

Inclusion of Patients and Advocates as Authors in Medical Publications: Progress Over the Past Decade

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Background

- Patients can provide unique insights into the health conditions with which they live, and they bring their perspective to the information being shared¹⁻³
- Patients are seeking accessible, relevant, and easy-to-understand information,⁴ and involving patients (or patient advocates) as authors may help ensure that medical communications meet their needs⁵
- This literature assessment was conducted to gain insight regarding progress made in the inclusion of patients and patient advocates as authors on medical publications

Objective

- To assess the inclusion of patient authors or advocates on peer-reviewed publications and published scientific congress abstracts

Methods

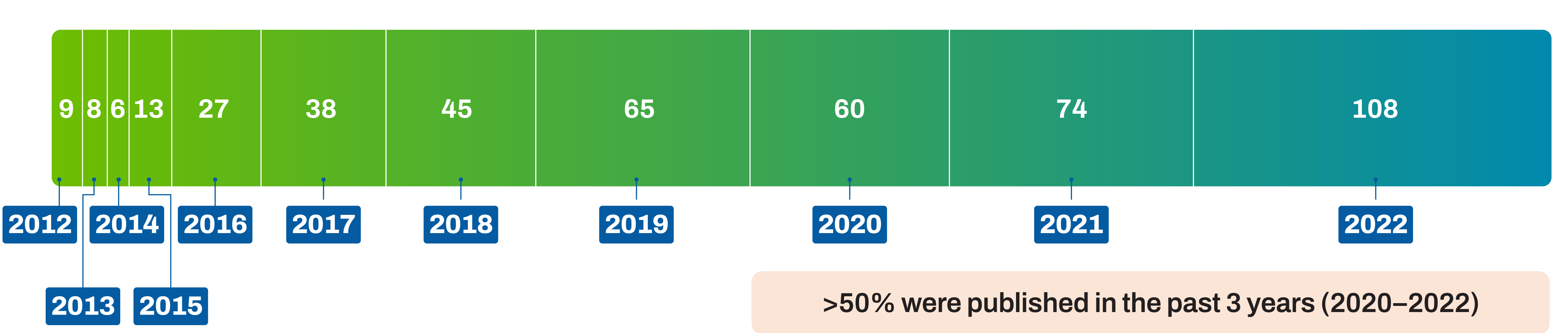
- An EMBASE search was conducted to identify papers with patient or patient advocate authors (indicated by the affiliation) published between the years 2012–2022
- Data were summarized using descriptive statistics

EMBASE Search Terms	
Year	
2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py OR 2022:py	
AND	
Study Type	Affiliation
'case control study':de OR 'case report':de OR 'clinical article':de OR 'clinical trial':de OR 'clinical trial topic':de OR 'cohort analysis':de OR 'comparative effectiveness':de OR 'comparative study':de OR 'controlled clinical trial':de OR 'controlled study':de OR 'cross sectional study':de OR 'double blind procedure':de OR 'feasibility study':de OR 'human':de OR 'interview':de OR 'longitudinal study':de OR 'major clinical study':de OR 'medical record review':de OR 'meta analysis':de OR 'methodology':de OR 'multicenter study':de OR 'normal human':de OR 'observational study':de OR 'pilot study':de OR 'practice guideline':de OR 'prospective study':de OR 'qualitative research':de OR 'questionnaire':de OR 'randomized controlled trial':de OR 'randomized controlled trial topic':de OR 'retrospective study':de OR 'systematic review':de	'patient author':ff OR 'patient advocate':ff
<p>Articles with patient or advocate author were categorized by:</p> <ul style="list-style-type: none"> • Publication type • Therapeutic area • Inclusion of a coauthor with a pharmaceutical industry affiliation <p>A single publication could be included in multiple categories</p>	
<p>Total publications in EMBASE for article types of interest 2012–2022</p>	

Search Results



Number of Publications With a Patient or Advocate Author by Year N=453



- There were few publications with patient/advocate authors during the years 2012–2015 (range, 6–13), with an annual trend for increasing numbers of publications with a patient/advocate author from 2016 (n=27) to 2022 (n=108)

