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We Have Something to Say: An International Cross-Sectional Survey of Experiences, Perspectives, and Needs of Patient Authors

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We Have Something to Say: An International Cross-Sectional Survey of Experiences, Perspectives, and Needs of Patient Authors

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Abstract

Background

How to best work with patient authors of peer-reviewed journal articles has been described primarily from the perspective of researchers and publication professionals. Relatively little is known about the experiences, views, and needs of patient authors from their own perspective. We performed a survey of patient authors to help address this evidence gap.

Methods

This was a cross-sectional, international, web-based survey open from November 2025 to March 2026. Participants were recruited through international patient advocacy networks, professional organisations, and social media.

Results

The survey was completed by 179 individuals from 27 countries self-identifying as patient authors. They were mostly female (74%), aged 45–64 years (55%), from high-income countries (95%), members of patient organisations (82%), and with at least an undergraduate degree (84%). Half (50%) started publishing within the previous 5 years, 45% had authored >5 articles, and 50% had led production of an article. Most contributed by providing written feedback (90%), editing others' writing (79%), collecting, analysing, describing, or interpreting findings (74%), helping design the research (69%), or writing at least some of the article (61%). Some (22%) led the research. A few (6%) reported not making contributions needed to meet standard authorship criteria. Of the 178 respondents who had collaborated with scientist or

healthcare provider co-authors, most strongly agreed or agreed they had the opportunity to express their viewpoints (87%), felt comfortable contributing ideas/viewpoints (79%), felt their input was seriously considered (78%), had a chance to influence final decisions (63%), and felt respected (82%). Nearly all agreed or strongly agreed that readers should know when patient authors had contributed to an article (93%) and were willing to be identified as patient authors (90%). The most frequently requested types of support were mentoring (60%) and written training materials (53%).

Conclusions

This international survey of patient authors showed that most had positive authorship experiences and opportunities to contribute substantially to peer-reviewed journal articles. They supported transparency in patient authorship and identified mentorship and written training materials as priorities to support patient authors. The limited diversity of patient authors in this survey suggests opportunities to broaden participation in patient authorship.

Keywords

Authorship, patient author, patient and public involvement and engagement, lived experience, publications, cross-sectional survey, patient advocacy, publishing, GRIPP2

Abbreviations

AI, artificial intelligence; PPIE, patient and public involvement and engagement

Plain English Summary

Patient authorship is when patients make substantial contributions to creating medical research articles and meet the same requirements as researchers to be named as authors. This is becoming more common as patients work together with researchers to improve healthcare. However, we do not know much about the experiences of patient authors, what they think about their roles, or what support they might need.

To learn more, we ran an online survey from November 2025 to March 2026. A total of 179 patient authors from 27 countries completed the survey. Most were middle-aged, well-educated women living in upper-income countries and members of patient organisations. Most had authored and contributed to several articles and, in some cases, had even led the writing or the research.

Generally, the patient authors responding to this survey were positive about their experiences working with researchers and healthcare professionals on articles. They felt that articles should clearly show when a patient author had contributed to it. They also suggested several ways of improving patient authorship, especially through mentoring and written training materials.

Overall, our survey showed that patient authors make valuable contributions to research articles, although they could benefit from additional support. Increasing the diversity of patient authors could help bring a wider range of patient experiences and perspectives into medical research.

Background

Increasingly, patients and caregivers are making substantial contributions to and sometimes even leading the production of peer-reviewed healthcare journal articles (1, 2). These contributions frequently merit authorship (1, 3, 4). The term “patient author” has been used to describe these individuals and identify articles they have contributed to (1, 2, 4). Patient authors are considered to include patients, caregivers, family members, and members of patient advocacy groups who provide input from a patient perspective and who meet authorship criteria, especially those of the International Committee of Medical Journal Editors (4).

Patient authorship is supported by and part of the methodology of patient and public involvement and engagement (PPIE) (5). PPIE represents a shift from doing research on and for patients to doing research with patients, ideally as equal partners. Increasingly, people with lived experience of health conditions and diseases are helping to set research priorities, shape research questions, design studies, interpret findings, and disseminate study results (6-9). This shift to partnering with patients is being driven by increasing funding requirements, calls for patient participation in regulatory processes, and growing recognition that research is stronger, more relevant, and more trustworthy when it includes perspectives from those it is meant to serve (10-14). Patient authorship is rapidly increasing, along with the healthcare community’s recognition of the value of patients’ insights and perspectives (1, 5, 11-15).

How to best work with patient authors has been described primarily from the perspective of researchers and publication professionals (1, 11, 12, 16). Relatively little is known about the experiences, views, and needs of patient authors from their own

perspective. We therefore conducted an international survey to understand patient authors' backgrounds, pathways into authorship, experiences, perceived barriers, support needs, and preferences for recognition.

Methods

Study Design

This was a cross-sectional, international, web-based survey of adult patients and caregivers who have been authors of articles published in peer-reviewed healthcare journals. The survey was open between November 10, 2025 and March 4, 2026. The full survey text is available in **Additional File 1**. In agreement with current definitions (1, 2, 4), throughout this article, we refer to these individuals collectively as "patient authors."

We used convenience sampling with voluntary participation to recruit patients through international patient advocacy networks, professional organisations, and social media channels (LinkedIn and X). To participate in the survey, individuals had to self-declare that they (i) had lived experience with a disease as either a patient or caregiver and (ii) had been listed as an author on a peer-reviewed healthcare journal article related to that same disease. They also had to have access to an internet connection and a computer or other device to respond to the survey, and they had to consent to participate in the survey and allow their anonymous, aggregated data to be published. There were no formal exclusion criteria other than failure to meet the eligibility requirements or not providing consent. Survey participants did not receive any payment or other financial incentives.

To guide the minimum recruitment target, PubMed was searched in November 2025 to identify the number of articles using "patient author" and "patient partner" as affiliation terms. This revealed 427 articles. Based on previous analyses suggesting approximately two patient authors per publication (1), the potentially eligible population was estimated at approximately 854 individuals. Given the difficulty of identifying this population and reaching all potential participants, we selected a pragmatic minimum target of 50 participants. No formal sample-size or power calculation was performed because no inferential statistical hypothesis testing was conducted.

Survey

This survey was developed by the authors of this article, which included experts in patient authorship and partnership, patient advocacy, and academic and pharmaceutical industry research. A survey methodologist reviewed the survey and refined it in collaboration with the authors. The topics and questions for this survey were selected based on existing literature on PPIE, publication ethics, and authorship practices, as well as by the lived experience of patient authors and authors of articles co-authored by patient authors. The initial survey was refined through multiple discussions with the authors and through one round of pilot testing by three patient authors with similar profiles as the target population but who were not involved in conducting the study.

The final survey included 31 questions (**Additional File 1**). Of these, 29 were multiple-choice questions. The remaining two were open-ended ("In your opinion, what other things could help improve the experience of being a patient or caregiver author?" [question 21] and "Do you have any recommendations or comments about how you

would like your contribution as a patient or caregiver author to be recognised in peer-reviewed healthcare journal articles?" [question 25]). Responses were anonymous, and no personally identifiable information was collected.

The survey began with a set of screening questions to confirm eligibility to participate (consent to participate and have anonymous, aggregated results published; lived experience as a patient or caregiver; and authorship of at least one peer-reviewed healthcare journal article related to that experience). This was followed by questions addressing the extent of experience publishing peer-reviewed healthcare journal articles, motivations for authorship, experiences during the publication process, perceived barriers and facilitators, interactions with research teams and journals, and recommendations to improve patient and caregiver inclusion as authors. Responses to questions about attitudes or feelings were based on a five-point, bi-directional Likert scale, where options were "strongly agree", "agree", "neutral", "disagree", and "strongly disagree". Responses to branching questions allowed the participant to skip non-applicable portions of the survey, so some were presented fewer than 31 total questions. Responses were required for multiple-choice but not for open-ended questions.

The survey was programmed by the survey methodologist and administered through a secure web-based survey platform (Alchemer, Louisville, CO, USA). Estimated completion time for the survey was approximately 10 to 15 min. Survey response data were stored securely in the Alchemer platform with applicable security and privacy controls, and analytic datasets were maintained in a restricted-access SharePoint repository accessible only to PL, DD, and authorized administrators.

Statistical Analysis of Quantitative Survey Data

Descriptive analysis of numerical data was conducted using R version 4.4.1 (R Foundation, Vienna, Austria). Responses to all multiple-choice questions were mandatory, so no item responses were missing. Potential non-response bias was not addressed because differences between respondents and non-respondents could not be assessed. An overall survey response rate could not be calculated because the number of eligible individuals who received or were exposed to the survey invitation was unknown.

Because we did not collect identifying information or internet protocol addresses, whether an individual completed the survey more than once could not be determined. Rather, the analytic dataset was analysed for exact duplicate response patterns.

Responses to multiple-choice questions were encoded according to a coding dictionary developed prior to statistical analysis. Ordinal response categories were assigned numerical values consistent with scale directionality (e.g., 1–5 for Likert items), and categorical variables were recoded as appropriate for analysis. Surveys from respondents who did not meet eligibility criteria and partially completed surveys were excluded prior to dataset finalisation.

Thematic analysis of open-text responses

Inductive thematic analysis of deidentified open-text responses to questions 21 and 25 was conducted separately with generative artificial intelligence (AI) assistance (ChatGPT, GPT-5.6 Sol, OpenAI, San Francisco, CA, USA) within the Thermo Fisher Scientific ChatGPT Enterprise environment. The thematic analysis was based on the principles described by Braun and Clarke (17) and by AI-supported bottom-up analysis

of open-text survey responses described by Parker et al. (18). No a priori coding framework, themes, or subthemes were specified.

