Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

From Involvement to Authorship: Co-Producing Publication Guidance with Public Contributors in Electronic Health Record Research

Heather Mah

heather.mah@lshtm.ac.uk

London School of Hygiene & Tropical Medicine

Em Prestige

London School of Hygiene & Tropical Medicine

Michael Natt

London School of Hygiene & Tropical Medicine

Sarah Barley-McMullen

London School of Hygiene & Tropical Medicine

Yvonne Adler

London School of Hygiene & Tropical Medicine

Farheen Yameen

London School of Hygiene & Tropical Medicine

Janice Elliott

London School of Hygiene & Tropical Medicine

Shrinkhala Dawadi

London School of Hygiene & Tropical Medicine

Luisa M Pettigrew

The Health Foundation

Emily Herrett

London School of Hygiene & Tropical Medicine

Jaidip Gill

University of Oxford

Ruth E Costello

London School of Hygiene & Tropical Medicine

Rachel Denholm

University of Bristol

John Macleod

University of Bristol

Laurie Tomlinson

London School of Hygiene & Tropical Medicine

Rohini Mathur

Queen Mary University of London Barts, Wolfson Institute of Population Health

Rosalind M Eggo

London School of Hygiene & Tropical Medicine

Research Article

Keywords: patient and public involvement and engagement, patient co-authorship, research publications, electronic health records, co-production

Posted Date: November 26th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11702619/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: Competing interest reported. REC has personal shares in AstraZeneca.

Abstract

Background:

There is a growing recognition of the importance of including patients and the public in research publications. However, there is limited guidance on how to effectively involve contributors as co-authors, particularly in quantitative studies using large datasets.

Methods:

This work drew on two projects exploring inequalities in primary care and respiratory virus burden using electronic health records (EHR). We aim to describe the co-production of guidance with a public advisory group to support meaningful co-authorship in research involving large health datasets. We worked with six contributors who varied in age, gender, ethnicity, socioeconomic status, and experiences of chronic illness, disability, and respiratory infections. We wanted to include public contributors as co-authors in our publications, however this required thoughtful planning to ensure their involvement was meaningful and not tokenistic. We held an online workshop to develop the guidance and discussed review timelines, how to give comments, payment, and strategies for reviewing technical drafts. This was informed by ongoing involvement activities and reflexive discussions, alongside researcher feedback. This paper was co-authored with advisory group members in line with the co-produced guidance developed through this work.

Results:

We identified four key areas for consideration: 1) establish roles and expectations across publication stages, 2) balance technical concepts and language with patient perspectives, 3) support contributors to give feedback that feedback that strengthened the interpretation, relevance and communication of the research, and informing how their feedback was used, and 4) negotiate authorship criteria, including comments while respecting anonymity, and the technical aspects involved in producing and publishing a manuscript. This highlighted a need to bring together technical expertise required to produce knowledge from large health datasets with the experiential expertise needed to interpret what that means for the public.

Conclusion:

Patient co-authorship in EHR research requires structure and support to ensure contributors are meaningfully involved across the publication process. Our co-produced guidance offers strategies to improve transparency, effectively engage with feedback, and recognise lived experience as a distinct and valuable form of expertise. This work shows how publication is not solely about disseminating research findings, but can be a collaborative process of knowledge production.

Plain English Summary

There is increasing recognition that patients and members of the public should be involved in health research, including to help write and publish research papers. However, there is little practical advice available on how to involve the public as co-authors in studies that use electronically-recorded patient health data, which can be technical and difficult to engage with.

This project aimed to develop guidance on how to involve a patient and public advisory group when publishing health research that uses electronic health records. The guidelines were developed from two studies exploring winter pressures in primary care and risks linked to respiratory viruses.

We worked with six contributors who had a range of backgrounds and experiences of chronic illness, disability and respiratory infections, and being carers. They were involved throughout the research process, including discussing findings and how results were presented.

