

## EDITORIALS

## Putting patients first

NICE guidance on the patient experience is a welcome small step on a long journey

Simon Eaton *national clinical lead*<sup>1</sup>, Alf Collins *national clinical lead*<sup>2</sup>, Angela Coulter *senior research scientist*<sup>3</sup>, Glyn Elwyn *visiting professor*<sup>4</sup>, Natalie Grazin *assistant director*<sup>5</sup>, Sue Roberts *chair*<sup>1</sup>

<sup>1</sup>Year of Care Partnerships, Northumbria Healthcare NHS Foundation Trust, North Shields NE29 8NH, UK ; <sup>2</sup>Health Foundation's Co-creating Health Programme, Health Foundation, London, UK; <sup>3</sup>Department of Public Health, University of Oxford, Oxford, UK; <sup>4</sup>Dartmouth Center for Health Care Delivery Science, Dartmouth College, New Hampshire, NH 03755, USA; <sup>5</sup>Health Foundation, London, UK

The recent publication of National Institute for Health and Clinical Excellence (NICE) guidance and quality standards on patient experience,<sup>1 2</sup> which are summarised in a linked article (doi:10.1136/bmj.d6422),<sup>3</sup> provides some statutory weight to complement recent important recommendations on dignity in care from the NHS Confederation, the Local Government Association, and Age UK.<sup>4</sup> The aims of the guidance, to create “sustainable change that will result in an ‘NHS cultural shift’ towards a truly patient-centred service” are laudable, and it is good to see that the principle that high quality patient experience should be at the heart of good clinical care is being upheld. Where implemented, NICE’s recommendations will lead to feasible and effective improvements in care. However, much of the guidance states the obvious, and many challenges remain to providing a health service that systematically, reliably, and demonstrably puts patients first.

It is a sad indictment of modern healthcare that we need such guidance in the first place. Restaurants and retailers may need to prompt new employees to offer good customer service, but most people would expect that delivering good service would be second nature for staff from the “the caring professions.” Sadly, evidence suggests that this is not the case.<sup>5</sup> The reality is that people who work in healthcare often seem to be immune to anxiety, excessive waiting, and impersonal and unnecessarily distressing experiences, and almost every day they walk past or participate in care that isn’t delivering a good experience.

How, then, can desirable standards be implemented? Improvements will not be seen unless we understand and improve the attitudes and behaviours of healthcare professionals as well as systems and structures of care. Key to this will be reliable and consistent measurement of patient experience, at a level of sophistication way beyond the hospital-wide annual patient surveys or the ward based experience metrics currently used. The detailed quality measures included in the quality standards document are a good place to start.<sup>1</sup> Ideally, these markers should be measured at the level of the clinical team and results systematically fed back to provide insight and drive

change. Improvement of biomedical care processes and outcomes has progressed enormously through the provision of comparative peer outcomes data to clinicians. Now provision of comparative peer outcomes data for patient experience should become a priority.

The definition of patient experience used in the recently published NICE guidance is, unfortunately, limited by an inability to see beyond hospitals and general practices into the lives of those cared for by health services. Arguably the most important challenges faced by the NHS, and most other health systems, are long term conditions, an ageing population, and multimorbidity. A much broader definition of “patient experience” to include the experience people have of living with conditions day to day, and not just of the healthcare they receive, will be needed for these challenges to be successfully met. The guidance offers only a cursory nod towards this with reference to patient education courses and information, but health systems will need to go much further. In truth, self management already is default care for people who live with long term conditions. If the experience of patients who self manage is to be improved, they must be recognised as active co-producers of their own health and supported to develop the knowledge and skills needed to become confident self managers of their conditions.

A compelling body of evidence makes it clear that well designed and well delivered interventions to support self management—particularly proactive behaviourally focused interventions designed to build self efficacy—have a positive effect on clinical symptoms and outcomes, attitudes and behaviours, quality of life, and use of healthcare resources.<sup>6 7</sup> Two UK national demonstration programmes, Co-creating Health and Year of Care, have successfully drawn on this strong evidence base and shown that it is possible to deliver such interventions routinely in day to day care within the NHS.<sup>8 9</sup> That such approaches are not the norm is one of the greatest failings of modern medicine, particularly as people with long term conditions consume around 70% of health and social care resources in the United Kingdom, and there is a national

imperative to embed self management support into the UK's health service.

The English Department of Health and NICE should consider the broader context of the patient experience and develop as a matter of urgency further separate guidance and standards on supporting the self management of health conditions. NICE must show an understanding that support for self management has a distinctive theoretical basis within health psychology, which profoundly distinguishes it from more didactic patient education and information provision, and that this is consistent with international best practice. The provision of guidance on a suitable standard of self management support would lay a firm foundation on which future clinical guidelines and standards relating to long term conditions could build, and it would endorse self management support as the organising principle for the care of long term conditions. This would have the effect of ensuring consistency of care across clinical pathways and between different clinical disciplines, which many patients with multimorbidities often find lacking.

NICE guidelines too often reinforce the myth of a "right way" to deliver care, at the risk of ignoring principles of shared decision making. Future guidance should strive to promote the right of patients to understand the options available and to be supported to make the decisions that are right for them.

To make a real difference more is needed than just writing things down. If those who deliver healthcare assume that these standards are already met we will fail our patients and ourselves. Patient experience needs to be measured, evaluated, and improved upon. The current guidance is a small, albeit

important, step in a much longer journey towards improved patient experience.

**Competing interests:** All authors have completed the ICMJE uniform disclosure form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

**Provenance and peer review:** Commissioned; not externally peer reviewed.

- 1 National Institute for Health and Clinical Excellence. Quality standard for patient experience in adult NHS services. 2012. [www.nice.org.uk/guidance/qualitystandards/patientexperience/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/patientexperience/home.jsp).
- 2 National Institute for Health and Clinical Excellence. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. CG 138. 2012. [www.nice.org.uk/cg138](http://www.nice.org.uk/cg138).
- 3 O'Flynn N, Staniszewska S. Improving the experience of care for people using NHS services: summary of NICE guidance. *BMJ* 2012;344:d6422.
- 4 NHS Confederation. Commission for Dignity in Care for Older People. Delivering dignity. 2012. [www.nhsconfed.org/priorities/Quality/Partnership-on-dignity/Pages/Publicconsultation.aspx](http://www.nhsconfed.org/priorities/Quality/Partnership-on-dignity/Pages/Publicconsultation.aspx).
- 5 Mid Staffordshire NHS Foundation Trust Inquiry. Independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005-March 2009, 2010. Stationery Office.
- 6 Health Foundation. Helping people help themselves. 2011. [www.health.org.uk/publications/evidence-helping-people-help-themselves/](http://www.health.org.uk/publications/evidence-helping-people-help-themselves/).
- 7 Coulter A. Engaging patients in healthcare. 2011. Open University Press.
- 8 Health Foundation. *Co-creating health*, 2012. [www.health.org.uk/areas-of-work/programmes/co-creating-health/](http://www.health.org.uk/areas-of-work/programmes/co-creating-health/).
- 9 Diabetes UK. Year of care. 2012. [www.diabetes.nhs.uk/year\\_of\\_care/](http://www.diabetes.nhs.uk/year_of_care/).

Cite this as: *BMJ* 2012;344:e2006

© BMJ Publishing Group Ltd 2012