Cooksey *et al. BMC Medical Research Methodology* (2025) 25:39
https://doi.org/10.1186/s12874-025-02495-4

BMC Medical Research Methodology

REVIEW **Open Access**

Patient partner engagement in the publication process: challenges and possible solutions

Krista E. Cooksey[1], Mark Neuman[2], Mara Bollini[3], Bethany Pennington[3], Hugo de O. Campos[4], Kathleen Oberst[5], Melissa Wurst[6] and Mary C. Politi[1*]

Abstract

Patient engagement in research is gaining traction as an international standard, and often requirement, of many health research funding agencies. Drivers of this increase include patient interest, increased attention to and recognition of the value of patients' voices in research, and more patients leading or partnering in the conduct research. Patient engagement includes collaborating and providing insights into research question and study design, and may extend to the publication process. When patients contribute to publications, they can bring unique perspectives that may enhance the impact, reach, and utility of the research in real-world contexts. Currently, there is limited systematic guidance to support patient partners as they navigate this complex publication process. As a result, it can be difficult for patient partners to understand when and how they should be included as authors, how to collaborate in the writing process, and how to complete mandatory tasks during the submission process. In this paper, we review barriers and facilitators within existing publication practices and offer recommendations to ensure that the scientific publication process is more transparent and accessible for patient partners.

Keywords Patient engagement, Patient partnership, Co-production, Collaboration, Co-authorship

Background

Patient engagement is an approach that includes patients as research partners across the research cycle: from planning to conducting to translating study knowledge [1]. Patient partners are individuals with relevant lived experience with health issues, personally or as a caregiver, family member, patient representative, or advocate. These individuals can offer valuable expertise as members of research teams and collaborators on research projects and activities [1–3]. In this context, we use the term "patient engagement" and consider it equivalent to international synonyms such as "patient and public involvement" or other related terms [1].

Patient engagement is gaining traction as a recognized practice in the planning and execution of research

---

*Correspondence:
Mary C. Politi
mpoliti@wustl.edu
[1]Department of Surgery, Division of Public Health Sciences, Washington University School of Medicine, St. Louis, Missouri, USA
[2]Department of Anesthesiology and Critical Care, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania, USA
[3]Department of Anesthesiology, Washington University School of Medicine, St. Louis, Missouri, USA
[4]All of Us Research Program, National Institutes of Health (NIH), Bethesda, MD, USA
[5]College of Human Medicine, Michigan State University, East Lansing, Michigan, USA
[6]Language Solutions Incorporated, St. Louis, Missouri, USA

projects. In fact, it is becoming an international standard and sometimes a requirement for health research and funding agencies [1, 4]. For example, funding from the Patient Centered Outcomes Research Institute (PCORI) requires patient and other partner engagement as a component of the study or project [5]. Similarly, international organizations such as the National Institute for Health Research (NIHR), England's largest health research funder, and the Canadian Institutes of Health Research (CIHR) strongly encourage or require research teams applying for funding to fully integrate patient partners as members of the research team [6].

Due to increased interest and requirements, research teams are encouraged to engage patient partners and patients are encouraged to take a more collaborative and active role in the whole trajectory of the research process. For example, journals such as *The BMJ* require a patient and public involvement (PPI) statement for all submissions [7]. These statements are intended to report how patient partners informed research question development, study design, and the overall conduct of the study [7]. Generally, these statements are consistent with current guidance and framing around patient engagement [8–11]. However, there remains a systematic lack of information and guidance about specific roles, contributions, and authorship structures to support patient partners during the publication process, a critical, yet complex, part of the research cycle.

Involving patient partners (those who collaborated on the research process and are interested in collaborating on the final phase of dissemination) in the publication process is important because it allows those with lived experiences to inform both the research development and the knowledge translation process in an accessible way for diverse end users [12]. Moreover, when patients contribute to publications, they can bring unique perspectives that may enhance the impact, reach, and utility of the research in real-world contexts [13].

