

Briefing: The importance of the National Cancer Patient Experience Survey

April 2013

1. Summary

As responsibility for the National Cancer Patient Experience Survey (CPES) transfers to NHS England, this briefing sets out Macmillan Cancer Support's views on the importance of the CPES, its role in improving transparency, supporting patient choice and driving improvements in care, and how it can be embedded in the new system.

Macmillan Cancer Support strongly believes that NHS England should:

- Commit to repeating the Cancer Patient Experience Survey annually;
- Include an indicator on cancer patient experience in the 2014/15 CCG Outcomes Indicator Set (CCGOIS).

2. Overview of the CPES

The CPES measures the experience of cancer patients across a range of aspects of care – significantly, these include relational aspects (such as how sensitively a person was told that they had cancer) as well functional issues (for example the length of time a person had to wait before first seeing a hospital doctor). While those who respond to the survey have either been an inpatient or day case, it covers non-acute aspects of care, and looks at how well care is joined-up outside of hospital.

The CPES has both a high number of responses (almost 72,000 in 2011/12) and a high response rate (68%¹ - compared to 53% for the 2011 national Adult Inpatient Survey²). In addition, 84% of 2011/12 CPES respondents were willing to participate in further surveys on their experiences of cancer services. It might therefore reasonably be suggested that there is a real appetite among cancer patients to provide feedback on their experience in this format.

The 2011/12 and 2010 surveys built on surveys conducted in 2000 and 2004. A 2012/13 survey is currently being conducted by the Department of Health. The CPES costs £400,000 each time it is conducted.

3. The importance of the CPES

We believe that NHS England should commit to conducting the CPES annually. This is for four reasons:

i. Building on the effectiveness of the CPES in promoting transparency and driving improvements

We know that the CPES has driven improvements in the care that patients receive. For example, on most questions in the 2011/12 survey scores improved from the 2010 survey. This is a significant achievement. There are a number of reasons for this:

- **Transparency and benchmarking of data:** The CPES provides national, publically available data which can be compared across Trusts. The benchmarking of performance against the CPES has been a real catalyst for change. Importantly, individual Trust-level reports were produced, and variation was highlighted by using red, amber, green (RAG) ratings to show each Trust's performance against each question.

¹ <https://www.wp.dh.gov.uk/publications/files/2012/08/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf>

² http://www.cqc.org.uk/sites/default/files/media/documents/ip11_national_tables_final.pdf

- **Trust-wide and MDT-level action plans throughout the country:** A report by the National Cancer Action Team, *Improvements in cancer patient experience ratings: how have they been made?*,³ shows that those Trusts which performed well in the 2011/12 survey put in place action plans in response to their 2010 results. The level of detail which the CPES provides about specific areas of care allows Trusts to focus their improvement efforts. We know that all London Trusts put action plans in place following the 2010 survey, while an example of a detailed action plan from outside London can be found [here](#). Importantly, the CPES can be broken down to multidisciplinary team (MDT) level, meaning that, alongside Trust-wide action plans, MDTs are able to identify and drive forward areas for improvement.

- **Ownership:** In contrast to surveys such as the Adult Inpatient Survey which do not clearly highlight where responsibility lies for ensuring improvements are made, responsibility for improvements against the CPES results can be attributed to an individual MDT. This means that each team can drive improvements in the services that they control.

- **Practical solutions in collaboration with the third sector and the wider cancer community:** Being cancer-specific, the cancer community has worked together to drive improvements against the CPES. For example, Macmillan produced league tables of the top ten best performing and bottom ten worst performing Trusts, which were published in the second annual report of *Improving Outcomes: A Strategy for Cancer*,⁴ and has worked closely with Trusts to support them to improve their scores. This work has involved the publication of a top tips guide on improving patient experience.⁵ The National Cancer Action Team also worked together with Cancer Networks to drive service improvements based on the results of the survey.⁶ Furthermore, Quality Health, which conducts the survey, has worked with a number of site-specific voluntary sector organisations to help them understand and use the results.

