

# Macmillan Cancer Support response to NICE CCG OIS Consultation



## General Comments

Macmillan's ambition is to reach and improve the lives of everyone living with cancer and to inspire millions of others to do the same. We're working with the NHS and others to ensure that everyone gets the treatment and support that's right for them.

Our vision is that whoever you are, wherever you live and whatever your circumstances, you have the treatment and drugs which are right for you. You are treated with respect and dignity and know what to expect during and in between appointments. You have the information you need to help you manage your condition and understand possible later consequences of treatment. You know what support is available to you and your loved ones such as the benefits you might be entitled to. You have a dedicated healthcare professional you trust and who you can contact if you have problems so that you and your loved ones can continue to live your lives.

We believe that it is vitally important that NICE and the Commissioning Board work together to ensure the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) incentivises commissioners to take key steps towards delivering on the above outcomes. Below we have set out our views on the proposed indicators and suggested additional indicators we believe should be included. In summary we believe the following should be prioritised:

- **The inclusion of a cancer patient experience indicator based on the Cancer Patient Experience Survey that would encourage commissioners to prioritise the provision of holistic and integrated care for cancer patients.** The indicators that relate specifically to cancer are too narrowly focused on clinical aspects of care and are not reflective of non-clinical aspects of care that are included in the NICE quality standards. We note that the equivalent consultation in 2012 proposed two indicators, *Patient Reported Outcomes Measures (PROMs): cancer & patient experience of cancer services*. Neither of these indicators has been taken forward.
- **The inclusion of the indicator, ELC05 Of people who have stated their preferred place of death, the proportion who died in their preferred place of death.** We believe this will incentivise CCGs to improve end of life care and prioritise the delivery of choice for patients about where they are cared for and die.

We note that there is inconsistency in the indicators that are being proposed for cancer patients based on tumour site. In particular, although we welcome the inclusion of an indicator on the proportion of lung cancer patients who have access to a clinical nurse specialist (CNS), it is unclear why this indicator has not been proposed for all cancer patients. The Cancer Patient Experience Survey clearly demonstrates the importance of access to a CNS for all cancer patients irrespective of site. This anomaly is most apparent with regards to the proposed breast cancer indicators, which, unlike the proposed lung

cancer indicators, do not include an indicator on access to a CNS. We would welcome clarification as to the rationale behind this decision

We are disappointed by the short timeframe given for the consultation, which impacts the ability of stakeholders to respond fully to the proposed indicators. It makes it particularly challenging to seek the views of people affected by cancer. We would welcome further opportunities to comment on the proposed indicators as they are further developed.

We are concerned by the lack of clarity as to why certain indicators e.g. *patient experience of cancer services*, that were recommended by the CCG OIS Advisory Committee, have been omitted from this consultation. We would welcome clarification regarding NICE's proposals for seeking views and developing those indicators that have been recommended but not included in this consultation document.

## Additional Indicators

### **Patient experience**

While we welcome the potential inclusion of a number of cancer-specific indicators under Domain 1, we think it is vitally important that the CCG OIS also incentivises and holds to account commissioners for improving the non-clinical care that people with cancer receive. We therefore strongly recommend that an indicator on cancer patient experience, based on the National Cancer Patient Experience Survey (CPES), is included in the 2014/15 CCG OIS.

Over the past year, Macmillan has been working together with a range of key stakeholders, including NICE, the Information Centre and the Department of Health, to examine the benefits of a cancer patient experience indicator and the form that it might take. A consensus document, agreed by a range of key stakeholders including those listed above, was produced following a workshop held in October 2012 (this has been included with our response for your information). The document highlights that the group sees merit in the inclusion of a cancer patient experience indicator in the CCG OIS. In addition, the NICE CCG OIS Advisory Committee concluded at its meeting in September that such an indicator would be *'useful in determining high quality commissioning'*. We are therefore surprised and disappointed that this indicator is not included in this consultation and would welcome clarification on why this is the case.

#### *Improvements required in cancer patient experience*

We are aware, from results of previous Cancer CPES, that there is an urgent need for improvements in cancer patient experience. This is for two reasons. The first is that there is vast variation across the country in terms of the care that cancer patients experience, and the second is that, in a number of key areas, improvements are needed across the board. For example, results from the 2011/12 CPES<sup>1</sup> 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 experience than those with more common cancers, while people in London and in more deprived areas reported less favourably on their care. At the same time, only 64% of all

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

patients who responded said they were able to discuss any worries or fears they had with staff in hospital as much as they wanted and only 24% of patients said they had been offered a written assessment and care plan.