We found several important ways for successful public co-authorship. These included clearly explaining roles and expectations, making technical research language more accessible, and ensuring contributors understood how their feedback was taken on. We also explored challenges such as deciding rules for who is listed as an author and understanding the technical processes involved in academic publishing.

The project resulted in co-produced guidance that offers practical ways to support meaningful co-authorship. It aims to improve transparency and collaboration, by recognising lived experience as an important contribution to health research publications.

Introduction

Involving patients and members of the public in improving the way research is designed, delivered and disseminated, also known as patient and public involvement and engagement (PPIE), has become an expectation of many research funders, journals, and institutions in the UK (National Institute for Health and Care Research [NIHR], 2024). There is also an increased recognition of the value that public contributors bring to the research process (Mah et al., 2025). However, historically this has been more in consultation roles such as advisory board or steering committee members. Recently, there has been an increased focus on developing more collaborative approaches such as working with PPIE members as co-investigators, co-designers, and co-authors. Co-authorship is one aspect of involvement where contributors can be valued for their lived experience as well as expertise beyond being a patient with a health condition.

Within epidemiological and public health research, these studies are increasingly driven by statistical modelling on large electronic health records (EHRs) datasets, and in our case, from general practices. These data and methods can provide opportunities to better understand and improve public health needs, however they are often complex, technical, and the data collected is not originally intended to be used for research. Therefore, interpretation and analysis often requires technical skills, and can make meaningful contributions from the public more challenging compared with other forms of research.

Existing guidance on authorship includes recommendations from the International Committee of Medical Journal Editors (ICMJE) on the criteria for authorship and the responsibilities of authors that include contributing to the interpretation of findings, reviewing the manuscript, approving the final version, and taking responsibility for the work (ICMJE, 2026). However, public contributors may need additional support to understand these roles particularly when research involves technical content. It is important to consider how public contributors can be supported to contribute to the interpretation and communication of findings, and how their contributions can be appropriately recognised through co-authorship.

There has been a recent increase in the numbers of people with lived experience being included as co-authors (Woolley et al., 2024). Co-authorship is also becoming a common method for public contributors to have non-financial reward as well as acknowledgement (Fox et al., 2023). However, there are concerns that this is sometimes done tokenistically, where contributors' names are included as co-authors but their contributions are not reflected in the manuscript. This can be context dependent as some contributors, both PPIE and researchers, may have contributed throughout the project but are less able to provide input into the final manuscript. This is part of a wider issue within academic publishing that includes the inconsistent application of authorship and honorary and reciprocal authorship (Oyenuga et al., 2026).

There is current guidance available on how to involve patients and the public in co-authorship within patient-oriented research that includes discussing authorship, explaining the publication process and support for contributors (Richards et al., 2020). While existing guidance addressed authorship criteria and publication ethics (e.g. Committee on Publication Ethics), there is less guidance on how to support public contributors to contribute to the interpretation and communication of findings from EHR research. Public contributors can help contextualise findings and question assumptions from a different perspective. We aimed to build on existing guidance by co-producing practical approaches to support public contributors as co-authors, including helping them engage with technical manuscripts, agreeing expectations, and being transparent with how feedback is incorporated throughout the research process. These processes are not always embedded in manuscript development, where expectations around authorship and the review process may be assumed rather than explicitly discussed.

This guidance is intended to support both public contributors and researchers as it offers researchers guidance on how to facilitate these discussions around complex research outputs with public contributors. A shared framework can help establish expectations, support communication, and provide a clearer understanding of how researchers and contributors can work together throughout the publication process.

Methods

Study Design

This work draws on two NIHR-funded England-based healthcare studies involving researchers and clinicians from multiple organisations, investigating winter pressures in primary care and respiratory virus risks using EHRs (NIHR n.d.-a; NIHR n.d.-b.). The overall aim of PPIE across these two studies was to involve members of the public throughout the research process, using their lived experience to help shape the interpretation and communication of EHR research. Undertaking PPIE highlighted the need to co-produce guidance to support the involvement of public contributors as co-authors in EHR research outputs.