ii. Further improvements are required in cancer patient experience

While improvements have been made, it is vital that the CPES continues as there is still more that needs to be done:

- There remain unacceptable variations across the country in terms of the care that cancer patients experience. For example results from the 2011/12 CPES⁷ showed a range across trusts from 45% to 86% of patients being given written information that was easy to understand on their type of cancer. We also know that people with less common and rarer cancers reported a worse

Case Study

**Ruth Hendy, Trust Lead Cancer Nurse,
University Hospitals Bristol NHS 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. At the same time, individual cancer teams were asked to review their team’s results and feed the relevant actions into their plans. The action plan focused particularly on areas where our survey scores were low, such as communication and information and access to clinical nurse specialists (CNSs). This resulted in the implementation of a wide range of initiatives, such as the installation of Macmillan Infopoints throughout the Trust which are staffed by volunteers and the work we did with CNSs to ensure that accurate contact details are given to all patients. 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 particular we saw significantly higher scores related to our priority areas for improvement. **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 <http://candocancercare.org/resources/Improvements%20in%20cancer%20patient%20experience%20FINAL.pdf>

⁴ <https://www.wp.dh.gov.uk/publications/files/2012/12/cancer.pdf>

⁵ http://www.macmillan.org.uk/Documents/AboutUs/Commissioners/Patientexperiencesurvey_Toptipsguide.pdf

⁶ Response of Health Minister Anna Soubry MP to a parliamentary question asked by Jim Cunningham MP:

<http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130214/text/130214w0002.htm>

⁷ <https://www.wp.dh.gov.uk/publications/files/2012/08/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf>

experience than those with more common cancers, while people in London and in more deprived areas reported less favourably on their care.

Case study

Catherine Dale, Programme Manager - Patient Centred Care, King's Health Partners Integrated Cancer Centre

"I have seen that the Cancer Patient Experience Survey (CPES) can create momentum and an interest in patient experience – comparing performance across different Trusts certainly helps to focus minds. Where efforts and resources have already gone into improving cancer patient experience, such as at Guy's and St Thomas', our improved CPES results have validated this focus. At King's, our relatively disappointing results have ensured that actions are taken to improve these. It is important to realise that real-time feedback and surveys, which are completed once the person has left hospital, give us different information – you miss out if you only do one. As well as surveys, in order to understand what is truly important to patients, it is vital to have conversations with patients and carers to explore any findings or proposed solutions. In most hospitals, services deal with a wide range of people, not just those with cancer. This means there is the potential that if we get it right for cancer patients we will be getting it right for others too."

- In a number of key areas, the vast majority of Trusts perform poorly. For example, only 24% of all patients who responded said they had been offered a written assessment and care plan, and only 64% of patients said they were able to discuss any worries or fears they had with staff in hospital as much as they wanted.

- A recent expert workshop organised by Macmillan Cancer Support⁸ recognised that a range of data is needed to drive improvements. This includes real-time data, such as that gathered through the Friends and Family Test. However, it was also agreed that the detailed CPES data, captured after a person has received their treatment and care, it required alongside headline data and complements other types of data, rather than being replaced by it.

iii. Supporting choice and helping to building a person-centred culture of compassion in the NHS

Tools such as Macmillan's league tables and the Trust-level reports on the CPES results are already contributing to the ambition of a 'revolution in transparency'⁹ across the NHS and to Robert Francis QC's recommendation 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.'¹⁰ We also know that the CPES results are actively being used to support patient choice, for example, Trusts' performance on key questions are included in Macmillan's 'Choosing your treatment and care' tool.¹¹

However, more can be done to utilise the CPES data in a transparent way to support meaningful choice for patients. The NHS Mandate states that the NHS must report results at the level of consultant-led teams.¹² We know that the ambition is for these scores to cover all five domains. Currently this is only possible for cancer – partly because of the availability of service-specific data from the CPES, which has relevance across all five domains. However, the tried and tested method of collecting condition-specific patient experience data pioneered by the CPES could also be used as a model for other conditions.

