

Supplementary materials

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Supplementary Table S1. Peer-reviewed literature search strings.

MEDLINE	
String concept	Queries
1. Patient (free text)	(patient* or lay or people or public or consumer* or user* or citizen* or carer* or caregiver* or lived experience or community).ti,kw
2. Patient (MeSH)	exp Patients/
3. Patient (MeSH)	exp Caregivers/
4. Involvement (free text)	(involv* or engag* or participat* or contribut* or collab* or partner* or author or authors or authoring or authorship or reviewer*).ti,kw
5. Involvement (MeSH)	exp Patient Participation/
6. Involvement (MeSH)	exp Community-Based Participatory Research/
7. Publication (free text)	(publication* or manuscript* or article*).ti,kw
8. Publication (MeSH)	exp Writing/
9. Publication (MeSH)	exp Peer Review, Research/
10. Combination	(1 or 2 or 3) and (4 or 5 or 6) and (7 or 8 or 9)
11. Limits	limit 10 to (english language and yr="2018 -Current")
Embase	
String concept	Queries
1. Patient (free text)	(patient* or lay or people or public or consumer* or user* or citizen* or carer* or caregiver* or lived experience or community).ti,kw
2. Patient (MeSH)	exp layperson/
3. Patient (MeSH)	exp caregiver/
4. Patient (MeSH)	exp personal experience/
5. Involvement (free text)	(involv* or engag* or participat* or contribut* or collab* or partner* or author or authors or authoring or authorship or reviewer*).ti,kw
6. Involvement (MeSH)	exp patient engagement/
7. Involvement (MeSH)	exp patient participation/
8. Involvement (MeSH)	exp citizen science/
9. Publication (free text)	(publication* or manuscript* or article*).ti,kw
10. Publication (MeSH)	exp writing/
11. Publication (MeSH)	exp peer review/
12. Publication (MeSH)	exp publishing/
13. Combination	(1 or 2 or 3 or 4) and (5 or 6 or 7 or 8) and (9 or 10 or 11 or 12)
14. Limits	limit 13 to (english language and yr="2018 -Current")
Web of Science	
String concept	Queries
1. Patient	(patient* or lay or people or public or consumer* or user* or citizen* or carer* or caregiver* or lived experience or community)
2. Involvement	(involv* or engag* or participat* or contribut* or collab* or partner* or author or authors or authoring or authorship or reviewer*)
3. Publication	(publication* or manuscript* or article*)
Combination	1 and 2 and 3
Full combination	TI=((patient* or lay or people or public or consumer* or user* or citizen* or carer* or caregiver* or lived experience or community) and (involv* or engag* or participat* or contribut* or collab* or partner* or author or authors or authoring or authorship or reviewer*) and (publication* or manuscript* or article*)) or KP=((patient* or lay or people or public or consumer* or user* or citizen* or carer* or caregiver* or lived experience or community) and (involv* or engag* or participat* or contribut* or collab* or partner* or author or authors or authoring or authorship or reviewer*) and (publication* or manuscript* or article*))

exp, expand; KP, Keywords Plus; kw, keyword; MeSH, medical subject heading; ti/TI, title; yr, year.

Supplementary Table S2. Grey and unindexed literature sources.

Source	Link	Notes
American Medical Writers Association (AMWA) journal	https://amwajournal.org/index.php/amwa	
Applied Clinical Trials	https://www.appliedclinicaltrialsonline.com/	Limited to 'Patient Participation'
Canadian Institute of Health Research, Institute of Musculoskeletal Health and Arthritis (CIHR-IMHA)	https://blogs.ubc.ca/imhablog/	
Drug Information Association (DIA)	https://www.diaglobal.org/	Limited to 'publications', 'website/content', and 'insight/news'
Envision the Patient	https://www.envisionthepatient.com/	
European Medical Writers Association (EMWA) journal (Medical Writing)	https://journal.emwa.org/	
Open Pharma	https://www.openpharma.blog/	Limited to 'patients'
Patient Centered Outcomes Research Institute (PCORI)	https://www.pcori.org/	Limited to 'Posts' and 'Webpages'
Patient Focused Medicines Development (PFMD)/The Synergist via Patient Engagement Synapse	https://patientengagement.synapseconnect.org/resources	Limited to 'Resources'
Project Management (PM) Society	https://pmsociety.org.uk/	
PxP	https://pxphub.org/	Limited to 'Blog'
Taylor & Francis	https://taylorandfrancis.com/	Limited to 'News'
The British Medical Journal (BMJ)	https://www.bmj.com/	Searched via Google
The Evidence Base	https://becarispublishing.com/evidencebaseonline	Limited to 'patient engagement'
The International Society for Patient Engagement Professionals (ISPEP)	https://www.ispephub.org/	
The MAP Newsletter	https://www.ismpp-newsletter.com/	
The Publication Plan	https://thepublicationplan.com/	
The Scholarly Kitchen	https://scholarlykitchen.sspnet.org/	
Google	https://google.com	Limited to first five pages of search results

Supplementary Table S3. Results and outcomes extraction table headings.

Category		Extraction heading
Citation information		URL/DOI
		Title
		Authors
		Year
		Journal/place published
		Citation details
Article information		Industry/sector
		Sponsors/affiliations
		Article type
		Country/global region
		Disease/therapeutic area
Patient involvement information		Identifiable patient author?
		Patient terminology used
		Involvement terminology used
Content information	<i>For meta-research about patient involvement in publications only</i>	Study population
		Quantitative or qualitative?
		Methods
		Sample size
	For all sources	Roles for patients
		Best practices and current practices
		Gaps, limitations, barriers, and challenges
		Recommendations or goals for the future to address unmet needs
Quality appraisal <i>Using the CASP checklist</i>		1. Was there a clear statement of the aims of the research?
		2. Is the qualitative methodology appropriate?
		3. Was the research design appropriate to address the aims of the research?
		4. Was the recruitment strategy appropriate to the aims of the research?
		5. Was the data collected in a way that addressed the research issue?
		6. Has the relationship between researcher and participants been adequately considered?
		7. Have ethical issues been taken into consideration?
		8. Was the data analysis sufficiently rigorous?
		9. Is there a clear statement of findings?
		10. Is the research valuable?
		Total quality score out of 10
Other		Notes / other reflections

CASP, critical appraisal skills programme; DOI, digital object identifier; URL, uniform resource locator.

Supplementary File S4. Lead author positionality information.

“This research is patient-led; as an insider patient researcher, author AR has lived experience of multiple chronic conditions and patient advocacy. In addition to being a doctoral candidate, AR is also a professional medical writer with experience in publications and patient engagement working within the medical communications industry.”

From: Rosenberg A, Clark L, McClelland GR. Patient involvement in publications: qualitative mapping of the current landscape within the pharmaceutical industry. *Curr Med Res Opin.* 2025;41(8):1475-89.

The theoretical framework of AR’s analysis was experientially-focused and utilized semantic analysis with a hermeneutic of empathy – i.e. analyzing content at face value and trusting sources to convey knowledge in the way they intend. This was driven by an underlying ontology of critical realism and an epistemology of post-positivism and contextualism – i.e. the belief that there are certain universal or natural truths, but that interpretation is shaped by the human experience and researcher subjectivity. In short, objective truths exist, but the act of observation influences data.

Supplementary Table S5. Full citation list of records included in the review ($N = 166$ total records).

