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Patients' perspectives on involvement in the peer review process: surveys of patient reviewers at two journals

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1 **Patients' perspectives on involvement in the peer review process:**
2 **surveys of patient reviewers at two journals**
3

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ABSTRACT

Objective

In 2014/15 *The BMJ* and *Research Involvement and Engagement (RIE)* became the first journals to routinely include patients and carers in the peer review process of journal articles. The aim of this survey was to explore the views of the patient reviewers for these two journals.

Design

A cross-sectional survey.

Setting and participants

People signed up as reviewers for *The BMJ* and *RIE*, including those who had not yet completed a review.

Results

The response rate was 69% (157/227) for those who had previously reviewed and 31% (67/217) for those who had not yet reviewed. Patient reviewers described being motivated to review by the opportunity to include the patient voice in the research process, influence the quality of the biomedical literature and ensure it meets the needs of patients. Of the 157 who had reviewed, 127 (81%) would recommend being a reviewer to other patients and carers. 144 (92%) thought more journals should adopt patient review. Few reviewers (16/224, 7%) reported concerns about being identified through open review. Annual acknowledgment on the journals' websites was welcomed as was free access to information behind subscription controls. Participants were keen to have access to more online resources and training to improve their reviewing skills. Suggestions on how to improve the reviewing experience included: allowing more time to review; better and more frequent communication; a more user-friendly process; improving guidance on how to review including videos; improving the matching of papers to reviewers' experience; providing more varied sample reviews, brief feedback on the usefulness of reviews; developing a sense of community amongst patient reviewers; and publicising of the contribution that patient review brings.

Conclusions

Patient reviewers shared practical ideas to improve the review experience and these strategies will be reviewed to enhance the guidance and support given to patient reviewers.

ARTICLE SUMMARY**Strengths and limitations of this study**

- The involvement of patients and carers in the peer review process of journal articles is a novel initiative.
- This is the first study to evaluate patients' experience of peer review.
- We explore the perspectives of patient reviewers at two journals with different publishers.
- We involved patients and carers in the design, conduct and dissemination of this study.
- We report only on the early experiences of patient reviewers and this may change over time.

Keywords

Peer review, patients, carers, patient and public involvement

INTRODUCTION

Peer review has been central to the scientific process for over 300 years.[1, 2] It plays a key role in funding and publication decisions and in improving the accuracy and clarity of reported published research. Peer review contributes to scientific integrity by helping identify robust research and weeding out methodologically weak studies. While the value and effectiveness of peer review continues to be debated vigorously, it is still regarded as an essential quality assurance mechanism for funding organisations and journals and it is the only widely accepted method for research validation.[1, 3-6] It is therefore a deeply entrenched process in international funding organisations and high quality journals. By playing a key part in determining what research gets funded and published, peer review has a pivotal role in determining the treatment and interventions patients receive and how medicine is practised.

Despite its pivotal role peer review is criticised on many fronts.[7, 1] Traditionally, it has been a closed process and it is only recently that there have been calls to include the views of all relevant stakeholders, including patients and the public. The role of patients and the public is also being stepped up as co-producers of health and social care research not least because their involvement has potential to increase the quality and value of the research and reduce waste.[8] Many grant funding organisations now incorporate members of the public in their review processes or panels e.g. the UK's National Institute for Health Research (NIHR) and the Patient-Centered Outcomes Research Institute (PCORI) in the US. By contrast, biomedical journals still do very little to involve patients and the public in their peer review processes.

To address this imbalance, *The BMJ* and *Research Involvement and Engagement (RIE)* journals have adopted innovative strategies aimed at co-producing their content with patients and carers, and both journals have patient editors.[9-12] The systematic incorporation of patient review of research manuscripts alongside traditional scientific peer review is a key component of these journal patient partnership strategies. Patient and public involvement in peer review of research manuscripts represents a landmark shift in the concept of peer review at journals, reflecting a desire to ensure research is appropriate and relevant to end users.

While some patient reviewers are able to comment on research methodology their strength collectively is in addressing the relevance and importance of the research to patients and carers and whether the treatment or intervention studied, or guidance given is practicable and acceptable to patients. They can also identify challenges patients and carers face; whether the outcomes measured in the studies described are important to patients and carers and if other outcomes or issues should have been considered. They can also suggest ways to strengthen papers to make them more useful for shared decision-making. Contributions will vary according to the background, skills and experience of the patient reviewer, as it does with academic reviewers. Some patients and carers may comment on the relevance of a study for a particular group, while those with academic training and research knowledge might comment on methodology. Others may focus on the clarity of the reported research and its interpretation to a lay audience. All these contributions and others have the potential to enhance the quality of the research and its uptake in practice.

Academic researchers are encouraged and motivated to publish their research as part of career advancement in a "publish or perish" environment[13] and reciprocal peer reviewing of articles is considered to be a professional duty.[14-17] In marked contrast, patient reviewers have no professional implicit or explicit obligations to review. With open access publishing and non-blinded review the responsibility of reviewing papers may be compounded by the challenge of being identified as a person with an illness or disability. Both *The BMJ* and *RIE* offer guidance for patient

1 reviewers, developed with patient editors, but these have not been informed by the experience of
2 patient reviewers and might not provide the level of support some need. In this collaborative survey
3 carried out by *The BMJ* and *RIE*, with embedded patient involvement, the aim was to find out what
4 motivates patients and carers to review research articles, their confidence to do so, their satisfaction
5 with the process, how they would like to be acknowledged for their contributions and their views on
6 how the process could be improved. This knowledge will be used to inform evidence-based guidance
7 for patient reviewers.
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For peer review only

METHODS

The research was reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee MS-IDREC-C1-2013-174.

Sampling

Patients and carers who were registered as patient reviewers for *The BMJ* or *Research Involvement and Engagement (RIE)* and were invited to review for one of the journals at least once between January 2015 and May 2017 were eligible to participate. The reviewer pool was split into two samples based on review history. Group A included reviewers who were invited to review and completed a review and Group B included reviewers who were invited to review but had not yet completed a review (by April 2017).

Reviewers' contact details were extracted from the relevant manuscript tracking systems and uploaded to SurveyMonkey. We excluded those who were registered as reviewers but whom had not been invited to review and those who have previously asked not to be contacted by *The BMJ* (for marketing or other reasons).

Questionnaire development and pre-testing

Survey items were developed by the research team which included patient reviewers from both participating journals (AD, RH, JE) and *The BMJ* and *RIE* patient editors (TR, AP, RS). The questionnaires were piloted before launching the survey with a further four BMJ patient reviewers to check the survey content was appropriate and addressed issues of importance to patient reviewers and that questions were not ambiguous.

Survey administration

Reviewers were sent a personalised email invitation to complete a survey (Appendix 1) administered by SurveyMonkey. There were two versions of the questionnaire; Group A received all the questions, however, Group B received only a subset of questions relevant to those who had not yet reviewed. Participants were informed that they could choose not to take part and withdraw at any time; survey completion was used to indicate consent to participate. They were told that the results of the survey would be submitted for publication and that we may choose to quote from their responses, but individuals would not be identified. All survey data was treated confidentially and only SS and EF saw the individual responses for their own journals. All data was de-identified before sharing with the wider research team. Non-respondents were sent up to two reminders to take part at two and four weeks after the initial mailing.

Patient involvement

Patient reviewers were involved in multiple stages of the research. Three patient reviewers (JE, RH, AD) are co-authors on this paper as they were core members of the research team and substantially contributed to the development of the questionnaire, refinement of the questionnaire, interpretation of results and manuscript revision. These three patient partners co-produced a poster of the findings for the "NIHR-INVOLVE" Conference 2017[18] to aid dissemination of the research to academic and industry research professionals, patients, policy makers, editors, and advocacy groups. We piloted the questionnaire with a further four *BMJ* patient reviewers (outside of the research team) and refined the questions based on their feedback. Three other members of the research team are patient editors with long term conditions committed to involving patients in research. More details can be found in the completed GRIPP2 reporting checklist.

RESULTS

Response rate

122 (74%) of the 164 *BMJ* and 35 (56%) of the 63 *RiE* reviewers in Group A responded and 51 (38%) of the 133 *BMJ* and 16 (31%) of the 84 *RiE* reviewers in Group B responded. As survey B was a subset of questions from survey A we have pooled the results and report for both samples combined where relevant.

Respondent characteristics

Table 1 shows the respondent characteristics for reviewers completing the surveys. The majority of reviewers live in the UK. Reviewers who had reviewed had completed a median of two reviews. Overall reviewers who had reviewed reported spending a median of 5 days a month on other patient involvement or engagement activities and those who had not yet reviewed reported this as 7 days a month. However, there were differences between the journals with *RiE* reviewers reporting more days spent doing these activities than *BMJ* reviewers.

Motivation to review

Patient reviewers described how they are motivated to review by the opportunity to include the patient voice in the research process; the opportunity to influence the quality of the literature and to help ensure it meets the needs of patients and is understandable by them; helping make research more relevant and useful to researchers, clinicians and patients; the intellectual challenge; and learning more about research on topics of interest to them.

Data are presented as the mean (standard deviation) of responses on a 5-point Likert scale for the n=157 who had reviewed. The factor rated most highly in importance to the decision to accept a paper to review was the opportunity to add the patient or carer perspective (4.49 (0.71)) (Figure 1), but more than half reported the following as very or extremely important: the contribution of the paper to the subject area (3.8, (0.9)), relevance of the topic to own experience/interests (3.8, (1.0)), desire to keep up-to-date on current research (3.6 (1.0)), and opportunity to learn something new from the paper (3.5 (1.0)).

