PLAIN LANGUAGE SUMMARIES IN MEDICAL JOURNALS: HOW ACCESSIBLE IS SCIENTIFIC RESEARCH TO THE GENERAL PUBLIC?



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INTRODUCTION

- As patient involvement in clinical research increases, so does the need for appropriate methods to present thorough and meaningful data to them.
- By using plain language summaries (PLS), patients and/or other general audiences can gain access to healthcare information in an understandable way.
- Recently, medical journals have started providing PLS in publications.
- The objective of this research was to assess how medical journals in five therapeutic areas with high patient burden, i.e., neurology (N), psychiatry/mental health (P/MH), respiratory disease (R), cardiology (C), and infectious disease (ID), incorporate PLS in their publications to make clinical research results accessible to broader audiences.

METHODS

- Using the Scimago Journal Rank indicator, we identified the top 50 journals in each of the prespecified 5 therapeutic areas (N, P/MH, R, C and ID). The searches were conducted in August 2023.
- We reviewed the publisher websites and guidance for authors of the identified journals to gather information on PLS and inclusive language. All reviewed websites were written in English.
- The information captured during the review included: whether there was a request for PLS during submission to the journal (required or optional), location of the PLS accompanying a published manuscript, journal publisher guidance for PLS development and for inclusive language, PubMed index and open access status of the journal. Microsoft Excel was used for documenting and analyzing the captured information.
- To ensure no information was missed, searches using keywords such as "plain", "lay", "summary", "friendly", "social media", "video", "infographic", and "tweet" were also conducted within each website and guidance document.

RESULTS

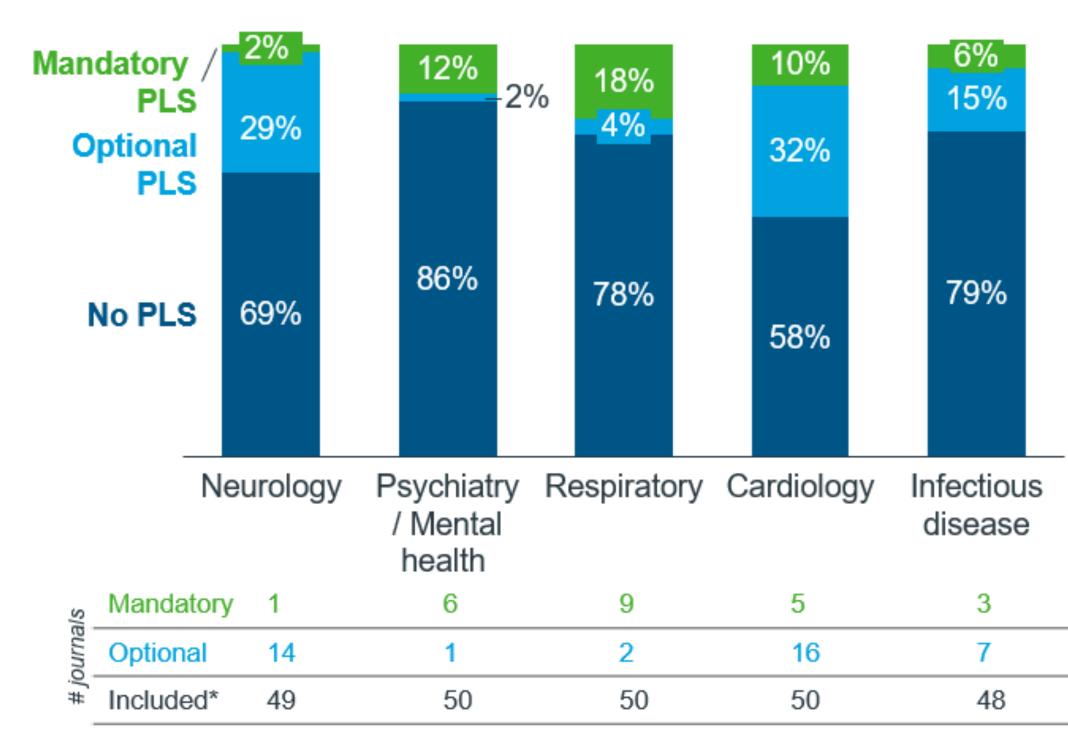
- A website with guidance to authors was available for most journals (N: 49/50, P/MH: 50/50, R: 50/50, C: 50/50, ID: 48/50).
- Approximately 26% (64/247) of the journals reviewed either offer the possibility to publish PLS or require PLS submission; this rate was highest among cardiology journals and lowest among psychiatry/mental health journals (Figure 1).
- Although several of the journals reviewed may also accept video abstracts and infographics, the primary intended audience for these formats consists of the journal readership, i.e., individuals with substantial scientific or medical expertise, rather than a general audience.
- While many journals support the development of PLS through writing services for authors, only two (Autism in Adulthood [published by Mary Ann Liebert) and Expert Review of Respiratory Medicine [published by Taylor and Francis]) require authors to involve patients in the development or review of the PLS (Figure 2).
- Among journals accepting a PLS, 64% (41/64) publish them within the article, below the abstract or title. Additionally, 33% (21/64) of the journals offer the possibility to publish PLS on social media, and 6% (4/64) publish them directly on their journal website (Figure 3).
- Among journals accepting a PLS, 48% (31/64) provide specific length recommendations. The suggested range is between 50 and 500 words, with most favoring 250-300 words. This is aligned with the accepted length or slightly longer than for the scientific abstract.
- Regarding publication access mode, hybrid access (both subscription-based and open access) is prevalent, with 60% (151/250) of journals offering this model across therapeutic areas (N: 25/50, P/MH: 34/50, R: 23/50, C: 39/50, ID: 30/50). Thirty-two percent (79/250) of journals provide full open access (N: 20/50, P/MH: 15/50, R: 16/50, C: 11/50, ID: 17/50).
- Among publishers with ≥5 journals in any therapeutic area, the leading publishers with the highest number of journals accepting PLS are Elsevier, John Wiley & Sons, Inc and SAGE (Table 1).
- In the last few years, an increased use of inclusive language (i.e., language that avoids exclusionary or pejorative bias) has been observed in social and news media. While a sizeable proportion of journals (109/247; 44%) recommend or require the use of basic inclusive language and refer to relevant guidelines (e.g., the SAGER¹), most do not specify what this entails beyond the use of appropriate terms to refer to gender, race, and ethnicity, while an equally high number of journals do not refer to inclusive language in their guidance to authors at all.

