

Leadership for patient engagement

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Contents

| | |
|--|-----------|
| 1 Introduction | 4 |
| 2 Why engaging patients matters | 5 |
| 3 Moving beyond isolated projects to a strategic approach | 7 |
| 4 What are the leadership roles? | 13 |
| 5 Conclusions | 16 |
| Acknowledgements | 17 |
| References | 18 |

1 Introduction

Patient and public engagement has been on the NHS agenda for many years, but the impact has been disappointing. There have been a great many public consultations, surveys, and one-off initiatives, but the service is still not sufficiently patient-centred. In particular there has been a lack of focus on engaging patients in their own clinical care, despite strong evidence that this could make a real difference to health outcomes. This paper argues that a more strategic approach is required to create the necessary shift in beliefs, attitudes and behaviours. Three NHS case studies – from acute care, primary care and commissioning – are described and reviewed in the light of evidence from successful organisational change in the US. Eight key features of successful leadership for patient and family-centred care are outlined.

2 Why engaging patients matters

Improving responsiveness and securing greater patient and public engagement in health care has been a policy priority for decades, but the typical NHS experience remains very far from patient-centred. Making a real shift in that direction would mean ensuring that care delivery is always responsive to people's physical, emotional, social and cultural needs, that interactions with staff are informative, empathetic and empowering, that personal values and preferences are elicited and acted upon, that reliable health information and advice is readily accessible via a variety of media, and that commissioning and service delivery are focused on people not diseases. This represents a major departure from traditional ways of working; achieving the change will be a significant leadership challenge for managers, clinicians and patient representatives.

Why should these groups accept this leadership challenge? I have argued elsewhere that promoting greater patient engagement is the best way to ensure the sustainability of our national health system (Coulter 2011; Coulter 2012). There are three main reasons why I believe this is the case.

Delivering appropriate care

Evidence of unexplained geographical variations in the use of medical interventions is illustrative of a lack of consensus among doctors about when and how to intervene for many common conditions (Appleby *et al* 2011). In the face of such clinical uncertainty, patients' informed preferences, values and attitudes to risk should form a key part of the decision-making process. A shared decision-making approach is required, where patients and clinicians work together to select tests, treatments and management or support packages, supported by patient decision aids that provide evidence based information to inform their choices. Despite encouragement from politicians and professional regulators, the evidence suggests that many clinicians are reluctant to inform and involve patients in this way (Coulter and Collins 2011; Stiggelbout *et al* 2012). There is clear evidence that most people want to play an active part in their own care and they expect health professionals to support them in this role (Chewning *et al* 2012; Ridd *et al* 2009; Flynn *et al* 2006). The extent to which patients want to take a lead in decision-making varies from person to person and by the seriousness of their health condition, but the desire for participation is not just a middle-aged, middle-class concern; it extends to many people from older and younger age groups and those living in disadvantaged communities. Indeed studies have shown that people from low literacy groups can benefit more than most when appropriate efforts are made to inform and empower them (Hibbard *et al* 2009; Volandes *et al* 2011).

Managing long-term conditions

Care for people with long-term conditions consumes about 70 per cent of health care expenditure, so achieving greater value in this area ought to be top priority for NHS organisations. Strengthening patients' ability to self-manage their condition is the most promising way to achieve this goal. Traditional paternalistic practice styles create dependency and undermine

people's confidence to look after themselves. This drives up demand for medical interventions and is a poor way to encourage people to adopt healthy behaviours. Collaborative relationships between clinicians and patients working together to create and implement personalised care plans are key to encouraging better self-management. Relevant support can be given in clinical consultations, but it can also be provided outside the consultation by offering counselling provided by trained health coaches, either face-to-face, on the telephone, or internet-based (Wennberg *et al* 2010). Voluntary and community groups can also provide relevant support and many do so. People who are well-informed and well-supported are more likely to make healthy lifestyle choices; they tend to adhere better to medication regimes, they make informed and personally relevant decisions about their treatment, and they use less health care (Mosen *et al* 2007; Bodenheimer *et al* 2002). Empowering patients may be the most effective way to manage demand, as well as being an essential component of good chronic disease management.

