

# Making the new NHS work for people with cancer

September 2012

**UK Office, 89 Albert Embankment, London SE1 7UQ Questions about cancer?  
Call the Macmillan Support Line free on 0808 808 00 00 or visit [macmillan.org.uk](http://macmillan.org.uk)**

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Macmillan Cancer Support would like to thank Laura Gilbert (author).

## Executive summary

England's cancer survival rates continue to lag behind the European average.<sup>1</sup> For cervical, colorectal and breast cancer they are among the poorest in the Organisation for Economic Co-operation and Development (OECD).<sup>2</sup> The Government has recognised the urgent need for improvement and has recently set out an ambition of saving an extra 5,000 lives from cancer per year.<sup>3</sup>

Patient experience is also an area where standards need to improve. Not only do people with cancer have vastly different experiences depending on where they live, but a national survey shows that some areas of care, such as care planning, fall short of quality standards across the board.<sup>4</sup> The Government has also prioritised cancer patient experience as a focus for improvement.<sup>5</sup>

Of course the reasons for these problems are complex. However, improvements in outcomes for people with cancer can be achieved if the health system is encouraged to focus on them. The NHS must be held to account for delivering better quality cancer services.

Accountability frameworks are being developed for the NHS at both national and local levels. Performance will be measured against a number of indicators, yet measures currently included in the frameworks do not cover cancer survival for all cancer patients or cancer patient experience. If the NHS is not monitoring cancer survival rates or experience, there will be little incentive to change practice.

Macmillan believes that everyone with cancer should be given the best possible chance of survival, and – vitally – that people with cancer should have a positive experience of the care they receive. If the new accountability frameworks are not improved, the Government's own ambitions for cancer care will not be met, and patients in this country will continue to be let down.

## Introduction

The Government has made some major changes to the NHS in England via the Health and Social Care Act (2012), including the introduction of a new commissioning architecture, which is to be fully in place by April 2013.

Local-level Clinical Commissioning Groups (CCGs), which will comprise GPs and other clinicians, will have responsibility for commissioning much of the healthcare for their local populations.

CCGs will be supported and held accountable by the national-level NHS Commissioning Board, which is currently operating as the NHS Commissioning Board Special Health Authority, with responsibilities including designing the new commissioning landscape. From April 2013, the NHS Commissioning Board will take on some functions from Primary Care Trusts (PCTs) and the Department of Health.

The NHS Outcomes Framework (OF) and the Commissioning Outcomes Framework (COF) will provide a structure of accountability for commissioning in the new NHS. The NHS Commissioning Board will be held accountable to the Secretary of State for Health according to its success against the OF.

In turn, CCGs will be held accountable to the NHS Commissioning Board based on their success against the COF. This will ensure that local commissioners are contributing to the national outcomes objectives outlined in the OF.

Outcomes indicators for the OF and the COF are in the process of being developed. It is important that this opportunity is used to ensure that both frameworks include the right incentives to adequately drive improvements in NHS services for people with cancer. Areas where Macmillan believes there is particular scope for improvement in NHS care include cancer survival and cancer patient experience.

# Incentivising improvements in cancer survival

## Why do cancer survival rates in England need improving?

It is positive news that more people with cancer are living longer overall. People now live nearly six times longer after their cancer diagnosis than was the case 40 years ago.<sup>6</sup>

Over the past decade, much effort has been put into improving cancer survival. For example, there has been good progress on breast cancer treatments and this appears to have had a clear impact on breast cancer survival. Five year survival for breast cancer rose from 80.6% in 2000 to a predicted level of 86.0% in women diagnosed in 2007.<sup>7</sup>

However, there has not been the same progress for cancers such as brain, lung and pancreatic cancer.<sup>8</sup> And there are wide variations within England in survival rates for some types of cancer.<sup>9</sup> Furthermore, cancer survival rates in England are poor in relation to other comparable countries. They are below the European average,<sup>10</sup> and for cervical, colorectal and breast cancer they are among the worst in the OECD.<sup>11</sup>

The International Cancer Benchmarking Partnership (ICBP) has compared survival rates for colorectal, breast, lung and ovarian cancer in the UK (England, Wales and Northern Ireland), Australia, Canada, Sweden, Norway and Denmark. It found that the UK lags behind the best performing countries,<sup>12</sup> and with the exception of breast cancer, the “survival gap” is not being reduced for the cancers analysed by the ICBP.<sup>13</sup>

We need to improve our performance if the Government’s aspiration of saving an extra 5,000 lives from cancer per year<sup>14</sup> is to be met. It is vital that everyone with cancer is given the best possible chance of survival.

