



National Voices

People shaping health and social care

AFTER FRANCIS: DOING JUSTICE

**A National Voices paper on
Ensuring safe and high quality patient care**

13 March 2013

SUMMARY AND RECOMMENDATIONS

The Francis inquiry into failings at Mid-Staffordshire NHS Foundation Trust demands a full response which does justice to those who suffered and died avoidably at Stafford hospital and which leaves a fitting legacy.

This is everybody's business: each health professional and organisation must consider its response.

It is also the business of the Government and the NHS leadership. The Government needs a plan for implementing Francis over time, which should be co-produced with the NHS, professional bodies, patient leaders and health charities.

Early action is needed to ensure that the lessons from Francis are manifestly embedded in the reorganised English NHS coming into effect on 1 April 2013. National Voices wants to see urgent progress on the following:

Honesty

- The Government should implement a statutory duty of candour for organisations to require them to tell patients when they have caused harm.

Openness

- There must be no "gagging" clauses.
- New whistle-blowing protection rights should be created for patients and their families.

Transparency

- Measures of clinical performance and measures of experience that matter to patients should be publicly available. These should cover individual clinical teams and they should cover all health specialisms and services.
- The NHS should make sure comparative information is accessible and meaningful. It should commission some of this from organisations, such as charities, who can ensure that it is understood by particular groups of patients and service users.
- Health and care organisations must gather and act upon comprehensive real time patient feedback – going well beyond the Friends and Family Test. All complaints data should be published.

- There should be a consistent, transparent and credible methodology for identifying and investigating serious shortcomings in safety and quality.

Patients and families

- The NHS Commissioning Board needs to fulfil its obligation to ensure the NHS becomes “dramatically better” at involving patients and their carers in decisions about their care.
- Patients should have a new legal right to participate in producing a care plan.
- Family carers should have a legal right to participate in decisions about their family members’ care plans (in NHS as in social care), subject to patient consent.
- The most vulnerable patients should have a new legal right to an independent advocate.

A public voice for patients and citizens

- Funding for local Healthwatch organisations should be ring-fenced.
- The new regulations for Healthwatch, which appear to constrain their freedom to comment on policy, should be replaced.
- There should be patients at every table where decisions are made.

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, connects with millions of people, and covers a diverse range of health conditions and communities. This paper has been produced in collaboration with our members.

RESPONDING TO FRANCIS

The Francis inquiry into failings at Mid-Staffordshire NHS Foundation Trust demands a fitting legacy. The public inquiry, the report of which was published on 6 February 2013, and the previous inquiry, also chaired by Robert Francis QC, exposed catastrophic failings of care that should not have occurred and which should not have been allowed to persist. Though Stafford was an

extreme case, the failings were not unique and they have implications for the whole of the NHS. The response to Francis must do justice to the many people who died or suffered unnecessarily; must address the failings painstakingly laid bare by the inquiry; and must leave the NHS in a better state.

We sense a danger that this will not happen. The initial Government response was to set up a clutch of further reviews. A mini-industry of meetings and conferences on the subject of Francis is already underway. Will it be all talk and no action? The size and scale of the inquiry report and its numerous recommendations provide the Government and the NHS with a ready-made excuse for side-stepping its demands should they want to, for example by repackaging existing policy and plans as a “response to Francis”. That would be a mistake.

The tragedy of Stafford hospital was that disastrously poor care was allowed to persist despite clear evidence over several years of serious problems at the trust. This was possible in part because, as Francis observes, “aspects of a negative culture have emerged at all levels of the NHS system”. In particular Francis has shown that the NHS lacks a sufficiently strong culture of openness, transparency, honesty and strong patient and public voice.

This is everybody’s business. Doing justice to Francis requires a local response as well as a national response.

At the local level every health professional, every organisation and every professional and leadership body needs to reflect on how they can improve the safety and quality of the care for which they are responsible, in the light of the Francis recommendations. Trust boards need to be clear whether they are recruiting, training, deploying and supporting staff well enough to ensure the delivery of safe, effective and compassionate care.

Equally, some things can only be led and orchestrated at national level. The Government plan needs to set out how Francis will be implemented over time. This plan should be co-produced with the NHS Commissioning Board, NHS and care organisations, and patient and service user leaders and organisations. The Government is not bound to agree with every one of the recommendations and should implement them in a way that is consistent with broader plans to improve the quality of care. But Government must explain how it will fulfil the aims set out by the inquiry – namely to ensure a changed culture in the NHS which is patient-focussed, compassionate, open, transparent, honest and accountable and which delivers safe and high quality

care. And, where there are departures from the Francis recommendations, these must be justified.

