

Do Patient-Experience Publications Have Authors with Patient Experience?

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Background

- Patient-experience research, defined as “capturing patients’ experiences, perspectives, needs, and priorities,” is increasingly valued, especially in health technology assessment (HTA)¹
- To enhance the relevance, credibility, and reach of patient-experience research, patients should be involved in:
 - Planning, conducting, and publishing this research¹⁻³
 - Disseminating research findings with their communities using accessible formats (eg, plain language summaries)¹
- Patient involvement in these research roles should adhere to the values for patient involvement in HTA (relevance, fairness, equity, legitimacy, capacity building),⁴ particularly if the research is used to support access to new treatments

“The collective value of (patient experience data) is reflected by the increasing requests for and use of these data across different healthcare stakeholder groups, such as patient advocacy organizations, regulators, HTA organizations, and pharmaceutical companies.”

– Schroeder K et al, 2022¹



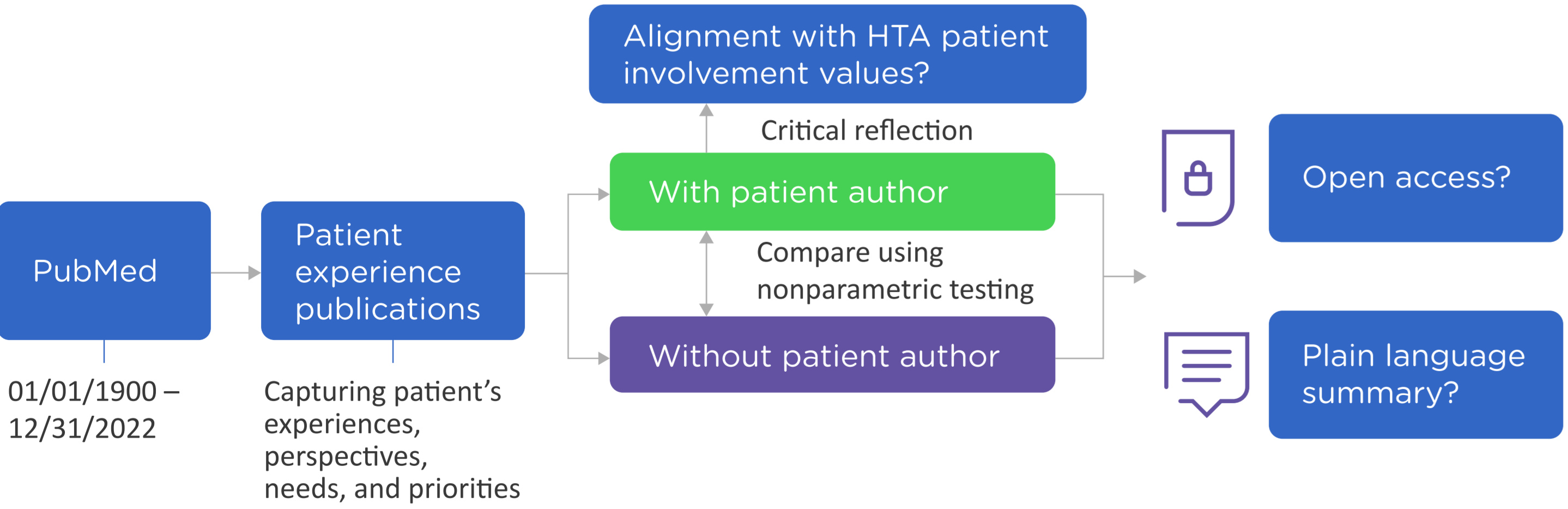
The term ‘patients’ refers to people living with health conditions, as well as their caregivers and families, and patient advocates/advocacy organizations

Objectives

- A Quantify** patient-experience publications and patient authorship
- B Compare** publication accessibility (open access, plain language summaries) with and without patient authorship
- C Evaluate** alignment of patient authorship with HTA patient involvement values

Methods

- We searched PubMed to identify a dataset of patient-experience publications (January 1, 1900–December 31, 2022)
- We used non-parametric testing to compare publication accessibility with and without patient authors
- We evaluated value alignment through critical reflection



References

1. Schroeder K, Bertelsen N, Scott J, et al. *Ther Innov Regul Sci.* 2022;56:848-858. 2. Geissler J, Huber S. *Lancet Haematol.* 2022;9:e399-e400. 3. Law N, Davio K, Blunck M, et al. *Neural Ther.* 2021;10:1103-1125. 4. Hunter A, Facey K, Thomas V, et al. *Front Med.* 2018;5:231.