MHP Health Mandate's recent report, *Quality at a glance: using aggregate measures to assess the quality of NHS hospitals*,¹³ reiterated the central role of condition-specific ratings for patients in making informed decisions about their care, stating that these were more useful than general ratings. In addition, the report highlighted that patient experience, alongside waiting times, matter most to the public in making a choice of hospital. The importance of condition-specific measures was also emphasised in the Government's response to the Francis Inquiry, as well as its ambition to put 'the experience of patients at the centre of what the NHS does and the way in which its success is judged.'¹⁴

⁸ The workshop took place on 1st March 2013 and brought together a range of stakeholders including people affected by cancer, commissioners and representatives from providers, including professionals.

⁹ <http://publications.dh.gov.uk/files/2012/11/mandate.pdf>

¹⁰ <http://www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf>

¹¹ <http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Colonandrectum/Choosingyourtreatmentandcare/Choosingyourtreatmentandcare.aspx>

¹² <http://publications.dh.gov.uk/files/2012/11/mandate.pdf>

¹³ <http://mhpc.com.wpengine.netdna-cdn.com/health/files/2013/03/Quality-at-a-glance.pdf>

¹⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170701/Patients_First_and_Foremost.pdf

iv. Relevance for other conditions

It is important to note that, while the CPES is completed by people with cancer, these patients come into contact with a number of different services across a Trust. This means that the CPES can be seen to be a measure of quality of care more broadly. Similarly, many of the improvement initiatives put in place will have benefits for patients across a Trust, not just those with cancer. Additionally, we believe the principles and methodology used by the CPES could be effectively employed for measuring and benchmarking the experience of care of people with other long-term conditions.

4. Embedding the CPES in the new NHS

We firmly believe that we must build on the improvements that have already been achieved as a result of the CPES, firstly by repeating the survey, and secondly by embedding it explicitly in the new NHS architecture. We know that some commissioners are already using the CPES as a basis for CQUIN payments; however more needs to be done to ensure that commissioners, as well as providers, are held to account against the CPES results. This should be achieved by using the survey as the basis for a cancer patient experience indicator for inclusion in the CCGOIS.

i. Lack of meaningful indicators in the CCGOIS to drive improvements in cancer patient experience

Alongside aspects of patient experience which are important to all people who come into contact with the health service, we want to make sure that the CCGOIS captures and incentivises improvements in those aspects of care which have a particular emphasis for people with cancer. These can be related to the emotional impact of a cancer diagnosis, the complicated interactions and choices which face a person with cancer, and the long-term impact of cancer on a person's whole life and family (Macmillan Cancer Support workshop, 1st March).

It is clear that the current CCGOIS indicators under Domain 4 do not adequately fulfil this purpose. For example, the current CCGOIS indicator on '*patient experience of hospital care*', which is based on the Adult Inpatient Survey, does not capture whether someone was given supported information about a range of needs that they might have – both medical and non-medical – nor whether someone experienced coordinated care outside of hospital.

ii. Importance and feasibility of a cancer patient experience indicator

The availability of data from the CPES makes such an indicator feasible now and the number of respondents to the survey means that the data from 2010 and 2011/12 can already be cut by CCG. As noted above, we recognise that the CPES is regarded as an example of best practice in terms of measuring holistic patient experience of care. We believe that the principles that make the CPES effective could be successfully applied to other conditions. Should this happen, an indicator in the CCGOIS could be adapted to reflect these changes.

Ultimately, we believe that a cancer patient experience indicator based on the CPES would:

- help to 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;
- help to 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;
- ensure that commissioners share responsibility with and hold providers to account for driving up standards of care for cancer patients;
- provide simple, top-level data which would ensure that the CCG Chief Executive is aware of the CCG's performance and is held to account for it.

5. Next steps

Macmillan is very keen to continue to work collaboratively with NHS England on the future of the CPES and to explore ways to drive further improvements in patient experience in the reformed NHS.

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