There is a paucity of literature exploring barriers and facilitators or offering guidance on including patients in the peer-reviewed publication process. There is a need to clearly define recommendations and existing authorship guidelines so patient partners can engage meaningfully and be fairly recognized for their contributions. Such guidance can even help researchers develop standardized practices that foster a culture where patient partners are consistently seen as valued collaborators even in the publication process. In this paper, we review barriers and facilitators within existing publication practices and offer recommendations to ensure that patients can more easily collaborate in this process.

Existing barriers to including patients as co-authors and partners in the publication process

Criteria for authorship and journal policies

Publishing research findings in academic journals is at the cornerstone of the academic system [14]. The International Committee of Medical Journal Editors' (ICMJE) Defining the Role of Authors and Contributors document is the current and most widely implemented standard for defining who should be included as an author or acknowledged in a publication. It is used internationally by organizations and scientific journals to provide information and criteria for authorship and acknowledgement in scientific papers [2]. The criteria for authorship [15] include "(1) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; and (2) drafting the work or revising it critically for important intellectual content; and (3) final approval of the version to be published; and (4) agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved."

These criteria were designed with traditional academic and industry authors in mind, which can present unique challenges. Patient partners may inadvertently be excluded from the publication process as a result of varying interpretations of how applicable the criteria might be applied to patient co-authors [16]. For example, in a survey of 112 Editors-in-Chief, 69% believed it was acceptable for patient partners to be co-authors, and 64% felt that patient partners could meet the first International Committee of Medical Journal Editors' criteria: substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work [14]. However, some editors felt that patient partner authorship was not feasible or relevant, which could preclude the inclusion of patient partners ultimately prohibiting research teams from appropriately conferring credit to patient partners.

Because of this challenge, some publishers favor revising the International Committee of Medical Journal Editors' guidelines. More than two-thirds of Editors-in-chief surveyed indicated that the guidelines should be revised to be more inclusive of patient partners, as only 4% indicated that their journal had a policy to specify how patient partners could be considered as co-authors [14]. Existing guidelines may not be sufficient and more specific guidance is needed about when and how to include patient partners as authors. In the absence of revised, targeted criteria, it may be difficult to systematically ensure that patient partners are fairly and equitably acknowledged in the entirety of the research project.

Authorship forms and the submission process: a case example

There is also a lack of widely available guidance for patient partners to achieve the third and fourth International Committee of Medical Journal Editors' criteria: final approval of the version to be published and agreement to be accountable for all aspects of the work. Authorship forms including individual author contributions, authorship statements, and verification of authorship documents attest to engagement in the research process and confirmation of meeting all four guidelines. Patient partners can have difficulty with the complicated, legalese authorship agreement forms to confirm co-authorship. In addition to the complex language on these forms, the forms are often housed on digital platforms behind logins and systems that patient partners may not know or use. While research teams may be used to communicating among authors through these channels, it can be challenging for patient partners to navigate an unknown platform in addition to unfamiliar, complex documents to attest to their author contributions.

Author bios & affiliations

Submitting author bios and affiliations may also be daunting for patient partners. For research team members, bios and affiliations are often associated with their institution of employment. However, determining the right affiliation for patient partners may not be as straightforward. For example, some patients consult research projects on behalf of an organization as patient advocates. In other cases, patients are representing themselves as a patient and decide to list the institution from which they sought care as their affiliation. Other times, they are unsure how to list their affiliation and bio if they are not public about their role as a patient or patient advocate, and instead are working with a research team due to long-standing relationships. Listing one's place of employment as a patient might not be relevant if they are not representing their employer and instead are representing themselves. It is important to offer instructions for writing bios and describing affiliations on a case-by-case basis, as all patient partners may not have the same affiliation or same preferences for their bio presentation.

Accurate affiliations have important implications for efficient and effective literature searches and identifying which authors are patient authors. In a systematic review conducted by Arnstein et al., researchers emphasized that "...there was no consistent or clear way that patient authors were described." [17] Consequently, when patient authors were identified, the listed affiliation with a university or hospital had to be clarified and confirmed by researchers reviewing methods and acknowledgement sections. Lack of standard guidelines and consistency in identifying patient authors makes it challenging to detect when patient perspectives are present and may add additional verification steps. Without proper systems in place, it may be challenging to appropriately distinguish and acknowledge patient partners for their role in the research and publication process. Not only does accuracy improve discoverability, but it also has positive implications for measuring impact [18].