Public Advisory Group

A PPIE Lead, who has a background in public engagement and participatory health research, was budgeted at 0.25 full-time equivalent (FTE) to support the management and coordination of the involvement activities for the winter pressures project and 0.10FTE for the fellowship on respiratory virus risk burden. This included creating and managing the advisory group, coordinating meetings, managing budgets, and being a liaison between contributors and the research team, and providing guidance to research staff on PPIE.

The PPIE Lead contacted various patient and community organisations and the opportunity to be involved was shared across existing research and involvement networks and online patient groups. The project worked with an advisory group of six contributors with different backgrounds in age, gender, ethnicity, socioeconomic status, and experiences of chronic illness, disability and respiratory infections, and being carers, living across England. Most had experience of being involved in other research projects, and some had a background in research and academia. Contributors were involved from the beginning of the research project through to the interpretation and presentation of results.

The advisory group has been meeting regularly with the research team across the duration of the projects. Our first meeting involving contributors and the research team took place in February 2025. Subsequent meetings involved researchers from different parts of the project presenting updates to their research, discussing emerging findings, and seeking contributors' perspectives. As contributors were located across England and some had health needs that affected travel, all meetings were held online in agreement with the advisory group. Other accessibility needs, such as health needs, caring responsibilities and other commitments were accommodated as required and the meeting structure and format has evolved in response to feedback to optimise understanding and participation.

Development of Guidance

The research team recognised the importance of including the public contributors across our research outputs, including journal publications, as this could help ensure that findings were communicated clearly, reflected the lived experiences and addressed issues relevant to patients and the public. However this required thoughtful planning with the contributors to understand how they wanted to be involved, and what support would enable them to contribute effectively and ensure their feedback on research output drafts were meaningfully incorporated.

The PPIE Lead facilitated an initial online workshop with contributors to develop the guidance and shared a skeleton draft ahead of the workshop. The group discussed expectations, time commitments for reviewing drafts, approaches to providing comments, payment, and support needed when reviewing technical content. These discussions helped to identify some of the challenges contributors experienced and different approaches that could help support their involvement. The guidance was developed through reflecting on experiences of ongoing involvement activities and discussions with contributors facilitated by the PPIE Lead, as well as researcher feedback on learnings and challenges to ensure the guidance reflected their perspectives and shared learning. This allowed different experiences to inform the guidance as an ongoing process rather than one standalone workshop.

This paper presents co-produced guidance (Supplementary File 1) developed with a public advisory group that was formed to help inform and shape EHR research. Drawing on reflections and learnings from two research projects, we discuss key considerations and practical strategies when involving public contributors as co-authors, focusing on transparency and flexibility in how contributors participate, while recognising lived experience as a distinct, legitimate, credible, and valuable contribution. We are taking this guidance and learning forward and applying how we engage with public contributors as co-authors in other research projects, including an NIHR-funded project using EHRs to better understand vaccine effectiveness (NIHR n.d.-c.).

The infographic (Figure 1) was developed to summarise the guidance into a one-page public friendly document for public contributors and research teams to use across different research contexts, beyond EHR research.

Contributors were also involved in co-authoring this manuscript following the principles outlined in the guidance, contributing to interpreting findings, and sharing their lived experiences throughout the research and publication process. We met with contributors to discuss how they would like to be involved in this manuscript, what the key messages should be, and what others can learn from our experience.

Throughout this process, we identified that public co-authorship requires different forms of support: for contributors to engage with technical content, offering flexible opportunities to be involved, and prompting structured feedback that can influence research interpretation and communication. Table 1 summarises the key challenges we identified during this process and the guidance developed in response.