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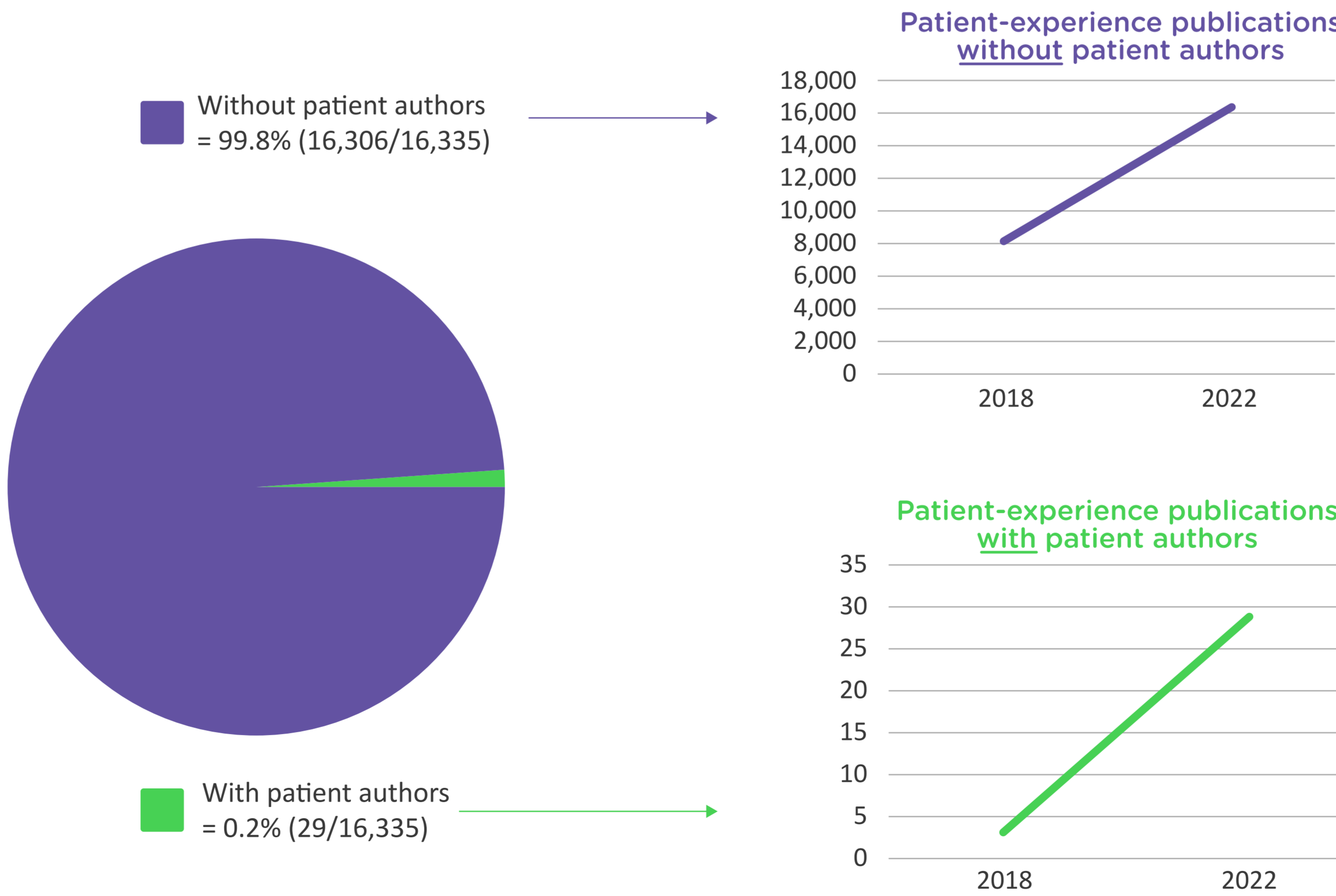


Results

A Patient-Experience Publications and Patient Authorship

Almost all (99.8%) patient-experience publications did **not** have authors with patient experience

Patient-experience publications have increased rapidly since 2018, especially those with patient authors



Results (continued)

B Publication Accessibility

- Patient authorship was significantly associated with increased accessibility



Open access: patient-experience publications **with** patient authors were significantly more likely to be published open access than those without patient authors (OR, 95% CI: 16.58, 4.16–143.88; $P < 0.0001$)



Plain language summaries: patient-experience publications **with** patient authors were significantly more likely to include a plain language summary than those without patient authors (OR, 95% CI: 97.02, 2.04–837.02; $P = 0.0124$)

C Patient Authorship and HTA Patient Involvement Values

- Patient authorship exemplified all HTA patient involvement values

Value	Demonstrated with patient authorship	Author quote
1 Relevance	✓	“Valuable lived experience and unique perspectives of patients are captured in the medical literature for use in HTA assessments”
2 Fairness	✓	“Patients have the same right to publish and have their important contributions captured in the literature as other key stakeholders”
3 Equity	✓	“Patient-experience publications should include diverse voices; the voice of patients should help identify areas where health systems are not distributing resources fairly”
4 Legitimacy	✓	“By co-authoring publications, patient authors can contribute to the body of evidence and participate in the HTA assessment process, adding to the credibility of the decision-making process”
5 Capacity building	✓	“Patient authors are the experts on the patient experience so authoring publications in this area draws on their expertise – this is a highly relevant and credible way to start building authorship capacity among patients who want to contribute as authors to the peer-reviewed literature”

Limitations

- Study limitations include PubMed searchability (eg, variable author affiliation and article tagging practices, especially for patient-experience research and plain language summaries)

Conclusions

- Patient-experience publications rarely included authors with patient experience
- Patient authorship was significantly associated with increased publication accessibility and exemplified HTA patient involvement values
- Patients should be involved in planning and conducting patient-experience research, as well as authoring patient-experience publications



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