Before thematic analysis was initiated, open-text responses underwent AI-assisted de-identification. Proposed redactions were independently adjudicated by the two lead authors (PL and DD). Disagreements were resolved through discussion and consensus.

Only codable responses as identified by AI and confirmed by PL and DD were included in thematic analysis and constituted the denominator for prevalence calculations. Blank/missing and non-intelligible responses were excluded. Potential item non-response error was addressed by restricting thematic prevalence estimates to codable responses and by reporting the disposition of open-text responses.

ChatGPT supported inductive coding, development and iterative refinement of themes and subthemes, multi-label classification of responses, and verification against supporting and divergent or disconfirming evidence. PL and DD independently reviewed the same AI-generated analytic outputs, including response classifications, theme and subtheme assignments and boundaries, and supporting and divergent evidence. Disagreements were resolved through discussion and consensus. Consensus decisions were incorporated into the final response-level matrices before prevalence was calculated as the proportion of unique codable respondents supporting each theme or subtheme. Respondents could contribute to multiple categories but were counted once within each category.

Detailed analytic and de-identification procedures, researcher reflexivity, quality control, audit-trail procedures, and verbatim prompts are provided in **Additional File 2**.

Ethics

The study was designed to adhere to the ethical principles of the Declaration of Helsinki. The study was conducted and reported in alignment with Regulation (EU) 2016/679 (General Data Protection Regulation) and is reported in compliance with the CROSS checklist for reporting survey research (19) (**Additional File 3**). Given the anonymised, low-risk, non-interventional study design and the nature of the survey topic, formal ethical review was not sought. The role of patient partners in the research is described in compliance with the GRIPP2 short form (20).

Role of Patient Partners

Several authors contributed lived-experience and patient-partner perspectives throughout the study, including defining survey themes, selecting and refining survey questions, interpreting results, and developing and reviewing the manuscript. This was to ensure that the survey addressed issues most relevant to patient authors, used appropriate terminology, and reflected lived-experience perspectives on authorship. However, not all authors with lived experience chose to identify themselves as such in their affiliations.

Results

Sample

The online survey was accessed by 278 individuals and completed by 179 (**Additional file 4**). No evidence of duplicate entries was found. Of the 179 participants, 133 (74%) declared as female, 42 (23%) as male, and four (2%) as preferring not to disclose their sex at birth (**Table 1**). Participants were most frequently middle-aged (n = 52 [29%] 55–

64 years and n = 47 [26%] 45–54 years), residing in high-income countries (n = 170; 95%), members (n = 63; 35%) or with staff or leadership positions (n=83; 46%) in patient organisations, native English speakers (n=117; 65%), and highly educated (n=88 [49%] with a post-graduate degree, n=16 [9%] with some post-graduate education, and n=43 [24%] with an undergraduate degree). The participants resided in 27 countries, most located in North America (n=77; 43%) and the Europe-Middle East-Africa region (n=76; 42%).

Table 1. Participant characteristics

Characteristic	n (%) N=179
Sex at birth	
Female	133 (74)
Male	42 (23)
Prefer not to say	4 (2)
Age, years	
12–17	0 (0)
18–24	1 (1)
25–34	9 (5)
35–44	25 (14)
45–54	47 (26)
55–64	52 (29)
65–74	35 (20)
≥75	10 (6)
Highest level of education	
No formal education	0 (0)
Some secondary education	1 (1)
Completed secondary education	9 (5)
Some undergraduate education	18 (10)
Completed undergraduate education	43 (24)
Some post-graduate education	16 (9)
Completed post-graduate education	88 (49)
Prefer not to say	4 (2)
English native language	
Yes	117 (65)
No	62 (35)
Patient organization membership	
Staff or leadership position	83 (46)
Member but not staff or leadership position	63 (35)
Not a member	33 (18)
Income classification	
Lower middle	6 (3)
Upper middle	3 (2)
High	170 (95)
Region	
North America	77 (43)
Europe, the Middle East and Africa	76 (42)
Asia Pacific	25 (14)
Latin America	1 (1)

Percentages for each characteristic may not total 100 due to rounding.

Quantitative Survey Results

Experience as a Patient Author

Just under half of the respondents (45%) had authored ≥5 peer-reviewed healthcare journal articles (5–10 [n=31; 17%], >10 [n=50; 28%]), although most frequently, they had authored 2–5 articles (n=69; 39%) (**Figure 1A**). Half (n=89; 50%) had led the production of at least one peer-reviewed healthcare journal article, most of whom had done so once (n=34; 19%) or 2–5 times (n=36; 20%). Non-authorship contributions were reported by 73% (n=131), with 15% (n=27) having done so 5–10 times and 13% (n=23) >10 times. Half of respondents (n=90; 50%) started authoring articles after 2020 (**Figure 1B**).

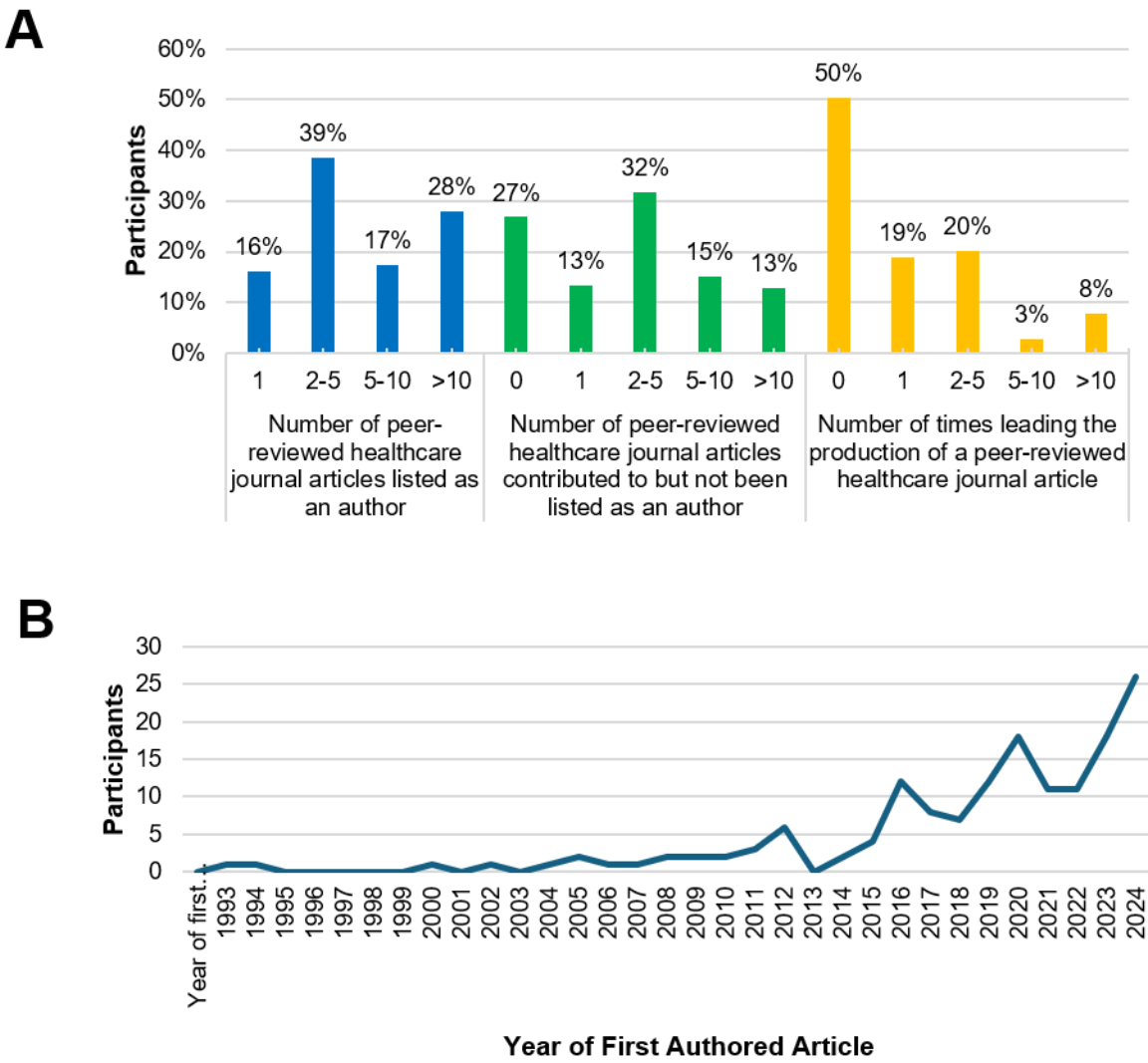


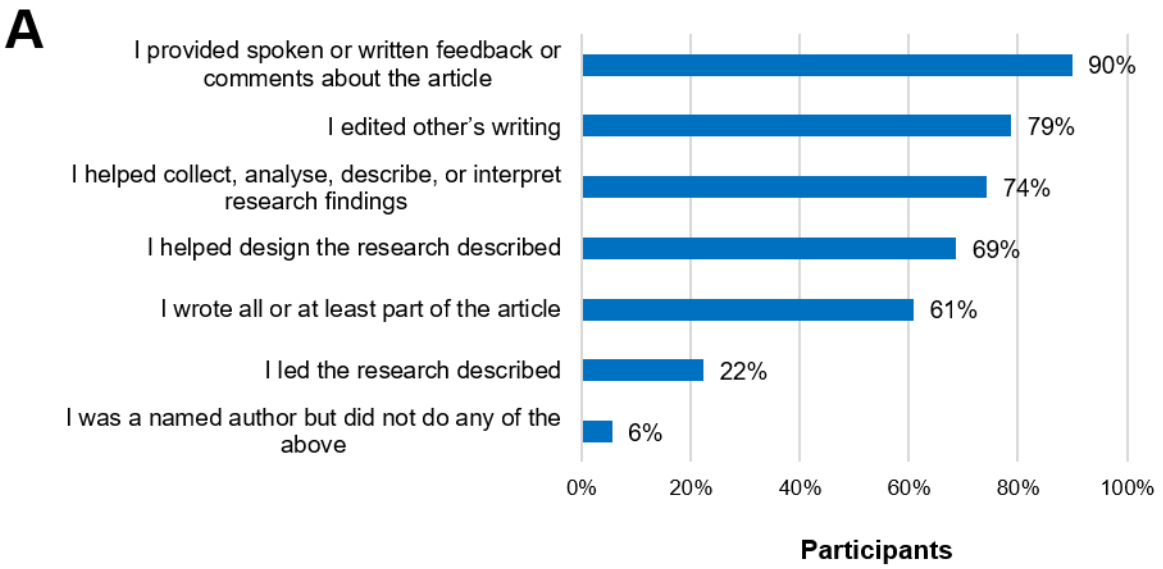
Figure 1. Patient author experiences

(A) In a multiple-choice question, participants (N=179) were asked for the number of peer-reviewed healthcare journal articles in which they were listed as an author, the number they contributed to but not listed as an author, and the number for which they led the production (right bars). (B) Participants (N=179) were asked the year they were first listed as an author of a peer-reviewed healthcare journal article.

