

IMPROVING CARE FOR PEOPLE WITH CANCER

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CANCER SUPPORT**

Putting cancer patient experience at
the heart of the new NHS

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Foreword

Cancer is the toughest fight most of us will face. Every day, cancer patients face this fight, and every day they are supported by great people providing great treatment, care and support. Staff caring for people with cancer demonstrate time and time again the ‘intelligent kindness’ referred to by Camilla Cavendish in her recent report.¹

It is not always like that of course. As someone interested enough to be reading this report, you will find it unacceptable that some people do not have the experience of care and treatment they should expect. And we of course know that, at its worst, bad patient experience can impact on a person’s health,² be related to poor recovery³ and cost the NHS money.⁴

The cancer community is very lucky to have an effective means of capturing the experiences of people with cancer at a national level: the National Cancer Patient Experience Survey. Not only does this empower patients by giving them a voice, it also drives important improvements in care on the ground. In addition, we are getting better at knowing what makes a good experience, how to deliver it and how to measure it.

At the same time, though, the survey shows us that significant improvements are still needed in central aspects of patient experience, for example, the relationships between staff and patients and the care received at key transition points, such as the end of treatment. Macmillan’s recent poll backed up this finding. It revealed that over a third of patients (38%) did not feel that they could always ask their nurse questions about their condition, and over 10% sometimes even felt humiliated by their doctor.⁵

There is also unacceptable variation in the experience of care that cancer patients have. For example, people with some of the rarer cancers are more likely to have a bad experience than those with more common cancers. To further the debate, Macmillan is publishing its *Atlas of Variation in Cancer Patient Experience* later in the year. This will include recommendations for providers and commissioners for reducing unfair variation in cancer patient experience.

The Francis Inquiry into the failings at Mid Staffordshire NHS Foundation Trust revealed a shocking culture of tolerance to appalling standards of care. This report sets out Macmillan's stance on how, in the wake of the Inquiry, we can make sure that people's experience of care is given the same weight as their clinical outcomes and safety. Ultimately, we want to see improvements in the experiences of people with cancer, building on the great work which is delivered daily.

I now look forward to working with colleagues from across the NHS to continue to drive improvements for everyone living with cancer.



Ciarán Devane
Chief Executive
Macmillan Cancer Support

1 Executive summary

Every person diagnosed with cancer should have a positive care experience and be treated with dignity and respect throughout their cancer journey. Good patient experience is closely connected to improving other outcomes such as recovery from an illness. However, the sad reality is that many people still have a poor experience of care.

This report makes a number of recommendations for improving the experience of people with cancer, including:

- the Department of Health makes the improvement of 'relational care', for example, patients being treated with dignity and respect, a priority area within the NHS Mandate
- NHS England develops an indicator on cancer patient experience for inclusion in the Clinical Commissioning Group Outcomes Indicator Set and is accountable for driving up patient experience
- NHS England repeats the National Cancer Patient Experience Survey annually

- the Care Quality Commission makes sure patient experience, and how patient experience data is collected, become key measures for performance when inspections of hospitals and other providers of care take place
- NHS England actively promotes practical solutions for improving cancer patient and staff experiences, such as the Macmillan Values Based Standard® and the Schwartz Center Rounds®.

Although the recommendations in this report are focused on organisations in England, we hope some of the key messages and findings will be helpful to our colleagues in the rest of the UK.

This report is informed by a series of interviews with experts and workshops attended by people affected by cancer and representatives from across the NHS.

2 What is a 'good' cancer patient experience?

People with cancer tell us that a 'good' patient experience would be one where they feel supported, respected and meaningfully involved in decisions about their care, from diagnosis onwards. It would also be one that recognises that cancer affects their whole life, including the people who are important to them.

In particular, the following factors were deemed important:

- **High quality communication** – patients must feel confident they can approach staff and ask questions. It is vital staff use language that patients can understand easily
- **Meaningful involvement** – patients want staff to support them so they can make informed choices about their treatment and care. They also want providers of care to encourage them to give feedback about their care and know it will be acted on
- **Coordinated care** – patients want to experience a clear and seamless journey

between different care settings such as GP practices, hospitals and cancer centres. They want to know who is taking over their care and who they should contact if they have questions or concerns.

'I'm a single mum with three daughters, whom I love dearly. So being told I had cancer was an awful shock to our family.

From the moment I had my first appointment with the specialist, I was assigned a Macmillan nurse. She supported me all the way through my chemo and radiotherapy treatment, and then followed things up with weekly calls to me at home.