Reasons for declining

Data are presented as the mean (standard deviation) of responses on a 5-point Likert scale. 101 reviewers reported that they had declined a request to review at some stage. The most highly rated factors important in the decision to decline to review was conflict with other workload (3.7 (1.4)), a tight deadline for completing the review (3.3 (1.4)), and conflicts with family commitments or responsibilities (2.8 (1.6)), Figure 2. Dislike of the open peer review process (1.1 (0.4)), having to use the online manuscript review system (1.3 (0.7)), and lack of formal recognition of reviewer contribution (1.3 (0.7)) were the least important factors. Other reasons given for declining to review included a lack of experience or interest in the topic, the irrelevance of the topic for patient review in general and not understanding the paper.

Confidence in reviewing

Of the 157 who had reviewed, 43 (27%) reported feeling either not at all or only slightly confident when doing their first review, but this proportion fell for those who had done more than one review, to 11/141 (8%) when doing their last review. Six (4%) reported they were extremely confident when doing their first review and 19 (13%) when doing their last review.

Factors reported as helping to improve confidence included: practice and gaining familiarity with the process; seeing other peer reviewers' comments on the paper; having access to sample reviews;

receiving feedback from editors; knowing their review was valued; being asked to review again; improved journal guidance and provision of frequently asked questions; seeing their own comments in letters to authors requesting revisions; and generally reading more peer reviewed articles and reviewing for other organisations simultaneously.

"It takes time in my estimation to get into a place where as a patient I am confident reviewing the work of academic scholars. At first I took the stance of "who am I to challenge them," but recognized after the first review I am the patient with the experience and perspective that can help to inform the practice of research."

"Initially I was worried that my lack of in-depth knowledge of statistical methods would make my comments seem petty or too simplistic. Yet when I read expert reviewers comments I saw that they picked up on some of my points which gave me the confidence to stick to my guns and write anything I felt was important to say."

Perceptions of open review process

At both journals, all reviewers' named comments are published alongside the article on the journals' websites. Only 16/224 (7%) of reviewers indicated they had concerns about doing open review. Six of these 16 expressed concerns which are generic to the concept of open review and only ten raised specific concerns they had in relation to being a patient and implications of open review. These focused on embarrassment or being perceived negatively by others, patient confidentiality, misuse of personal information published online, implications for future job applications and impact on receiving disability benefits.

"I am cautious about who I share information with in terms of my health. Just putting my name out there as a patient reviewer exposes some of that. I have decided that the benefits of being a BMJ peer reviewer are greater to me than the risk of exposing myself that way, but it was a consideration."

Reviewer satisfaction

Likelihood to recommend to other patients and carers

127 (81%) of the 157 who had reviewed (82% *BMJ*, 77% *RIE*) would recommend being a patient reviewer to other patients and carers, 3 (2%) would not and 26 (17%) were unsure. Reasons for potentially not recommending to others included the lack of a sense of community amongst patient reviewers, non-user friendly submission software and disappointment that the paper reviewed was accepted despite their comments that the paper was not methodologically strong or well presented. Hesitancy to recommend focused on the fact that reviewing is not for everyone and that it is a highly subjective exercise.

Should other journals adopt patient review?

Based on their reviewing experience so far, 144 (92%) of the 157 reviewers (91% *BMJ*, 94% *RIE*) thought more journals should adopt patient review.

"We need to show maturity in academic working and co-creation with patients and carers. Patients and carers already influence whether grants are awarded (millions of pounds) so this is another step in closing the evidence to practice loop."

"Patients bring a unique perspective to scientific articles. Far from being a luxury, patient views are an important factor in research relevance."

1 “... it should prove mutually beneficial and give researchers a 'patient's eye view of
2 potential/existing treatments as well as suggesting further avenues for research.”
3

4 “Very good scheme and needs to be developed to become a beacon for other general
5 medical journals.”
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8 Hesitancies included worry that patient review could become a tick box exercise, needing
9 reassurance that patient reviewers' comments were being considered, and the appropriateness of
10 journal content for patient review.
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12 *Perceptions of authors and other reviewers*

13 35 (22%) reviewers indicated that they had reviewed a paper which the editors asked the authors to
14 revise and respond to all the reviewers' comments (and subsequently shared these with the
15 reviewers). 29/35 (83%) “strongly agreed” or “agreed” that the authors of the paper addressed the
16 points they raised in their reviews. 28/35 (80%) “strongly agreed” or “agreed” that the authors were
17 courteous when addressing the points they raised in their reviews. 22 (63%) felt they were able to
18 include points important to patients or carers in their review(s) that were not raised by the other
19 (academic) peer reviewers. 10 (29%) couldn't remember or felt it was difficult to judge and only three
20 (9%) felt that they were unable to do so.
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23 *Helpfulness of journal instructions*

24 Overall 95/157 (61%) who had reviewed perceived the current instructions received on what to
25 include in the review as “*extremely*” or “*very helpful*” (*BMJ*: 63%, *RIE*: 51%); 49 (31%) found them
26 only moderately helpful; and 13 (8%) slightly or not at all helpful. Reviewers made constructive
27 suggestions on how the guidance could be improved.
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30 **How to improve the experience**

31 Suggestions on how to improve the overall experience included: allowing more time to review;
32 improving and more frequent communications e.g. by newsletter; making the submission process
33 and automated communications more user friendly; adding more and improved guidance on how to
34 review including videos of the submission process and explaining what to expect and when; better
35 matching of papers to reviewers' experience; providing more varied sample reviews; more support,
36 encouragement, training and forums to answer questions; editors providing (brief) feedback on
37 usefulness of reviews and how papers have changed as a result of the reviews; better sharing of
38 information around decisions made on manuscripts reviewed; developing a sense of community (an
39 online network) amongst patient reviewers; peer to peer mentoring; raising the profile of patient
40 review by illustrating the value added and changes made; and treating patient reviewers as equal
41 partners in the peer review process.
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45 **How to acknowledge patient reviewers' help**

46 Patient reviewers at both journals are acknowledged annually on the journal websites and this was
47 very well received by participants. All *BMJ* reviewers receive an annual free subscription to the online
48 version of the journal (bmj.com), as only research articles are open access, and this was very
49 popular with *BMJ* respondents. *RIE* is already open access for anyone to read. Having access to
50 information was important and respondents were keen to receive longer-term subscriptions for the
51 journal, the ability to pass it on to a family member, or subscriptions or access to articles in other
52 journals published by *BMJ*. Participants were also keen to have access to more online resources,
53 conferences, and training to improve their reviewing skills.
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1 *"I think I am adequately "compensated" for my work and I appreciate the subscription.*
2 *As an advocate who rarely gets paid for my work, journal access is a big deal to me. I*
3 *do this because it's a passion and I want to see the dynamic change. I'm doing my part*
4 *and that's what gratifies me most."*
5

6
7 *RIE* offers patients or service users who have reviewed a certain number of articles within any period
8 of 12 months an Article Processing Charge (APC) waiver for an article submitted to the journal. Only
9 a three *RIE* reviewers commented on the value of the waiver for the APC. One was very positive of
10 its value and had used the APC waiver to publish the experience of their patient group in the journal,
11 another felt all patient reviewers should have the APC waived, another that it should be transferable
12 to another person.
13

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15 The majority of free-text comments did not focus on monetary incentives but some reviewers did
16 suggest honorariums, payment, gift vouchers, a prize draw and donations to charity after accruing
17 reviews. There were suggestions that the lack of any form of compensation for reviewing might put
18 off some potential patient reviewers, although no evidence was offered for this view. Others wanted
19 something physical that they could show others, for example: a certificate of participation; a pin
20 badge or keyring for long standing reviewers; a gadget; an annual award for the best reviewer and an
21 announcement of this; graded awards (e.g. Gold, Silver, Bronze) based on reviewer performance; a
22 reward system tied to Publons (<https://publons.com/home>); a formal letter by post after a fixed
23 number of reviews; and something to state in their CVs.
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27 In free-text comments reviewers expressed interest in being named as patient reviewers on the
28 published articles themselves rather than just in the accompanying published reviews or for an
29 indication in the article that it has been reviewed by patients. Others wanted more publicity over the
30 contribution that patient review brings to the journals, the opportunity to contribute patient opinions on
31 published articles or to be included as co-authors in commentaries and blogs. They suggested a
32 patient reviewer TweetChat led by journal staff, more feedback about how their reviews were
33 beneficial and to schedule patient reviewer meetings in order to build community and to develop
34 expertise.
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DISCUSSION

This is the first study to evaluate patients' and carers' experience of peer review in academic journals. A large majority of patient reviewers were enthusiastic about their experience, would recommend others to act as reviewers, and thought other journals should adopt patient review. Few reported concerns about being identified through open review. Reviewers identified areas where the journals could improve and how they would like to be acknowledged for their contributions. Annual acknowledgement of reviewers' contributions on the journals' websites was welcomed. *BMJ* reviewers welcomed the free subscription to the journal as a reward for reviewing (all content in *RIE* is open access). Only three *RIE* reviewers commented on the APC waiver. Some reviewers cautioned about tokenism, and underlined the need for more feedback on how patient review is valued by authors and editors. Fostering a sense of community among patient reviewers was advocated. Despite the different approach and guidelines for patient review between *The BMJ* and *RIE* the reviewers' views on most issues were similar.

While the motivating factors for academics to review papers are known[14-17] this study assessed what motivates patients and carers to review. It establishes that the overarching motivating factor is the opportunity to add patient or carer perspectives. It is of interest to note that motivating factors reported by academic reviewers were also considered important to patient reviewers e.g. the contribution of the paper to the subject area, relevance of the topic to their own experience/interests, a desire to keep up-to-date on current research, and the opportunity to learn something new from the paper. Similar to academic reviewers, patient reviewers valued being given an online subscription to the journal[14, 17] and indicated a desire for access to more information from journals and publishers. Again, similar to academic reviewers, the most important factor in declining to review was conflict with other workload,[14] but a higher proportion of patients reported the tight deadline for completing the review affected their decision to decline than academics.