Category	Citation	Citation code
Peer-reviewed literature ($n = 64$)	Anstey AV, et al. Patient engagement with the BJD: why and how? <i>British Journal of Dermatology</i> . 2019;180:1274-1276. https://doi.org/10.1111/bjd.17847	PR1
	Arumugam A, et al. Patient and public involvement in research: a review of practical resources for young investigators. <i>BMC Rheumatology</i> . 2023;7:2. https://doi.org/10.1186/s41927-023-00327-w	PR2
	Boyce N, et al. Service user reviewers: extending peer review in <i>The Lancet Psychiatry</i> . <i>The Lancet Psychiatry</i> . 2018;5:780-781. https://doi.org/10.1016/S2215-0366(18)30353-5	PR3
	Calhoun K, et al. 283 Progress in Community Health Partnerships writing, dissemination and reviewer Learning Community for community-patient authors and reviewers (henceforth, PCHP LC). <i>Journal of Clinical Translational Science</i> . 2024;8(s1):86-87. https://doi.org/10.1017/cts.2024.259	PR4
	Chapman SJ, et al. Patient and public partnership at BMJ Open Respiratory Research. <i>BMJ Open Respiratory Research</i> . 2021;8:e001140. https://doi.org/10.1136/bmjresp-2021-001140	PR5
	Cobey KD, et al. Editors-in-chief perceptions of patients as (co) authors on publications and the acceptability of the ICMJE authorship: a cross-sectional survey. <i>Research Involvement and Engagement</i> . 2021;7:39. https://doi.org/10.1186/s40900-021-00290-1	PR6
	Colder Carras M, et al. Strengthening review and publication of participatory mental health research to promote empowerment and prevent co-optation. <i>Psychiatric Services</i> . 2023;74(2):166-172. https://doi.org/10.1176/appi.ps.20220085	PR7
	Cooksey KE, et al. Patient partner engagement in the publication process: challenges and possible solutions. <i>BMC Medical Research Methodology</i> . 2025;25:39. https://doi.org/10.1186/s12874-025-02495-4	PR8
	Daowd K, et al. 'This is PEEP' participatory qualitative study: learning from a provincial consultation and advisory group of people with lived and living experience of substance use in British Columbia, Canada. <i>BMJ Open</i> . 2024;14:e085183. https://doi.org/10.1136/bmjopen-2024-085183	PR9
	Doble E and Scowcroft H. Patient partnership: a roundup from the BMJ patient advisory panel. <i>BMJ</i> . 2021;374:n1773. https://doi.org/10.1136/bmj.n1773	PR10
	Doble E, et al. Patient partnership at BMJ: only by working together can we improve the health and wellbeing of people and the planet. <i>BMJ</i> . 2023;383:p2505. https://doi.org/10.1136/bmj.p2505	PR11
	Ellis U, et al. Identification and reporting of patient and public partner authorship on knowledge syntheses: rapid review. <i>Journal of Participatory Medicine</i> . 2021;13(2):e27141. https://doi.org/10.2196/27141	PR12
	Fallon J, et al. Inclusion of patients and advocates as authors in medical publications: progress over the past decade. <i>Sleep Medicine</i> . 2023;115:S254. https://doi.org/10.1016/j.sleep.2023.11.699	PR13
	Flicker S and Nixon SA. Writing peer-reviewed articles with diverse teams: considerations for novice scholars conducting community-engaged research. <i>Health Promotion International</i> . 2018;33(1):152-161. https://doi.org/10.1093/heapro/daw059	PR14
	Fowler EA, et al. Involving patient partners in the KRESCENT peer review: intent, process, challenges, and opportunities. <i>Canadian Journal of Kidney Health and Disease</i> . 2022;9:1-11. https://doi.org/10.1177/2054358122136402	PR15
	Fox G, et al. Recognizing patient partner contributions to health research: a systematic review of reported practices. <i>Research Involvement and Engagement</i> . 2023;9:80. https://doi.org/10.1186/s40900-023-00488-5	PR16
	Gustaffson L, et al. Enhancing inclusive and visible consumer authorship: recommendations for research and publishing practice. <i>Australian Occupational Therapy Journal</i> . 2024;71:209-212. https://doi.org/10.1111/1440-1630.12946	PR17
	Hamilton CB, et al. Developing and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. <i>PLOS One</i> . 2018;13(11):e0206588. https://doi.org/10.371/journal.pone.0206588	PR18
	Hessler Jones D, et al. Bringing lived expertise to academic publishing through community reviewers. <i>Health Services Research</i> . 2025;60(Suppl.3):e14616. https://doi.org/10.1111/1475-6773.14616	PR19
	Huml Am, et al. Community members as reviewers of medical journal manuscripts: a randomized controlled trial. <i>Journal of General Internal Medicine</i> . 2022;38(6):1393-1401. https://doi.org/10.1007/s11606-022-07802-z	PR20
	Jones J, et al. Reporting on patient and public involvement (PPI) in research publications: using the GRIPP2 checklists with lay co-researchers. <i>Research Involvement and Engagement</i> . 2021;7:52. https://doi.org/10.1186/s40900-021-00295-w	PR21
	Lambert S, et al. Is the patient voice being heard in peer-reviewed medical publications. <i>Current Medical Research and Opinion</i> . 2021;37(sup1):21-39. https://doi.org/10.1080/03007995.2021.1894669	PR22

Laskowski-Jones L. Patients as partners in publishing? <i>Nursing</i> . 2018;48(9). https://doi.org/10.1097/01.nurse.0000544222.54277.2f	PR23
Leventhal P, et al. PT11 Authoring of peer-reviewed articles on the experiences of patients with rare diseases by patients and their caregivers: a rapid review. <i>Value in Health</i> . 2024;27(12):S570-S571. https://doi.org/10.1016/j.ival.2024.10.3842	PR24
Lewis DM and Doble E. We need more patient and public reviews on research papers - and the resources to do so. <i>BMJ</i> . 2021;275:n2891. https://doi.org/10.1136/bmj.n2891	PR25
Lewis D and Scott P. BMJ HCI launches partnership programme for patients and carers as authors and peer reviewers. <i>BMJ Health and Care Informatics</i> . 2021;28:e100471. https://doi.org/10.1136/bmjhci-2021-100471	PR26
Li EW. 159 Does end-user-engaged peer review improve the relevance, replicability, and accessibility of research evidence? <i>BMJ Evidence-Based Medicine</i> . 2022;27(Suppl1):A1-A63. https://doi.org/10.1136/bmjebm-2022-PODabstracts.80	PR27
Lin KW, et al. Welcoming AFP's patient partners. <i>American Family Physician</i> . 2020;101(12):713-714.	PR28
Lobban D, et al. Patient involvement in publications of industry-sponsored research: cross-sectional survey. <i>Current Medical Research and Opinion</i> . 2018;34(sup1):9-28. https://doi.org/10.1080/03007995.2018.1440994	PR29
Lobban D, et al. Plain language summaries of publications: addressing the how via a stakeholder survey and workshop. <i>Current Medical Research and Opinion</i> . 2019;25(sup2):3-59. https://doi.org/10.1080/03007995.2019.1587943	PR30
Lynch E, et al. Credit where it's due: recognising lived experience in research authorship. <i>Patient Education and Counseling</i> . 2025;130:108472. https://doi.org/10.1016/j.pec.2024.108472	PR31
McFarthing K, et al. People with Parkinson's as partners for the Journal of Parkinson's Disease. <i>Journal of Parkinson's Disease</i> . 2023;13:125-126. https://doi.org/10.3233/JPD-239000	PR32
Miles S, et al. Reimagining authorship guidelines to promote equity in co-produced academic collaborations. <i>Global Public Health</i> . 2021;17(10):2547-2559. https://doi.org/10.1080/17441692.2021.1971277	PR33
Mitani K, et al. Insights gained from working with patient authors on industry-sponsored publications: case studies from Japan. <i>Current Medical Research and Opinion</i> . 2023;39(sup1):41-58. https://doi.org/10.1080/03007995.2023.2184562	PR34
Mojadeddi ZM, et al. Low degree of patient involvement in contemporary surgical research: a scoping review. <i>Journal of Postgraduate Medicine</i> . 2023;69(3):153-158. https://doi.org/10.4103/jpgm.jpgm_83_23	PR35
Moss V, et al. Barriers and solutions to working with patient authors: a survey of publication professionals. <i>Current Medical Research and Opinion</i> . 2022;38(sup1):25-45. https://doi.org/10.1080/03007995.2022.2044117	PR36
Narayanan R, et al. Patient lay summaries in biomedical journals: what and how much is currently available? <i>Current Medical Research and Opinion</i> . 2018;34(sup1):9-28. https://doi.org/10.1080/03007995.2018.1440994	PR37
Natarajan S, et al. Engagement of patient advocacy groups in rare disease clinical development and publication of results. <i>Current Medical Research and Opinion</i> . 2018;34(sup1):9-28. https://doi.org/10.1080/03007995.2018.1440994	PR38
Oliver J, et al. Hidden in plain sight? Identifying patient-authored publications. <i>Research Involvement and Engagement</i> . 2022;8:12. https://doi.org/10.1186/s40900-022-00346-w	PR39
Pateman K, et al. Partnering with consumers to co-design a person-centred coding framework for qualitative patient experience data. <i>Patient Education and Counseling</i> . 2023;116:107938. https://doi.org/10.1016/j.pec.2023.107938	PR40
Perri M, et al. A rapid review of current engagement strategies of people who use drugs in monitoring and reporting on substance use-related harms. <i>Harm Reduction Journal</i> . 2023;20:169. https://doi.org/10.1186/s12954-023-00902-x	PR41
Piano C, et al. Patient involvement in the peer-review process: an investigation across therapy areas. <i>Current Medical Research and Opinion</i> . 2019;35(sup2):5-29. https://doi.org/10.1080/03007995.2019.1587943	PR42
Pollock A, et al. Stakeholder involvement in systematic reviews: a scoping review. <i>Systematic Reviews</i> . 2018;7:208. https://doi.org/10.1186/s13643-018-0852-0	PR43
Pollock A, et al. Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. <i>Journal of Health Services Research and Policy</i> . 2019;24(4):245-255. https://doi.org/10.1177/1355819619841647	PR44
Price A, et al. Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study. <i>BMJ Open</i> . 2018;8:e020452. https://doi.org/10.1163/bmjopen-2107-020452	PR45
Richards T, et al. Better together: patient partnership in medical journals. <i>BMJ</i> . 2018;362:k3798. https://doi.org/10.1136/bmj.k3798	PR46
Richards DP, et al. Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. <i>Research Involvement and Engagement</i> . 2020;6:38. https://doi.org/10.1186/s40900-020-00213-6	PR47
Riggare S, et al. Patient editorial board for JNNP. <i>Journal of Neurology, Neurosurgery and Psychiatry</i> . 2019;90:369-370. https://doi.org/10.1136/jnnp-2019-320455	PR48

