

MACMILLAN'S
VISION FOR
BUILDING AND
STRENGTHENING
A COMMON
CULTURE OF
CARE

WE ARE
MACMILLAN.
CANCER SUPPORT

Francis Inquiry report: One year on



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‘The extent of the failure of the system shown in this report suggests that a fundamental culture change is needed.¹ There needs to be a relentless focus on the patient’s interests and the obligation to keep patients safe and protected from substandard care. This means that the patient must be first in everything that is done: there must be no tolerance of substandard care; frontline staff must be empowered with responsibility and freedom to act in this way under strong and stable leadership in stable organisations.’²

Robert Francis QC

1. INTRODUCTION

One year ago, the Francis Inquiry report into the failings at the Mid Staffordshire NHS Foundation Trust was published. This report exposed a sub-culture within parts of the NHS that repeatedly and severely compromised patient safety, experience and quality of care. At the most extreme, it led to patients dying needlessly due to dehydration and exposure to severe neglect.

Since the publication of the Francis Inquiry report, the Department of Health has published its full response. It sets out detailed plans to address the majority of the recommendations, including those on culture, compassionate care, leadership, information, openness, transparency and candour. The government's response shows a commitment to ensuring that patient experience and safety remain at the heart of the NHS.

Other bodies such as the Royal College of Physicians, the British Medical Association, the NHS Confederation and others have also issued their analysis, alongside leading think tanks including the King's Fund and the Nuffield Trust. These responses are a welcome first step. However, there is still a long way to go to translate the recommendations into reality.

A fundamental change to the culture of care is the backbone of the recommendations of the Francis Inquiry report. While the NHS has a significant role in delivering the change that is needed, it will not be able to do this alone. There is a duty for every part of the health service to take action and work together to ensure no patient has to experience the appalling care revealed at Mid-Staffordshire again.

At Macmillan Cancer Support, we're already working with partners to support the health system in a number of ways. Our goal is to build and strengthen a common culture of care to help deliver Robert Francis's vision. The purpose of this report is to set out:

- the key elements that make up a common culture of care
- an outline of the issues and progress made since the publication of the Francis Inquiry report
- Macmillan's work to support improvements in the culture of care
- our recommendations on where further changes are required.

2. BUILDING THE RIGHT CULTURE OF CARE

The public inquiry report into the failings of care at Mid Staffordshire NHS Foundation Trust told a story of appalling suffering for many patients. There was a lack of action at the root of these failings. This was described as a lack of action to tackle an 'insidious negative culture involving a tolerance of poor standards and a disengagement from managerial and leadership responsibilities.'³ This lack of an individual and collective culture of care had a trickle-down effect on frontline staff. Some of these staff were also afraid to speak up about instances of poor care due to fears of facing bullying and harassment.

To address the primary cause of these problems, the Francis Inquiry report made some recommendations. These were to develop a common culture where patients are the priority in all the NHS does, and staff are caring, compassionate and committed.⁴ In response, the government indicated that a profound change in culture was needed at all levels of the NHS.⁵

To ensure this common culture of care is effectively embedded in the NHS, we believe the following three elements are essential:

- prioritising patient experience across the NHS
- supporting staff to deliver high-quality care⁶
- empowering patients to lead change and improve leadership at trust level and in the community.



A letter from the Cancer Voices Network to Jeremy Hunt highlighted the importance of patient experience and the need to improve communication, meaningful involvement and coordination:

'The need to address these issues, identified through our lived experience, is urgent. It is brought even more sharply into focus by the Francis report's emphasis on the importance of taking responsibility for improvements in patient experience, training for staff providing healthcare, and valuing and then acting on the patient and carer feedback. This could have acted as a fire alarm warning of the problems at Mid Staffordshire Hospital.'

3. PRIORITISING PATIENT EXPERIENCE ACROSS THE NHS

3.1 Underlying challenges and progress since Francis

The failure of the Mid Staffordshire NHS Foundation Trust to put patients and their priorities at the centre of their work was a key finding from Robert Francis's report. In particular, the report found that the trust prioritised its finances and Foundation Trust application over providing a high quality of care that put patients first.

Besides the trust, other health bodies placed too much emphasis on 'doing the system's business'.⁷ They also focused on priorities far removed from what matters most to patients and their experiences of care. For example, commissioners were found to focus 'as elsewhere in the NHS system, on financial control and a handful of access targets'⁸. Robert Francis reports that commissioners did not have the tools available to effectively monitor and improve the quality of services they planned and commissioned, or to seek solutions for patients.

