How can we maximise patient engagement with Plain Language Summary of Publication articles (PLSPs)? A publisher's perspective

Rachel Jenkins[1], Johanna Todd[2],
Olivia Alexander
Taylor & Francis
London, UK

[1] (iD) 0000-0003-4290-5038

[2] (iD) 0000-0002-6531-9712

Correspondence to:
Rachel Jenkins
r.jenkins@future-science-group.com

Abstract

Plain Language Summary of Publication articles (PLSPs) are aimed at non-specialist audiences, using non-technical/jargon-free and easy to understand language to provide summaries of publications. The introduction of PLSPs has added to the growing need for medical publishers to reach and engage patient audiences. This has introduced new challenges for publishers, including raising awareness of the existence of PLSPs and making them easily discoverable for patients as well as fostering trust in medical publications within the patient community. This article discusses ways in which publishers can work towards overcoming these challenges and maximise patient engagement.

Introduction

I t is widely recognised that making bio-medical research understandable to non-specialist audiences is vital for promoting patient engagement activities.[1] In the last few years, Plain Language Summary of Publication articles (PLSPs) have quickly gained popularity as a publication extender that can make biomedical research more understandable, particularly in the era of open access and the open science movement, which is making biomedical research more freely available to non-traditional audiences. Aimed at non-specialist audiences, PLSPs have built on abstract-style plain language summaries, using non-technical language to provide infographic-style, standalone summaries of published trials and research studies.[2] By increasing the understanding of scientific content, PLSPs have the potential to increase readership and downloads of an original article. Multiple publishers, including Taylor & Francis, Sage, Becaris Publishing, and Adis, now offer the option to publish different styles of PLSPs in their journal framework, providing authors with a choice of journals to submit to across a wide range of topics in healthcare. Despite the positive steps this takes towards patient-centered care, PLSPs present unique challenges for publishers. The first challenge is that the main audience for medical journals are healthcare professionals. This means that even when published, PLSPs aren't always discoverable to genera-lised, non-scientific audiences. Second, with high volumes of health information available online, it can be tricky to distinguish legitimate infor-mation from information that is misleading and inaccurate. How can people without prior medical knowledge or awareness of medical journals trust that what they are reading is accurate and complete? Third, and perhaps the most fundamental challenge, is that patient audiences need to be aware of what PLSPs are in the first place to search for them. Here, we discuss actions that can work towards establishing trust

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and increasing awareness and discoverability of PLSPs with the aim of maximising engagement of patient audiences.

Patient and caregiver perspectives
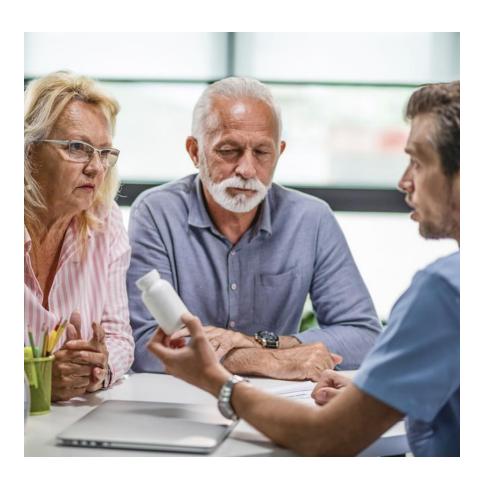
Patient and caregiver authorship

Including patients and caregivers as authors adds unique insights to PLSPs and establishes trust with audiences who may be encouraged to engage with a publication that includes a representative of their community. Research titled "Who are the authors of Plain Language Summaries of Publications?" presented at the 19th Annual Meeting of the International Society for Medical Publication Professionals (ISMPP) 2023 found that including a patient or caregiver author may increase the general reach and engagement of a PLSP.[3] The research compared the authoship groups and engagement of 72 PLSPs published by Future Science Group between August 5, 2020, and February 28, 2023. On average, PLSPs with a patient or caregiver author (n=10) had higher downloads and Altmetric scores.

Publishers should encourage and facilitate the ethical involve-ment of patients and caregivers in medical publications. It is essential that authorship criteria are followed during the creation of PLSPs. The Good Publication Practice (GPP) 2022 guidelines recommend following the International Committee of Medical Journal Editors (ICMJE) recommendations for authorship criteria for all authors, including patients and caregivers.[4,5] There are multiple resources available online that provide guidance and recommendations for how to include patients in publications.[4,6,7]

It is important for patient and caregiver

patient reviewers on the purpose and process of peer review, including practical advice on how to submit their review via electronic submission systems, and recognition for the review e.g. via Publons.[8]

An ethical question faced by publishers is whether to provide renumeration to patient reviewers for their review. There is debate surrounding paying traditional peer reviewers as it can introduce a conflict of interest; however, it is important to consider that patients are often not part of the research publication pipeline and take time out of their 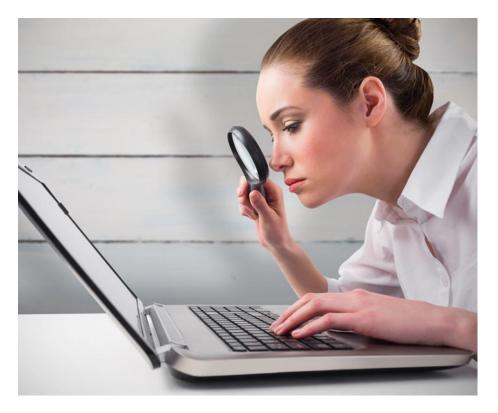day-to-day lives to review PLSPs.[9] Thus, providing payment to patients for peer reviewing PLSPs supports a larger, more diverse pool of reviewers by removing cost as a limiting factor.