The results suggest that it is feasible to introduce patient review alongside peer review of research papers. Patients and carers greatly appreciate the opportunity to be involved and see value in it. However, they also indicated areas for development and questioned some of our practice. This emphasises the importance of seeking feedback and making the subsequent changes to demonstrate that we value their opinion. Some areas are easily fixed whilst others are restrained by the software, expense or demands of a fast publication process designed to meet the needs of authors and researchers. Journals do not typically pay peer reviewers. While the majority of reviewers did not focus on monetary compensation or incentives, some suggested lack of monetary compensation was a barrier if the goal was to solicit views from a fully representative sample of patients. Some organisations offer patients honoraria for reviewing e.g. NICE's Health Technology Appraisal (HTA), although these requests are to review documents substantially longer than a research paper. Responses to this survey identified a range of ways that patient reviewers can be thanked and acknowledged other than through financial compensation.

We received a good response rate of 69% overall for those who had previously reviewed, reflecting a high level of ongoing engagement and support for this initiative. The respondents were involved in other patient involvement activities for an average of five days a month reflecting the increasingly strong commitment to include the patient's voice in health research and healthcare provision. *RIE* reviewers reported spending more time on these activities than *BMJ* reviewers. This finding reflects the fact that many of the patient reviewers for *RIE* have been recruited from groups already working in research, such as the National Cancer Research Institute (NCRI) Consumer Forum in the UK or are European Patients' Academy (EUPATI) Fellows, and thus likely to have experience and expertise in critical appraisal of protocols and research studies (especially on the patient-related aspects of the

1 research). *BMJ* reviewers are asked to respond to a broader patient-specific set of questions and are
2 not expected to have any research experience. Despite these differences, responses to the surveys
3 were so similar for both journals that we needed to report only the combined response.
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6 Our study is limited by including the experiences of patient reviewers at only two journals. However,
7 these two journals were the first to introduce patient review alongside academic peer review and
8 have sufficient experience of implementing it to enable the survey. At the time of the survey, we were
9 not aware of any other journals systematically including patients in reviewing research papers. The
10 two journals have different approaches and guidance, but their reviewers report similar experiences
11 and challenges. Some respondents had only limited experience of reviewing and their perceptions
12 may change with time. As this is a recent and novel initiative, it is important to survey patient
13 reviewers again as we make changes to the guidance and seek to provide them with more support.
14 Whilst respondents did not focus on the need for monetary rewards and financial incentives it is
15 important to acknowledge that their views may not be representative of all potential patient reviewers.
16 Similarly, while open review did not appear to be a concern for most patients we have no way of
17 knowing how many have been put off reviewing because of this.
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21 Patient review of health research is a development in response to the call for greater patient and
22 public involvement in research and healthcare in general. Peer review of research papers happens at
23 the end of the research process and we recognise and agree on the importance of involving patients
24 early on at the start of the research process and throughout it, to increase its value and minimise
25 waste in research,[19, 20] and to help make evidence more relevant and accessible to end users.[21-
26 23, 24, 25] *The BMJ* and *RIE* see partnering with patients, their carers, wider support networks, and
27 the public as an ethical imperative essential to improving the quality, safety, value, and sustainability
28 of health systems.[9-12, 26] Patient review is just a single initiative under these partnership strategies
29 the journals have introduced. Both journals also have patients and carers as members of their
30 Editorial Boards and patient editors to bring the patients' perspective to internal discussions and
31 decision-making. The results of this survey will be used to help improve the guidance, support and
32 ultimately the experience of patient reviewers for the participating journals and other journals that
33 adopt it.
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DECLARATIONS

Data sharing

Data are available upon reasonable request.

Competing interests

SSt and TR are employed by *The BMJ*; AP is the Patient Editor (Research and Evaluation) at *The BMJ*; SSt and RS are the Co-Editors in Chief of the *Research Involvement and Engagement*; AD and RH are patient reviewers for *The BMJ*; JE is a patient research advocate and an Editorial Board Member of *Research Involvement and Engagement*; EF is employed by BMC, part of Springer Nature, which publishes *Research Involvement and Engagement*. All authors support the call for greater public involvement in research.

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Author Contributions

AP and SS wrote the study protocol, interpreted the survey results, and wrote the first draft of the manuscript. SS created the surveys on SurveyMonkey, administered the surveys to *BMJ* reviewers, and analysed the pooled anonymised data. EF administered the surveys to *RIE* and project managed the wider study and collaboration. All authors helped develop the survey questions, commented on the results and helped write the paper for publication. All authors approved the final version of the paper for submission.

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Table 1: Respondent characteristics

Group A: Have reviewed	<i>BMJ</i> (n=122)	<i>RIE</i> (n=35)	All (n=157)
Median (LQ, UQ) number of reviews completed	2 (1, 4)	2 (1, 3)	2 (1, 4)
Country of residence (%)			
UK	63 (52)	28 (80)	91 (58)
Europe (excluding UK)	20 (16)	3 (9)	23 (15)
North America	36 (30)	2 (6)	38 (24)
Australia / New Zealand	3 (2)	2 (6)	5 (3)
Median (LQ, UQ) number of days per month spent on patient involvement and engagement activities	5 (2, 11)	11 (3, 24)	5 (2, 15)
Group B: Have NOT reviewed	<i>BMJ</i> (n=51)	<i>RIE</i> (n=16)	All (n=67)
Country of residence (%)			
UK	22 (43)	5 (31)	27 (40)
Europe (excluding UK)	10 (20)	10 (63)	20 (30)
North America	14 (27)	0 (0)	14 (21)
Australia / New Zealand	0 (0)	0 (0)	0 (0)
Asia	1 (2)	0 (0)	1 (1)
Median (LQ, UQ) number of days per month spent on patient involvement and engagement activities	6 (2, 14)	21 (10, 26)	7 (3, 21)

Note Percentages do not sum to 100% because of missing data.

LQ: lower quartile

UQ: upper quartile

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Figure legends

Figure 1: Importance of specific factors in the decision to accept to review (n=157 who had previously reviewed)

Figure 2: Importance of specific factors in the decision to decline to review (n=101 who had previously declined an invitation to review)

Appendix 1: Questionnaire

For peer review only

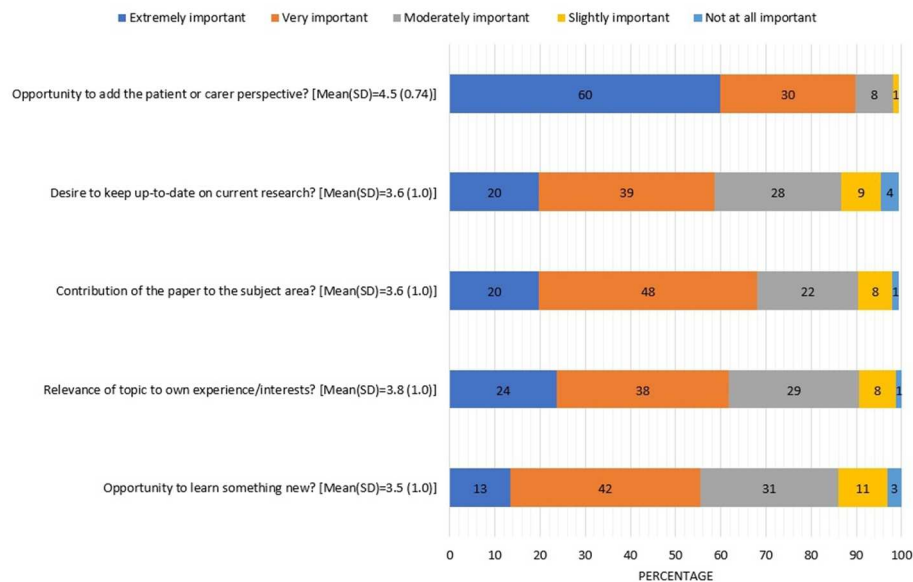


Figure 1: Importance of specific factors in the decision to accept to review (n=157 who had previously reviewed)

224x133mm (120 x 120 DPI)

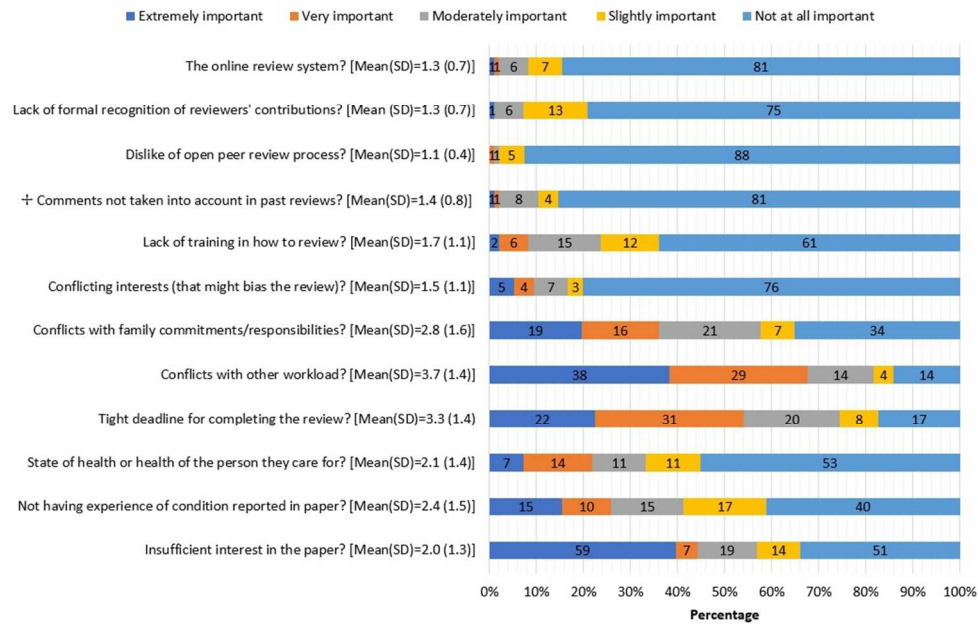


Figure 2: Importance of specific factors in the decision to decline to review (n=101 who had previously declined an invitation to review)

224x143mm (120 x 120 DPI)

Appendix 1: Questionnaire

Note: question numbers preceded with an asterisk (*) are the subset of questions received by Group B who had not previously reviewed.