Challenge identified during review of research outputs	Co-produced guidance
It could be difficult to understand the purpose and context of technical research outputs.	Provide a cover sheet summarising the research, explaining why the study matters, and the type of feedback sought.
It was not always clear what kind of feedback would be helpful.	Provide structured prompts focusing on interpretation, clarity, accessibility, key messages, and implications for patients and the public.
Technical manuscripts may create barriers to involvement.	Support contributors to focus on sections where their lived experience and perspectives can add value, rather than expecting review of the entire manuscript.
Contributors were not always informed how their feedback had influenced the research output.	Share a summary explaining how PPIE feedback informed revisions and, where relevant, explain why some suggestions could not be incorporated.
Contributors may be involved across multiple projects, or there may be a considerable time between discussing findings and reviewing research outputs.	Share recent presentation slides, meeting summaries, and relevant supplementary materials to provide context and support informed review.
Expectations around authorship and recognition differed between contributors.	Discuss authorship early, make participation voluntary, and agree to recognition on an individual basis.
Publication processes may be unfamiliar to public contributors.	Offer guidance, training opportunities, and practical support throughout the process.
Contributors may need different amounts of time to review manuscripts due to individual preferences, commitments and accessibility needs, including neurodivergence and language barriers.	Agree timeframes and deadlines in advance, allowing flexibility and considering individual needs.

Table 1: Challenges identified by research staff and public contributors and approaches developed to support public co-authorship.

Results

Establishing Shared Expectations for Co-authorship

The process of involving contributors in publications highlighted that we needed to work together to establish clear expectations about roles, responsibilities, and recognition. While contributors were involved from the beginning of the project, publication was a different stage of involvement. We discussed payment arrangements during the workshop to agree on a fair payment approach for reviewing research outputs in line with the recent NIHR uplift guidance on payment for PPIE (NIHR, 2025). Contributors shared previous experiences in other roles of different payment structures including flat-rate and hourly payments. Based on these discussions, we agreed that contributors would be paid

hourly for reviewing, limited to a maximum of four hours. This time limit reflected the expected time commitment required, while avoiding placing excessive burden on their involvement as well as the constraints of the available project budget.

Authorship was discussed with contributors, including the different ways they could contribute and how these could be recognised. We discussed the expectations associated with co-authorship and the importance of reviewing and approving the final manuscript. We agreed that authorship involvement was voluntary and contributors could decide if they wanted to take part in each output. While some contributors chose to be named as co-authors, others preferred not to be named. We therefore recognised anonymous contributions in the acknowledgements section. This highlights the importance of ensuring that authorship is a choice rather than expectation and recognising contributions in ways that align with their preferences.

Creating Supportive Structures Across the Publication Process

When preparing journal manuscripts, our initial approach was to share the complete draft with contributors and invite general comments and feedback. While contributors provided valuable input, this process highlighted that providing access to a manuscript did not automatically create the conditions to meaningfully contribute. It also prompted researchers to reflect on how they communicated technical content, how they structured requests for feedback, and how contributors' perspectives could be incorporated into the research and publication process. We recognised that expectations around the type of feedback sought was unclear, particularly when reviewing a large, technical manuscript that included concepts unfamiliar to some contributors.

As a result, we worked with contributors to develop a cover sheet for researchers to complete when sharing research outputs (Supplementary File 2). This included a lay summary of the draft and key questions to guide feedback including clarity, relevance, and suggested improvements. We also developed a feedback form for contributors to complete, in addition to providing comments directly on the draft, to help support more consistent and structured feedback while allowing contributors to comment on relevant issues from their perspective (Supplementary File 3).

Despite researchers discussing results and findings with the advisory group prior to sending research outputs, there was sometimes a time lag between the meeting and receiving the draft which could add to the time burden. Due to one of the research projects having several research sub-teams and ongoing analyses, as well as some contributors being involved with other research projects and institutions, it could be difficult to recall the context, findings and previous discussions related to a particular research output. Contributors requested recent presentations and any useful supplementary material related to the research to be sent along with the draft.

Additionally, contributors identified the importance of receiving feedback about how their input was, or was not used, to inform the research output. We agreed that, while responses to each individual's comments would not be provided, researchers would provide a summary outlining how the manuscript

changed following PPIE input and, if relevant, give reasons why some suggestions were not able to be taken into account. This helped the process to be more transparent by informing contributors how their feedback had influenced the final output. Public contributors also found comments from the author to help with their learning as an added benefit, as well as understanding how to provide future feedback.