Respondents contributed to peer-reviewed articles in a variety of ways, especially by providing written feedback or comments (n=161; 90%), editing others' writing (n=141; 79%), collecting, analysing, describing, or interpreting findings (n=133; 74%), and helping design the research (n=123; 69%) (**Figure 2A**). Most (n=109; 61%) reported having written at least part of the articles. Just under one-quarter of respondents (n=40;

22%) reported leading the research described in articles on which they were authors. A few respondents (n=10; 6%) did not contribute in any of these ways.

Of the 89 respondents who reported leading the research, 84 (94%) did so in collaboration with co-authors. In most cases, the 84 respondents who had led the research were always (n=31; 37%) or usually (n=18; 21%) listed as the first author, but in some cases, they were listed as the first author only sometimes (n=15, 18%), occasionally (n=4; 5%), or never (n=16; 19%) (**Figure 2B**).



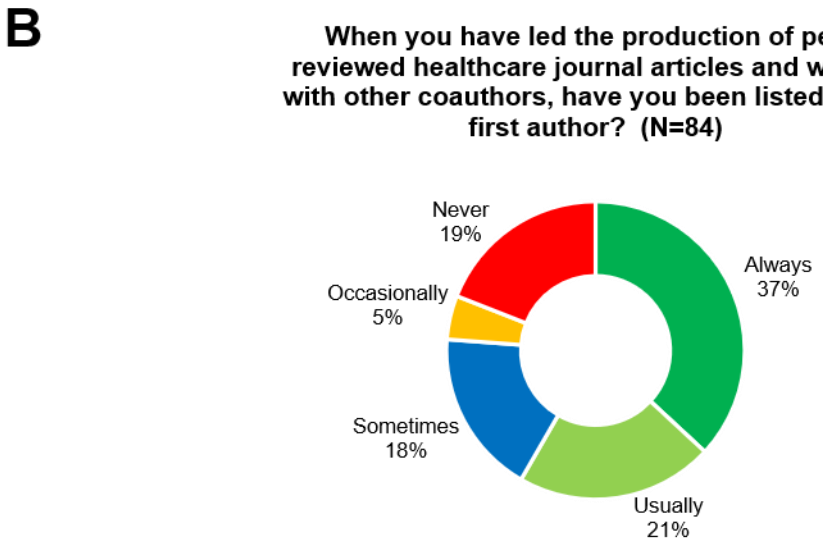


Figure 2. Contributions as an author
(A) In a multiple-choice question, participants (N=179) were asked to indicate ways that they had contributed to peer-reviewed journal articles as an author. Multiple options could be selected. (B) Participants who had led the production of a peer-reviewed medical journal article and had collaborated with co-authors (N=84) were asked on a five-point Likert scale how frequently they had been listed as the first author.

Experiences Collaborating with Other Authors

When collaborating with other authors on peer-reviewed healthcare journal articles, most respondents strongly agreed (n=64; 36%) or agreed (n=90; 50%) that they had understood their responsibilities and the requirements to be an author (**Figure 3A**). Similarly, most strongly agreed (n=47; 26%) or agreed (n=95; 53%) that they had

290 received sufficient information about how the research was done and about the results
291 obtained (**Figure 3B**). However, they were less positive when asked about whether they
292 had received sufficient training, with 15% (n=27) strongly agreeing, and 23% (n=41)
293 agreeing, 26% (n=46) neutral, 30% (n=54) disagreeing, and 6% (n=11) strongly
294 disagreeing (**Figure 3C**).

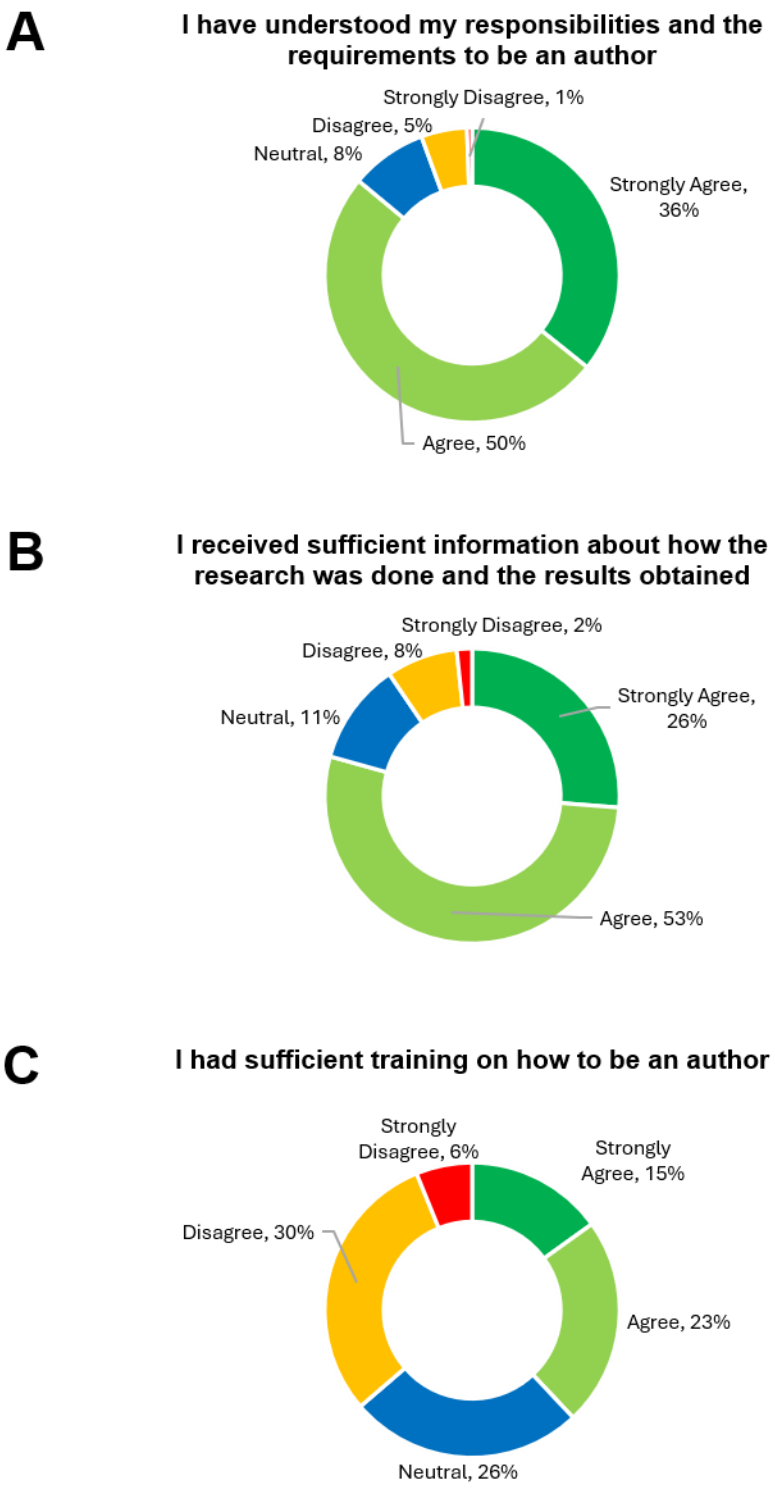


Figure 3. Experiences when invited to collaborate on healthcare journal articles
Participants (N=179) were asked on a 5-point Likert scale about their experiences when invited to collaborate on peer-reviewed healthcare journal articles related to (A) understanding responsibilities and requirements to be an author, (B) receiving sufficient information about how the research was done and the results obtained, and (C) having sufficient training on how to be an author.

Experiences Working with Scientists and Healthcare Provider Co-authors on Peer-Reviewed Healthcare Journal Articles

All but one respondent (n=178; 99%) reported having been invited to collaborate on healthcare journal articles with scientist or healthcare provider co-authors. Most of these respondents strongly agreed or agreed that they had the opportunity to clearly express their viewpoints (n=155; 87%; **Figure 4A**), felt comfortable to contribute ideas or express viewpoints (n=141; 79%; **Figure 4B**), felt that their input was seriously considered (n=138; 78%; **Figure 4C**), had a chance to influence final decisions about the articles (n=113; 63%; **Figure 4D**), and felt respected (n=146; 82%; **Figure 4E**).