Motivation to review

*1) What were your main reasons for agreeing to be a patient reviewer for [The BMJ / RIE]? _____

2) Thinking of the last research paper you reviewed for [The BMJ / RIE], how important were each of the following factors in your decision to accept to review?

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
a) The opportunity to learn something new from the paper?					
b) The relevance of the topic to your own experience/interests?					
c) The contribution of the paper to the subject area?					
d) The desire to keep up-to-date on current research?					
e) The opportunity to add the patient or carer perspective?					

Reasons for declining to review

*3a) Have you ever declined a request to review a research paper for [The BMJ / RIE]?

- Yes
- No
- Not sure

If Yes,

*3b) Thinking of the last paper you declined to review for [The BMJ / RIE], what was your main reason(s) for declining? _____

*4) Thinking of the last research paper you declined to review for [The BMJ / RIE], how important were each of the following factors in your decision to decline to review?

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
a) Insufficient interest in the paper?					
b) Not having experience of the condition reported in the paper?					
c) Your state of health or the state of health of the person you care for?					
d) Tight deadline for completing the review?					
e) Conflicts with other workload?					
f) Conflicts with family commitments or responsibilities?					
g) Having conflicting interests (that might bias your review)?					
h) Not having received training in how to review a paper?					
i) Comments not taken into account in past reviewing experience?					
j) Dislike of the open peer review process?					
k) Lack of formal recognition of reviewer contribution?					
l) Having to use the online review system?					

Quality of instructions and guidance received

5) How helpful were the instructions you received from [The BMJ / RIE] about what to include in your review?

- Not at all helpful
- Slightly helpful
- Moderately helpful
- Very helpful
- Extremely helpful

6) How confident did you feel when you conducted your **first** review for [The BMJ / RIE]?

- Not at all confident
- Slightly confident
- Moderately confident
- Very confident
- Extremely confident

1
2 7) How confident did you feel when you conducted your **last** review for [The BMJ / RIE]?

- 3
4 Not at all confident
5 Slightly confident
6 Moderately confident
7 Very confident
8 Extremely confident
9
10 Not applicable (I have completed only one review)
11
12
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15

16 8) If you have noticed a change in your confidence to review, what do you think has caused this?
17
18
19

20 [Open review](#)

21
22 For transparency, [The BMJ / RIE] has a policy of open review, where all reviewers are asked to sign their
23 reviews and the signed review is seen by the authors of the paper and the readers of the article (if the article is
24 published by us).
25
26

27 *9) Do you have any concerns about doing open review for [The BMJ / RIE] ?

- 28 Yes
29 No
30 Not sure
31
32
33

34 If yes, please give brief details:
35
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39 [Acknowledgement](#)

40 **BMJ version**

41 We do not pay patient or academic reviewers to review for *The BMJ* but we do give a free one year online
42 subscription to the journal (bmj.com). We also publish a thank you to all those who reviewed for us in the
43 previous year and list their names on our website.
44
45

46 **RIE version**

47 We do not pay patient or academic reviewers to review for *RIE* but patients or service users who have reviewed
48 a certain number of articles within any period of 12 months, are entitled to receive one Article Processing Charge
49 (APC) waiver for an article submitted to the journal. We also publish a thank you to all those who reviewed for us
50 in the previous year and list their names on our website.
51
52

53 *10) How else might [The BMJ / RIE] acknowledge patient reviewers for their help? _____
54
55

56 [Communications with editors and authors](#)

57
58 11) Have you reviewed a paper for [The BMJ / RIE] where the editor subsequently asked the authors to revise it
59 and respond to all the reviewers' comments and [The BMJ / RIE] shared these comments with you?

- 60 Yes No

If No, use skip format so they don't see Q12a, Q12b, and go straight to Q13 (Overall experience)

If Yes,

Thinking of the last paper that you reviewed for [The BMJ / RIE] where you saw the authors' response to all the reviewers' comments.....

12a) To what extent do you agree that the authors of the paper addressed the points you raised in your review?

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

12b) To what extent do you agree that the authors were courteous when addressing the points you raised in your review?

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

Review content

13) Have you been able to include points important to patients or carers in your review(s) that were not raised by the other (academic) peer reviewers?

- Yes
 No
 Other (please specify): _____

14) What other areas or aspects of research papers do you think patient reviewers should be encouraged to comment on that [The BMJ / RIE] does not currently ask you to address? _____

Overall experience

15) Would you recommend being a patient reviewer for [The BMJ / RIE] to other patients and carers?

- Yes
 No
 Not sure

Please explain your response to the question above: _____

16) On the basis of your experience so far do you think that more journals should adopt patient review?

- Yes
 No
 Not sure
 Other (please specify): _____

*17) What thoughts would you like to share with editors at other journals thinking about involving patients and carers in the peer review process? _____

*18) How can we improve the experience of being a patient reviewer for [The BMJ / RIE]? _____

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2
3 [Any further comments?](#)
4

5 *19) Any other comments about being a patient reviewer for [The BMJ / RIE]? _____
6

7 [Finally a few questions about yourself](#)
8

9 *20) Are you:

- 10
11 A patient?
12
13 A carer?
14
15 Both a patient and a carer?
16
17 Other (please specify): _____
18

19 *21) Have you ever reviewed papers as a patient or carer for any other publications and or organisations?
20 (Please tick all that apply).

- 21 No
22
23 [The BMJ / Research Involvement and Education, RIE]
24
25 The Journal of Participatory Medicine
26
27 Cochrane
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29 Other (please specify): _____
30

31 *22) In which country do you mainly live? [drop down menu]

32 *23) On average, approximately how many days a month do you spend on Patient Involvement and Engagement
33 activities, other than patient reviewing?
34

35 Drop down menu: Less than one day; 1; 2; 3;31 days
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41 **Thank you for your valuable time and supporting this initiative**
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GRIPP2 short form

		Reported on page No.
1: Aim	<p>Report the aim of PPI in the study Patients and carers were involved in this study with the aim of ensuring that the survey questions were clear, enabled people to express their own experiences and were of importance to them.</p>	P5
2: Methods	<p>Provide a clear description of the methods used for PPI in the study Patients and carers involved in the study (AD, RH, JE) were core members of the research team and were involved in the inception of the study or invited to participate at the start of the study. The patients and carers aimed to make substantial contributions to each stage of the research and were included in all study meetings and communications. Patient partners co-produced a poster of the findings for the “NIHR INVOLVE Conference 2017” to aid dissemination of the research to academic and industry research professionals, patients, policy makers, editors, and advocacy groups. Early drafts of the survey were reviewed and piloted by an additional four BMJ patient reviewers and changes were made to the questionnaire.</p>	P5, P12

<p>1 2 3 4 3: Study results 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21</p>	<p>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes The patients and carers made substantial contributions to multiple stages of the research.</p> <p>During questionnaire development and piloting, patient reviewers (and not just those in the research team) helped generate applicable questions of importance to them, suggested the removal of some questions, shortened the questionnaire, changed the wording of questions to clarify meaning, encouraged the use of plain language, and broadened some questions to ensure experiences were captured.</p> <p>The patients and carers commented on the results and helped write the manuscript for publication. They were key in ensuring the paper was written in plain language. They will help write a plain language summary for dissemination of the results to the study participants and to relevant organisations.</p>	<p>P5</p>
<p>22 23 24 25 26 27 28 29</p>	<p>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects PPI influenced all aspects of the study. It increased the relevance of survey questions which was pivotal in engaging patient reviewers to take part in the survey. PPI contributions were constructive, timely and improved the quality of the research conducted and reported.</p>	
<p>30 31 5: Reflections/critical perspective 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47</p>	<p>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience Involving patients and carers in this study was a very positive experience and input from patients and carers made the project a success. The project demonstrated the feasibility of working with patients and carers to appraise the quality of the research paper. The patients and carers shared research involvement provided a sense of 'ownership'.</p>	

BMJ Open

Perspectives on involvement in the peer review process: surveys of patient and public reviewers at two journals

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023357.R1
Article Type:	Research
Date Submitted by the Author:	09-Aug-2018
Complete List of Authors:	Schroter, Sara; The BMJ Price, Amy; Oxford University, Evidence Based Health Care; The BMJ Fleming, Ella; BMC part of Springer Nature Demaine, Andrew; Patient and public reviewer, The BMJ Elliot, Jim; Patient Research Advocate and Editorial Board Member of Research Involvement and Engagement Harmston, Rebecca; Patient and public reviewer, The BMJ Richards, Tessa; The BMJ Staniszewska, Sophie; University of Warwick, Warwick Research in Nursing, Warwick Medical School ; Co-Editor in Chief, Research Involvement and Engagement Stephens, Richard; Co-Editor in Chief, Research Involvement and Engagement; Consumer Lead, NCRI
Primary Subject Heading:	Patient-centred medicine
Secondary Subject Heading:	Medical publishing and peer review
Keywords:	INTERNAL MEDICINE, GENERAL MEDICINE (see Internal Medicine), MEDICAL ETHICS

SCHOLARONE™
Manuscripts

**Perspectives on involvement in the peer review process:
surveys of patient and public reviewers at two journals**

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Word count: 4200 (exc abstract and quotes)

ABSTRACT

Objective

In 2014/15 *The BMJ* and *Research Involvement and Engagement (RIE)* became the first journals to routinely include patients and the public in the peer review process of journal articles. This survey explores the perspectives and early experiences of these reviewers.

