

Great expectations? Reflections on the future of patient and public involvement in the NHS

Jo Ellins

Introduction

Once more, the NHS is in a period of significant structural and organisational change. Since the publication of the NHS white paper in 2010,¹ much has been made of the implications of the proposed plans in areas such as commissioning, private sector provision and the future of public health. Many of these have been explored by earlier articles in this series, but what does all this mean for patients and the public? As with many previous reform programmes, the white paper was framed around the goal of creating a patient-centred service – an NHS to ‘put patients first’. To this end, it promised to increase significantly opportunities for patients to be involved in their own care, and in decisions about the design and delivery of health services in their area.

This article reviews the current state of, and likely future for, patient and public involvement in the NHS. The main focus is an examination of three roles that patients can play in the management of their healthcare, each of which has the potential to help to improve NHS quality and outcomes: evaluators, consumers and co-producers.

Public views of the NHS

The NHS is often referred to as a ‘national treasure’, but what does the British public really think of its health service? The proportion of the general public satisfied with the running of the NHS rose dramatically under New Labour (1997–2010), reaching 64% in 2009. More recent data from public opinion polls in England, however, suggest that this trend may be starting to reverse. In April 2011, the market research company Ipsos MORI reported the results of its bi-annual survey on behalf of the Department of Health, tracking public perceptions of the NHS and social care. Satisfaction was found to be ‘drifting downward’, with most of the fall due to non-users of health services (ie ‘public’ rather than ‘patient’ respondents) becoming more critical.² A key concern was the government’s current health reforms. A large majority of those surveyed considered there to be much waste and inefficiency in the NHS, and anticipated a major funding crisis in the future. Despite this, messages in the health reform programme about addressing inefficiencies were widely interpreted by the public as being about ‘making cuts’ and were viewed with great concern. Fewer than one in five respondents expected the changes currently being made to the NHS to improve services for patients.²

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Public perceptions of the health service are clearly important, not least for politicians as the NHS remains a key election battleground. But they are not a reliable basis for assessing how well the service is doing, or making decisions about its future development. This is mainly because, without recent direct experience to draw on, the public bases its views on other sources of information. The most significant driver of public satisfaction is support for the government and, as Nigel Edwards points out, ‘disenchantment with the government translates into scepticism about the NHS and vice versa.’³ This makes it virtually impossible to disentangle the public’s opinion on how the NHS is being run from its judgements about the government’s management of not only public services, but the country as a whole. All this suggests that discussing patients’ actual experiences of healthcare would be a better starting point for exploring the future of the NHS.

Patients’ experiences of the NHS

Many of the factors most strongly shaping patients’ satisfaction with the NHS are interpersonal: those aspects of care which are experienced through interactions with caregivers. The issue that patients in acute settings value above all is whether they are treated with respect and dignity (Box 1).⁴ This does not mean that the *medical* care doesn’t matter; indeed studies suggest that patients – especially older ones – usually take for granted that health professionals are technically knowledgeable and competent.⁵

Findings from the NHS patient survey programme – now in its 10th year – show that people who are currently using, or have recently had experience of, health services are generally far more satisfied with the NHS than the general public. Typically the difference between patient and public satisfaction with individual services is 20 to 30 percentage points.⁴ Moreover, patients report

Box 1. Key drivers of patients’ satisfaction with NHS acute trusts.

- Respect and dignity
- Pain control
- Clean wards/toilets
- Medicines explained
- Side effects communicated
- Accident and emergency organisation
- Privacy to discuss treatment

Source: Ipsos MORI, 2007

significant improvements in certain aspects of their care in recent years. The greatest changes have been in those areas that have been the focus of sustained investment and/or coordinated action, such as targets or national service frameworks. These include cancer, coronary heart disease, mental health and waiting times.⁶

Overall satisfaction, however, can disguise the many aspects of healthcare where patients' experiences are less positive or where expectations are unmet. In particular, patients are often less informed about or involved in their care than they would like, and information and support to enable them to play a more active role is frequently lacking. Reviewing national patient survey data, Richards and Coulter concluded there are 'worrying signs that care for the majority [is] still delivered in a paternalistic manner, with many patients given little opportunity to express their preferences or influence decisions'.⁶ There is much progress still to be made in terms of the interpersonal dimensions of care that patients value above all. For example, in the 2010 NHS inpatient survey, one third of patients felt that doctors did not (or did not always) answer their questions in an understandable way, while a quarter reported that doctors had talked in front of them as if they were not present.⁷

The changing expectations of older people, the main users of NHS services, poses a further challenge. For some years, studies reported that older people are more likely to want the paternalistic style referred to above, with their doctor making decisions about their care. But this is not an age-related preference *per se*, but rather a characteristic of the current older population, which is more deferential and less information savvy.⁸ The upcoming older generation, the baby boomers, is likely to be more assertive, consumerist and demanding of public services. Indeed, evidence suggests that older adults are already more proactive in requests for certain services, and the number of complaints from this group about their healthcare is rising.⁹ This has profound implications for the organisation of NHS services, and for those who deliver them.