Improving quality

The most successful commercial companies know that maintaining a single-minded focus on the end user is the only way to guarantee success. The same ought to be true in health care, but this insight is often crowded out by a multitude of competing priorities, including guidelines, policies, procedures and reporting requirements that are very far from person-centred. This is self-defeating because giving due priority to patients' experience of care can make a real difference to health outcomes. For example, studies have found that patients whose treatment is deemed patient-centred are more likely to trust their clinicians (Keating *et al* 2002), more likely to adhere to treatment recommendations (Haynes *et al* 2008), and less likely to die following a major event such as acute myocardial infarction (Meterko *et al* 2010). And there is evidence that the quality of patients' experience is closely related to staff experience – happy staff make happy patients (Raleigh *et al* 2009). So effective managerial support, good working conditions and positive staff morale are essential steps towards providing a good-quality experience for patients. Monitoring patients' experience via regular surveys is also necessary, but not sufficient, to ensure that services are truly patient-centred. This needs to be supplemented by other ways of ensuring that staff focus on patients' needs. The ability to view services through patients' eyes should be the starting point for any quality improvement programme. Understanding the patient's perspective is especially important in commissioning, since functions such as development of service specifications, redesigning existing services, and monitoring performance require a continued focus on local needs.

3 Moving beyond isolated projects to a strategic approach

What is being done in the NHS to tackle these issues? When preparing this report I circulated a request for examples of effective leadership in the field of patient engagement via various NHS networks. My request elicited a large and enthusiastic response. It is clear that a great deal of effort is now being devoted to finding out what patients and the public want from services. Many people sent me information about consultation and feedback initiatives, or about events designed to engage local people in discussions about how services could be improved. There was no shortage of examples of staff working with voluntary groups, community groups and individual patients to develop new initiatives and additional services. Direct involvement of patients or carers was helping to improve services in many parts of the country, including patients and carers sitting on various governance and quality committees or helping to review facilities, patients acting as mentors to staff, volunteer coaches helping with rapid recovery for surgical patients, expectant mothers being assisted by *doulas* (birth companions), people with dementia involved in developing good practice guidelines, patients with neurological conditions developing guidance for commissioners, people in priority neighbourhoods working together to tackle determinants of health, and so on.

However admirable and no doubt useful these examples are, they hardly scratch the surface of the organisational and cultural change that will be required if the NHS is to become truly patient-centred. Developing new initiatives or add-on projects is easier to achieve than changing mainstream practice. To date, much effort has been focused on securing direct involvement of patients, carers and the public in commissioning and service reviews, so there have been numerous consultations and outreach efforts, some of them quite sophisticated and large-scale. But there has been much less emphasis on tackling the quality of everyday interactions between individual patients and the clinicians who form the front line of the service. Yet it is this face-to-face contact that most of us care most about when we are patients. It looks as if the NHS has put the cart before the horse when it comes to patient and public engagement.

Fostering a more patient-centred clinical culture requires clinicians to develop a set of attitudes and skills that hardly feature in current training programmes. Despite shared decision-making and self-management being high on the policy agenda, the skills for informing and engaging patients are not taught to most trainees, so progress has been frustratingly slow (Elwyn *et al* 2010). Transforming entrenched clinical practice styles is difficult – the resistance comes mainly from health professionals, not patients. Barriers include lack of awareness, lack of incentives, lack of knowledge and skills, concerns about time and resource pressures, a desire to avoid stress by keeping a distance from patients' emotional problems, and negative attitudes among some clinicians due to fears about loss of power, loss of face, or loss of income. There is also an unwillingness to experiment with new roles or new ways of relating to patients, a consequence of a rule-bound, risk-averse culture that discourages innovation.