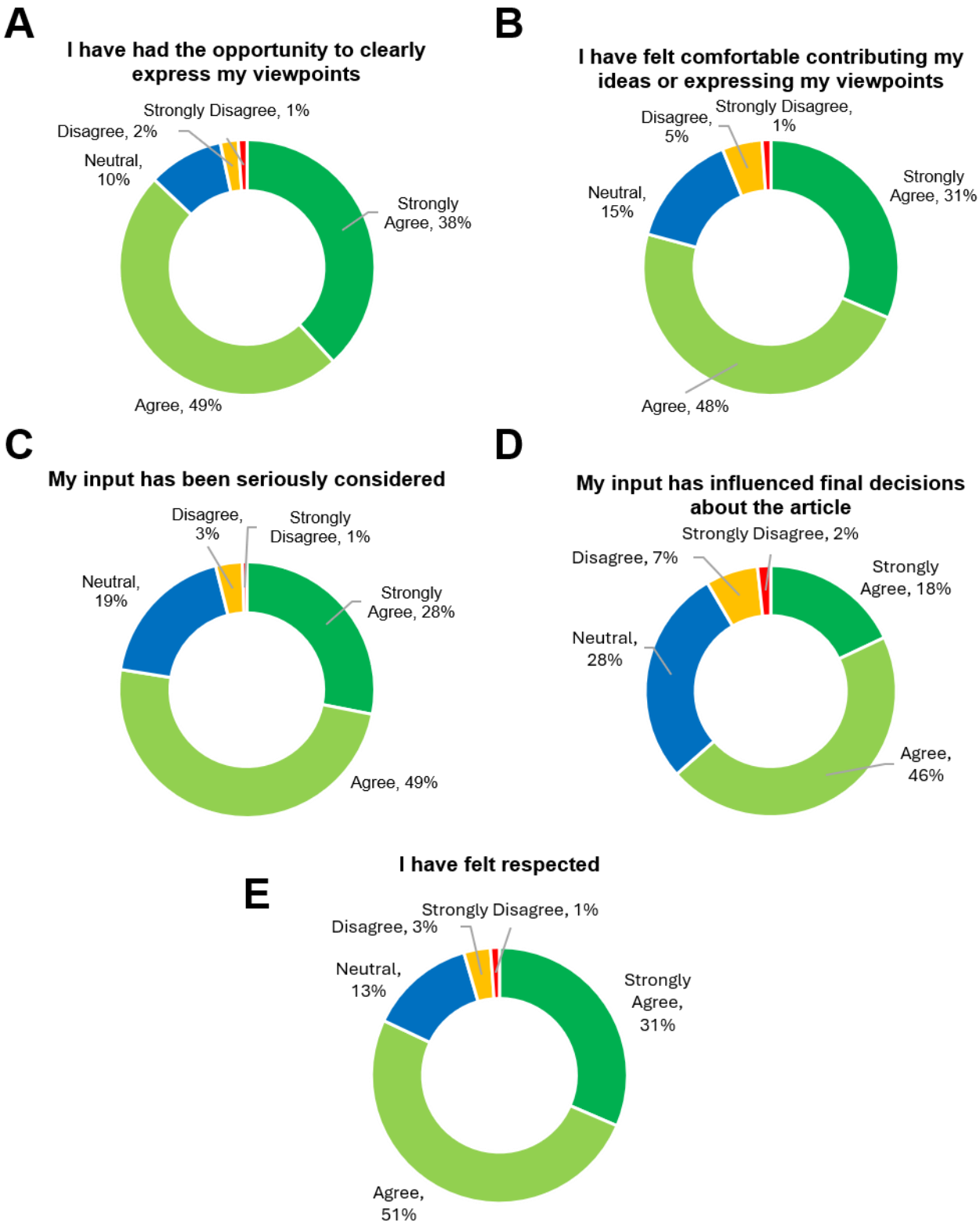


Figure 4. Experiences collaborating with scientist or healthcare professional co-authors
Participants who had collaborated with scientist or healthcare professional co-authors (N=178) were asked on a 5-point Likert scale about their experiences working with their collaborators related to (A) having the opportunity to clearly express viewpoints, (B) feeling comfortable contributing ideas or expressing viewpoints, (C) having input seriously considered, (D) having input influence final decisions, and (E) feeling respected.

Willingness to be Identified as a Patient Author

Almost all respondents strongly agreed or agreed that it is important for readers to know when patients or caregivers had contributed to an article as an author (n=166; 93%; **Figure 5A**) and that they were willing to be visibly identified as such, even if this would cause them to publicly disclose their personal connection to a specific condition or a disease (n=161; 90%; **Figure 5B**).

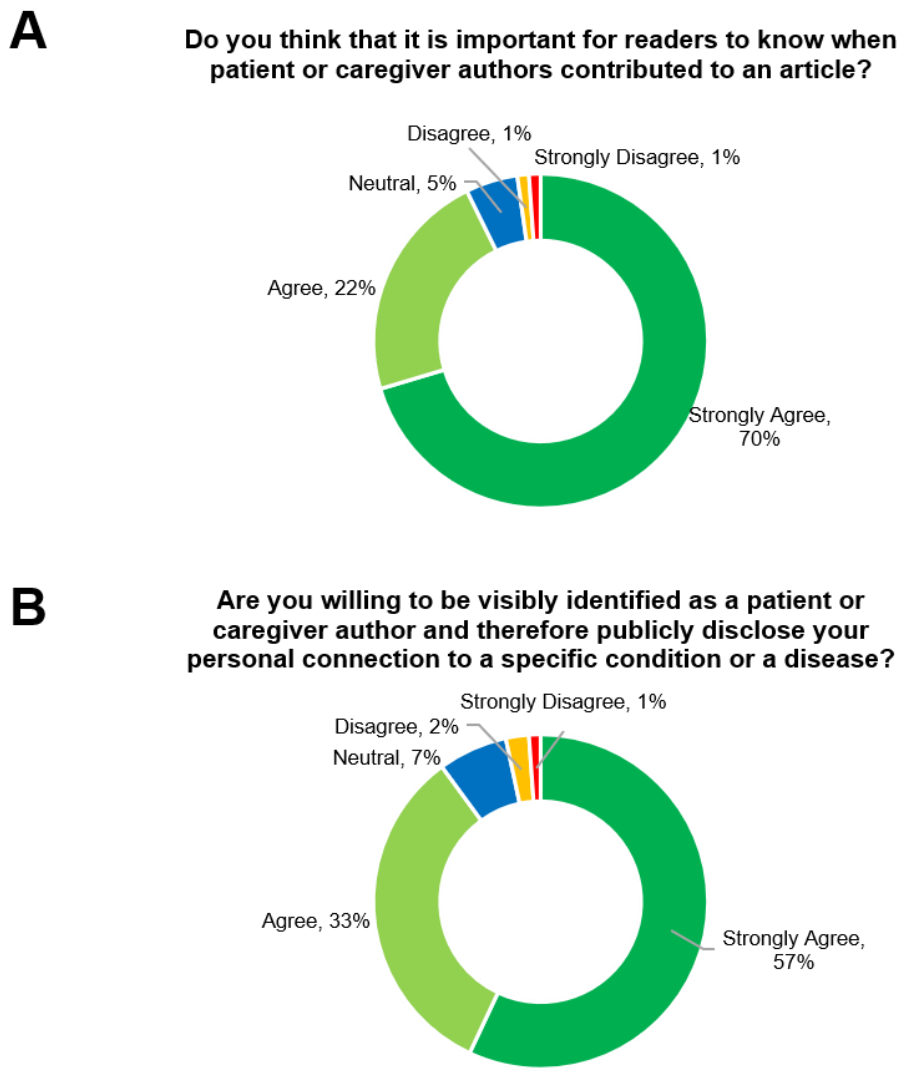


Figure 5. Recognition of patient authors' contributions
Participants (N=179) were asked on a 5-point Likert scale about (A) whether they think that it is important for readers to know when patient or caregiver authors contributed to an article and (B) whether they are willing to be visibly identified as a patient or caregiver author and therefore publicly disclose a personal connection to a specific condition or a disease.

Of the 18 respondents who were neutral (n=12; 7%), disagreed (n=4; 2%), or strongly disagreed (n=2; 1%) about being willing to visibly identified, the most frequent reasons were not wanting to disclose personal health information for themselves or a person they care for (n=10; 56%), being concerned about a negative impact on the professional life or career for themselves or a person they care for (n=9; 50%), and not wanting themselves or a person they care for to be stigmatised or judged based on a health condition (n=8; 44%) (**Figure 6**).

