



**National Voices**

People shaping health  
and social care

## **NOT THE FRANCIS REPORT**

**A National Voices Report  
on  
How to Ensure Safety & Quality**

**15 October 2012**

## SUMMARY

The NHS is under stress as demand rises and money tightens. Too much care is in the wrong place and organised in the wrong way. There is growing concern about the capacity of the NHS to sustain a high quality and safe service. Highly publicised failings such as those in Mid Staffordshire NHS Foundation Trust and in other places have shaken public trust but have not led to a clear resolution. There is a sense that “there could be another Mid-Staffs” and that lessons from earlier failings have not been learned and implemented. Much of the Coalition Government’s term of office has been overshadowed by the long awaited second Francis inquiry.

In fact, we already know what to do. There is no shortage of evidence and wisdom to underpin much needed improvements that will make health and social care safer and of better quality. There is a great deal of consensus about what these should be. What is more, across the country, countless dedicated health professionals and managers are quietly getting on with changes and innovations that are improving things for patients, service users and families.

What seems to be lacking is any sense of urgency to get things done on a system wide basis. Instead, the massive effort of setting up new health bodies is sapping energy and time, and “Waiting for Francis” is having a paralysing effect.

Rather than waiting for the much delayed second Francis report, the Government and NHS leaders need to step up their reform efforts. This National Voices report is published on the same day - 15 October - that Sir Robert Francis’s report was supposed to appear. It sets out our priorities, based on a range of evidence, including what our members are telling us.

## RECOMMENDATIONS

1. There needs to be a concerted drive towards creating an open and compassionate culture in all organisations providing health and care services, underpinned by accountability for upholding the NHS Constitution.
2. National Voices welcomes the new **Speaking Up** charter launched today which sets out commitments to foster a culture of openness and transparency and to enable people to raise concerns safely and without fear of reprisal. But we also need a [statutory duty of candour](#) so that NHS organisations must come clean to patients and families where things have gone wrong. The current NHS Constitution pledge to be “open” is not enough.

3. There needs to be a drive by the NHS and all care organisations to listen to patients and carers. This has to be a top priority for trust boards. Patient feedback systems need to be systematic and comprehensive, with results openly reported at all levels of management, so there is no hiding place for patches of poor care. **The Friends and Families Test is a crude measure on which the NHS would be unwise to place too much reliance.**

4. There needs to be concerted effort to involve patients and families fully in decisions about their care and treatment, or “no decision about me without me” will remain an empty slogan.

5. The NHS must invest in **patient leadership**: the leadership capability of people who play a wide range of roles in supporting patients and service users, speaking out on their behalf, and helping to design services and hold them to account.

6. The NHS Commissioning Board (NHSCB), local health and social care commissioners, and the professions need to lead on the creation of **an integrated health service based around primary care**. This has been talked about for decades but there has been little action. Key elements are preventive services; care planning and named care coordinators to help vulnerable people to live well and avoid unnecessary hospital admissions; and joining up health and social care services. Good out of hours care and round the clock crisis support are essential.

7. **The Government needs to implement the Dilnot reforms** as a necessary first step for ensuring sufficient funding for social care and an equitable distribution of costs between taxpayer and self-funder. The lack of urgency in this regard is a scandal. Without these reforms, care will remain inadequate, efforts to join up services in the community will be hampered, and too many older people will endure avoidable hospital admissions.

8. **Urgent work is needed to ensure that the safety and quality of hospitals does not vary according to how old the patient is or when they are admitted.** The current variability is unethical and scandalous. Trust boards should be held accountable for how well they reduce current gaps. Action is needed to implement the recommendations of the Royal College of Physicians’ “Hospitals on the Edge” report in particular, to improve continuity of care within hospitals.

9. **Hospital services need radical reorganisation.** Safety and quality demand a greater concentration of some services. The NHS has a poor record when it comes to making a good case for change, involving local communities and winning support. Some important changes have been ducked for decades. National Voices has agreed to work with key system

leaders on a methodology for doing this well, ensuring that local communities have a voice and that concerns - for example transport – are properly addressed.