In May 2026 we signposted contributors to attend an online session that focused on having a voice in peer-reviewed literature delivered by an external patient organisation, and paid for their time to attend. Those who attended commented that it helped to remind them why they got involved in PPIE and that it was helpful to hear other people's experiences outside of the current project.

The Role of a Dedicated PPIE Lead

During a meeting to discuss this manuscript, contributors emphasised the importance of having a dedicated staff member as PPIE Lead within the research team to act as a "bridge" between the advisory group and wider research team. The PPIE Lead helped to clarify expectations around authorship and feedback, ensure contributors' comments were communicated to researchers, and coordinate the sharing and receipt of comments within agreed timelines. Contributors highlighted the value of having a consistent point of contact who could provide support and facilitate communication between themselves and the wider research team. This role provided continuity across the publication process and helped contributors navigate academic publication practices without requiring them to independently manage communication across different research teams. Although we did not encounter significant disagreements between contributors and researchers during this process, a dedicated PPIE Lead can also help to navigate differences of opinion and facilitate discussions, including during manuscript development.

The experience also highlighted that this role requires dedicated time, expertise, and resources. Although funding for PPIE commonly focuses on payments to public contributors, less attention may be given to the staff time and professional PPIE expertise needed to coordinate, support, and sustain meaningful involvement (De Simoni et al., 2023). Where a dedicated PPIE Lead is required, this should therefore be considered when planning and budgeting for PPIE activities. These experiences suggest that responsibility for making the publication process accessible and inclusive should sit with the research team, supported by appropriate PPIE expertise and resources, rather than relying on contributors to adapt to existing academic structures or pro-actively raise concerns about how the process is being managed.

Balancing Technical Expertise and Experiential Expertise

Within EHR research, involving public contributors as co-authors does not require them to have the same technical expertise as researchers, although some will bring professional and academic backgrounds. We found that a key challenge is not reducing the technical content, but involving contributors to influence how research is interpreted and presented, while maintaining technical detail for academic audiences. Contributors brought lived experience, professional backgrounds, and questions about the

relevance and interpretation of findings while researchers contributed expertise on the study topic, methods, and analyses, although these were not mutually exclusive. For example, in our research using EHR data to identify patient groups based on patterns of health conditions and healthcare use, the technical methods and classifications may not fully convey the experiences behind these patterns. Contributors can help contextualise these findings by considering what the classifications mean in practice and whether the interpretation reflects the experiences of patients and the public.

Having a targeted approach when reviewing particularly lengthy manuscripts helped contributors to focus on key areas where their lived experience could add value. Contributors were not expected to comment on every section of the manuscript, but encouraged to give input where their lived experience could provide important context. This is consistent with guidance suggesting that patient partners can make substantial intellectual contributions without being involved in all aspects of a research project or having expertise in its scientific methodology (Richards et al., 2020).

Influencing Interpretation, Language, and Dissemination Practices

We also found that contributors' involvement improved various aspects of research interpretation, communication, and dissemination. One example was how contributors helped to change the language researchers used during meetings and therefore in research outputs as well. During a PPIE meeting at the beginning of the project, contributors raised concerns about the use of the term "post-COVID" to describe the period following the COVID-19 lockdowns that was being examined in the research. They pointed out how this language did not reflect people's lived experiences, particularly those living with Long COVID. It also risked reinforcing assumptions that the pandemic had ended. The research team changed the term to "post-lockdown" to describe this period so it no longer implied that COVID-19 was in the past. This prompted the research team to reconsider the terminology used as well as the wider narrative that is presented when disseminating research.

Another example was where a contributor highlighted the use of 'non-White' in a manuscript and explained that this term was not consistent with current guidance on writing about ethnicity, recommending 'minority ethnic group' instead. Such feedback then informed future manuscripts, and provided support for the usage when subsequent questions around language arose. This highlights not only a need for wider understanding of how we write about inequalities, but also the benefit of involvement of those with lived experience.