## How could we incentivise better cancer survival rates?

Macmillan welcomes the inclusion of survival indicators for breast, lung and colorectal cancer in the NHS Outcomes Framework (OF). However, we are very concerned that it has been recommended that the first iteration of the Commissioning Outcomes Framework (COF) should not include key cancer survival indicators.

CCGs will be responsible at the local level for delivering *Improving Outcomes: a strategy for cancer*, the Government’s blueprint for the NHS to drive improvements in cancer outcomes. They will therefore play a key role in contributing to the Government’s goal of saving 5,000 extra lives from cancer per year by 2014/15.<sup>15</sup> If this goal is to be met, the COF must include cancer survival indicators, which would promote:

- **Accountability and transparency** - The commissioning of many cancer services is being passed to CCGs. COF cancer survival indicators would ensure that CCGs are held accountable for cancer survival outcomes delivered by the services they commission. This would provide transparency on performance. As the National Institute

for Health and Clinical Excellence's (NICE) COF Advisory Committee notes, 'survival rates are generally more useful than mortality rates in assessing quality commissioning'.<sup>16</sup> And leading UK academics highlight cancer survival as 'a key index of the overall effectiveness of health services in the management of patients with cancer'.<sup>17</sup>

- **A coherent and integrated approach** - To achieve the goal of improving cancer survival rates, it is important that local and national NHS bodies have a coherent and integrated approach. Aligning the COF and the OF would ensure that local commissioners contribute to the national outcomes objectives. The OF and the COF both need to incentivise improvements in cancer survival rates.
- **Earlier diagnosis** - Early diagnosis is key to improving cancer survival. Including cancer survival indicators in the COF would incentivise local commissioners to make improvements in early diagnosis. For example, the Government has recognised the important role of CCGs in commissioning additional direct access tests.<sup>18</sup> Improved access to diagnostic tests would help in diagnosing less clear-cut cancer cases, which would benefit people with less common and rarer cancers.
- **Greater equality** - There are still wide variations across the country in one and five year cancer survival.<sup>19</sup> Including cancer survival indicators in the COF would highlight regional variations in performance and incentivise local commissioners to promote equality, for example by commissioning services that improve diagnosis.

It has been claimed that survival rates are dependent on the socio-economic status of an area. However, socio-economic factors will have an impact on a wide range of indicators. It is noted in the 2012/13 OF that in the case of cancer survival indicators there are several drivers of the outcome that are beyond NHS control, including socio-economic status. But this has not prevented the inclusion of these indicators in the OF, and is not a strong reason to exclude them from the COF.

### Why are one year cancer survival indicators important?

Including one year survival indicators in the COF - as well as five year indicators - is vital if the Government's objective of saving 5,000 extra lives from cancer per year is to be met.

Including one year survival indicators in the COF would better support proactive local commissioning than five year survival indicators alone. This is because:

- One year survival rates provide an earlier indication of how a CCG is performing than five year survival rates. They therefore support commissioners to take early action to improve their survival rates if necessary. One year survival rates are meaningful for commissioners since they relate closely to five year survival rates: the All Party Parliamentary Group on Cancer (APPGC) heard from experts that cancer patients who

survive one year stand as much chance of surviving five years as patients in other European countries.<sup>20</sup>

- As Professor Sir Mike Richards notes, 'For almost all cancer types, inequalities [between affluent and deprived groups] were observed within one year of diagnosis.'<sup>21</sup> Including one year survival indicators in the COF would therefore enable local commissioners to monitor inequalities at the earliest opportunity.
- Better one year cancer survival rates are recognised as suggesting earlier diagnosis.<sup>22</sup> The APPGC recommended a one year survival indicator, to encourage earlier diagnosis of cancer.<sup>23</sup> One year survival indicators for breast, lung and colorectal cancer were subsequently included in the OF.