10. Regulation plays an important but limited role in ensuring quality and safety. There are many regulatory bodies and they need to concentrate their efforts on working smarter and better together. Extending the scope of regulation, for example by bringing managers and health care assistants into their purview, would in our judgement be wrong-headed. It would create bureaucracy and add little if any value.

## **INTRODUCTION**

The NHS is under stress. Demand is rising as the population of people with chronic conditions and disabilities grows. Funding is not keeping pace with demand. The major reorganisation of the structures of the NHS is inevitably distracting time and attention from front-line care.

The former health minister Lord Darzi famously said that quality should be the “organising principle” of the NHS, but for patients and their families it doesn’t always feel like that. The task of ensuring safety and quality is becoming ever more challenging. Three inquiries into what went wrong in the Mid Staffordshire NHS Foundation Trust between 2005-2009 revealed a catalogue of failings in that hospital. It is widely held that what happened in Mid Staffordshire, while extreme, was not unique and that similar failings could happen elsewhere.

The results of a fourth inquiry – the second by Sir Robert Francis QC – are awaited. That inquiry is predicated on the assumption that there are broader lessons to be learned – especially in the way that NHS services are purchased, monitored and regulated. The 2<sup>nd</sup> Francis inquiry was commissioned as long ago as June 2010 and had already been delayed before its expected publication in October 2012. It has now been put back again to January 2013.

The report is eagerly awaited. Sir Robert’s recommendations are expected to be hard-hitting and it is rumoured that they might contradict aspects of Government policy. National Voices is worried about the “Waiting for Francis” effect. Taking account of the time for the Government to respond to his recommendations, there could be further months of uncertainty while the planners and providers of care “wait for further instructions”. We think the waiting has gone on long enough. We think that there is already enough

collective wisdom about what needs to be done to ensure that healthcare is safe, effective and responsive to patients' needs.

That is why National Voices is publishing this short report – on the day that Francis himself was, until recently, expected to publish – setting out what needs to be done.

## **ABOUT NATIONAL VOICES**

National Voices is the national coalition of health and social care charities in England, with more than 150 member organisations. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. Our broad membership, rooted in people's experience, represents millions of people, and covers a diverse range of health conditions and communities.

## **WHAT WENT WRONG IN MID-STAFFORDSHIRE?**

The failures of the Mid Staffordshire Trust during the period 2005-2009 have been well catalogued and it is not the purpose of this report to rehearse them. In short there were serious deficiencies in the quality of care and in the quality of management, leadership and governance. The culture of the Trust was not conducive to good care of patients or the support of staff. There was a forceful management style, perceived by some as bullying. The earlier Francis inquiry highlighted a number of key themes:

- corporate focus on process at the expense of outcomes;
- a failure to listen to those who have received care through proper consideration of their complaints and survey feedback;
- staff disengaged from the process of management;
- insufficient attention to the maintenance of professional standards;
- lack of adequate support for staff through appraisal, supervision and professional development;
- a weak professional voice in management decisions;
- a failure to meet the challenge of the care of the elderly through provision of an adequate professional resource. Some of the treatment of elderly patients could properly be characterised as abuse of vulnerable persons;
- a lack of external and internal transparency;

- false reassurance taken from external assessments; and
- a disregard of the significance of the mortality statistics.

The purpose of listing these failings is not to direct further adverse comment at the Trust, but to make the point that none of these failings is unique and that therefore the notion that there “could be more Mid Staffordshires” is more than just lazy scaremongering. That is before we even get into questions of oversight and regulation, and the role of commissioners and regulators.

## **HOW SAFE AND EFFECTIVE IS THE NHS NOW?**

Despite the pressures that the NHS is facing, the broad picture presented by official statistics is that services are bearing up pretty well. For example the Secretary of State’s annual report published in July 2012 showed that the NHS was performing well against key indicators of waiting times, mortality and hospital acquired infections.

Once we start to dig deeper the picture is more mixed. We know that the majority of the millions of daily patient encounters with the health service go well, but there is also growing evidence of systematic deficiencies in the way our services are designed and run and growing concern among patient and professional groups about the quality and sustainability of our health and care systems.