While we must be cautious about drawing general conclusions from this failure in one hospital, those who gave evidence suggested the commissioners in the West Midlands were not unique. Building on the findings from Mid Staffordshire, our work shows patient experience is still not being prioritised throughout the healthcare system.

As a result of these challenges, the Francis Inquiry report made certain recommendations. The NHS and everyone who works for it must 'adopt and demonstrate a shared culture in which the patient is the priority in everything done'.⁹ Translating this into practice requires an investment in a learning culture within an organisation that enables staff to put patients first consistently and across the board.

Since the publication of the Francis Inquiry report, some initial steps have been taken by the government, the NHS and other bodies to make progress in prioritising patient experience. Striving to get the basics of quality care right, including safety, effectiveness and patient experience¹⁰ is a common priority.

As a result, NHS England has set out a number of areas of action to ensure that patient experience becomes everybody's business.¹¹ In addition, the Care Quality Commission has introduced a new system of rating hospitals – a key focus is patient care and safety. A central part is patients' involvement in hospital inspection teams, as experts by experience.

Despite these improvements, much more needs to be done to ensure that the commitments translate into meaningful improvements for patients who use the health service.

3.2 Macmillan's work to prioritise patient experience

a. Report on 'Improving care for people with cancer'

Our report *Improving care for people with cancer. Putting cancer patient experience at the heart of the new NHS* (August 2013) clearly outlines why patient experience is so important. It also highlights that it is still not prioritised across the NHS and this is seen in specific areas:

→ **Nationally**

Patient experience is one of the five domains within the accountability framework for the health service. However, it is not adequately reflected in the mechanisms the government uses to set health priorities and hold the NHS to account, for example, the NHS Mandate and NHS Outcomes Framework.

→ **Within providers**

Several hospitals across the country are proactively driving improvements in patient experience. Yet the extent to which patient experience is a priority for different hospitals varies considerably. For example, a study showed that when boards raised patient experience as an agenda item, only 5% of these items had further action attached to them.¹²

→ **Commissioners**

Commissioners of services, including cancer services, can help to make sure providers prioritise patient experience. For instance, we're aware that the South Yorkshire Clinical Commissioning Group's Cancer Board and the Bristol Cancer Programme Board have discussed the results of the Cancer Patient Experience Survey. What's more, they have started to use it in their work. However, it is uncertain whether this is a consistent practice across the country.

Improving care for people with cancer includes a number of recommendations aimed at ensuring patient experience is prioritised throughout the NHS.

b. Patient experience project with NHS England

We are also taking forward a joint project with NHS England. This looks particularly at how patient experience can be prioritised in relation to other elements of high quality care: clinical effectiveness and safety. With NHS England, we're

supporting the organisations represented on the National Quality Board (comprised of national statutory organisations and professional bodies for health and social care) in developing a strategic, system-wide approach to improving patient experience.

c. Commissioner tools to support patient experience

We know that commissioners are well placed to proactively drive improvements in patient experience, but they need support to do so. To provide this support, we've developed practical tools and resources:

- ➔ The *Improving Cancer Patient Experience Care Map*¹³ pinpoints the essential services patients know would improve their experiences of care. The pathway has been designed by patients to show 'what good looks like' in the way services are commissioned. This supports commissioners to see what an exemplary patient pathway would look like from a patient's perspective, and is a model for future commissioning.
- ➔ Our *Atlas of variation in cancer patient experience*¹⁴ outlines the current challenges commissioners face in achieving positive patient experience across the country. It uncovers variations in patient experience at commissioner level. It explores the relationship between cancer patient experience, deprivation and the impact of public spending on cancer services upon patient experience. Usefully, it provides solutions to this by supporting commissioners to identify priority areas for improvement where they can have the biggest impact in improving cancer patient experience.

3.3 Further work that is needed to prioritise patient experience

We need to see other work alongside ours driving improvements in patient experience. National decision-makers in the government and NHS need to take immediate steps to ensure patient experience is a priority, with levers and incentives reflecting this. We therefore recommend that:

- the Department of Health makes improving relational care, such as treating patients with dignity and respect, a priority area within the NHS Mandate
- NHS England develops measures to hold Clinical Commissioning Groups to account on cancer patient experience through local accountability frameworks
- the Care Quality Commission develops meaningful measures it can use to assess providers' performance on patient experience. In particular, the Care Quality Commission should use findings from the Cancer Patient Experience Survey to inform any ratings developed for cancer services.