Conflict of interest (COI) disclosures

As part of the submission process, authors must also submit a signed conflict of interest (COI) statement. A conflict of interest occurs when an individual's private,

Case Example of Difficulty with Authorship Forms: In submitting a paper for publication with a patient partner, for example, we experienced a bottleneck because the journal would not send the paper out for external peer review until all author agreement forms were signed. One patient partner and meaningful co-author responded to the email by replying to the automated journal email indicating that the patient was part of the research process. The email bounced back, as it was not sent to a moderated inbox. Next, when the patient realized that there was a link to a form to complete, the link took the partner to a login page that required creating an account with the journal. When the patient co-author completed the login, the journal tried to link the account to an Open Researcher and Contributor ID (ORCiD), which the patient did not have. After that step was completed with the assistance of research team members, the form prompted the patient to answer questions such as whether they were paid for their contribution to the work (they were paid as a consultant and were unsure what to check), whether the work was done as work-for-hire vs. the author's own work, whether the government funded the work (a grant funded the research, but the work was the authors' own and not work owned by the government), and numerous questions that did not have clear answers. While this process was generally routine for the academic co-authors, it highlighted the lack of clear instructions and real-time guidance to make authorship forms more inclusive and less opaque for patient partners. As co-creators of the work, the corresponding author set up a time to talk to the patient and walk through each part of the form in clearer language to streamline the process and work with the partner to understand each section. However, there was almost a month delay and substantial stress and frustration while each step created barriers to submission and attestation of author contributions.

or competing interests, diverge from their scientific research or publication responsibilities causing reasonable observers to question if their actions are motivated by these competing interests [19]. Conflict of interest may be personal, commercial, political, academic, or financial. Generally, conflict of interest statements ensure the credibility of the journal, authors, and the scientific process [19]. In fact, some call for a "strict disclosure policy" for all collaborators in the publication process to maintain scientific integrity of research publications [20]. While maintaining the integrity of the research is of the utmost importance, it is important to consider how strict policies may further prevent patient partner engagement in the publication process. For example, patient partners may be employed in non-scientific, non-sales roles at healthcare or pharmaceutical companies. According to the International Committee of Medical Journal Editors' definition and terms for conflict of interest disclosures: any potential conflicts of interest "involving the work under consideration for publication" (during the time involving the work, from initial conception and planning to present), any "relevant financial activities outside the submitted work" (up to 3 years prior to submission), and any "other relationships or activities that readers could perceive to have influenced, or that give the appearance of potentially influencing" what is written in the submitted work (based on all relationships that were present during the 3 years prior to submission) must be declared [21]. However, it is unclear whether patients' place of employment would constitute real risk when they are conducting work based on their personal experiences and not their employment. Additionally, patient partners may understandably feel uncomfortable with disclosing personal investments in healthcare or pharmaceutical companies. Finally, although not financial, some patients wonder if they have a heightened sense of investment and interest in findings based on lived experiences. Overall, conflict of interest disclosures may add an additional layer of complexity to the submission process for patient partners. Although current infrastructures are designed to minimize competing interests and preserve ethical research practices, strict, one-size-fits-all policies may inadvertently also minimize patient engagement in the publication process.

Compensation

There are conflicting ideologies toward offering compensation for patient partners collaborating in the publication process. On the one hand, some believe nonfinancial payment is appropriate because being a coauthor on manuscripts or research materials is a nonfinancial demonstration of appreciation of authors' time, expertise, and engagement throughout the research process [22]. Additional nonfinancial demonstrations of appreciation include donations to organizations, providing services or training opportunities, special invitations, or honorary appointments. On the other hand, because co-authorship might not confer the same status or offer the same value for non-academics, some suggest that financial compensation is more appropriate for patient partners than non-financial recognitions alone. Financial compensation opportunities include payment as contractors or employees, honoraria, gift cards, or stipends.