### **Satisfaction**

Overall public satisfaction with the NHS is a rough and ready measure; it does not accurately reflect the direct experience of patients and families and is affected by the wider political and media debate about the NHS and reforms. It is nonetheless striking that the latest British Social Attitudes survey shows that overall satisfaction with the NHS dropped from an all time high of 70 per cent in 2010 to 58 per cent in 2011.

### **Safety**

Recent data from the NHS Safety Thermometer – an improvement tool for measuring, monitoring and analysing patient harms – shows that on average 9 percent of patients suffer avoidable harms of various kinds in NHS trusts – and that in some trusts the rate is 20 per cent or more. Annual surveys show that of those hospital inpatients and outpatients given new medicines, more than 4 in every 10 say they were not told about possible side effects. Nearly 4 in every 10 inpatients were not told about danger signals to watch out for when they went home.

The welcome move towards greater transparency about NHS performance has increasingly put the spotlight on wide variations in safety, quality and health outcomes across the NHS. While there are debates to be had about the interpretation of data, and where to draw the boundaries between acceptable and unacceptable variation, there is also growing consensus about some things. Some hospital care is not safe enough because it is not done at sufficient scale and needs to be centralised in a smaller number of larger units. This is what has happened in the provision of acute stroke services in London – with excellent results - and what is now happening with child heart surgery across England. There is also growing acceptance that the well-evidenced poorer safety record of hospitals at weekends and during public holidays is unacceptable and arguably unethical.

The recent Royal College of Physicians report [Hospitals on the Edge?](#) presents a stark picture of hospitals struggling to cope with increasing demand and calls for radical changes to the way that care is organised within hospitals, in particular to prevent patients being unnecessarily shunted from ward to ward.

### **Older people**

There is growing concern about the capacity of the NHS and social care systems to provide satisfactory care for the growing number of older people with multiple health problems, especially those aged over 75. The lack of round-the-clock, joined up care, delivered in people's homes or close to them, results in too many people being admitted to hospital, staying too long and deteriorating while they are there. This is a particular problem in relation to those with dementia. The Alzheimer's Society has called for a reduction in the number of people with dementia being cared for in hospital.

### **Basic care, dignity and compassion**

There is growing concern about the capacity of the NHS to deliver basic standards of care to older and other vulnerable groups, with sufficient compassion and protecting people's dignity. The 2011 inpatients survey showed that nearly 4 in 10 patients who needed help to eat didn't get it, or only got it sometimes.

There has been something approaching a crisis of confidence in nursing, with a succession of prime-ministerial initiatives, and a new quality initiative called ["6 C's"](#) (care, compassion, competence, communication, courage, commitment) launched for consultation by the new chief nursing officer. Sadly, there have been care scandals in a variety of settings beyond Mid Staffordshire. This recent [Delivering Dignity](#) report, to which National Voices contributed, contains many sensible recommendations for reform.

## **Management culture and raising concerns**

There is growing recognition that forceful and sometimes bullying management cultures in the NHS and other care organisations can make it difficult for staff to challenge poor practice and speak out in the interests of patients. The annual NHS staff surveys contain some very worrying findings on the extent to which staff do not feel supported by their managers. Whistleblowing legislation provides essential protection, but what is also needed is an open culture in which people are encouraged to surface problems early so that they can be nipped in the bud.

## **Patient and service user involvement**

About a third of patients in primary care settings report that they are not as involved as they wanted to be in decisions about their care and treatment. This rises to nearly half for hospital inpatients. These figures have barely changed in a decade of monitoring. There is strong evidence that the full participation of patients in decisions about their care and treatment can lead to improved health outcomes; improved quality – especially in relation to patient experience – and more effective and appropriate use of resources.

Conversely, the ["misdiagnosis" of patient preferences](#) can have serious consequences. At worst it can mean enduring inappropriate treatment for lack of information and a proper explanation of the pros and cons of different courses of action. For example, too many men undergo prostate surgery which is of dubious benefit to them and which carries very high risks of complications – such as incontinence or impotence - of which they are not fully aware. It can also mean a denial of fundamental choices, such as the choice to die at home. Such failures can arguably be seen as unethical.