It is often said that clinicians are more influenced by evidence of patient benefit than by policy commitments or managerial imperatives, yet in this case extensive evidence of patient benefit has often been ignored (Coulter and Ellins 2007). Just producing or summarising research evidence and hoping that clinicians will note it and change their practice accordingly plainly doesn't work (Grol and Grimshaw 2003). A much more comprehensive and tailored approach is required, built on an in-depth understanding of likely barriers and facilitators. However, some NHS organisations are now rising to the challenge of developing a strategic approach to patient engagement. Three examples are described below to demonstrate the scale and complexity of the task required.

Improving patients' experience of hospital care

Most NHS trusts have designated leaders for key priorities such as patient safety and clinical governance, but it is rare for patient experience to be the sole focus of a director-level post. Northumbria Healthcare NHS Foundation Trust is an exception to this rule. The trust, which employs 9,000 staff, provides integrated care over a large geographical area in north east England, including three general hospitals and seven community hospitals. In December 2009 the trust appointed Annie Laverty, an experienced speech and language therapist, to a newly created senior post of director of patient experience. Since then she has been leading a process of transformation across the organisation, with strong support from the chief executive and board. Their goal was to understand what matters most to patients and staff and to re-orient service goals based on that understanding.

Regular face-to-face patient surveys were central to the new approach. Fortnightly surveys are carried out in each ward by independent researchers using hand-held devices, with about 400 patients interviewed each time. The questionnaires include items drawn from the Care Quality Commission's national patient surveys to allow for benchmarking, plus an open-ended section to identify any problems not otherwise covered. The method allows for rapid production of results and fast feedback to staff. Results are presented at department, ward and consultant levels and these are forwarded to the board for review and published on the trust's intranet. Highlights are summarised in posters pinned to ward noticeboards and displayed in public areas. Variations in results help to identify both excellent performance and areas that need improvement. Rapid feedback enables staff to see the results of any improvements they have made, providing both stimulus and reward. Often relatively small and inexpensive changes to ward facilities have been found to produce measurable benefit for patients. In some cases the survey results have helped identify a need for staff development and training, or for specific service developments. When the survey results point to pockets of poor performance, these are given extra attention and support until the problem has been rectified. Some of the consultants were initially resistant to the publication of individual scores, but these are now widely accepted and referred to during staff appraisals. Summary snapshots taken at six-monthly intervals have shown consistent and significant improvements across the trust.

Building on the rich picture provided by the patient feedback programme, the trust has embraced a number of specific initiatives designed to engage patients and carers, both in their own care and in the wider work of the

organisation. A three-year grant from the National Institute of Health Research to one of the trust's hospitals facilitated the development and evaluation of a patient information service for people living with long-term conditions, including Parkinson's disease, chronic obstructive pulmonary disease (COPD) and inflammatory bowel disease. A steering group of patient and carer representatives and members of voluntary organisations oversaw the development of the service, which aimed to ensure that the information provided fully met individual needs, was integrated into clinical care and was available at every stage in a care pathway. Health professionals provide information prescriptions to signpost available resources and library information specialists ensure that the information is accessible to those who need it.

Recognising that the life-changing impact of stroke is often poorly addressed, the trust introduced a stroke volunteer support programme to provide timely access to psychosocial information and support to stroke patients and their carers during their hospital stay. Twenty-four volunteers were recruited, all of whom had personal experience of stroke, either as a patient or as a carer. A 30-hour training programme delivered over nine three-and-a-half hour sessions was provided to equip the volunteers to work alongside staff and newly diagnosed patients in the trust's three acute stroke units. Over a 12-month period more than 400 visits were made to 364 stroke patients and their relatives, helping to reduce anxiety and isolation, increasing people's confidence and providing positive role models and practical coping strategies.

