

Making the case for payments to nonsalaried Patient Authors



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1. Introduction

Patients may be viewed as the author, co-author or potential author of the events which make up their own life¹, the medical notes that accompany their contact with healthcare professionals², teaching materials that train those healthcare workers, patient-facing information about disease and its treatment, and scholarly articles reporting scientific study. This paper is about the last of these items.

Patient Author Rebecca McNaughton, who has contributed to the co-production of this paper, states:

“Patient Authors of scholarly articles reporting scientific study enable a paper’s relevancy and reach. Patient Authors bring a range of transferable skills, often disregarded through the lens of ‘patient’, and those who are new to academic writing can complete training³ and expect support from their professional peers. A ‘critical friend’ approach by Patient Authors facilitates challenges to outdated academic norms in terms of a paper’s formality, language, visuals, focus and content. Essentially, the real lives of Patient Authors breathe life into what can otherwise read as anodyne content presented in a dry and often inaccessible way. Patient Authorship is good for the paper. And it’s good for the Patient. Both of which surely motivate genuine co-production throughout the research process.

The UK’s National Institute for Health and Care Research insists that the research it funds is coproduced with people who have lived experience of the issues under scrutiny, that payments can be offered for coproduction activities, and that coproduction includes the co-authorship of academic papers reporting the findings of the study. This broad coproduction task is referred to here as Patient and Public Involvement and Engagement, the people who engage are Public Contributors, the money is called a Patient and Public Involvement (PPI) payment, and nonsalaried Public Contributors who are named as authors of the academic papers arising from the study are called Patient Authors⁴.

The policy imperative requiring coproduction is not always matched in practice. Many commentators have observed that research institutions commonly have inadequate systems for recognising Public Contributors and making appropriate and timely PPI payments to them, so Patient Authors often fall foul of these broader failings⁵. Nonsalaried Patient Authors should be offered a PPI payment for their efforts⁶, since researchers and some manuscript reviewers⁷ also receive payment for their writing. Worries arise when there is a perceived conflict of interest, especially if the payment comes from a pharmaceutical company and the article is submitted to a medical journal⁸.

This resource paper explores practices in respect of PPI payments for Patient Authors and exposes attempts at justification mounted by academic teams who prefer not to offer them. We look at what individual published papers can tell us about the conduct of research teams in relation to PPI payments for Patient Authors. Reporting on PPIE is often missing entirely or vague⁹, so we might guess that it will be hard to find specific examples where Patient Authors are engaged and offered a PPI payment. In one example, a Patient Author was offered a PPI payment for her work on the manuscript, but this was omitted from the paper itself and the Patient Author chose to keep this matter private.

One might argue that PPIE activities are extremely varied and so remuneration for any specific task is unlikely to be reported in the literature, whether it be Patient Author, Co-Applicant, Collaborative Data Analyst or anything else. This may be the case for Patient Authors Chambers and Reaume who were reimbursed for their time spent on the study¹⁰, with no hint that authorship tasks were excluded from the payment regime. But dare we make that assumption? As the old aphorism has it, absence of evidence is not evidence of absence. With these caveats in mind, this resource paper is founded on the idea that there is something distinctive about co-authoring academic publications

which makes it worth checking. The confluence of academic ambition, publication ethics, managerial pressure and perhaps even fear or envy might have the unintended effect of denying Patient Authors the offer of PPI payments, so transparency is necessary.

Rebecca shares her experience:

When I accept an invitation to co-author an academic paper, and to therefore make a contribution in which I write, review, edit and advise, I now do so only on the understanding that I will be fairly reimbursed for my time and competency, in the same way as academic and/or clinical authors. I expect the paper to clearly explain the ways in which the research team has managed payments for Patient Authors and welcome a choice of payment: I reject the notional and singular offer of a gift voucher asking, "Can I buy my weekly groceries or pay my gas bill with this?"

This resource paper collates insights from 38 published papers where Patient Authors have written alongside academics and been offered PPI payments for doing so.

A note on terminology: We would have preferred to use the title 'Public Author' in acknowledgement that these issues reach beyond health into social care and the wider community. However, the growing international movement to recognise Patient Authors is weakened by the inconsistent use of keywords¹¹, so it is better to support it rather than add to the confusion by insisting on our own preference.

This paper highlights the activities of the patient authors, with traditional citations relegated to endnotes¹².

Recommendation #1

Always use the term 'Patient Author' in your manuscript and explain it. If there are none, explain why. Indicate whether unpaid family carers are subsumed into this group.

2. Executive summary

1. We found 38 occasions when Patient Authors had published academic papers and been offered PPI payments for their contribution to the manuscript.
2. Existing guidance, policy and practice offers many encouragements and no substantive reasons why PPI payments should be denied to Patient Authors.
3. Patient Authors should register with ORCID and use their identification.
4. A good positionality statement reveals both lived and academic experience, enabling readers to understand the work more thoroughly.
5. Explain what Patient Authors did in relation to the creation of the paper.
6. Offer a PPI payment to nonsalaried Patient Authors for their manuscript-related activities.
7. Publish in an open access journal so Public Contributors can read the work.
8. Involve Public Contributors in reviewing local policy and practice surrounding PPI payments for Patient Authors and base in the light of the findings reported in this paper.

3. Why pay nonsalaried Patient Authors?

As Rebecca stated above, "It's good for the Patient Author and it's good for the paper." Patient Authors bring a valuable contribution as outsiders with an independent voice. Papers which included Patient Authors are more likely to be available as open access and more likely to have a plain

language summary, enhancing opportunities for public understanding. Similarly, there are indications that publications which include patient authors are more likely to be downloaded and gain higher attention scores¹³. Patient Authors can represent a broader range of patient experience, enjoy freedom from formal obligations towards the university, eagerly ensure that non-academic citizens find the work accessible and free of jargon, and, as Citizen Ethicists¹⁴, test the moral foundations of the work.

Benefits for patients. As Patient Author Carol Rhodes wrote:

*“in my experience many patients and researchers go above and beyond what is asked of them, because they sincerely believe that patient involvement is an absolute must for good rigorous... research that can go on to be implemented to improve patients’ daily care.”*¹⁵ Benefits to the patient form the prime driver for authentic health research.

Recommendation #2

Include Patient Authors in your writing team.

Benefits for the Patient Author can include a positive impact on recovery¹⁶, acquisition of new transferable skills, validation, and career progression. This will only happen if the context provides an implicit commitment to these goals from all involved in health care. A consistent approach to paying for time, whether that is in attending an advisory group meeting or reviewing and commenting on a draft manuscript at home, generates a sense of fairness and respect for the Patient Author.

Benefits for the academic author. Cobey’s survey¹⁷ of journal Editors-in-Chief found several that noted the advantages of creating an equitable relationship between patients and researchers. Working together as co-authors has the potential to reduce power differentials. Van Schelven et al¹⁸ confirm that PPI payments, “increases their commitment to their tasks and the project, and thereby clarifies mutual expectations about roles and responsibilities.”

Benefits for the paper. Payment promotes promise: “If I’m paid, I’ll commit to doing and investing in ‘a good job’ and therefore the paper gets ‘the best of me’. Otherwise, tokenism is met, perhaps, with tokensim. Public Authors improve the paper’s relevancy and therefore people’s motivation to read it. The ‘real life’ content complements scientific material, bringing the paper to life and adding life to the paper! A ‘critical friend’ approach facilitates challenges to outdated academic norms in terms of paper formality, language, visuals, focus and content. Patient Authors introduce creative ideas to help with disseminating the research findings to audiences that extend beyond academics and clinicians to the public, including patients and carers. They call for summaries, zines, and social media that take the findings to the spaces patients and carers occupy in their daily lives.

Benefits for the publisher. Cobey et al’s survey mentioned above found 13 Editors-in-Chief who asserted that patient authors make a positive contribution to the work they publish.

4. Take a whole system approach

Before we jump into a discussion of PPI payments for nonsalaried Patient Authors, it is helpful to define a healthy systems approach. This consists of five inter-related aspects, as shown in the diagram. Working on just one will have limited benefit, while a coherent approach will lead to investments in one area delivering benefits in another. Each approach has limitations which can be compensated for through adopting another approach alongside it, strengthening the overall result. For example, employing people with lived experience is good, but may not bring the robust challenge that can be delivered by nonsalaried persons.



4.1. Employ staff with lived experience

A journal article¹⁹ was coauthored by four people who included a positionality statement in their text. This explained that Patient Authors Ashley N Ng, Tessa-May Zirnsak and Catherine Brazier were employed as teaching and research academics and identify as having health related conditions, while the study was instigated by Richard Gray, who does not identify as a lived experience researcher. Five points arise from this example:

1. We might hope that the universities where these Patient Authors work have made reasonable adjustments and accommodations to their training, recruitment and promotion mechanisms to ensure that people living with health conditions are proportionately represented across their workforce²⁰. A simple example of the necessary steps occurs when the Personal Specification for ordinary vacancies includes relevant lived experience as a desirable element in job candidates.
2. We could celebrate the workplace culture that makes it acceptable for these patient authors to declare rather than hide their health status.
3. We observe that lived experience of a health condition exists alongside and in dynamic relationship with professional training and expertise, each informing and challenging the other so that these 'dually qualified' staff add a vital contribution to the research effort. In another example, Patient Author Julie Wray used her lived experience of cancer to enrich the paper²¹, whilst also being employed in a university School of Nursing.
4. Receiving a salary may be considered as a reason to forego any entitlement to a PPI payment, or the university may welcome this additional income and deploy its staff to work on this authorship task, taking the income but not enriching the employee. If their contract of employment permits, the employee may decide to undertake the work in their own time and keep the money for themselves. Or the research funder may limit their offer of PPI payments to anyone who is nonsalaried, thus disqualifying salaried authors from entitlement.
5. We note a distinctive contribution which was not made in this case – that of nonsalaried Patient Authors. Such individuals could have represented a broader range of patient experience. Moreover, they would have been free of formal, contractual obligations towards the university, eager to ensure that non-academic citizens found the work accessible and free of jargon, and, as Citizen Ethicists²², able to challenge the moral foundations of the work.

Recommendation #3

Instead of conflating identities, use multiple affiliations for authors, so one writer can identify as a salaried researcher employed by the university and Patient Author, while another can identify as member of the Lived Experience Advisory Panel and Patient Author.

Patient Author Susannah Pashley is employed in the NHS and brought lived experience to her research team²³. We might speculate on why Tom Shakespeare, who is a Professor of Disability Studies, has achondroplasia and uses a wheelchair, made no reference to this in a recent paper²⁴.

4.2. Create salaried roles for Experts by Experience

Patient Author Sue Marks is not an academic staff member but holds a contract with the University as an Expert by Experience to participate in research projects and provide a lay person's perspective. She received a wage for her time spent on the study²⁵.

Alison Faulkner embodies an alternative way to engage with research organisations. Whilst her co-author Sarah Carr was employed at a university (bringing lived experience alongside her academic credentials), Faulkner was contracted as a lived experience consultant and paid for the work commensurate with other contracted staff engaged to consult to the university²⁶.

Opportunities arise beyond the university too. The BMJ contracts with, commissions work from, and pays freelance patient editors including Patient Authors Amy Price and Emma Doble²⁷. Patient Authors in Canada are described as 'paid Family Faculty' which may mean that they have clinical roles²⁸. Stella Lawrence is both a Patient Author²⁹ and a Lead Support Worker in mental health services, an approach that is increasingly utilised in mental health, addiction services, offender management and elsewhere.

4.3. Distinguish PPI Facilitators from Patient Authors

Recent years have seen a surge in jobs where staff are employed to engage, support and inform Public Contributors. Such workers have some knowledge of community development strategies, skills in promoting the public understanding of science and a working knowledge of research methods. Some have lived experience of a health condition or social care issue. Their role as a salaried emerging profession distinguishes them from nonsalaried Patient Authors.

Patient Authors³⁰ Ian Hobday, Chris Satchwell, Sarah Smith and Sarah Taylor acted alongside academics and Heather Parsons, the PPIE Facilitator for the study. Elsewhere, Patient Author Margaret Stanley was initially appointed as a Lay Researcher and then the role was renamed as PPIE Coordinator³¹ in recognition of her work. Patient Author Anthony Cope was already an experienced Public Contributor when the research team developed a research partner role and appointed him to the post to liaise with a wider group of patients and contribute to writing the manuscript³². These innovations help to create a personal and career development pathway.

4.4. Partner with other organisations

Some research projects work in partnership with charitable or patient-led organisations and find that this can improve recruitment to the study and enhance the adoption of recommendations.

Maddie Copley is affiliated to the charity Age Concern, joined the Advisory Group and became co-author of a paper on dementia³³. If 'affiliated' means she was employed by Age Concern, then she may have been advising the research group within her work time and not been entitled to any PPI payments. However, alternative arrangements are possible. The study team may have decided to offer a PPI payment anyway and the charity may have received it as a donation to offset the time and costs of deploying their staff member to help the research. Moreover, she may have been employed by Age Concern as a person with lived experience and therefore be speaking out from both her personal lived experience and her role as a professional service provider. There were no other co-authors on this team who might have been Patient Authors. Meanwhile in Madrid, Patient Author

Constance Colin is employed as General Coordinator of the Phelan-McDermid Syndrome Association and so did not draw on PPI payments³⁴.

Some research studies partner with staff who provide health or social care services to research participants³⁵. While Patient Author Begonya Nafria-Escalera is employed as Head of Patient Engagement in Research at a hospital in Barcelona and so does not draw on PPI payments³⁶, her colleague, Patient Author Joan Chantrell was offered PPI payments for co-authoring their paper alongside two care home managers and ten academics³⁷. Clinical and care staff count as legitimate stakeholders alongside the academic team but are distinct from the next group – nonsalaried Public Contributors.

Sometimes the research team find that their own organisation is unwilling to create effective systems for paying Patient Authors themselves and so the research team responds by outsourcing the arrangements. For example, a Patient Author was offered support and payment for her work on two manuscripts³⁸ by the Race Equality Foundation who then invoiced the research institution in line with payment rates set by the research funder.

4.5. Engage nonsalaried Patient Authors

People with lived experience of the topic being studied, along with carers, have a distinct contribution to make to the design and delivery of research. As we have seen, some appear in the professional workforce as academic researchers, whilst others are nonsalaried and may be offered a PPI payment, honorarium or gift card in recognition of their contribution. As this group are not contracted to work for the research institution, a service provider or a charity, they bring a valuable contribution as outsiders with an independent voice. They can get involved in all stages of the research production pathway, including co-authorship of academic papers but are generally not research participants in the study, as they coproduce the research rather than contribute data.

In common with their salaried counterparts, nonsalaried Public Contributors who get involved in activities related to the production of a manuscript must meet the standard requirements for academic authorship. For example, Patient Author Monira Ahmed Chowdhury joined her colleagues in declaring “All authors attest they meet the ICMJE criteria for authorship”³⁹.

A free online training course is available for Patient Authors, co-created with Patient Authors⁴⁰. It supports both manuscript writing and good publication practice to help Patient Authors who might otherwise inadvertently fail to comply with these principles. In the first module, participants are introduced to the notion of conflicts of interest and the need to disclose both financial and nonfinancial interests.

Recommendation #4

Seek out and use learning materials that equip Patient Authors for their task.

5. Make decisions together about writing

Section 3 above covered the various ways by which people with lived experience may become Patient Authors of a scholarly manuscript which reports the findings of a research study. Next, we close in on the role of the Patient Author by addressing some key decisions, including the choice of journal, selection of authors, ranking and acknowledging their standpoint in relation to the topic being studied before moving on to the actual tasks involved in drafting, editing and submission. These themes are discussed in the paragraphs below.

5.1. Select a journal

Research findings should be available to all, pressing research teams to favour the journals listed in the Open Access directory⁴¹ unlike the paper that purported to promote racial inclusion in research⁴² but was hidden behind a paywall, inaccessible to ordinary citizens.

Lobban and team⁴³ found that papers which included Patient Authors are more likely to be available as open access and more likely to have a plain language summary, enhancing opportunities for public understanding. Similarly, there are indications that publications which include patient authors are more likely to be downloaded and gain higher attention scores⁴⁴.

