Towards the patient revolution

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In an editorial last year we called for a patient revolution (doi:10.1136/bmj.f2614). We said that patients, far more than clinicians, understand the impact of disease and treatment. We said that clinicians and patients therefore needed to work in partnership if we are to improve healthcare. We talked about corruption in the mission of healthcare and the need to challenge deeply ingrained practices and behaviours. We said that we wanted to develop a strategy for patient partnership at the BMJ, that we planned to establish a panel of patients and clinicians to help us with this work—and that we would report back on progress.

Well, last week we held our first patient partnership workshop, and as Tessa Richards explains in her blog (bmj.com/blogs) we were humbled and inspired by the enthusiasm of the patients and patient advocates who came to help us advance the quest to make patient partnership a reality.

We expected to be challenged by the panel, and we were. Was this just eye candy for the BMJ, we were asked, a form of tokenism to help the journal look and feel good? Or were we serious in our commitment to change things at the BMJ so that we can campaign for a cultural shift in medicine? I hope we managed to convince those present that we are indeed serious.

We have made a small start by adding expert patients to the peer review process for selected research papers. And we plan to publish our draft strategy on patient partnership in the next three months. I expect this will incorporate many of the recommendations from the workshop. These included having a patient voice on all the committees that make decisions about the BMJ’s content and strategy, asking authors of research articles to explain how they involved patients in the design of their study, and having an expert patient as a coauthor on every clinical review.

Our hope is that these changes to our own policies and practice will provide us with a sturdier platform from which to advocate change. Our panel wants the BMJ to campaign for patients to be equal partners in the design and delivery of healthcare and in clinical research and to tackle the power imbalance between patients and the “medical industrial complex.”

I wonder, though, whether our main challenge will be just keeping up with the speed of change. As Paul Wicks and colleagues explain (doi:10.1136/bmj.g368), when it comes to clinical trials some patients are already well ahead of the game. By sharing their own data and analyses through social media, trial participants are breaking the cultural and actual codes of clinical trials. This “disobedience” shows that participants know they are statistically and literally the “power” in trials. Wicks and colleagues, all from the patient network PatientsLikeMe, warn of tragic outcomes unless we forge a new social contract. “With the new tools at their disposal patients will hold us all accountable in new and necessary ways,” they conclude.

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