

PATIENT PARTNERSHIP **Tessa Richards**

Tell us how it was for you

The chance for health professionals to respond directly to patients' online reports will help improve care

Ten years ago a friend suggested that I write up my experience of weathering emergency thoraco-abdominal surgery for adrenal cancer. "It will be a useful cathartic exercise," she said. So I did, and maybe it was, but I didn't share the story. Skilled care saved my life. Might any critical comment be seen as carping rather than constructive?

Now the value of collecting and learning from patients' accounts of their experience of illness and care is well established and enshrined in policy, notably the UK Health and Social Care Act 2012. It's widely seen as an essential tool to monitor and drive up the quality of care and to improve the delivery of services and the experience of patients who use them.

Yet despite "patient-centric" policy commitments and an obligation stemming from the Francis report into failings at Mid Staffordshire to listen, learn, and respond to the view of patients and carers, the gap between policy and practice still yawns.¹ Swathes of information are being collected from patients, but most is not being systematically analysed in a timely way and used to inform change. And the patients who supply it get little feedback. Experts in patient experience data argue that substantive investment is needed in the science of gathering and using it.

One challenge is that there is no gold standard way to record patients' experiences. Methods vary from in-depth qualitative approaches, such as narrative interviews, to large scale collection of quantitative survey data, much in the form of responses to closed questions. Kiosks in hospitals and tablet computers on wards are mushrooming to encourage completion of the NHS friends and family test.²

Trusts say they value feedback and are happy to point to high satisfaction ratings, but nuanced information is harder to come by. There are inspiring examples of clinicians improving services after listening to patients and gleaning information from

"shadowing" the often slow, complex care pathways they navigate. But such clinicians are in the vanguard. More doctors and managers need to "get" the value of doing it, a recent King's Fund conference concluded.³

Alongside systemic inertia, reluctance to respond to patient feedback stems from several factors, including lack of capacity among staff and doubts about the quality and representativeness of the data. Research has found, however, that web based ratings of services correlate with objective measures of hospital performance.⁴ And it is blindingly evident that patients' observations bring valuable insight. One sphere where this is fully acknowledged at the European Union level is in reporting the side effects of drugs.^{5,6}

Concern about the cost of collecting data on patient experiences is being allayed by the exponential growth of "user" generated experience. The information logged in patient forums, blogs, and social media may lack the rigour of syntheses of patient experiences produced by platforms such as healthtalkonline.org but has advantages. It is generated fast, is easy to access, and offers opportunity for timely responses.

Patient Opinion is an innovative example of the genre (www.patientopinion.org.uk). It brokers "real time" conversations online between patients and the organisations charged with improving their care. Patients are invited to post comments about their experience, good and bad. These are moderated, anonymised, and sent to local providers and commissioners identified from a sender's postcode. Comments are also sent to the Care Quality Commission, the charity Healthwatch, and patient organisations and MPs who request them. The stories (around 65 000 are logged) can be searched by condition, procedure, trust, or commissioning group.

On a recent trawl of the site's content on rheumatology services I noted contrasting comments. In one



“Patients hugely value personal responses and the chance to track what's happening online

**bmj.com**

Read Tessa Richards's own account of her patient experience (*BMJ* 2013;347:f6913); Power to the people: what will bring about the patient centred revolution? (*BMJ* 2013;347:f6701)

A collection of BMJ patient journey articles selected by the former patient editor, Peter Lapsley, shortly before he died is now available as a Kindle e-book on the Amazon website (<http://amzn.to/18ijgOE>).

area there was a complaint about "a disorganised shambles," in a second high praise for "efficient nurse run" care. Both comments had attracted a personal response from the respective providers.

By facilitating exchange Patient Opinion hopes to help promote a change in NHS culture, where patient feedback is seen as critical intelligence, not a threat. Interest in the model is growing, and Australia has recently adopted it.

James Munro, the initiative's co-founder, observes that many of the problems patients identify can readily be dealt with through local changes in processes, and he emphasises that patients hugely value personal responses and the chance to track what's happening online.

Mike Cooke, chief executive of Nottinghamshire NHS Trust, endorses this view. At the King's Fund meeting he said, "Around 250 trust staff regularly visit the site," and 100 of 850 comments posted to date have spurred change. At an earlier meeting to discuss how Patient Opinion data are used, Justin Chisnall from the Medway NHS Foundation Trust agreed that it provided useful information but that "more intelligent ways of dealing with it" were needed. He also sent out a warning shot: "Commissioners have responsibility to act for all, not pander to individuals."

While each patient's story is unique, comment on online sites and detailed narratives reveal common frustrations and needs—not least to be seen as a person made vulnerable by illness, in need of humane as well as efficient and effective care, as my story illustrates (*BMJ* 2013;347:f6913).⁷

It's never been easier to tap into the "wisdom of the crowd," and there is no shortage of initiatives to learn from on how to work with patients to mutual benefit. We should do so more.

Tessa Richards is a senior editor, *BMJ* trichards@bmj.com

References are in the version on bmj.com.

Cite this as: *BMJ* 2013;347:f6872