Journal articles listed on Google Scholar or PubMed, published between 01 January 2026 and the date shown in the footer below and containing a relevant usage of the acronym PPIE formed our initial sample of 147 papers. There has been significant progress in recent years, as shown by the fact that 91% of these papers (n=134) of these papers were open access, with just a handful restricted to people able and willing to pay for them⁴⁵. This sample was boosted by the addition of older, relevant publications to create a convenience sample of 339 papers, of which 310 (91%) were open access.

We hoped that journals would welcome contributions from Patient Authors and indeed found that Patient Authors were named and identifiable on 190 (61%) of the 310 open access papers, with these papers found in 69 different journals. Two journals accounted for 46% of the 190 papers (*Research Involvement & Engagement* published 52 of these papers and *Health Expectations* another 35). Whilst these two journals occupy a significant leadership position, we conclude that the practice of welcoming Patient Authors is widespread.

Recommendation #5

Always choose an Open Access journal for your submissions.

5.2. Identify Patient Authors

Resources are available to provide general advice⁴⁶, clarify the role of the Patient Author⁴⁷ and show that they must meet the same publication standards as their academic colleagues⁴⁸. Co-authoring arrangements between academic authors and Patient Authors is a growing but still rare phenomenon in scholarly publications⁴⁹, but it is clear that Patient Authorship is more than writing a Plain Language Summary⁵⁰, although few journals have an appropriate policy⁵¹. Colomer-Lahiguera et al's 2023 review of PPI in cancer research found that a third of the included studies had patients as co-authors⁵² while a review by Vanneste et al considered trials published between 2015 and 2023 and found only around 10% of articles reporting PPI included a PPI co-author⁵³. Even where PPI or Patient Authorship is the main topic of the paper, remuneration is not often mentioned⁵⁴.

Standards in scientific reporting require authors to be identifiable so that matters of integrity can be examined. Meanwhile, Patient Authors have the right of anonymity if the study topic is sensitive and publishing their identity could precipitate harm⁵⁵. The decision to disclose or obscure identity should be considered carefully, unlike the unfortunate example where Patient Authors Entwistle, Suleman and Tysall are only identified as such if one happens to find the right webpage and apply some local knowledge⁵⁶. Others⁵⁷ have noted the difficulty in identifying patient authors in the corpus of academic research and recommended the standardisation of reporting conventions⁵⁸ to facilitate searches.

Individual patient authors can be partially anonymised when the name of their group is listed amongst the authors rather than the individual names of group members, such as the Young People's Advisory Group⁵⁹. Elsewhere, in what might be an oversight, two Patient Authors were offered PPI payments for editing the manuscript⁶⁰ and surely appear in the author list but remain unidentifiable. In contrast, Brenda Smith and Jan Speechley are listed as Patient Authors and then appear for a second time in the Acknowledgements section of their paper⁶¹. The CARESS Team comprised ten

Public Contributors and is listed as a corporate author, with all members named individually in the acknowledgements section of their paper⁶², and two of their number, Paul Swindell and Stuart Menzies, also appear as individual Patient Authors.

The decision to identify as a Patient Author is not usually made once for all, but rather fluctuates with context, research topic and audience, in the same way as many other factors affecting personal presentation. For example, Alicia Hilderley is listed as a Patient Author in one 2025 publication⁶³ and a postdoctoral researcher in another⁶⁴. Her explanation below⁶⁵ highlights the importance of offering payment, even when it is declined:

“My role on both papers was a patient partner with lived experience in oncology, but this work also overlaps with my role as a postdoctoral researcher. I decline remuneration when my patient partner time can be considered as part of my postdoctoral salaried time. This is the case when I’m contributing to work about patient engagement and/or clinical trials. When my time as a patient partner is in my personal time outside of work, I do accept remuneration. This is the case when I’m partnering on projects related to my lived experience that are unrelated to my postdoctoral scope.”

Action is needed to correct for the lower status and power experienced by nonsalaried Public Contributors in contrast with their academic colleagues which is expressed as differences in: income; tenure, socialisation into the academic community; access to the symbols of power such as a parking place, door key, ID badge, desk and email address; identification with a stigmatised health condition; and familiarity with jargon. These inequalities are exacerbated when Patient Authors are outnumbered by academic authors – our sample of 310 open access papers lists a total of 3158 authors, of whom only 475 (15%)⁶⁶ were listed as Patient Authors⁶⁷.

One way to support people in this environment is to engage two or more Patient Authors rather than expect a lone voice to be heard. In our sample of 190 papers that were co-authored by one or more Patient Authors, almost half (35%) were coauthored by a single Patient Author acting alone, as was the case for Patient Author Faisan Awan who joined a team of 26 academics⁶⁸. In contrast, Patient Authors Joletta Belton, Savia de Souza, Trudy Flynn, Alex Haaggaard, Linda Hunter, Amy Price, Dawn P. Richards, Sarah Riggare and Janice Tufte were each offered an honorarium for working together on a paper⁶⁹ alongside just three academic colleagues⁷⁰, no doubt creating a culture that was friendly towards lived experience.

Recommendation #6

Wherever possible, include two or more Patient Authors in the writing team.

A second way to build competence is to invite a Patient Author to carry forward their learning from one paper into a second co-authorship experience. Of our 387 unique Patient Authors, 51 (13%) had two or more papers to their name in our sample.

A third and perhaps debateable way to reduce power differences with academic colleagues is to engage high status Patient Authors rather than unremarkable citizens. A paper⁷¹ about birth trauma was published by a team of academics working with Patient Authors Zenab Barry (Senior PPI Officer), Daghni Rajasingam (Consultant Obstetrician), Rachael Buabeng (Founder of Mummy’s Day Out) and Nina Khazaezadeh (interim Chief Midwife for London).

Cooksey et al⁷² and Van Schelven et al⁷³ confirm that Patient Authors were involved but, as no attribution or explanation is given, they are either ghost writers or anonymised within the larger group of coauthors.

ORCID is the most frequently used index for uniquely identifying authors who have contributed to an academic publication, although take-up remains low and Patient Authors are half as likely to use an ORCID ID compared to their academic counterparts⁷⁴. Our sample of papers identifies 387 unique Patient Authors, of whom 33 have given their ORCID ID, including Trishna Bharadia, Jan Geissler and

Laura Porter⁷⁵. Fifteen of these 33 Patient Authors appear on ORCID as senior salaried professionals, leaving us wondering if early career researchers need support to declare their patient status, and if nonsalaried Patient Authors need support to register and deploy strengths-based descriptors. Indeed, Scott and colleagues⁷⁶ recommend that:

“Training, support, and financial reimbursement [be] provided to support people to become co-authors (including administrative support e.g., set-up of ORCID).”

Few academic publishers pay authors for their work, but when books and journals are sold, lent by libraries or sections are photocopied, sometimes some of the money belongs to the author. The [ALCS](#) and [PLR](#) can collect this money and send it to authors as long as the publisher is based in the UK and the work is not deemed to be open access. In 2025, ALCS distributed £35 million amongst almost 110,000 authors. It may be interesting to survey Patient Authors to find out if they have been encouraged to register with ALCS⁷⁷ and claim royalties.

Recommendation #7

Encourage Patient Authors to obtain and use an ORCID ID and register with ALCS.

5.3. Consider author ranking

Maxine Whitton is identified as the Consumer Lead Author on her paper⁷⁸ and takes the prestigious place as first author, as does Sandra Paget⁷⁹ and Sue Marks⁸⁰. Elsewhere, Patient Authors Mary Newburn and Miranda Scanlon are listed as first and second authors on their paper⁸¹, five members of a Patients Council appear as the first five authors on their paper⁸², and Patient Author Sylia Bailey is honoured as last author⁸³.

5.4. Make a positionality statement

We have already seen that it is helpful to indicate whether academic authors bring lived experience alongside their academic credentials, as in the case of Patient Author Dr Susanti Susanti who has co-authored a research paper⁸⁴ on bowel cancer, survived treatment for it, and defended a PhD on this disease. The same principal of disclosure applies to academic achievements, as shown by Patient Author Nuno Pinto, who listed her PhD, and her Patient Author colleague Katrin Hugendubel who listed her MSc⁸⁵. This stimulates reflection about stereotypes and diversity amongst Patient Authors.

Recommendation #8

Include a positionality statement that describes the whole team of authors.

Beyond educational achievement, broader descriptions may help in recognising the standpoint of authors. Patient Authors Hoens, McQuitty, McKinnon and English are described⁸⁶ as Caucasian women with an arthritis diagnosis, previous experience of engaging in health research and members of an Arthritis Patient Advisory Board. Patient Author Garrity is described⁸⁷ as a woman with cerebral palsy, 18 years old and completing her final year of school (the age and stage of her co-authors is not given!). Patient Authors Åsa Månsson D’Souza, Johanna Sörensen, David Hill and Carolin Viklund “worked or studied in various fields but none of them had a background in healthcare or health related research.”⁸⁸

Marion Cowe and Diane Munday were Patient Authors, and perhaps part of a larger team of co-researchers. Their paper⁸⁹ blends disclosure and anonymity by reporting that one co-researcher had a child with Cystic Fibrosis, one had diabetes, one had arthritis, and two had cared for a family member with dementia, but it is not clear how Marion Cowe and Diane Munday relate to these unattributed descriptions. Similarly, Jim Mann, Annette Berndt, Christine Wallsworth, Neil Horne and Mario Gregario were Patient Authors on a paper alongside academics⁹⁰. Two contributed as

Patient Authors and three as carer authors, but these important aspects of their identity, position and contribution were not attributed to named individuals, perhaps to maintain a measure of confidentiality.

Positionality affects all stakeholders in the research, whether it be in relation to affluence, gender, life experience or social roles. A clear statement provides the background context for the narrower ‘conflict of interest’ statement, of which more below.

5.5. Describe what the Patient Authors did

*“The expectations of me as a co-author were clear, I had time to complete my work”.*⁹¹

Patient Author Kristian Röttger Gonzalez was involved in the conception and development of an evidence map, in the interpretation of findings, and in writing the manuscript along with academics⁹². Patient Authors Susanne Geneser and Marie Lykke Rasmussen contributed to the study concept and design and contributed with critical revision of the manuscript⁹³. Service User Authors Ernie Mallen and Angela Melling ‘were integral in the synthesis and interpretation of this data and were involved in several discussions about the content, findings and format of the final manuscript⁹⁴.’ Patient Authors Alun Toghill and Christopher Garnsworthy⁹⁵ were invited to join academic colleagues for a total of three Writing Days to address, respectively, the dissemination plan, academic outputs and the final study report.

Patient Authors Alison M Hoens, Annette M McKinnon, Shanon McQuitty and Kelly English ‘assisted in writing our paper⁹⁶ by reviewing an early draft and providing feedback. They were offered an honorarium to acknowledge their contributions consistent with current Canadian guidance’. Similarly, Patient Authors JoAnne Mosel, Sandra Moroz and Tayaba Khan ‘provided feedback on the final manuscript⁹⁷ and all participants were provided with an honorarium.’

Patient Authors Åsa Månsson D’Souza, Johanna Sörensen, David Hill and Carolin Viklund were “paid for their participation in project meetings and time working with assignments” which shows that agreed solitary tasks could have been remunerated, although the text⁹⁸ does not explicitly declare that these authors’ manuscript-related tasks were included in the payment regime. Similarly, a group of Patient Authors were paid for their time, but the manuscript⁹⁹ does not explicitly state that this included their co-authorship activities.

Patient Author Susannah Pashley is salaried and so was not offered PPI payments, but the paper quantifies her contribution by declaring that her “feedback resulted in at least 20 changes to the manuscript”¹⁰⁰. A further step in coproduction of the academic manuscript is provided by Patient Authors Clara Martins de Barros and Carole Lamouline, as shown in the following table¹⁰¹.

	Patient Authors		Academic authors			
	CL	CMDB	AP	MAH	NM	PB
Conceptualisation			•			
Write the first draft			•			
Edit the first draft	•	•		•	•	•
Write the second draft	•	•				
Final revision		•	•	•	•	•

The process of patient-led writing can go yet further, as illustrated by Patient Authors Molly J. Halligan, Aerin E. Thompson, Destiny Docherty, Patricia Kelly and Emma Pryde who collaborated with one another to produce the manuscript¹⁰² “with no direct input [from academic or clinical colleagues] except for the abstract, clinician summary, and formatting of the study”.

The Patient Authorship Experience Self-assessment Tool offers an opportunity for Patient Authors and their academic colleagues to give structured feedback across eight domains¹⁰³.

6. Address financial matters

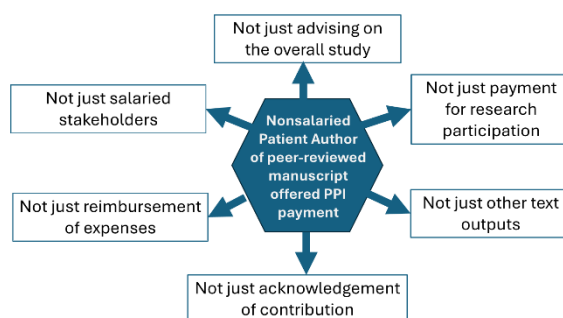
PPI payments need to be thought about well in advance of the writing task, so that funding is available, expectations are managed successfully and people are treated with respect. This involves clarity about the nature of payments and conflicts of interest, alignment with guidance and development of a local position which is sufficiently flexible to address the complexities of real life.

6.1. Clarify what PPI payments are

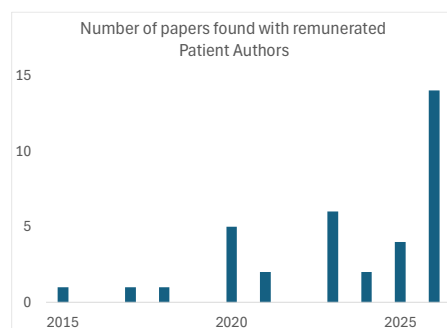
“Participating [as a co-author] in this commentary has been an enormous benefit to me and my family through my role with paid (hourly) work. This allows me to feel like an equal collaborator, not simply a consultant, and helps me justify my time away from my family. This experience not only benefits me financially but also helps maintain my participation in the workforce.”

Candice Barrans, Parent Partner, writing in Pietramala et al 2026¹⁰⁴.

PPI payments are offered to nonsalaried patients rather than other stakeholders, such as professionals working in third sector organisations. They are separate from payments offered for research participation, This paper is about payments for authorship, not just for broader involvement in coproducing the research. A PPI payment for authorship activities is made in relation to an academic paper which is published to report the findings of the research, and this is separate to payments received for other text-based coproduction activities on the study, such as commenting on the wording of the Patient Information Sheet or the content of an interview topic guide. Being listed as an author is separate from being recognised in an acknowledgement statement or testimonial¹⁰⁵. PPI payments are separate from reimbursement of out-of-pocket expenses, such as travel or care costs; and are payments, not gift cards or biscuits.



This search has so far identified 38 open access papers published anytime that included one or more Patient Authors who were offered a PPI payment in respect of their contribution to the manuscript. A glance at the correspondence author’s email address reveals that eleven were produced in Canada, one in Denmark, one in Australia and the remaining twenty two were produced by seventeen different universities in the UK. The practice seems to be spreading.



6.2. Declare conflicts of interest and mitigation

Patient Authors Julie Marker and Nikki Davis were offered payment and confirmed that ‘All authors declare that they have no known competing financial interests or personal relationships that could

have appeared to influence the work reported in this paper¹⁰⁶. This broad statement was time limited by Patient Authors Caroline Crandell, Jack Jaques and Katy Pickles who declared that they had “no financial relationships with any organizations that might have an interest in the submitted work in the previous three years.” A different approach was taken by Patient Authors Annie Banham, Fiona Hale and Mo Christie who declared “support for attending online meetings as a patient representative” as a competing interest.