Although there is a lack of consensus about compensation for patient partners, existing guidance suggests that compensation for publication activities is acceptable. The 2022 Good Publication Practice (GPP) updated guidelines provide guidance on patient partner compensation and specifies that "Author agreements may state that authors will not receive payment in exchange for listing their name on a publication byline; however, this statement does not automatically disqualify from authorship professional medical writers or any other person earning a salary from professional activities that may confer authorship. Nor should such a statement be interpreted as a prohibition for compensating patients or other participants in publication activities, such as patient advocates…for their time." [23] Based on these guidelines, it is possible, acceptable, and can be respectful to compensate patient partners for their time in publication activities since their engagement is generally outside of their typical work. It is an equitable practice to provide financial compensation to patient partners when funds are available. As a result, patient partners receive both monetary benefits and invaluable benefits such as citations for CVs and academic applications, skills such as academic writing and learning how to navigate the peer-review process, and increased exposure for additional patient partner opportunities.

Recommendations to ensure that patient research partners can collaborate on the publication process

Discuss the process and authorship at the beginning

It is important to establish a common understanding of the publication process for both the research team and patient partners [2]. Patient partners may be unfamiliar with the steps, timeline, and parts of submitting manuscripts for publication, so it is useful to discuss the publishing landscape at the onset of the research project. This transparency can provide patient partners an opportunity to reflect on the process and determine a level of engagement that is congruent with their capacity (schedules) and capability (personal goals or interests). In fact, consulting existing resources like the Contributor Role Taxonomy (CRediT) that details 14 contribution types may facilitate collaboration and provide useful guidance in determining which patient partners and what skills/

Table 1 Good publication practice (GPP) principles for authorship and accountability

1. Publication planning and development should reflect the collaborative nature of research and the full range of skills required to conduct, analyze, interpret, and report research findings. Authorship criteria should be considered at the start of research.
2. Authors must be able to make informed decisions and should have access to study data and other relevant information to enable them to be accountable for publication contents and the accuracy and integrity of the work.
3. Author bylines and acknowledgments should follow relevant authorship criteria, using the International Committee of Medical Journal Editors' guidelines as a default, to accurately reflect all contributions.
4. Before publication preparation begins, the rights, roles, requirements, and responsibilities of contributors and authors should be confirmed in writing.

roles would best suit project output needs [24]. Discussions about publications in advance provide an opportunity to identify and proactively address any barriers that might preclude patient partner engagement.

Additionally, it is important for the entire team, including researchers and patient partners, to be aware of each other's roles so that the team can establish and document responsibilities and expectations surrounding writing and editing, agree upon the order of authorship, and set a plan to appropriately acknowledge each level of contribution in the final manuscript [2]. This approach allows for open communication throughout the research process, promoting patient partners' confidence in the integrity of the contributions of their co-authors, being accountable for the parts of the work they have done, and being able to identify which co-authors are responsible for specific other parts of the work per additional International Committee of Medical Journal Editors' guidance [25].

Provide plain language instructions to improve accessibility and reduce barriers

According to *Involving Patients as Authors of Company-Sponsored Journal Publication*, one of the biggest barriers for patient partners in the publication process is confusing documents with overly complex, academic jargon [26]. Offering plain language summaries of documents required for publication may help mitigate this barrier. For example, the Good Publication Practice (GPP) guidelines provide recommendations to maintain ethical and transparent publication practices and comply with legal and regulatory requirements [27]. (see Table 1).

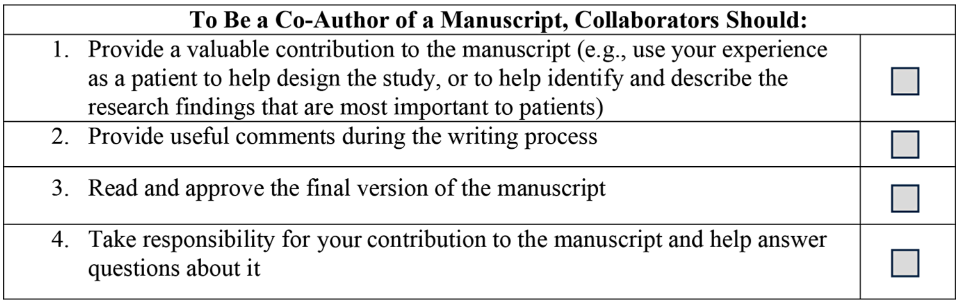
To make these complex guidelines more accessible and understandable, we have adapted Envision Pharma Group's plain language summary of the International Committee of Medical Journal Editors' authorship criteria and plain language Good Publication Practice guidelines for patient co-authors [28]. (see Tables 2 and 3).

