Hidden in Plain Sight? Identifying Patient Authors

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Conclusions:

Our research highlights that patient authors are increasingly publishing research in journals such as RIE. 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 collaborators.1

• Patient authors provide valuable insights from their lived experience, supporting diversity, equity, and inclusion in the literature.2 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).

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 Author.

• 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.

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.

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

Figure 1

Patient-authored publications in RIE

Patient authors were identified by hand but this process was time-consuming and may not reliably identify all patient-authored publications.

<table>
<thead>
<tr>
<th>Year</th>
<th>Papers Published</th>
<th>Patient-authored publications</th>
</tr>
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<tbody>
<tr>
<td>2015</td>
<td></td>
<td>31%</td>
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<tr>
<td>2016</td>
<td></td>
<td>39%</td>
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<td>2017</td>
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<tr>
<td>2020</td>
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</table>

*There could be more than 1 patient author on these publications.

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

1. Researchers, funders, and patient advocates to increase awareness and use of the “patient author” tag
2. 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
3. Publishers to include specific searchable tag for publications that use the “patient author” tag as an affiliation
4. PubMed to include specific searchable tag for papers that use the “patient author” tag as an affiliation

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- DL serves on the ISMPP European Meeting Committee and is a member of the BMJ’s patient authorship working group.

REFERENCE:


KEYWORDS:

• patient involvement
• patient authorship
• research integrity
• engagement

Patient-authors in RIE

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.

PubMed permits authors to have multiple affiliations.

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

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.

* Search 1/1/2015 to 10/3/2021.

Key Results

Use of patient author as an affiliation

1 patient author

Posters Published


Patient-authors 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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