	Rose D. The publishing dilemmas of authors who have lived experience with mental illness. <i>Psychiatric Services</i> . 2024;75(10):1060-1062. https://doi.org/10.1176/appi.ps.20240026	PR49
	Salmi L and Blease C. A step-by-step guide to peer review: a template for patients and novice reviewers. <i>BMJ Health and Care Informatics</i> . 2021;28:e100392. https://doi.org/10.1136/bmjhci-2021-100392	PR50
	Schroter S, et al. Perspectives on involvement in the peer-review process: surveys of patient and public reviewers at two journals. <i>BMJ Open</i> . 2018;8:e100932. https://doi.org/10.1136/bmjopen-2018-023357	PR51
	Sheikhan N, et al. Co-authoring and reporting on lived experience engagement in mental health and/or substance research: a qualitative study and guidance document. <i>Health Expectations</i> . 2025;28:e70198. https://doi.org/10.1111/hex.70198	PR52
	Simon C, et al. We are the researched, the researchers, and the discounted: the experiences of drug user activists as researchers. <i>International Journal of Drug Policy</i> . 2021;98:103364. https://doi.org/10.1016/j.drugpo.2021-103364	PR53
	Sloan Donachy G. Seeking consent: some thoughts about sharing a draft with a patient. <i>Journal of Child Psychotherapy</i> . 2022;48(3):389-397. https://doi.org/10.1080/0075417X.2022.2139401	PR54
	Smylie J, et al. Requirement for meaningful engagement of First Nations, Inuit, Metis, and Indigenous Peoples in publications about them. <i>Canadian Journal of Public Health</i> . 2020;111:826-830. https://doi.org/10.17269/s41997-020-00450-y	PR55
	Sutton L, et al. Patient engagement in designing and publishing research in prostate cancer: a scoping review. <i>Future Oncology</i> . 2024;20(35):2779-2790. https://doi.org/10.2217/fon-2023-0543	PR56
	Tindal K, et al. Bereaved patient involvement in co-designed stillbirth research: experiences of Project Engage. <i>Women and Birth</i> . 2025;38:101838. https://doi.org/10.1016/j.wombi.2024.101838	PR57
	Vanderhout S, et al. Prevalence of patient partner authorship and acknowledgement in child health research publications: an umbrella review. <i>Journal of Clinical Epidemiology</i> . 2023;164:35-44. https://doi.org/10.1016/j.jclinepi.2023.10.012	PR58
	Wadsworth AC, et al. Patient involvement... or not? Analysis of "Patient Involvement" statement in clinical trial publications in The BMJ. <i>Current Medical Research and Opinion</i> . 2018;34(sup1):29-40. https://doi.org/10.1080/03007995.2018.1440990	RP59
	Weschke S, et al. Reporting of patient involvement: a mixed methods analysis of current practice in health research publications using a targeted search strategy. <i>BMJ Open</i> . 2022;13:064170. https://doi.org/10.1136/bmjopen-2022-064170	PR60
	Woolley KL, et al. Development and use of two tools to facilitate and evaluate patient authorship. <i>Current Medical Research and Opinion</i> . 2019;35(sup2):5029. https://doi.org/10.1080/03007995.2019.1587943	PR61
	Woolley KL, et al. "It's easier when you know how...": a publications training course for patient advocates, co-created by patient advocates and publication professionals. <i>Current Medical Research and Opinion</i> . 2021;37(sup1):5-20. https://doi.org/10.1080/03007995.2021.1899492	PR62
	Woolley KL, et al. Patient authorship of medical research publications: an evolution, revolution, and solution? <i>Learned Publishing</i> . 2024;37:e1607. https://doi.org/10.1002/leap.1607	PR63
	Zarshenas S, et al. Recommended characteristics and processes for writing lay summaries of healthcare evidence: a co-created scoping review and consultation exercise. <i>Research Involvement and Engagement</i> . 2023;9:121. https://doi.org/10.1186/s40900-023-00531-5	PR64
Grey and unindexed literature (n = 102)^a	Schindler T. Generating plain language summaries of scientific publications with ethical foundations: a practical "How-To" guide cocreated with patients. <i>AMWA Journal</i> . 2022;37(2):4-8. https://doi.org/10.55752/amwa.2022.155	G1
	BMJ Publishing Group. Co-production guidance for education articles. The BMJ. 2021. https://www.bmj.com/sites/default/files/attachments/resources/2021/06/educationcoproguidance_2021_0.pdf	G2
	Doble E, et al. The BMJ will remunerate patient and public reviewers. <i>BMJ</i> . 2024;387:g2581. https://doi.org/10.1136/bmj.g2581	G3
	BMJ Publishing Group. Guidance for BMJ patient and public reviewers - patient and public review at The BMJ. The BMJ. 2025. https://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers	G4
	BMJ Publishing Group. Patient advisory panel members. The BMJ. 2025. https://www.bmj.com/about-bmj/advisory-panels/patient-panel-members	G5
	BMJ Publishing Group. Patient and public partnership. The BMJ. 2025. https://www.bmj.com/campaign/patient-partnership	G6
	DeTora L, et al. Updated Good Publication Practice guidelines: what to expect in 2023. <i>DIA Global Forum</i> . 2022. https://globalforum.diaglobal.org/issue/december-2022/updated-good-publication-practice-guidelines-what-to-expect-in-2023/	G7
	Dormer L, et al. Patients as authors of company-sponsored journal publications: part B—publisher perspective. <i>DIA Global Forum</i> . 2022. https://globalforum.diaglobal.org/issue/august-2022/involving-patients-as-authors-of-company-sponsored-journal-publications-part-b-publisher-perspective/	G8
	Lobban D, et al. Involving patients as authors of company-sponsored journal publications: part A—patient and industry perspectives. <i>DIA Global Forum</i> . 2022. https://globalforum.diaglobal.org/issue/august-2022/involving-patients-as-authors-of-company-sponsored-journal-publications/	G9

Sykes A, et al. Key wins for patients in GPP update. DIA Global Forum. 2023. https://globalforum.diaglobal.org/issue/february-2023/key-wins-for-patients-in-gpp-update/	G10
Jenkins R, et al. How can we maximise patient engagement with Plain Language Summary of Publication articles (PLSPs)? A publisher's perspective. Medical Writing. 2024;33(1):26-29. https://doi.org/10.56012/ppko1083	G11
Leventhal P, et al. Can patients and caregivers be authors of peer-reviewed publications? Medical Writing. 2024;33(4):98-100. https://doi.org/10.56102/idd2040	G12
Yoshikawa A, et al. Involving patients in company-sponsored medical publications: Learning from collaboration with a patient advocacy group to engage patient authors. Medical Writing. 2024;33(3):89-93. https://doi.org/10.56102/rowv7554	G13
Envision Pharma Group. Guide for patient authors on meeting the International Committee of Medical Journal Editors (ICMJE) criteria. Envision the Patient. 2022. https://www.envisionthepatient.com/patient-authorship	G14
Envision Pharma Group. Overview. Envision the Patient. 2025. https://www.envisionthepatient.com/patient-authorship	G15
Envision Pharma Group. Patient author candidate framework. Envision the Patient. 2024. https://www.envisionthepatient.com/patient-authorship	G16
Envision Pharma Group. Guide for patient authors on disclosures. Envision the Patient. 2022. https://www.envisionthepatient.com/patient-authorship	G17
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^aAll grey and unindexed literature websites were accessed on 1 June 2025. G, grey and unindexed literature; PR, peer-reviewed literature.

Supplementary Table S6. Quality appraisals using the CASP checklist ($n = 10$ meta-research records for which quality appraisal was applicable).

Citation code	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total	
PR6	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	
PR12	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	8	
PR16	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	8	
PR20	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9	
PR21	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	8	
PR34	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	7	
PR38	Yes	No	No	Yes	Yes	Yes	Yes	No	Yes	No	6	
PR51	Yes	No	No	Yes	Yes	Yes	Yes	No	Yes	Yes	7	
PR52	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10	
PR60	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	8	
											Median	8
											Range	6-10
											Lower quartile	7.25
											Upper quartile	8.75
											Interquartile range	1.5

CASP, critical appraisal skills programme; PR, peer-reviewed literature; Q, question.

Supplementary Table S7. Terminology used for patient author affiliations ($n = 46$ records with identifiable patient authors).

Affiliation terminology	Number of records ^a
Patient Partner	12
Patient Author	6
Patient Advocate	5
Patient Editor	5
Consumer Representative	3
Patient	3
Cochrane Consumer Network	2
Consumer	2
Health Advocate	2
People with Lived Experience	2
Activist	1
Bereaved Parents	1
Cancer Survivor	1
Caregiver Author	1
Consumer Co-Researcher	1
Consumer Reviewer	1
EUPATI Fellow	1
Expert by Lived Experience	1
Global Patient Ambassador	1
Independent Advocate for Patients in Research	1
Lay Co-Researcher	1
Lived Experience and Service User Researcher and Activist	1
Lived Experience Researcher	1
Parkinson's Research Advocate	1
Patient Advisory Board	1
Patient Advisory Representative	1
Patient and Public Partner (PPP)	1
Patient and Public Representative	1
Patient and Public Reviewer	1
Patient Contributor	1
Patient Research Advocate	1
Patient Reviewer	1
People Who Use Drugs	1
People With Lived Experience and Families (PWLE/F)	1
Professionals for Ethical Engagement of Peers (PEEP)	1
Public Involvement in Research Group Member	1
Stakeholder Representative	1
Survivor Researcher	1

^aSome records used multiple affiliation terminologies, therefore the total number of tallies exceeds $n = 46$. EUPATI, European Patients' Academy on Therapeutic Innovation.

Supplementary Table S8. Publication locations of patient author affiliations ($n = 46$ records with identifiable patient authors).

Affiliation location	Number of records ^a
Byline affiliation	23
Body text (general)	16
Body text (patient and public involvement statement)	11
Body text (methods)	10
Abstract	9
Conflict of interest statement	7
Author contribution statement	2
Author information or bio	2
Acknowledgements	1
Body text (authorship statement)	1
Byline footnote	1
Funding statement	1

^aSome records used multiple affiliation locations, therefore the total number of tallies exceeds $n = 46$.

Supplementary Table S9. Pharmaceutical and adjacent industry companies listed as author affiliations or funders ($n = 88$ records with identifiable pharmaceutical or adjacent industry author affiliation or funders).