**NHS London has recognised the importance of measuring one year survival rates.** A set of 22 outcome standards for GP practices, which were developed with GPs, includes one year survival for breast cancer and lung cancer.<sup>24</sup>

### Why do we need to expand survival indicators to all cancers?

Macmillan welcomes the inclusion in the OF of one and five year survival indicators for breast, lung and colorectal cancer, three of the most common types of cancer. However, this means that the OF does not include survival rates for less common and rarer cancers, including cervical and ovarian cancer, where we know the UK lags behind (see above).

In fact, together breast, lung and colorectal cancers represent only 41% of new cancer diagnoses in the UK, and account for 39% of deaths from cancer, while less common and rarer cancers account for almost half of all cancer cases.<sup>25\*</sup>

We are concerned that a focus only on breast, lung and colorectal cancers could act as a disincentive for commissioners to invest in services for other kinds of cancers. We want to ensure this does not happen and that outcomes continue to improve for everyone with cancer.

There is already evidence of inequalities in access to treatment and services for patients with less common and rarer cancers, such as:

- **Barriers to accessing the most effective drug treatments** - The most requested drugs through the Cancer Drugs Fund are used to treat less common and rarer cancers, indicating an unmet need within the NHS.<sup>26</sup>
- **Difficulties related to diagnosis** - In response to a survey by the Rarer Cancers Foundation, over half of respondents said that they had to visit their GP on more than two occasions before receiving a correct diagnosis. And nearly two thirds of

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\* We recognise that prostate cancer is a common cancer, and so is not included in these figures.

respondents experienced a delay of at least three months between first visiting their GP and receiving a correct diagnosis.<sup>27</sup>

People do not choose which cancer they get. But if indicators only measure survival rates for breast, lung and colorectal cancers, the outcomes frameworks will discriminate against around half of people with cancer, and variations between survival rates may continue to grow.

Furthermore, as the Government has recognised, focusing only on the most common cancers would make it very unlikely for the Government to achieve its own ambition of saving an additional 5,000 lives every year by 2014/15.<sup>28</sup>

Including survival indicators for all cancers in the OF and COF would provide a strong incentive for the newly reformed NHS to deliver on the Government's ambition, and ensure that people with less common and rarer cancers do not lose out.

Good data exists on a number of other cancers. The Office for National Statistics produces one and five year survival data annually for 21 cancer types, and data for some cancers is published at Trust level. Work now needs to be taken forward to map data to CCGs.

### Conclusions and recommendations

It is vitally important that everyone with cancer is given the best possible chance of survival. Cancer survival rates must therefore be measured in the OF and the COF, and for more than just breast, lung and colorectal cancers. Focused efforts are now required to develop OF and COF indicators that measure survival rates for all cancers in the most effective way and that can be used to hold CCGs accountable. This will contribute to delivering the Government's commitment to improving cancer outcomes and saving 5,000 additional lives from cancer by 2014/15.

#### Key recommendations:

- The NHS Commissioning Board should include one and five year cancer survival indicators in the first iteration of the Commissioning Outcomes Framework (COF).
- Cancer survival indicators in the NHS Outcomes Framework and the COF should be expanded beyond breast, lung and colorectal to all cancer types, to ensure that people with less common and rarer cancers are not discriminated against.

# Ensuring better cancer patient experience

## Why is patient experience important?

Experience of care is important to most people with cancer. The Government has made it clear that positive patient experience is a vital component of quality healthcare provision, not least by including patient experience as one of the NHS Outcomes Framework domains. That underlines the fact that good patient experience is an outcome in itself, so it is an important factor in the care that people with cancer receive.

People living with cancer tell us how important patient experience is to them.<sup>29</sup>

### Will from Surrey:

'I have been consulted and made to feel a part of the decision making process throughout my treatment. The nurses are always available to me for support and answer any questions, which has made the experience much easier to handle.'