Engaging patients in healthcare: three possible roles

Future NHS users are likely to have higher expectations of services and want more participation in decisions affecting them. By fostering greater personal responsibility for health, patient involvement may also be critical to ensuring long-term sustainability of the NHS as a tax-funded system.¹⁰ US researcher Judith Hibbard identified three key roles that patients can play in the healthcare system, all with the potential to improve the quality and outcomes of care.¹¹ These are:

- evaluator: providing assessments of the care they receive
- consumer: making informed choices among providers
- co-producer: being active participants in their care.

Patients as evaluators

In the UK context, the most established of Hibbard's three patient roles is that of care evaluator. As quality measurement

and reporting have developed within the NHS, so too have efforts to assess quality as it is perceived and experienced by patients. Such assessments provide an insight into how healthcare is seen 'through the patient's eyes', and have broadened definitions of quality so these now routinely consider responsiveness to individual needs, preferences and values.¹² Originally designed to collect information on patients' experiences of care, assessment tools are now being introduced for patients to evaluate individual practitioners, treatment outcomes and aspects of their own involvement.

But the challenge that patients face as evaluators is having their views heard and taken into account by the organisations providing and/or commissioning their care. Patient feedback tends to be used on an *ad hoc* and selective basis, rather than systematically or rigorously. Local services are most likely to respond to issues raised about the care environment, the provision of information and accessibility (eg opening times and appointment systems). Patients have had substantially less influence over core aspects of care quality and safety, or major strategic decisions about service planning and priorities.¹³ The time and resources being invested in gathering feedback hardly seems justified if this information is not used to improve services. There is also a real danger that patients are left feeling disillusioned and cynical about the extent to which the NHS actually wants to listen, or is capable of doing so.

This situation has not gone unrecognised and has prompted two main responses. First, there has been significant uptake by NHS organisations in the use of 'real-time' techniques enabling patient feedback to be gathered – and shared with staff – at or near to the point of care. Real-time can provide much fresher data than national patient survey programmes, where there can be a gap of many months between patients returning questionnaires and organisations receiving results.¹⁴ Whether this freshness increases the use and impact of patient feedback is yet to be seen. The second response has been to establish financial incentives and penalties to encourage the use of patient feedback for quality improvement. The most recent of these, the CQUIN payment framework, makes a small proportion (0.5%) of providers' income dependent on the achievement of quality and innovation goals, which include improving patients' experiences.

These responses are welcome, but their impact is likely to be limited unless more attention is paid to the factors that shape willingness and ability to act on patient feedback. Alongside opportunities for patient voice, equal consideration should be given to developing the capacity of NHS organisations and professionals to listen. For some organisations this will mean a considerable shift in culture, so that patients' experiences and feedback are seen as core business at all levels. Leadership has a vital role to play; as Brown and colleagues note, 'If the Board does not show how it takes patient views into account in its decisions, then it is unrealistic to expect front-line staff to do this in their own work'.¹⁴ Organisations are most effective at tackling the issues raised in patient feedback where a quality improvement infrastructure, capacity and skills are in place.¹⁵ A key question for the NHS is how a focus on quality

improvement can be retained while significant budget cuts are taking effect.

Patients as consumers

The 2010 white paper promised a radical extension of opportunities for patient choice, which up to now has been largely confined to routine elective care and maternity services. As well as being able to opt for elective treatment from 'any willing provider', patients will have new choices in the following areas: named consultant-led teams, diagnostic testing, long-term conditions, end-of-life care and some mental health services.¹ The proposed abolition of general practice (GP) boundaries would also enable patients to register with any GP practice, regardless of where they live.

Nowhere has patient choice been more contentious than in the NHS. The consumerist ideal of individuals acting in pursuit of their own self-interest fits uneasily with the collectivist values of equity and fairness upon which the NHS was established. Critics of market-based reforms argue that the future of the NHS as a universal service based on clinical need rather than ability to pay, depends on healthcare being seen as a public good, not an individual benefit.¹⁶ A further issue arises in terms of the spare capacity that is needed within the health system in order for patients to be able to exercise choice. This creates another potential conflict, this time between government policies aimed at promoting choice, and those which seek to improve productivity and efficiency.