The plan must also be clear about priorities and have a sense of urgency. Some things require early action. In this paper National Voices sets out proposals for early adoption that would strengthen openness, transparency, honesty and the patient and public voice and ensure that key lessons from the Francis inquiry are embedded in the reorganised English NHS from 1 April 2013.

Openness

Robert Francis defines openness as *“enabling concerns to be raised and disclosed freely without fear, and for questions to be answered”*.

In October 2012 some 30 NHS, professional and regulatory bodies, led by NHS Employers, signed a voluntary ["speaking up"](#) charter. The purpose of this charter was to show “leadership from national organisations to promote a culture in the NHS where staff can report concerns with confidence”. The launch of this charter and the large number of signatories were ample demonstration that lack of openness and a culture of suppressing uncomfortable truths are widely recognised within the NHS as being endemic and problematic.

Further evidence is provided by successive annual NHS staff surveys. The results of the [2012 survey](#) of more than 100,000 staff were published on 28 February 2013 and make grim reading. They reveal that significant minorities of staff feel undervalued, bullied, disconnected from senior managers and under-confident that concerns would be acted upon if raised.

Meanwhile, what has happened to the Speaking Up charter? Since its launch, it seems to have quietly gone away. Why?

- National Voices recommends that the leadership of the NHS relaunches the Speaking Up charter - or finds a better, alternative vehicle.

National Voices agrees with Robert Francis that there should be no “gagging clauses” used to suppress concerns about patient safety and quality of care. Compromise agreements are a well-recognised practice in which employer and employee part company on mutually agreed terms so as to avoid redundancy, dismissal, litigation, or reputational harm (since both parties

agree to refrain from adverse comment about the circumstances of the employee's departure).

Widespread concern has been expressed that the use of compromise agreements has become too common in the NHS and that "paying people off" has become a routine alternative to addressing the issues and problems that they have raised. As well as the avoidable cost to taxpayer there is concern that the associated confidentiality clauses are used to "gag" the airing of legitimate concerns, especially about the safety and quality of care in particular institutions.

- The NHS needs clear guidance about the appropriate use of compromise agreements which reinforces the principle that **gagging clauses are not acceptable**. Individual cases that raise concerns should be investigated. With suitable safeguards for personal confidentiality, the public has a right to know where and when such agreements are being made, and what they are costing. This information should be in the public domain.

It is also important that patients and families feel able to raise concerns without adverse consequences. Many people are unhappy with aspects of the care that they or their family members experience, but fear to speak out in case they become victimised. The fact that this is a real problem is explicitly acknowledged in the NHS Constitution. The Constitution sets out people's right to make complaints and have them properly investigated. It goes on to say that the NHS "also commits to ensure you are treated with courtesy and you receive appropriate support throughout the handling of a complaint; and the fact that you have complained will not adversely affect your future treatment (pledge)".

- In the light of Francis, National Voices thinks this is no longer good enough. The status of a "pledge" is unclear. **Patients and their families - often very vulnerable people - deserve "whistleblower" rights** akin to those that apply in the workplace. We recommend that in the context of the current revamping of the NHS Constitution, the Government looks for opportunities, perhaps in the current Care and Support Bill, to turn this "pledge" into a legal right.

Boards of organisations must be held to account for their success in promoting an open culture which welcomes comment from staff, patients, relatives, carers, visitors and advocates. As part of this accountability it is important that data about each organisation from the annual staff survey, patient surveys and complaints are in the public domain.

Candour

To err is human, but to cover up is unforgivable. Robert Francis defines candour as *“ensuring that patients harmed by a healthcare service are informed of the fact and that an appropriate remedy is offered, whether or not a complaint has been made or a question asked about it”*.

We are delighted that Francis has recommended that organisations should be under a statutory duty of candour. When things go seriously wrong patients and their families and carers should always be told – but this does not always happen. The absence of such a legal duty is a key contributor to a culture of cover-up and denial and an impediment to truth, redress, justice and organisational learning in the event of healthcare failings. A legal duty of candour has been a long standing demand of National Voices and other charities, notably Action against Medical Accidents (AvMA), whose case for the duty is set out eloquently [here](#).