Design

A cross-sectional survey.

Setting and participants

Patient and public reviewers for *The BMJ* and *RIE* who have been invited to review.

Results

The response rate was 69% (157/227) for those who had previously reviewed and 31% (67/217) for those who had not yet reviewed. Reviewers described being motivated to review by the opportunity to include the patient voice in the research process, influence the quality of the biomedical literature and ensure it meets the needs of patients. Of the 157 who had reviewed, 127 (81%) would recommend being a reviewer to other patients and carers. 144 (92%) thought more journals should adopt patient and public review. Few reviewers (16/224, 7%) reported concerns about doing open review. Annual acknowledgment on the journals' websites was welcomed as was free access to journal information. Participants were keen to have access to more online resources and training to improve their reviewing skills. Suggestions on how to improve the reviewing experience included: allowing more time to review; better and more frequent communication; a more user-friendly process; improving guidance on how to review including videos; improving the matching of papers to reviewers' experience; providing more varied sample reviews, brief feedback on the usefulness of reviews; developing a sense of community amongst reviewers; and publicising of the contribution that patient and public review brings.

Conclusions

Patient and public reviewers shared practical ideas to improve the review experience and these will be reviewed to enhance the guidance and support given to them.

ARTICLE SUMMARY

Strengths and limitations of this study

- The involvement of patients and the public in the peer review process of journal articles is a novel initiative.
- This is the first study to evaluate the experience of patient and public reviewers.
- We explore the perspectives of patient and public reviewers at two journals with different publishers.
- We involved patients and carers in the design, conduct and dissemination of this study.
- We report only on the early experiences of patient and public reviewers and this may change over time.

Keywords

Peer review, patients, public, patient and public involvement

INTRODUCTION

Peer review has been central to the scientific process for over 300 years.[1, 2] It plays a key role in funding and publication decisions and in improving the accuracy and clarity of reported published research. Peer review contributes to scientific integrity by helping identify robust research and weeding out methodologically weak studies. While the value and effectiveness of peer review continues to be debated vigorously, it is still regarded as an essential quality assurance mechanism for funding organisations and journals and it is the only widely accepted method for research validation.[1, 3-6] It is therefore a deeply entrenched process in international funding organisations and high quality journals. By playing a key part in determining what research gets funded and published, peer review has a pivotal role in determining the treatment and interventions patients receive and how medicine is practised.

Despite its pivotal role peer review is criticised on many fronts.[7, 1] Traditionally, it has been a closed process and the majority of journals still practice blinded review. It is only recently that there have been calls to include the views of all relevant stakeholders, including patients and the public. The role of patients and the public is also being stepped up as co-producers of health and social care research not least because their involvement has potential to increase the quality and value of the research and reduce waste.[8] Many grant funding organisations now incorporate members of the public in their review processes or panels e.g. the UK's National Institute for Health Research (NIHR) and the Patient-Centered Outcomes Research Institute (PCORI) in the US. By contrast, biomedical journals still do very little to involve patients and the public in their peer review processes. To address this imbalance, *The BMJ* and *Research Involvement and Engagement (RIE)* journals have adopted innovative strategies aimed at co-producing their content with patients and the public, and both journals have patient editors.[9-12] The systematic incorporation of patient and public review of research manuscripts alongside traditional scientific peer review is a key component of these journal patient partnership strategies. Patient and public involvement in peer review of research manuscripts represents a landmark shift in the concept of peer review at journals, reflecting a desire to ensure research is appropriate and relevant to end users. These journals also practise open peer review where the authors and reviewers know each other's identities and reviews of published articles are published online beside the article for readers.

While some patient and public reviewers are able to comment on research methodology their strength collectively is in addressing the relevance and importance of the research to patients and carers and whether the treatment or intervention studied, or guidance given is practicable and acceptable to patients. They can also identify challenges patients and carers face; whether the outcomes measured in the studies described are important to patients and carers and if other outcomes or issues should have been considered. They can also suggest ways to strengthen papers to make them more useful for shared decision-making. Contributions will vary according to the background, skills and experience of the patient and public reviewer, as it does with academic reviewers. Some patients and carers may comment on the relevance of a study for a particular group, while those with academic training and research knowledge might comment on methodology. Others may focus on the clarity of the reported research and its interpretation to a lay audience. All these contributions and others have the potential to enhance the quality of the research and its uptake in practice.

Academic researchers are encouraged and motivated to publish their research as part of career advancement in a "publish or perish" environment[13] and reciprocal peer reviewing of articles is considered to be a professional duty.[14-17] In marked contrast, patient and public reviewers have no professional implicit or explicit obligations to review. With open access publishing and non-blinded

1 review the responsibility of reviewing papers may be compounded by the challenge of being
2 identified as a person with an illness or disability. Both *The BMJ* and *RIE* offer guidance for patient
3 and public reviewers, developed with patient editors, but these have not been informed by the
4 experience of patient and public reviewers and might not provide the level of support some need. In
5 this collaborative survey carried out by *The BMJ* and *RIE*, with embedded patient involvement, we
6 explore the early experiences of our patient and public reviewers. Reviewers were asked what
7 motivates them to review research articles, if and why they have declined to review, their confidence
8 in reviewing, their perceptions of open review, their satisfaction with the process, how they would like
9 to be acknowledged for their contributions and their views on how the process could be improved.
10 This knowledge will be used to inform evidence-based guidance for patient and public reviewers.
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METHODS

The research was reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee MS-IDREC-C1-2013-174.

Sampling

Patients and public reviewers who were registered as reviewers for *The BMJ* or *Research Involvement and Engagement (RIE)* and were invited to review for one of the journals at least once between January 2015 and May 2017 were eligible to participate. The reviewer pool was split into two samples based on review history; those who had already completed a review and those who had been invited but not yet completed a review (by April 2017). This was so that questions which were not relevant to those who had not yet reviewed could be excluded.

Reviewers' contact details were extracted from the relevant manuscript tracking systems and uploaded to SurveyMonkey. We excluded those who were registered as reviewers but whom had not been invited to review and those who have previously asked not to be contacted by *The BMJ* for marketing purposes.

Questionnaire development and pre-testing

Survey items were developed by the research team which included patient and public reviewers from both participating journals (AD, RH, JE) and *The BMJ* and *RIE* patient editors (TR, AP, RS). The questionnaires were pre-tested before launching the survey with a further four BMJ patient and public reviewers to check the survey content was appropriate and addressed issues of importance to patient and public reviewers and that questions were not ambiguous.

Survey administration

Reviewers were sent a personalised email invitation to complete a survey (Appendix 1) administered by SurveyMonkey. There were two versions of the questionnaire; those who had already completed a review received all the questions and those who hadn't received only a subset. Participants were informed that they could choose not to take part and withdraw at any time; survey completion was used to indicate consent to participate. They were told that the results of the survey would be submitted for publication and that we may choose to quote from their responses, but individuals would not be identified. All survey data was treated confidentially and only SS and EF saw the individual responses for their own journals. All data was de-identified before sharing with the wider research team. Non-respondents were sent up to two reminders to take part at two and four weeks after the initial mailing.

Patient involvement

Patient and public reviewers were involved in multiple stages of the research. Three patient and public reviewers (JE, RH, AD) are co-authors on this paper as they were core members of the research team and substantially contributed to the development of the questionnaire, refinement of the questionnaire, interpretation of results and manuscript revision. These three patient partners co-produced an abstract and poster of the findings for the "NIHR-INVOLVE" Conference 2017[18] to aid dissemination of the research to academic and industry research professionals, patients, policy makers, editors, and advocacy groups. We pre-tested the questionnaire with a further four *BMJ* patient and public reviewers (outside of the research team) and refined the questions based on their feedback. Three other members of the research team are patient editors with long term conditions committed to involving patients in research. More details can be found in the completed GRIPP2 reporting checklist for improving the reporting of patient and public involvement in research (see supplementary material).

RESULTS

Response rate

122 (74%) of the 164 *BMJ* and 35 (56%) of the 63 *RIE* reviewers who had previously reviewed responded and 51 (38%) of the 133 *BMJ* and 16 (19%) of the 84 *RIE* reviewers who had not yet reviewed responded. We pooled the results for the overlapping content and report for both samples combined where relevant.

Respondent characteristics

Table 1 shows the respondent characteristics for reviewers completing the surveys. The majority of reviewers lived in the UK. Reviewers who had reviewed had completed a median of two reviews. Overall reviewers who had reviewed reported spending a median of 5 days a month on other patient involvement or engagement activities and those who had not yet reviewed reported this as 7 days a month. However, there were differences between the journals with *RIE* reviewers reporting more days spent doing these activities than *BMJ* reviewers.

Motivation to review

Patient and public reviewers who had already reviewed described in free text comments how they are motivated to review by the opportunity to include the patient voice in the research process; the opportunity to influence the quality of the literature and to help ensure it meets the needs of patients and is understandable by them; helping make research more relevant and useful to researchers, clinicians and patients; the intellectual challenge; and learning more about research on topics of interest to them.

Data are presented as the mean (standard deviation) of responses on a 5-point Likert scale for the n=157 who had reviewed. The factor rated most highly in importance to the decision to accept a paper to review was the opportunity to add the patient or carer perspective (4.49 (0.71)) (Figure 1), but more than half reported the following as very or extremely important: the contribution of the paper to the subject area (3.8, (0.9)), relevance of the topic to own experience/interests (3.8, (1.0)), desire to keep up-to-date on current research (3.6 (1.0)), and opportunity to learn something new from the paper (3.5 (1.0)).