The current government and the previous government have often appeared to be more interested in promoting consumer choice in the NHS than in promoting patient and service-user involvement. The evidence would suggest that involvement has more impact and is more valued by patients.

## **Fragmented care**

There is a growing recognition that a fragmented and disjointed system of care – such as is frequently experienced by those with multiple health problems requiring interventions from several sources – is an impediment to safe, effective and efficient care. There is also serious concern that the Coalition Government's reforms do not provide strong mechanisms for coordinating care better. National Voices' [recent work](#) on this theme, for example our report [What do people want from integrated care?](#) has set out a way forward that focuses attention on the experience of patients and their

families. Think tanks such as the King's Fund and the Nuffield Trust have also done important work on this theme and National Voices is working with them to take this work forward.

## **WHAT NEEDS TO HAPPEN?**

One would have thought that in the light of this evidence of systematic problems and pressures and a growing body of expert opinion and recommendations for change that there would be a greater sense of urgency.

We are currently going through a major structural reorganisation in England, an efficiency programme which, despite its name "Quality, Innovation, Productivity and Prevention", is driven by the need to meet the £20 billion "Nicholson Challenge", and a dizzying array of smaller scale initiatives.

The new Secretary of State for Health Jeremy Hunt has set out some new high level priorities that echo the themes of this report, for example the importance of care, and the need to rise to the challenge of dementia, and he has emphasised that the new organisational structures now need to drive a change of culture in the NHS. These are very welcome signals but it remains unclear how this change will be driven and with what force.

Where there has been a concerted national drive, it is notable that significant improvement can be made. For example, patients' ratings of the cleanliness of wards and toilets are high and on an improving trend. There has been commendable success in reducing hospital acquired infections.

We need this kind of concerted effort on a boarder front. Here are the priorities that National Voices identifies as key, based on the work we are doing to strengthen the voice of patients and families in health and social care, and informed by our members.

### **1. We need an open and compassionate culture in our health and care services**

National Voices is involved in current work to strengthen the [NHS Constitution](#). The Constitution articulates the values, principles and behaviours that should drive the NHS, alongside legal rights and other commitments. It sets out what patients and families can expect of the NHS: timely access to comprehensive services and treatments when they need them; an assurance of quality and professional standards; respect for dignity and human rights; the right of involvement in decisions and choice; and redress when things go wrong. If the NHS consistently did what the

Constitution says, it would not be necessary for National Voices to write this document.

The Constitution is therefore very important. It is also little known and has few teeth. It now needs to be refreshed and embedded in the work of the NHS. Patients, carers and families need to be able to use the Constitution to challenge poor practice or adverse decisions. We believe that all organisations providing care services should be consistently held to account for how well they live by the NHS Constitution.

We welcome the new **Speaking Out** charter which has been signed by many organisations in health and which sets out commitments to foster a culture of openness and transparency and to enable people to raise concerns safely and without fear of reprisal.

National Voices is generally sceptical about the power of legislative and regulatory instruments to achieve behaviour change. In the case of openness we think a change in law is needed as part of the efforts to overcome a long-standing and persistent culture of secrecy, cover-up and authoritarian management in the NHS. We therefore support **a statutory duty of candour** which would require health organisations to be open with patients and families in the event that harm had been done. It is a critical ingredient for “preventing another Mid Staffs”.

## **2. We need a culture of really involving and listening to patients and carers**

A major lesson from Mid Staffordshire was the failure to listen to patients and families. The importance of listening has gone up the agenda but we think there are some critical ingredients for getting it right.

**First, patients need to have the chance to be fully involved in decisions** about their own care and treatment. As discussed above, getting this right will improve health outcomes and help ensure a better allocation of resources. It will also help to deal with the “silent misdiagnosis” of patient preferences which can lead to inappropriate treatments.

The patient engagement expert Angela Coulter has demonstrated, for example in [Leadership for Patient Engagement](#), that involving patients fully is key to ensuring a sustainable health service because of its impact on the quality of decision making, the management of long term conditions and the improvement of safety and quality. She has also argued that engagement of patients is a vital leadership task for the NHS.