Frequent Publication Types

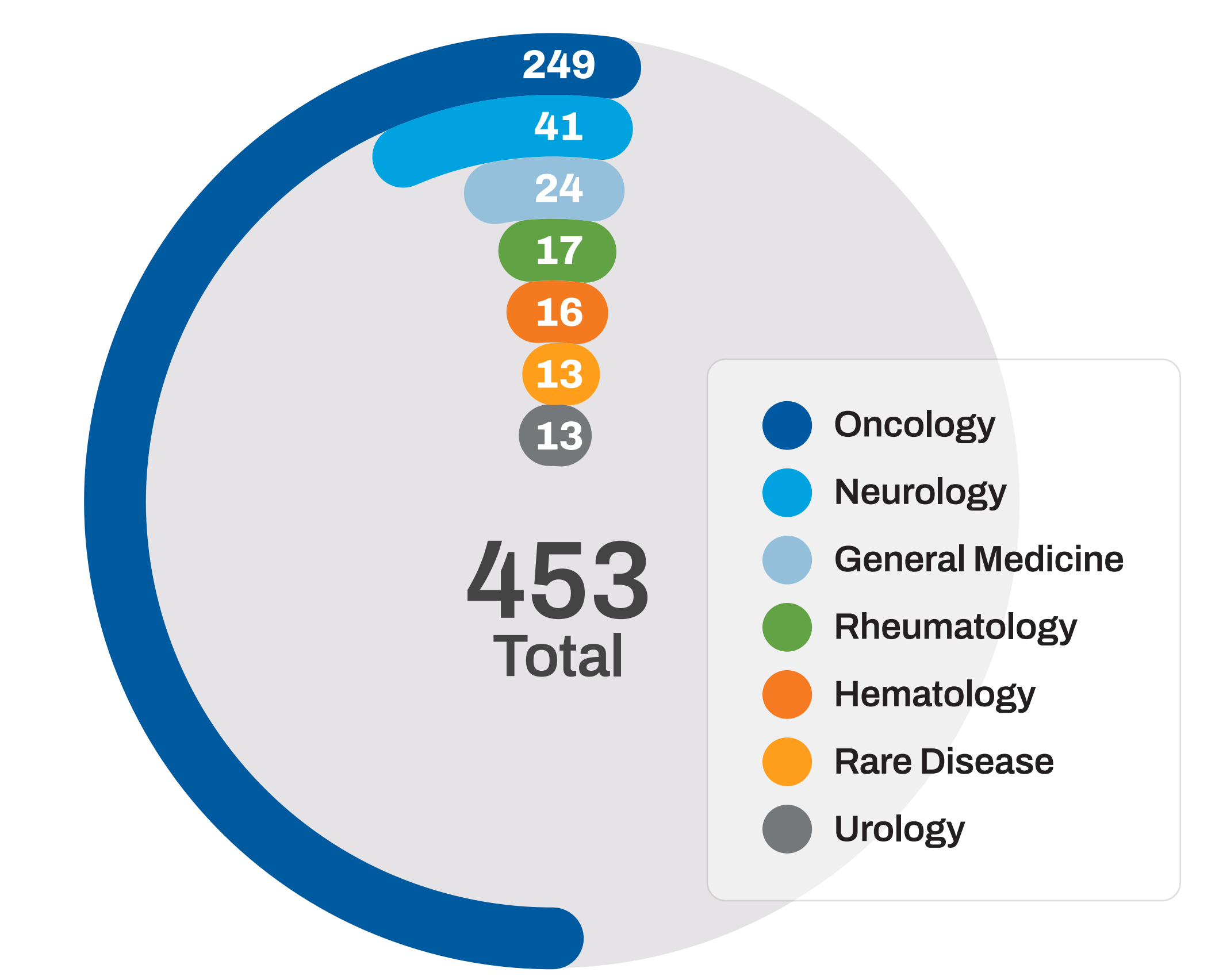


Other publication types with ≥10 publications:

- Phase 3 studies (n=22)
- Workshop proceedings (n=19)
- Patient perspectives (n=17)
- Commentaries (n=15)
- Phase 2 studies (n=15)
- Consensus statements (n=13)
- Editorials (n=12)
- Interviews (n=10)
- Qualitative studies (n=10)
- Retrospective cohorts (n=10)

Therapeutic Areas

- The predominant therapeutic area in which patients/advocates were authors was oncology (n=249; 55.0%)



- Relatively few publications with patient/advocate authorship included a coauthor with a pharmaceutical company affiliation (n=68; 15.0%)

Limitations

- Publications with patient authors may have been missed if “patient author” was not included as an affiliation
- Based on affiliations, it was not possible to determine whether the patient author was solely an advocate or also a person with the disorder being studied

Conclusions

- Beginning in 2016, patient/patient advocate authorship has steadily increased in alignment with current best practices; however, their involvement remains <math><0.005\%</math> (453/>14M) of published literature during the same time period
- Further efforts are needed to incorporate this initiative into standard practice across the therapeutic spectrum



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References

1. Hoos A, et al. *Ther Innov Regul Sci*. 2015;49(6):929-939.
2. Cavaller-Bellaubi M, et al. *Ther Innov Regul Sci*. 2021;55(5):936-953.
3. Arnstein L, et al. *Res Involv Engagem*. 2020;6:34.
4. Yeoman G, et al. *BMJ Innov*. 2017;3(2):76-83.
5. Woolley KL, et al. *MAP Newsletter*. 2020;May 13

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