Reasons for declining

Data are presented as the mean (standard deviation) of responses on a 5-point Likert scale. Across both samples, 101 reviewers reported that they had declined a request to review at some stage. The most highly rated factors important in the decision to decline to review was conflict with other workload (3.7 (1.4)), a tight deadline for completing the review (3.3 (1.4)), and conflicts with family commitments or responsibilities (2.8 (1.6)), Figure 2. Dislike of the open peer review process (1.1 (0.4)), having to use the online manuscript review system (1.3 (0.7)), and lack of formal recognition of reviewer contribution (1.3 (0.7)) were the least important factors. Other reasons reviewers mentioned for declining to review included a lack of experience or interest in the topic, the irrelevance of the topic for patient and public review in general and not understanding the paper.

Confidence in reviewing

Of the 157 who had reviewed, 43 (27%) reported feeling either not at all or only slightly confident when doing their first review, but this proportion fell for those who had done more than one review, to 11/141 (8%) when doing their last review. Six (4%) reported they were extremely confident when doing their first review and 19 (13%) when doing their last review.

Reviewers explained that the following had helped to improve their confidence: practice and gaining familiarity with the process; seeing other peer reviewers' comments on the paper; having access to sample reviews; receiving feedback from editors; knowing their review was valued; being asked to review again; improved journal guidance and provision of frequently asked questions; seeing their own comments in letters to authors requesting revisions; and generally reading more peer reviewed articles and reviewing for other organisations simultaneously.

"It takes time in my estimation to get into a place where as a patient I am confident reviewing the work of academic scholars. At first I took the stance of "who am I to challenge them," but recognized after the first review I am the patient with the experience and perspective that can help to inform the practice of research."

"Initially I was worried that my lack of in-depth knowledge of statistical methods would make my comments seem petty or too simplistic. Yet when I read expert reviewers comments I saw that they picked up on some of my points which gave me the confidence to stick to my guns and write anything I felt was important to say."

Perceptions of open review process

At both journals, all reviewers' named comments are published alongside the article on the journals' websites. When asked if they had concerns about open review, 181/224 (81%) said no, 16 (5%) said yes, and 25 (7%) were unsure. Of the 16 who said yes, 15 had already reviewed a manuscript. Reported concerns included some which were generic to the concept of open review (e.g. worries about being completely critical of a paper or misunderstanding something) and some which were specific to being a patient (e.g. embarrassment or being perceived negatively by others, patient confidentiality, misuse of personal information published online, implications for future job applications and impact on receiving disability benefits).

"I am cautious about who I share information with in terms of my health. Just putting my name out there as a patient reviewer exposes some of that. I have decided that the benefits of being a BMJ peer reviewer are greater to me than the risk of exposing myself that way, but it was a consideration."

Reviewer satisfaction

Likelihood to recommend to other patients and carers

127 (81%) of the 157 who had reviewed (82% *BMJ*, 77% *RIE*) would recommend being a patient and public reviewer to other patients and carers, 3 (2%) would not and 26 (17%) were unsure. Reasons for potentially not recommending to others included the lack of a sense of community amongst patient and public reviewers, non user-friendly submission software and disappointment that the paper reviewed was accepted despite their comments that the paper was not methodologically strong or well presented. Hesitancy to recommend focused on the fact that reviewing is not for everyone and that it is a highly subjective exercise.

Should other journals adopt patient and public review?

Based on their reviewing experience so far, 144 (92%) of the 157 reviewers (91% *BMJ*, 94% *RIE*) thought more journals should adopt patient and public review.

"We need to show maturity in academic working and co-creation with patients and carers. Patients and carers already influence whether grants are awarded (millions of pounds) so this is another step in closing the evidence to practice loop."

1 *“Patients bring a unique perspective to scientific articles. Far from being a luxury,*
 2 *patient views are an important factor in research relevance.”*

3
 4 *“... it should prove mutually beneficial and give researchers a 'patient's eye view of*
 5 *potential/existing treatments as well as suggesting further avenues for research.”*

6
 7
 8 *“Very good scheme and needs to be developed to become a beacon for other general*
 9 *medical journals.”*

10
 11 Hesitancies included worry that patient and public review could become a tick box exercise, needing
 12 reassurance that patient and public reviewers' comments were being considered, and the
 13 appropriateness of journal content for patient and public review.
 14

15 *Perceptions of authors and other reviewers*

16 35 (22%) reviewers indicated that they had reviewed a paper for which the editors later shared the
 17 peer reviewers' comments. 29/35 (83%) “strongly agreed” or “agreed” that the authors of the paper
 18 addressed the points they had raised in their reviews and 28/35 (80%) “strongly agreed” or “agreed”
 19 that the authors were courteous when addressing their points. After having seen the peer reviewers'
 20 comments on the paper they reviewed, 22 (63%) felt they had been able to include points important
 21 to patients or carers in their own review(s) that were not raised by the peer reviewers, 10 (29%)
 22 couldn't remember or felt it was difficult to judge and only three (9%) felt that they were unable to do
 23 so.
 24
 25

26 *Helpfulness of journal instructions*

27 Overall 95/157 (61%) who had reviewed perceived the current instructions received on what to
 28 include in the review as “extremely” or “very helpful” (BMJ: 63%, RIE: 51%); 49 (31%) found them
 29 only moderately helpful; and 13 (8%) slightly or not at all helpful. Reviewers made constructive
 30 suggestions on how the guidance could be improved.
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34 **How to acknowledge patient and public reviewers' help**

35 Patient and public reviewers at both journals are acknowledged annually on the journal websites and
 36 analysis of the free text comments about how reviewers should be acknowledged showed this was
 37 well received by participants. All *BMJ* reviewers receive an annual free subscription to the online
 38 version of the journal (bmj.com), as only research articles are open access, and this was popular with
 39 *BMJ* respondents. *RIE* is already open access for anyone to read. Having access to information was
 40 important and respondents were keen to receive longer-term subscriptions for the journal, the ability
 41 to pass it on to a family member, or subscriptions or access to articles in other journals published by
 42 *BMJ*. Participants were also keen to have access to more online resources, conferences, and training
 43 to improve their reviewing skills.
 44
 45

46 *“I think I am adequately "compensated" for my work and I appreciate the subscription.*
 47 *As an advocate who rarely gets paid for my work, journal access is a big deal to me. I*
 48 *do this because it's a passion and I want to see the dynamic change. I'm doing my part*
 49 *and that's what gratifies me most.”*
 50
 51

52 *RIE* offers patients or service users who have reviewed a certain number of articles within any period
 53 of 12 months an Article Processing Charge (APC) waiver for an article submitted to the journal. Only
 54 three *RIE* reviewers commented on the value of the waiver for the APC. One was very positive of its
 55 value and had used the APC waiver to publish the experience of their patient group in the journal,
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1 another felt all patient and public reviewers should have the APC waived, another that it should be
2 transferable to another person.
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4 The majority of free-text comments did not focus on monetary incentives but some reviewers did
5 suggest honorariums, payment, gift vouchers, a prize draw and donations to charity after accruing
6 reviews. There were suggestions that the lack of any form of compensation for reviewing might put
7 off some potential patient and public reviewers. Others wanted something physical that they could
8 show others, for example: a certificate of participation; a pin badge or keyring for long standing
9 reviewers; a gadget; an annual award for the best reviewer and an announcement of this; graded
10 awards (e.g. Gold, Silver, Bronze) based on reviewer performance; a reward system tied to Publons
11 (<https://publons.com/home>); a formal letter by post after a fixed number of reviews; and something to
12 state in their CVs.
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16 In free-text comments reviewers expressed interest in being named as patient and public reviewers
17 on the published articles themselves rather than just in the accompanying published reviews or for an
18 indication in the article that it has been reviewed by patients. Others wanted more publicity over the
19 contribution that patient and public review brings to the journals, the opportunity to contribute patient
20 opinions on published articles or to be included as co-authors in commentaries and blogs. They
21 suggested a patient and public reviewer TweetChat led by journal staff, more feedback about how
22 their reviews were beneficial and to schedule patient and public reviewer meetings in order to build
23 community and to develop expertise.
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26 **How to improve the experience**

27 Suggestions on how to improve the overall experience included: allowing more time to review;
28 improving and more frequent communications e.g. by newsletter; making the submission process
29 and automated communications more user friendly; adding more and improved guidance on how to
30 review including videos of the submission process and explaining what to expect and when; better
31 matching of papers to reviewers' experience; providing more varied sample reviews; more support,
32 encouragement, training and forums to answer questions; editors providing (brief) feedback on
33 usefulness of reviews and how papers have changed as a result of the reviews; better sharing of
34 information around decisions made on manuscripts reviewed; developing a sense of community (an
35 online network) amongst patient and public reviewers; peer to peer mentoring; raising the profile of
36 patient review by illustrating the value added and changes made; and treating patient and public
37 reviewers as equal partners in the peer review process.
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DISCUSSION

This is the first study to explore the experience of patient and public reviewers involved in the peer review process of academic journals. A large majority of patient and public reviewers were enthusiastic about their experience, would recommend others to act as reviewers, and thought other journals should adopt patient and public review. Few reported concerns about being identified through open review. Reviewers identified areas where the journals could improve and how they would like to be acknowledged for their contributions. Annual acknowledgement of reviewers' contributions on the journals' websites was welcomed. *BMJ* reviewers welcomed the free subscription to the journal as a reward for reviewing (all content in *RIE* is open access). Only three *RIE* reviewers commented on the APC waiver. Some reviewers cautioned about tokenism, and underlined the need for more feedback on how patient and public review is valued by authors and editors. Fostering a sense of community among patient and public reviewers was advocated. Despite the different approach and guidelines for patient and public review between *The BMJ* and *RIE* the reviewers' views on most issues were similar.