Even more remarkable results were achieved from work carried out in the trust to improve diet and feeding support for patients recovering from hip fracture. The hip fracture quality improvement programme (Hip Qip) aimed to provide prompt surgery, early rehabilitation, effective preventive care and an early return home for these patients. The mechanisms included special efforts to learn about and respond to individual needs and the promotion of effective teamworking by staff across different disciplines. Having achieved excellent results for timely treatment following hip fracture, attention focused on improving recovery and getting patients back on their feet. Trust staff were aware of evidence from randomised trials suggesting that paying special attention to the nutritional needs of hip fracture patients could aid recovery (Duncan *et al* 2006). Two nutritional support workers were employed and special efforts were made to find out what types of food patients enjoyed and to make it available. The nutritional assistants made sure that it was presented attractively, in utensils that enabled people to eat with dignity. Ward rounds were banned at mealtimes to promote a calm environment, nutritional supplements were introduced when necessary, and extra support was available for those who needed help with eating. The results were very encouraging. All medically fit patients were mobilised by one day following surgery and mortality following hip fracture dropped by more than 30 per cent. The trust's regular patient survey results provided confirmation that patients appreciated the new regime and benefited from it.

New practice styles to support self-care in diabetes

In 2007 Diabetes UK, NHS Diabetes, The Health Foundation and the Department of Health launched a programme, the Year of Care, to introduce systematic care planning and self-management support for people with diabetes (Diabetes UK 2011). The programme was led by Dr Sue Roberts,

a physician and former national clinical director for diabetes. The starting point for the programme was the conviction that providing individual patients with personally relevant information about their clinical care, together with prompts about how to reflect on this before a consultation, would be a good way to engage them in a collaborative care planning process. A pilot programme was launched in three sites, NHS Calderdale and Kirklees (as it was then), NHS North of Tyne and NHS Tower Hamlets, with participation from 130 general practices. Patients were initially invited to attend a data collection consultation with a health care assistant, after which they were sent summaries of their test results to review before a second scheduled appointment. The second appointment, which took place about two weeks later, was usually with a practice nurse trained to provide support for self-management. Discussions covered biomedical, emotional and practical issues, information and education, goal setting and action planning.

General practice staff quickly learnt that they needed to review and often change the way the practice was structured and managed to accommodate this new way of working (Mathers *et al* 2011). All members of the practice team, including receptionists, nurses and doctors, were given clearly delineated roles, so that tasks meshed together seamlessly. All required training and support to develop the right attitudes and skills to support patients in self-care. Negative reactions such as 'not suitable for our patients' or 'we do this already' had to be tackled directly by encouraging reflection and modelling appropriate behaviours. DVDs of care planning consultations were used to help people see how these differed from their usual consultation styles.

The changes took time to bed in, but were strengthened by an environment that motivated good practice. Leadership was crucial, as was clarity of purpose, grass roots facilitation, attention to solving practical problems, and co-ordination. Effective teamworking was led by clinical champions who encouraged and engaged staff and monitored progress and outcomes. Administration of appointments systems often had to be adapted to accommodate the new roles. Information and clinical coding systems were not always fit for purpose and new modules had to be developed to enable recording and sharing of care plans and performance monitoring. Engagement with the wider community was also necessary to make best use of local support services. Wherever possible these were adapted to include non-traditional support services run by voluntary groups, for example, cookery classes for Asian men. Commissioners initially had to be persuaded to support the approach, ensuring that it was accommodated within agreed care packages for diabetes, but they recognised that many long-term conditions could benefit from the same community services, leading to economies of scale. Unmet needs were addressed by aggregating individual care plans to identify gaps in existing provision.

A change that might have looked relatively simple at first glance had ramifications that extended across the local health economy and beyond. Those responsible for the programme were convinced that the effort was worthwhile. More than 1,000 practitioners received training during the course of the three-year pilot and more than 40 trainers were accredited to lead and replicate the process and spread the learning. An independent evaluation concluded that diabetes patients in the three communities experienced better care and were better able to self-manage their condition as a result of their participation in the programme. Professionals gained new knowledge

and skills and greater job satisfaction, and the practices' organisation, teamwork and productivity improved significantly. The initial focus was on diabetes but the model has proved to be readily adaptable to other long-term conditions, having been successfully tested in Tower Hamlets with patients with chronic obstructive pulmonary disease and cardiovascular disease.

