

## EDITOR'S CHOICE

---

## Patient powered health

Trevor Jackson *deputy editor, BMJ*

“Today the website Mumsnet is the source of all information on pregnancy and beyond,” writes long serving *BMJ* columnist James Owen Drife, in a wry take on what it feels like for an emeritus professor of obstetrics and gynaecology to become a grandfather (doi:10.1136/bmj.f2214). “Phone calls to an obstetric parent are for quality control purposes only,” he adds.

Drife’s lighthearted comments about the power of an online network such as Mumsnet echo those of this week’s *BMJ* essayist, Dave deBronkart (doi:10.1136/bmj.f1990). It was through contact with other net savvy patients that deBronkart went from a cancer diagnosis to becoming an international patient superstar known as e-patient Dave.

After doctors found a shadow on his lung during routine shoulder radiography, deBronkart was diagnosed as having stage IV, grade 4 metastatic renal cell carcinoma, with bone metastases in his femur, ulna, and cranium; five metastases in his lungs; and muscle metastases in his thigh and tongue. Yet six months after his diagnosis, his treatment ended, and he writes, “I have not had a drop of anything since.”

Dave deBronkart’s subsequent celebrity—he has since spoken at 200 meetings—owes much to his claim that an online patient community helped save his life. As soon as his diagnosis was confirmed, his primary physician told him, “You’re an online kind of guy, Dave—you might like to join this group.” The group was ACOR.org, “a network of simple plain-text listservs [online mailing lists] for patients with various cancers.” Within two hours of posting his first message, deBronkart writes, “I got facts and practical advice that to this day don’t exist in any

journal article or establishment website.” This included information about the best treatments and side effects from those who had already experienced them.

The internet and online communities are often rightly criticised as sources of misinformation and bad advice. But deBronkart’s story illustrates the contribution that informed and engaged patients can make to the complexities of medicine. “The value delivered by skilled clinicians is still there, but now we can see that it’s no longer the only source,” he writes. “Please, let patients help improve healthcare. Let patients help steer our decisions, strategic and practical. Let patients help define what value in medicine is.”

Letting patients help define value and quality in medicine is one of the things that the *BMJ* has sought to do in its Patient’s Journey series. Looking back over the first 100 articles in the series (doi:10.1136/bmj.f1988), the *BMJ*’s patient editor, Peter Lapsley, says that he has been impressed by doctors’ willingness to learn from these stories. “There is no privileged vantage point from which to decide who is right and who is wrong.” This leads him to state what he believes may be the most significant lesson of all: “the importance of good doctor-patient communication, which needs to be as jargon-free as possible, be empathetic, and bridge educational, social, and age related boundaries.” Which sounds like the kind of democratic approach to medicine that online communities can be so good at.

Cite this as: *BMJ* 2013;346:f2255

© BMJ Publishing Group Ltd 2013