Pharmaceutical or adjacent industry company	Number of records ^a
Aspire Scientific	33
Envision Pharma Group	24
International Society for Medical Publication Professionals	21
Oxford PharmaGenesis	5
UCB	5
Pfizer	4
AstraZeneca	3
Boehringer Ingelheim	3
GSK	3
Complete Medical Communications	2
Evidera-PPD	2
Excerpta Medica	2
Ipsen	2
International Society for Patient Engagement Professionals	2
Merck	2
Novartis	2
Prime Global	2
Roche	2
90TEN	1
Amgen	1
Amica Scientific	1
Avadel Pharmaceuticals	1
Bayer	1
BioCryst Pharmaceuticals	1
Bioscript Group	1
Delonix Medical Affairs	1
Eli Lilly	1
European Medical Writers Association	1
Janssen	1
Johnson & Johnson India	1
Medistrava	1
OPEN Health	1
Reata Pharmaceuticals	1
SIRO Clinpharm	1
Solanum Medical Communications	1
Spirit Medical Communications	1
The Curry Rockefeller Group	1
TVF Communications	1

^aSome records listed multiple pharmaceutical or adjacent industry authors or funders, therefore the total number of tallies exceeds $n = 88$. **Bolding** indicates those that are pharmaceutical companies.

Supplementary Table S10. Descriptions and associated citations of best practices primary analysis.

Best practice/Code	Description	Associated citations
Overall strategy and governance		
Follow other general guidelines and frameworks for good patient involvement and engagement	For example: the CIHR SPOR's Patient Engagement framework; PFMD's Patient Engagement Quality Guidance; and Organizing Engagement's Core Principles for Public Engagement. These examples share collective themes of inclusion and representation, respect, shared purpose, transparency, and sustainability.	PR16, PR63, PR64, G8
Follow GPP	For all publication processes, from governance through to dissemination, follow the most recent iteration of GPP, which includes best practice recommendations for patient involvement in authorship, reviewing, and publication steering committees.	PR56, G7, G18, G22, G31, G49, G51, G54, G60, G66, G70, G82, G95
Utilise existing resources	Many resources and guidance materials already exist to support patient involvement in publications and should be used.	G41, G49, G68, G70, G76, G81, G82, G83, G86
Adhere to existing pharmaceutical compliance frameworks	Ensure all activities, processes, and policies are adherent to relevant compliance frameworks such as the ABPI, EFPIA, and IFPMA.	G93
Develop and follow evidence-based recommendations specific to patient involvement in publications	<i>"Evidence-based recommendations should be followed to minimise risks and maximise the benefits of involving patients as authors, for everyone."</i> [G67]. Such as the best practice recommendations put forward in this paper.	G67, G86, G94
Regularly update guidance in keeping with evolving practices	As recommendations, best practices, and meta-research practices evolve and new ones are synthesised, guidance should be regularly revisited and revised to be kept up to date with current knowledge.	PR63, G10, G86
Establish a global patient team with cross-functional and multistakeholder representation	To improve internal consistency, establish a central function for patient involvement activities that works collaboratively with other functions e.g. clinical development, medical affairs, patient advocacy, legal and compliance, and finance. Meet regularly and share best practices to embed processes and keep other functions informed. <i>"Patient engagement should not be considered in silo for one activity but should be looked at from a broader perspective i.e., considering the patient engagement journey as an end-to end activity from study design to publications"</i> [G95]. Such centralised efforts will help to reduce redundancies and multiple requests asked of the same patients and patient groups.	G10, G11, G29, G30, G68, G83, G85, G95
Gain leadership support	Embed top-down support for patient involvement from leadership to foster a patient-inclusive culture.	PR63, G29, G78, G81, G83
Plan for robust investment in patient involvement	Ensure budgets, resources, and timelines are sufficient to facilitate robust and effective patient involvement.	G28
Consider if such a team should be driven by Medical Affairs	As described.	G26, G93
Ensure that other internal functions have insight into publications	De-siloing; other functions should be aware of publication and patient involvement processes.	G10, G29, G83
Work closely with compliance and legal teams	Keep compliance and legal teams informed early on and throughout; gain their input on processes and policies.	G30, G78, G80, G83
Work closely with patient advocacy teams	Engage early and regularly with patient advocacy teams who are likely to already have and maintain relationships with patients and PAGs.	G92
Establish a comprehensive and consistent patient involvement strategy and policy	Establish and follow a defined, enterprise-wide strategy and policy for involving patients in publications to ensure consistency across teams. Co-create the strategy with patients and gain cross-functional consensus. Such strategy and policy should cover aspects such as authorship requirements, defined internal processes, affiliations for authorship, remuneration, training tools, etc.	PR5, PR6, PR46, PR62, PR63, G9, G10, G44, G77, G83, G85, G88, G95

Align authorship policies with ICMJE criteria	Internal authorship policies should adhere to the ICMJE criteria for authorship for all authors, whether patients or not. However, the ways in which patient authors can fulfil the criteria may look different to academic and clinical authors.	PR6, PR9, PR34, PR35, PR39, PR45, PR47, G2, G8, G9, G10, G11, G20, G41, G52, G54, G58, G66, G75, G82, G83, G101
Adopt an inclusive definition of patient author	Use a definition of patient that accounts for diversity of stakeholder perspectives and those who may represent multiple perspectives but are not expected to have a clinical or scientific background, i.e. <i>"A patient author should fulfil the following criteria: A person who lives with or is affected by a disease or condition (i.e., a broad definition of patient that includes those with lived conditions or receiving health or social care, caregivers, family members and members of patient advocacy groups who represent them); A person who provides unique and valuable input from their personal patient perspective to the publication."</i> [PR39, G25, G101]. Patients should be able to self-identify and other stakeholders should not act as gatekeepers of the patient identity.	PR17, PR42, PR39, PR55, G1, G4, G14, G18, G25, G81, G86, G101, G203
Utilise acknowledgements where ICMJE criteria are not fully met	As described.	PR2, PR7, PR8, PR16, PR47, PR58, G13, G24, G56
Tailor global policies to local markets	Where universal policies are not applicable or appropriate for a local market, tailor policies to meet the cultural and structural needs of local markets.	G83
Ensure policies and processes cover situations with paediatric patient authors	Children and young people are also co-authoring as patient authors where they meet the ICMJE criteria, so any processes and policies should account for this scenario, including the additional involvement of parents and caregivers.	PR58, G56
Establish an internal patient-driven governance body for patient oversight across publication processes	This is a long-term effort, not a one-off advisory board. For example, see Pfizer's Collaborative Board [G9; G81; G72].	PR62, G9, G10, G75
Co-create publication materials for patients with patients	All patient-related materials for publications including policy, SOPs, training resources, onboarding and welcome kits, contracts, etc should be co-created with patients to ensure materials are meaningful and <i>"relevant, appropriate to the patient level, valued, fair, and transparent"</i> [G78].	G53, G60, G75, G78, G92, G94
Develop plain language Author Agreement contracts	Translate Author Agreement materials into plain language and ensure it covers ICMJE authorship criteria, patients' rights and responsibilities, project purpose, capacity and capability requirements, remuneration (or lack thereof), and references to relevant guidelines and materials (e.g. GPP). If agreements and contracts cannot be written in plain language for legal reasons, create a companion plain language explainer to accompany the legal document.	G18, G54
Develop onboarding and induction materials in plain language	Include information in plain language such as expectations of authorship, company-specific information or policies, practical guidance, plain language summaries of resources e.g., GPP, glossaries, and workflow infographics. Consider making these materials open access, where appropriate, so that others may benefit from them or use them for inspiration for their own materials.	PR8, PR17, PR19, PR21, PR34, PR63, G10, G13, G15, G18, G22, G30, G48, G51, G55, G67, G68, G78, G91, G100
Provide access to training on publications for patients	Upskill patients and build capacity for involvement, either through developing internal training resources or through access to external resources, for example the WECAN 'Patients in Publications' e-learning module [G98].	PR3, PR8, PR14, PR17, PR39, PR47, PR52, PR56, PR64, G8, G9, G13, G19, G23, G29, G32, G48, G50, G53, G54, G56, G62, G69, G72, G75, G91, G94, G98
Ensure training materials comprehensively cover processes and principles	As well as describing processes, training should also cover principles for scientific integrity in publishing, e.g. open science, transparency, ethics, predatory journals, etc.	PR17, G23, G48, G101
Follow adult learning principles	When developing training and development content, ensure adult learning principles and pedagogy best practices are followed to enable effective knowledge transfer (i.e., Knowles' Theory of Andragogy).	PR62