Using patients' stories to drive change in end-of-life care

While most clinical commissioning groups are still in embryonic form, several of the early pathfinders have been breaking new ground in their efforts to ensure that commissioning is person-centred. One such example is the Healthworks Clinical Commissioning Group in Sandwell and Birmingham. In March 2011 the GP leaders of this consortium of 22 practices, with a total registered population of 151,000, decided to drive improvements by engaging the active participation of local stakeholders, including patients and providers. Adopting a strategic process called experience-led commissioning, developed by Georgina Craig Associates with input from the University of Oxford's Health Experiences Research Group and Professor Glen Roberts from King's College (see www.experienceledcare.co.uk), patients' accounts of their illness and care experiences were used as the starting point for a change management programme. Drawing on the principles of experience-based design (Bate and Robert 2008), the idea was to help professionals understand patients' experiences and emotional responses during a care pathway and to use these to stimulate service design and improvement.

End-of-life care was an early priority for Healthworks. Built around a series of five facilitated events attended by patients and carers, community groups, voluntary organisations, frontline clinicians and managers from provider organisations, the local authority and Healthworks, the process used co-design principles to tackle needs assessment, service design and specification, contract design and performance monitoring. Participants developed detailed insights into end-of-life care needs. The starting point was a national database of patients' stories (The Database of Patient Experience developed by the Health Experiences Research Group at the University of Oxford), supplemented by interviews with local patients and carers and a summary of public health indicators, including epidemiological and service use data. Trigger films of patients and carers talking about their experiences helped to create emotional investment in the process and build consensus on what a good end-of-life care service should look like. The fact that these drew on academic research was helpful in persuading sceptical clinicians to engage with the process. All participants, including patients and carers, were asked to describe the assets they could contribute and were invited to make a personal commitment to devote something of value to the change process, eg, time, effort, free use of a meeting room or other free or voluntary resources. Participants then worked together on all aspects of the commissioning and quality improvement plan, agreeing actions and monitoring methods, based on the map of community assets and commitments gained at the preceding events.

An independent evaluation of the project pointed to a range of positive outcomes, including a workable end-of-life commissioning strategy and a management action plan, a map of local assets for improving end-of-life care, and the identification and recruitment of change champions (lay people, managers and health professionals) to help implement the strategy

(Cheshire and Ridge 2012). A system for coaching and mentoring is now being put in place to support those involved and progress will be monitored using measurements co-designed with the provider organisations. Critical success factors included strong commitment from the GP leaders who were willing to trust the process and cede control when necessary, expert facilitation of the stakeholder events, including keeping participants focused on the task and encouraging them to talk about solutions, not just problems, and engagement of providers alongside commissioners, patients and other community members, with the result that the strategy was owned and signed up to by all parties.

The team is now involved in training 15 end-of-life improvement champions and a small part-time implementation management team to take the process forward without external help. They are exploring the introduction of a cascade programme, which would support a team of accredited facilitators to apply the process across a wide range of clinical conditions, creating a shared commissioning resource within other commissioning bodies. The cascade programme is also creating a vehicle for sharing the learning with other commissioning groups. The use of patient stories as a starting point and the focus on managing change gave the process a very different feel to traditional ways of reviewing and redesigning care pathways. According to the evaluators, the process was *more 'human' and 'real', involved 'meaningful' user engagement, contributions from a wide range of stakeholders, and was run as a change management process* (Cheshire and Ridge 2012). Observable progress was achieved in a relatively short space of time: in less than a year, the team managed to secure broad stakeholder ownership of the strategy, a solid basis of trust in the improvement plan and strong commitment to see it through.

