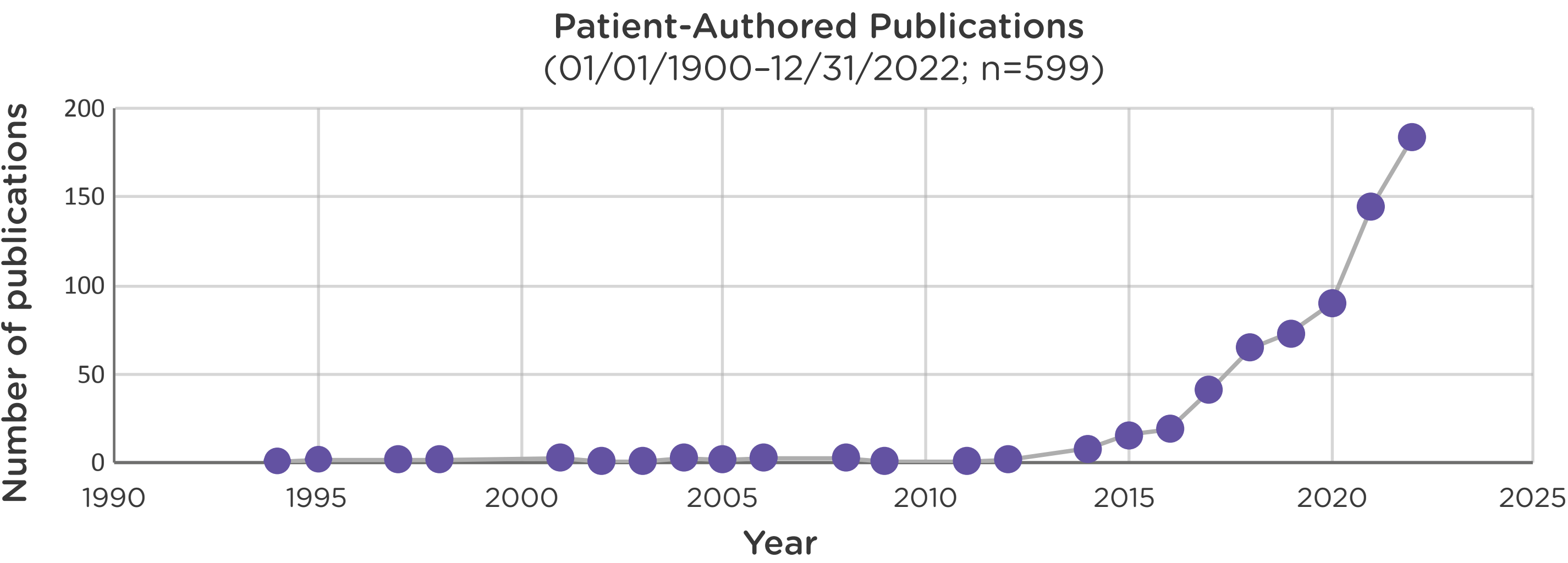
Methods



Results

Patient-Authored Publications (n=599 publications)

- Change Over Time**
 - Patient-authored publications almost tripled in the past 5 years (274% increase)



