

EDITORIAL

Making best use of patient experience

Most of us know what good patient experience looks like, right?

Everyone is familiar with words like respect, dignity and compassion. Thank you cards and boxes of chocolates are visible signs of appreciation from patients who feel well looked after by healthcare staff. And everyone recognises the importance of good communication.

But something's missing from this equation. How do we give patients the power to move beyond simply offering thanks? How can they contribute to positive changes in the way services work? We need to ask the right questions, systematically gather responses and then use the evidence to improve NHS practice and service delivery. Only when patients are fully engaged in shaping policy, developing services and promoting good practice will they be true partners in the therapeutic process.

Not that people have not tried to get a better fit between professionals and patients, and engineer better, more responsive services.

It is nearly 10 years since the Darzi review (Department of Health, 2008) and 5 years since the result of the Francis Inquiry (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013). Darzi called patient experience one of the three cornerstones of high-quality health care, alongside patient safety and clinical effectiveness (Department of Health, 2008). Francis was clear that one of the causes for the serious failings at Mid Staffordshire was that the Trust board "did not listen sufficiently to its patients" (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013, Executive Summary p.3).

The listening problem remains. Mid-Staffs was a low point in recent NHS history, but services continue to be dogged by large-scale failures, spurring further inquiries. These include the Kirkup Inquiry into maternity and neonatal services provided by the Morecambe Bay Trust between 2003–2013, (Kirkup, 2015) and the Mazars Review into the deaths of people with learning disabilities and mental health problems at the Southern Health Trust (NHS England, 2015).

A common finding is the failure of service leaders to engage with patients and relatives. Lack of engagement was seen as a contributory factor to wider failures that resulted in unnecessary and avoidable deaths. Even last year, Secretary of State Jeremy Hunt ordered an inquiry into the concern about a "cluster" of deaths of mothers and babies at the Shrewsbury and Telford Trust (BBC News, 2017).

Other reports have highlighted the importance of patient experience and emphasise the risks of ignoring the patient voice. The Clwyd/Hart report and the Berwick review recognised that "patient experience" has a wider dimension beyond the one-to-one

interaction between healthcare staff and patients (Berwick, 2013; Clywd & Hart, 2013).

Yet, despite this fair wind, organisations (as opposed to individual members of staff) continue to find it hard to respond to what patients are saying.

This is not a new issue. Shared knowledge between patient and doctor is a characteristic of folk and nonrational medicine. As medicine develops, it becomes more complex, resulting in a greater division of labour with a stronger focus on professional expertise. The patient voice is squeezed out. Even in the early years of the NHS, there was recognition of the risk of separating the treatment of disease from the treatment of the patient as a person (Titmuss, 1958).

Quality and safety of services are rightly emphasised in the debate generated by these recent inquiries. The suggested mode of engagement with patients is, however, more ambiguous. For example, it has been said that "organisations should seek out the patient and carer voice as an essential asset in monitoring the safety and quality of care" (Berwick, 2013, p.5). But focusing on a monitoring role is unlikely to fully engage patients. The evidence says that "simply providing hospitals with patient feedback does not automatically have a positive effect on quality standards" (Sheard et al., 2017, p.20).

In other words, organisations need to tune in to patients' views and experiences if they want to have a chance of engaging these (patient) views and improving their own performance. Such a change is essential for a new partnership that will help improve services and manage risk. It also offers the prospect of a better balance between patients and professionals, with the potential for more effective (and cost-effective) services.

To some degree, this is happening already. But the healthcare system is a victim of its own success. In seeking to meet the call "that something must be done", the system has created an avalanche of patient experience information. Such experience is now tracked, monitored and measured to an almost obsessive degree—some examples of this measured experience are set out in Table 1 below.

The enthusiasm to meet the challenges in Darzi, Francis and other reports does the NHS credit. It now needs to systematise its efforts, focusing on how things work from the patient's viewpoint, rather than validating existing practice through a ticking of boxes.

