

# 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 NHS England to:

- Make a commitment to conduct the National Cancer Patient Experience Survey annually
- Include a cancer patient experience indicator in the 2014/15 Clinical Commissioning Group Outcomes Indicator Set.

## 2. Patients at the heart of the NHS

Putting the quality of patient care at the heart of the NHS has been a recurring commitment made by the Government<sup>i</sup>. The Secretary of State for Health and the chairs of key organisations involved in health care recently made a pledge to 'seek out and act on feedback, both positive and negative' and to 'put patients first'<sup>ii</sup>. A similar commitment has been made by the Opposition, as the Shadow Health Secretary called for increased 'accountability and transparency'<sup>iii</sup> in the NHS and the need for cross party agreement.

The National Cancer Patient Experience Survey (CPES), currently run by NHS England, is a way of delivering these cross party commitments by giving cancer patients a meaningful voice. It is also a tool for holding the NHS bodies to account for delivering person-centred care. However, the future of the CPES remains uncertain, as it is yet to be confirmed whether the CPES will be conducted regularly, if at all.

## 3. Conducting the National Cancer Patient Experience Survey annually to transform cancer services

### 3.1 The survey provides a candid assessment of areas for improvement

The CPES provides valuable information on which hospital trusts' cancer patients are receiving a positive experience of care and where further progress is required. The 2011/12 CPES showed unacceptable **variations** of cancer patient experience across the

country. This includes dissimilar care in terms of quality between common and rarer cancer types and in geographical areas. For instance, the majority of the best performing trusts are in the north of England whilst some of the worst performing ones are in London.

The results also showed **shortcomings on emotional support**. Approximately 50% of newly diagnosed cancer patients experience levels of anxiety and depression severe enough to adversely affect their quality of life.<sup>iv</sup> Also 36% of patients said they were not able to discuss their worries or fears with staff in hospital as much as they wanted.

**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.'*

The survey also showed the need for improvements on shared **decision making and care planning**, as only 24% of patients said they had been offered a written assessment and care plan. Also, only 69% of patients reported they were given **easy to understand written information** about their type of cancer and just 60% said their family or someone close to them was given the information needed to help care for them at home.

**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.'*

The CPES showed **limited access to financial information**, as only 52% of patients said hospital staff gave them information about how to access benefits they might be entitled to.

**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.'*

### 3.2 The CPES is a proven tool for improving service delivery

The CPES has driven improvements in the care that patients receive. On most questions in the 2011/12 survey scores improved from the 2010 survey. It has driven change in:

- **Transparency.** The CPES provides national, publically available data which can be compared across hospital trusts. The benchmarking of performance has been a real catalyst for change. Individual trust-level reports were produced, and variation was highlighted by using red, amber, green (RAG) ratings to show trust's performance against each question.
- **Patient's choice.** The CPES results are actively being used to support patient choice. For example the trusts' performance on key questions in the survey are included in

Macmillan's 'choosing your treatment and care' tool.<sup>v</sup> We also produced league tables of the top ten best performing and bottom ten worst performing trusts and have worked closely with hospitals to support them to improve their scores.

- **Delivery of cancer services by hospitals and frontline staff.** Across the country, hospital trusts have used the CPES results to put together action plans. A report by the National Cancer Action Team, showed that those trusts which performed well in the 2011/12 survey were ones that had taken action in response to their 2010 results.<sup>vi</sup> The CPES can also be broken down to multidisciplinary team level (i.e. professionals responsible for cancer care in hospitals) so they are able to identify and drive forward improvements.
- **Incentivising providers to improve standards.** Commissioners have also used the CPES to create 'quality and innovation payments' (CQUINs) to reward excellence by linking a proportion of a providers' income to the achievement of quality improvement goals.
- **Practical solutions in collaboration with the third sector.** As the results of the survey are cancer-specific, the cancer community has worked together to drive improvements. For example, Macmillan has developed a 'values-based standard' made up of adoptable behaviours for NHS staff to ensure that cancer patients are treated as individuals, with dignity and respect and delivering truly patient-centred care.