Overall, using plain language summaries to reduce barriers for patient co-authors has important implications for accessibility of published research. Publications with patient co-authors can be more accessible than traditional papers and are significantly more likely to include a plain language summary than those without patient co-authors [29]. Moreover, plain language summaries of publications with patient co-authors have higher average Altmetric scores and downloads than those without patient authors [30]. This transparency emphasizes the important role of patient co-authors and highlights additional opportunities to work with patient co-authors to prepare plain language guides to accompany complex written agreements [31].

Offer trainings using available resources

Providing trainings to patient co-authors on how to easily navigate the publication process will also reduce barriers. Workgroup of European Cancer Patient Advocacy Networks (WECAN), an organization aiming to improve cancer patients' outcomes, offers four open-access online training modules on patient engagement in publications. These trainings are designed to be for patient advocates who have been invited to be co-authors or peer reviewers for journal articles or those planning to publish their own research [32]. These modules include an overview of the

Table 2 Adapted plain language international committee of medical journal editors' requirements to make the authorship attestation process clearer



To Be a Co-Author of a Manuscript, Collaborators Should:	
1. Provide a valuable contribution to the manuscript (e.g., use your experience as a patient to help design the study, or to help identify and describe the research findings that are most important to patients)	☐
2. Provide useful comments during the writing process	☐
3. Read and approve the final version of the manuscript	☐
4. Take responsibility for your contribution to the manuscript and help answer questions about it	☐

Table 3 Plain language authorship guidelines

What should you expect to do as a patient partner co-author?
Read and discuss information (e.g., the research protocol) that will help you understand the research findings.
Share your skills (e.g., experience as a patient) to help interpret and report research findings.
Suggest places you think would be suitable for sharing the research findings. Many conferences and journals support patient co-authors and patient-focused research.
Provide feedback while preparing the manuscript (e.g., reading a draft, sharing your comments) and approving the final version.
Sign a written Authorship Agreement at the start of the project. The agreement should describe your rights and responsibilities and state that no one can interfere with these rights.
Report research findings in a complete, accurate, and timely way. Whether you think the findings are good, bad, or uncertain, you must report them truthfully.
Follow good publication practice (GPP) guidelines.
Report your name, role, and financial or nonfinancial relationships you have that could be seen as influencing the publication.
What should you expect from the research team to support your role as a patient partner?
Designate a research team member to assist patient partners throughout the writing and submission process and provide support for any barriers.
Reimburse patient partners to cover travel costs of being a co-author and in some cases, compensate patient partners for authorship contributions. Authors are not necessarily paid for writing time, but can be, though this would need to be reported to journals if so.
Respect the confidentiality and privacy of patient partners collaborating in the research and include a thank you to the patient group in the publication.
Incorporate the feedback provided in a way such that patient partner co-authors' contributions are valued similarly to other research team members' contributions.

publication process, explanations of how to effectively plan for the publication, offer resources during the writing process, and provide information about the submission process and beyond.

Similarly, Envision the Patient, a dedicated team focusing on bringing patients into medicine development within Envision Pharma Group, developed a series of patient authorship resource guides including plain language overviews of the publication process, how patient authors can meet the International Committee of Medical Journal Editors' criteria, how patient authors can meet disclosure standards to ensure publishing transparency, and guidance for when patient authors are compensated for the time spent authoring a publication [14].

Additional opportunities for training include offering glossaries of publication terms, resources to familiarize individuals with digital systems used for communication among authors [31], and overviews of specific types of publications such as systematic reviews with plain language summaries [33, 34].

