



Hidden in Plain Sight? Identifying Patient Authors

Jacqui Oliver,¹ Dawn Lobban,¹
Laura Dormer,² Joanne Walker,³
Richard Stephens,³ and Karen Woolley⁴⁻⁶

¹ Envision Pharma Group, Wilmslow, UK
² Future Science Group, London, UK
³ Patient author and Co-Editor-In-Chief of Research Involvement and Engagement, London, UK
⁴ University of Queensland, Brisbane, Queensland, Australia
⁵ University of the Sunshine Coast, Maroochydore, Queensland, Australia
⁶ Consultant, Envision Pharma Group, Sydney, Australia


Conclusions:

 Our research highlights that patient authors are increasingly publishing research in journals such as *R/E*. However, they are often hidden as there is no reliable way to identify them

 We advocate use of the PubMed “Patient Author” affiliation tag. Broad and consistent use of this tag could enable online searching that is:


easy, fast, robust, repeatable

There is no comparable alternative to the PubMed search function

 Key stakeholders should work together to promote awareness and use of the “Patient Author” tag to enable an efficient and reliable way to identify patient-authored publications

Background and Objective

- Patients who meet authorship criteria are increasingly authoring publications based on research led by patients, industry sponsors, or academic collaborators¹⁻³
- Patient authors provide valuable insights from their lived experience, supporting diversity, equity, and inclusion in the literature.⁴ However, it is difficult to measure the extent of patient authorship
- Identifying patient authors could improve affiliation transparency, facilitate patient authorship research, via role model behavior, and help validate researchers’ claims regarding patient involvement (eg, for grant submissions)

 Our aim was to understand how patient authors can be reliably and efficiently identified in the published literature and to propose key steps to improve their discoverability.

Research Design and Methods

We investigated patient-authored publications in:

- **PubMed** using the advanced search function to identify authors who listed their affiliation as Patient Author⁵
- **The journal Research Involvement and Engagement (RIE)**, identifying patient authored-publications 2015 and 2020 by hand. We expected to identify more patient-authored publications in this journal compared with other journals, as the focus is on patient involvement and engagement in research at all stages


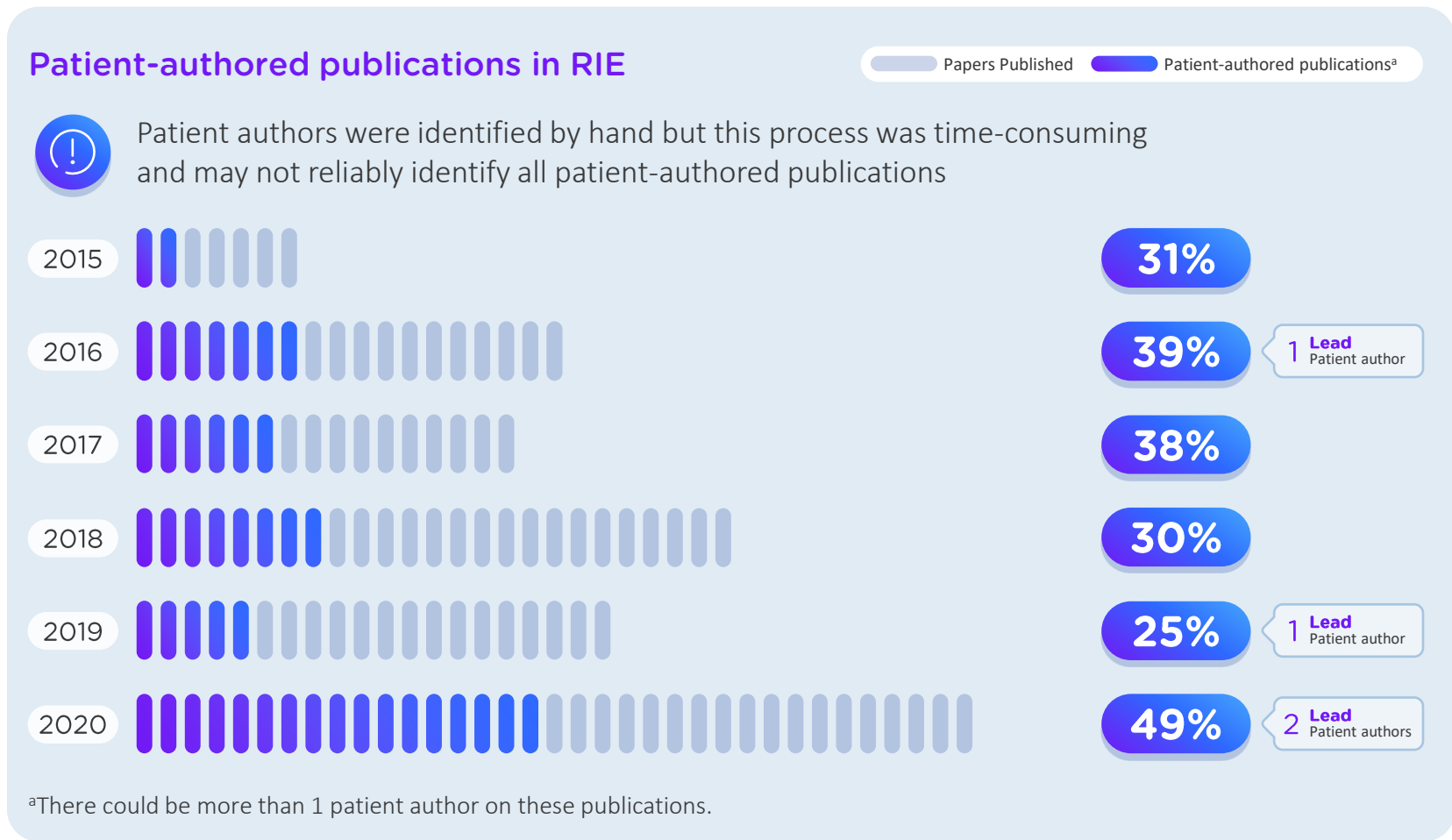

 We identified key steps that stakeholder groups could take to optimize discoverability of patient authors.

Figure 1




Key steps that stakeholders can take to improve discoverability of patient authors




Researchers, funders, and patient advocates

to increase awareness and use of the “patient author” tag




Patient authors

to include the “patient author” tag as at least 1 affiliation on the submitted manuscript




Manuscript submission platforms

to offer a method to use the “patient author” tag by the authors themselves during submission to identify and report on patient-authored publications



Publishers

to include the “patient author” tag as an affiliation in the citation data submitted to PubMed




PubMed

to include specific searchable tag for publications that use the “patient author” tag as an affiliation

Key Results

Use of patient author as an affiliation

 PubMed permits authors to have multiple affiliations

Over the last 6 years, there have been **over 7 million** publications in PubMed.

Only 5 were identified as patient-authored publications using the PubMed search function^a

6
Patient authors



4 publications were published by Future Science Group, who have implemented ‘a Patient Author’ affiliation as a feature.

1 publication was in the BMJ. This appears to be a one-off. More articles are published on the BMJ website with authors listed as patient authors or patient partners.

^a Search 1/1/2015 to 10/3/2021.

Patient-authored publications in RIE

Over the last 6 years, patient-authored publications in *RIE* have **increased from 4 publications in 2015 to 34 in 2020 (Figure 1)**

Patients have been lead and sole authors on some of these publications.

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