An extract from a letter from the Cancer Voices Network to Jeremy Hunt:

'The Francis Report showed that things can go wrong at all levels of NHS organisations. The right tone at leadership level is key to promoting positive cultural change and ensuring junior professionals do not become disillusioned by a culture which only rewards cure, not care.'

4. SUPPORTING STAFF TO DELIVER THE BEST OF CARE AND STRENGTHEN THE CULTURE

4.1 Underlying challenges with supporting staff and early progress

The Francis Inquiry report also highlighted a serious lack of staff support. It indicated a lack of engagement of clinicians at all levels and leadership at the trust.¹⁵ Staff views were also disregarded. The report states: ‘Those who didn’t have a management role would complain regularly but were told to “get back in their box”.’¹⁶

To address this challenge, the Francis Inquiry report emphasised the need for supported development for the whole leadership team at the trust¹⁷, as well as frontline staff. Regarding nursing, the report also recommended recognising achievement, giving regular, comprehensive feedback on performance and concerns, and encouraging staff to report concerns and give priority to patient wellbeing.¹⁸

Since the report’s publication, the government has clearly stated that well-treated staff treat patients well and that staff wellbeing is the foundation on which compassionate care must be built. This is based on evidence suggesting that ‘effective staff engagement is absolutely essential for creating positive cultures of safe, compassionate care’.¹⁹ Furthermore, a new nurse and midwifery leadership programme was created with an action area dedicated to building and strengthening leadership.²⁰

This clear link between patient and staff experience can be seen in cancer care. For instance, this is evident in our analysis of the relationship between the Cancer Patient Experience Survey and the NHS Staff Survey results. These show that at a trust level there were a number of relationships between poor staff and poor patient experience in these areas:²¹

- the organisational culture, specifically experiences of discrimination, harassment or violence from colleagues
- the management and running of the trusts, specifically provision of equal opportunities, availability of hand washing materials and training in health and safety
- how engaged staff are, specifically whether or not they intend to leave.

It is encouraging that the government and NHS England acknowledge the important link between patient and staff experience, and the need to support staff to deliver a culture of care. We also welcome plans to introduce a Friends and Family Test (asking whether they would recommend the organisation that they work for, as an employer and as a place to be treated) for staff. However, much more needs to be done to effectively support staff to help them deliver a culture of care.

'I've always loved coming into work. I love my job. I love that every day that I come into work, even though I'm doing the same job of administering chemotherapy, it's different patients we're treating every day. They're all different – we treat them all as individuals.'

Mark, a senior nurse from Hertfordshire

4.2 Macmillan's work to develop the right culture of care and support for staff

There is a need for practical solutions to bring the common culture of care which Robert Francis advocated to life. To contribute to this, at Macmillan we've developed a number of practical solutions.

a. Macmillan Values Based Standard®

We co-designed the Macmillan Values Based Standard® with more than 300 patients, staff, carers and family members to provide a practical and innovative solution to improving patient and staff experience. This is based on eight moments that patients and staff said matter most to them. Patients wanted staff to get these right and staff wanted to be empowered to deliver them.

This approach empowers patients and staff equally. Staff are supported to improve the way they deliver care in these aspects of patient experience. They are enabled to practise eight behaviours that embody dignity and respect on a daily basis. Meanwhile, patients and staff are enabled to co-design these improvements:

- naming patients – 'I am the expert on me'
- private communication – 'My business is my business'
- communicating with more sensitivity – 'I'm more than my condition'
- clinical treatment and decision-making – 'I'd like to understand what will happen to me'
- acknowledge me if I'm in urgent need of support – 'I'd like not to be ignored'

- control over my personal space and environment – ‘I’d like to feel comfortable’
- managing on my own – ‘I don’t want to feel alone in this’
- getting care right – ‘my concerns can be acted upon.’

The Macmillan Values Based Standard® is currently being implemented by providers in a number of areas across the UK, including London, Birmingham and Scotland. Early findings have demonstrated that implementing the Macmillan Values Based Standard has led to improvements in patient experience.

At Macmillan, we’re pleased that Jane Ellison MP, Parliamentary Under Secretary of State for Health, recently stated: ‘NHS England is encouraging the use of the Macmillan Values Based Standard®, and other patient-led tools, which engage patients and staff in co-creating and measuring some of the things that matter so much with regard to dignity and respect.’²²

b. Supporting the Schwartz Center Rounds®

Staff having the time and space to reflect on the care they provide enables them to deliver better care. Schwartz Center Rounds are regular sessions provided by the Point of Care Foundation. These Rounds bring trust staff from all disciplines together to discuss challenging instances of delivering care and what they might have done differently. They also promote what has worked well to spread best practice across the organisation.