4 What are the leadership roles?

Each of the case studies outlined above demonstrates what can be achieved when far-sighted clinicians get involved in leading transformational change in their organisations. Each programme championed a new way of working with patients, treating them as co-producers of health, not just passive recipients of care. In each case the changes were initiated by clinical leaders committed to learning from patients' experience and using this knowledge to make health care delivery more patient-centred. They focused on clear goals, were ambitious, strategic, and willing to take risks, including challenging their colleagues to change traditional work patterns and communication styles. In each of the case studies considerable efforts were made to help staff view their services through patients' eyes, empowering them to engage directly with patients and respond to their needs appropriately.

Despite numerous descriptive accounts of patient and public involvement in NHS-led projects, there is a dearth of hard evidence on the impact of these initiatives (Crawford *et al* 2002; Mockford *et al* 2012). Nor has there been much UK-based research into the leadership qualities required to implement successful change in this area. We have to look overseas to find studies that shed light on the factors that might promote or inhibit effective patient engagement in the NHS.

A study of six US academic medical centres highlighted the importance of cultural change in sustaining improvements in patients' experience (Shaller and Darby 2009). Each of the six hospitals was engaged in a process of making their services more patient and family-centred. All had succeeded in making improvements in targeted areas by finding ways to overcome various barriers, including disinterest or resistance from their colleagues. The study involved site visits and detailed interviews with senior leadership, board members, frontline staff and patient representatives who were asked to give individual accounts of their involvement in a quality improvement programme. Interviewees described the process they went through as a journey. The journey had often been triggered by dramatic events or quality failures which highlighted an urgent need for change. The process was different in each organisation, never followed a straight line, was initiated at different levels in the organisation and moved at different paces. Nevertheless, when they were able to keep focused on the overarching goal of improving patients' experience, the results as measured by improvements in national patient survey scores were impressive.

These study methods were later replicated by a different research team in a different set of eight US health care organisations to see if the characteristics identified by Shaller and Darby were influential in organisations with a proven track record for improving the patient care experience (Luxford *et al* 2011). Each of this second set of organisations had either won national awards, or had excellent patient survey results or some other form of external recognition. Five informants in each site were interviewed about the key organisation-level facilitators that contributed to their success and the challenges they faced. The findings reinforced the importance of adopting an organisation-wide approach for successfully advancing patient-centred care.

Taken together, these two studies and the three NHS case studies can help us to identify at least eight core elements of a successful change strategy.

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- **Strong, committed senior leadership** – Visionary leadership committed to achieving the goals of patient and family-centred care is essential for achieving transformational change. The initiative might emerge from any level in the organisation, but success and sustainability depend on effective distributed leadership with active support from the CEO and board. It is important that this support is empowering rather than directive, enabling people at the front line to innovate without fear of retribution if things don't turn out as expected.
 - **Dedicated champions** – A dynamic, dedicated champion with a brief to improve patient engagement and patient experience as the central focus of their responsibilities is essential for driving change at the operational level.
 - **Active engagement of patients and families** – Active collaboration with patients and carers is crucial. Engagement can range from involvement in organisational decisions (eg, service developments) to engagement at the point of care. Patients and carers should be represented on committees and other decision-making forums, but it is even more important to ensure that staff are actively involving individual patients in decisions about their care.
 - **Clarity of goals** – Clear goals and effective methods for communicating these at every level, from board to management to frontline workers to patients and families, are essential for spreading and reinforcing patient-centred values and procedures. A lack of clear objectives currently characterises much patient and public involvement work in the NHS, leading to confusion and sometimes disillusion and discouragement.
 - **Focus on the workforce** – The principles of patient and family-centred care should be incorporated into human resource policies, helping to determine the way staff are recruited, trained and rewarded. Use of patient or carer feedback in staff development and appraisal can be very helpful. Recruitment and selection matter too, and some organisations make a point of including patients on interview panels. Constantly developing and reviewing the staff culture and work environment is crucial. The best organisations ensure that achievements receive public recognition through newsletter articles, award ceremonies, wall posters, and so on.
 - **Building staff capacity** – The provision of special training in communication skills, patient-centred care values, customer service and leadership skills, quality improvement concepts and methods is key, as are examples of new roles, tools and initiatives that had been shown to work well in other settings.
 - **Adequate resourcing of care delivery redesign** – Successful organisations support systems solutions whenever necessary, for example, introducing new appointment and scheduling systems, improving access arrangements, developing facilities for family members to stay overnight, and so on.
 - **Performance measurement and feedback** – Continuous measurement and reporting on patients' experiences is essential for