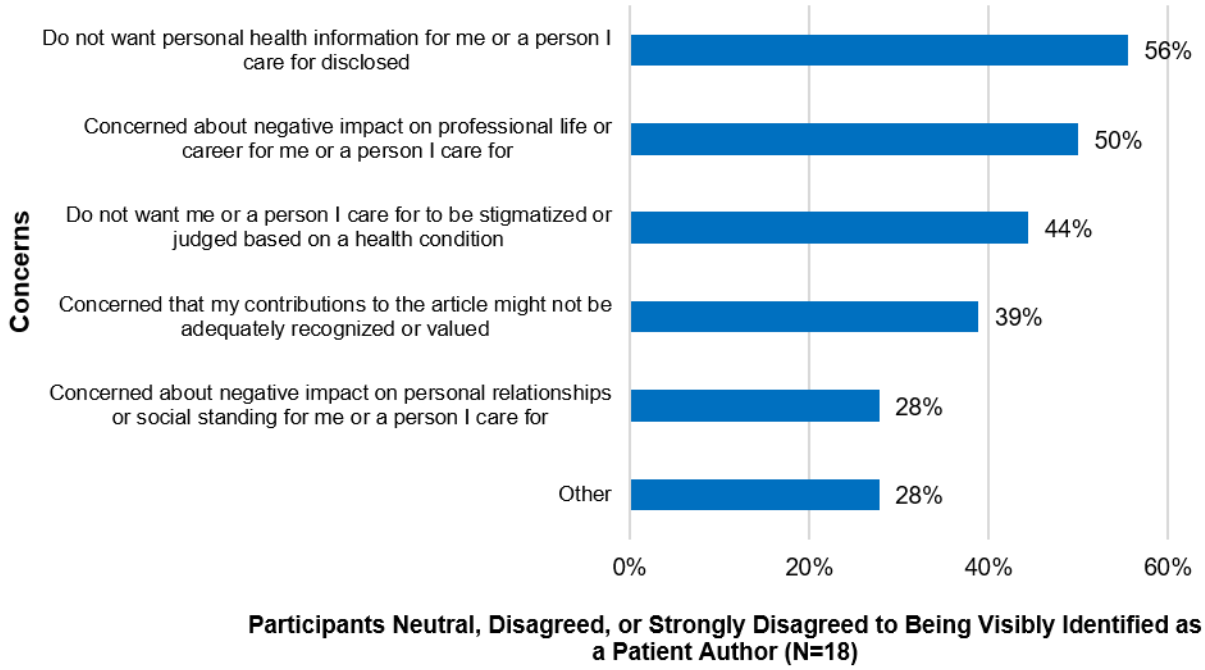


Figure 6. Reasons for concern about being visibly identified as a patient author
In a multiple-choice question, participants who were neutral (n=12), disagreed (n=4), or strongly disagreed (n=2) about being willing to be visibly identified as a patient author were asked for the reasons. Multiple options could be selected.

Support Needs

In a multiple-choice question, participants were asked what they considered the three most helpful ways of supporting their work as an author. The most frequent selections were mentoring by other people experienced in writing healthcare journal articles (n=108; 60%) and written training materials (n=95; 53%) (**Figure 7**). This was followed by

opportunities during the writing process to express themselves, ask questions, and have their opinions heard (n=65; 36%), interactive training workshops (n=65; 36%), and software tools, resources, or templates to help structure, format, and write articles (n=59; 33%).

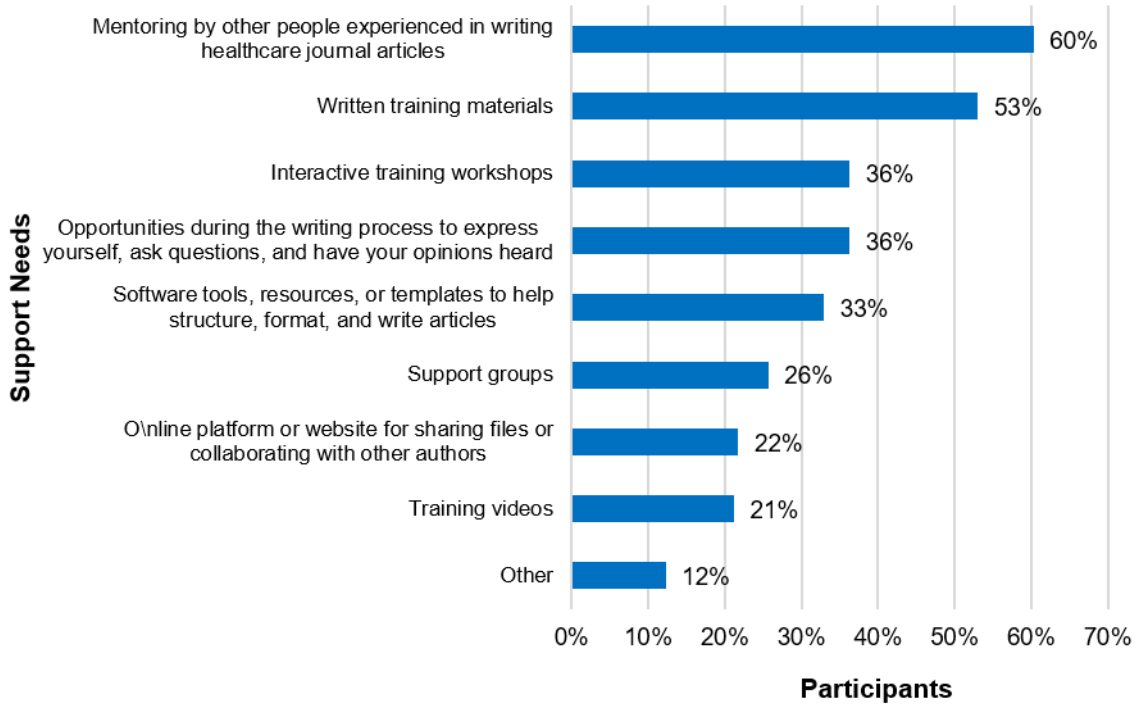


Figure 7. Support needs
In a multiple-choice question, participants (N=179) were asked were asked for their top three options to support their work as a patient author.

Thematic Analysis of Open-text Responses

Suggestions for Recognition of Contribution

In an open-ended question, participants were asked, “In your opinion, what other things could help improve the experience of being a patient or caregiver author?” Codable responses were collected from 136 participants (**Table 2** and **Additional file 5**).

Table 2. Suggestions for improvements in patient authorship experiences

Theme	Subtheme	n (%) N=136
Navigating authorship through guidance, learning, and support	Overall theme	76 (56%)
	Clear roles, expectations, processes, and communication	36 (26%)
	Training and capacity building for writing/research/publication	29 (21%)
	Mentorship, peer learning, and community support	27 (20%)
Meaningful participation through early involvement, voice, and opportunity	Overall theme	40 (29%)
	Early and sustained involvement with genuine opportunities to contribute	29 (21%)
	Space to be heard, influence decisions, and stay connected	22 (16%)
Practical conditions that make participation feasible	Overall theme	37 (27%)
	Fair compensation and funding access	15 (11%)
	Time, flexibility, accommodations, and patience	16 (12%)
	Access to literature, tools, platforms, and other practical resources	16 (12%)
Equal partnership and recognition of lived-experience expertise	Overall theme	36 (26%)
	Respect, equality, anti-tokenism, and valuing lived experience	33 (24%)
	Culture change and training for researchers/clinicians/collaborators	21 (15%)
Journal and institutional systems that accommodate and legitimize patient authors	Overall theme	33 (24%)
	Journal/institutional policies, requirements, and patient-friendly infrastructure	25 (18%)
	Authorship identity, affiliation, contribution recognition, and legitimacy	22 (16%)

Participants were asked to provide open-text responses to, "In your opinion, what other things could help improve the experience of being a patient or caregiver author?" Themes and subthemes were identified inductively with support from ChatGPT using GPT-5.6 Sol (OpenAI), which coded responses, developed and refined candidate themes and subthemes, and verified them against supporting and divergent responses; outputs were independently reviewed by two researchers and finalized through consensus adjudication.

The most common them, cited by 56% (n=76) of respondents, described authorship as an experience that could be improved through greater clarity about what patient and caregiver authors are expected to do and how publication processes work, alongside opportunities to develop relevant skills and receive support from others. Respondents asked for clear roles, expectations, processes, and communication; training and capacity building for writing, research, and publication; and mentorship, peer learning, and community support. Respondents asked for support that was practical and

responsive to different levels of familiarity and experience, accessible, flexible, and able to accommodate limitations of health, time, and availability.

Four other themes were each mentioned by one-quarter to one-third of respondents. A request for meaningful participation through early involvement, voice, and opportunity was mentioned by 29% (n=40). They described having improved authorship experiences when they were involved early and remained involved throughout the work, rather than being invited only at a late stage. This included early and sustained involvement with genuine opportunities to contribute and having space to be heard and influence decisions.

Practical conditions that make participation feasible were mentioned by 27% (n=37). They asked for material and logistical factors that could enable patient and caregiver authors to participate, including fair compensation and access to funding; sufficient time, flexibility, accommodations, and patience; and access to literature, tools, platforms, and other practical resources.

Nearly the same number of participants (27%; n=36) called for lived experience to be recognized as a legitimate form of expertise that could make a substantive contribution to research and authorship, and for patient and caregiver authors to be treated as equal partners rather than included as tokens. They expressed concerns about tokenism and treating an individual's lived experience as representative of a wider patient population. However, they also cautioned against assuming that lived experience alone conferred sufficient scientific or writing expertise required for peer-reviewed authorship.

Finally, journal and institutional systems that accommodate and legitimize patient authors were requested by 24% (n=33). Recommendations included journal or

institutional policies, requirements, and patient-friendly infrastructure; and mechanisms addressing authorship identity, affiliation, contribution recognition, and legitimacy.

Suggestions for Improving Experiences as a Patient Author

In a second open-ended question, participants were asked, “Do you have any recommendations or comments about how you would like your contribution as a patient or caregiver author to be recognized in peer-reviewed healthcare journal articles? For example, do you have ideas for how articles with patient or caregivers might be identified?” Codable responses were collected from 125 participants (**Table 3** and **Additional file 5**).

