

Macmillan briefing on dignity and respect ahead of the General Election

Briefing for: MPs and peers

Purpose: To provide a briefing on the importance of dignity and respect of patients and staff support

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1. Introduction

Macmillan Cancer Support strongly believes that all patients should have a positive experience of care and be treated with the highest levels of dignity and respect. However, the public inquiry report into the failings of care at Mid Staffordshire NHS Foundation Trust told a story of appalling suffering for many patients and a lack of staff engagement and support. To address these problems, the Francis Inquiry recommended developing a common culture where patients are the priority. It also recognised the need for leadership at all levels, from ward to the top of the Department of Health, improved staff involvement and supported development across the NHS.

Dignity must not be denied. Ahead of the General Election, Macmillan is calling on all political parties to ensure:

- All patients, including cancer patients, are treated with the highest levels of dignity and respect.
- NHS staff are supported to deliver this ambition.

2. Patients at the heart of the NHS

The NHS Mandate sets an ambition for the health service to be recognised globally as having the highest standards of caring. In practice, this means that compassion must be at the heart of all health and social care services. To achieve this aspiration, the Mandate sets an aim to transform the health service to a system '*where compassionate care and patient experience are as important as clinical outcomes*'.ⁱ

Macmillan welcomes and shares this ambition. Nonetheless, our evidence shows that across the NHS, patient experience is **still not regarded as having equal importance as clinical outcomes, including effectiveness and patient safety**. Experts we spoke to told us that this is because patient experience is not meaningfully prioritised at all levels of the system. For example, when hospital boards raised patient experience as an agenda item, only 5% of these items had further actions attached to them. Without hospital boards leading the way and emphasising the importance of patient experience, frontline staff are less likely to see it as a priority.ⁱⁱ

The effects of the lack of prioritisation of patient experience can be seen in cancer care. The National Cancer Patient Experience Survey (CPES), run by NHS England, provides

valuable information on which hospital trusts' cancer patients are receiving a positive experience of care, and where further progress is required. The CPES gives cancer patients a meaningful voice and helps to drive improvements on the ground. Unfortunately, for many people, experiences of cancer care are not positive.

Simon from Dorset: *"If I had had the courage to speak up and voice my fears and concerns when I was facing treatment for prostate cancer, my partner and I would have been far better prepared emotionally to face what was to come. As it was, I had to learn the answers the hard way, as I went along."*

The results of the 2013 CPES showed that urgent improvements are needed in care planning, provision of information, coordinated care, financial support and relational care, such as treating patients with dignity and respect.ⁱⁱⁱ For example, 42% of respondents said that not all doctors and nurses asked what name they preferred to be called by, and 31% of patients said they did not have confidence and trust in all the ward nurses treating them. Furthermore, there is stark variation in patient experience across the country.^{iv}

Recent evidence suggests that there are significant inequalities in patient experience. The following groups report poorer experiences of care:^v

- Patients affected by rarer cancers such as urological, brain and central nervous system
- Younger patients, who tend to report more negative experiences across a number of different elements of patient experience
- Ethnic minorities, specifically Chinese patients report the worse experiences, followed by Asian and black patients
- Women, who tend to report more critical experiences of care across most elements of experience
- Patients treated by London hospitals compared with those treated by hospitals in other English regions.

Although the results of the CPES are published annually, there are concerns about **the accessibility of this data** for patients, trusts and other local bodies. There is no official comparison of the results of the survey between different trusts, which would help to support patients' choice and promote transparency in the health service. Furthermore, even though a number of trusts develop action plans based on the results of the CPES, these are not always easily available, nor do Clinical Commissioning Groups and NHS England always actively measure trusts' progress against them. All of this leads to a gap in accountability on cancer patient experience. This evidence shows that the ambition in the NHS Mandate is not being delivered consistently.

3. Supporting NHS staff to deliver the best experience of care

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.'*

Since the publication of the Francis Inquiry report, the Government has stated that well-treated staff treat patients well and that staff wellbeing is the foundation on which compassionate care must be built.^{vi} The recent review of staff engagement and empowerment in the NHS, commissioned by the Minister for Care and Support, Norman Lamb MP, in November 2013 corroborated these assertions. It even went further to state that '*NHS organisations with high levels of staff engagement – where staff are strongly committed to their work and involved in decision-making – deliver better quality care.*'^{vii} It indicated that these organisations report lower mortality rates, better patient experience and lower rates of sickness absence and staff turnover.