A further example related to the interpretation of findings. In one study, findings were initially presented with a focus on respiratory syncytial virus (RSV) and influenza as the main drivers of seasonal illness. Contributors highlighted the need to consider the contribution of COVID-19 due to its clinical impact on patients as well as on winter pressures. Following this feedback, the discussion of COVID-19 was expanded in the paper, demonstrating how PPIE helped to also show which aspects of findings could be given more attention.

Finally, we received consistent feedback regarding the inclusion of plain language summaries alongside our manuscripts. This highlighted a need from the public which is inconsistently met by journals, with many not providing space for such summaries. In response, one of the projects began creating a series of blog posts to accompany manuscripts and communicate findings in more accessible language.

Discussion

Previous discussions of patient authorship have highlighted the importance of recognising lived experience as a form of expertise in research publications. However, much of the focus has been on advocating for including patients and the public, rather than the practical structures required to meaningfully involve contributors. Our experiences add to the literature by focusing on the practical aspects, particularly within technically complex research. We demonstrate that for co-authorship to be effective it requires consideration of roles, expectations, communication, and support throughout manuscript development rather than including public contributors in the final stages of submission and publication.

Our experience suggests that co-authorship does not mean that all authors contribute identically and as is also the case for both lived-experience and traditional researchers. It requires recognising that different forms of experience contribute to different aspects of knowledge production. While researchers bring methodological and subject-specific expertise, public contributors bring valuable experiential knowledge to the research as well as their own professional backgrounds and expertise. This has important implications for how contributions and authorship are understood within academic publishing. Traditional authorship frameworks often prioritise contributions towards study design or reviewing final manuscript drafts. However, public contributors can also make valuable contributions through challenging common assumptions within research narratives.

Importantly, this approach required researchers to adapt current publication practices rather than expecting public contributors to navigate these complex processes. Providing clear expectations, accessible summaries, and focused questions helped support contributors to participate. For EHR research where research outputs may contain complex concepts and methods, this support is important to ensure PPIE is not simply about improving readability.

This co-produced guidance provides a practical approach to support both researchers and contributors working together as co-authors, particularly for EHR research. Rather than suggesting a fixed model of involvement, the guidance outlines strategies that can be adapted and applied to different research contexts. Our experience shows that co-authorship needs to be considered throughout the research process, not just at the point of submission, for contributors to engage fully in the process.

This guidance may be useful for research teams, PPIE leads, public contributors, and institutions developing approaches for involving members of the public as co-authors. Practical aspects, such as providing a lay summary and focused questions, a structured way to provide feedback, sharing additional background information, and feeding back on how input was used, can help to make the

publication process more accessible and understandable. Implementing this approach requires planning for public co-authorship from the beginning of the project rather than after outputs have already been prepared by the research team. This is particularly important in large research projects that involve multiple work streams across different institutions as well as to ensure that there is adequate budget to pay contributors accordingly and employ a PPIE Lead to facilitate meaningful contributions.

Implementing this guidance requires more than just providing templates and forms. It has required us as a research team to reflect on, and reconsider, how authorship is understood and delivered in practice. There are also wider implications for journals, publishers, funders, and research institutions where barriers may unintentionally exist within current publication systems including fixed authorship expectations, unfamiliar submission requirements, and assumptions about how authors contribute.

These projects that we have been working on have shown the importance of the PPIE professional to coordinate activities and liaise between contributors and the research team, and the need to ensure adequate budgeting for this (De Simoni et al., 2023). Researchers and conference organisers should also consider practical and financial barriers that may affect contributors' ability to participate in such dissemination activities. This includes considering the needs of contributors with disabilities or health conditions, as well as those with caring responsibilities, and ensuring that appropriate adjustments and associated costs are considered in advance (NIHR, 2024). The PPIE Lead presented this guidance at the PEDRI Forum in London in September 2026. The advisory group were involved in developing the slides and some were able to attend remotely online who could not attend in person.