Table 3. Suggestions for recognition

Theme	Subtheme	n (%)
Choice, privacy, stigma and respectful recognition	Overall theme	47 (38%)
	Choice over disclosure	7 (6%)
	Privacy/anonymity/contact protection	5 (4%)
	Stigma and respectful recognition	34 (27%)
	Avoiding tokenism/diminishment	9 (7%)
Affiliation, credentials and author metadata	Overall theme	47 (38%)
	Affiliation-based identification	32 (26%)
	Professional role/credentials	15 (12%)
	Footnotes/author biography/metadata	8 (6%)
Standardized labels and terminology	Overall theme	45 (36%)
	Standardized patient/caregiver author title	38 (30%)
	Searchable/common terminology	10 (8%)
	Respectful terminology and naming	7 (6%)
Authorship and equal recognition	Overall theme	37 (30%)
	Full co-authorship/equal status	25 (20%)
	Recognition as authors rather than acknowledgements	9 (7%)
	Professional expertise beyond lived experience	6 (5%)
Article-level visibility and discoverability	Overall theme	37 (30%)
	Article tags/badges/icons	21 (17%)
	Database indexing/metadata/searchability	14 (11%)
	Visual indicators/banners/labels	12 (10%)
Placement and presentation within the article	Overall theme	37 (30%)
	Byline/author list	12 (10%)
	Methods/PPIE/contribution sections	7 (6%)
	Abstract/summary/opening/conclusion	6 (5%)
	Acknowledgements/end matter	20 (16%)
Recognition beyond the article and dissemination	Overall theme	30 (24%)
	Conference/dissemination recognition	9 (7%)
	Patient-facing access/plain-language outputs	8 (6%)
	Compensation/career or status recognition	4 (3%)
	Community/organization recognition	15 (12%)
Contribution transparency and role statements	Overall theme	25 (20%)
	Author contribution statement	8 (6%)
	Patient/public involvement statement	10 (8%)
	Description of contribution and impact	12 (10%)
Journal policy, incentives and accountability	Overall theme	19 (15%)
	Journal standards/requirements	10 (8%)
	Incentives/prioritization/publishing access	5 (4%)
	Quality monitoring/accountability	7 (6%)
	Disclosure of no patient involvement	3 (2%)
Equity, access and structural barriers	Overall theme	9 (7%)
	Affiliation/credential barriers	4 (3%)
	Inclusive participation and access	3 (2%)
	Support for underrepresented/marginalized contributors	3 (2%)

Participants were asked to provide open-text responses to, “Do you have any recommendations or comments about how you would like your contribution as a patient or caregiver author to be recognized in peer-reviewed healthcare journal articles?” Themes and subthemes were identified inductively with support from ChatGPT using GPT-5.6 Sol (OpenAI), which coded responses, developed and refined candidate themes and subthemes, and verified them against supporting and divergent responses; outputs were independently reviewed by two researchers and finalized through consensus adjudication.

The theme of affiliation, credentials, and author metadata was mentioned by 38% (n=47) of respondents. Within this theme, respondents described several ways of integrating recognition of patient and caregiver authors within conventional publication structures. These included using affiliations to identify authors as patients, caregivers, advocates, or representatives of patient organizations (e.g., “Patient Author”); reporting professional roles or credentials alongside lived-experience roles so that authors’ broader expertise was visible; and using footnotes, author biographies, or other metadata to provide additional information about an author’s identity and contribution.

Choice, privacy, stigma, and respectful recognition was also mentioned by 38% of respondents (n=47). They emphasized that recognition should not simply make patient or caregiver status more visible but should respect individual preferences about whether and how lived experience is disclosed. Concerns included protecting privacy, anonymity, and contact information, particularly where identification could reveal sensitive health information; avoiding terminology or forms of identification that could be stigmatizing or reduce an author to their patient or caregiver status; and ensuring that recognition did not diminish other professional, academic, or research expertise. Respondents also cautioned against tokenistic recognition that defined individuals primarily by their lived experience rather than acknowledging the breadth of their contributions and expertise.

Standardized labels and terminology were mentioned by 36% (n=45). They proposed consistent titles or descriptors to identify patient and caregiver authors, with some emphasizing that common terminology could make their involvement easier to recognize and publications easier to identify through literature searches. At the same

time, respondents emphasized that terminology should be respectful and should not diminish, stigmatize, or define authors solely by their patient or caregiver status.

Authorship and equal recognition were mentioned by 30% (n=37). Respondents requested for patient and caregiver contributors to be recognized as genuine members of the authorship team rather than treated as peripheral contributors because their expertise arose from lived experience. They included full co-authorship and equal status where their contributions warranted authorship, including being named as authors rather than relegated to acknowledgements. Respondents also emphasized that patient or caregiver status should not obscure professional, academic, research, and advocacy expertise.

Article-level visibility and discoverability was also mentioned by 30% (n=37). Respondents proposed several ways of making patient and caregiver involvement readily identifiable through mechanisms such as tags, badges, or icons; database indexing, metadata, or searchability; and visual indicators, banners, or labels.

Similarly, 30% (n=37) mentioned the theme of placement and presentation within the article. They asked for patient and caregiver involvement to be explicitly recognized in identifiable locations rather than left implicit or difficult for readers to determine, such as in the byline or author list or in the methods, patient/public involvement, or contribution sections. Some wanted involvement highlighted more prominently in the abstract, summary, opening material, or conclusion, enabling readers to recognize patient or caregiver involvement without searching the full article. Acknowledgements or other end matter were also proposed as locations for recognition.

A desire for recognition beyond the article and dissemination was identified in 24% (n=30) of responses. Respondents asked for patient and caregiver contributions to be recognized beyond authorship information within the published article, including through participation and acknowledgement at conferences and other dissemination activities. They also wanted research involving patient and caregiver authors to be accessible to patient communities, including through open or patient-facing access and plain-language outputs, and for patient authors to have opportunities to help disseminate findings to the communities they represented. Some respondents called for recognition with more tangible value, including compensation and recognition that could contribute to career, professional, or contributor status. Others emphasized recognition of the patient organizations, advocacy groups, or communities associated with or represented by contributors, including making their involvement visible when research was shared more widely.

The theme of contribution transparency and role statements, mentioned by 20% (n=25), reflected requests for recognition to communicate what patient and caregiver contributors actually did, rather than simply identifying them as having been involved. Respondents asked for author contribution statements that specified their roles and contributions, as well as patient/public involvement statements that made patient and caregiver participation in the research and publication process explicit. They also wanted articles to describe how and when they had contributed and how their input had influenced or shaped the research or manuscript, allowing readers to understand the nature and value of their involvement.

Less common themes addressed broader structural issues. The theme journal policy, incentives, and accountability (n=19; 15%) reflected a request for journals and relevant standards bodies to establish clearer and more consistent requirements for recognizing and reporting patient involvement, create incentives or greater publishing opportunities for work involving patients and caregivers, and introduce mechanisms for monitoring the quality and extent of involvement. Some also proposed a requirement for articles to disclose when patients or caregivers had not been involved, potentially including an explanation for their absence. Within the theme equity, access, and structural barriers (n=9; 7%), respondents asked for publication and authorship systems that did not disadvantage contributors who lacked conventional academic credentials or institutional affiliations. They called for more inclusive routes to participation and recognition, including accommodating authors without traditional academic status and supporting the inclusion of underrepresented or marginalized contributors.

Discussion

This was an international survey to examine the experiences, views, and support needs of patient authors from their own perspective. It included 179 respondents across 27 countries, which highlights the relevance of this subject. The results provide valuable information on the state of patient authorship, current gaps and challenges, and priorities for addressing them.

The majority of respondents reported experiencing respectful and productive collaboration and contributed substantially to peer-reviewed journal articles. They generally felt that they could express their viewpoints and ideas, were listened to and respected, could influence decisions, and played roles that warrant authorship. The

majority also supported transparency about patient authorship, such as through affiliation tags (e.g., “Patient Author”).

This survey also shed light on who patient authors are: most were middle-aged, female, from high-income countries, highly educated, native English speakers, and members or leaders of patient organisations, although the extent of their experience varied. They also generally were familiar with healthcare research and patient engagement. This narrow demographic could reflect sampling bias, but it agrees with other research on patient authorship (1, 2, 21) and scholarly publishing in general (22, 23). Further, as highlighted in this survey, many have professional credentials and affiliations, are familiar with academic culture and scientific publishing, and have access to computers, internet, specialised software. This raises questions of whether a wider range of patients should participate in research and authorship.

Although almost all respondents reported positive experiences when collaborating with researchers and healthcare professionals, they indicated some challenges. For example, 3% to 9% of respondents did not feel that their input was recognised, respected, or seriously considered; 19% had led the production of an article without ever being listed as the first author; 6% had been included as an author without having made contributions that meet standard authorship criteria (24); and 37% were neutral or did not agree that they had the opportunity to influence the manuscript. These issues are common to PPIE (25, 26) and authorship in general (27, 28).

Many of the open-text comments expressed a strong desire for respect and a real opportunity to contribute. Respondents emphasised that patient authors should have the opportunity for early, sustained, and well-defined participation, in agreement with

others' recommendations for patient authorship (12) and PPIE (26, 29). Respondents clearly desired equal partnership with researchers, where patient authors have real opportunities to be heard and influence decisions and where their lived experience is considered legitimate and valuable. To get there, they encourage a cultural change amongst researchers, clinicians, and other collaborators through training on how to work with patient authors, reciprocal capacity building, and changes in journal and institutional processes.

One of the goals of this survey was to learn about what support patient authors prefer. Nearly half of respondents felt neutral or did not agree that they had received sufficient training on how to be an author. In open-text responses, a request for guidance, learning, and support was the most common theme related to support needs. Mentoring by experts in preparing journal articles was the most highly valued type of support requested, followed by written training materials. Training and support were requested to be practical, accessible, flexible, and tailored to differing levels of publication experience and familiarity with research, while accommodating limitations imposed by health, energy, availability. Excellent open-access, plain-language resources that address many of these needs have been developed by the Workgroup of European Cancer Patient Advocacy Networks Foundation in collaboration with Envision Pharma Group (30). Beyond training and mentoring for themselves, respondents called for researchers, clinicians, and other collaborators to receive training on working with patient authors to promote equal partnership, value lived experience, and reduce tokenism.