Invite patients to attend internal colleague training, where appropriate	To support comprehensive awareness across stakeholders, patients should be invited to attend training opportunities intended for other stakeholders.	G48
Provide support to patients throughout processes	Enable participation as active team members through provision of multiple means of support.	PR1, PR14, PR17, PR50, G9, G10, G13, G75, G82, G94
Conduct a needs assessment	Understand what support is needed for individual patients by first conducting a needs assessment and gaining their input on what supportive measures they feel are most beneficial for their circumstances.	PR62, G68, G92, G10
Facilitate mentorship opportunities with experienced patients	Pair less experienced patients with more experienced patients and those familiar with the publications industry and processes who can provide mentorship, moral support, encouragement, and inspiration.	PR52, PR64, G9, G70
Have a dedicated point of contact	Designate a single, consistent point of contact to act as the relationship owner for patients to become familiar with and know to turn to for queries. Utilise both 'office hours' and ad hoc approaches to providing support and answering queries.	PR19, PR20, PR63, G4, G10, G32, G54, G56, G73, G85, G102
Provide technical support or manage technical steps on behalf of patients	For example, for approval management systems, submission portals, and proofing systems.	PR17, G30, G38, G48, G54, G56, G70
Be prepared to navigate negative and emotional situations	Be prepared for emotional responses to arise during involvement, e.g., when discussing lived experiences or in response to negative peer review responses. Facilitators of patient involvement must be well-equipped to navigate and manage such situations.	PR17, G23
Provide access to training on involvement for colleagues working with patients	Support colleagues to work effectively with patients in involvement activities by training them on best practices.	G9, G41
Facilitators of patient involvement should also complete the patient training	To support comprehensive awareness across stakeholders, facilitators of patient involvement should complete training designed for patients.	PR63
Ensure technical infrastructure is set up to facilitate involvement	I.e., contracting systems, payment systems, and any additional legal and compliance procedures. Ensure that any need for these systems and infrastructures is proactively considered prior to involvement.	G1, G83
Keep processes simple and not over-complicated	Ensure systems and infrastructure are user-friendly.	PR21, G10
Ensure technical systems are inclusive of non-academic users	For example, by not requiring institutional email addresses to access such systems.	PR19, PR63, G4, G35, G89
Avoid tokenism and gift, guest, or ghost authorship	Ensure that participation in authorship is ethical by encouraging genuine, authentic, and meaningful contributions from patient authors and not treating authorship as a box-ticking exercise.	PR33, PR39, G34, G73, G80, G82, G84
Facilitate deeper and meaningful involvement beyond what is strictly mandatory	Minimise tokenism by going above and beyond what is strictly mandatory (e.g., patient involvement statements mandated by journals) to facilitate and conduct broader patient involvement.	PR60
Ensure the involvement is mutually beneficial	Minimise tokenism by facilitating bidirectional involvement that benefits and empowers the patients involved.	G71, G75, G81
Establish safeguards	Protect patients, especially vulnerable patients, through the introduction of safeguards to prevent manipulation or undue influencing of patient perspectives.	G50
Demonstrate effective patient involvement	Demonstrate and showcase best practices for ethical and effective patient involvement. Use industry events and professional societies to share learnings on best practices, especially for those who are innovating and leading advancements.	PR63, G10, G70, G95
Reward good examples of best practice	Use rewards and awards to showcase good examples and motivate good practices, e.g., the BMJ Awards or PEOF Awards	G6, G102
Take inspiration from how other research sectors are involving patients	Look to and learn from others outside of private industry for inspiration, e.g., academia, the charity sector, healthcare systems.	G70
Use published examples of patient authorship as a precedent to reinforce validity	Share and use published examples as real world case studies for increased legitimacy and credibility.	G48
Professional societies should demonstrate leadership in patient involvement	Professional societies, e.g., ISMPP, should set the bar for patient involvement by proactively demonstrating leadership and integrating patient involvement into their routine practices.	G40, G74, G90

Provide professional development for publication professionals to upskill as patient involvement professionals	As the role of a medical writer and publications professional evolves, ensure that professional development opportunities are available to upskill in patient involvement.	G10, G23
Partner with trusted, patient-inclusive medical writers and publication professionals	Medical writers and publication professionals are critical for effective delivery of pharmaceutical publications. Sponsors should partner with service provider agencies that have a proven track record of patient-inclusive practices.	PR62, G54, G57, G66, G69, G71, G80, G86, G90, G91, G100
Aim to work with multiple patients within a single project	Involving multiple patients within a single project (could be across multiple roles) helps to share the burden of involvement, feel less outnumbered by other researchers/authors/publication professionals, expands viewpoints, and minimises tokenism as the single token patient.	PR32, PR63, PR64
Publication planning		
Establish a patient publication steering committee (PPSC)	Complement academic and clinical publication steering committees with a patient publication steering committee, or alternatively embed patients in a single integrated publication steering committee.	PR39, PR63, G5, G22, G31, G48, G49, G54, G56, G57, G60, G64, G66, G67, G69, G71, G78, G86, G92
Use a PPSC to identify research topics where patients can best add value	E.g., qualitative research topics on lived experience, patient experience data, patient-reported outcomes, meta-research of involvement practices, quality improvement, topics with clinical implementation impacts.	PR52, PR56, PR63, G31, G50, G60, G75, G82, G93, G102
Ensure documentation is in place for qualitative research and broader patient involvement meta-research involving human participants	Ensure that all work involving human participants – including qualitative and exploratory studies, as well as meta-research on patient involvement practices – has the appropriate ethical approval or exemption documentation needed for publication.	G9, G30, G80
Use a PPSC to identify publication types where patients can best add value	E.g., PLS and PLSPs, editorial commentaries, companion papers, dedicated Patient Perspectives, original research articles, podcast articles, etc.	PR24, PR29, PR30, PR46, PR48, PR54, PR56, PR63, G8, G27, G28, G50, G52, G61, G65, G86, G93, G101, G102
Use a PPSC to identify publications for PLS inclusion	Follow the defined remit or scope of any PLS policy, and additionally identify relevant publications that may not be covered by the policy.	G56
Establish term limits	Use term limits of committee members to refresh expertise and perspectives, in keeping with processes used for academic/clinical steering committees.	G5
Recognise and give credit for effort through authorship	Patients who have contributed sufficiently and meet ICMJE criteria should be included as authors in recognition of their efforts. Note that this recognition or exposure does not replace fair financial remuneration.	PR16, PR52, G94
Ensure that authorship is an informed decision	The decision to opt in to authorship ultimately lies with patients as autonomous beings, with open dialogue around expectations and risk to ensure fully informed decision-making.	PR33, G60, G74
Have balanced and informed discussions about bidirectional risks and benefits of authorship	To ensure fully informed decision-making regarding authorship, comprehensively and transparently discuss potential risks of authorship with patients, e.g., data privacy and possible identification. Equally, share the value and benefits of authorship, e.g., <i>"advancing advocacy efforts, lending credibility to critical ideas, introducing innovative approaches to research, and moving a field forward"</i> [PR14]. Additional bidirectional benefits include demonstrating the integration of patient engagement values, driving relevance and engagement of research and publications to patients, improving credibility, contributing to professional development through honing writing skills, establishing routes to further involvement in patient advocacy, and writing representing a therapeutic outlet.	PR10, PR12, PR14, PR45, PR46, PR52, PR54, PR57, PR63, G3, G7, G10, G13, G16, G31, G48, G59, G60, G65, G68, G69, G70, G71, G72, G73, G85, G86, G87, G96, G101
Empower patient authors to decline authorship if it does not suit them	Make it clear that involvement is entirely voluntary and there is no obligation to say yes.	G4, G102
Plan for involvement in advance	Patient involvement takes time to identify, contract, and build relationships, so involvement should be planned for in advance.	G72, G83, G86

Plan to involve patients as early as possible in the research cycle or within the development process	Early involvement is a critical strategy for ensuring non-tokenistic, meaningful involvement, and minimises risks of downstream disagreements and discordant messaging, e.g., if an author is brought on late in the process.	PR2, PR18, PR47, PR51, PR52, PR56, PR58, PR63, G1, G8, G10, G26, G30, G31, G32, G48, G57, G62, G64, G68, G73, G74, G76, G78, G82
Proactively create opportunities for patient authorship	Collaborate with upstream colleagues to involve patients in activities that would enable them to fulfil ICMJE criteria, i.e., study conception or design, or data acquisition, analysis, or interpretation.	PR2, PR52, PR56, PR63, G8, G10, G13, G26, G28, G29, G48, G49, G86, G91, G92
Ensure involvement of at least one patient partner	Within a pre-defined remit of a patient-oriented scope (whatever that may be to an individual organisation), ensure at least one patient – author or reviewer – has been involved in the development process. This is particularly critical for publications on topics such as patient-reported outcomes or patient experience data.	G60, G72, G81
Ensure patient involvement in PLS and PLSPs	Patient involvement in the development of PLS and PLSPs is essential – whether as authors, reviewers, or sensitivity readers/user testers. This is a good opportunity to incorporate involvement where other opportunities have not been feasible (e.g., in the absence of patient authorship on the main manuscript), but should not be done tokenistically.	PR64, G1, G33, G56, G62, G71, G97
Commit to developing a PLS for all patient-authored content	Publication plans should include PLS – whether text, infographic, or video – for all submissions that involve patient authors.	PR14, PR64, G55, G60, G70, G86
Demonstrate respect for patient audiences	Show respect for patient readership through the inclusion of PLS tailored to their literacy needs.	G1, G54
Empower patient authors to upskill in their writing by starting with PLS	PLS represent an opportunity for patient authors to contribute and develop their own writing and authorship skills.	PR39, PR64, G23
View involvement in PLS development as an initial step or gateway towards further involvement	Particularly where organisations do not yet have systems set up to support broader patient involvement, start with involvement in PLS as an initial step, but with a view to growing involvement capacities and capabilities.	G63, G78, G80, G93
Consider prioritising working with academic and clinical authors who are known to be patient-inclusive	Where there is reasonable opportunity, aim to collaborate with academic and clinical authors " <i>who have a proven track record of working successfully with patient partners</i> " [PR63] to address and improve power imbalances. However, be aware that there is potential to introduce bias.	PR63
Educate academic and clinical authors on the validity and value of patient authors	Particularly for those who may not have collaborated with patient authors before, provide education on the epistemological value of lived experience and the validity and legitimacy of patient authors to pre-empt possible negative interactions or devaluing of patient authors.	PR63, PR64, G12, G29, G30, G48, G70, G86
Identify appropriate potential patient authors to collaborate with	In addition to ICMJE criteria fulfilment, it may also be useful to identify potential patient authors for collaboration based on factors such as relevant lived experience expertise, willingness to contribute and to be named publicly, access to resources for drafting and reviewing (e.g., software, internet), time availability. Potential routes for identification include patients known to academic and clinical authors, patient advocacy groups, social media, PPI groups.	PR34, PR57, G1, G2, G9, G13, G22, G30, G46, G48, G67, G68, G69, G72, G74, G78, G80, G102
Consider if writing skills are needed	Depending on the level of drafting input required (as opposed to intellectually reviewing and revising content initially developed by medical writers), it may be helpful for patient authors to have prior experience with writing – though this may not necessarily need to be academic writing.	PR32, G13, G56
Consider the level of patient expertise needed	Depending on the publication topic, consider if the patient expertise needed is 'Patient by Experience' with a greater focus on lived experience of a condition, or 'Patient Expert'/'Patient KOL' with a greater focus on knowledge of systems and processes.	PR28, G47, G50, G68, G69, G70, G71, G75, G78, G81, G82, G86
Consider other roles and perspectives they represent	Experienced 'Patient Experts' may be regularly working with multiple organisations, which for some can represent a greater degree of independence and objectivity as opposed to being contracted to only a single organisation.	PR51, G9, G82
'Multiple hat' patients can act as a link between industry and patient communities	Patients who wear 'multiple hats' of lived experiences and expertise – e.g., patient researchers or patients working as professionals within the system – are typically well-connected within multiple communities. This is important both for identification and for effective involvement.	PR57, PR58, G69