- **The Government must now take early action to make candour legally binding on health and care organisations.** This can be done readily by laying revised regulations governing the Care Quality Commission.

National Voices recognises the argument that applying the force of the law to cultivate culture change carries the risk of unintended consequences – in particular the risk of further entrenching a culture of fear and denial. We believe that the benefits of a statutory duty of candour for organisations outweigh the risks. Sometimes a change of law is a defining moment: both capturing and accelerating a mood of change and strong moral purpose. We believe that the NHS has reached this defining moment in relation to the need for candour.

Some of the related Francis recommendations need further consideration: whether or not individuals should also be under a duty of candour; and the extent to which criminal sanctions should apply in the case of a breach of the duty. The response on these matters should form part of the Government’s detailed plan for implementing Francis. The fact that these recommendations need further work should not be used as a reason to delay action to establish a duty for organisations.

National Voices also agrees with those who say that a legal duty of candour is not sufficient on its own to create a culture of honesty and reconciliation. Other action is important too, for example organisations ensuring that staff feel safe and supported to apologise; and moves to develop non-adversarial

forms of redress for patients, such as the no-fault compensation scheme in Scotland.

Transparency

Robert Francis defines transparency as *“allowing true information about performance and outcomes to be shared with staff, patients and the public.”*

Transparency is the 21st century way of building trust between citizens and institutions. The more that everyone knows what organisations are doing, and how well they are doing it, the more incentive there is for those organisations to up their game, the more people are in a position to exert informed choice and the less room there is for poor practice to hide.

21st century transparency is also a two way process, that goes beyond disclosure by those in power. It includes the growing use of social media for patients and service users to give feedback, build communities of interest, and generate and share their data.

While transparency is welcomed in principle it is often resisted in practice by professional and managerial groups who fear scrutiny in general or, more commonly, fear adverse inferences being drawn from incorrect interpretations of data which might be incomplete, inaccurate or in other ways potentially misleading. These fears are understandable but need to be tackled head on and overcome rather than allowed to become an obstacle.

There is still too little readily available information which allows meaningful comparisons to be made on aspects of performance and outcomes that really matter to patients and the public and to those commissioning, delivering and regulating services. A key part of the Francis legacy must be to accelerate the drive towards transparency.

What is the goal? That everyone is able to see how well each part of the health and social care system is performing against desired outcomes, reflecting safety, effectiveness and patient experience as fundamental dimensions of care. That requires effort on four fronts:

- putting more existing information in the public domain;
- collecting new information where it is relevant and in particular on measures of experience, recognising that it is a fundamental (but still too neglected) dimension of quality of care
- investing to present the information in useable and meaningful ways; and

- ensuring that information is acted upon.

More specifically, National Voices calls for demonstrable progress on the following:

- **Meeting the goal of comparative information on outcomes being available in all aspects of healthcare**, at the level of the individual clinical team and at least annually.
- **More public information is needed on the experience and outcomes of care from the point of view of the patient.** Patient Reported Outcome Measures (PROMs) exist for a small group of procedures. They need to be rolled out more widely and reported on at the level of the individual clinical team. We also need to move to measures which are not only *reported* on but also *defined* by patients – ensuring that what is measured really matters to patients.
- **The existing system-wide surveys of patients, for example the national in-patient survey, must be continued as they provide important, comparative trend data. There is a case for extending these surveys.** For example the national cancer patient experience survey is proving its value in helping to drive quality improvement. There is a case for similar national condition-wide surveys where they are part of national strategies for improvement – for instance, in the areas of care that will have clinical networks supported by the NHS Commissioning Board. One example is the mental health inpatient survey which was abolished in 2009 and which should be reinstated.
- **Every NHS organisation should be gathering real time and near real time patient experience data** systematically, comprehensively and frequently, with the results reported to all levels of management and published. 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.
- **The Friends and Family test**, which is being introduced in the NHS, can be seen as providing a symbolic focus on the importance of ascertaining patient experience. It could be the “hook” on which more detailed experience measurement is hung. However, the question “would you recommend this service to a friend or family member” of itself says only so much. **National Voices is worried about over-reliance on this test, which is a crude and easily “gamed” measure of “satisfaction” rather than of experience.**