The welfare benefit and social care system can create conflicts of interest for an author who receives payment for their writing. Back in 1988, an American polio survivor called Paul Longmore depended on a ventilator and was unable to use his hands, so needed a care assistant and support package that cost around \$20,000 each year. He spent ten years writing a ground-breaking book by holding a pen between his teeth and using it to punch the keys of his typewriter. His book received critical acclaim, and he hoped to earn \$10,000 in royalties. When he found out that the royalties would disqualify him from all welfare, he publicly burned his book as a protest¹⁰⁷. In response, the American Social Security system was changed by the ‘Longmore Amendment’ but many disincentives remain embedded in the welfare systems of the USA and elsewhere.

The International Committee of Medical Journal Editors (ICMJE) has published a standard Disclosure Form and Professor Woolley has suggested some responses that Patient Authors might wish to consider¹⁰⁸. It provides a practical way to help all authors (not just Patient Authors) be transparent about their financial and nonfinancial interests.

It is common for a team of authors to make a declaration like this one, “All the authors have read and approved the manuscript before submission.” Where research teams are invoking the CREDIT guidance¹⁰⁹ to award co-authorship to Public Contributors who have been involved in other stages of the research whilst releasing them from any duties in relation to the manuscript, then they should not be obliged to read and approve the manuscript, and this affirmation needs to be confined to the people who do so.

Academic papers generally conclude with a declaration of financial or commercial interests. In one of the published papers in this sample¹¹⁰, an academic author declared a financial relationship (consulting, advisory and funding grants) with no fewer than 16 pharmaceutical companies, with a second author of the same paper declaring 12 such relationships, yet without censure. This hints at the following possibilities:

- This publisher was unusually lenient, or
- As long as such interests are declared, there is no problem
- High status academic authors are valuable to publishers as they help with circulation, while Patient Authors may be subjected to more scrutiny.

The most explicit statement yet found in a paper in our sample asserted, “The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors disclose receipt of financial support for the research, authorship, and/or publication of this article from the research funding body.”¹¹¹

None of the Patient Authors cited in this paper have reported their remuneration for work on the manuscript as a ‘financial interest’, perhaps in the same way that salaried researchers do not declare that they have been paid in accordance with the Universities’ National Pay Framework in the UK¹¹² or its equivalent elsewhere. Meanwhile, Richard Stephens, Patient Author, quite properly acknowledged that he was also co-Editor-in-Chief of the journal in which his paper appeared¹¹³.

A wider point that might be raised here concerns the range of competing interests which Patient Authors might hold. Senior academics are much in demand by pharmaceutical companies, conference organisers and the like, while Patient Authors may be less in demand and only rarely invited to take up these prestigious roles. Lead researchers may make an unspoken assumption that Patient Authors have few, if any interests which should be considered and perhaps acknowledged, and so not discuss the question of conflict of interest with their Patient Author colleagues. The research team may have reached well beyond the intellectual elite in society in order to properly gather an outsider view and quite legitimately involve Patient Authors who have little financial, intellectual or commercial capital.

"Indeed, because professional affinities and rivalries, nepotism, scientific or technological competition, religious beliefs, and political or ideological views are often the fuels for our passions and for our careers, private competing interests are perhaps even more potent than financial ones¹¹⁴.

6.3. Understand the guidance on PPI payments

"Can we compensate patient participants and patient advocates for time spent in publications activities?"

Yes. Compensation may be offered at a reasonable rate for participation in publications activities, including, but not limited to, Steering Committee membership, reviewing manuscripts and/or plain language summaries, and travel to meetings."

Good Publication Practice 2022

While the position set out in GPP grants permission – ‘compensation may be offered’ rather than ‘must be offered’ – it is notable that there is plenty of guidance recommending that payments are offered to Public Contributors and this declaration makes it clear that there is no reason to treat authorship activities differently to other roles along the research production pathway.

The UK’s National Institute for Health and Care Research has issued guidance on payment rates¹¹⁵ (which is not very actively enforced¹¹⁶) and made the following comment about its application to Patient Authors:

"Public contributors and research teams can have a discussion around the time/effort needed for this task and come to an agreement on where this falls within the payment rates guidance. As an example, the Research Delivery Network has recently recruited a public member to be co-author on an upcoming publication and we agreed upfront an amount of £330 using the guidance. This will of course be reviewed once the task is underway to assess if there are any additional tasks or extended time input required and the amount adjusted accordingly."¹¹⁷

Reporting frameworks for PPIE (such as GRIPP2) omit the issue of payment, so it is necessary to go further than they care to go.

6.4. Adopt a position on payment rates

Recommendation #9

The following recommendations could form a guide when setting out a position on payment for Patient Authors.

Offer PPI payments for manuscript-related activities carried out by nonsalaried Patient Authors.

1. **Make a declaration of principle** as Vanderhout has done: 'In all publications¹¹⁸ I have worked on with patient partners, they have been offered compensation (beyond reimbursement) in the form of gift card or cash honoraria for their time spent on the project/research itself, plus time spent co-authoring the paper.' Patient Authors Carole Lamouline and Clara Martins de Barros¹¹⁹ benefitted from clarity at the Policy Research Unit (PIRU) where the policy specifically includes "reading, reviewing and contributing to documents" as activities eligible for PPI payment, set at £35 per hour¹²⁰.
2. **Apply the principle consistently** across all academic outputs. Isabel Andrews, Steve Fallon, Ali Gibson, Trevor Jones and Heather Peacock are all Patient Authors on the ROWTATE study¹²¹, and, in a consistent approach across nearly a dozen papers arising from the study, were offered PPI payments for all their manuscript-related activities. When this fails, it is important to admit the fact and restate the goal. Thus Patient author Garrity was "remunerated for some but not all her time due to available budget and aspects of the work were completed in a voluntary capacity", and the manuscript¹²² reaffirms that payment is imperative.
3. **Comply with guidance.** Patient Author Eileen Davidson was offered payments "in line with NIHR guidance", a statement which did not declare the exact sums involved¹²³. We might remark that this could be matched by a statement indicating that salaried staff were paid in line with the Universities' Agreed salary framework, whilst not publishing the exact sums involved to retain a measure of confidentiality for the recipients.
4. **Specify funding sources.** Patient Authors Victoria Abbott-Fleming and Sarah Greaves were paid from a budget embedded in the funding award for the study¹²⁴, based on NIHR guidance and which compensated them for their time as Public Contributors. In Canada, Patient Authors Anne Marie Edmonds and Tom Porter reported that, "Patient partner honoraria and expenses were provided by SCPOR."¹²⁵
5. **Decide on who can be offered PPI payments.** As nonsalaried Public Authors, Trudy Flynn, Linda Hunter, Allan Stordy and Christine Thomas were offered an honorarium for their involvement in developing and writing their paper¹²⁶. This was in line with Canadian guidance¹²⁷ which offers \$C200 per 2-hour meeting paid as either cash or a gift card to nonsalaried authors. Meanwhile, in Pakistan, "All members of the PPIE group... will be compensated for their time and travel... [others] will not receive compensation, as their participation will occur during their regular working hours."¹²⁸ In the UK, Patient Author Justin Greenwood was offered an Amazon voucher in recognition of his review and comments on the initial draft of the paper and a revision¹²⁹.
6. **Consider whether to offer a fixed sum** irrespective of time, task or productivity, or an hourly rate. The undefined term honorarium is sometimes used. Patient Authors Annette M McKinnon, Shanon McQuitty and Kelly English "received honoraria for the time they spent on contributing to the writing process, including time spent in discussing ideas, writing, editing, and commenting on the paper¹³⁰." Patient Authors Sue Boex, Yvonne Diment, Richard Grant, Jim Leach and Uma Sharma were each offered £20 per hour plus travel expenses for their involvement as co-researchers in data collection, analysis, facilitation of focus group and dissemination and all authors read and approved the final manuscript¹³¹. Similarly, parent partner Candice Barrans was offered an hourly rate for her 'Patient' Authorship¹³². Mia Tackney offered an hourly rate to nonsalaried Patient Authors, set at two hours for each cycle of manuscript review¹³³, while

the team at PIRU preferred to establish a strong relationship with Patient Authors, trust them to give an honest account of the time they spent on manuscript-related activities and then offer payment for the time declared¹³⁴.

7. **Select the form** in which compensation is to be offered. Shopping vouchers were offered to Cherelle Augustine, Patrick Ojeer and Nordia Willis for their time spent as Patient Authors¹³⁵, and to Patient Author Elga Zivtins for hers¹³⁶. In line with other commentators¹³⁷ we prefer bank transfers. As Victoria Lowers explains:

“We were clear from the outset that we would provide cash reimbursement (not vouchers), alongside travel, parking, and refreshments. As a meeting-based model did not fully capture the contribution of PPIE contributors as ‘experts by experience’, so we offered payment for time spent at the recommended INVOLVE rate (e.g. £75 for a half day). On that basis, patient authorship activities (including drafting, reviewing, and editing manuscripts¹³⁸) were treated in the same way as other contributions. Within the university context, this is broadly comparable to pay for an experienced research assistant, which we felt was appropriate.”¹³⁹

8. **Report the payment offer** in publications. Where payments and reimbursement of expenses are not offered, this should be justified.

Sometimes the link between payment offers and authorship activities is opaque. Patient Authors Alicia Hildersley and Maureen Smith were offered remuneration for their involvement in the overall research project¹⁴⁰ but specific amounts of remuneration were not attributable to specific tasks, so the sums offered for authorship were not defined¹⁴¹. Other papers¹⁴² also reveal that PPI payments were offered and Patient Authors were engaged but fail to define the link or show which tasks attracted payment, permitting authorship tasks to be excluded from the payment regime.

6.5. Recognise complexity

Patient Authors have many intersecting roles which may or may not influence the decision to offer a PPI payment as shown by the following Patient Authors who have listed some of their other roles:

- **Trishna Bharadia** is a member of a patient panel
- **Hilary Garrett** is listed in ‘author affiliations’ as both a Public Contributor and Honorary Researcher. In the ‘conflicts of interest’ section, she appears as Public Advisory Co-Lead with NIHR ARC NW Coast (Equitable Place-Based Health and Care Theme); a public member of the NIHR Health and Care Professionals Doctoral Committee; a public contributor to the Models of Care Workstream for the Cross-NIHR Collaboration on Multiple Long-Term Conditions; a public member of the HDRUK North Executive Steering Board; and a Public Advisor (co-production) for Lancashire County Council Adult Services Policy & Strategic Commissioning and the Social Care Institute for Excellence.¹⁴³
- **Abbie Rance** is employed to liaise with BAME groups and is co-author on a paper¹⁴⁴ reporting on how research can engage with BAME communities.
- **Richard Stevens** receives honoraria for his role as a journal editor
- **Simon R Stones** owns stock options in a pharmaceutical company
- Patient Author **James Turton**¹⁴⁵ has Multiple Sclerosis. He is a registered biomedical scientist and his Orcid entry lists four higher education qualifications, eight jobs and thirty academic publications. He is currently both a Public Contributor and a PPI Facilitator.

- **Karen Woolley** is an Adjunct Professor but was paid as a medical writer on the manuscript¹⁴⁶ at a nominal rate¹⁴⁷

Patient Authors perform a variety of roles, some of which may provide a salary, honoraria or other financial reward. Some local payment policies would offer payment irrespective of the financial circumstances of the recipient, while most exclude people in fulltime employment or who are paid from the public purse.

The matter is further complicated by the overlapping nature of lived experience, clinical care, professional roles, and academic expertise. Three of the journal Editors-in-Chief surveyed by Cobey et al were worried that promoting a study participant to the role of Patient Author would introduce bias into the work¹⁴⁸. A fully qualified researcher may have lived experience of the condition being studied, while the representative of a patient group may be a salaried third sector professional, and the PPIE manager may have related lived experience, full academic credentials or expertise in community engagement and the public understanding of science. Sometimes the description of arrangements is clouded by muddled language, as in the case of the the study by Wort et al, where ‘public partners’ who coproduced a cluster of ten studies were rebadged as study participants and then offered a PPI payment for completing a questionnaire, but the resultant paper did not include any Patient Authors.

7. Lower barriers to making PPI payments to Patient Authors

“I sat in this meeting, and this professor was talking about altruism. I could have hit him. I wonder if he is altruistic when he negotiates his salary? And I’m not talking about huge salaries, I’m talking about feeling treated like an equal.”¹⁴⁹

Some research teams choose not to offer a PPI payment to Patient Authors, perhaps for one or more of the reasons shown in the table below. For some, these views may not emerge in response to the idea of engaging Patient Authors, but only when the possibility of payment is raised.

Topic	Claim	Response
Private	The offer of PPI payments is a private matter which is nobody else’s business.	Fair point. However, PPIE payments usually come from the public purse. If privacy means most people get nothing and practice remains shrouded in mystery, then this is embarrassing to the scientific community.
Spam	Journals insist on publishing email addresses of all authors, whereupon Patient Authors are bombarded with unwanted spam from predatory journals.	Not true. In our sample of papers on PPI, where the average paper has 9 authors, 87% contained only one or two email addresses ¹⁵⁰ .
Sensitive	Patient Authors prefer to remain anonymous as their disclosure of lived experience would attract censure.	Explain this in the paper so that obscuring Patient Author identity is not misread as a failure to give recognition.

Topic	Claim	Response
Fraud	Patient Authors are assumed to be defrauding the welfare benefits agency or tax department, so academic colleagues collude by denying payment or keeping payment details out of public view to protect them.	Attend to the integrity of your own profession. Test and discard stereotypes in favour of data. Explain the reporting obligations incumbent upon Patient Authors.
Malicious State	Any attention drawn to Patient Authors will destabilise precarious welfare benefit arrangements so best not to risk paying or publicising details.	Ensure Patient Authors make an informed decision for themselves, rather than academics deciding on their behalf.
Willing volunteers	Some Patient Authors are willing to write for nothing, so no need to offer payment.	This arrangement excludes people on modest incomes.
Waste	Lean thinking demands every project penny is spent on essentials. Unless the funder insists on the paper, the Patient Author and the payment, cut it out.	Confirm that funders are willing to assign funds to offer PPI payments to Patient Authors. Restore curiosity as a driver of research endeavour by encouraging the whole team to waste time being creative. Apply discipline across all activities and all stakeholders to achieve equity.
Gratitude	Public Contributors have been offered PPI payments for other things they have done, so they owe the research team some free labour. In the past, some Public Contributors have refused the offer of payment ¹⁵¹ , so we don't need to offer it.	While some Patient Authors refuse the offer of payment, we do not know how many do so or the reasons why. Has a climate been formed that subtly expects people to refuse the offer? Refusal by some does not justify withholding the offer from all.
Financial interest	<p>Publishers are suspected of rejecting any manuscript where PPI payments have been made to Patient Authors because they fear the payment will create bias.</p> <p>Two research teams found by Fox et al (2023)¹⁵² reported that they deliberately did not offer financial compensation to ensure patient partners were free to express their thoughts without any pressures associated with receiving payments.</p>	<p>PPI payments might be compared to the salary of an academic, which is not viewed as a cause of bias. Excessive payments would be deemed coercive, whomsoever received them.</p> <p>A statement could be included at the end of the manuscript stating that UK academic staff were paid in accordance with the Framework Agreement for the Modernisation of HE Pay Structures (2003) while Patient Authors were offered remuneration in line with NIHR guidance.</p>

Topic	Claim	Response
Price inelasticity	Public Contributors are eager to become Patient Authors, so academics can cynically reduce the payment to zero without reducing demand for the role.	It may be true, but it isn't ethical.
Product promotion	Where pharmaceutical or medical device manufacturers are funding the research, payment may be viewed as an exchange for product promotion.	Keep payments modest – fair market value. Declare and take steps to mitigate potential conflicts of interest.
Price setting	It is too hard to set a price on an activity that might be rushed in a few minutes or take many hours, so £0 is the easiest solution.	There are many other PPI activities (reviewing patient-facing documentation, preparing for meetings, planning a speech) that are hard to set a price on, but we do so.
Cash handling	Getting the money to the Patient Author is tricky.	Patient Authors to register with ALCS to obtain publication royalties.
Timing	Most writing is done after the study has formally closed ¹⁵³ and budgets have been locked. ¹⁵⁴	Respect timing preferences and periods when Patient Authors or academics may be unavailable ¹⁵⁵ . This timing issue can leave academics with the feeling that they are writing in their own time rather than as part of the funded study. This is true for other dissemination activities too. The system for the administration of grants needs to enable PPI funds to be offered when they are needed ¹⁵⁶ .
Inadequate systems	Our research organisation has not yet developed good systems for authorisation and timely payments to Public Contributors, irrespective of their role and contribution. Patient Authors are casualties of these wider failings.	Create a system that is fit for purpose.
Overtime	Overwork means that salaried academics are obliged to write in their 'own time', so Patient Authors should be treated the same.	Workload pressure on academics is not a reason to treat Patient Authors badly. Wage levels for academics are considerably higher than the PPI payments offered to Patient Authors.
Creativity	Employees have their best ideas in the shower and the best writing partnerships arise from unexpected chemistry between people which cannot be demanded, regulated or remunerated.	Acknowledge that some great work will always be done beyond the contract of employment or supervision of managers. Some papers will be unfunded as they are voluntary coalitions. Despite this, payment should be made offered whenever possible.