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Translations

For PLSPs to have a global reach and be accessible to patient audiences from different countries and cultures, they need to be translated into local languages. Clearly communicating a PLSP in different languages can help readers to fully understand the content, building trust and ensuring people are accurately receiving the information. Currently, there is a lack of research looking at the impact of translations on PLSPs specifically, but previous research has shown that language is a key barrier for engagement across the healthcare pipeline.[10]

There are multiple challenges when translating plain language into different languages. Generally, there are different ways that the same complex sentence can be written in plain language. Sentences from one writer may have a completely different structure and wording compared to another. This also applies when translating plain language into different languages. In addition, the same words and phrases may be considered culturally appropriate or inappropriate across different cultures so would need adapting depending on the target audience. Therefore, the multilingual translation of plain language text may not be a literal translation, but instead nuanced to what makes the most sense in that language and what is most accurate and clear.

Considering these nuances when creating and publishing multilingual PLSPs, it is important to use a systematic approach with multiple rounds

authors to be made aware of the implications of any personal identifying information, such as name, disease state, treatment history, etc., being perpetually available on journal websites, indexing services, and search engines. Some publishers may require consent forms to be completed by patient and caregiver authors to ensure they consent to their identifying information being used.

In addition to authorship of a PLSP, patients and caregivers may provide their own perspective on the content of the PLSP. These perspectives can enable patients and caregivers to share their experience rather than limiting the narrative to only facts and statistics. This can help foster trust in medical information and raise awareness of the patient voice. Indeed, similar to patient- or caregiver-authored PLSPs, PLSPs that include a patient perspective section have higher downloads and Altmetric scores when compared to PLSPs that do not.[3] When including perspectives, it is important to recognise that

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individual patient and caregiver experiences and outcomes differ. PLSPs are tools that can help empower people to draw their own conclusions about their own or someone else's care plan. Therefore, perspective sections should aim to empower readers to learn about the condition and treatment options instead of providing individual conclusions about treatment outcomes.

Patient peer review

As with patient authorship, peer review of PLSPs by patients provides insights into what is relevant and is of importance to the patient community, whilst ensuring the content is clear and the language is aimed at a non-specialist audience. Involving patients in the review process for PLSPs is a vital step for establishing trust in the content and showcases a publisher's commitment to patient-centred publications.

Some patient reviewers may not have worked on a PLSP before or had experience with the peer review process. Publishers may offer guidance to

of checks to minimise errors and maximise quality.[11,12] A growing number of qualified professionals specialise in plain language translation of medical publications, as well as publishers who offer these as third-party or in-house services. Using a professional service can help to maximise quality as these services often have inbuilt quality control systems. This quality control may include a review of the initial translation by a second translator, final proofing checks ensuring consistency, accuracy, and completeness throughout the translated PLSP, back translations, localised patient reviews, and mono-linguistic reviews against a plain language brief.

Once published, it is important to consider where the translations will be hosted so that they are discoverable for patients who may not be confident using a journal website. Many publishers have now moved on from hosting content in the supplementary material and instead use better signposting to the translations on the article page and host on platforms such as Figshare.[13] These platforms increase discoverability of supplementary content but are not optimised for audiences with no experience in the publishing world.

Search engine optimisation

When exploring how people discover PLSPs, survey research presented at the 19th Annual Meeting of the ISMPP 2023 showed that out of 17 patients who responded, 41% discovered PLSPs through Google.[14] This may be because patients with no previous publication experience do not use PubMed or publisher websites as a means of finding PLSPs, which tend to be the main routes of discovering traditional journal articles. The same survey discovered that out of 32 healthcare professionals, 41% found PLSPs via PubMed, compared to 12% of patients.[14] Therefore, if publishers can apply best practices for search engine optimisation (SEO) on each PLSP, then it can improve a PLSP's chances of being discovered on Google, making them more findable for patients. This includes optimising the meta data by using key words, for example including the term "plain language summary" in the title of each PLSP. Using SEO brings some challenges as it relies on a person typing these keywords into their search engine, and it is possible that many patients will not be aware of the term "plain language summary".