- Complaints data should be published at the level of individual organisation and service.
- The Government has insisted that the NHS be held to account for performance against a comprehensive framework of outcomes and that there should be greater transparency about such outcomes. There has been much debate about the relative roles of the state and the market in creating such conditions. National Voices believes that the state has a responsibility to ensure that citizens, as taxpayers, are able to hold public services to account for their performance and, as users of services, can make informed choices. **There must therefore be sufficient public investment in the presentation of data in meaningful and useable forms.** This should include the commissioning of specialist charities to present the data in forms which meet the needs of particular groups of people.
- Boards of organisations must treat it as a priority to collect and analyse performance 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 and complaints which should be embraced as tools to improve care and, in some cases, to give warning lights.
- **There needs to be a consistent and transparent methodology whereby commissioners and regulators identify and investigate those organisations and services which are causing concern based on their comparative performance on various measures.** In the wake of the publication of the Francis Report the Prime Minister announced a review under Sir Bruce Keogh of the handful of hospitals with the worst mortality rates to determine whether action was necessary. It is a serious indictment of the NHS that an ad-hoc review of this kind should be thought necessary. It would not be necessary if there was already a trusted system in place to deal on a continuing basis with relatively poor performance. A key output of the new Keogh review must be to bequeath such a methodology to the NHS.

Patients and their families

Robert Francis writes: *“It is a significant part of the Stafford story that patients and relatives felt excluded from effective participation in the patients’ care”*.

Indeed patients of Stafford hospital and their families were failed in every way possible. As citizens, their human rights were denied. As potential partners, their participation was blocked. As co-owners of the NHS, their insights and contributions were not listened to. As customers of the service, their experiences were not deemed important.

We know these failings are not unique to Stafford. We see the Francis report as an opportunity for the health and social care systems to embrace the full role of patients as citizens, partners, co-owners, customers and also as leaders.

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 safety and care quality, and more effective and appropriate use of resources.

National Voices campaigned successfully for a specific duty of patient involvement in the Health and Social Care Act 2012 and has pressed for robust implementation.

- The Department of Health’s Mandate to the NHS Commissioning Board requires the Board to ensure that the NHS becomes “dramatically better at involving patients and their carers” and **we now need to see 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, and support for active self management need to become mainstream, and much of this could happen quickly by spreading existing good practice. There is also a longer term need to change the recruitment, education and training for professionals and to improve health literacy among the general population.

As the Care and Support Bill goes through Parliament there is an opportunity to strengthen some rights and remove unnecessary anomalies between health and social care.

The Bill will create a right for people assessed as being in need of social care to have a care plan. No such right exists for patients in the NHS. Care

planning is a fundamental building block of successful personalised care yet is still the exception rather than the rule for people with chronic conditions.

- National Voices recommends that a **legal right to participate in producing a care plan** is established in the NHS.
- The Care and Support Bill will create a **right for family carers to be involved in decisions** about the social care of their family members and to have their own needs assessed. National Voices recommends that, subject to the consent of the patient, equivalent rights are established in relation to NHS services.
- The Care and Support Bill has been criticised for omitting a right to independent advocacy for people who are not otherwise able to participate in decisions about their care. We believe that this omission should be corrected and that an **equivalent right to an independent advocate** be established in relation to NHS services.

Healthwatch

Robert Francis writes: *“It is now quite clear that what replaced [Community Health Councils], two attempts at reorganisation in 10 years, failed to produce an improved voice for patients and the public, but achieved the opposite”.*

The Healthwatch organisations coming into effect on 1 April 2013 are intended by the Government to be a strong champion for local patients and service users. They are the latest attempt to provide a public voice for patients at local level, following a wave of reorganisations that Francis rightly brands a failure. National Voices’ own [submission](#) to the Francis team in December 2011 expressed concern at the likely gap between the policy intention and the reality.

The Francis Inquiry was right to point out the weakness of the collective patient and public voice in Stafford and to call for measures to strengthen the new local Healthwatch organisations. We welcome these recommendations and call upon the Government to implement them with urgency. In particular:

- **Funding for local Healthwatches should be ring-fenced** according to the allocations made by the Department of Health to local authorities, and not left to the discretion of individual local authorities

The lack of ring-fencing has led to absurd anomalies. For example National Voices has been told that in Leeds Healthwatch will have a budget of £400,000 but in Manchester only £80,000.