While the motivating factors for academics to review papers are known[14-17] this study assessed what motivates patients and carers to review. It establishes that the overarching motivating factor is the opportunity to add patient or carer perspectives. It is of interest to note that motivating factors reported by academic reviewers were also considered important to patient and public reviewers e.g. the contribution of the paper to the subject area, relevance of the topic to their own experience/interests, a desire to keep up-to-date on current research, and the opportunity to learn something new from the paper. Similar to academic reviewers, patient and public reviewers valued being given an online subscription to the journal[14, 17] and indicated a desire for access to more information from journals and publishers. Again, similar to academic reviewers, the most important factor in declining to review was conflict with other workload,[14] but a higher proportion of patients reported the tight deadline for completing the review affected their decision to decline than academics.

The results suggest that it is feasible to introduce patient and public review alongside peer review of research papers. Patients and the public greatly appreciate the opportunity to be involved and see value in it. However, they also indicated areas for development and questioned some of our practice. This emphasises the importance of seeking feedback and making the subsequent changes to demonstrate that we value their opinion. Some areas are easily fixed whilst others are restrained by the software, expense or demands of a fast publication process designed to meet the needs of authors and researchers. Journals do not typically pay peer reviewers. While the majority of reviewers did not focus on monetary compensation or incentives, some suggested lack of monetary compensation was a barrier if the goal was to solicit views from a fully representative sample of patients. Some organisations offer patients honoraria for reviewing e.g. NICE's Health Technology Appraisal (HTA), although these requests are to review documents substantially longer than a research paper. Responses to this survey identified a range of ways that patient and public reviewers can be thanked and acknowledged other than through financial compensation.

We received a good response rate of 69% overall for those who had previously reviewed, reflecting a high level of ongoing engagement and support for this initiative. The respondents were involved in other patient involvement activities for an average of five days a month reflecting the increasingly strong commitment to include the patient's voice in health research and healthcare provision. *RIE* reviewers reported spending more time on these activities than *BMJ* reviewers. This finding reflects the fact that many of the patient and public reviewers for *RIE* have been recruited from groups already working in research, such as the National Cancer Research Institute (NCRI) Consumer

1 Forum in the UK or are European Patients' Academy (EUPATI) Fellows, and thus likely to have
2 experience and expertise in critical appraisal of protocols and research studies (especially on the
3 patient-related aspects of the research). *BMJ* reviewers are asked to respond to a broader patient-
4 specific set of questions and are not expected to have any research experience. Despite these
5 differences, responses to the surveys were so similar for both journals that we needed to report only
6 the combined response.
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9 Our study is limited by including the experiences of patient and public reviewers at only two journals.
10 However, these two journals were the first to introduce patient and public review alongside academic
11 peer review and have sufficient experience of implementing it to enable the survey. At the time of the
12 survey, we were not aware of any other journals systematically including patients in reviewing
13 research papers. The two journals have different approaches and guidance, but their reviewers
14 report similar experiences and challenges. Some respondents had only limited experience of
15 reviewing and their perceptions may change with time. As this is a recent and novel initiative, it is
16 important to survey patient and public reviewers again as we make changes to the guidance and
17 seek to provide them with more support. Whilst respondents did not focus on the need for monetary
18 rewards and financial incentives it is important to acknowledge that their views may not be
19 representative of all potential patient and public reviewers. Similarly, while open review did not
20 appear to be a concern for most patients we have no way of knowing how many have been put off
21 reviewing because of this.
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25 Patient and public review of health research is a development in response to the call for greater
26 patient and public involvement in research and healthcare in general. Peer review of research papers
27 happens at the end of the research process and we recognise and agree on the importance of
28 involving patients early on at the start of the research process and throughout it, to increase its value
29 and minimise waste in research,[19, 20] and to help make evidence more relevant and accessible to
30 end users.[21-23, 24, 25] *The BMJ* and *RIE* see partnering with patients, their carers, wider support
31 networks, and the public as an ethical imperative essential to improving the quality, safety, value, and
32 sustainability of health systems.[9-12, 26] Patient and public review is just a single initiative under
33 these partnership strategies the journals have introduced. Both journals also have patients and
34 carers as members of their Editorial Boards and patient editors to bring the patients' perspective to
35 internal discussions and decision-making. The results of this survey will be used to help improve the
36 guidance, support and ultimately the experience of patient and public reviewers for the participating
37 journals and other journals that adopt it. Further research is planned to identify where and how
38 patient and public reviewers add value to the peer review process.
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DECLARATIONS

Data sharing

Data are available upon reasonable request.

Competing interests

SSt and TR are employed by *The BMJ*; AP is the Patient Editor (Research and Evaluation) at *The BMJ*; SSt and RS are the Co-Editors in Chief of the *Research Involvement and Engagement*; AD and RH are patient and public reviewers for *The BMJ*; JE is a patient research advocate and an Editorial Board Member of *Research Involvement and Engagement*; EF is employed by BMC, part of Springer Nature, which publishes *Research Involvement and Engagement*. All authors support the call for greater public involvement in research.

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Author Contributions

AP and SSc wrote the study protocol, interpreted the survey results, and wrote the first draft of the manuscript. SSc created the surveys on SurveyMonkey, administered the surveys to *BMJ* reviewers, and analysed the pooled anonymised data. EF administered the surveys to *RIE* and project managed the wider study and collaboration. All authors (SSc, AP, EF, AD, JE, RH, TR, SSt, RS) helped develop the survey questions, commented on the results and helped write the paper for publication. All authors (SSc, AP, EF, AD, JE, RH, TR, SSt, RS) approved the final version of the paper for submission.

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Peer review only

Table 1: Respondent characteristics

Had already reviewed	<i>BMJ</i> (n=122)	<i>RIE</i> (n=35)	All (n=157)
Median (LQ, UQ) number of reviews completed	2 (1, 4)	2 (1, 3)	2 (1, 4)
Country of residence (%)			
UK	63 (52)	28 (80)	91 (58)
Europe (excluding UK)	20 (16)	3 (9)	23 (15)
North America	36 (30)	2 (6)	38 (24)
Australia / New Zealand	3 (2)	2 (6)	5 (3)
Median (LQ, UQ) number of days per month spent on patient involvement and engagement activities	5 (2, 11)	11 (3, 24)	5 (2, 15)
Had not already reviewed	<i>BMJ</i> (n=51)	<i>RIE</i> (n=16)	All (n=67)
Country of residence (%)			
UK	22 (43)	5 (31)	27 (40)
Europe (excluding UK)	10 (20)	10 (63)	20 (30)
North America	14 (27)	0 (0)	14 (21)
Australia / New Zealand	0 (0)	0 (0)	0 (0)
Asia	1 (2)	0 (0)	1 (1)
Median (LQ, UQ) number of days per month spent on patient involvement and engagement activities	6 (2, 14)	21 (10, 26)	7 (3, 21)

Note Percentages do not sum to 100% because of missing data.

LQ: lower quartile

UQ: upper quartile

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Figure legends

Figure 1: Importance of specific factors in the decision to accept to review (n=157 who had previously reviewed)

Figure 2: Importance of specific factors in the decision to decline to review (n=101 who had previously declined an invitation to review)

Appendix 1: Questionnaire

For peer review only

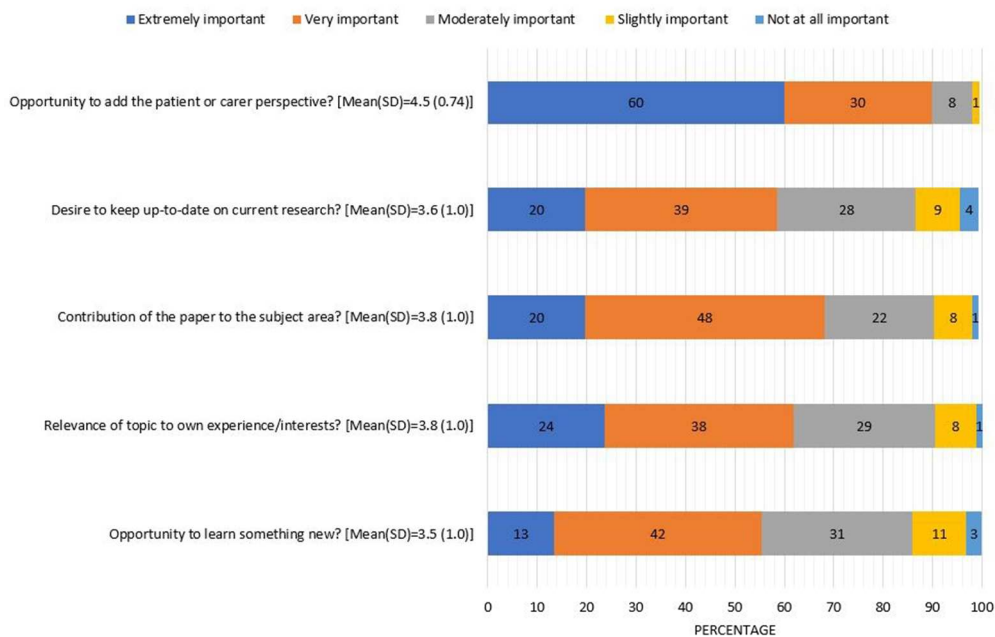


Figure 1: Importance of specific factors in the decision to accept to review (n=157 who had previously reviewed)

82x53mm (300 x 300 DPI)

