Better together: patient partnership in medical journals

The BMJ's experience can be a springboard for others

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The BMJ has had patient editors for over 20 years, and they have brought a new dimension to our work and thinking. None more so than the peerless Rosamund Snow. But her predecessors left their mark too, including Peter Lapsley, who 10 years ago underlined that “patients have more to contribute to the BMJ than simply [recounting] their experience of illness and treatment.” He died before we launched our revolutionary patient partnership strategy, but he would have welcomed the changes it has brought to our editorial processes and the movement, supported by patients, now spreading to other journals.

Our strategy was co-produced with an international patient advisory panel and continues to be co-steered by them. The lively exchanges with and between panel members and The BMJ staff, moderated by the journal’s patient editors, raises editorial awareness of patient led initiatives and issues that matter to patients and carers and informs commissioning decisions across the journal. Panel members are often among the first to comment on articles, and many patients and their linked communities follow and respond to our Twitter feeds and debates.

The database we have built to embed patient review of submissions alongside peer review has grown steadily. We refer to people who help us in this way as “patient and public reviewers.” This acknowledges that although most reviewers have long term conditions, some are carers, parents, those who access services only intermittently and don't think of themselves as patients, and members of health related charitable and voluntary organisations. Similarly, our patient panel includes health professionals and policy experts who champion patient empowerment and shared decision making. Accordingly, our strategy has been renamed a “patient and public partnership” strategy, a terminology now in common use among other organisations.

The requirement introduced four years ago that authors of research in The BMJ must report if and how they involved patients and the public in their studies supports growing advocacy to embed partnership in the global research enterprise. Other journals now requiring a PPI (patient and public involvement) statement include BMJ Open, BJOG, Research Involvement and Engagement, and several leading titles in BMJ’s portfolio of specialist journals. We recently pledged to advance debate on establishing new tenets to govern patients' roles and rights in research.

Content written and co-written by patients—including BMJ Opinion, the What Your Patient is Thinking series, commentaries, and editorials—provides valuable insights, not least into the reality of care at the sharp end and ideas on how to improve it. Podcasts about organisations advancing partnership and the Partnership in Practice series aim to fulfil our pledge to illuminate the “science and art” of partnership in clinical practice, policy, and medical education.

Although we set internal targets for co-production of content, we recognise that chasing numbers is not enough. It is the quality and timeliness of the input that matters most. For our educational content we have clarified our guidance on co-production of articles to support authors. Co-production and review of educational articles by patients and carers provide a wider understanding of living with illness and its biopsychosocial impact, which is often recognised or poorly understood by health professionals. We are now spreading the principles of co-production across BMJ’s learning and clinical decision support resources.

The campaign to include patients in medical meetings, initiated by Lucien Engelen in 2013, has been a notable success. Organisers of conferences now regularly self accredit as #PatientsIncluded. The BMJ has made strides here, notably in the International Quality and Safety in Healthcare forums, and is committed to identifying best practice and avoiding tokenism. Having patients on organising committees is crucial. Patients and patient advocates also routinely sit on the judging panels for the BMJ Awards.

Evaluation of a strategy that is as much about changing hearts and minds as practice and policy is not easy, but we are making progress. A comparison of PPI reported in research papers published in The BMJ before and one year after the introduction of our PPI reporting policy showed an increase, albeit a small one. Peer review by patients and the public has been shown to be feasible, and editors think it adds value. A survey of reviewers showed that they welcome being part of the editorial
decision making process and they provided useful information on how to improve our processes and guidance. A study of the “value” added by patient and public review is planned. One particular concern from a survey of clinical trialists was the minimal effort and resources devoted to disseminating study results to participants and related communities. We are committed to making improvements in this important area.

Person centred care and shared decision making are embedded in the lexicons of Western health systems. But all too often patients and carers observe a wide gap between aspiration and reality, as the recent Gosport scandal reminds us.

Medical journals can play a part in helping narrow this gap by working with, not only nominally for, patients and the public. There is no single approach to partnership. Each journal must forge its own path. Several have begun the journey. We urge others to join them.

Follow the patient editors on Twitter @BMJPatientEd

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