Patient advocacy groups

Potentially the best way to increase discoverability and awareness of and trust in PLSPs is to share them with patient advocacy groups (PAGs), which represent and support patients and their caregivers living with a specific condition.[15] Patients often rely on these groups as sources of credible information and support, for example, plain language resources about their condition and treatment options. Publishers should be encouraged to share PLSPs with PAGs as they are in a position to disseminate the material directly to patients and on their social media channels, whereas pharmaceutical companies are unable to do this without it being considered promotional. In the 19th Annual Meeting of the ISMPP 2023 survey, alongside 41% of PLSPs being discovered via Google, 18% were discovered through individual recommendations and 12% through social media.[14] Other research has found that the most popular reason that patients used social media for health-related reasons was for social support, such as sharing resources and that social media is an important method for patient organisations to discover research.[16,17] This suggests the power of sharing PLSPs with patients who have relevant networks and are more likely to recommend material to others.

Conclusion

The advancement of patient-centred communication, such as PLSPs, has introduced nuanced challenges for medical publishers, who are now looking to actively reach and engage patient audiences. This requires a multi-stakeholder approach, including patients and their caregivers, translators, PAGs, publication professionals, and many more. To optimise engagement with patients, publishers need to focus on improving discoverability and awareness, and increasing trust in publishers, researchers, and their publications.

Disclaimers

Disclosures and conflicts of interest

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References

1. Pushparajah DS, Manning E, Michels E, et al. Value of developing plain language summaries of scientific and clinical articles: a survey of patients and physicians. Ther Innov Regul Sci. 2018;52:474–81. doi:10.1177/2168479017738723

2. Plain Language Summaries. How to write & publish [cited 2023 Nov 29]. Available from: https://www.plainlanguagesummaries.com/how-to/

3. Elliot C, Oliver J, Manning L, et al. Who are the authors of Plain Language Summaries of Publications? Poster at the 19th Annual Meeting of the ISMPP; April 24–26, 2023; Washington DC, USA.

4. DeTora LM, Toroser D, Sykes A, et al. Good Publication Practice (GPP) guidelines for company-sponsored biomedical research: 2022 update. Ann Intern Med. 2022;175(9):1298–304.

5. International Committee of Medical Journal Editors (ICMJE). Defining the role of authors and contributors [cited 2023 Nov 29]. Available from: https://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html

6. Arnstein L, Wadsworth AC, Yamamoto BA, et al. Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. Res Involv Engagem. 2020;6(1):34.

7. Envision the Patient. Patient authorship resources [cited 2023 Nov 29]. Available from: https://www.patientauthorship.com/

8. The BMJ. Guidance for BMJ patient and public reviewers [cited 2023 Nov 29]. Available from: https://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers

9. Cheah PY, Piasecki J. Should peer reviewers be paid to review academic papers? 2022;399(10335):1601.

10. NHS England. Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups [cited 2023 Nov 29]. Available from: https://www.england.nhs.uk/aac/publication/increasing-diversity-in-research-participation/

11. Correia AS. Involving patients and translators in Plain Language Summaries. Med & Mark. 2022 Nov 1 [cited 2023 Nov 29]. Available from: https://www.medmark.pt/post/capturing-the-patients-voice-in-translation-the-role-of-translation-and-linguistic-validation

12. Credevo. The importance of translation in clinical trials [cited 2023 Nov 29]. Available from: https://credevo.com/articles/2023/02/05/the-importance-of-translation-in-clinical-trials/

13. Figshare.com [cited 2023 Nov 29]. Available from: https://figshare.com/

14. Oliver J, Lobban D, Dormer L, et al. Understanding the value of Plain Language Summaries of Publications: Updated findings from an online survey of readers. Poster at the 19th Annual Meeting of the ISMPP; April 24–26, 2023; Washington DC, USA.

15. Beacon: for rare diseases. Why patient groups matter [cited 2023 Nov 29]. Available from: https://www.rarebeacon.org/rare-diseases/why-patient-groups-matter/

16. ProMedical. Impact of social media on healthcare [cited 2023 Nov 29]. Available from: https://www.promedical.co.uk/news/impact-of-social-media-on-healthcare/

17. Rosenberg A, Shepherd A, Halford C, et al. Social media use by patient organisations in discovery and dissemination of medical research: pilot survey. Poster at the 2024 European Meeting of ISMPP; January 23–24, 2024; London, UK.

Author information

Rachel Jenkins, Head of Plain Language Summaries at Taylor & Francis, formerly Future Science Group, London, UK, has worked in medical publishing for almost 7 years, with her current role focusing on plain language in publishing, including PLSPs. She has extensive experience working across both editorial and digital products, and is passion-ate about improving inclusion and diversity in biomedical research.

Johanna Todd, Senior Commissioning Editor, at Taylor & Francis, formerly Future Science Group, started her career in medical publishing over 7 years ago. During this time, she has worked across multiple areas of editorial, digital extenders and plain language summaries.

Olivia Alexander, Editor, has been working as an editor for PLSPs over the last year at Taylor & Francis, formerly known as the Future Science Group. Her current role at Taylor & Francis includes responsibilities such as editing PLSPs, coordinating translations of PLSPs into multiple languages, and maintaining relationships with patient advocates. She is especially passionate about ensuring access to scientific research for all audiences.