We have called upon the NHS Commissioning Board to lead a drive to ensure that the essential ingredients of patient involvement are in place everywhere:

tailored information for patients, shared decisions about treatment, personalised care planning, support for active self management, and the education and training for professionals to achieve these, should become mainstream in the NHS. Information is vital but it is not just a question of leaflets and websites. Patients need to be able to have informed and equal conversations with health professionals and be able to ask pertinent questions. The [“Ask 3 Questions” campaign](#) could be part of changing the culture.

**Second, providers of care must gather good evidence about the experience and views of patients and families**, including by making it very easy for people to offer feedback at the point of care, as well as later.

In the 2011 national inpatients survey, 87 per cent of respondents said they were not offered the opportunity to give their views on the quality of care. There is a long way to go.

Every NHS organisation should be establishing patient experience collection that is systematic, frequent and comprehensive, with the results reported to all levels of management. The purpose of these systems should be for continual quality improvement, but they should also have the effect of ensuring there is no hiding place for pockets of poor care, such as a bad ward. NHS Northumbria Foundation Trust is an exemplar.

Boards of organisations must treat it as a priority to collect and analyse suitable information and act upon it – and they should be held to account for how well they do this. It should be impossible to ignore feedback, which should be embraced as a tool to improve care and, in some cases, to give warning lights.

No single source of information is likely to be sufficient to give care providers a full and rounded picture of how well they are doing. The “Friends and Families Test” favoured by the Government is a high level and rather superficial measure and it would be unwise for the NHS to place undue reliance on it.

**Third, organisations need to invest in patient leadership to ensure a powerful collective voice.** Patient reference and participation groups, peer supporters, health champions, Foundation Trust governors, experts by experience and others in a representative, leadership or supportive capacity can and do make a big difference in helping to improve understanding of the user experience; improve services in collaboration with care organisations; support patients and families; and hold services to account. Lay people will

also be needed to play a role as members of clinical commissioning groups, members of Health and Wellbeing Boards and of local HealthWatches.

The notion of patient and lay leadership is starting to take off as a result of the efforts of the Centre for Patient Leadership and championing by National Voices and others in the voluntary and community sector. Broadly speaking it is about ensuring a wide and diverse pool of people taking part, being clear about roles and expectations, and supporting and developing people to make an effective contribution. It is about giving teeth and meaning to the often vague concept of “public involvement”. People in lay leadership roles can rarely if ever be “representative” of patients in the round, but it does not follow that they have no legitimacy. Patient leadership programmes, by addressing questions of recruitment, role and skill, can ensure that people have both legitimacy and impact.

Information and communication are critical to ensuring a culture of listening to and involving patients and families. The recent Government Information Strategy [The Power of Information](#) sets out a ten year vision which is strong on aspiration but less clear on implementation. **Annex A** sets out National Voices’ views on the tests that must be met if the strategy is to be successful.

### **3. There needs to be round the clock support to enable people to stay well, manage their health problems and avoid unnecessary hospitalisation.**

A safe and sustainable health service provides the right care in the right place at the right time. The NHS needs to provide better and more joined up care closer to home if quality is to improve and pressure on hospitals relieved. This has been the policy for years but the policy has not in fact been implemented effectively.

As the commissioner of primary care services in England the new NHS Commissioning Board has the prime leadership role and must now drive a significant transformation of primary care, along with professional leadership bodies and local commissioners. Some of the key elements are as follows:

- A systematic approach to identifying those people most in need of support, especially those with multiple chronic conditions, and ensuring that they are involved in producing a care plan and given information, advice and support to manage their health, with the full involvement of their families
- Ensuring that people so identified experience a coordinated service, with a care coordinator that they know and trust

- Ensuring good out of hours services and round the clock crisis help for those at risk of an emergency admission.
- Primary, community and secondary health services working together well and with social services, in particular by sharing information in real time as patients transfer from one service to another
- Commissioners drawing on the full potential of voluntary and community organisations. The voluntary sector provides vital help, information and support to patients, service-users and families. It has expertise which can inform the design of care pathways and services. It provides a bridge to excluded or marginalised communities. It can help fill the gaps in fragmented services. Commissioners must not fall into the common traps of either by-passing and ignoring the voluntary sector or of exploiting it: free-riding on its services without meeting its costs.
- Making full use of modern digital technologies to improve communications and empower patients and families, while avoiding the trap of using technology to downgrade services, isolate the vulnerable and remove necessary face to face contact.