### **3.3 Importance of the CPES for cancer patients**

The CPES has a very high number of respondents with almost 72,000 patients in 2011/12. It also has a high response rate at 68% (the 2011 Inpatient Survey only has 53% response rate). Furthermore, 84% of CPES respondents were willing to participate in further surveys on their experiences of cancer services. It is clear that there is a real appetite among cancer patients to provide feedback on their experience through the survey.

### **3.4 NHS staff acknowledge the value of the CPES to drive improvements**

Throughout England, senior staff within the NHS recognise the value of the CPES in driving improvements in their local trusts.

#### **Ruth Hendy, Trust Lead Cancer Nurse, University Hospitals Bristol Foundation Trust**

*'Although some of our results from the CPES in 2010 were encouraging, others were disappointing. A detailed action plan was put together which was presented to and agreed by the trust board. [...] We were delighted that, when the Survey was repeated in 2011-12, our results showed that we were the seventh most improved Trust across the whole of the country. [...] In my experience, the CPES is a vital tool for ensuring that improvements in cancer patient experience are prioritised, which – in the case of the Trust where I work – can result in care which is tangibly better for patients.'*

### **3.5 An annual CPES will help to build a person-centred culture of compassion**

The Francis Inquiry report recommended that 'information must be made available about the performance and outcomes of the service provided to enable patients to make treatment choices and have a proper understanding of the outcomes for them.'<sup>vii</sup> It also stated that 'metrics need to be established which are relevant to the quality of care and

patient safety across the service.<sup>viii</sup> The CPES is a valuable tool designed to fulfil this purpose, and, as highlighted above, has been shown to drive service improvements.

Although the Government is conducting the survey in 2013, a commitment for it to be held yearly is yet to be made. As such, **Macmillan is calling on NHS England to conduct the CPES annually**. Given that the Secretary of State reiterated the importance of 'service-specific scores', an annual CPES will allow the Government to 'track and trace' improvements. It will also help the new Chief Inspector of Hospitals and the Care Quality Commission to monitor improvements where changes to key scores of the CPES 'can be an indicator that services are deteriorating'<sup>ix</sup> and prompt timely action plans and corrective measures to prevent failures on cancer care. This data will also be useful for the Government's annual progress report on the implementation of the Francis report.

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

Given the evidence above about the usefulness and popularity of the CPES as a feedback tool, Macmillan believes Clinical Commissioning Groups (CCGs) should be held to account for driving improvements in cancer patient experience. To achieve this, a **cancer patient experience indicator should be developed for inclusion in the 2014/15 Clinical Commissioning Group Outcomes Indicator Set (CCGOIS)**. 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.

#### **5. How can MPs and peers support improvements in cancer patient experience?**

We would be extremely grateful if you could:

- Write to Sir David Nicholson, Chief Executive of NHS England, and urge him to conduct the National Cancer Patient Experience Survey annually and for it to be developed as an indicator in the accountability frameworks of the NHS.
- Ask Parliamentary questions on the issues mentioned in this briefing. Naturally, we can offer suggested wording.

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<sup>i</sup> 26 March 2013. Jeremy Hunt response to Francis Recommendations.

<sup>ii</sup> Statement of Common Purpose. Government response to Francis Report.

<sup>iii</sup> 14 March 2013. Andy Burnham response to backbenchers debate on accountability and transparency of the NHS

<sup>iv</sup> Arnes J, et al. Patients' supportive care needs beyond the end of treatment. *Journal of Clinical Oncology*. 2009.27 (36) 6172-9

<sup>v</sup> <http://bit.ly/NKOEve>

<sup>vi</sup> National Action Cancer Team. *Improvements in cancer patient experience ratings: how have they been made?*

<sup>vii</sup> <http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf>

<sup>viii</sup> Recommendation No. 143 Francis Inquiry Report

<sup>ix</sup> Ibid I, Page 54