CONCLUSIONS

- In today's era of patient-centricity, journal editors must advocate for the inclusion of PLS in their journals and provide clear and comprehensive instructions about how to go about this, including the use of inclusive language.
- Despite several initiatives, including the European Union Clinical Trials Regulation, requiring or encouraging researchers to publish PLS of clinical trials results, the inclusion of PLS among the top 50 journals in neurology, psychiatry/mental health, respiratory disease, cardiology and infectious disease remains remarkably low, with 26% of journals requiring or accepting PLS. There is no consistency amongst journals in how the PLS is shared with patients.
- These findings align with our previous research in oncology and dermatology, where 20% and 60% of journals, respectively, provide the option to submit and publish PLS².
- Given the growing trend of involving patients as stakeholders in drug development, it is crucial to extend this involvement to the development, review, and accessibility of PLS. However, out of the 250 journals reviewed, only two mandate or encourage patient involvement in these activities. This gap highlights a missed opportunity to enhance the accessibility of research findings and ensure that they are presented in a way that serves the needs and perspectives of patients.
- The low use of PLS may also be indicative of patients not being aware of their existence, which leads to a lack of requests for PLS being included in medical and scientific journals. However, with the progressive increase of PLS being made available through pharmaceutical company websites, patients may also expect to be able to access PLS that support publications in academic journals.
- Journals can improve their standards for the use of inclusive language by issuing more detailed guidance that takes into account the needs and preferences of the patient community.

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Figure 1. Proportion of journals that require PLS or offer the possibility to submit PLS



*Included journals are those that provide a website with guidance to authors

Figure 2. Journals with mandatory or optional PLS requiring patient involvement in the development of the PLS

