Logging The BMJ’s “patient journey”

Big changes, big challenges, much learning, and encouraging progress

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Recognising the crucial role of patients in tackling “corruption in the mission of healthcare,” two years ago The BMJ set up an international patient advisory panel to help us develop a strategy to promote patient partnership. We figured that “walking the talk” in our own editorial processes was the best way to advance change.

We launched our strategy last June, and its development is charted on thebmj.com (www.bmj.com/campaign/patient-partnership). At a recent meeting with our patient panel we agreed that our annual report card should read, “Good start, but more work is needed.”

This was predictable. Patients and health professionals know all too well that while it’s easy to make token gestures, it’s hugely challenging to achieve genuine partnership, whether in policy making, clinical practice, service delivery, or research. But as with any worthwhile challenge, it’s taught us a lot.

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Our innovative monthly educational series in which patients choose the topics, and identify the learning points from which doctors can earn continuing medical education (CME) credit, has attracted a lot of interest online (www.bmj.com/specialties/what-your-patient-thinking). Most responses to the series have been positive; for example, “It’s humbling . . . and led me to reflect more critically (and wincingly) on my personal work.” Nevertheless, we have ruffled the odd feather; “What authority do patients have to influence the educational curriculum?”

The patient’s voice is also being heard directly in regular blogs and personal views, which are shared widely on social media. Patient commentaries and interviews enliven papers and add to the learning potential. Patients are also beginning to participate positively and creatively.

Authors of research papers are now asked to state if, and how, they involved patients when choosing their research question, study design, and outcome measures and in implementing and disseminating study results. Responses are being documented and monitored. In future we are likely to consider clinical research papers only if the authors can demonstrate partnership with patients in their study.

The move to ask authors of educational papers to invite patients and carers to become contributors or coauthors is bearing fruit. The rationale is clear. Improving healthcare depends on health professionals having a better understanding of the burdens of illness and treatment and of the difficulties and dangers that patients encounter while navigating fragmented delivery systems. Capturing and learning from patient experience are essential and help to bridge the gap between what, sadly, can still seem like two parallel universes.

Some authors have been baffled by being asked how they involved patients in their research and by the idea that input from patients into their articles is important. But we have been heartened by the growing number of authors who are responding positively and creatively.

In February the publication of a spotlight series on patient centred care contributed to our quest to advance the science and art of patient partnership and shared decision making. Topics covered included co-designing services with patients, stimulating providers to compete to provide person centred care, progress in the (essential) march to ownership of personal health records, and the power of patient advocacy to hold the public health sector to account in India (www.bmj.com/patient-spotlight).
The award of a “Patients Included” certificate for our work has spurred us to further action, with respect to how we ensure participation by patients not only in the meetings that we run but also in those that we sponsor. BMJ is developing its own policy in response to the recently launched #PatientsIncluded campaign, and next year will see us take a firm line in only supporting conferences that meet the criteria we set.

Heralding change, members of the patient panel at this year’s International Forum on Quality and Safety in Healthcare ran their own session, moderated others, and participated on each side of a debate on whether “the patient knows best.” Some of their feedback on the experience was sharply critical and has triggered changes for next year’s forum.

Interest in our initiative is rising, as are invitations to describe our activities and to discuss their impact. The question of effects is one we continue to wrestle with. How do you measure change in hearts, minds, practice, and policy in a complex sector that is subject to myriad influences? So far we have focused on tracking processes but we plan to evaluate patient review of research papers.

As we extend the international reach of our patient partnership initiative we invite readers to let us know about projects they are working on from which others can learn. We see this as a joint endeavour in which there is no turning back.

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