Review only

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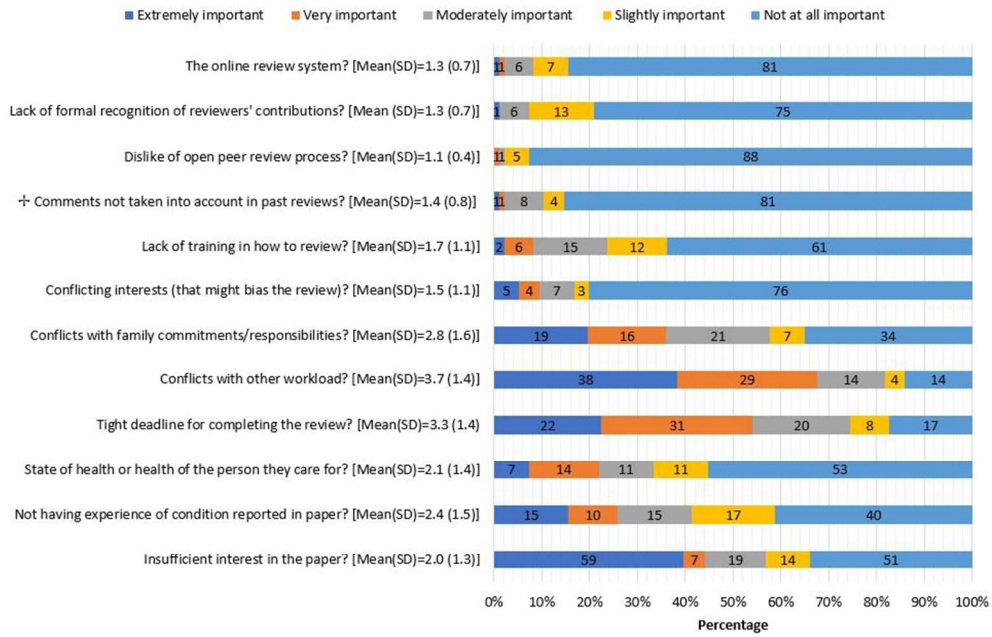


Figure 2: Importance of specific factors in the decision to decline to review (n=101 who had previously declined an invitation to review)

82x53mm (300 x 300 DPI)

Appendix 1: Questionnaire

Note: question numbers preceded with an asterisk (*) are the subset of questions received by the group who had not previously reviewed.

Motivation to review

*1) What were your main reasons for agreeing to be a patient reviewer for [The BMJ / RIE]? _____

2) Thinking of the last research paper you reviewed for [The BMJ / RIE], how important were each of the following factors in your decision to accept to review?

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
a) The opportunity to learn something new from the paper?					
b) The relevance of the topic to your own experience/interests?					
c) The contribution of the paper to the subject area?					
d) The desire to keep up-to-date on current research?					
e) The opportunity to add the patient or carer perspective?					

Reasons for declining to review

*3a) Have you ever declined a request to review a research paper for [The BMJ / RIE]?

- Yes
- No
- Not sure

If Yes,

*3b) Thinking of the last paper you declined to review for [The BMJ / RIE], what was your main reason(s) for declining? _____

*4) Thinking of the last research paper you declined to review for [The BMJ / RIE], how important were each of the following factors in your decision to decline to review?

	Not at all important	Slightly important	Moderately important	Very important	Extremely important
a) Insufficient interest in the paper?					
b) Not having experience of the condition reported in the paper?					
c) Your state of health or the state of health of the person you care for?					
d) Tight deadline for completing the review?					
e) Conflicts with other workload?					
f) Conflicts with family commitments or responsibilities?					
g) Having conflicting interests (that might bias your review)?					
h) Not having received training in how to review a paper?					
i) Comments not taken into account in past reviewing experience?					
j) Dislike of the open peer review process?					
k) Lack of formal recognition of reviewer contribution?					
l) Having to use the online review system?					

Quality of instructions and guidance received

5) How helpful were the instructions you received from [The BMJ / RIE] about what to include in your review?

- Not at all helpful
- Slightly helpful
- Moderately helpful
- Very helpful
- Extremely helpful

6) How confident did you feel when you conducted your **first** review for [The BMJ / RIE]?

- Not at all confident
- Slightly confident
- Moderately confident
- Very confident
- Extremely confident

1
2 7) How confident did you feel when you conducted your **last** review for [The BMJ / RIE]?

- 3
4 Not at all confident
5 Slightly confident
6 Moderately confident
7 Very confident
8 Extremely confident
9
10 Not applicable (I have completed only one review)
11
12
13
14
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16 8) If you have noticed a change in your confidence to review, what do you think has caused this?
17
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19

20 [Open review](#)

21
22 For transparency, [The BMJ / RIE] has a policy of open review, where all reviewers are asked to sign their
23 reviews and the signed review is seen by the authors of the paper and the readers of the article (if the article is
24 published by us).
25

26
27 *9) Do you have any concerns about doing open review for [The BMJ / RIE] ?

- 28 Yes
29 No
30 Not sure
31
32
33

34 If yes, please give brief details:
35
36

37
38 [Acknowledgement](#)

39 **BMJ version**

40
41 We do not pay patient or academic reviewers to review for *The BMJ* but we do give a free one year online
42 subscription to the journal (bmj.com). We also publish a thank you to all those who reviewed for us in the
43 previous year and list their names on our website.
44
45

46 **RIE version**

47 We do not pay patient or academic reviewers to review for *RIE* but patients or service users who have reviewed
48 a certain number of articles within any period of 12 months, are entitled to receive one Article Processing Charge
49 (APC) waiver for an article submitted to the journal. We also publish a thank you to all those who reviewed for us
50 in the previous year and list their names on our website.
51
52

53 *10) How else might [The BMJ / RIE] acknowledge patient reviewers for their help? _____
54
55

56 [Communications with editors and authors](#)

57
58 11) Have you reviewed a paper for [The BMJ / RIE] where the editor subsequently asked the authors to revise it
59 and respond to all the reviewers' comments and [The BMJ / RIE] shared these comments with you?

- 60 Yes No

If No, use skip format so they don't see Q12a, Q12b, and go straight to Q13 (Overall experience)

If Yes,

Thinking of the last paper that you reviewed for [The BMJ / RIE] where you saw the authors' response to all the reviewers' comments.....

12a) To what extent do you agree that the authors of the paper addressed the points you raised in your review?

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

12b) To what extent do you agree that the authors were courteous when addressing the points you raised in your review?

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

Review content

13) Have you been able to include points important to patients or carers in your review(s) that were not raised by the other (academic) peer reviewers?

- Yes
 No
 Other (please specify): _____

14) What other areas or aspects of research papers do you think patient reviewers should be encouraged to comment on that [The BMJ / RIE] does not currently ask you to address? _____

Overall experience

15) Would you recommend being a patient reviewer for [The BMJ / RIE] to other patients and carers?

- Yes
 No
 Not sure

Please explain your response to the question above: _____

16) On the basis of your experience so far do you think that more journals should adopt patient review?

- Yes
 No
 Not sure
 Other (please specify): _____

*17) What thoughts would you like to share with editors at other journals thinking about involving patients and carers in the peer review process? _____

*18) How can we improve the experience of being a patient reviewer for [The BMJ / RIE]? _____

1
2
3 [Any further comments?](#)
4

5 *19) Any other comments about being a patient reviewer for [The BMJ / RIE]? _____
6

7 [Finally a few questions about yourself](#)
8

9 *20) Are you:

- 11 A patient?
12
13 A carer?
14
15 Both a patient and a carer?
16
17 Other (please specify): _____
18

19 *21) Have you ever reviewed papers as a patient or carer for any other publications and or organisations?
20 (Please tick all that apply).

- 21 No
22
23 [The BMJ / Research Involvement and Education, RIE]
24
25 The Journal of Participatory Medicine
26
27 Cochrane
28
29 Other (please specify): _____
30

31 *22) In which country do you mainly live? [drop down menu]
32

33 *23) On average, approximately how many days a month do you spend on Patient Involvement and Engagement
34 activities, other than patient reviewing?
35

36 Drop down menu: Less than one day; 1; 2; 3;31 days
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41 **Thank you for your valuable time and supporting this initiative**
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GRIPP2 short form

		Reported on page No.
1: Aim	<p>Report the aim of PPI in the study</p> <p>Patients and carers were involved in this study with the aim of ensuring that the survey questions were clear, enabled people to express their own experiences and were of importance to them.</p>	P5
2: Methods	<p>Provide a clear description of the methods used for PPI in the study</p> <p>Patients and carers involved in the study (AD, RH, JE) were core members of the research team and were involved in the inception of the study or invited to participate at the start of the study. The patients and carers aimed to make substantial contributions to each stage of the research and were included in all study meetings and communications. Patient partners co-produced a poster of the findings for the “NIHR INVOLVE Conference 2017” to aid dissemination of the research to academic and industry research professionals, patients, policy makers, editors, and advocacy groups.</p> <p>Early drafts of the survey were reviewed and piloted by an additional four BMJ patient reviewers and changes were made to the questionnaire.</p>	P5, P12
3: Study results	<p>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</p> <p>The patients and carers made substantial contributions to multiple stages of the research.</p> <p>During questionnaire development and piloting, patient reviewers (and not just those in the research team) helped generate applicable questions of importance to them, suggested the removal of some questions, shortened the questionnaire, changed the wording of questions to clarify meaning, encouraged the use of plain language, and broadened some questions to ensure experiences were captured.</p> <p>The patients and carers commented on the results and helped write the manuscript for publication. They were key in ensuring the paper was written in plain language. They will help write a plain language summary for dissemination of the results to the study participants and to relevant organisations.</p>	P5

<p>1 2 3 4 5 6 7 8</p> 4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects PPI influenced all aspects of the study. It increased the relevance of survey questions which was pivotal in engaging patient reviewers to take part in the survey. PPI contributions were constructive, timely and improved the quality of the research conducted and reported.	
<p>9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46</p> 5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience Involving patients and carers in this study was a very positive experience and input from patients and carers made the project a success. The project demonstrated the feasibility of working with patients and carers to appraise the quality of the research paper. The patients and carers shared research involvement provided a sense of 'ownership'.	