Topic	Claim	Response
Volunteer	Academics advance through voluntary additional activities beyond their core roles, so Patient Authors should match these additional duties.	Patient Authors are already contributing as non-contracted volunteers.
Attitude	Academics don't really believe that Public Contributors are making a comparable contribution, so are unwilling to share the status and rewards of authorship ¹⁵⁷ . At heart, some people simply oppose the engagement of Patient Authors.	Attend to the evidence that diverse research teams do better work ¹⁵⁸ and that patient-authored publications gain better attention scores (such as the <i>h</i> -index ¹⁵⁹). Encourage honest discussion but be prepared to insist.
Writing is unique	Other PPI activities (such as creating Patient Information Leaflets) attract PPI payments, but writing for the academic press requires scientific training and knowledge of publication ethics which Patient Authors do not have.	A diverse team of authors produce better quality outputs ¹⁶⁰ . Review how your whole study design integrates experiential and scientific ways of knowing.
Journal editors	Journal editors fear reputational harm if they publish anything by a Patient Author who has received a PPI payment for their writing.	Find and cite the policy of the International Committee of Medical Journal Editors
Precedent	Researchers and publishers fear being innovative.	Find early adopters (Patient Authors Research Teams and journals) to show that others have done this without difficulty. The guideline ¹⁶¹ for reporting research outcomes does not include a requirement to report on PPI payments.
Leaks	Researchers fear that Patient Authors will disseminate findings before publication ¹⁶²	Explain why confidentiality is required.
Fragile patient authors	Payments emphasise the obligation to deliver a credible piece of work, and this is assumed to be just too much pressure ¹⁶³ . We release patients from such a burdensome expectation by paying nothing.	Ask people if their lived experience has made them fragile or resilient. Create options for the Patient Author to accept or decline the offer of payment.

Topic	Claim	Response
Corruption	<p>People who want paying are the wrong sort of human and so should be excluded.</p> <p>Many examples¹⁶⁴ of misuse of authorship ethics can be found in the academic community so insist on higher standards from Patient Authors.</p>	<p>If pay corrupts, then stop paying staff. As Marc Ewen has stated: “Payment isn’t bias. Power imbalance is.” This becomes a debate about PPI payments in general¹⁶⁵ rather than PPI payments specifically for Patient Authors. Aim for co-production on the basis of equity rather than extractive approaches which retain academic power.</p>

8. Conclusion

It is highly unusual for academic papers to clearly state whether Patient Authors have been offered a PPI payment for contributing to the creation of an academic, peer-reviewed paper. However, we have found thirty papers that have made this clear. None consider the offer of payment to be a conflict of interest, just like the routine receipt of a salary is not listed as a conflict by their academic counterparts. In passing, we noted that Patient Authors are half as likely to use ORCID as their academic counterparts, that positionality statements are rare and vague, and that we simply do not know¹⁶⁶ if the warm glow of success felt by academics following publication burns as brightly in the hearts of patients and the public. Maybe Patient Authors would rather pocket the cash and bask in the warmth of knowing that they have improved the patient experience for others.

We hope these inquiries will unearth more examples of Patient Authors, published papers and journals that have offered payment as a sign of respect for the dignity of the Patient Author, rather than an accusation that they would sell their souls for a few pieces of silver.

How this paper is being written

The investigation that generated this paper is driven by simple curiosity. The work is unfunded and is conducted as a piece of citizen science rather than under the control of any organisation. Accountability is achieved by following the *Writing in Public* framework¹⁶⁷. We are grateful to the people¹⁶⁸ who have contributed to this evolving resource but bear responsibility as authors for the text appearing here¹⁶⁹. Please send your suggestions for further improvements.

Weaknesses of the approach taken in this exploration include the lack of prospective ethics oversight from a Research Ethics Committee, which would offer an independent opinion before commencement, the absence of a formal confidentiality and anonymity protocol, and prior informed consent from participants about attribution and how their contributions will be presented. These matters could be repaired if an academic team took up the challenge of investigating payments for Patient Authors.

Appendix 1: Locating and listening to the experts

*International Committee of Medical Journal Editors*¹⁷⁰ requires that:

- authors have agreed on the final version and have made a substantial contribution to at least one of the following:
- research conception and design, acquisition of data, or analysis and interpretation of data - or
- drafting the article or revising it critically for important intellectual content.

The secretary of ICMJE made an informal statement about payments to Patient Authors in 2018¹⁷¹. Richards et al¹⁷² offered advice on how the ICMJE guidelines should be interpreted in relation to Patient Authors in 2020 but said nothing about compensation beyond the bland remark that it will matter to some people. In 2021, Coby et al¹⁷³ found nothing further from ICMJE.

International Society for Medical Publications Professionals (ISMPP¹⁷⁴) Good Publication Practice guidelines (GPP 2022)¹⁷⁵ made their position clear in their Frequently Asked Questions¹⁷⁶ as shown in the box above, and the need for clearer guidelines when setting compensation levels for Patient Authors has been further reinforced by Bharadia et al¹⁷⁷.

Other infrastructure organisations that may influence publication practice include the: [Council of Science Editors \(CSE\)](#), [European Association of Science Editors \(EASE\)](#), [Asian Council of Science Editors](#), [World Association of Medical Editors \(WAME\)](#), COPE International Standards for editors and authors.

Academic Journals. Not all journals have an authorship policy, and of those that do, not all align with the ICMJE guidance¹⁷⁸. Authorship practices are applied inconsistently across disciplines¹⁷⁹ and not all researchers consider the guidelines to be realistic or fair¹⁸⁰. Cobey et al's survey of 112 editors-in-chief of medical journals carried out in 2020 found that almost a third of editors did not consider it appropriate that Public Contributors should co-author academic papers, just four of the journals had a policy on the matter, while sixteen stated that their journal had published a paper with a patient or patient partner as an author or co-author in the last 12 months.¹⁸¹ Some journals may include an occasional paper to give a patient perspective, whilst excluding Patient Authors from other types of paper. Attitudes may have changed. Nicholls et al (2025) observed that reporting of remuneration is not a requirement of any guidelines, while Gray et al¹⁸² found that nursing science journals generally did not require PPIE to be reported at all.

PPIE pioneers include: UK – the National Institute of Health and Care Research (NIHR); USA – PCORI; Canada – SPOR¹⁸³ and CIHR¹⁸⁴; Australia – NHMRC; Europe – EUPATI.

Local policymakers. Fox and colleagues¹⁸⁵ located and analysed 65 policy documents related to compensation for patient partners and found that 95% suggested payment be offered to Public Contributors and none opposed it. This review does not go into detail about payments for Patient Authors.

The PatientsIncluded Charter for Journals¹⁸⁶ requires that research be open access, and that editorials or articles authored by patients frequently appear.

Guidelines on research methods. The following guidelines are intended to either shape the conduct of research or offer ways to report on or evaluate the impact of PPIE on research studies: 4Pi¹⁸⁷, CONSORT¹⁸⁸, COREQ¹⁸⁹, EDGE¹⁹⁰, PEIRS¹⁹¹, PiiAF¹⁹², PPEET¹⁹³, PRISM and SPIRIT 2025¹⁹⁴. None of them say much about payments to Patient Authors.

In contrast, the ACTIVE framework devised by Pollock et al¹⁹⁵ to describe stakeholder involvement in systematic reviews specifies Patient Author involvement in writing and publishing the research protocol (stage 3) and in writing and publishing the results of the study (stage 11). PIRIT¹⁹⁶ has been used to evaluate the experiences of co-authors¹⁹⁷.

GRIPP2¹⁹⁸ was devised to guide reporting on patient and public involvement in health research, and this standard has been subject to critique¹⁹⁹ and says little about payments for Patient Authors. Nicholls and colleagues²⁰⁰ surveyed published papers on health research and found 316 that cited either GRIPP or GRIPP2²⁰¹ in their report and actively engaged patient partners²⁰². This group would have included many research teams committed to coproduction. Almost half of their papers (49% of the 316) included Patient Authors, but only a quarter (n=79) reported that remuneration was offered. Although remuneration was offered, and the recipients included Patient Authors, the relationship between these two variables is not elucidated so we cannot be entirely sure that they were offered payment for authorship activities²⁰³.

Appendix 2: Search strategy

An alert was placed on Google Scholar²⁰⁴ to capture all papers published after 01 January 2026 that referred to PPIE. Any papers which used the acronym for another purpose²⁰⁵ were removed from the sample along with single-author papers, such as PhD theses, leaving those written by a team. The text of resulting papers was searched for relevant material using the following search terms: £, \$, fee, gift, vouch, expens, honor, compens, remun, reim, pay, paid, consumer, author, writ, manuscript, NIHR, PPI, PPIE. Reference lists in the paper were also scrutinised in a search for older, relevant material.

The following email message was sent to the corresponding author as soon as their paper was included in this dataset²⁰⁶. The aim is to locate specific examples of papers where Patient Authors have joined the writing team, find out if they have been offered payment, and track some of the lessons for future practice. Here is the email message.

“Dear Researcher

I see that you are the corresponding author for a recently published paper entitled....and that your team of co-authors included one or more nonsalaried Patient Authors (sometimes called Patient Authors, people with lived experience, experts by experience or Public Contributors).

I am trying to find out whether research teams offer PPI payments for Patient Authorship, and why they choose to pay, or choose not to do so. This is not about whether you offer PPI payments for Public Contributors who attend an advisory group, review other documents, collect or analyse data, or speak at a dissemination event (the indirect activities that legitimise the person being eligible to be a co-author). I am trying to locate examples where Patient Authors have been offered a PPI payment for the time and effort involved in drafting, reviewing, commenting, editing and/or submitting the manuscript.

I appreciate that these are sensitive matters, as you balance obligations towards the funder, devise creative ways to engage with non-academic colleagues, meet publication ethics requirements and uphold privacy rights for Patient Authors, but I hope you or the Patient Authors you have worked with will be able and willing to share with me what happened on this matter during the production of your paper.

As my investigations continue, I will continue to update my draft report on this topic, which anyone can freely access at <https://peterbates.org.uk/wp-content/uploads/2026/01/Making-the-case-for-PPI-payments-for-Public-Authors.pdf>. This is an unfunded bit of citizen science, driven by curiosity and a wish to see Patient Authors being appropriately recognised for their knowledge, skills and efforts.

Finally, may I thank you for publishing in partnership with Patient Authors and invite you to send me any reflections or comments on this topic which will enrich this evolving paper.”

So far, a version of the above email has been sent to 96 corresponding authors and 33 (34%) have kindly responded. If information from their response was used in this report, a further email was sent to them seeking consent or inviting revision. One corresponding author replied, “*now you have highlighted the issue we will ensure this is considered in the future.*” In contrast, Patel et al²⁰⁷ received replies to only 14% of their email inquiries asking authors if there was PPIE in the trial that had not been reported in the manuscript.

Appendix 3: Typologies of PPI activities

Public Contributors may engage in many different activities in the knowledge production journey, from being nominated as co-applicants in the funding application, through sitting on an advisory board or the Trial Management Group, to data collection, interpretation and publication.

Evans et al²⁰⁸ offer a typology of PPIE activities, but the closest (item 22: “Sharing knowledge from a research study (e.g., helping write up the results)”) is still broader than the role of the Patient Author.

Vanneste et al²⁰⁹ break it down a little further by distinguishing:

- Phase 1, 2 and 3 – pre-trial planning, trial development and trial execution.
- Phase 4 – Post trial reporting
 - 4.1. Writing study results
 - 4.2. Reviewing study results
 - 4.3. Study implementation
 - 4.4. Study dissemination
 - 4.5. Lay language summary

¹ See, for example, Razban F, Mehdipour-Rabori R, Rayyani M & Mangolian Shahrabaki P (2022). Meeting death and embracing existential loneliness: A cancer patient’s experience of being the sole author of his life. *Death Studies*, 46(1), 208–223. <https://doi.org/10.1080/07481187.2020.1725932>

² Fischbach RL, Sionelo-Bayog A, Needle A & Delbanco TL (1980) The patient and practitioner as co-authors of the medical record. *Patient counselling and health education*. Jan 1;2(1):1-5.

³ Training is available at <https://wecanadvocate.eu/publicationstraining/>.

⁴ A weighty case has been made for the adoption of the metatag ‘Patient Author’ in citation indexes as this will help to identify papers and their authors. I have abandoned the broader term ‘Public Author’ which would have included people who draw on social care, family members and other citizens who would not consider themselves to be patients. The point is trivial in comparison to the merit of being able to identify Patient Authors. See, for example, Oliver J, Lobban D, Dormer L, Walker J, Stephens R, Woolley K. Hidden in plain sight? Identifying patient-authored publications. *Research Involvement and Engagement*. 2022;8(1):12.

⁵ This includes funding bodies who open and close budget availability at the wrong times, research teams who fail to plan their PPIE activities, Research Ethics Committees who burden Public Contributors with requirements appertaining to Research Participants or staff, Research Departments who deny Public Contributors access to NHS patients, and Finance Departments who delay timely payment or refuse to pay.

⁶ Smith E, Bélisle-Pipon JC & Resnik D (2019) Patients as Research Partners; How to Value their Perceptions, Contribution and Labor? Citizen Science: Theory and Practice. *Citizen Science*. 4(1). **Also** Souleymanov R, Kuzmanović D, Marshall Z, Scheim AI, Mikiki M, Worthington C, Millson M. The ethics of community-based research with people who use drugs: results of a scoping review. *BMC medical ethics*. 2016 Apr 29;17(1):25.

⁷ “From January 2025, [The BMJ will remunerate patient and public reviewers](#). Patients and members of the public who complete a review for The BMJ will be offered £50 or a 12 month online subscription to one of the BMJ journals as a thank you for their service.” Doble E, Schroter S, Price A & Abbasi K (2024) The BMJ will remunerate patient and public reviewers *BMJ*; 387 DOI: <https://doi.org/10.1136/bmj.q2581>.

⁸ Payment may encourage Patient Authors to promote their financial sponsor or its products in the text. One study found readers to be more sceptical of articles with declared pharmaceutical industry involvement (see Chaudhry S, Schroter S, Smith R, Morris J. Does declaration of competing interests affect reader perceptions? A randomised trial. *BMJ*. 2002; 325:1391–1392). This scepticism is justified, as some parts of the pharmaceutical industry have biased scientific reporting to favour of their own commercial interests (Langdon-Neuner, E. (2008). Medical Ghost-Writing. *Mens Sana Monographs*, 6(1), 257–273 available [here](#). It has been reported that Dr Andrew Wakefield received nearly half a million pounds from the legal establishment in connection with his campaign to link MMR and autism that included publishing falsified evidence – see Boyce T (2007) *Health, Risk and News: The MMR Vaccine and the Media*. More recently, Dr. José Baselga admitted he had received over \$3 million from the private sector yet disclosed none of these connections in his publications – see [here](#).