Macmillan's research on this issue also shows that the treatment of hospital staff is intrinsically linked to patient experience. Where staff suffer high levels of discrimination or harassment, cancer patients are up to 18 times more likely to receive poor care^{viii}. Happy staff means supported patients. Yet, the 2013 NHS Staff Survey shows that a significant proportion of staff are having a poor experience. For example, only 41% of staff were satisfied with the extent to which they felt their hospital values their work^{ix}. Similarly, 44% of NHS Staff have not received any training on how to deliver good patient/service user experience in the past year.^x

A survey of 200 health professionals who deal with cancer patients, conducted in 2014, showed:^{xi}

- 76% said that the Government is not doing enough to support NHS staff to build a culture of care where patients are the priority.
- 77% of respondents report experiencing an unmanageable workload.
- 83% of health professionals said that NHS staff need more support from managers to treat cancer patients with the highest levels of dignity and respect.

This evidence shows that almost two years after the publication of the Francis Inquiry report, NHS staff are still reporting low levels of support, engagement and morale. National leadership for improving staff experience is required to address these concerns. All employers must be meaningfully measured on the experience of their staff and held to account for improving it. This includes, all staff – both clinical and non-clinical – having time and support to access regular development opportunities on providing a good experience and to reflect on the emotional impact of caring.

Mark, a senior nurse from Hertfordshire said: '*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.*'

In addition to time and support, it is equally important to roll-out solutions that work on the ground. For example, Macmillan has developed measures to improve patient and staff experience including the **Macmillan Values Based Standard®**: eight practical behaviours designed to improve the relationship between staff and patients across the NHS. We are also supporting the delivery of the **Schwartz Center Rounds®**^{xii}: regular

sessions which provide professionals from all disciplines with the opportunity to discuss challenging instances of patient care.

4. How can MPs and peers support improvements in cancer patient experience?

This briefing shows much more needs to be done to ensure all patients are treated with the highest levels of dignity and respect. It also highlights that national leadership is needed to support NHS staff to deliver the best possible care.

To ensure all cancer patients are treated with the highest levels of dignity and respect, and staff are fully supported to deliver this, the Government should:

- Actively **shine a light on poor care and demand hospitals take action** to improve by:
 - Publishing a clear comparison of cancer patient experience in hospital trusts across the country.
 - Requiring trusts to publish action plans addressing weaknesses in cancer patient experience and staff engagement, and reporting annually on their progress.
- Make sure all frontline staff have **time to access training to deliver care with dignity and respect**. This could include courses on advanced communication skills to have sensitive conversations with cancer patients, their families and carers.

We would be extremely grateful if you could:

- Write to the leadership of your party responsible for policy development raising Macmillan's calls ahead of the General Election.
- Ask Parliamentary Questions on the issues mentioned in this briefing. Naturally, we can offer suggested wording.

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ⁱ NHS Mandate. Page 8. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf

ⁱⁱ Macmillan Cancer Support. *Improving care for people with cancer*. 2013

ⁱⁱⁱ NHS England. *Cancer Patient Experience Survey 2013: national report*. 2013.

^{iv} Macmillan Cancer Support. *Dignity must not be denied: putting cancer patient at the heart of the General Election 2015*. 2014 and *Cancer Patient Experience Survey: Insight Report and League Table 2012–13*. 2013

^v These findings are based on analysis of the 2011-12 CPES by the University of Cambridge, funded by Macmillan Cancer Support. This uses mixed effects logistic regression models to predict positive/negative experience and calculate ranks within each socio-demographic category considered.

<http://www.macmillan.org.uk/Documents/AboutUs/Research/Keystats/2013CPESInsightBriefingFINAL.pdf>

^{vi} Department of Health. *Hard Truths. The Journey to Putting Patients First*. Volume one. 2013. Page 20 and 36.

^{vii} Chris Ham. *Improving NHS care by engaging staff and devolving decision making*. July 2014

^{viii} The relationship between cancer patient experience and staff survey results, Picker Institute Europe (30 July 2013). Picker Institute Europe was commissioned by Macmillan Cancer Support to investigate the relationship between the results for the Cancer Patient Experience Survey (CPES) and the NHS Staff Survey. The data were from the 2011 CPES and the 2011 NHS Staff Survey. <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/ReportCPES-StaffexperienceP2709v4.pdf>

^{ix} NHS. *Briefing Note: Issues Highlighted by the 2013 NHS Staff Survey in England*. 2013

^x NHS Staff Survey 2013. <http://www.nhsstaffsurveys.com/Page/1006/Latest-Results/2013-Results/> (Sept 2014)

Research Now/Macmillan Cancer Support online survey of 200 health professionals who deal with cancer patients (GPs, oncology consultants, oncology nurses, and healthcare assistants). Fieldwork conducted June 2014. Survey results are unweighted.

^{xii} Developed and provided by the Point of Care Foundation.