These concerns might, at least in part, be allayed if it was shown that patient choice improved services and outcomes, especially for more disadvantaged groups. But such evidence is in short supply. Irrespective of quality of care or waiting times, patients are more likely to opt for treatment at their local hospital if they are older, are on a low income and/or have a lower level of education.¹⁷ The possibility that these groups are simply less interested in choice is not being borne out by research. A recent national study found that older people and people with lower levels of education were among the patient groups most likely to rate having a choice of provider as important to them.¹⁸ More information is needed about the factors that make choices meaningful for patients, and how this process can be effectively supported.

A key area for improvement is patient information. Most information currently provided is comparative performance and outcomes data, made available through online services such as the NHS Choices website. For many patients, this approach is neither accessible nor appealing, and use of NHS Choices is extremely low.¹⁸ Education, literacy and age affect people's ability to understand and compare comparative information, and some patients can be easily overwhelmed by the task.¹⁹ A common response in this situation is to take a decision based on a single, easier to understand variable such as distance to travel, ruling out consideration of important factors such as quality and safety.²⁰ There is a risk that opportunities to make informed choices will be *de facto* restricted to highly educated patients,

unless the needs of more disadvantaged populations are better taken into account. This should be a priority as patient choice is extended across the NHS.

Patients as co-producers

The final role that patients can play is as co-producers in the care process. This role recognises, and seeks to promote, patients' day-to-day involvement in their own healthcare, both as decision makers and care managers. This encompasses many different activities including practising self-care, managing long-term conditions, contributing to treatment decisions, making recommended lifestyle changes, taking preventive actions, monitoring medication regimens and following agreed care plans.¹¹ The emphasis of co-production is on health professionals and patients working together to achieve common goals in an approach that respects clinical expertise and skills, and patients' values, priorities and circumstances. Health professionals are not removed from the process, but collaboration requires a shift in their role from 'provider' to 'partner', or even to 'enabler'.²¹

Until recently, much attention in this area has been on promoting patients as care managers, for example through new health information and advice services such as NHS Direct and the establishment of educational programmes teaching practical skills to support self-management of chronic illness. While these initiatives have been generally well received by patients and public, their integration into care pathways and routine practice is far from complete.²² Under the coalition government, there has been a marked shift of interest towards patient involvement in individual treatment and care decisions, championed by the slogan 'nothing about me, without me'. The white paper set out a vision for 'the principle of 'shared decision-making' to become the norm', and this is increasingly being presented as a key vehicle for bringing about more patient-centred care. Further development of educational resources and decision support tools can be expected as plans to embed shared decision-making in the NHS are implemented.

The gap between desired and actual levels of patient involvement is particularly wide in terms of shared decision-making. Thus, 48% of respondents to the most recent NHS inpatients survey were less involved than they wanted to be in decisions about their care and treatment; this figure was better for maternity services (26%) but far worse in the area of mental health (66%).^{23,24} But co-production is not just about meeting patients' expectations for participation, as important as that may be. Evidence suggests that when patients engage in shared decision-making, self-management and other aspects of their own care, better health outcomes can be achieved.²⁵ A good example is patient self-monitoring of oral anticoagulation therapy, which significantly improves thromboembolic events and mortality compared to usual care.²⁶

It is not enough to prepare patients for co-production; a truly collaborative relationship demands new (or enhanced) skills of health professionals too.²⁷ Strategies to empower patients make little difference if clinicians are unwilling to involve people in

their care, or are unable to do so effectively. The importance of good communication skills cannot be underestimated, as these are ultimately the foundation on which strong partnerships are built. A consistent finding in this area of research is that poor communication is all too common, and this acts as a barrier to patients becoming more involved in their care.²⁸ There is considerable scope to increase the focus on communication skills – and other patient engagement competences – in medical education and training. Tools supporting a collaborative approach to consultations should also be more widely available. Only by equipping both patients *and* health professionals will the benefits of co-produced healthcare be realised and sustained.

Conclusion

This article has outlined three main roles that patients can play in healthcare, all of which are likely to be further developed within the NHS over the coming years. To date, the focus has been on creating new opportunities for patient involvement and a considerable number of initiatives have been launched to this end. But these opportunities are of limited value, and may even produce undesirable outcomes, if not accompanied by measures enabling them to be fully realised in practice. Strategies to support patients have been established, although more tailored approaches that target the barriers to involvement that some groups are more likely to face are also required. Equally there needs to be a far greater focus on creating an environment conducive to patients evaluating services, making informed choices, and actively participating in their own care. This means further fundamental change in the relationship between the NHS and the people who use its services, and between individual healthcare professionals and their patients.

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