Solicit feedback from patient partners on their authorship experience

In addition to a paucity of literature exploring the challenges patient authors face in the publication process, there is currently no standard, validated mechanism for evaluating collaboration efforts with patient partners and receiving feedback about their experiences. Stocks et al. highlighted a lack of quantitative evaluation tools for the quality of patient and public involvement (PPI) [35]. Similarly, in a study investigating the process and impact of patient and public involvement and engagement (PPIE) on a systematic review, Hyde et al. noted that although patient and public members did not drop out of the study, often used as a proxy for satisfaction, there remained a lack of understanding of how members felt about their integration into the study and in general, there was a lack of tools for understanding their experiences [36].

One currently available assessment is the Patient Engagement Quality Guidance (PEQG) tool. The Patient Engagement Quality Guidance (PEQG) tool was co-created with people from over 51 organizations, including patient organizations, pharmaceutical companies, and academic researchers [37]. Although this was designed to assess patient engagement projects, it does not focus on the publication process specifically and is 17 pages, which may require a significant time commitment from patient authors [22].

The second currently available assessment is the Patient Authorship Experience (PAE) self-assessment. This assessment was developed to quickly and directly gain feedback about the patient authorship experience. This tool has two versions: one for patient authors and another for non-patient authors and evaluates eight publication relevant domains using a bipolar, five-point, psychometric, Likert scale [17].

Conclusions

Patient engagement in co-producing research is important and increasing. Not only are patients collaborating in research design and research conduction, but they are becoming more involved in the publication process as authors and co-authors. Given this continued increase in patient engagement in the publication life cycle, it is timely to consider how to mitigate barriers and improve their experience. More robust research is needed to identify existing barriers and proactively address forthcoming barriers given the ever-changing landscape of patient engagement in publication processes. This paper serves to begin this process by describing some key barriers and opportunities to improve the process. By calling for more transparency, guidance, and plain language communication about authorship roles, responsibilities, and training opportunities, we can support patient partners across all stages of research.

Abbreviations

PCORI	Patient Centered Outcomes Research Institute
ICMJE	International Committee of Medical Journal Editors'
COI	Conflict of Interest
ORCiD	Contributor Role Taxonomy
CRediT	Conflict of Interest
WECAN	Workgroup of European Cancer Patient Advocacy Networks
PPI	Patient and public involvement
PPIE	Patient and public involvement and engagement

Acknowledgements
N/A.

Author contributions

Krista E. Cooksey, BA conception and design of the content, analysis and interpretation of the literature, drafted the work and revised it critically; Mark Neuman, MD, MSc, Mara Bollini, MHA, BSN, RN, CPPS, Bethany Pennington, PharmD, BCPS, Hugo de O. Campos, Kathleen Oberst, RN, PhD, and Melissa Wurst, MA, substantially revised it critically; Mary C. Politi, PhD conception and design of the content, analysis and interpretation of the literature, revised the work critically. All authors approved of the final version submitted.

Funding
Patient partners were involved in the development and writing of this manuscript and serve as members of the Patient Partner Panel for the Trajectories of Recovery after Intravenous Propofol vs. inhaled VolatilE anesthesia (THRIVE) study, a Patient-Centered Outcomes Research Institute (PCORI) Project Program Award (PLACER-2020C3-21106). All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This manuscript does not report on any human subjects data, thus there is no ethics approval needed.

Consent for publication

N/A.

Competing interests

Dr. Politi was a consultant for UCB Biopharma in 2022 and EpiQ in 2023 on topics unrelated to this manuscript.