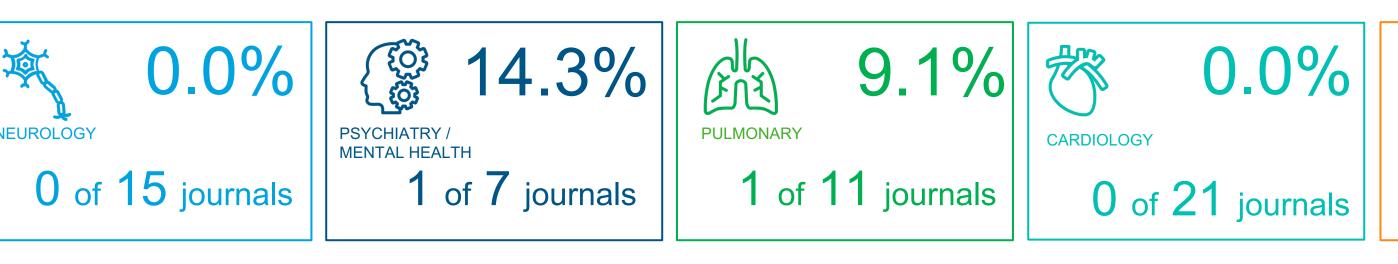
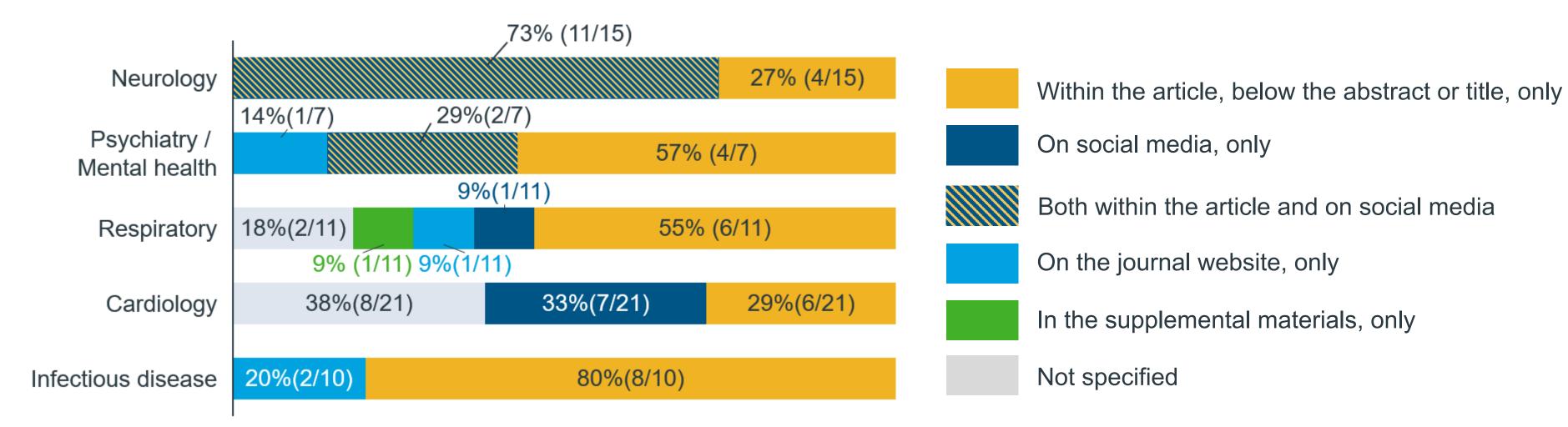


Figure 3. Locations where PLS can be accessed



Data represent % of journals that publish PLS in the specified locations among total number of journals that accept and require PLS. Some journals provide multiple location options for displaying PLS, such as within the article and on social media

Table 1. Top five publishers with highest rate of PLS acceptance

	Number of journals that accept PLS (n/N; %)					
	Neurology	Psychiatry/ Mental health	Respiratory	Cardiology	Infectious disease	Total
Elsevier (includes Saunders)	0/5 (0%)	2/15 (13%)	3/17 (18%)	7/16 (44%)	4/15 (27%)	16/
John Wiley & Sons, Inc	5/11 (45%)	1/8 (13%)	1/3 (33%)	1/1 (100%)	2/4 (50%)	10
SAGE	7/7 (100%)	0/2 (0%)	1/2 (50%)	2/2 (100%)	0/0 (0%)	10
Oxford Academic Press	0/3 (0%)	0/1 (0%)	0/1 (0%)	6/8 (80%)	1/7 (27%)	7
BioMed Central Ltd - Springer Nature	0/9 (0%)	0/3 (0%)	0/5 (0%)	4/6 (67%)	1/1 (100%)	5

Data are provided as number of journals accepting or requesting PLS (n) among those with the same publisher in the corresponding therapeutic area (e.g., 15 journals out of the 50 reviewed in psychiatry/mental health belong to Elsevier. Out of these 15, 2 of them offer the possibility to publish PLS or require PLS submission (2/15*100=13%)

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