⁹ In a systematic literature review of PPIE in randomised controlled trials in Otolaryngology research, a total of 346 papers were subjected to full text review and 268 of them made no reference to the presence or absence of PPIE in the study. There is no reference to Patient Authors in either the production of the review or in the ten studies that were eligible for inclusion in the systematic review of findings. Lodhi, S., Kong, D., Linton, S. et al. Patient and public involvement and engagement (PPIE) in Otolaryngology research: a systematic review of randomised controlled trials. *European Archives of Oto-rhino-laryngology* 282, 6005–6015 (2025). <https://doi.org/10.1007/s00405-025-09515-5>. Also Bates P (2022) [The 37 Test](#) shows that despite the UK NIHR policy directive that PPIE is built into all research, it does not appear in all of their funded study protocols.

¹⁰ Bird M, McGillion M, Chambers EM, Dix J, Fajardo CJ, Gilmour M, Levesque K, Lim A, Mierdel S, Ouellette C, Polanski AN (2021) A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework. *Research involvement and engagement*. Mar 1;7(1):12. Also Patient Authors Margaret Ogden and David Lewis were paid for their time spent in meetings and at “the same sessional rate for their work assisting in research preparation and delivery outside meetings”. It would be hard to argue that this excludes manuscript-related co-authorship activities, but the text does not actually confirm their inclusion – see Madden M, Morris S, Ogden M, Lewis D, Stewart D, McCambridge J (2020) Producing co-production: reflections on the development of a complex intervention. *Health Expectations*. Jun;23(3):659-69. Perhaps the most notable example is that of Patient Author Maureen Smith who was offered financial compensation for her involvement in a review of compensation policies, but we must assume that this included manuscript-related activities. See Fox G, Fergusson DA, Sadeknyury A, Nicholls SG, Smith M, Stacey D, Lalu MM. What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines. *Health Expectations*. 2024 Feb;27(1):e13970.

¹¹ Arnstein L, Wadsworth AC, Yamamoto BA, Stephens R, Sehmi K, Jones R, Sargent A, Gegeny T, Woolley KL. Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. *Research Involvement & Engagement*. 2020 Jun 24;6:34. doi:10.1186/s40900-020-00190-w. PMID: 32587753; PMCID: PMC7313171.

¹² This approach is occasionally problematic. Dumbele et al included Patient Authors and ascribed their affiliations to their organisations, whilst making the bare assertion “All were paid for their time.” It is not clear which authors were Patients or if any of them were salaried by the organisations they represented, so we are unable to confidently include this important paper in our collection of examples where nonsalaried Patient Authors were offered a PPI payment for their manuscript-related activities. Their positionality statement is brilliant! Dembele L, Nathan S, Carter A, Costello J, Hodgins M, Singh R, Martin B, Cullen P. Researching with lived experience: A shared critical reflection between co-researchers. *International Journal of Qualitative Methods*. 2024 May 20;23:16094069241257945.

- ¹³ Arnstein et al (2020) op cit. Our sample of papers on PPIE were found in 159 different journals. 69 journals published these papers with Patient Authors; 86 did not. The Journal Impact Factor for those that published with Patient Authors (mean 5.50, median 2.90) was comparable to those that did not (mean 4.89, median 3.10).
- ¹⁴ Bates P & Willis A (2023) 'Ethics, Integrity and Coproduction in mental health research' Chap 7 in O'Sullivan R (ed) *Moving beyond the rhetoric – research with older service users – why ethics and integrity matter*. Brighton: Emerald.
- ¹⁵ Blackburn S, McLachlan S, Jowett S, Kinghorn P, Gill P, Higginbottom A, Rhodes C, Stevenson F, Jinks C. The extent, quality and impact of patient and public involvement in primary care research: a mixed methods study. *Research Involvement & Engagement*. 2018 May 24;4:16. doi: 10.1186/s40900-018-0100-8. PMID: 29850029; PMCID: PMC5966874.
- ¹⁶ Recovery in mental health encompasses Connectedness, Hope and Optimism, Identity, Meaning of Life and Empowerment – known as the CHIME framework. See Omundo J, Stiehl SA, Schulz M, Zingsheim A. CHIME in practice: a qualitative exploration of CHIME framework training experiences and outcomes for service users and mental health professionals. *The Journal of Mental Health Training, Education and Practice*. 2025 May 30;20(3):170-83.
- ¹⁷ Cobey KD, Monfaredi Z, Poole E *et al* (2021) Editors-in-chief perceptions of patients as (co) authors on publications and the acceptability of ICMJE authorship criteria: a cross-sectional survey. *Research Involvement & Engagement* 7, 39. <https://doi.org/10.1186/s40900-021-00290-1>.
- ¹⁸ Van Schelven F, Van Der Meulen E, Kroeze N, Ketelaar M, Boeije H. Patient and public involvement of young people with a chronic condition: lessons learned and practical tips from a large participatory program. *Research Involvement and Engagement*. 2020 Sep 30;6(1):59.
- ¹⁹ Gray R, Brasier C, Zirnsak TM, Ng AH. Reporting of patient and public involvement and engagement (PPIE) in clinical trials published in nursing science journals: a descriptive study. *Research Involvement and Engagement*. 2021 Dec 14;7(1):88.
- ²⁰ Changes to workplace arrangements permit employees to produce the same outputs as every other fulltime worker, while 'low threshold' roles, such as short working hours or reductions in eligibility requirements.
- ²¹ Li, Y., Lu, W., Ho, E.K.Y. *et al*. Patient and public perceptions of involvement and engagement in healthcare research: a descriptive exploratory qualitative study in Hong Kong. *Research Involvement & Engagement* 12, 59 (2026). <https://doi.org/10.1186/s40900-026-00895-4>.
- ²² [Citizen Ethicists – Peter Bates](#)
- ²³ Rutherford R, Pashley S, Heggs D, Bowes N (2024) Exploring the experiences of lived-experience and staff researchers collaborating on a forensic mental health research project. *International Journal of Forensic Mental Health*. 2024 Dec 6:14999013261425674.
- ²⁴ Hunt X, Shakespeare T, Vilyte G, Melendez-Torres GJ, Henry J, Bradshaw M, Naidoo S, Mbuyamba R, Aljassem S, Suubi E, Aljassem N, Makhetha M & Bantjes J. (2023) Effectiveness of social inclusion interventions for anxiety and depression among adolescents: A systematic review. *International Journal of Environmental Research and Public Health*, 20(3), 1895. <https://doi.org/10.3390/ijerph20031895>.
- ²⁵ Marks S, Mathie E, Smiddy J, Jones J, da Silva-Gane M. Reflections and experiences of a co-researcher involved in a renal research study. *Research Involvement and Engagement*. 2018 Oct 29;4(1):36.
- ²⁶ Faulkner A, Carr S, Gould D, Khisa C, Hafford-Letchfield T, Cohen R, Megele C, Holley J. 'Dignity and respect': An example of service user leadership and co-production in mental health research. *Health Expectations*. 2021 May;24:10-9.
- ²⁷ Doble et al 2024, op cit.
- ²⁸ Bainter J, Fry M, Miller B, Miller T, Nyberg A, O'Dell A, Shaffer G, Vernon L (2020) Family presence in the NICU: constraints and opportunities in the COVID-19 era. *Pediatric Nursing*. Sep 1;46(5):256-9.

- ²⁹ Stella Lawrence is employed as a Lead Support Worker. She is a patient author of Hayes D, Camacho EM, Ronaldson A et al (2024) Evidence-based Recovery Colleges: developing a typology based on organisational characteristics, fidelity and funding. *Social Psychiatry and Psychiatric Epidemiology* 59, 759–768. <https://doi.org/10.1007/s00127-023-02452-w>.
- ³⁰ Hough K, Grasmeder M, Parsons H et al (2024) Patient and public involvement and engagement (PPIE): how valuable and how hard? An evaluation of ALL_EARS@UoS PPIE group, 18 months on. *Research Involvement & Engagement* 10, 38. <https://doi.org/10.1186/s40900-024-00567-1>
- ³¹ Lowers V, Stanley M, Hennessy J et al (2026) Layering perspectives: a structured approach to meaningful patient and public involvement and engagement in the RETURN dental trial. *Research Involvement & Engagement*. <https://doi.org/10.1186/s40900-026-00857-w>.
- ³² Lynham AJ, Cope A, Milosevic S, Jones IR, Walters JT. Acceptability of the Cardiff Online Cognitive Assessment for Clinical Screening of Patients With Psychosis: Protocol for a Mixed Methods Study. *JMIR Research Protocols*. 2026 Mar 3;15(1):e84218.
- ³³ Abdelhamid A, Bunn D, Copley M, Cowap V, Dickinson A, Gray L, Howe A, Killett A, Lee J, Li F, Poland F. Effectiveness of interventions to directly support food and drink intake in people with dementia: systematic review and meta-analysis. *BMC geriatrics*. 2016 Jan 22;16(1):26.
- ³⁴ Catalá-López F, Ganuza E, Alonso-Arroyo A, et al. Assessing the impact, uptake and use of reporting guidelines for patient and public involvement in research: GRIPP2 – study protocol for a meta research project. *BMJ Open* 2026;16:e115612. doi:10.1136/bmjopen-2025-115612. Personal correspondence, April 2026.
- ³⁵ Zhao Y, Aunger J, Garrett H, Hewitson P, Davies A, Pareek M, Molyneux S (2026) The 'public' in public involvement: A call to centre frontline staff voices in health workforce research. *Health Expectations*. Apr;29(2):e70616. doi: 10.1111/hex.70616. PMID: 41886695.
- ³⁶ Catalá-López 2026 op cit.
- ³⁷ The correspondence author confirmed (personal communication April 2026) that a PPI payment was offered the Patient Author for their co-authorship of Gasteiger N, Ford CR, Hawley-Hague H, Wilkinson J, Jones D, Whittaker W, Ullah A, Kislov R, Stanmore E, Laverty L, Chantrell J (2026) VR-CARE: a protocol for a mixed-methods study and pilot trial with embedded process evaluation to develop and evaluate virtual reality training for risk reduction in care homes. *BMJ open*. Mar;16(3):e116603.
- ³⁸ Anita Mehay, personal correspondence, May 2026. The papers concerned are Watt RG, Lodder A, Box L, Brand A, Butt J, Crawford M, Heilmann A, Hoare Z, Karlsen S, Kelly Y, Manning K. Effectiveness and cost-effectiveness of a parenting programme to improve family wellbeing in England (TOGETHER): a multicentre, single-blind, randomised controlled trial. *The Lancet Public Health*. 2026 Apr 1;11(4):e233-44. **Also** Mehay A, Box L, Manning K, Lodder A, Patel TB, Clutterbuck D, Butt J, Watt RG. From tokenism to transformation: lessons from the TOGETHER study for building inclusive and equitable research. *Research Involvement and Engagement*. 2026 Mar 30.
- ³⁹ Daniel N, Smith C, Miah N, Akroyd C, Bingham T, Brooks H, Chowdhury MA, Kaur G, Kundra R, Prendergast M, Chantkowski M (2026) Enablers and barriers to participation in vaccine trials: a narrative synthesis. *Vaccine*. Feb 15;73:128183.
- ⁴⁰ <https://wecanadvocate.eu/publicationstraining/>. Broader training has also been developed for academic researchers on working with patient partners – see Tscherning SC, Vedelø TW, Jensen FO et al (2026) Supporting researchers to involve patient partners in health service research: developing and assessing the feasibility and acceptability of a co-produced training programme for researchers. *Research Involvement & Engagement*. <https://doi.org/10.1186/s40900-026-00874-9>.
- ⁴¹ Directory of Open Access Journals – see [Directory of Open Access Journals – DOAJ](#).
- ⁴² Dube A, Ataiyero Y & Jones S (2026) Ensuring racial inclusion in research: the role of research ethics committees and patient and public involvement and engagement. *Evidence-Based Nursing*. Jan 1;29(1):63-4.

⁴³ Lobban D, Boughey A, Stephens R, Stones S & Woolley K (2023) Do patient-experience publications have authors with patient experience? *Current Medical Research and Opinion*, 39(Suppl. 1), 5–39. <https://doi.org/10.1080/03007995.2023.2194075>.

⁴⁴ Elliott C, Oliver J, Manning L, Jenkins R, Walke J & Lobban D (2023) Who are the authors of plain language summaries of publications? *Current Medical Research and Opinion*, 39(Suppl. 1), 5–39. <https://doi.org/10.1080/03007995.2023.2194075>. **Also** Woolley KL, Stones SR, Stephens R, Bharadia T, Yamamoto B, Geissler J, Yang B, Oliver J, Boughey A, Elliott C, Dormer L. Patient authorship of medical research publications: An evolution, revolution, and solution? *Learned Publishing*. 2024 Jul;37(3):e1607.

⁴⁵ In contrast, Scott and colleagues found that 97% of their sample of 523 papers were published in open access journals. See Scott HM, Price L, Ogden M, Bharadia T, Burke P, Horne R, Harding-Bell A, Tonkin A & Thomson A (2026) A rapid evaluation of the reporting and publishing practices of patient and public involvement and engagement in health research within a UK university institute. *Research Involvement and Engagement*. Feb 14.

⁴⁶ Richards DP, Birnie KA, Eubanks K, Lane T, Linkiewich D, Singer L, Stinson JN & Begley KN (2020) Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. *Research Involvement and Engagement*, 6, 38. <https://doi.org/10.1186/s40900-020-00213-6>.

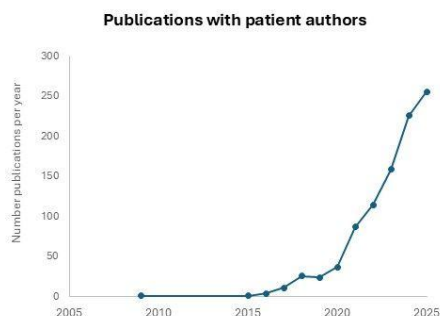
⁴⁷ Bates P (2015) [How to involve the public as co-authors](#). The conditions that Patient Authors need to meet to be counted as an author of an academic paper are set out in International Committee of Medical Journal Editors. Recommendations: Defining the role of authors and contributors. 2025 [cited 2025 Jun 20]. Available from: <https://www.icmje.org/Recommendations/Defining-the-Role-of-Authors-and-Contributors>.

⁴⁸ Pietramala D, Zamma G, Barrans C. *et al* (2026) Giving credit where credit's due - recognition of patient partners in health research. *Research Involvement and Engagement* **12**, 4 (2026). <https://doi.org/10.1186/s40900-025-00817-w>. The CREDIT authorship criteria mean that a Public Contributor may well have contributed sufficiently during the research project to merit authorship and would not necessarily have to actively contribute to writing the paper.

⁴⁹ Vanderhout and colleagues found 69 of the 306 (23%) lead authors who answered their questionnaire indicated that they had involved Patients and the Public in 'writing or reviewing manuscripts' but this does not mean that they were recognised as Patient Authors or remunerated. See Vanderhout S, Nevins P, Nicholls SG, Macarthur C, Brehaut JC, Potter BK, Gillies K, Goulao B, Smith M, Hilderley A, Carroll K (2023) Patient and public involvement in pragmatic trials: online survey of corresponding authors of published trials. *Canadian Medical Association Open Access Journal*. Sep 1;11(5):E826-37. **Also** Vanderhout S, Richards DP, Butcher N, Courtney K, Nicholls SG, Fergusson D, et al. Prevalence of patient partner authorship and acknowledgment in child health research publications: an umbrella review. *J Clin Epidemiol* [Internet]. 2023 Oct 21 [cited 2023 Oct 21];0(0). Available from: [Prevalence of patient partner authorship and acknowledgment in child health research publications: an umbrella review - PubMed](#). **Also** Karen Woolley posted the following charts on her LinkedIn page - [\(1\) Post | LinkedIn](#).

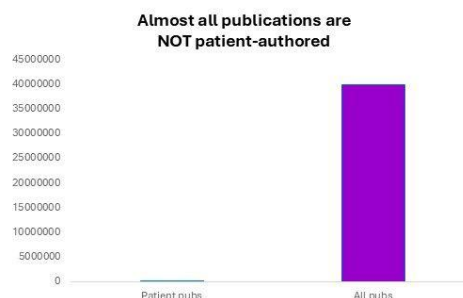
Patient-authored publications

Another record year...
the patient voice is growing louder



N = 878; number of publications in PubMed with “Patient Author” OR “Patient Partner” listed in the Affiliation section. We know this is a conservative count!