Recognise that different lived experiences are relevant to different topics	Beyond relevant therapy area lived experience, consider how different experiences may or may not align with broader research areas and methodologies. E.g., <i>"people with a rare condition and few treatment options may be more interested in early-phase data than people with conditions for which many treatment options are available"</i> [G56].	G56, G95
Maintain a database of prior patient authors who may be re-contacted	As described.	G72
Consider collaborating with PAGs	Collaborate with PAGs – particularly where relationships are already established – to identify individuals to involve.	PR38, G13, G28, G31, G50, G56, G72, G74, G102
Publication development		
Tailor level of involvement to patient capacity and capability	Whether author or reviewer and whether leading on drafting or contributing to interpretation through other methods, tailor the level of the involvement in the publication to the capacity, capability, expertise, and wishes of the patients involved.	PR8, PR14, PR47, PR51, PR52, PR64, G39
Use established theoretical frameworks of involvement as a guide	E.g., Arnstein's Ladder of Participation. Such frameworks can also be used in the reporting of involvement.	PR7, PR8
Establish agreed expectations across the whole authorship team	At the outset of a project, ensure all team members are clearly aware of each other's expectations and responsibilities, with patients inputting on the terms of involvement. Document this understanding in a shared terms of reference or charter document. Expectations should include time commitments and deadlines, level of individual contributions, project goals, remuneration policies, process workflows, rounds of review, remits of review, guidelines to adhere to, individuals' rights, and where to go to for help. Ensure that expectations are pragmatic and realistic for patient authors as well as for academic and clinical authors and publication professionals.	PR8, PR14, PR16, PR20, PR25, PR33, PR47, PR52, PR63, G1, G12, G13, G16, G18, G23, G31, G48, G54, G56, G60, G73, G74, G76, G81, G85, G86, G92, G94, G100
Ensure understanding of expectations is bidirectional for all team members	Ensure patient authors and clinical and academic authors understand each other's roles and responsibilities and what each bring to the table in terms of expertise.	PR47, G1, G37
Explain external limitations	Clearly indicate where external factors are dictating processes and are beyond control of the broader team, such as journal special issue deadlines or word counts.	G48
Have flexible timelines and processes	Provide <i>"generous deadlines"</i> [G54] but remain flexible should patient author availability change. Adapt frequency of meetings and timing of review rounds to patient author needs, which may vary over the course of the project, especially among those with dynamic and fluctuating conditions; <i>"work to the patient's schedule"</i> [G73]. Have contingency plans to be prepared for a potential <i>"sudden lack of availability due to work, illness, or other commitments"</i> [G23].	PR47, PR54, PR63, PR64, G9, G10, G13, G14, G16, G23, G30, G31, G38, G48, G54, G56, G60, G68, G72, G73, G77, G80, G81, G102
Communicate time commitments	Discuss estimated timelines and expectations, as well as anticipated milestones, at the outset and adapt as needed. Provide advance notice of upcoming review periods and deadlines.	G38, G48
Factor time zone differences	Factor in relevant time zone differences when scheduling meetings and deadlines.	G56
Host a kick off meeting with all authors	As described.	PR34, G30, G38
Consider hosting a pre-kick off meeting with just patient authors, if needed	If needed, host a pre-kick off call or an introductory call with the patient author(s) and lead contacts (e.g., publication manager, medical writer). This is especially important for relationship-building. If there is already a strong relationship or if the patient author has a lot of publications experience, this may not be needed.	PR34, G48,
Agree on manuscript objectives and key messages	Prior to drafting, discuss and agree on manuscript objectives and key messages, e.g., in a kick off meeting. This discussion should include contextualising the project within the broader scientific picture and highlighting the benefits and purposes of publishing this research.	PR14, PR47, PR62, PR63, G13, G38, G54, G92
Discuss data privacy concerns	Ensure patient authors understand the public nature of authorship (especially if serving as corresponding author). Aim to name a non-patient co-author as corresponding author.	G23, G54, G60, G83, G101
Align on authorship byline order early, transparently, and equitably	To minimise disappointment and disagreements at a later stage, authorship byline order should be discussed transparently at an early stage of publication development. The order should be determined in a way that is "fair and equitable" [PR17], with a nuanced approach given the inclusion of patient authors.	PR14, PR17, PR33, PR47, PR57, G76, G94

Select target journals that are patient-oriented or are published by patient-inclusive publishers	If a desired target journal is not itself patient-oriented, target a publisher that is known to be patient-inclusive and has the resources and systems in place to enable patient involvement.	G69, G85, G86
Have continuous and equitable communication throughout the development process	Maintain regular communication through email updates and meetings where appropriate. Keep team members up to date on deadlines, expectations, next steps, etc. Keep communication channels open to encourage ongoing dialogue between all team members and maintain engagement.	PR2, PR14, PR16, PR17, PR21, PR33, PR43, PR52, PR64, G54, G56, G76
Document discussions and agreements	Regularly document discussions and decisions, e.g., meeting minutes or presentations, and provide access to the documentation for all team members.	PR17
Regularly confirm mutual understanding	During regular communications, check in with all parties to confirm mutual agreement and understanding.	G23, G54
Allow dedicated time and space for questions	Ensure mutual agreement and understanding by creating dedicated spaces and times to answer questions, as well as welcoming questions throughout the process.	PR54, G13, G18
Circulate all files and records to all authors	Ensure all authors have full and timely access to electronic documentation of all materials – contracts/agreements, source materials, drafts, agendas/minutes, timelines etc – whether through direct file sharing or access to a shared drive.	G54, G56
Provide patient authors with access to data reports	Patient authors should have full access, equal to that of clinical and academic authors working on a publication (external to sponsor).	G30
Involve patient authors throughout all stages of the development process	Maintain consistent involvement of patient authors at all draft and revision stages, including with a view from a broader perspective for end-to-end involvement rather than siloed within individual activities.	PR9, PR64, G79, G81, G82, G94, G95
Recognise that there are different ways for patient authors to contribute to drafting	Depending on expertise and appetite for involvement, patient authors may intellectually contribute to publication content at different levels. Some patient authors may prefer to do the initial drafting, some may prefer to review and critically revise medical writer-drafted content. Further, some patient authors may have additional clinical or scientific expertise and may input on these aspects as well.	PR18, PR21, PR27, PR43, PR44, PR45, PR47, PR51, PR52, PR54, PR56, PR58, PR64, G2, G14, G18, G23, G28, G37, G48, G86, G94
Consider utilising patient perspective call-out boxes within broader publications	Explicitly highlight patient author contributions by including quotes or patient-written sections of interpretation as call-out boxes, where appropriate.	G28
Consider sharing leadership of different sections or outputs	Share the initial drafting by delegating different sections or outputs and publication extenders among authors, including patient authors, to take individual ownership of.	PR14, PR52, PR63, PR64, G56
Align different content sections drafted by different authors with editorial standards whilst preserving the patient voice	If patient authors are writing and drafting their own content from scratch, or if drafting is shared among multiple authors, provide editorial support to ensure that editorial standards such as house style or journal style are met, whilst ensuring to preserve the patient author's voice.	G23, G31, G69, G71, G75, G78, G85
Use templates for PLS	Ensure consistency across outputs by using templates.	PR64
Patient-authored content should reflect patient priorities and perspectives	To ensure that involvement is not tokenistic, patient priorities and perspectives should be respected and reflected within content development.	G71
Confirm content decisions with patient authors	Explicitly confirm content and language decisions with patient authors throughout the process.	PR52
Ensure patient perspectives are embedded within the interpretation and discussion of findings	To ensure that patient authors are meeting ICMJE criteria, their perspectives on results interpretation is vital to include.	PR14, PR18, PR21, PR33, PR45, G63, G68, G72
Invite review and input from non-author patient contributors	This is particularly important for PLS, PLSPs, and wherever health literacy and accessibility are particular considerations if patients are a target audience, and especially if patient authors have not been already involved.	PR54, G33, G46, G52, G55, G56, G57, G72, G78, G86, G97
Invite user-testing of PLS	In particular, invite patient reviewers to user-test the suitability of PLS language.	PR64, G1, G33, G50, G56, G62, G71, G92