## What improvements are needed in cancer patient experience?

Some positive progress has been made in improving cancer patient experience, but more needs to be done. The 2011/12 Cancer Patient Experience Survey (CPES) results<sup>30</sup> show that there is room for improvement in some key areas of non-clinical care that are important to cancer patients:

- **Communication** - Good communication facilitates early diagnosis, improves self-management, reduces emergency admissions, reduces inequalities in access and provision of care, and supports people in returning to as normal a life as possible following cancer treatment. It is also critical in empowering people to exercise informed choice.<sup>31</sup> But in the 2011/12 survey, **only 73% of patients** said that they completely understood the explanation as to what was wrong with them (down from 74% in 2010).
- **Information and support** - It is also vital to ensure that cancer patients understand the information they are given. But in the 2011/12 CPES, **only 69% of patients** who said they needed it reported that they were given easy to understand written information about their type of cancer.
- **Emotional support** - Approximately 50% of newly diagnosed cancer patients (150,000 people per year) experience levels of anxiety and depression severe enough to adversely affect their quality of life.<sup>32</sup> In the 2011/12 survey, however, **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.
- **Shared decision making and care planning** - A YouGov survey commissioned by Macmillan showed that 91% of cancer patients who responded wanted to be very or

fairly involved in making decisions about their care and treatment.<sup>33</sup> This is supported by NICE guidance.<sup>34</sup> However, in the 2011/12 survey, **only 70% of patients** said that their views were definitely taken into account when the team of doctors and nurses were discussing which treatment they should have. And **only 24% of patients** said they had been offered a written assessment and care plan.

- **Continuity of care** - Cancer care is often fragmented, with people being cared for by different organisations. This can make it difficult for patients to know who their key contact is if they, or their carer, have a question or a problem.<sup>35</sup> On almost all questions in the 2011/12 CPES, patients with a named Clinical Nurse Specialist (CNS) gave more positive scores than those who did not have a CNS. But **only 75% of patients** found it easy to contact their CNS (no improvement in this score since 2010).
- **Financial support** - Having cancer can be expensive. There is considerable under-claiming of financial benefits by people who are eligible for them. People with cancer may experience barriers to obtaining welfare benefits, such as not being aware that they might be entitled or not knowing of sources of benefits information and advice.<sup>36</sup> In the 2011/12 CPES **only 52% of patients** said hospital staff gave them information about how to get any benefits they might be entitled to.

### How could we incentivise improvements in cancer patient experience?

Macmillan is pleased to see that a potential future Commissioning Outcomes Framework (COF) indicator on cancer patient experience has been suggested. This now needs to be taken forward as a priority in order to incentivise improvements in non-clinical care and reduce variation in cancer care experience.

We believe that the indicator should be based on the CPES (COF indicators based on other patient experience surveys have already been proposed). Building on surveys in 2000 and 2004, the CPES was conducted in 2010 and 2011/12, and has been re-commissioned for 2013. It aims to monitor progress on improving outcomes in cancer patient experience, and provide information to drive improvements. CPES data from 2010 and 2011/12 is already available at a level which can be analysed by CCG.

A COF indicator based on the CPES would:

- **Incentivise the improvement of non-clinical care**, by ensuring that local commissioners focus on the whole of the cancer pathway and prioritise the non-clinical aspects of care that are important to patients, eg good communication. This indicator would encourage local commissioners to ensure that people affected by cancer are placed at the heart of services and that their views and opinions are respected.
- **Help to reduce variation in cancer care experience.** The 2011/12 CPES showed significant geographical variation in aspects of patient experience. For example, scores ranged from:

- 68% to 94% of patients rating their care as excellent or very good
- 45% to 86% of patients being given written information on their type of cancer that was easy to understand
- 59% to 92% of patients saying it was easy to contact their CNS.

There were also variations between cancer types. People with more common cancers reported better patient experience than those with less common and rarer cancers. Some of the biggest variations exist around diagnosis, provision of written information on tests and treatments, and where to go for financial support.<sup>37</sup>

The CPES data can enable targeted improvements in patient experience where required. An indicator based on the CPES would incentivise local commissioners to make improvements and ensure that further inequalities and wider variations do not develop.

Macmillan would also like to see a corresponding indicator on cancer patient experience in a future edition of the NHS Outcomes Framework. This would create alignment and ensure that cancer patient experience is a focus at both local and national levels.