The process of drafting and reviewing this paper has sparked much thought and discussion around authorship within the wider research team and academia, in addition to public co-authorship. When working within a large research team, there can sometimes be the assumption that being a named co-investigator on a project can automatically lead to co-authorship. However, authorship needs to consider how each person has contributed to each output and the relevant authorship criteria. We have also reflected on the intended audiences of different research outputs and the challenges of balancing technical detail required for academic publications while communicating findings in ways that are accessible to the public. This highlights the importance that decisions about authorship and how research is shared needs to be considered throughout the research process, not just at the point of publication.

Limitations

As this guidance was developed within two England-based research studies involving one public advisory group, it reflects contributors’ experience within this context. Different research settings, advisory groups, and research topics may identify different needs or challenges, requiring guidance to be adapted to these particular circumstances. Additionally, the contributors involved in this work were already engaged in research involvement activities and may not represent the experiences of those newer to PPIE. Several contributors brought previous experience of reviewing research manuscripts and

co-authoring journal publications, which helped them to be familiar with the publication process and to inform the guidance. Finally, at the time of writing, the guidance had been applied to a limited number of research outputs (three journal manuscripts, two conference abstracts, and one blog). Therefore, we have not yet evaluated the impact of this guidance. Future work could explore the implementation of public co-authoring across different research contexts, to better understand its impact on contributors, researchers, and research outputs.

Conclusion

Co-authoring with public contributors requires structured support to ensure they can provide input throughout the publication process, with clear expectations and recognition of lived experience as a valuable contribution. This co-produced guidance offers a way to improve transparency making co-authoring less of a tokenistic gesture. However, it still continues to present certain challenges when supporting members of the public to be involved in a process that was not designed for them and when engaging in EHR research. We acknowledge that this is an on-going, iterative, reflexive, and active process that we will continue to develop as we discuss ways to improve and strengthen how we work with public contributors as co-authors. We have demonstrated how publications are not solely for dissemination but, when public contributors are included, can become a site for the co-production of knowledge.

Abbreviations

EHR
Electronic Health Records
FTE
Full-Time Equivalent
ICMJE
International Committee of Medical Journal Editors
NIHR
National Institute for Health and Care Research
PPIE
Patient and Public Involvement and Engagement
RSV
Respiratory Syncytial Virus

Declarations

Ethics approval and consent to participate

The underlying studies received appropriate ethical approvals and governance permissions for the use of EHR data. (NIHR Winter Pressures: LSHTM Ethics Ref: 31473, IRAS project ID: 349399 Protocol

number: 31473REC reference: 24/HRA/5020; Respiratory Virus Risks: LSHTM Ethics Ref: 29879, IRAS project ID: 340706). Public involvement activities were conducted as part of the projects' PPIE. Ethical approval was not required for these activities as they involved contributors providing advice on research processes and outputs rather than participating as research participants. Contributors provided consent for their involvement and for their contributions to be recognised in publications where applicable.

Consent for publication

Not Applicable

Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Competing interests

REC has personal shares in AstraZeneca.

Funding

These research projects were funded by the NIHR Health and Social Care Delivery Research programme (NIHR158218) and NIHR Fellowship (NIHR303287), and NIHR Programme Grants for Applied Research Programme (NIHR209347). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. The funders had no role in the study design, data collection and analysis, and interpretation of results, in the writing of the manuscript, and in the decision to submit the article for publication.

RME, SD and REC were supported by the Medical Research Council (MR/X033260/1). RME is supported by the NIHR (NIHR207404). RM is supported by Barts Charity (MGU0504).

Authors' contributions

HM conceived the paper and led the development of the manuscript. HM facilitated the public involvement activities and coordinated the co-production of the guidance. RME provided overall supervision and oversight of the research and contributed to the interpretation of findings and revision of the manuscript.