The result of this effort is information overload. Specialist patient experience staff are struggling to keep up with the flow of information and data. One said, "it's a nightmare to see what's going on. Trying to triangulate between 12 different data sources coming from different angles, [each] presented differently" (InHealth Associates & Membership Engagement Services, 2015, p.15).

TABLE 1 How patient experience is captured

- The NHS Friends and Family Test, published monthly
- The Care Quality Commission (CQC) national surveys on the experiences of inpatients, maternity services, children and young people, emergency department and community mental health services
- NHS England's national cancer patient experience survey and national GP patient survey
- NHS Choices' online "Trip Advisor" style star rating system and feedback and complaints system about the NHS in England
- The Office for National Statistics (ONS) national survey of bereaved people

In addition, between 2–3,000 local Healthwatch network reports are published each year across 150 separate websites. And patient experience teams in every Trust and CCG sift compliments and complaints, run patient engagement committees and conduct regular surveys and focus groups

Some of this information is, of course, necessary to make sense of patient experience and extract the key lessons for good practice. Indeed, oversupply of information is not—in itself—a problem. It is perfectly possible to cope with large quantities of data as long as they are well organised. Clinicians are familiar with management information systems that help them to understand and use complex information. They have clinical databases that make research accessible and searchable, and they can look up clinical guidelines that help them remember key practice points.

The material on patient experience is not so well organised. There is no single data repository. Neither NHS England, CQC nor Healthwatch keep such a database or a set of agreed cross-organisational standards to ensure the evidence base is robust, plausible and respected. The qualitative and quantitative evidence that does exist is published across hundreds of different websites. The result is that the evidence is not systematic, has gaps, is of variable quality and hard to find. It has been noted that "staff and patient experience teams are sometimes so busy gathering data and compiling reports, that less time is available to do something with the data—efforts to improve services are in danger of being squeezed out" (InHealth Associates et al., 2015, p.37).

There are other risks too—for example, that in the absence of easy access to good evidence, "patient experience" is sought through small numbers of patient representatives, whose views may in fact be somewhat unrepresentative, but can nevertheless exert power and influence decisions.

Equally, there is no archive on which to draw despite over 40 years of government initiatives on patient voice. The Community Health Councils (CHCs) established in 1974 started the process. Successive reorganisations saw CHCs give way to Patient and Public Involvement Forums, Local Involvement Networks and, now, Healthwatch. Each new initiative has resulted in a considerable loss of knowledge through changes of staffing, contract arrangements and definitions of organisational purpose.

Good practice within organisations relies on good organisational memory. Organisations that keep losing their learning run a high risk of repeating their mistakes, and so it has proved. Each new

government-led "patient voice" initiative has rerun the same or similar inquiries as their predecessors, usually with the same results. We have examined the literature and found dozens of repeated studies on topics such as patient experience of leaving hospital, young people's experiences of Child and Adolescent Mental Health Services and experience among the general public of attempts to get GP appointments.

Getting a grip on the information flow is vital if the patient experience is to be taken seriously by professionals and policy-makers.

A start has been made in bringing the different data streams together through a new initiative—the Patient Experience Library (PXL). It seeks to provide a patient's eye view of service quality, acting independently of NHS national bodies. It has collated and catalogued the whole of UK patient experience literature in a single online database. Over 40,000 documents, from Healthwatch, health charities, academics, think tanks and government bodies are now available in searchable format.

The PXL's main focus is surveys and studies, but it also holds extensive literature on patient and public involvement, including practical toolkits and guidelines. New documents are added each week. The library also acts as an archive, preserving valuable knowledge produced by now defunct bodies such as the NHS Institute. Its oldest document is "The Unpopular Patient", (Stockwell, 1972) a classic study that still has relevance more than forty years after it was published.

It is now breaking down the evidence base into a more usable format. One example is the "Patient Experience in Trusts" map, which enables health professionals and the general public to scan a map of England, find their local NHS Trust, and with one click, bring up the key patient experience data for that Trust. Educational institutions are now starting to work with the library to dig deeper into the evidence base and find other ways to extract and disseminate the learning (Figure 1).