The Francis inquiry reported too late to be able to comment on new regulations for the operation of Healthwatch. Widespread concern has been

expressed that these regulations will “gag” local Healthwatches by unreasonably restricting their power to comment on the policies adopted by local authorities and local NHS bodies and National Voices has discussed these concerns with the Department of Health.

On the face of it, there is a clear contradiction between the drafting of the regulations and the intentions announced by Ministers. In the light of the Francis report it would seem unacceptable for the Government to tolerate such a contradiction even if it has arisen accidentally. The Government has now issued clarification of the regulations but regulations requiring such clarification are not fit for purpose.

- National Voices recommends that the new Healthwatch regulations are withdrawn and revised ones substituted which are clear about the powers of Healthwatch to campaign and comment on policy.

The revised regulations should be based on the same law and principles set out in the Charity Commission’s [guidance](#) to trustees on campaigning and political activity (CC9).

These exclude a charity from solely pursuing political activities, from being used as a mouthpiece for the political views of members or staff, and from funding or supporting political parties. They require organisations to be independent and balanced.

However they do permit an organisation to engage in political campaigns or activities ‘only in the context of supporting the delivery of its charitable purposes’, and this may include campaigning to change a law or policy or decision, where that is demonstrably in pursuit of those purposes.

Patients at every table

The collective expression of patient and service user voice cannot be exerted by Healthwatch alone. Robert Francis has important things to say about the role of Foundation Trust governors and public involvement in the work of commissioning. There is a quiet army of volunteers and representatives seeking to improve health and social care in a variety of roles. As well as the members of the new Healthwatches, there are FT governors, lay members of the new clinical commissioning groups, members of patient participation groups; members of clinical reference groups, community leaders, health champions, peer supporters, and campaigners and activists focussed on particular needs and causes.

The importance of their contribution is becoming better recognised but it is not universally embraced in the health and social care systems. There is still a tendency to view individuals with some wariness and to regard communities as in need of “consultation” rather than full involvement in a process of co-production.

Cure the NHS and its leader, Julie Bailey, demonstrated that a group of families could come together out of shared anger at how the NHS had let them down and channel that anger to seek justice and change. Anger is an important spur for citizens to become involved in shaping services. The NHS does not like dealing with anger. It needs to get better at embracing and working with the angry. At the same time, angry campaigners need help, support and access to training and development to be able to channel that anger constructively.

National Voices espouses the notion of **patient leadership**. We are supporting it directly through our own training programmes, and we want to see it take hold throughout the NHS. There is no contradiction between being a “real patient” and a “professional patient”. We need a bigger and more diverse range of people who can support patients and service users, speak out on their behalf, help to design services and hold the NHS to account. They need help, support and development to be able to perform these roles with confidence, competence and legitimacy. They should be at every table where decisions are being contemplated and taken, including the recruitment and training of staff. Local commissioners and provider organisations should invest in their recruitment, training and support, and budget for this. Patient leaders will help them do their jobs better and make their money go further. The investment they make in patient and lay leaders will repay itself and more.

Wider reforms

Implementing Francis must not divert the Government and NHS from a wider set of reforms which were outside the scope of the Mid Staffordshire public inquiry, but which are also vital if we are to avoid another Stafford-style scandal. An agenda for reform was set out in National Voices’ earlier document [Not the Francis Report](#) which describes the increasing pressures bearing on the NHS and the need for a rebalancing of the pattern of care away from an over-reliance on hospitals for the oldest and frailest patients. If we are to have a safe, effective and high quality service in the future, there must be a drive towards:

- **an integrated health service based around out of hospital 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 people with long term conditions and disabilities to live well and avoid unnecessary hospital admissions; support and education for self-management and joining up health and social care services. Good 24/7 crisis support is essential to replace the current patchy and often inadequate “out of hours” services.
- **a proper settlement for the reform and funding of social care** and for the financial support of sick and disabled people through the benefits system. The Government has made a first step towards setting out some of the financial parameters for social care funding in the long term. But in the here and now, resources for social care are falling, as are benefits. The consequences are that the needs of vulnerable people are increasingly not being met and too many older people are enduring avoidable hospital admissions.
- **24/7 hospitals** which ensure that the safety and quality of inpatient care does not vary according to how old the patient is (a real issue both for the very old and the very young) or what time of day, week or year they are admitted. That means closer attention to ensuring sufficient staffing levels, skill mixes and team working.
- **A radical reorganisation of hospital services.** 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.