Public contributors (MN, YA, FY, SBM, JE) contributed to the development of the guidance, shared their experiences of involvement in research publications, and contributed to the interpretation of findings and development of key messages. They reviewed and critically revised the manuscript, providing perspectives informed by their lived experience and involvement in research.

LMP, RD, LT, RM, REC, JG, EH, SD, JM, EP, RME contributed to the interpretation of findings and critically reviewed the manuscript. EP contributed to the development and design of Figure 1. All named authors reviewed and approved the final manuscript and agree to be accountable for their contributions.

Acknowledgements

We would like to thank the PPIE advisory group for their insightful contributions to this research. We are grateful to the named contributors some of whom are co-authors, Yvonne Adler, Sarah Barley-McMullen, Janice Elliott, Michael Natt, Farheen Yameen, as well as to those members who have chosen not to be named, whose perspectives were integral to shaping this research and guidance.

References

1. De Simoni A, Jackson T, Humphrey I, Preston W, Mah J, Wood H, Porteous HE, C. Patient and public involvement in research: the need for budgeting PPI staff costs in funding applications. Res Involv Engagem. 2023;9(1):16.
2. Fox G, Lalu MM, Sabloff T, Nicholls SG, Smith M, Stacey D, Fergusson DA. Recognizing patient partner contributions to health research: a systematic review of reported practices. Res Involv Engagem. 2023;9(1):80.
3. International Committee of Medical Journal Editors. (2026). Recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals. https://www.icmje.org/recommendations/
4. Mah H, Dobson R, Thomson A. (2025). The importance of lived experience: A scoping review on the value of patient and public involvement in health research. Health Expect, 28(2), e70205.
5. National Institute for Health and Care Research. (2024). *Practical support for public involvement*. NIHR School for Primary Care Research. https://www.spcr.nihr.ac.uk/PPI/resources-for-researchers/practical-support
6. National Institute for Health and Care Research. (2024). *Public involvement.* NIHR. https://www.nihr.ac.uk/get-involved/public-involvement
7. National Institute for Health and Care Research. (2025). *Public contributor reward policy.* NIHR. https://www.nihr.ac.uk/about-us/who-we-are/policies-and-guidelines/public-contributor-reward-policy
8. National Institute for Health and Care Research. (n.d.-a). *Impact and inequalities of winter pressures in primary care: providing the evidence base for mitigation strategies.* NIHR Funding and Awards. (Award Reference 158218). https://fundingawards.nihr.ac.uk/award/NIHR158218
9. National Institute for Health and Care Research. (n.d.-b). *Mitigating health inequalities in Respiratory Syncytial Virus: an OpenSAFELY analysis of RSV burden and impact of potential maternal vaccine programmesNIHR Funding and Awards*. (Award Reference NIHR303287). https://fundingawards.nihr.ac.uk/award/NIHR303287

10. National Institute for Health and Care Research. (n.d.-c). *Advancing evaluation of respiratory virus vaccine effectiveness in real time data* (Award reference NIHR209347). NIHR Funding and Awards. https://www.fundingawards.nihr.ac.uk/award/NIHR209347
11. Oyenuga MO, Apata SB, Oladele TO, Jeresa S. (2026). You Put my name, I Put your name: exploring unethical practices in academic publishing using the authorship misappropriation Diamond framework. Ethics Behav, 1–24.
12. Richards DP, Birnie KA, Eubanks K, Lane T, Linkiewich D, Singer L, Begley KN. Guidance on authorship with and acknowledgement of patient partners in patient-oriented research. Res Involv Engagem. 2020;6(1):38.
13. Woolley KL, Stones SR, Stephens R, Bharadia T, Yamamoto B, Geissler J, Lobban D. (2024). Patient authorship of medical research publications: an evolution, revolution, and solution? Learn Publish, 37(3), e1607.

Figures



Figure 1

Infographic of Co-Authorship Guidance

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryFile3PPIEContributorFeedbackForm.docx
- SupplementaryFIle2PPIEPublicationReviewCoverSheet.docx
- SupplementaryFile1PPIEGuidanceforReviewingResearchOutputs.docx