Received: 14 August 2024 / Accepted: 5 February 2025

References

1. Lauzon-Schnittka J, Audette-Chapdelaine S, Boutin D, et al. The experience of patient partners in research: a qualitative systematic review and thematic synthesis. Res Involv Engagem. 2022;8(1):55. https://doi.org/10.1186/s40900-022-00388-0. [published Online First: 2022/10/04].
2. Richards DP, Birnie KA, Eubanks K, et al. Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. Res Involv Engagem. 2020;6:38. https://doi.org/10.1186/s40900-020-00213-6. [published Online First: 2020/07/09].
3. Chudyk AM, Stoddard R, Duhamel TA, et al. Future directions for patient engagement in research: a participatory workshop with Canadian patient partners and academic researchers. Health Res Policy Syst. 2024;22(1):24. https://doi.org/10.1186/s12961-024-01106-w.
4. Easley J, Wassersug R, Matthias S, et al. Patient Engagement in Health Research: perspectives from patient participants. Curr Oncol (Toronto Ont). 2023;30(3):2770–80. https://doi.org/10.3390/curroncol30030210. [published Online First: 2023/03/29].
5. Engagement FAQs Patient Centered Outcomes Research Institute. [Available from: https://www.pcori.org/funding-opportunities/applicant-and-awardee-resources/frequently-asked-questions/engagement-faqs#:~:text=Do%20all%20PFAs%20require%20an,in%20Research%20within%20their%20plan. accessed 11/5 2024.
6. Richards DP, Twomey R, Flynn T, et al. Patient engagement in a Canadian health research funding institute: implementation and impact. BMJ Open. 2024;14(7):e082502. https://doi.org/10.1136/bmjopen-2023-082502.
7. New requirements for patient and public involvement statements in BMJ Open: BMJ, [updated. March 23, 2018. Available from: https://blogs.bmj.com/bmjopen/2018/03/23/new-requirements-for-patient-and-public-involvement-statements-in-bmj-open/ accessed 11/5 2024.
8. Bloom D, Beetsch J, Harker M, et al. The rules of Engagement: CTTI recommendations for successful collaborations between sponsors and patient groups around clinical trials. Therapeutic Innov Regul Sci. 2017;52(2):206–13. https://doi.org/10.1177/2168479017720247.
9. Higgins T, Larson E, Schnall R. Unraveling the meaning of patient engagement: a concept analysis. Patient Educ Couns. 2017;100(1):30–6. https://doi.org/10.1016/j.pec.2016.09.002.
10. Haroutounian S, Holzer KJ, Kerns RD, et al. Patient engagement in designing, conducting, and disseminating clinical pain research: IMMPACT recommended considerations. Pain. 2024;165(5):1013–28. https://doi.org/10.1097/j.pain.0000000000003121. [published Online First: 2024/01/10].
11. Harrington RL, Hanna ML, Oehrlein EM, et al. Defining Patient Engagement in Research: results of a systematic review and analysis: report of the ISPOR patient-centered Special Interest Group. Value Health. 2020;23(6):677–88. https://doi.org/10.1016/j.jval.2020.01.019.
12. Stones S, Ghith J, McSorley S, et al. Bringing scientific congresses to patients and healthcare professionals through plain language podcasts: a case study. Curr Med Res Opin. 2022;38(Suppl 1):5–24.
13. Maurer M, Mangrum R, Hilliard-Boone T, et al. Understanding the influence and impact of Stakeholder Engagement in patient-centered Outcomes Research: a qualitative study. J Gen Intern Med. 2022;37(Suppl 1):6–13. https://doi.org/10.1007/s11606-021-07104-w. [published Online First: 2022/03/30].
14. Cobey KD, Monfaredi Z, Poole E, et al. Editors-in-chief perceptions of patients as (co) authors on publications and the acceptability of ICMJE authorship criteria: a cross-sectional survey. Res Involv Engagem. 2021;7(1):39. https://doi.org/10.1186/s40900-021-00290-1.
15. Jordan I, Strain K, Richards D, et al. Patient partner compensation in research and health care: the patient perspective on why andhow. Patient Experience J. 2018;5:6. https://doi.org/10.35680/2372-0247.1334.
16. Laura Dormer RS, Caroline Halford. Patients as authors of Company-Sponsored Journal publications. Part B—Publisher Perspective. DIA Global Forum.
17. 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. https://doi.org/10.1186/s40900-020-00190-w.
18. Ellis U, Kitchin V, Vis-Dunbar M. Identification and reporting of patient and Public Partner Authorship on Knowledge syntheses: Rapid Review. J Participatory Med. 2021;13(2):e27141. https://doi.org/10.2196/27141. [published Online First: 2021/06/11].
19. Peh WC, Ng KH. Conflict-of-interest, copyright and other declarations. Singapore Med J. 2010;51(11):844–6. quiz 47. [published Online First: 2010/12/09].