Some of the hospitals implementing the Macmillan Values Based Standard will also implement Schwartz Center Rounds to provide staff with opportunities for reflective practice.

Case study: Imperial College London Healthcare Trust

Working in partnership with us, Imperial's implementation of the Macmillan Values Based Standard has led to improvements in patient and staff experience.

We worked collaboratively with Imperial to achieve this by:

- introducing patient and staff surveys based on the eight behaviours in the Macmillan Values Based Standard®. These measure the impact of implementing this approach on improving patient and staff experience, to identify links between the two and support the Trust to address any issues.
- triangulating their ongoing survey data with sources of rich qualitative insight gathered through one-to-one patient interviews, staff workshops and co-design sessions where patients and staff came together
- feeding back this data in a meaningful way – staff were invited to a 'way forward' event to discuss the data and decide which action areas to prioritise. Some of these actions were quick and easy to implement, for example reminding the team how important it is to answer the call bell quickly at every handover. However, some areas of intervention require longer-term, multidisciplinary solutions, such as redesigning the ward rounds.

4.3 Further work is needed to build and strengthen a culture of care which supports staff

The government's commitments to implementing Robert Francis's recommendations to develop a common culture of care are a welcome first step. However, much more needs to be done to ensure that this culture of care becomes reality. We recommend:

- NHS England actively promotes practical solutions to improve the experiences of cancer patients, and the staff who interact with them, such as the Macmillan Values Based Standard and Schwartz Center Rounds
- the Department of Health includes an indicator on staff experience in the NHS Outcomes Framework
- Health Education England prioritises communication skills as part of every health professional's training, as well as encouraging ongoing skills development and reflective practice.

5. EMPOWERING PATIENTS AND THE PUBLIC TO LEAD LOCAL CHANGE

5.1 Underlying challenges with empowering patients and early progress

'They just appeared to be building up the backlog of complaints on the computer system and not providing us with any details of the complaints. It felt like we were being strung along.'

A member of a patient forum

Failure to listen to feedback from patients and value them as equal partners in their care was a key reason for the continuation of poor care at Mid Staffordshire. Patients are experts by experience – as they experience the quality of relational care first hand. Yet the Francis Inquiry report made clear that the trust management did not have a culture of listening to patients. They attached little importance to patient surveys that continually provided early warning signs of poor care.

As the organisational culture did not value feedback, the Francis Inquiry report highlighted that some patients were reluctant to complain due to fear of the consequences. Meanwhile, those who did complain were not given any support in the form of information, advocacy or advice services.²³



An extract from a letter from the Cancer Voices Network to Jeremy Hunt:

'We would like to see people affected by cancer have more say in their treatment and in how NHS services are designed. The Francis Report indicated that current patient and public involvement structures may not always be effective, so the change we need is for the public to be empowered not just involved. We believe such empowerment can be a powerful driver of change. So that a culture that sometimes dehumanises patients recognises the need to not just listen but also really hear the views of those receiving care.'

In response to these challenges, the Francis report placed a strong focus on a number of factors. It wanted to make patient-led local scrutiny bodies effective, enable patients and carers to effectively carry out their role, and value and act on patient feedback. Since the publication of the Francis Inquiry, the government has acknowledged the importance of these recommendations. It has particularly recognised that local Healthwatch organisations²⁴ should focus on their role as effective consumer champions for local communities. This is rather than getting bogged down in questions of form or procedure.

The response also acknowledged that 'listening to patients and the public and responding to what they say is at the heart of a compassionate healthcare system. Patients must be involved and given their say at every level of the system.'²⁵ As part of its approach to delivering this, the government introduced the Friends and Family test in 2013. This is important as it provides data that highlights serious breaches in the quality of care provided to patients. Alongside this, it is essential that more detailed patient experience data, such as that collected through the Cancer Patient Experience Survey, is used to support targeted efforts to drive up patient experience.

The NHS has been effective in recording patients' feedback on cancer care in a variety of ways. These include: through the Cancer Patient Experience Survey; a number of Patient Reported Outcome Measure surveys;²⁶ and individual surveys and focus groups on patient experience led by individual trusts. We're pleased that NHS England recognises the importance of the Cancer Patient Experience Survey and is reviewing its survey programme to improve the content. However, much more needs to be done to ensure patient feedback is effectively acted on.