Another year of extreme rarity...
the patient voice can barely be heard



Patient-authored publications (n = 878) account for only 0.002% of all the publications in PubMed (N= 39,898,388)

Data from PubMed Advanced Search 31 Dec 2025

⁵⁰ Gainey KM, Smith J, McCaffery KJ *et al* (2023) What author instructions do health journals provide for writing Plain Language Summaries? A scoping review. *Patient* 16, 31–42. <https://doi.org/10.1007/s40271-022-00606-7>.

⁵¹ Resnik *et al* found only 31% of his sample of 600 journals had a policy prohibiting gift, ghost or guest authorship. Resnik DB, Tyler AM, Black JR, *et al* (2016) Authorship policies of scientific journals *Journal of Medical Ethics*. 42:199-202.

⁵² Colomer-Lahiguera S, Steimer M, Ellis U, *et al*. Patient and public involvement in cancer research: a scoping review. *Cancer Med*. 2023;12:15530–43. <https://doi.org/10.1002/cam4.6200>.

⁵³ Vanneste A, Wens I, Sinnaeve P, *et al*. Evolution of reported patient and public involvement over time in randomised controlled trials in major medical journals and in their protocols: meta-epidemiological evaluation. *BMJ*. 2025;389:e082697. <https://doi.org/10.1136/bmj-2024-082697>.

⁵⁴ There is no reference to remuneration for Patient Authors in Geissler J, Ryll B, di Priolo SL, Uhlenhopp M (2017) Improving patient involvement in medicines research and development: a practical roadmap. *Therapeutic Innovation & Regulatory Science*. Sep;51(5):612-9. The US [National Health Council](#) publish a 'Patient Engagement Activities Framework' and a 'Fair Market Value Calculator' but neither include any reference to Patient Authors. Canadian guidance is silent on the specifics of payment to Patient Authors – see [Recommendations on Patient Engagement Compensation](#). The [Fair Patient Engagement Planner](#) created by Envision the Patient (part of Envision Pharma Group) does not include Patient Authors within its list of patient activities or fair market value discussions. Leventhal et al do not mention remuneration in their introduction to patient authors – see Leventhal P, Drachmann D, Skovlund S. Can patients and caregivers be authors of peer-reviewed publications? *Medical Writing*. 2024 Dec 1;33(4). Ocloo and colleagues conducted a systematic review which noted some general issues with PPI payments but made no reference to the role of Patient Author - see Ocloo J, Garfield S, Franklin BD, Dawson S (2021) Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health research policy and systems*. Jan 20;19(1):8. There is no reference to Patient Authors in Lammons W, Buffardi AL, Marks D. Measuring impacts of patient and public involvement and engagement (PPIE): a narrative review synthesis of review evidence. *Research Involvement and Engagement*. 2025 Jul 4;11:76. Nor is the role mentioned in Richards DP, Jordan I, Strain K, Press Z (2018) Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal*. ;5(3):6-12. Miles et al 2022 op cit provide some very useful guidelines on Patient Authorship, co-produced by paid Patient Authors, yet those guidelines say nothing about payment for authorship-related activities. A historic framework for evaluating the quality of public involvement in research includes reimbursement of expenses but not payments – see Boote J, Barber R, Cooper C. Principles and indicators of successful consumer involvement in NHS research: results of a Delphi study and subgroup analysis. *Health Policy*. 2006;75(3):280–97.

⁵⁵ See Bates P (2025) [Should I use a pseudonym?](#)

⁵⁶ Patient Authors in this paper are only identifiable if one goes to [GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research | The BMJ](#) (not the pdf of the published paper) and happens to know that UNTRAP is the name of the patient panel. See Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *British Medical Journal*. Aug 2;358. It is true that many academic authors also appear without acknowledgement of their profession or other characteristics that shape their perspective – making it even more important to include a positionality statement where such influences can be acknowledged.

⁵⁷ 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. **Also** Ellis U, Kitchin V, Vis-Dunbar M. Patient and public partner Authorship on systematic and scoping reviews: an overview of reviews. Cochrane Colloquium. Santiago: Cochrane Colloquium; 2019.

⁵⁸ Leventhal op cit.

⁵⁹ Abrehart N, Frost K, Young Persons Advisory Group, Harris R, Wragg A, Stewart D, Sharif H, Matthews R, Marciani L. "A little (PPI) MAGIC can take you a long way": involving children and young people in research from inception of a novel medical device to multi-centre clinical trial Roald Dahl, James and the Giant Peach (1961). *Research Involvement and Engagement*. 2021 Jan 6;7(1):2. **Also** Osorio F, Garlick B, Weaver-Holding E, McBain C, Thomson D. RAD-PIT: Novel PPIE-driven protocol co-design for the use of Macimorelin as a diagnostic test of pituitary function for patients undergoing proton and photon radiotherapy. *Endocrine Abstracts* 2026 Feb 13 (Vol. 117). Bioscientifica. **Also** Jacques K, Mulligan R, Allerton D, Anderson C, Andrew S, Bates G, Best K, Bibby I, Blackwell J, Cotobal Martin C, Dong C, Ganendran M, Gardner R, Irving PM, Kennedy NA, McCormick S, McGregor N, Megginson A, Parkes G, Patel KV, Prichard J, Saunders K, Speight A, Subramanian S, Stewart C, Young G, Watson H, Lamb CA, Open-IBD Lived Experience Advisory Panel and Open-IBD Collaborators (2026) P1045 The impact of patient and public involvement and engagement (PPIE) on the design and operationalisation of a multi-centre inception cohort study: Insights from Open-IBD, *Journal of Crohn's and Colitis*, Volume 20, Issue Supplement_1, January, jjaf231.1226, <https://doi.org/10.1093/ecco-jcc/jjaf231.1226>

⁶⁰ Two unidentified but remunerated Patient Authors are within the group of authors who produced Abayomi JC, Charnley MS, Cassidy L, McCann MT, Jones J, Wright M, Newson LM (2020) A patient and public involvement investigation into healthy eating and weight management advice during pregnancy. *International Journal for Quality in Health Care*. Feb;32(1):28-34. **Also** An unidentified Patient Author is hidden within the list of authors of Lu W, Li Y, Evans C, Currow D, Bayuo J, Zheng T, Lu Z, Li M, Wray J, Yorke J (2025) Evolution of Patient and Public Involvement and Engagement in Health-Related Research: A Concept Analysis. *Journal of advanced nursing*. Aug 16.

⁶¹ Evans HG, Robinson OC, von Nerée L, Smith B, Yu R, Bellavia E, Speechley J, Walsh J, Stanworth S, Foy R. Defining Patient and Public Involvement and Engagement Tasks in Health Data Research: A Consensus Study. *Health Expectations*. 2026 Feb;29(1):e70578.

⁶² Pearson NA, McGregor G, Sandhu H, Couper K, Bruce J, Swindell P, Menzies S, Ellard DR, Kandiyali R, Ennis S, Patel S. Cardiac Arrest Recovery Enablement and Supported Self-management (CARESS): a study protocol for the feasibility testing of an online psychosocial and exercise rehabilitation programme for cardiac arrest survivors and co-survivors. *Resuscitation Plus*. 2026 Feb 12:101270.

⁶³ Vanderhout S, Taneja S, Nevins P, Nicholls SG, Potter BK, Smith M, Hilderley A, Fergusson DA, Macarthur C & Taljaard M (2025) Patient and Public Involvement in Paediatric Pragmatic Randomized Controlled Trials: A Mixed Methods Study. *Children*, 12(12), 1638. <https://doi.org/10.3390/children12121638>.

⁶⁴ Vurrabindi D, Hilderley AJ, Kirton A, Andersen J, Cassidy C, Kingsnorth S, Munce S, Agnew B, Cambridge L, Herrero M, Leverington E. Facilitators and barriers to implementation of early intensive manual therapies for young children with cerebral palsy across Canada. *BMC Health Services Research*. 2025 Apr 4;25(1):503.

⁶⁵ Personal communication, March 2026.

⁶⁶ This count includes duplicates where one author has contributed to two or more papers.

⁶⁷ This is a count of appearances, so a single author appearing on two papers is counted twice. A count of unique authors appears elsewhere in this paper.

⁶⁸ Reid J, Blair C, Slee A et al (2026) Multi-modal integrated intervention combining exercise, anti-inflammatory, and dietary advice (MMIEAD) for adults with kidney cachexia: protocol for a mixed-methods feasibility cluster randomised controlled trial and process evaluation. *Pilot Feasibility Stud*. <https://doi.org/10.1186/s40814-026-01784-z>.

⁶⁹ Richards DP, Mulhall H, Belton J et al (2024) Co-creating and hosting Pxp: a conference about patient engagement in research for and by patient partners. *Research Involvement & Engagement* 10, 77. <https://doi.org/10.1186/s40900-024-00603-0>. **Also** Richards DP, Bowden J, Gee P, Haagaard A, Kothari A, McKinnon A, Primeau CA, Tricco AC, Wang E, Woolley KL, Li LC (2025). The ultimate power play in research - partnering with patients, partnering with power. *Research involvement and engagement*. Jun 17;11(1):65.

⁷⁰ This is clumsy language, as some of the Patient Authors listed have substantial academic credentials alongside their status as Patient or Caregiver Authors. The point stands.

⁷¹ Bailey EC, Barry Z, Buabeng R, Fellows RE, Khazaezadeh N, Rajasingam D, Silverio SA, Sheen KS (2026) The birth trauma earthquake: A qualitative investigation of first-time mothers who perceived their birth as traumatic. *Women and Birth*. Apr 1;39(2):102171.

⁷² Cooksey KE, Neuman M, Bollini M, Pennington B, de O Campos H, Oberst K, Wurst M, Politi MC (2025) Patient partner engagement in the publication process: challenges and possible solutions. *BMC Medical Research Methodology*. Feb 15;25(1):39. doi: 10.1186/s12874-025-02495-4. PMID: 39955495; PMCID: PMC11829384.

⁷³ Van Schelven et al 2020, op cit.

⁷⁴ In my sample of 339 PPIE related papers published anytime, there are 2683 appearances of academic authors and 475 appearances of Patient Authors (this includes duplicates where one author has published two or more papers) - a ratio of six academic authors to each patient author. These appearances showed that 25% of academic authors used their ORCID ID, compared with only 9% of Patient Authors. In March 2026, ORCID explained how Patient Authors can obtain an ORCID ID: “Anyone who participates in research, scholarship, or innovation can register an ORCID iD for themselves free of charge at <https://orcid.org/register>. by following the detailed instructions regarding each registration step at [How do I register for an ORCID ID?](#) There's no requirement to be affiliated with an organization in order to register. During registration, when prompted to add an organization, individuals may click the Skip this step without adding an affiliation button at the bottom of the page (below the Next step button) to proceed. These data have been added to the ORCID [Community Feedback board](#) where the team will review and prioritize it for action. While our current registration is open to everyone regardless of affiliation, we appreciate there may be a need for more tailored engagement with the Patient Author community.”

⁷⁵ Bharadia T, Geissler J, Robson R *et al* (2025) Seven Actions Towards Advancing Patient Authorship and Collaboration in Peer-Reviewed Publications. *Patient* **18**, 403–414. <https://doi.org/10.1007/s40271-025-00750-w>.

⁷⁶ Scott HM *et al* 2026, *op cit*.

⁷⁷ ALCS is a limited company which harvests royalties for works published in the UK, takes an overhead and then distributes the payments to authors. See [ALCS](#). In 2021, ALCS also began to collect a share of the sale price of second-hand books from certain retailers and to transfer these funds to authors. ALCS members are automatically enrolled in this scheme which is called AuthorSHARE.

⁷⁸ Whitton ME, Pinart M, Batchelor J, Leonardi-Bee J, González U, Jiyad Z, Eleftheriadou V, Ezzedine K. Interventions for vitiligo. *Cochrane Database of Systematic Reviews*. 2015(2).

⁷⁹ Paget S, Pacho A. Access to Inclusion Thinking Beyond Reasonable Adjustments. *Health expectations: an international journal of public participation in health care and health policy*. 2025 Jan 16;28(1):e70157.

⁸⁰ Marks *et al* 2018, *op cit*.

⁸¹ Newburn M, Scanlon M, Plachcinski R, Macfarlane AJ. Involving service users in the Birth Timing project, a data linkage study analysing the timing of births and their outcomes. *International Journal of Population Data Science*. 2020 Nov 2;5(3):1366.

⁸² Taylor J, Dekker S, Jurg D, Skandsen J, Grossman M, Marijnissen AK, Ladel C, Mobasheri A, Larkin J, Weinans H, Kanter-Schlifke I. Making the patient voice heard in a research consortium: experiences from an EU project (IMI-APPROACH). *Research involvement and engagement*. 2021 May 10;7(1):24.

⁸³ Maidment I, Lawson S, Wong G, Booth A, Watson A, Zaman H, Mullan J, McKeown J, Bailey S. Towards an understanding of the burdens of medication management affecting older people: the MEMORABLE realist synthesis. *BMC geriatrics*. 2020 Jun 5;20(1):183.

⁸⁴ McSorley ST, Burton P, Chantler D *et al* (2026) Faecal haemoglobin-based referral and investigation prioritisation is associated with colorectal cancer-specific survival in symptomatic patients: a retrospective observational study. *British Journal of Cancer*. <https://doi.org/10.1038/s41416-026-03378-1>.

⁸⁵ Sherriff N, Zeeman L, McGlynn N, Pinto N, Hugendubel K, Mirandola M, Gios L, Davis R, Donisi V, Farinella F, Amadeo F. Co-producing knowledge of lesbian, gay, bisexual, trans and intersex (LGBTI) health-care inequalities via rapid reviews of grey literature in 27 EU Member States. *Health Expectations*. 2019 Aug;22(4):688-700.

⁸⁶ Hamilton CB, Hoens AM, McQuitty S, McKinnon AM, English K, Backman CL, Azimi T, Khodarahmi N, Li LC (2018) Development and pre-testing of the Patient Engagement In Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. *PLoS One*. Nov 1;13(11):e0206588.

- ⁸⁷ Cavens C, Imms C, Drake G, Garrity N, Wallen M (2022) Perspectives of children and adolescents with cerebral palsy about involvement as research partners: a qualitative study. *Disability and Rehabilitation*. Jul 31;44(16):4293-302.
- ⁸⁸ Hovén E, Eriksson L, Månsson D'Souza Å, Sörensen J, Hill D, Viklund C, Wettergren L, Lampic C. What makes it work? Exploring experiences of patient research partners and researchers involved in a long-term co-creative research collaboration. *Research involvement and engagement*. 2020 Jun 19;6(1):33.
- ⁸⁹ Wilson P, Mathie E, Keenan J, McNeilly E, Goodman C, Howe A, Poland F, Staniszewska S, Kendall S, Munday D, Cowe M. ReseArch with Patient and Public invOLvement: a RealisT evaluation-the RAPPORT study. *Health services and delivery research*. 2015;3(38).
- ⁹⁰ Hung L, Chow B, Shadarevian J, O'Neill R, Berndt A, Wallsworth C, Horne N, Gregorio M, Mann J, Son C, Chaudhury H. Using touchscreen tablets to support social connections and reduce responsive behaviours among people with dementia in care settings: A scoping review. *Dementia*. 2021 Apr;20(3):1124-43.
- ⁹¹ This unnamed Patient Author is quoted in Boden C, Edmonds AM, Porter T, et al (2021) Patient partners' perspectives of meaningful engagement in synthesis reviews: A patient-oriented rapid review. *Health Expectations* 24:1056–1071. <https://doi.org/10.1111/hex.13279>.
- ⁹² Gonzalez AI, Schmucker C, Nothacker J, Motschall E, Nguyen TS, Brueckle MS, Blom J, Van Den Akker M, Röttger K, Wegwarth O, Hoffmann T. Health-related preferences of older patients with multimorbidity: an evidence map. *BMJ open*. 2019 Dec 1;9(12):e034485.
- ⁹³ Vogsen M, Geneser S, Rasmussen ML, Hørder M, Hildebrandt MG. Learning from patient involvement in a clinical study analyzing PET/CT in women with advanced breast cancer. *Research Involvement and Engagement*. 2020 Jan 6;6(1):1.
- ⁹⁴ Gordon M, Gupta S, Thornton D, Reid M, Mullen E, Melling A. Patient/service user involvement in medical education: A best evidence medical education (BEME) systematic review: BEME Guide No. 58. *Medical teacher*. 2020 Jan 2;42(1):4-16.
- ⁹⁵ Koniotou M, Evans BA, Chatters R, Fothergill R, Garnsworthy C, Gaze S, Halter M, Mason S, Peconi J, Porter A, Siriwardena AN. Involving older people in a multi-centre randomised trial of a complex intervention in pre-hospital emergency care: implementation of a collaborative model. *Trials*. 2015 Jul 10;16(1):298.
- ⁹⁶ Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, Li LC. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expectations*. 2021 Jun;24(3):863-79.
- ⁹⁷ Zarshenas S, Mosel J, Chui A, Seaton S, Singh H, Moroz S, Khan T, Logan S, Colquhoun H. Recommended characteristics and processes for writing lay summaries of healthcare evidence: a co-created scoping review and consultation exercise. *Research Involvement and Engagement*. 2023 Dec 20;9(1):121.
- ⁹⁸ Hovén et al (2020) op cit.
- ⁹⁹ Taylor et al 2021, op cit.
- ¹⁰⁰ Rutherford et al (2026) op cit.
- ¹⁰¹ Pacho, A., de Barros, C.M., Lamouline, C. et al. When xenotransplantation enters the conversation: reflections on public involvement in research on a novel and controversial technology. *Research Involvement & Engagement* 12, 55 (2026). <https://doi.org/10.1186/s40900-026-00894-5>.
- ¹⁰² Halligan MJ, Thompson AE, Docherty D, Kelly P, Pryde E, Chuah CS, Hall R, Ho GT (2026) Patient-led thematic analysis on the impact of living with inflammatory bowel disease: a contemporary appraisal of 415 patient-reported outcomes to improve care and research. *Crohns & Colitis* 360. Jan;8(1):otag011.
- ¹⁰³ 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. *Research Involvement & Engagement*. 2020;6(1):34. <https://doi.org/10.1186/s40900-020-00190-w>.