It's been a tough time; I'm suffering side effects and have lost confidence but even now my Macmillan nurse is always there at my check-ups to see how I'm doing and ask how the girls are.'

Laurel from London

3 Why is a good patient experience so important?

Making sure people with cancer have a good experience has a number of key benefits:

- **Important to patients** – a good experience makes people feel supported and respected
- **Links to other outcomes** – a recent review shows patient experience is positively linked to other key outcomes, including health outcomes, patients adhering to their treatment plans and use of resources. It also states that improving patient experience is likely to increase improvements in safety and clinical outcomes.⁶ Macmillan is currently working with the Picker Institute to investigate further the link between patient experience and other outcomes
- **Saves the NHS money** – a study has shown that a positive experience can reduce a patient’s length of stay in hospital and staff turnover, which can save hospitals money⁷
- **Marker of success** – in response to the Francis Inquiry report, Jeremy Hunt, Secretary of State for Health, stated that a culture of compassion will now be a key marker of success.⁸ Poor patient experience can be a warning sign for more widespread failings. For example, Bruce Keogh’s review into 14 NHS trusts with high mortality rates found that standards of patient experience were also poor at the majority of the trusts⁹
- **Links to staff experience and retention** – there is a close link between staff and patient experience – when staff feel valued and respected, they are more likely to treat patients in the same way and be happier in their role.¹⁰ Therefore, a good patient experience is linked to staff wellbeing and retention.



4 What are the problems and how can we begin to tackle them?

Despite the central importance of patient experience, many people with cancer do not experience the care and support that they should expect. For example, on average, only 56% of cancer patients in England said that all doctors and nurses asked them what name they wanted to be called by. These scores also varied hugely across the country: the best performing trust scored 82%, but the worst scored only 24%.¹¹

This section sets out what we think are the key problems and makes recommendations to begin to address them.

4.1 Patient experience is not a priority

Across the NHS, patient experience is still not regarded as having equal importance as clinical effectiveness and patient safety. Experts we spoke to told us this is partly because patient experience is not meaningfully prioritised at all levels of the healthcare system.

Prioritising patient experience in national frameworks and measures

The government's decision to make patient experience one of the five domains against which the health system will be held to account underlines its increasing national importance. However, this is not properly reflected in the mechanisms with which the government sets health priorities and holds the NHS to account, for example, the NHS Mandate and NHS Outcomes Framework.

In the wake of the Francis Inquiry report, the NHS Mandate needs a stronger focus on improving relational care for all people. This concerns the relationship between a member of staff and a patient, for example, how they communicate with the patient and whether they treat them with dignity and respect.

The NHS Outcomes Framework's patient experience outcome indicators can be improved in a number of areas:

- The majority of current indicators are based on generic surveys, such as the Inpatient Survey. This has resulted in clinical teams dismissing findings by saying they're not relevant to them¹²
- Current indicators do not focus on everything that's important to a patient with cancer, for example, whether information is provided to help with medical and non-medical issues, such as accessing benefits.

Macmillan recommends:

- **the Department of Health makes the improvement of relational care a priority area within the NHS Mandate**
- **NHS England makes sure patient experience indicators in national frameworks reflect what is important to cancer patients and drive improvements in care.**

Prioritising patient experience within providers

Although there are many examples of hospitals driving improvements in patient experience, a recent survey shows its importance to different hospital boards varies considerably. When boards raised patient experience as an agenda item, only 5% of these items had further action attached to them.¹³ Without hospital boards leading the way and emphasising the importance of patient experience, frontline staff are less likely to see it as a priority.

With an increasing emphasis on moving care away from hospitals and into the community, it is essential to understand and improve patient experience outside hospitals. Currently, there is a severe lack of comparable data on the experiences of people with cancer outside a hospital setting, for example, the GP Patient Survey doesn't cover all the issues that are important to people with cancer, such as early diagnosis and continuity of care.

'While in hospital, I developed problems going to the toilet. I was told that in order to have a catheter inserted I would need a blood test first, as I was at high risk of infection.

However, one night, a nurse tried to put in a catheter, saying I had agreed to it with the doctor. I hadn't. I had been asleep when he came round, so he just put in my notes that I was happy with it.

In spite of my pain, I demanded a blood test. It showed there was E. coli in my blood. Had the catheter gone in I could have ended up in intensive care. I talked to the doctor; he was confrontational and unsympathetic.'

