

Macmillan briefing on cancer patient experience



Briefing for: MPs and peers

Purpose: To provide a briefing on Macmillan's priorities for cancer patient experience

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1. Introduction

Having a positive experience of care matters to people living with cancer as much as effective treatment and clinical safety. Good cancer patient experience is strongly connected to improved health outcomes, a person's well-being, their ability to understand and relate to professionals and to take personal responsibility for care choices. However, for many people, cancer care is not a positive experience. Macmillan Cancer Support strongly believes that all cancer patients should have a positive experience of care and be treated with dignity, kindness, respect and compassion throughout their cancer journey.

To improve the experiences of cancer patients Macmillan urges:

- The **Department of Health** to make the improvement of 'relational care' a priority area within the NHS Mandateⁱ
- The **Care Quality Commission** and the **Chief Inspector of Hospitals** to ensure patient experience data is a key measure for performance in hospital inspections
- **NHS England** to develop measures to hold Clinical Commissioning Groups to account on cancer patient experience through local accountability frameworks.

2. Patients at the heart of the NHS and the Cancer Patient Experience Survey

Putting the quality of patient care at the heart of the NHS has been a recurring commitment made by the Governmentⁱⁱ. Chairs of key organisations involved in health care also pledged to 'seek out and act on feedback, both positive and negative' and to 'put patients first'.ⁱⁱⁱ A similar commitment has been made by the Opposition, as the Shadow Health Secretary called for increased 'accountability and transparency'^{iv} in the NHS and the need for cross party agreement on this issue.

The National Cancer Patient Experience Survey (CPES), currently 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 is a way of delivering these cross party commitments by giving cancer patients a meaningful voice and is a vital tool for holding the NHS bodies to account for delivering person-centred care. Macmillan is very pleased that NHS England listened to the cancer community and confirmed that they "[...] have no plans to stop carrying out the CPES"^v. Although this is a welcome first step, there are a number of areas where substantial progress is still needed to ensure that cancer patient experience improves across the country.

3. Patient Experience is not a priority in the NHS

Patient experiences depend on two separate aspects of care. **Functional care** which covers waiting times or access to diagnostic tests and **relational care** concerning relationships between a member of staff and a patient, including how nurses and doctors communicate with the patient and being treated with dignity and respect. Research shows that some patients view relational care as more important than functional.

3.1 Areas for improvement

For many people, experiences of cancer care are not positive. The results of the 2012/13 CPES showed that improvements are needed on:^{vi}

- **Care planning and information.** Before starting treatment almost half of patients (45%) were not fully informed about side effects that could affect them in future. Almost four in five (78%) were not offered a written assessment and care plan, and around four in ten (41%) were not given enough support from health and social services after leaving hospital.

Brian, living with cancer, West Sussex: *'I had first-class care for prostate cancer, but there were times when I could have done with a little more information, particularly with regard to the side-effects of the hormone therapy. I only saw the specialist nurse once and that was when I was informed that I had definitely got cancer. She gave me more information than the oncologist about the side-effects, but I query whether this is the right time to give this information. Because your mind is in a whirl as you have just been told you have cancer and things just don't sink in that well.'*

- **Financial support.** Although significant improvement has been made since the first survey in 2010, almost half of patients (46%) who would have liked information about how to get financial help or any benefits, are still not receiving this.

Valerie, living with cancer, South East: *'When I was told I would need radiotherapy, I thought, "when will I get back to work? How long will it take?" When I asked, nobody was very specific. They said, "Well some people work while they're having their radiotherapy." I couldn't do that because I had to travel for radiotherapy and it was a whole day gone from start to finish.'*

- **Relational care.** Relational care such as communication, trusting nurses and being treated with dignity and respect is essential for cancer patients. However, 42% of respondents said that not all doctors and nurses asked what name they preferred to be called by.

Charlotte, living with cancer, Lincolnshire: *'My emotional support was my family – I was given no offer of emotional support: until recently I wasn't even aware of the term cancer nurse specialist, let alone knew the fact that I should have had one assigned to me and been able to contact her.'*

Patients have also reported that they are not experiencing a **seamless coordinated journey, yet this is a key element that makes up good patient experience.** The latest CPES revealed that only 64% of patients felt the different people treating and caring for

them always worked well together to give them the best possible care. Cancer patients come into contact with a wide range of clinicians, nurses and organisations both in hospital and in the community at different points, for example when patients are referred by their consultant to get diagnostic tests. People have told Macmillan that they felt abandoned after treatment.

Furthermore, unacceptable variations of cancer care and patient experience continue across the country. This includes dissimilar care in terms of quality between common and rarer cancer types and between different geographical areas. For instance, the majority of the worst performing trusts continue to be in London.

3.2 Pressing need to prioritise patient experience at all levels

Despite these problems, Macmillan's new report shows that 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 that this is because patient experience is **not meaningfully prioritised at all levels of the system:**

- **Nationally.** 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.
- **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. Without hospital boards leading the way and emphasising the importance of patient experience, frontline staff are less likely to see it as a priority.
- **Commissioners.** Macmillan strongly believes the commissioners of cancer services can help to make sure providers prioritise patient experience. This applies to the commissioners of both specialised and non-specialised cancer services. 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.

Macmillan is calling on the Department of Health to make the improvement of 'relational care' a priority area within the NHS Mandate and on NHS England to work with providers and commissioners to drive improvements on this area.

4. Holding Clinical Commissioning Groups to account on cancer patient experience

To ensure that patient experience is prioritised, it is essential that Clinical Commissioning Groups (CCGs) are held to account for driving improvements in cancer patient experience. To achieve this, a **cancer patient experience indicator should be developed for**

inclusion in national quality frameworks such as the Clinical Commissioning Group Outcomes Indicator Set. We believe that an indicator on cancer patient experience will:

- Ensure that local commissioners focus on the whole of the cancer pathway and prioritise the non-clinical aspects of care that are important to cancer patients
- Continue to drive improvements in patient experience and ensure that further inequalities and wider variations in cancer patient experience do not develop
- Differentiate performance and demonstrate improvements
- Provide simple, top-level data which would allow CCG chief executives to be aware of their CCG's performance and to be held to account for it.

Macmillan calls on NHS England to make sure a patient experience indicator is included in national frameworks to drive improvements in care and hold CCGs to account.

5. Using the patient voice: assessment and inspection

We welcome the appointment of a chief inspector of hospitals at the Care Quality Commission 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, using 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.

Macmillan calls on the Care Quality Commission to make 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 CPES should inform any ratings developed for cancer services.

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

We would be extremely grateful if you could:

- Write to the Department of Health, the Care Quality Commission and NHS England raising the points mentioned in this briefing
- Ask Parliamentary questions on the issues mentioned in this briefing. Naturally, we can offer suggested wording.

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ⁱ Please see section 3

ⁱⁱ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf

ⁱⁱⁱ Ibid ii. Statement of Common Purpose. Government response to Francis Report.

^{iv} 14 March 2013. Andy Burnham response to backbenchers debate on accountability and transparency of the NHS.

<http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130314/debtext/130314-0002.htm#13031445000003>

^v <http://www.independent.co.uk/life-style/health-and-families/health-news/18000-cancer-patients-files-are-lost-every-year-8753705.html>

^{vi} All figures are from the National Cancer Patient Experience Survey. NHS England. Cancer Patient Experience Survey 2013 National Report. 2013. Listed above are evaluative questions where the national average showed 60% or less scored positively.