The PXL offers the prospect of a single, fully searchable database of the available evidence on patient experience, recognising caveats on quality and standards. But getting a grip on information flows is only part of the solution. The other primary challenges that remain are

- asking the right questions. This requires close working with patients on the shape, type and form of questions likely to produce useful results before any wider views are sought, and
- using existing—and ultimately more robust—information in a way that systematically harnesses the patient experience to shape policy, improve services and promote good practice.

A rethink is needed on how we tap into patient experience. A rethink that takes account of these challenges and acknowledges the possibility of unpalatable answers, which may disturb—or at least question—the current balance of power between organisations, professionals and patients.

This is not a shot in the dark. There are encouraging omens.

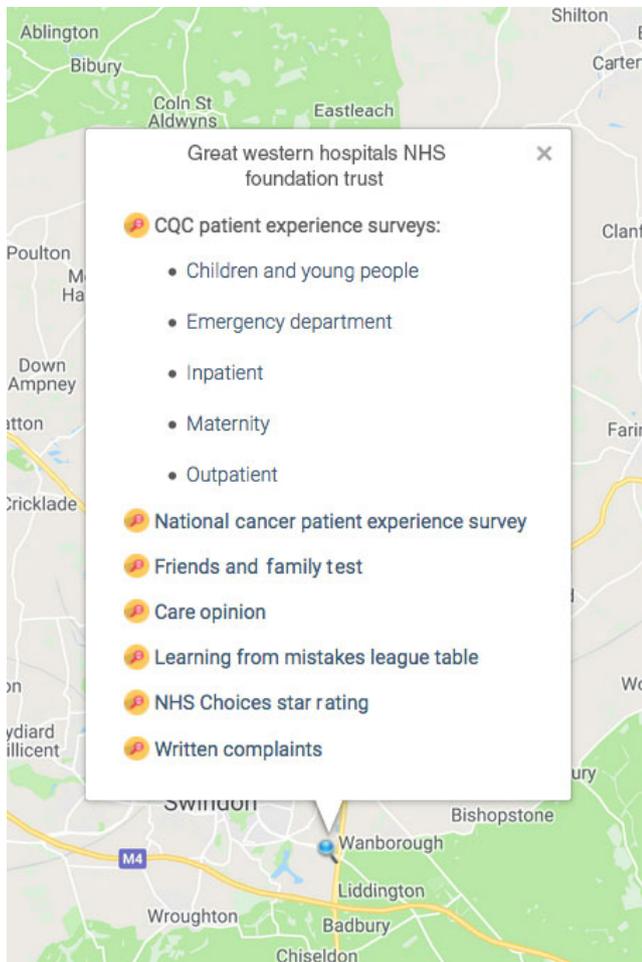


FIGURE 1 Patient experience in trusts map [Colour figure can be viewed at wileyonlinelibrary.com]

NHS England's Five Year Forward View is unequivocal about engaging patients. It has called for a new relationship with patients, citizens and communities. Critical of its own past performance and, of what it calls, the "factory" model of care and repair, it recognises that "as a result we have not fully harnessed the renewable energy represented by patients and communities"—an important, untapped resource for the NHS (NHS England, 2014, p.10).

Likewise, the King's Fund is seeking to promote patient leadership through promoting practical ways of building new collaborative relationships, which place patients closer to the heart of the NHS. Such a relationship is fundamental to the future of the NHS. After all, "patients are why the NHS exists" (Searle, 2016, Introduction). For patients and practitioners, "achieving a more collaborative dynamic will require a change in the way that all of us work. The ability to adapt, communicate and shift between roles will be important for all who seek to establish a new, collaborative relationship that puts safety and quality at the [centre] of health and care in our communities" (Searle, 2016, Introduction).

We all have a part to play in this agenda.

CONFLICT OF INTEREST

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