Diana from London



There are a number of ways in which providers – both hospitals and those in a primary or community setting – can be incentivised to improve patient experience:

- **Listening to patients: measurement**

Measuring and publishing how well people rate the care provided by a hospital has already driven improvements. For example, the National Cancer Patient Experience Survey (CPES) – an NHS England survey of over 70,000 patients – has been a vital catalyst for change. In almost all areas covered by the CPES, patient experience has improved from the 2010 survey to the 2011–12 survey. Macmillan has helped to drive this by producing league tables of the 10 best performing and 10 worst performing NHS trusts.

We believe the survey must be repeated annually so we can build on improvements. At the

same time, we want to work with NHS England and other partners to ensure that the CPES continues to meet the needs of cancer patients and the NHS.

We also recognise the importance of the NHS friends and family test. It asks patients whether they would recommend hospital wards and A&E departments to their friends and family if they needed similar care or treatment. Alongside the more detailed results of the CPES, the high-level data the test gathers will be important in highlighting serious breaches in quality of care.

With the number of people living with cancer increasing, the development of measures of patient experience outside a hospital setting and over time must be prioritised. The pilot Patient Reported Outcome Measures (PROMs) surveys¹⁴ that measured the experiences and quality of life of people one, two, three and five years after

their cancer diagnosis is a start. We now need to build on this work to understand more about what people's experiences of care are over time.

Overall, if the same transparency of data that has been applied to hospitals is applied to other care settings, improvements in the experiences of care of people outside of hospital should follow.

- **Using the patient voice: assessment and inspection**

We welcome the appointment of a chief inspector of hospitals and increased investment in meaningful inspections. It is now vital that patient experience is put at the heart of the inspection process.

When ratings are produced at a cancer team and service level, results from the CPES would make sure patient experience is taken into account.

In addition, a central way to drive improvements is to use patient-reported data to monitor and assess providers of care, for example, as part of the Foundation Trust assessment process.

- **Empowering patients: tools and best practice**

People living with cancer should be empowered to demand a better experience of care and hold the NHS to account when their experience falls below what should be expected. Tools have been used to support patients to assess their clinical care, such as Diabetes UK's 15 healthcare essentials checklist.¹⁵ We think there is an urgent need for these to be developed to support people with cancer to assess their experiences too.

Working with people affected by cancer, Macmillan is developing a guide for patients explaining how they can use the CPES results to influence change in their local area.

Macmillan recommends:

- **NHS England repeats the National Cancer Patient Experience Survey annually**
- **NHS England prioritises the development of measures that assess patient experience outside a hospital setting and over time**
- **NHS England works with the Trust Development Authority and Monitor to ensure that a trust's ability to reach Foundation Trust status is explicitly dependent on their performance on patient experience**
- **the Care Quality Commission makes sure patient experience, and how patient experience data is collected, become key measures for performance when inspections of hospitals and other providers of care take place**
- **the Care Quality Commission uses findings from the Cancer Patient Experience Survey to inform any ratings developed for cancer services**
- **NHS England prioritises the development of tools that empower patients to assess their experience of care.**

Ensuring that patient experience is a priority for commissioners

Macmillan strongly believes the commissioners of cancer services can help to make sure providers prioritise patient experience. However, we need to incentivise and hold to account commissioners to do this and hold them to account if they don't. We also need to equip them with the knowledge, tools and support to help them improve patient experience.

In the new NHS, NHS England will directly commission a large proportion of cancer services, including primary care and 'specialised services' – chemotherapy and radiotherapy for every cancer type and all services for people with rarer cancers. In its role as a commissioner, NHS England is in an ideal position to lead by example and improve patient experience.

'I do not get any advice. I feel alone and rejected by the system. The whole thing is an utter shambles, with no overall person keeping tabs on you, just different units who do not talk to each other, do not read your notes and prescribe medicines that react with each other.'

A person with Non-Hodgkin lymphoma

Macmillan recommends:

- NHS England holds local commissioners to account for improving cancer patient experience by developing an indicator on cancer patient experience for inclusion in the Clinical Commissioning Group Outcomes Indicator Set
- NHS England develops template contracts, Commissioning for Quality and Innovation (CQUINs) payment frameworks and service specifications that clinical commissioning groups can use to drive up standards of patient experience
- the National Institute for Health and Care Excellence (NICE) makes sure its guidance and quality standards adequately reflect the importance of a good patient experience
- the Department of Health develops clear frameworks that make NHS England accountable for driving up patient experience as part of its commissioning role.