assessing progress, strengthening accountability and identifying new opportunities to improve performance. Both narrative feedback and surveys have a role to play – the important thing is to match the method to the purpose. Patients’ stories can be a particularly useful catalyst for change, but surveys are essential for monitoring trends.

A King’s Fund-supported learning set whose members were responsible for leading patient-centred change in NHS organisations confirmed that the factors listed above were applicable in their context too. They stressed the need for an effective lead from the CEO and board and for a senior person, ideally a director-level post, with an exclusive focus on leading improvement in this area – not simply adding the task to the portfolio of someone already snowed under with other responsibilities. Effective leadership at all levels in the organisation was seen as essential, with staff feeling empowered to push for change. Active involvement of doctors in the quality improvement process was seen as very beneficial, as was involvement of senior nursing staff, patients and carers. Regular ‘real-time’ patient surveys with fast turnaround of the results were viewed as helpful for stimulating change, enabling staff to see the practical impact of changes they had made. Patients’ stories were reported to be especially useful for helping staff to connect emotionally and maintain focus on the task. Positive role models were also important – strong departmental leaders who set a good example and wouldn’t tolerate poor performance.

NHS staff talked about the challenges they often faced when trying to innovate in this area, including a widespread perception that improving patients’ experience is not as high a priority on the national policy agenda as patient safety or sound financial management. Other barriers include the challenge of coping with multiple competing pressures, a feeling of being hidebound by policies, procedures and regulatory requirements, the lack of a dedicated team to focus on quality improvement, and negative or defensive reactions from colleagues. These barriers are echoed in a number of international studies (eg, Davies *et al* 2008; Legare *et al* 2008; Groene *et al* 2009) so they are not unique to the NHS, but they represent real hurdles that can only be overcome with concerted effort.

5 Conclusions

The examples described above are not unique; I heard of several other NHS organisations that were implementing impressive change strategies along these lines. They demonstrate that achieving a more patient-centred service in the NHS is possible, but they also beg a number of questions. Where does responsibility for improving patients' experience lie within most NHS trusts, primary and community care organisations and commissioning groups? Why is improving patients' experience seen as less of a priority than ensuring patient safety? Why do paternalistic attitudes to patients persist in many parts of the service? Why do professional training courses pay so little attention to methods for involving patients in their own care? Why are there so few directors of patient experience in NHS organisations? Why does the provision of high-quality information for patients not receive more attention from staff? Why has it proved so difficult to persuade NHS organisations to take notice of and act on the various methods of gathering patient feedback that are now ubiquitous but frequently ignored?

The features of successful change identified in the US studies were found to hold good in NHS settings too. None of the programmes rested on the efforts of a single, heroic leader. All depended on a number of people who were willing to try different ways of doing things, and all managed to secure engagement from staff at different levels in the organisation, from ward to board. Provision of positive role models and continuous efforts to support effective teamwork were common characteristics. Each programme focused attention on staff development, using patient feedback to stimulate change and monitor performance. In two of the three case studies training and mentoring was extended to patient volunteers in addition to staff.

Tackling these problems ought to be a high priority for everyone working in the NHS. After all, a high-quality health service should be organised around the needs of those who use it, and strengthening responsiveness to patients may be the best way to ensure that the service remains sustainable into the future.

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