

EDITORIALS

The BMJ's own patient journey

Seeks to promote patient partnership by walking the talk

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A year ago *The BMJ* committed to setting up an international panel of patients, patient advocates, and clinicians to help us develop a strategy to advance the “patient revolution” in healthcare.¹ This week we are launching it, with due thanks to the members of our advisory panel.² Over the past six months they have stimulated, provoked, steered, and supported us to make landmark changes to our editorial processes. Changes that we hope will add to national and international efforts to improve the quality, safety, value, and sustainability of health systems through realising the transformative potential of working in partnership with patients, their families, communities, and advocacy groups.³ So what have we done?

Firstly, we have embedded patient peer review of research papers. We started in January with randomised controlled trials and have now extended it to all research papers where patient input would clearly be helpful. We are also calling for the submission of robust research papers that advance the science, art, implementation, and assessment of the impact of patient partnership, shared decision making, and patient centred care. Authors of research papers are being asked to document if and how they involved patients in defining the research question and outcome measures, the design and implementation of the study, and the dissemination of its results.^{4 5} Comment on the burden on patients of new interventions and treatments will also be required. This is not intended to be a box ticking exercise, but to encourage and properly report on collaborative research between patients and investigators.

Secondly, we are inviting more analysis and comment articles to extend the debate and add to the evidence on the benefits and barriers to patient participation in all its spheres, including the design and delivery of services, medical education, the shaping of health policy, and the setting of the research agenda. The National Institute for Health Research and the Patient Centred Outcomes Research Institute already involve patients in setting research priorities, but the power of networked patients to independently initiate research and influence its conduct is growing.⁵ Best practice for collaborative working has yet to be defined but should pay dividends.^{6 7}

Co-production is more than a buzz word and it describes a third important change that we have made. Authors of clinical reviews and other educational articles, including selected editorials, are

being asked to obtain input from patients and document their contribution. We are working towards our first patient co-authored “state of the art” review. Educational articles will also be reviewed by patients. You can help to build up our database of patient reviewers by extending this invitation to them.⁸

The BMJ's interest in patient partnership is not new. In 1999 we published a theme issue on the topic and a year later an issue led and written by patients. We may do this again, but our current initiative is not about one off gestures. We want partnership to become integral to how we work and think, as well as being something we advocate in healthcare. New expert patients on our editorial board and a newly appointed patient editor will help us in this quest and in time will enable us to meet a fourth pledge: to have patients participating in internal decision making committees. They are already flagging up innovative initiatives and helping us to get the patient's voice into the journal more. Past articles written by patients underline the self evident truth that people with experience of illness and of navigating health services have much to teach us.⁹⁻¹²

Our advisers have issued some clarion calls. One is to avoid tokenism. Initiatives to promote patient involvement and provide patient centred care are all too often poorly informed by patients and don't promote partnership.¹³ A second is “do it well.” The failure to systematically collect and use the data on patient experience of care has been criticised.¹⁴ A third is to get the “authentic” voice of patients heard; not just that of the articulate minority. This is a challenge that we all grapple with, and one that is recognised by our patient advisers.¹⁵ We will continue to publish individual perspectives but are extending our links with patient networks and advocacy organisations to help tap into collective views. As we do this we recognise the importance of transparency. As in academic medicine, commercial influences are pervasive, and we are requesting and publishing conflict of interest statements from patient reviewers and authors exactly as we do with medical authors and reviewers.

The fifth tranche of our strategy is a campaigning one. We support patient control or co-ownership of personal health records and the “Patients included” initiative.¹⁶ Patients are thin on the ground in medical forums (the time and expense of attending deters many) and not routinely invited as speakers,

or on to steering committees. Here again our plan is to lead by example.

Our new strategy aligns with our “too much medicine” and “open data” campaigns and our support for “minimally disruptive medicine.”¹⁷ *The BMJ* remains a journal for doctors, but with Consumer Reports, which is partnered with the Choosing Wisely initiative, we are providing input into lay versions of the papers in our “overdiagnosis” series, to promote public awareness of the commercial and technological drivers shaping healthcare. Patients’ rights are another focus. Recent emphasis has been put on the right to be empowered to self manage chronic conditions.¹⁸ Worldwide, the big issue remains the right to access good quality, affordable healthcare.

Patient partnership is a lot easier to talk about than to realise. It demands mutual respect and understanding. Our strategy is being implemented incrementally and will evolve as we evaluate its impact. But we are excited by its potential and hope readers will be too.

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- 1 Richards T, Montori VM, Godlee F, Lapsley P, Paul D. Let the patient revolution begin. *BMJ* 2013;346:f2614.
- 2 About The BMJ. Patient panel members. www.bmj.com/about-bmj/advisory-panels/patient-panel-members.
- 3 Hibbard JH1, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)* 2013;32:207-14.
- 4 About The BMJ. Research. www.bmj.com/about-bmj/resources-authors/article-types/research.
- 5 Wicks P. Could digital patient communities be the launch pad for patient-centric trial design? *Trials* 2014;15:172.
- 6 Domecq JP, Prutsky G, Elraiyah T, Wang Z, Nabhan M, Shippee N, et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* 2014;14:89.
- 7 Chalmers I, Bracken MB, Djulbegovic B, Garattini S, Grant J, Gulmezoglu AM, et al. How to increase value and reduce waste when research priorities are set. *Lancet* 2014;383:156-65.
- 8 About the BMJ. Guidance for BMJ Patient Reviewers. www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers.
- 9 Young K. Doctors’ understanding of rheumatoid disease does not align with patients’ experiences. *BMJ* 2013;346:f2901.
- 10 De Bonkhart D. How the e-patient community helped save my life: an essay by Dave de Bronkart. *BMJ* 2013;346:f1990.
- 11 Lapsley P. Lessons from patient journeys. *BMJ* 2013;346:f1988.
- 12 Richards T. Journey of a patient editor. *BMJ* 2013;347:f6913.
- 13 Cure Parkinson’s Trust. What does “patient-driven” mean? 2014. www.cureparkinsons.org.uk/Sites/parkinsons-movement/News/what-does-patient-drive-mean.
- 14 Coulter A, Locock L, Ziebland S, Calabrese J. Collecting data on patient experience is not enough: they must be used to improve care. *BMJ* 2014;348:g2225.
- 15 Gruman J. The N=1 problem of the patient representative. Center for Advancing Health, 2013. www.cfah.org/blog/2013/the-n1-problem-of-the-patient-representative.
- 16 Engelen L. Patients not included. *BMJ Blogs* 2013. <http://blogs.bmj.com/bmj/2013/08/16/lucien-engelen-patients-not-included/>.
- 17 May C, Montori VM, Mair, FS. We need minimally disruptive medicine. *BMJ* 2009;339:b2803.
- 18 Wise J. MPs and peers call for greater patient power. *BMJ* 2014;348:g3264.

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