Another goal of this survey was to learn about patient authors' desires for recognition. Visible and transparent recognition of patient authors can encourage patient authorship and make it easier to perform research on patient authorship. Until recently, finding articles with patient authors in databases has proven difficult because of lack of a standard way of reporting their contributions (2, 4, 5). Oliver et al. proposed using "Patient Author" as an affiliation (4), although they recognised sensitivity to terminology and called for further efforts to build consensus on metatags. This represents an important advance in understanding patient authorship. Our survey has provided an opportunity to hear directly from patient authors about these issues and, for the first time, put their concerns into perspective. Most respondents strongly supported consistent, transparent, and visible recognition of patient authorship, such as through affiliation tags, while also emphasising flexibility and personal choice in how they do it. Standardization, for example using "Patient Author" as an affiliation, was valued not only for recognizing individual authors but also for making patient-authored publications easier to identify and retrieve. On the other hand, a few expressed mixed feelings about including the word "patient" in their affiliation because they felt that it may diminish professional identity or reduce a person to a diagnosis, issues previously raised by one of this survey's authors (31). Further collaborative efforts are needed to find a solution for individuals who do not want to be recognized in this way. Non-affiliation metadata or article tags indicating lived experience contributions were suggested by some respondents, but these options are not currently available. In any case, patient authors should be informed about the importance of discoverability before making decisions about how their contribution should be recognized. Finally, we recommend using the GRIPP2 checklist (20) to strengthen transparent reporting of PPIE,

complement formal authorship attribution, and increase visibility of patient contributions, although it cannot be used as a metatag to identify patient-authored publications.

Several respondents (11%) raised the issue of compensation. Best practices for compensating patient authors for their time as research partners are being actively debated (11, 12). Some consider authorship itself and other nonfinancial compensation as sufficient for patient authors, and some have a policy of not paying authors, while others consider financial compensation for patient authorship appropriate. The respondents who raised this issue did not consider whether payment for their work is appropriate but rather emphasised that, like other professional collaborators, they should receive equitable financial compensation for their expertise and time. Indeed, financial compensation for patient authors is specifically permitted in Good Publication Practice (32), the main ethical guidelines for publication of company-sponsored biomedical research. Fair market value for patient authorship remains to be defined, although some respondents asked for lived experience to be considered as valuable as scientific or healthcare experience.

The recently published RECOVER Representative Authorship survey (33) provides the closest comparison with our findings, although it was limited to a single research programme (long COVID), a single country (US), and a considerably smaller sample (17 respondents). Compared with the RECOVER survey, the patient authors in our survey reported more positive experiences working with scientists and healthcare providers. They were also more likely to feel comfortable sharing their views, feel that their input was respected and taken seriously, and feel able to influence final decisions. This may

be because our survey participants were generally more educated and more experienced as authors, which may have made it easier for them to collaborate with researchers and healthcare providers as equal partners. Despite these differences, qualitative findings from the two surveys highlighted many of the same priorities, including a need for meaningful collaboration rather than tokenistic involvement, a desire for practical support to help patient authors work effectively with research teams, and a request for authorship practices that are fair, flexible, and support respectful collaboration with patient authors.

Strengths and Limitations

The main potential limitation of this survey relates to the study sample. Participants were mostly recruited through direct contact with patient associations or through LinkedIn, a professional social media platform. This could have resulted in the narrow demographic of the sample, although the population appeared similar to those in other studies on patient authorship (1, 2, 21), the population appeared representative. Also, the survey did not include patients or caregivers who had sought authorship but were excluded, discouraged, or otherwise unable to participate in the preparation of journal articles. The results may therefore not provide a full picture of the systemic barriers to patient authorship and may overemphasise positive experiences. In addition, eligibility for participation in the survey focused on authorship related to each participant's own disease or caregiving experience. This may have excluded individuals contributing to broader research on methodology, policy, or larger areas of healthcare than their own disease. Besides these potential limitations related to the sample, the retrospective design of most questions could have resulted in recall or attribution bias.

Another potential limitation relates to how we collected information on sex/gender. To avoid the complexities of measuring gender identity across different cultures and languages, after considerable debate, we chose to ask participants about sex at birth and provided the option to decline to answer. Few participants (2%) declined to answer this question, although one comment on social media expressed concern about this aspect of the survey. We recognise that sex assigned at birth does not fully capture the diversity of gender identities or lived gender-related experiences and that this approach may have excluded or alienated some individuals.

A key strength of this study was that people with experience as patient authors and expertise in advocacy and PPIE were involved throughout the design and interpretation of the study. Their contributions helped ensure that the survey addressed issues important to patient authors.

Conclusions and Future Directions

Our study suggests that patient authorship is evolving from a novelty to a more established practice in healthcare research. As such, it deserves its own infrastructure, mentorship, training, and institutional support. Although experiences were largely positive, continued effort is needed to address occasional epistemic injustice, which is where certain forms of knowledge, in this case lived experience, are systematically undervalued (34). Having collaborators recognise lived experience as legitimate, valuable, and complementary to, rather than separate from, scientific and clinical expertise is essential for building trust with patient partners (35-38) and was emphasised by several respondents in this survey. This aligns with the ongoing shift

from “patient centricity” to “patient partnership,” where patients are active contributors to healthcare research and dissemination rather than passive recipients of care (11).

Future research on patient authorship should explore the experiences of individuals who attempted but were unable to become authors, as well as perspectives from underrepresented groups. Research on the perspectives, barriers, and needs of academic and clinical research coauthors may also benefit patient research partners who collaborate as authors of peer-reviewed journal articles. Furthermore, research evaluating mentorship, training, and other interventions should help define best practices, while longitudinal research could help understand how patient authorship changes over time and whether current efforts lead to improvements.

References

1. Woolley KL, Stones SR, Stephens R, Bharadia T, Yamamoto B, Geissler J, et al. Patient authorship of medical research publications: An evolution, revolution, and solution? Learned Publishing. 2024;37(3):e1607. doi: 10.1002/leap.1607

2. Arnstein L, Wadsworth AC, Yamamoto BA, Stephens R, Sehmi K, Jones R, et al. Patient involvement in preparing health research peer-reviewed publications or results summaries: a systematic review and evidence-based recommendations. Res Involv Engagem. 2020;6:34. doi: 10.1186/s40900-020-00190-w

3. Leventhal P, Drachmann D, Skovlund S. Can patients and caregivers be authors of peer-reviewed publications? Medical Writing. 2024;33(4):98-100. doi: 10.56012/idde2040

668 4. Oliver J, Lobban D, Dormer L, Walker J, Stephens R, Woolley K. Hidden in plain
669 sight? Identifying patient-authored publications. Res Involv Engagem. 2022;8(1):12. doi:
670 10.1186/s40900-022-00346-w
671 5. Ellis U, Kitchin V, Vis-Dunbar M. Identification and Reporting of Patient and Public
672 Partner Authorship on Knowledge Syntheses: Rapid Review. J Particip Med.
673 2021;13(2):e27141. doi: 10.2196/27141
674 6. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman
675 R. Mapping the impact of patient and public involvement on health and social care
676 research: a systematic review. Health Expect. 2014;17(5):637-50. doi: 10.1111/j.1369-
677 7625.2012.00795.x
678 7. Hawke LD, Sheikhan NY, Roberts S, McKee S. Research evidence and
679 implementation gaps in the engagement of people with lived experience in mental
680 health and substance use research: a scoping review. Res Involv Engagem.
681 2023;9(1):32. doi: 10.1186/s40900-023-00442-5
682 8. Sacristán JA, Aguarón A, Avendaño-Solá C, Garrido P, Carrión J, Gutiérrez A, et al.
683 Patient involvement in clinical research: why, when, and how. Patient Prefer Adherence.
684 2016;10:631-40. doi: 10.2147/ppa.S104259
685 9. Deane K, Delbecque L, Gorbenko O, Hamoir AM, Hoos A, Nafria B, et al. Co-
686 creation of patient engagement quality guidance for medicines development: an
687 international multistakeholder initiative. BMJ Innov. 2019;5(1):43-55. doi:
688 10.1136/bmjinnov-2018-000317
689 10. Bertelsen N, Oehrlein E, Lewis B, Westrich-Robertson T, Elliott J, Willgoss T, et al.
690 Patient Engagement and Patient Experience Data in Regulatory Review and Health

691 Technology Assessment: Where Are We Today? Ther Innov Regul Sci. 2025;59(4):737-
692 52. doi: 10.1007/s43441-025-00770-6
693 11. Bharadia T, Geissler J, Robson R, Lastikova L, Porter LD, Richmond G, et al. Seven
694 Actions Towards Advancing Patient Authorship and Collaboration in Peer-Reviewed
695 Publications. Patient. 2025;18(5):403-14. doi: 10.1007/s40271-025-00750-w
696 12. Cooksey KE, Neuman M, Bollini M, Pennington B, de OCH, Oberst K, et al. Patient
697 partner engagement in the publication process: challenges and possible solutions.
698 BMC Med Res Methodol. 2025;25(1):39. doi: 10.1186/s12874-025-02495-4
699 13. Marzban S, Najafi M, Agolli A, Ashrafi E. Impact of Patient Engagement on
700 Healthcare Quality: A Scoping Review. J Patient Exp. 2022;9:23743735221125439. doi:
701 10.1177/23743735221125439
702 14. Stones SR, Lobban D, Skobe C, Gokool N, Bharadia T, Geraci A, Matheis RJ.
703 Patients as partners in medical publications: the ISMPP journey of engagement. Curr
704 Med Res Opin. 2025;41(8):1491-8. doi: 10.1080/03007995.2025.2556317
705 15. Rosenberg A, Clark L, McClelland GR. Patient involvement in publications:
706 qualitative mapping of the current landscape within the pharmaceutical industry. Curr
707 Med Res Opin. 2025;41(8):1475-89. doi: 10.1080/03007995.2025.2545496
708 16. Richards DP, Birnie KA, Eubanks K, Lane T, Linkiewich D, Singer L, et al. Guidance
709 on authorship with and acknowledgement of patient partners in patient-oriented
710 research. Res Involv Engagem. 2020;6:38. doi: 10.1186/s40900-020-00213-6
711 17. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in
712 Psychology. 2006;3(2):77-101. doi: 10.1191/1478088706qp063oa