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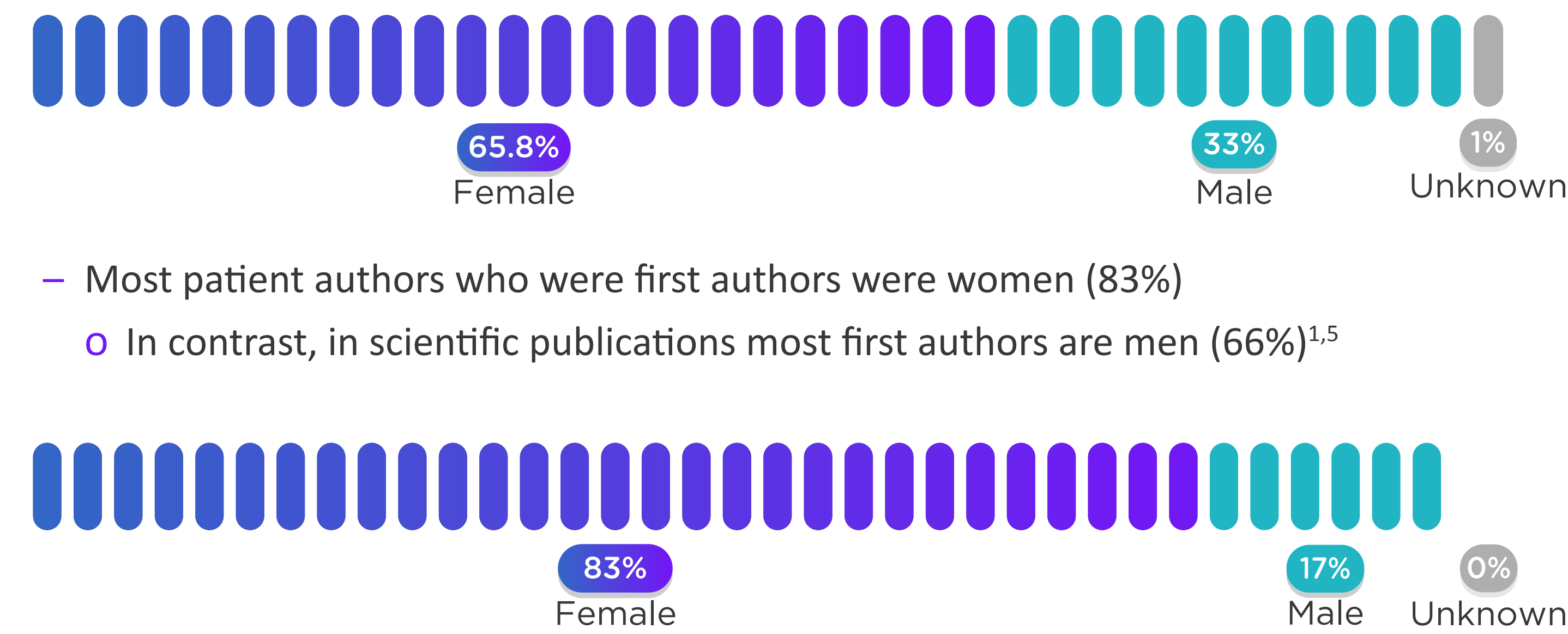


Results (continued)

- Characteristics**
 - Most publications were available as open access (65%)
 - Publications were rarely associated with a plain language summary (1%)
 - The most frequent publication types were reviews/systematic reviews, clinical studies/clinical trials, and letters
 - No patient-authored publications have been retracted

Patient Authors

- Number**
 - There were 413 manually verified patient authors in a random sample (50%) of 232 patient-authored publications
 - The mean number of patient authors per publication was 1.8
- Gender**
 - Most patient authors were women (66%)
 - In contrast, in scientific publications most authors are men (70%)^{1,4}



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Results (continued)

- Income**
 - Most patient authors came from high-income countries (99.5%)
 - Similarly, in scientific publications, almost all publications come from high and upper-middle income countries (>90%)^{1,6}



- Language**
 - All patient authors published in English (100%)
 - Similarly, in scientific publications almost all publications are in English (>90%)⁷

Limitations

- Study limitations include PubMed searchability (eg, variable author affiliation and article tagging practices affect search output), gender estimation (eg, high accuracy, but binary outcomes), and data extraction (eg, time- and labor-intensive manual steps require pragmatic sampling)

Conclusions

- This is the first study to show that most patient authors are women from high-income countries who are publishing in English
- Compared to known publication biases,^{1,4-7} the income and language dominance persist but the gender dominance is reversed
- As patient-authored publications are increasing rapidly, our findings could help to target evidence-based efforts to enhance patient author diversity, equity, and inclusion
- Our research could also enhance methods to measure – transparently, reproducibly, and efficiently – patient-authored publications (eg, broader discussion and consensus on ‘patient author’ affiliation terms)



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