¹⁰⁴ Pietramala et al 2026, op cit.

¹⁰⁵ Nicholls and colleagues combined the group of Patient Authors with the group of Public Contributors who were named in the acknowledgements section of the paper but did not attain the status of authors, and so it is difficult to draw conclusions about remuneration for authorship. See Nicholls SG, Nevins P, Fox G, Vanderhout S, Brehaut J, Carroll K, Fergusson D, Hilderley A, MacArthur C, Potter BK, Smith M (2025) Recognition, remuneration and reimbursement of patient and public involvement partners in pragmatic randomised controlled trials. A survey of author practices. *Research Involvement and Engagement*. 2025 Dec 11;11(1):140. **Also** Fox G, Lalu MM, Sabloff T, Nicholls SG, Smith M, Stacey D, et al. (2023) Recognizing patient partner contributions to health research: a systematic review of reported practices. *Research Involvement and Engagement*. 9(1):80. The Nicholls et al paper takes a broad view of 'recognition' that includes both Patient Authors and those acknowledged in the paper whose contribution fell short of co-authorship.

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¹⁰⁷ Longmore P. *Why I burned my book*. Temple University Press; 2003.

¹⁰⁸ [Item - Patient author completion of proposed ICMJE Disclosure Form - figshare - Figshare](#)

¹⁰⁹ Pietramala et al (2026) op cit.

¹¹⁰ Daniel N, Smith C, Miah N, Akroyd C, Bingham T, Brooks H, Chowdhury MA, Kaur G, Kundra R, Prendergast M, Chantkowski M. Enablers and barriers to participation in vaccine trials: a narrative synthesis. *Vaccine*. 2026 Feb 15;73:128183.

¹¹¹ Pollock A et al 2019, op cit.

¹¹² [Collective pay negotiations](#).

¹¹³ South A, Sturgeon K, Tahsin A et al (2026) Walking the walk: a case study of partnering with patients in designing and delivering a patient and public involvement implementation plan. *Research Involvement & Engagement* 12, 21. <https://doi.org/10.1186/s40900-026-00851-2>.

¹¹⁴ The *PLoS Medicine* Editors (2008) Making Sense of Non-Financial Competing Interests. *PLoS Med* 5(9): e199. <https://doi.org/10.1371/journal.pmed.0050199>.

¹¹⁵ See [NIHR Payment guidance for researchers and professionals involving people in research](#). The NIHR has also published a [Public Contributor Roles Framework](#), but it makes no reference to Patient Authors.

¹¹⁶ Bates P (2025) [Going cheap on expenses](#) shows that the NIHR's own online noticeboard which is intended to advertise opportunities for Public Contributors often carries adverts which are in breach of NIHR guidance.

¹¹⁷ Personal communication, March 2026.

¹¹⁸ Personal communication, March 2026. See, for example, Vanderhout S, Nevins P, Nicholls SG, Macarthur C, Brehaut JC, Potter BK, Gillies K, Goulao B, Smith M, Hilderley A, Carroll K. Patient and public involvement in pragmatic trials: online survey of corresponding authors of published trials. *Canadian Medical Association Open Access Journal*. 2023 Sep 1;11(5):E826-37.

¹¹⁹ Pacho A, de Barros CM, Lamouline C. et al. When xenotransplantation enters the conversation: reflections on public involvement in research on a novel and controversial technology. *Research Involvement & Engagement* 12, 55 (2026). <https://doi.org/10.1186/s40900-026-00894-5>

¹²⁰ [payment,-recognition-and-reward-policy-piru-public-contributors-v1.3-mar-2026.pdf](#).

¹²¹ Personal communication, March 2026. Kellezi B, Peacock H, Jones T, Gibson A, Andrews I, Fallon S, Lindley R, Radford K, Bridger K, Mann C, Roadevin C (2026) Public and Patient Involvement and Engagement in Clinical Trials: A Multi-Perspective Mixed-Methods Evaluation of the ROWTATE Programme. *Health Expectations*. Apr;29(2):e70636.

¹²² Cavens et al (2022), op cit.

¹²³ Gavin JP, Rossiter L, Fenerty V, Leese J, Adams J, Hammond A, Davidson E, Backman CL. Public and professional involvement in a systematic review investigating the impact of occupational therapy on the self-management of rheumatoid arthritis. *British Journal of Occupational Therapy*. 2024 Apr;87(4):201-12.

¹²⁴ Blake H, Abbott-Fleming V, Greaves S, Somerset S, Chaplin WJ, Wainwright E, Walker-Bone K. Five years of patient and public involvement and engagement (PPIE) in the development and evaluation of the Pain-at-Work toolkit to support employees' self-management of chronic pain at work. *Research Involvement and Engagement*. 2025 Jul 15;11(1):81.

¹²⁵ Boden et al (2021) op cit.

¹²⁶ Richards DP, Twomey R, Flynn T, et al. Patient engagement in a Canadian health research funding institute: implementation and impact. *BMJ Open* 2024;14:e082502. doi:10.1136/bmjopen-2023-082502

¹²⁷ IMHA's Patient Compensation Guideline.

¹²⁸ Hussaini A, Khan M, Ahmed N, Hashmi M, Farooq S, Masood A, Murthy S, Saleem S, Shuja Z, Zaman S, Dondorp AM (2025) Evaluation of the Establishment of a Public and Patient Involvement and Engagement Group to Support Clinical Trials in Pakistan: Protocol for a Mixed-Methods Study. *Wellcome Open Research*. Dec 15;10.

¹²⁹ The details were confirmed by Clareece Nevill, May 2026 (personal communication). Nevill CR, Cooper H, Czynnikowska B, Fairgrieve L, Greenwood J, Grewal-Santini G, Nevill J, Teece L, Wells M, Freeman SC, Booth S. Developing Public-Friendly Visualisations to Improve PPIE Glossaries for Statistical Methodology Research. *Health Expectations*. 2026 Jun;29(3):e70690.

¹³⁰ Hamilton CB, Hoens AM, McKinnon AM, McQuitty S, English K, Hawke LD, Li LC (2021) Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expectations* Jun;24(3):863-79. The quotation in the text is from a personal communication, March 2026.

¹³¹ Mockford C, Murray M, Seers K, Oyebode J, Grant R, Boex S, Staniszewska S, Diment Y, Leach J, Sharma U, Clarke R. A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges. *Research Involvement and Engagement*. 2016 Mar 3;2(1):8.

¹³² Pietramala et al 2026, op cit.

¹³³ Tackney MS, Steele A, Zeissler ML, Villar SS, Dearling J, Markham S, Yameen F. Can discussions with patients and the public clarify missing data mechanisms for digital outcome measures? (preprint at [Can discussions with patients and the public clarify missing data mechanisms for digital outcome measures?](#)). Details provided via personal correspondence, May 2026.

¹³⁴ Agata Pacho, personal correspondence, May 2026.

¹³⁵ "We gave high street gift vouchers to compensate them for their time." Miles S, Renedo A, Augustine C, Ojeer P, Willis N & Marston C (2020). Obstacles to use of patient expertise to improve care: a co-produced longitudinal study of the experiences of young people with sickle cell disease in non-specialist hospital settings. *Critical Public Health*, 30(5), 544–554. <https://doi.org/10.1080/09581596.2019.1650893>.

¹³⁶ Kontou, K., Daynes, E., Singh, S. et al. The effectiveness and acceptability of face-to-face rehabilitation for patients with Long Covid who were not hospitalised with their acute infection: a mixed-methods study comprising a randomised controlled trial (RCT) with embedded qualitative component. *Trials* (2026). <https://doi.org/10.1186/s13063-025-09419-z>

¹³⁷ The merits and demerits of vouchers are discussed in Bates P (2022) [How to set payment levels for research participants](#). These arguments regarding PPI payments for research participants run parallel to those for Patient Authors.

¹³⁸ Lowers et al (op cit) 2026.

¹³⁹ Personal communication, April 2026.

¹⁴⁰ Nicholls SG, Nevins P, Fox G, Vanderhout S, Brehaut J, Carroll K, Fergusson D, Hilderley A, MacArthur C, Potter BK, Smith M. Recognition, remuneration and reimbursement of patient and public involvement partners in pragmatic randomised controlled trials. A survey of author practices. *Research Involvement and Engagement*. 2025 Dec 11;11(1):140.

¹⁴¹ The study concerned is reported as Nicholls et al, 2025, op cit. The clarification about payments was made via personal communication, February 2026.

¹⁴² Maureen Smith was a Patient Author in Fox et al 2023 (op cit) and on Nicholls et al 2025 (op cit). The first of these includes a definite statement that financial compensation was offered, although in neither case were tasks specified or a specific sum assigned to authorship activities (personal correspondence, Feb 2026). See Fox G et al 2023 op cit. Also Patient Authors Jenny Coles, John Copping, Jacky Murphy and Jean Nicholls were offered PPI payments, but the text is vague on whether payments were attached to authorship tasks or just to the broader meetings of the Lived Experience Advisory Panel. See Al-Janabi H, Coles J, Copping J, Dhanji N, McLoughlin C, Murphy J, Nicholls J (2021) Patient and public involvement (PPI) in health economics methodology research: reflections and recommendations. *The Patient-Patient-Centered Outcomes Research*. Jul;14(4):421-7.

¹⁴³ Zhao Y et al 2026, op cit.

¹⁴⁴ Stepanova E, Cooper M, Robinson-Barella A, et al (2026) Cultural competency in research: A practical framework for use by researchers, policymakers, community leads and others when working with people from diverse groups, *Health Expectations* 29: e70544, <https://doi.org/10.1111/hex.70544>.

¹⁴⁵ Golijani-Moghaddam N, Dawson DL, Evangelou N, Turton J, Hawton A, Goodwin E, Law GR, Asghar Z, Roche B, Rowan E, Burge R. Feasibility and acceptability of Strengthening Mental Abilities with Relational Training (SMART) for cognitive difficulties in multiple sclerosis: a randomised controlled trial. Professor Golijani-Maghaddam confirmed (personal communication, May 2026) that payments were offered to Dr Turton at NIHR rates for manuscript-related activities.

¹⁴⁶ Woolley et al 2024, op cit.

¹⁴⁷ Personal communication, February 2026.

¹⁴⁸ These concerns can lead to a study design in which the group of study participants is distinct from the group of Patient Authors. See Bates P <https://peterbates.org.uk/wp-content/uploads/2023/03/How-to-manage-overlapping-roles.pdf>.

¹⁴⁹ Quoted in Karlsson et al 2023, op cit.

¹⁵⁰ We checked a total of 348 papers from our dataset of papers published anytime on PPI. 33 (9%) of these papers did not provide an email at all, 295 (85%) provided one email address for the corresponding author, 8 (2%) provided two email addresses and the remaining 12 (3%) papers liberally shared a total of 167 email addresses with the reading public. It is possible that journal editors ask all authors for their email address to verify their integrity, but we conclude that these data are generally not published. Further, we might speculate that a few outliers may adopt the deplorable practice of selling the resulting data to predatory journals, but we have no evidence for this.

¹⁵¹ “Public Contributors were offered reimbursement of expenses and unanimously declined” in Hancock A, Bleiker J, Hodgson D. The role and value of co-production in creating a shared understanding and conceptual framework of compassion. *Radiography*. 2026 Jan 1;32(1):103208. **Also** “No reimbursement has been accepted by the authors for preparing this article” – so presumably Patient Authors Jenny Boards and Ian Clarke were offered payment rather than merely reimbursement of expenses. See Porter CE, Roleston C, Bethune C, Boards J, Brown CS, Clarke I, Fielding J, Howard P, Jamieson C, Misbah SA, Moss AC. Widening access to penicillin allergy assessment in the United Kingdom—a proposed implementation plan for the National Health Service (NHS). *JAC-Antimicrobial Resistance*. 2026 Feb;8(1):dlaf240.

¹⁵² Fox G, Lalu MM, Sabloff T, Nicholls SG, Smith M, Stacey D, Almoli F, Fergusson DA. Recognizing patient partner contributions to health research: a systematic review of reported practices. *Research involvement and engagement*. 2023 Sep 9;9(1):80.

¹⁵³ Hamilton S (2016) *Influencing the debate – peer research in academic journals*. See <http://mcpin.org/influencing-the-debate-peer-research-in-academic-journals/>.

¹⁵⁴ This is what happened in Kirkham’s team (Personal communication, February 2026). “We had a group of 7 PPIE contributors who were all paid £20 per hour to review documents, provide feedback and attend meetings for a specific project within the WILL Trial, which was to create a patient facing poster. However, by the time the manuscript was being drafted the WILL trial had closed, and therefore we no longer had access to funding for any PPIE activities. We reached out to our PPIE members to explain this and asked if they would still like to review the manuscript without any payment. Al Richards and Emma Jukes were the two that agreed and were keen to be co-authors.” The resulting paper was Kirkham K, Tohill S, Wade J, Stubbs C, von Dadelszen P, Richards A, Jukes EM, Magee LA. Experiences of conducting effective Patient and Public Involvement and Engagement (PPIE) by the WILL Trial (When to Induce Labour to Limit risk in pregnancy hypertension) management team. *Trials*. 2026 Jan 21. The same thing happened in Brown J, Baer G, Cameron S, Jackson K, Lamouline C, Morley R, Ormsby D, Synnot A, Todhunter-Brown A. Stakeholder involvement in a Cochrane review of physical rehabilitation after stroke: Description and reflections. *Cochrane Evidence Synthesis and Methods*. 2023 Dec;1(10):e12032.

¹⁵⁵ It is good practice to check out availability at an early stage in the writing project. See <https://ismpp-newsletter.com/2020/05/26/patient-authorship-three-key-questions-answers-for-medical-communication-professionals-part-b/>

¹⁵⁶ “We would argue that funders should adopt the practice of allowing spending on grants after the end date for dissemination activities – this is already done by some funders (including NIHR...) and would help to ensure research partners are paid for their work and are not excluded from later publications because of a requirement to work pro bono.” Miles S, Renedo A & Marston C (2022) [Reimagining authorship guidelines to promote equity in co-produced academic collaborations](#). *Global Public Health*.;17(10):2547–59.