Share content and receive feedback in formats that suit individual patients	Consider if patient authors and reviewers have access to licenced word processor software or if freely available versions need to be used, e.g., Google Docs. Consider if individuals prefer to give feedback verbally. Be prepared for logistical and resource barriers and adapt processes to suit individual needs.	PR19, PR21, PR33, PR34, PR47, G10, G23, G31, G38, G54, G55, G56, G68, G71, G76, G81
Consider providing overarching questions for eliciting author and contributor feedback on drafts	Particularly for authors who may feel it will be helpful for them, provide some overarching questions when sending out drafts for author reviews to help prompt and maximise utility of feedback, i.e., open-ended questions that could guide authors to focus on specific areas where there may be more uncertainty of meaning.	PR52, G23, G31, G38, G54
Encourage honest and critical input on content	When sharing drafts for review and input, encourage critical feedback. Empower patient authors to feel like they can safely disagree and not just have to approve without meaningful input.	PR54, G39, G81
Encourage reflexivity in feedback and reviews	Empower patient authors to reflect on their lived experiences and use their personal knowledge and expertise as a lens for interpretation of publication content.	G23
Communicate feedback on patient contributions	Provide clear, bidirectional feedback on how patient contributions and insights e.g., edits, suggestions, content requests (whether as authors or reviewers) have been incorporated into drafts. Where contributions are not incorporated, provide rationale and opportunities to discuss further.	PR52, G23, G30, G38, G39, G68, G81
Ensure reporting and documentation is transparent and compliant	Follow appropriate guidelines and reporting checklists to maintain compliance. Document patient author input on relevant publication management systems, as is standard for all authors.	PR10, PR17, PR58, G9, G16
Include a patient involvement statement in the publication	Detail patient involvement (or lack thereof) through the inclusion of a patient involvement statement. " <i>Proper acknowledgement of patient engagement activities and inclusion of patient advocacy groups in publication efforts will serve to benefit both patients and sponsors, contributing to improved ethics and transparency, and will allow sponsors and regulators greater insight into how this engagement can impact clinical development outcomes.</i> " [PR38].	PR5, PR12, PR38, PR58, G25, G44, G88
Use the GRIPP2 reporting checklist	Just as the use of other EQUATOR Network reporting checklists are encouraged (and oftentimes mandated) depending on methodology-type, the GRIPP2 checklist – either long form or short form – should also be included to comprehensively and compliantly report on patient involvement. Research should be designed and conducted from the outset with downstream transparent and adherent reporting in mind.	PR2, PR21, PR58, PR63, G35, G77, G86
Declare conflicts of interest	Follow standard processes to declare all relevant conflicts of interest of all authors, including additional affiliations and financial and non-financial competing interests and relationships.	G23, G54, G101, G102
Disclose if patient authors/reviewers were trial/study participants	If patient authors or reviewers were participants in the clinical trial or experiential study, this participation should be disclosed.	G50, G72
Utilise ORCID iDs	Support patient authors in setting up an ORCID iD, including explaining the purpose and benefits of doing so.	PR17, PR63,
Declare authorship contributions in contribution statements	As for all publications and authors, ensure patient author contributions are identified and reported within an author contributions statement, ideally using frameworks such as the CRediT taxonomy for standardisation.	PR33, PR41, PR45, PR58, G101
Communicate patient authorship to journals	Proactively alert journal editors to the inclusion of patient authors by reaching out in pre-submission enquiries and highlighting this in the cover letter.	G32, G101
Journal processes		
Involve patients on advisory boards to steer journal direction	Patient involvement on journal editorial and advisory boards helps to guide journal strategy, objectives, aims, and processes towards a patient-inclusive direction.	PR5, PR10, PR48, PR56, G6, G27, G44, G52, G57, G61, G73, G77, G85, G88, G102
Explicitly encourage patient authorship and patient involvement in submitted research	Encouragement, and requirements where appropriate, from journals help drive uptake of practices.	PR39, PR56, PR63, G2, G6, G8, G69, G77, G96, G100, G102
Provide author instructions on the inclusion of patient authors	Patient-inclusive journals that provide specific guidance and encouragement for patient involvement help to " <i>break down historical barriers and [affirm] that patients and their networks are not only co-authoring publications but are also a valued audience</i> " [G100].	G27, G44, G58, G61, G85, G88, G100, G101

Publish dedicated Patient Perspective article types	For example, the <i>BMJ</i> 's 'What Is Your Patient Thinking' column.	PR10, PR11, G2, G6, G8, G11, G23, G27, G73, G75, G88
Mandate and provide guidance on patient involvement statements	Encourage the inclusion of PPI statements as a required submission element. Provide guidance in author instructions regarding the level and type of details expected.	PR21
Ensure patient-authored content is subjected to the same level of peer review rigour as other journal content	Maintain publication ethics and robustness by applying the same rigour of peer review to patient-authored content as is done for traditional scientific content.	G101
Apply patient peer review to all patient-oriented submissions	For example, PLSP articles, patient experience data, patient-reported outcomes.	PR15, G60, G61, G75, G88, G94, G102
Utilise ad hoc patient peer review if systems for formalised patient peer review are not yet in place	As described.	PR42
Apply patient peer review in conjunction with scientific peer review	Editorial decisions should be based on a combination of patient and scientific/academic peer review reports.	G6, G102
Communicate feedback on patient peer reviewer contributions	Relay to patient peer reviewers how their reviews have been used by authors to update manuscripts. Provide feedback on the utility and helpfulness of the peer review report, to help patient peer reviewers improve their reviews in future and build confidence.	PR19, PR20, PR51, G102
Empower patient peer reviewers to decline reviews	Empower patient peer reviewers to decline review invitations if they feel like it is not within their field of expertise or if they do not have capacity.	G4, G102
Encourage patient peer reviewers to be candid about expertise limitations	As with all peer reviewers, be clear about what kind of expertise is being sought in a particular review and encourage patient peer reviewers to consider if they have the relevant experience and expertise.	PR50
Provide guidance and training for patient peer reviewers	Provide guidelines to patient peer reviewers on conducting and sharing peer review feedback. Include guidelines around appropriate language and tone of review comments.	PR19, PR20, PR25, PR50, G11, G89
Include guiding questions for to prompt rigorous reviews	Share specific questions to focus on, e.g., " <i>relevance and importance of the study's aims; the feasibility of the treatment or intervention being studied; whether the outcomes being studied were appropriate; the level of patient engagement; and any suggestions to the authors</i> " [PR15].	PR15, PR19, PR51, G61, G89, G102
Provide example reviews	Share examples of historic peer review reports to demonstrate expectations.	PR25, PR51, PR54, G48, G89
Provide templates	Use a template peer review report for patient peer reviewers to populate, to help streamline the process.	PR25
If practicing open peer review, clarify this to patient peer reviewers and offer anonymity	Ensure that patient peer reviewers understand the implications of open peer review. If needed to protect patient data privacy and confidentiality, offer anonymity as appropriate.	PR51, G3, G102
Demonstrate patient inclusivity through 'Patients Included'™ accreditation	The 'Patients Included'™ accreditation mark can be employed by individual journals fulfilling the four charter requirements of patients serving as editors, authors, and reviewers, and being open access.	G6
Evaluation		
Use relevant and appropriate metrics of successful patient involvement	For example, number of patient authors, number of patient-authored outputs, uptake by patient communities, stratified by bibliometric characteristics to gain a more in-depth understanding. Use quality measurement tools such as the PFMD's Patient Engagement Quality Guidance.	PR63, G54, G73, G76, G92
Use traditional publication metrics	For example, Altmetrics, journal impact factor, downloads, citations. However, these should be secondary to patient-relevant metrics as suggested above.	PR63
Gather feedback on processes from patient authors	Enable continuous improvement of processes by eliciting feedback in structured and consistent avenues for comparison across projects, e.g., a standardised survey, or the Patient Author Experience self-assessment tool. This can be done at the end of a project to reflect on the whole experience, and can also be done throughout as a continuous feedback loop to regularly recalibrate and improve.	PR8, PR39, PR61, PR63, PR64, G4, G54, G56, G73, G76, G81, G89, G92, G102
Act on feedback	Don't just collect feedback, but instrumentally use it to improve processes.	G89, G92
Dissemination		

Co-create a consolidated dissemination plan	Discuss dissemination options with all stakeholders and team members and consider avenues such as " <i>advocacy platforms, health care websites, or social media</i> " [G23], ensuring to consider and address challenges associated with perceived promotion of public sharing.	G23, G56, G67, G71, G86
Make use of community connections	Patient authors could utilise their existing communities and networks to disseminate research findings; journals could share materials directly with PAGs.	PR63, G8, G30, G63, G67
Journals and patient authors can consider sharing on social media	All parties should follow PMCPA guidance for social media and any other applicable guidelines for local markets.	PR39, G11, G86
Beyond and across the lifecycle		
Recognise lived experience as a valid epistemology	Recognise and respect that lived experience is a valid and legitimate form of knowledge or epistemology that has been historically excluded from what 'counts' as knowledge (epistemic injustice).	PR17, PR23, PR33, PR40, PR55, PR56, PR57, PR58, PR63, G7, G29, G30, G32, G48, G56, G60, G67, G68, G69, G70, G72, G82, G84, G86
Expand perspectives and expertise represented	Do not limit the knowledge and expertise available to you by excluding one form (lived experience); instead broaden perspectives and viewpoints and in turn limit bias associated with narrow viewpoints.	PR15, PR57
Synthesise robust knowledge through generative dialogue	Integrate perspectives, forms of expertise, and epistemologies through open and generative cross-stakeholder dialogue. " <i>Facilitate generative dialogue to allow us to access and combine the different experiential, academic, theoretical and 'biomedical' knowledges held to different degrees by different individuals within the authorship team.</i> " [PR33].	PR33, G74, G92
Foster active and equitable partnerships	Involvement is an active process, " <i>based on principles of partnership, collaboration, fairness, and transparency</i> " [G56], and necessitates equity between stakeholders as well as collaborative and inclusive approaches.	PR40, PR52, PR60, PR62, PR64, G2, G7, G56, G62, G72, G79, G80, G81, G92
Address power imbalances	In industry-patient partnerships, power imbalances often persist. Those working with patients must actively and continuously work to understand and address such imbalances through prioritising equity. Enabling, empowering, and equipping patients with equal opportunities and capabilities to increase their influence and power. At the same time, address the other side of the dynamic by educating clinicians/academics/pharma on the value of patient expertise and prioritising working with such stakeholders who have demonstrated understanding and willingness to share equity.	PR7, PR33, PR39, PR52, PR58, PR64, G12
Create environments for meaningful participation	Hold space for meaningful participation by fostering a non-judgmental and comfortable environment, where individuals can feel empowered and safe to raise perspectives of concern or disagreement.	PR7, PR14, G81
Demonstrate equal partnership through authorship	Within a research or project team, ensure that patients are full and equal partners by giving them a voice in the literature.	PR58
Embed inclusivity throughout all processes	Inclusion is a " <i>critical foundation for building trust</i> " [G76]. Make inclusivity explicitly embedded within policies, practices, and processes.	G10, G76
Meet patients where they are at	" <i>To achieve successful patient engagement, we must adapt our processes to make them work for the patient</i> " [G68].	G56, G68, G71, G78
Build relationships between team members	Relationships are fundamental to teamworking. Invest time and effort into cultivating friendly and respectful long-term relationships between and across team members.	PR47, PR52, PR54, G23, G31, G32, G69, G78
Be aware of and sensitive to challenges that patients are facing	When working and cultivating relationships with patient authors, be cognizant of the fact that they are likely facing health challenges that may affect their work and availability and be prepared for such challenges to impact timelines.	G23, G70, G75, G93, G100
Build trust in relationships	Fostering trust and confidence in relationships and processes leads to more open and honest working relationships.	PR52, G23, G48, G76
Meet in-person on occasion, where possible, to improve rapport	When and where possible, the opportunity to meet face-to-face can be beneficial for building rapport in relationships.	G54
Be proactive in initiating new relationships with patients	Publication professionals and patient engagement professionals should be proactive in their outreach to new patient relationships.	G66