20. Sharma S. Disclosure of conflict of interest in scientific publications. Perspect Clin Res. 2020;11(4):137–38. https://doi.org/10.4103/picr.PICR_287_20. [published Online First: 2021/01/26].
21. Bauchner H, Fontanarosa PB, Flanagin A. Conflicts of interests, authors, and journals: New challenges for a persistent problem. JAMA. 2018;320(22):2315–18. https://doi.org/10.1001/jama.2018.17593.
22. Fox G, Fergusson DA, Sadeknury A, et al. What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines. Health Expectations: Int J Public Participation Health care Health Policy. 2024;27(1):e13970. https://doi.org/10.1111/hex.13970. [published Online First: 2024/06/12].
23. 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. https://doi.org/10.7326/m22-1460. [published Online First: 2022/08/30].
24. Holcombe A, Authorship. Giving credit where it's due American Psychological Association 2021 [Available from: https://www.apa.org/pubs/journals/resources/publishing-tips/giving-credit accessed 6/14/2024.
25. Fontanarosa P, Bauchner H, Flanagin A. Authorship and Team Science. JAMA. 2017;318(24):2433–37. https://doi.org/10.1001/jama.2017.19341.
26. Dawn Lobban RS, Veronica Porkess. Involving patients as authors of Company-Sponsored Journal publications. Part A—Patient and Industry Perspectives. DIA Global Forum.
27. Good Publication Practice for Communicating Company-Sponsored Medical Research. GPP3. Ann Intern Med. 2015;163(6):461–64. https://doi.org/10.7326/m15-0288%m26259067.
28. Woolley K. Plain Language Summary of Good Publication Practice Guideline (Version 1). 2019 doi: https://doi.org/10.6084/m9.figshare.11292047.v1
29. Woolley KL, Stones SR, Stephens R, Learned Publishing et al.;n/a(n/a) doi: https://doi.org/10.1002/leap.1607
30. Rosenberg A, Walker J, Griffiths S, et al. Plain language summaries: enabling increased diversity, equity, inclusion and accessibility in scholarly publishing. Learn Publish. 2023;36(1):109–18. https://doi.org/10.1002/leap.1524.
31. Patient Authorship. Three Key Questions (& Answers!) for Medical Communication Professionals [Part B] 2020 [Available from: https://www.ismpp-newsletter.com/2020/05/26/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-b/ accessed 6/14/2024.
32. Patient Authorship Resources and Guidance Envision the Patient. [Available from: https://www.envisionthepatient.com/patient-authorship#resources accessed 6/24/2024.
33. Nicole Pitcher DM, Hughes C. Template and guidance for writing a Cochrane Plain language summary: Cochrane; 2022 [Available from: https://training.cochrane.org/handbook/current/guidance-writing-cochrane-plain-language-summary.pdf accessed 8/2/2024.
34. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci. 2011;6(1):42. https://doi.org/10.1186/1748-5908-6-42.
35. Stocks SJ, Giles SJ, Cheraghi-Sohi S, et al. Application of a tool for the evaluation of public and patient involvement in research. BMJ Open. 2015;5(3):e006390. https://doi.org/10.1136/bmjopen-2014-006390.
36. Hyde C, Dunn KM, Higginbottom A, et al. Process and impact of patient involvement in a systematic review of shared decision making in primary care consultations. Health Expect. 2017;20(2):298–308. https://doi.org/10.1111/hex.12458.
37. Deane K, Delbecque L, Gorbenko O, et al. Co-creation of patient engagement quality guidance for medicines development: an international multistakeholder initiative. BMJ Innovations. 2019;5(1):43–55. https://doi.org/10.1136/bmjinnov-2018-000317. [published Online First: 2019/10/28].

Publisher's note