5.2 Macmillan's work to empower patients and the public to lead local change

Macmillan is working to translate the Francis Inquiry recommendations into reality by empowering patients to drive change.

a. Supporting patients and the public to lead local change through local Healthwatch

→ Patient Leadership

We've commissioned a patient leadership programme to support people affected by cancer who hold or aspire to hold a leadership role within their local Healthwatch. In the longer term, this will be adapted to support patient leadership within the health structures in other parts of the country. It will also be used to support patients to hold leadership roles in other local bodies, such as Strategic Clinical Networks and Community Health Councils in Wales, which are not condition specific.

→ Facilitating recruitment

We have facilitated the recruitment of 100 people affected by cancer to local Healthwatches in a range of roles. To support the recruitment drive for new members, we developed an *Involvement to interaction factsheet* to make it easier for patients to join and engage with local Healthwatches.

b. Empowering patients and the public to use data to lead local change

We've carried out activity to ensure patient feedback is collected and that the data is accessible for patients to drive improvements.

→ **Retaining the Cancer Patient Experience Survey**

Following our campaigning activity, NHS England confirmed continuation of the Cancer Patient Experience Survey in 2014/15. As a result, the survey has been commissioned for 2014/15, and a review to improve it in the longer term is currently underway. The survey is a vital tool for holding national and local NHS bodies to account for delivering person-centred care.

→ **Patient guide to using the Cancer Patient Experience Survey as an influencing tool**

We've worked with people affected by cancer to produce practical tools to empower patients, as well as the public to use data to influence change, such as the *Patient guide to using the CPES*.

Case study: University College London Hospital (UCLH)

The multidisciplinary Head and Neck team at UCLH worked in partnership with us to implement the Macmillan Values Based Standard®. The team triangulated their Cancer Patient Experience Survey results with local survey data and observations of clinicians. This created a powerful holistic picture of priority areas of action to improve patient experience. It has helped to engage clinical staff in tackling the issues and co-designing potential solutions.

5.3 Further work needed to empower patients and the public to lead local change

To enable patients and the public to become effective consumer champions, it's important that local Healthwatches, supported by local authorities, ensure that:

- members and potential members are proactively given information on how best to engage with the local structures and processes
- local Healthwatch leaders are offered training to enable them to fulfil their roles effectively
- staff are given support on active listening and how to act on feedback. The organisational culture enables this by providing support and releasing time for staff to engage in these activities.

Furthermore, action across the NHS is also essential to drive improvements. To ensure patients and the public are fully empowered to lead change, we urge that:

- NHS England secures the future of the Cancer Patient Experience Survey beyond 2014/15 and prioritises developing other measures that assess patient experience outside a hospital setting and across the patient journey
- commissioners and providers work together to investigate the underlying cause of low scores in the survey, and take appropriate action to improve response rates and performance where necessary²⁷
- NHS England, providers and commissioners take action to tackle unacceptable variation in patient experience. In particular those seen in the experiences of older people, people from black and ethnic minority communities, and people with rarer cancers.

6. CONCLUSION

The publication of the Francis Inquiry report has been essential in putting patients at the centre of the NHS by promoting a fundamental culture change.

As this report has outlined, we believe a common culture of care, as envisaged by the Francis Inquiry report, can be achieved by taking action in three key areas:

- prioritising patient experience
- supporting staff
- empowering patients.

However, this will not happen unless all those who have a role in patient care work together and take responsibility for delivering the changes needed.

Many organisations and individuals that work in the NHS are doing vital work to improve patient care. Many welcome first steps are being made to address the issues highlighted by the Francis Inquiry too. The government's full response, the new Care Quality Commission hospital inspection regime and NHS England's prioritisation of specific actions and areas of focus for improving patient experience are examples. In addition, this report has set out what we're doing at Macmillan in partnership with organisations at national and local levels.

We recognise that the full extent of the change needed will not happen in one year. However it is essential that all organisations across the NHS and government take decisive steps for delivering improvements as soon as possible. There is

still much more to be done to effectively build and strengthen a common culture that will ensure the failure in care that happened at Mid Staffordshire doesn't happen again.

This report outlines what we at Macmillan believe needs to happen to make a common culture of care a reality. We hope to work with all those involved in patient care to make sure this vision is realised.

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Cancer is the toughest fight most of us will ever face. When people have cancer, they don't just worry about what will happen to their bodies, they worry about what will happen to their lives. At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support people through. From help with money worries and advice about work, to someone who'll listen, we're there. We help people make the choices they need to take back control, so they can start to feel like themselves again.

No one should face cancer alone.
Together, we are all Macmillan Cancer Support.

For cancer support every step of the way
call Macmillan on **0808 808 00 00**
(Monday to Friday, 9am to 8pm)
or visit **macmillan.org.uk**