Encourage all team members to reflect on and share their positionality	To help establish bidirectional trust, all team members should reflect on their positionality, expertise, and motivations and be transparent about this with their team members	PR17, PR47, PR52, G76, G89
Consider being honest and transparent around own struggles	Where appropriate and with consent, help patients feel less alone in the process by sharing others' struggles	G48, G69
Listen actively	Undertake active listening of the voices and perspectives of patients to understand their priorities, experiences, and needs.	PR33, G10, G62, G81
Respect and honour all voices	Demonstrate active listening through authentic engagement of all voices and perspectives at the table.	PR14
Communicate clearly and transparently	Be " <i>transparent and communicative in ways you may not normally be</i> " [G69], tailoring communication practices – e.g., tone and frequency – to different stakeholders to keep everyone engaged. Clear communication is critical for building long-term relationships.	G56, G69, G74, G78
Consider accessibility and sensitivity	Consider accessibility needs and accommodations needed to enable participation	G71, G81
Include language-based accommodations	Accessibility accommodations must include considerations for individuals with low literacy or limited English language proficiency to contribute meaningfully in a language or format that suits their needs.	PR17
Follow health literacy principles	An important element of inclusive language is considerations for health literacy and following good health literacy principles.	G69, G71, G76
Be aware of language preferences among patient communities	Show cultural awareness by being mindful of and sensitive to language preferences, specific to the patient community at hand.	PR33, PR54, G13, G30, G49, G68, G76
Use multimedia and audiovisual resources	To improve accessibility and engagement, use videos, infographics, and audio snippets.	G76
In general, prioritise virtual engagements over in-person	Minimise travel and financial burdens of access by utilising virtual meeting technology as much as possible, recognising that a balance is necessary to build in-person relationships without excluding those unable to attend.	PR39, PR62, G68
Optimise diversity and representation	Aim for meaningful and diverse representation of patients and of other stakeholders involved. Specific aspects and characteristics of diversity to prioritise will depend on individual projects. Consider factors such as geographic location (country and urbanicity); Indigeneity; receipt of healthcare and social services; socioeconomic status and social deprivation; experience, expertise, and skills; sex and gender; LGBTQ+ identification; age; employment; education; clinical characteristics and comorbidities; race and ethnicity. For therapy area-specific projects, aim for representation that reflects the real-world patient community.	PR3, PR10, PR14, PR19, PR55, PR57, PR63, G1, G10, G13, G28, G29, G54, G56, G68, G75, G81, G92
Understand that patients are not a homogenous group	When considering representation, keep in mind that " <i>patients are individuals and not a homogenous group</i> " [G71]. Understand that individual patients cannot speak for entire communities.	G71, G81
Translate materials into other languages where needed	Enhance internationality and global representation – support the inclusion of non-English-speaking patients by translating materials and providing interpreters or using app-based event translation services.	PR34, G30, G54, G69
Raise visibility and awareness of patient authorship	Continue to establish and cement best practices through increased visibility and awareness of patient authorship as a standard and precedent activity.	PR63, G2, G61, G71, G72, G81
Share learnings	Encourage others to engage with patient authorship by sharing learnings, recommendations, and best practices.	PR11, PR39, PR63, G15, G49, G56, G70, G93
Thank patients and show gratitude for their contributions	Whether an author, peer reviewer, steering committee member, or advisory board participant, or another role patients should always be explicitly thanked for their contributions.	PR19, PR51, G4, G10, G18

ABPI, Association of the British Pharmaceutical Industry; BMJ, British Medical Journal; CIHR SPOR, Canadian Institutes of Health Research Strategy for Patient-Oriented Research; CRediT, Contributor Role Taxonomy; EFPIA, European Federation of Pharmaceutical Industries and Associations; EQUATOR, Enhancing the QUALity and Transparency Of health Research; G, grey and unindexed literature; GPP, Good Publication Practice; GRIPP, Guidance for Reporting Involvement of Patient and the Public; ICMJE, International Committee of Medical Journal Editors; IFPMA, International Federation of Pharmaceutical Manufacturers and Associations; ISMP, International Society for Medical Publication Professionals; KOL, key opinion leader; LGBTQ+, lesbian, gay, bi, trans, and queer +; ORCID iD, Open Researcher and Contributor Identification; PAG, patient advocacy group; PEOF, Patient Engagement Open Forum; PFMD, Patient Focused Medicines Development; PLS, plain language summary; PLSP, Plain Language Summary Publication; PMCPA, Prescription Medicines Code of Practice Authority; PPI, patient and public involvement; PPSC, patient publication steering committee; PR, peer-reviewed literature; SOP, standard operating procedure; WECAN, Workgroup of European Cancer patient Advocacy Networks.

Supplementary Table S11. Coding tree and associated citations of conflicting best practices *a priori* secondary analysis.

Conflicting best practice/Code	Associated citations
How should patient authors be identified and affiliated?	
A variety of 'patient author' affiliations are currently in use	PR12, PR24, PR52, PR58, G12, G41
• Evolving language on patient identity	PR26, PR52
Affiliations should identify patient-relevant work	PR12, PR17, PR31, PR39, PR52, PR58, PR49, PR63, G8, G12, G17, G30, G35, G59, G86
• Clear patient identification establishes validity of patient authorship	PR21, PR31, PR39, PR45, PR58, G23, G35
• Clear patient identification serves as public recognition of lived experience	PR12, PR31, PR58, G61, G100
• Consistency in terminology helps future bibliometrics	PR11, PR12, PR24, PR31, PR39, PR58, PR63, G8, G12, G30, G35, G36, G40, G41, G48, G53, G61, G70, G80, G85, G101
Individuals should make an informed choice of affiliation to be reflect their identity	PR17, PR31, PR52, G8, G11, G35, G36, G85
• Individuals can have multiple affiliations	PR17, PR39, G12, G17, G85
• Should affiliations include their day job?	PR8, G17, G35
o Do not include day job affiliations if not relevant to the work	PR6, PR8
o If applicable, affiliation should include patient advocacy groups, patient charities, etc	PR24, PR38, PR45, PR58, G12
• Should affiliations include the research institution or sponsor that involved them?	PR17, PR31
o Affiliating with the research institution or sponsor compromises and obscures the patient perspective	PR17, G35
• Consider anonymity and stigmatising circumstances	PR16, PR17, PR21, PR31, PR47, PR49, PR51, PR52, PR57, PR58, G8, G9, G12, G13, G17, G21, G23, G34, G38, G60, G83, G85
Provide clear internal instructions and journal guidelines for preferred affiliations	PR8, G8, G10, G38
• Academic affiliations should not be required	PR17, PR31, G58
• Some journals use consent forms for publicly identified patients	PR58, G11
Can patient authors be remunerated?	
Non-remuneration of all authors is the norm	PR16, G18, G43, G44, G49, G50, G51, G80, G83, G95
• Remuneration for non-authorship activities prior to publication, e.g. publication steering committee	G42, G43, G72, G83
Patient reviewers (non-peer) are remunerated for their time	G38, G43, G83
Patient peer reviewers are often and should be remunerated for their time	PR20, PR21, PR26, PR51, G3, G4, G11, G34, G99, G102
Patient authors should be remunerated for their time	PR8, PR16, PR26, PR33, PR47, PR57, G9, G10, G20, G35, G42, G49, G51, G73, G75, G80, G82, G85
• Non-remuneration of patient authors creates selection bias	PR25, PR33, PR47, PR53, G3, G11, G20, G49, G85
• Good Publication Practice does not prohibit remuneration	G26, G51, G83
• Have clear compliance and conflict of interest processes for remuneration	PR8, PR63, G9, G10, G18, G20, G21, G23, G42, G82, G94, G101
• Payment value should be reasonable	PR53, G20, G75
o Fair market value for remuneration	G42, G81, G85
• Consider not remunerating if affiliated with a research-adjacent institution (multiple hats)	PR57
Alternative methods of recognition	PR20, PR51, PR53, G42, G48, G51
Companies must establish clear internal policies about remuneration	G49, G51, G84
• Be transparent with patients about remuneration policies	G16, G48, G72, G76, G85
• Explicit and transparent travel and expense reimbursement policy	G10, G48, G54

G, grey and unindexed literature; PR, peer-reviewed literature.