### Why is the CPES a strong measure of cancer patient experience?

The CPES covers the experiences of people who have had some hospital care, as well as other aspects of care. It may be important to consider whether other indicators on long-term cancer care may be needed in future, to add to what the CPES already shows us. However, the CPES has some significant strengths as a measure of patient experience, including:

- The number of responses: almost 72,000 in 2011/12, slightly higher than the 2011 national inpatient survey.
- A high response rate (68%), compared to 53% for the 2011 national inpatient survey.
- The Department of Health has noted that the high response rate ‘means that for most Trusts there are sufficient numbers of responders to make robust comparisons between Trusts, and in many instances for all cancers and between tumour groups within Trusts.’<sup>38</sup>
- 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.
- The 2010 CPES report noted the advantage of survey results being focused clearly on cancer services, not on patients’ other NHS experiences.<sup>39</sup> Commissioners can therefore be held to account specifically on patients’ experiences of cancer services.
- Since 2010 the CPES has covered all cancer groups (with some minor exceptions in 2011/12), so it is able to differentiate to a greater extent between patients’ experience in different cancer groups, including patients with some less common and rarer cancers.

## How can the CPES make a difference in practice?

The CPES has prompted specific actions to drive service improvement, with the aim of improving patient experience. For example, University College London Hospital (UCLH) has worked with Macmillan in their new cancer centre to improve patient experience, after performing relatively poorly in the 2010 CPES. Actions included setting up a high profile cancer patient experience board. The transition of cancer care into the new Macmillan UCLH Cancer Centre during the end of 2011/start of 2012 meant that UCLH's 2011/12 CPES results were still poor, but real time monitoring throughout the rest of 2012 and into 2013 will allow improvements to be closely monitored and action plans tailored accordingly.

In terms of outcomes based on patient experience, the following case studies<sup>40</sup> show how services for people affected by cancer can have a positive impact:

- **Information and Support services at Basildon Macmillan info space, Basildon University Hospital NHS Foundation Trust** - Through the Info Space, cancer patients can access services such as counselling, complementary therapy and creative therapy. These services help patients with self-management, relaxation and pain management, expressing their feelings and meeting others to share experiences. Most importantly, the service has made a difference to the quality of life for people living with cancer.
- **Psychological support for people affected by cancer, Luton and Dunstable NHS Foundation Trust** - A Macmillan-funded specialist psychotherapist provides systemic family psychotherapy to families, couples and individuals referred for support. The service is delivered in various clinic settings, in nursing homes, the hospice, at home and in the hospital setting if needed. Education and supervision is provided to CNSs, enabling more patients and families to be assessed for support. Patient questionnaires and assessment tools show reduced incidence of anxiety and depression.

An indicator based on the CPES would incentivise local commissioners to ensure that improving patient experience continues to be prioritised, and that action plans and targeted improvements continue to be devised and implemented.

## Conclusions and recommendations

It is crucial that people with cancer are able to have a positive experience of the care they receive. The 2011/12 CPES shows that there is much room for improvement in key areas of non-clinical care that are important to patients.

**Key recommendation:** The NHS Commissioning Board should include an indicator based on the Cancer Patient Experience Survey in the COF, to ensure that local commissioners are incentivised to improve care for cancer patients.

## Summary of recommendations

This report has demonstrated that there is significant room for improvement in cancer survival rates as well as in aspects of non-clinical care that are important to cancer patients.

As the new NHS landscape takes shape, it is vital to take the opportunity to address these areas and ensure that people with cancer get the best care possible. The newly reformed NHS must therefore be incentivised to improve survival rates for all cancer types and patient experience for everyone affected by cancer.

### Key recommendations:

- The NHS Commissioning Board should include one and five year cancer survival indicators in the first iteration of the Commissioning Outcomes Framework (COF).
- Cancer survival indicators in the NHS Outcomes Framework and the COF should be expanded beyond breast, lung and colorectal to all cancer types, to ensure that people with less common and rarer cancers are not discriminated against.
- The NHS Commissioning Board should include an indicator based on the Cancer Patient Experience Survey in the COF, to ensure that local commissioners are incentivised to improve care for cancer patients.

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<sup>2</sup> Ibid.

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