¹⁵⁷ Pietramala et al 2026, op cit.

¹⁵⁸ Woolley AW, Chabris CF, Pentland A, Nada Hashmi. Evidence for a collective intelligence factor in the performance of human groups. *Science*. 2010;330:686–8. Also Yang Y, Tian TY, Woodruff TK, Jones BF, Uzzi B. Gender-diverse teams produce more novel and higher-impact scientific ideas. *Proceedings of the National Academy of Sciences USA*. 2022;119:e2200841119.

¹⁵⁹ Hirsch JE (2005) An index to quantify an individual's scientific research output. *Proceedings of the National Academy of Sciences* Nov 15;102(46):16569-72.

¹⁶⁰ Nazer L, Abusara A, Aloran B et al. Patient diversity and author representation in clinical studies supporting the Surviving Sepsis Campaign guidelines for management of sepsis and septic shock 2021: a systematic review of citations. *BMC Infectious Diseases* **23**, 751 (2023). <https://doi.org/10.1186/s12879-023-08745-4>

¹⁶¹ Staniszewska et al 2017 op cit.

¹⁶² Chambers R, O’Brien LM, Linnell S, Sharp S. Why don’t health researchers report consumer involvement? *Quality in Primary Care*, 2004; 12: 151–157. Also Brett JO, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health expectations*. 2014 Oct;17(5):637-50.

¹⁶³ Lisbeth notes that some entrepreneurial expert patients are under such demand pressure that they cannot afford to be sick! See Egger C, Bereczky T, Snede L, Zvonareva O. Patient engagement in drug development: dialogically problematizing participation. *Science as Culture*. 2025 Jan 2;34(1):31-51.

¹⁶⁴ Pallotti V, Arzo Caroselli V, Esandi ME, Esandi MD (2025) Questionable practices concerning authorship and their prevalence: An umbrella review of evidence. *Journal of Academic Ethics*. Jun 23:1-21.

¹⁶⁵ A series of arguments for and against paying people for research participation are set out in Bates P (2022) [How to set payment levels for research participants](#). The arguments regarding PPI payments for Patient Authors run parallel to those for study participants.

¹⁶⁶ Leese et al might know. Leese J, Macdonald G, Kerr S, Gulka L, Hoens AM, Lum W, et al. Adding another spinning plate to an already busy life'. Benefits and risks in patient partner–researcher relationships: a qualitative study of patient partners' experiences in a Canadian health research setting. *BMJ Open*. 2018;8(8):e022154. See also Bates P <https://peterbates.org.uk/wp-content/uploads/2023/03/How-to-manage-overlapping-roles.pdf>.

¹⁶⁷ Bates P (2024) [How-to-write-in-public.pdf \(peterbates.org.uk\)](#).

¹⁶⁸ Feedback was gratefully received from Isla Dowds-Skinner, Marc Ewen, Alicia Hilderley, Jordan Holt, Linzy Houchen-Wolloff, Angela Polanco, Stan Papoulias, Jon Sandoe and Felicity Shenton.

¹⁶⁹ Readers engage with the contents of this paper at their own risk and undertake not to hold the author liable for any injury, loss, or damage arising through reading or acting on its contents. Whilst every reasonable effort has been made to comply with UK legislation, if you believe that the public display of this document or any of its contents breaches copyright please contact peter.bates96@outlook.com providing details, and public access to the offending work will be removed immediately.

¹⁷⁰ See [ICMJE | Recommendations | Author Responsibilities—Disclosure of Financial and Non-Financial Relationships and Activities, and Conflicts of Interest](#). The form is available in many languages at [ICMJE | Disclosure of Interest | Translations](#).

¹⁷¹ See [Payment for authors – Peter Bates](#). The ICMJE secretary (personal communication 25/05/2017) added that (1) Funding of any kind should be disclosed, irrespective of its source (whether from for-profit and non-profit organisations and for salary or honoraria) and individual circumstances may dictate the specific response from editors. The source of funding per se should not influence the judgement of journal editors about the merit of the submission; (2) The crucial matter is research integrity and independence; and so in testing this, journal editors should not treat patient authors more leniently or sternly than academics or clinicians; and (3) Everyone receiving a payment should make a potential conflict of interest declaration, so that journal editors can be equally alert to issues of bias in the salaried academic or clinician as they are to the patient author who receives a participation payment or honorarium. Surveying the guidance issued by individual journals might shed some light on whether these principles are upheld in everyday practice.

¹⁷² Richards DP, Birnie KA, Eubanks K, et al (2020) Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. *Research Involvement and Engagement*. 6:38. <https://doi.org/10.1186/s40900-020-00213-6>. **Also** Cooksey KE, Neuman M, Bollini M, Pennington B, de Campos O, Oberst H. Patient partner engagement in the publication process: challenges and possible solutions. *BMC Med Res Methodol*. 2025;25(1):39. **Also** Bélisle-Pipon J-C, Rouleau G and Birko S, 2018 Early-career researchers' views on ethical dimensions of patient engagement in research, *BMC Medical Ethics*, 19: 21 DOI: 10.1186/s12910-018-0260-y. [PubMed: 29514618]. **Also** Hewlett S, Wit M. de, Richards P, Quest E, Hughes R, Heiberg T and Kirwan J, 2006 Patients and professionals as research partners: Challenges, practicalities, and benefits, *Arthritis Care & Research*, 55(4): 676–680. DOI: 10.1002/art.22091. [PubMed: 16874772].

¹⁷³ Cobey et al (2021) op cit.

¹⁷⁴ See [ISMPP \(International Society for Medical Publication Professionals\): Overview | LinkedIn](#).

¹⁷⁵ The *Good Publication Practice* guidelines have gone through several iterations (GPP1 in 2003, GPP2 in 2009, GPP3 in 2015 and GPP 2022 in 2022). GPP 2022 is reported in DeTora LM, Toroser D, Sykes A, Vanderlinden C, Plunkett FJ, Lane T, Hanekamp E, Dormer L, DiBiasi F, Bridges D, Baltzer L. Good Publication Practice (GPP) guidelines for company-sponsored biomedical research: 2022 update. *Annals of Internal Medicine*. 2022 Sep;175(9):1298-304. <https://doi.org/10.7326/M22-1460>. It is notable that the most recent iteration is not available as an open access publication.

¹⁷⁶ [GPP 2022 FAQ](#)

- ¹⁷⁷ Bharadia T, Geissler J, Robson R *et al* (2025) Seven Actions Towards Advancing Patient Authorship and Collaboration in Peer-Reviewed Publications. *Patient* **18**, 403–414. <https://doi.org/10.1007/s40271-025-00750-w>
- ¹⁷⁸ Resnik DB, Tyler AM, Black JR, Kissling G. Authorship policies of scientific journals. *Journal of Medical Ethics*. 2016 Mar 1;42(3):199-202.
- ¹⁷⁹ Bélisle-Pipon J-C, Rouleau G and Birko S (2018) Early-career researchers' views on ethical dimensions of patient engagement in research, *BMC Medical Ethics*, 19: 21 DOI: 10.1186/s12910-018-0260-y. [PubMed: 29514618].
- ¹⁸⁰ Hosseini, M., & Gordijn, B. (2020). A review of the literature on ethical issues related to scientific authorship. *Accountability in Research*, 27(5), 284–324. <https://doi.org/10.1080/08989621.2020.1750957>.
- ¹⁸¹ Cobey *et al* (2021) *op cit*. The British Medical Journal began to involve patients in the manuscript publication process from 2014, beginning with the introduction of patient reviewers.
- ¹⁸² Gray R, Brasier C, Zirnsak T-M, *et al* (2021) Reporting of patient and public involvement and engagement (PPIE) in clinical trials published in nursing science journals: a descriptive study. *Research Involvement and Engagement* 7:88.
- ¹⁸³ See SPOR Networks in Chronic Disease and the PICHI Network. Recommendations on Patient Engagement Compensation. 2018. https://diabetesaction.ca/wp-content/uploads/2018/07/TASK-FORCE-IN-PATIENTENGAGEMENT-COMPENSATION-REPORT_FINAL-1.pdf. Accessed 24 Feb 2020.
- ¹⁸⁴ [Considerations when paying patient partners in research - CIHR](#) makes no specific reference to payments for Patient Authors.
- ¹⁸⁵ Fox *et al* 2024, *op cit*.
- ¹⁸⁶ The other two demands of the [PatientsIncluded Charter for Journals](#) are (i) at least two patients as members of the editorial board and (ii) Patients may act as peer-reviewers.
- ¹⁸⁷ Faulkner, A. *et al*. 4Pi National Involvement Standards: Involvement for Influence. 2015
- ¹⁸⁸ Schulz KF, Altman DG, Moher D, for the CONSORT Group (2010) CONSORT 2010 statement: updated guidelines for reporting parallel group randomised trials. *PLoS Med* 7(3): e1000251. <https://doi.org/10.1371/journal.pmed.1000251>.
- ¹⁸⁹ Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*. 2007 Dec 1;19(6):349-57.
- ¹⁹⁰ Engagement, N. C. C. for P. Introducing the EDGE Tool Self-Assessing Your Support for Public Engagement. 2023. https://www.publicengagement.ac.uk/sites/default/files/2023-08/introducing_the_edge_tool.pdf.
- ¹⁹¹ Question FV3 in PEIRS asks Public Contributors to rate the extent to which “I was offered sufficient recognition for my contributions (for example, payment, authorship, or gifts).” Hamilton CB, *et al*. Shortening and validation of the Patient Engagement In Research Scale (PEIRS) for measuring meaningful patient and family caregiver engagement. *Health Expectations*. 2021;24:863–79.
- ¹⁹² Popay J, Collins M & PiiAF Study Group. *The Public Involvement Impact Assessment Framework (PiiAF) Guidance*. 2014.
- ¹⁹³ Public and Patient Engagement Collaborative. Public and Patient Engagement Evaluation Tool (PPEET). McMaster University vol. 10.

¹⁹⁴Hróbjartsson et al provide an example of good practice in which Public Contributors are provided with a gift card worth AU\$30 payment for 'each hour of involvement in the study'. See NHróbjartsson A, Boutron I, Hopewell S, Moher D, Schulz KF, Collins GS, Tunn R, Aggarwal R, Berkwitz M, Berlin JA, Bhandari N (2025) SPIRIT 2025 explanation and elaboration: updated guideline for protocols of randomised trials. *BMJ*. Apr 28;389.

¹⁹⁵ Pollock A, Campbell P, Struthers C, et al. Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. *Journal of Health Services Research & Policy*. 2019;24(4):245-255. doi:[10.1177/1355819619841647](https://doi.org/10.1177/1355819619841647). Online supplement 5 provides data on patient engagement in publishing results. Heather Goodare was a Patient Author in the publication of this paper, but nothing is said about PPI payments.

¹⁹⁶ Newman A, McAlister B, Seddon K, Peddle S & Nelson A (2023) Public Involvement In Research Impact Toolkit (PIRIT)," Cardiff University, Wales <https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit>.

¹⁹⁷ Houchen-Wolloff L, Bell J, Pritchard R, Poinasamy K, Holmes K, Walker S, Smith N, Hastie C, Rogers N, Adams D, Nathu R (2026) Consortium-Based Patient and Public Involvement and Engagement for Long COVID Research: A Pirit-Focused Impact Evaluation of the PHOSP-COVID Study. *Health expectations: an international journal of public participation in health care and health policy*. Apr;29(2):e70591.

¹⁹⁸ Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman DG, Moher D, Barber R, Denegri S, Entwistle A (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *British Medical Journal*. Aug 2;358.

¹⁹⁹ Jones J, Cowe M, Marks S, McAllister T, Mendoza A, Ponniah C, et al. Reporting on patient and public involvement (PPI) in research publications: using the GRIPP2 checklists with Lay co-researchers. *Research Involvement & Engagement*. 2021;7(1):52.

²⁰⁰ Nicholls SG, Nevins P, Fox G, Vanderhout S, Brehaut J, Carroll K, Fergusson D, Hilderley A, MacArthur C, Potter BK, Smith M (2025) Recognition, remuneration and reimbursement of patient and public involvement partners in pragmatic randomised controlled trials. A survey of author practices. *Research Involvement and Engagement*. 2025 Dec 11;11(1):140. **Also** Fox G, Lalu MM, Sabloff T, Nicholls SG, Smith M, Stacey D, et al. (2023) Recognizing patient partner contributions to health research: a systematic review of reported practices. *Research Involvement and Engagement*. 9(1):80. The Nicholls et al paper takes a broad view of 'recognition' that includes both Patient Authors and those acknowledged in the paper whose contribution fell short of co-authorship.

²⁰¹ Alan Bevan, who is employed as a researcher and also brings his own lived experience to the table, has published a critique of GRIPP2 in Scholz B & Bevan A (2021) Toward more mindful reporting of patient and public involvement in healthcare. *Research Involvement & Engagement*. 7(1):61.

²⁰² The reporting of remuneration and reimbursement is not a requirement of the Consolidated Standards of Reporting Trials (CONSORT 2025) reporting guideline. Also check out the SPIRIT reposting guideline which recommends reporting PPI activities and GPP. EUPATI guidelines merely declare that compensation arrangements should be transparent. See Hopewell S, Chan AW, Collins GS, et al. CONSORT, 2025 explanation and elaboration: updated guideline for reporting randomised trials. *BMJ*.2025;389:e081124. <https://doi.org/10.1136/bmj-2024-081124>. **Also** Moher D, Hopewell S, Schulz KF, et al. CONSORT, 2010 explanation and elaboration: updated guidelines for reporting parallel group randomised trials. *BMJ*. 2010;340:c869. <https://doi.org/10.1136/bmj.c869>. **Also** Hopewell S, Chan AW, Collins GS, et al. CONSORT, 2025 statement: updated guideline for reporting randomised trials. *BMJ*. 2025;389:e081123. <https://doi.org/10.1136/bmj-2024-081123>. **Also** Hrobjartsson A, Boutron I, Hopewell S, et al. SPIRIT, 2025 explanation and elaboration: updated guideline for protocols of randomised trials. *BMJ*. 2025;389:e081660. <https://doi.org/10.1136/bmj-2024-081660>. **Also** Warner K, See W, Haerry D, Klingmann I, Hunter A, May M. EUPATI guidance for patient involvement in medicines research and development (R&D); guidance for pharmaceutical industry-led medicines R&D. *Frontiers in medicine*. 2018 Oct 9;5:270.

²⁰³ Fox G, Lalu MM, Sabloff T, et al (2023) Recognizing patient partner contributions to health research: a systematic review of reported practices. *Research Involvement and Engagement*. 9:80. <https://doi.org/10.1186/s40900-023-00488-5>. This team have kindly supplied the list of papers they found where Public Contributors were offered PPI payments and served as Patient Authors, but the precise relationship is unclear as to whether the payments were offered for authorship activities or something else.

²⁰⁴ The following paper reports on a more thorough approach to finding relevant papers: Rogers M, Bethel A, Boddy K. Development and testing of a Medline search filter for identifying patient and public involvement in health research. *Health Info Libr J*. 2017;34(2):125–33. My goal is to simply find *some* papers where Patient Authors have been compensated for their authorship activities; others can seek knowledge about frequency.

²⁰⁵ Such as Public-Private Partnerships Investment in Energy.

²⁰⁶ In one example, email addresses were supplied for all authors, but the inquiry was addressed to the named corresponding author for the study. See Lowers et al (op cit) 2026.

²⁰⁷ Patel VA, Shelswell J, Hillyard N, Pavitt S, Barber SK (2012) A study of the reporting of patient and public involvement and engagement (PPIE) in orthodontic research. *J Orthod*. 48(1):42–51. <https://doi.org/10.1177/1465312520968574>.

²⁰⁸ Evans HG et al 2026 op cit.

²⁰⁹ Vanneste A, Wens I, Sinnaeve P, et al. Evolution of reported patient and public involvement over time in randomised controlled trials in major medical journals and in their protocols: meta-epidemiological evaluation. *BMJ*. 2025;389:e082697. <https://doi.org/10.1136/bmj-2024-082697>.