713 18. Parker MJ, Anderson C, Stone C, Oh Y. A Large Language Model Approach to
714 Educational Survey Feedback Analysis. International Journal of Artificial Intelligence in
715 Education. 2025;35(2):444-81. doi: https://doi.org/10.1007/s40593-024-00414-0
716 19. Sharma A, Minh Duc NT, Luu Lam Thang T, Nam NH, Ng SJ, Abbas KS, et al. A
717 Consensus-Based Checklist for Reporting of Survey Studies (CROSS). J Gen Intern Med.
718 2021;36(10):3179-87. doi: 10.1007/s11606-021-06737-1
719 20. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2
720 reporting checklists: tools to improve reporting of patient and public involvement in
721 research. Res Involv Engagem. 2017;3:13. doi: 10.1186/s40900-017-0062-2
722 21. Woolley K, Boughey A, Bharadiae T, Stephens R, Yamamoto N, Lobban D, editors.
723 Diversity in Patient Authors: A Randomized Bibliographic Analysis. International Society
724 for Medical Publication Professionals 2024 Europen Meeting; 2024 23-24 January 2024;
725 London, UK.
726 22. Amano T, Ramírez-Castañeda V, Berdejo-Espinola V, Borokini I, Chowdhury S,
727 Golivets M, et al. Language, economic and gender disparities widen the scientific
728 productivity gap. PLoS Biol. 2025;23(9):e3003372. doi: 10.1371/journal.pbio.3003372
729 23. Bol JA, Sheffel A, Zia N, Meghani A. How to address the geographical bias in
730 academic publishing. BMJ Glob Health. 2023;8(12). doi: 10.1136/bmjgh-2023-013111
731 24. International Committee of Medical Journal Editors. Recommendations for the
732 Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals 2026
733 [Available from: https://www.icmje.org/recommendations/.
734 25. Hahn DL, Hoffmann AE, Felzien M, LeMaster JW, Xu J, Fagnan LJ. Tokenism in
735 patient engagement. Fam Pract. 2017;34(3):290-5. doi: 10.1093/fampra/cmw097

736 26. Richards DP, Bowden J, Gee P, Haagaard A, Kothari A, McKinnon A, et al. The
737 ultimate power play in research - partnering with patients, partnering with power. Res
738 Involv Engagem. 2025;11(1):65. doi: 10.1186/s40900-025-00745-9
739 27. Savchenko E, Rosenfeld A. Authorship conflicts in academia: an international
740 cross-discipline survey. Scientometrics. 2024;129(4):2101-21. doi: 10.1007/s11192-
741 024-04972-x
742 28. Smith E, Williams-Jones B, Master Z, Larivière V, Sugimoto CR, Paul-Hus A, et al.
743 Researchers' Perceptions of Ethical Authorship Distribution in Collaborative Research
744 Teams. Sci Eng Ethics. 2020;26(4):1995-2022. doi: 10.1007/s11948-019-00113-3
745 29. Bird M, Ouellette C, Whitmore C, Li L, Nair K, McGillion MH, et al. Preparing for
746 patient partnership: A scoping review of patient partner engagement and evaluation in
747 research. Health Expect. 2020;23(3):523-39. doi: 10.1111/hex.13040
748 30. WECAN Foundation. WECAN training module on “Patients in Publications” 2026
749 [Available from: https://wecanadvocate.eu/patients-in-publications/.
750 31. Richards DP. The patient as a person 2018 [Available from:
751 https://blogs.bmj.com/bmj/2018/02/14/dawn-p-richards-the-patient-as-a-person/.
752 32. DeTora LM, Lane T, Sykes A, DiBiasi F, Toroser D, Citrome L. Good Publication
753 Practice (GPP) Guidelines for Company-Sponsored Biomedical Research: 2022 Update.
754 Ann Intern Med. 2023;176(3):eL220490. doi: 10.7326/L22-0490
755 33. Esquenazi-Karonika S, Mathews PD, Wood MJ, Mudumbi PM, Linton J, Briscoe J,
756 et al. Quality improvement of a community-engaged authorship system: lessons
757 learned from the RECOVER initiative. BMC Health Serv Res. 2025;25(1):919. doi:
758 10.1186/s12913-025-12914-3

34. Bhakuni H, Abimbola S. Epistemic injustice in academic global health. Lancet Glob Health. 2021;9(10):e1465-e70. doi: 10.1016/S2214-109X(21)00301-6

35. Zibrowski E, Carr T, McDonald S, Thiessen H, van Dusen R, Goodridge D, et al. A rapid realist review of patient engagement in patient-oriented research and health care system impacts: part one. Res Involv Engagem. 2021;7(1):72. doi: 10.1186/s40900-021-00299-6

36. Santana MJ, Duquette D, Fairie P, Nielssen I, Bele S, Ahmed S, et al. Patient-identified priorities for successful partnerships in patient-oriented research. Res Involv Engagem. 2022;8(1):49. doi: 10.1186/s40900-022-00384-4

37. Olsen M, de Pinho Campos K, Fones G. Meaningful engagement with people with lived experience: challenging, messy, and more vital than ever. Bmj. 2025;390:r1138. doi: 10.1136/bmj.r1138

38. Tembo D, Hickey G, Montenegro C, Chandler D, Nelson E, Porter K, et al. Effective engagement and involvement with community stakeholders in the co-production of global health research. Bmj. 2021;372:n178. doi: 10.1136/bmj.n178

Declarations

Ethics Approval and Consent to Participate

Given the anonymised, low-risk, non-interventional study design and the nature of the survey topic, formal ethical review was not sought. Prior to initiating the survey, participants provided electronic informed consent to participate in the survey and allow their anonymous answers to be published.

Consent for Publication

Consent to have aggregate results published was obtained from all survey participants.

Availability of Data and Materials

Deidentified data from the current study are available from the corresponding author on reasonable request.

Competing Interests

PL is an employee of Thermo Fisher Scientific, which provided publication fees for the manuscript.

DD is an employee of Thermo Fisher Scientific, which provided publication fees for the manuscript. She is also the founder and president of the rare disease patient organization, Ketotic Hypoglycemia International.

KLW has non-financial competing interests based on her role as a global advocate for increasing involvement of patients in medical research, including peer-reviewed publications. KLW is Co-Guest Editor for the Special Collection on Patients and Publications in Research Involvement and Engagement. She was recused from all editorial decisions on submitted manuscripts where she was an author. KLW has no current financial competing interests to disclose, but did prepare free-access, patient-led, patient authorship resources and training courses while a paid employee at the medical affairs company, Envision Pharma Group.

DPP is the founder and Director of Five02 Labs, which has received consultancy/advisory fees from UCB Biopharma.

NB works with the pharmaceutical and biotech industry on patient involvement practices for which he is paid consultancy fees. Over the past 18 months, this includes: Chiesi, UCB, Gilead, Zambon, Astellas, Bayer, Boehringer Ingelheim, Intuitive and Novartis.

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Authors' Contributions

All authors participated in the conceptualisation and design of the survey, interpretation of the data, and approval of the final version of the manuscript submitted for publication. In addition, PL participated in acquisition and analysis of data; PL and DD drafted the manuscript; and KW, DPR, and NB edited and critically reviewed the work.

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Generative artificial intelligence (ChatGPT using GPT-5.6 Sol; OpenAI, San Francisco, CA, USA) within the Thermo Fisher Scientific ChatGPT Enterprise environment was used to support de-identification and inductive thematic analysis of open-text survey

responses, as well as initial outlining and drafting of portions of the Methods and Results, brainstorming, identification of potentially relevant references, and drafting of Additional files 2 and 5. All AI-assisted analytic outputs were independently reviewed by PL and DD and finalized through researcher consensus, and all manuscript content and references were reviewed and verified by the authors.

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Karen Woolley, PhD, is a patient advocate and an internationally recognised expert in patient authorship. She is a Professor at the University of Queensland and at the University of the Sunshine Coast. Professor Woolley is the recipient of the 2024 Lifetime

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Dawn Richards, PhD, is a patient advocacy and public engagement leader. Her current and past collaborators include Clinical Trials Ontario, CIHR's Institute of Musculoskeletal Health and Arthritis and Institute of Infection and Immunity, the Network of Networks, the Brain-Heart Interconnectome, the Strategy for Patient-Oriented Research Chronic Pain Network, the Chronic Pain Centre of Excellence for Canadian Veterans, and the University Health Network. She is also a member of the BMJ Patient Panel and has written extensively on patient partner compensation, recognizing patients beyond their diagnoses, and co-creating research initiatives with patients and public partners.

Neil Bertelsen, MSc, MBA, is a global patient advocacy and patient engagement leader with expertise in health technology assessment, patient access, healthcare strategy, and multi-stakeholder collaboration. Neil is a past Chair and current Steering Committee member of the Health Technology Assessment International Patient and Citizen Involvement Group, and he serves on the Board of Patient Focused Medicines Development, an international coalition dedicated to advancing patient engagement in medicines development. He has also served on the board of the Terrence Higgins Trust, Europe's largest HIV and sexual health advocacy organisation, and was editor of Positive Times, the UK's first national publication for people living with HIV.

List of Additional Files

Additional file 1. Survey text

Additional file 2. Detailed thematic analysis methods

Additional file 3. CROSS checklist

Additional file 4. Participant flow

Additional file 5. Detailed thematic analysis results

Supplementary Files

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