4.2 Patients are not experiencing a seamless and coordinated journey

The NHS Patient Experience Framework identifies ‘coordination and integration of care’ as one of eight key elements of patient experience.

Yet, coordination of care can be particularly poor for people with cancer. They often come into contact with a wide range of professionals and organisations, in hospital and the community. The 2011/12 CPES revealed that only 62% of patients felt the different people treating and caring for them always worked well together to give them the best possible care.¹⁶

In addition, there are concerns that people who access specialised services experience uncoordinated care when moving between nationally commissioned services and locally commissioned cancer services, such as follow-up care in the community.

‘Once my treatment was over, I was abandoned. There was no system to support me, no one asked me how I would cope emotionally, and when I started suffering side effects, I felt like I was making a fuss about nothing.

The absolute silence of support was deafening. I’m still lacking in energy and I experience flashing lights, so do I still have cancer? Has it been cured? Is it going to return? No one is there to answer my questions.’

Fran from London

Commissioners, including NHS England, and Health and Wellbeing Boards, are uniquely placed to look at transition points between services and play a lead role in providing patients with seamless care experiences.

We are pleased the government recently announced its strong commitment to improving coordination of care.¹⁷ We support the ongoing work to develop indicators that will measure patient experience of integrated care.

Macmillan recommends:

- **NHS England, in its role as a commissioner, leads by example and takes responsibility for making sure people experience coordinated care**
- **Strategic clinical networks prioritise within their cancer work plans the improvement of patient experience at key transition points between services.**

4.3 The relationships between patients and staff need to improve

Recent research has consistently shown patients prioritise the relational aspects of patient experience over functional aspects such as waiting times or access to diagnostic tests.¹⁸ Unfortunately, many of the lowest scores in the CPES are concerned with relational care. For example, almost a third (31%) of patients revealed they did not have confidence and trust in all the ward nurses treating them.¹⁹

Changing ‘culture’ – people’s behaviours and attitudes – is of course extremely difficult. However, a key part of the puzzle is the growing evidence clearly linking good staff experiences with good patient experiences.²⁰ This view is echoed by Bruce Keogh, Medical Director of the NHS in England, who has the ambition that ‘all NHS organisations will understand the positive impact that happy and engaged staff have on patient outcomes’.²¹ ‘Staff’ includes everyone who comes into contact with the patient – not just nurses.

‘Mum hated being in hospital. There was an elderly lady next to her on the ward that often needed to go to the toilet and was routinely ignored by the nurses. What made it worse is that Dad had to work and the nurses wouldn’t let him go to visit outside visiting time. It was a really difficult time.

I felt so guilty because I lived far away from the rest of the family. It was really difficult to see her. Mum was lonely and depressed in hospital.’

Naomi from Northumberland

Also key to improving patient experience is improving communication between staff and patients. However, to do this it's crucial every member of staff is supported and receives initial and ongoing training in communication skills throughout their career. In addition, it is vital providers employ staff who value patients and understand how their behaviour can impact on a patient's outcomes.

As well as incentivising change through frameworks and measures, it is equally important to develop solutions that work on the ground and share best practice. We believe there is an appetite for a patient experience community to come together to drive change and NHS England is in a strong position to host this.

At Macmillan, we are looking at a number of ways to improve relational care including:

- **Macmillan Values Based Standard**[®] – created with over 300 patients, staff, carers and family members, the Standard consists of eight practical behaviours designed to help change the dynamic of the relationship between staff and patients. For each of the behaviours, there are also associated leadership behaviours.
- **Schwartz Center Rounds**^{® 22} – these regular sessions provide professionals from all disciplines the opportunity to discuss challenging instances of patient care and collectively discuss what they might have done differently.

Macmillan recommends:

- the Department of Health includes an indicator on staff experience in the NHS Outcomes Framework
- NHS England actively promotes practical solutions for improving cancer patient and staff experiences, such as the Macmillan Values Based Standard[®] and the Schwartz Center Rounds[®]
- Health Education England prioritises communication skills as part of every health professional's training and ongoing skills development
- NHS England establishes and hosts a community for sharing best practice in patient experience.

5 Next steps

We hope this report will further the conversation about how the NHS can make sure patient experience is given the same weight as clinical outcomes and safety, helping to improve the outcomes of people with cancer.

We also look forward to working with partners from across the NHS, as well as patients and their families, to implement the recommendations in this report.

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Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

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–8pm) or visit **macmillan.org.uk**

Hard of hearing?
Use textphone 0808 808 0121, or Text Relay.
Non English speaker? Interpreters available.

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