#### **4. We need a properly funded social care system**

For historical reasons we have two completely different systems of care. One provided through the NHS which is comprehensive, free at the point of use, and has ring-fenced funding; the other which is provided through local authorities, is means-tested, far from comprehensive, is currently subject to cuts and restrictions, and the quality and availability of which are widely variable from place to place.

Many people, particularly disabled people and very old people, need both health and social care services working seamlessly together. The current funding and organisational situation almost guarantees the opposite. The struggle to navigate the complexities of this dual system and to obtain a half decent package of care for an elderly relative is becoming the defining narrative of our time for a generation of hard-pressed family carers. And that is before we even consider the problems for disabled people and those with learning disabilities. We have got to the point where the quality and availability of care services are barely acceptable in what is supposed to be a civilised society.

The Coalition Government has made commendable progress in taking forward much needed legal and policy reform in social care, getting to the

point of a Care and Support Bill which affirms important rights. However, there has also been a marked reluctance to grasp the nettle of funding reform. Despite a set of solutions having been provided by the Dilnot Commission – not perfect but the right place to start – the Government’s current formula is that the Dilnot recommendations will be considered in the context of the next spending review, the date of which has not even been set. This is just an elegant way of kicking the issue into the long grass yet again.

It is not good enough. There is nothing to prevent the Government, ideally with cross party consensus, proceeding now with developing a set of detailed, costed proposals based on the Dilnot recommendations and with the support of the range of expert organisations, including National Voices, that come together in the Care and Support Alliance. Get on with it!

## **5. We need radical re-organisation of hospital services**

Urgent work is needed to ensure that the safety and quality of hospitals does not vary according to how old the patient is or when they are admitted. The current variability is unethical and scandalous. Trust boards should be held accountable for how well they reduce current gaps. Action is needed to implement the recommendations of the Royal College of Physicians’ “Hospitals on the Edge” report, in particular to improve continuity of care within hospitals.

Hospital services need radical reorganisation. Safety and quality demand a greater concentration of some services. The NHS has a poor record when it comes to making a good case for change, involving local communities and winning support. Some important changes have been ducked for decades. National Voices has agreed to work with key system leaders on a methodology for doing this well, ensuring that local communities have a voice and that concerns - for example transport – are properly addressed.

## **6. We need better not more regulation**

Regulation plays an important but limited role in ensuring quality and safety. There are many regulatory bodies and they need to concentrate their efforts on working smarter and better together. Extending the scope of regulation, for example by bringing managers and health care assistants into their purview, would in our judgement be wrong-headed. It would create bureaucracy and add little if any value. Senior managers need sharp accountability and a culture of consequences if things go wrong. Healthcare assistants need good training, development, management and appraisal, and to be fully included as part of the ward or community team.

## **ANNEX A: TEN TESTS OF SUCCESS FOR THE GOVERNMENT'S INFORMATION STRATEGY**

It is easy to book an appointment

You have not lost my notes. And you won't charge me for access to my notes and records

I know who is in overall charge of my care – or my relative's care – and can speak to them

You recognise that good information at key stages is part of my therapy and commission it accordingly

I get information about all the impacts of my condition and how to mitigate them – including social, emotional and family effects and financial implications

Information is tailored to me, and my circumstances, to help me manage my condition

I am offered support to use information – it is not just dumped on me

I will not have the wrong treatment for me because you explained the options and their risks and benefits

I can easily communicate with health and care services, regardless of whether or not I have a disability; where I live or whether I have access to modern technology

I know how to feed back, challenge or complain if I am not happy. And I will do this in the confidence that something will be done