### *Lack of meaningful indicators in the CCG OIS to drive improvements in cancer patient experience*

Based on the need for improvements in the care that cancer patients experience, we welcome the fact that the Government has prioritised patient experience by making it the focus of one of its five domains. However, at present, the lack of meaningful patient experience indicators in the 2013/14 CCG OIS and this consultation does not chime with this emphasis on improving patient experience. More specifically, it is clear that the current CCG OIS indicators under Domain 4 do not adequately capture all aspects of what is important to cancer patients in terms of their care and experience. For example, the current CCG OIS 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.

Likewise the indicator on '*patient experience of hospital care*' does not capture whether someone has access to a Clinical Nurse Specialist (CNS), yet CPES results demonstrate a strong correlation between those cancer patients who state that they have access to a CNS and those who answer positively to other questions in the CPES. This shows the central role that the CNS plays in ensuring that cancer patients have a positive experience of care. However, currently, we fear CCGs will not be incentivised through the CCG OIS to ensure that all cancer patients have access to a CNS.

### *Effectiveness of the CPES in driving improvements*

In contrast to the Adult Inpatient Survey, the CPES captures detailed, service-specific data about Trusts' performance across a range of aspects of cancer patient experience – importantly, these include aspects relating to the relationship between staff and patients as well process issues, such as waiting times. While it is collected in a hospital setting, it covers non-acute aspects of care, and looks at how well care is joined-up. We know that the CPES has already driven improvements in care at a provider level: significantly, on most questions in the 2011-12 CPES, scores improved from the 2010 Survey. In addition, all London Trusts put action plans in place following the 2010 CPES, while Portsmouth Hospitals NHS Trust, which was in the bottom ten in 2011, put plans in place to ensure improvements were made, and was the most improved Trust in England in 2012.

### *Importance and feasibility of a cancer patient experience indicator*

We firmly believe that the next step is to build on these improvements and to embed the CPES explicitly in the new NHS architecture by using it as the basis for a cancer patient experience indicator for the CCG OIS. The *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* highlights that staff and patient surveys 'continually gave signs of dissatisfaction with the way the Trust was run, and yet no effective action was taken.' This emphasises the importance of ensuring that Trusts, and those who commission services from them, are held to account for their performance as captured through key surveys, such as the CPES.

We are aware that this proposed indicator is condition-specific and could not be replicated for other conditions at this time. However, we do not believe that this should prevent this indicator from being established. Currently, over two million people are living with and beyond cancer and this will rise to four million by 2030.<sup>2</sup> In addition, we know that cancer is a unique and complex medical condition and those living with cancer can have a different experience to people with other long-term medical conditions. We are also aware of the importance of detailed, service-specific data on patient experience in supporting targeted improvements. Macmillan will be hosting a workshop in March to explore these issues further and would be happy to share the outcomes of this event with the CCG OIS team.

The availability of data from the CPES makes such an indicator feasible now. The CPES has a high sample size and response rate, and we know that data from 2010 and 2011/12 is already easily accessible for CCGs to analyse. 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 CCG OIS could be adapted to reflect these changes.

As highlighted above, a cancer patient experience indicator needs to measure what is really important to cancer patients. We would welcome the opportunity to work with NICE in developing an indicator which would achieve this.

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, ensuring that further inequalities and wider variations in cancer patient experience do not develop. An indicator would also 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.

### **Employment of people with long-term conditions**

We note that the indicator '*Employment of people with long-term conditions*', which was consulted on by NICE for inclusion in the 2013/14 iteration of the CCG OIS, has not been taken forward or included in this consultation document. This is despite the indicator being included in the NHS Outcomes Framework (NHS OF 2.2) under the improvement area '*improving functional ability for people with long-term conditions*.'

As we have stated previously, Macmillan strongly supports the inclusion of this indicator in both the Outcomes Framework and in commissioning frameworks. Work makes a significant contribution to improving quality of life for people with long-term conditions, including people with cancer. However, the NHS needs to be better incentivised to see work as a positive health outcome. An indicator on employment in the CCG OIS would act as an incentive for commissioners to help people with long-term conditions including cancer return to work.

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<sup>2</sup> Maddams J, Cancer prevalence in the United Kingdom: estimates for 2008, British Journal of Cancer, (2009)

Over 700,000 people of working age are living with cancer in the UK<sup>3</sup> and over 100,000 people of working age are diagnosed with cancer each year<sup>4</sup>. It is now widely acknowledged that work is important for health and wellbeing, and has positive health-related quality of life outcomes.<sup>5</sup> Most people with cancer want to return to work when they feel ready and well enough, but they struggle to do so. As survival rates increase, many more working age people with cancer are struggling to stay in or return to work. It has been estimated that the cost to the economy of cancer survivors being unable to return to work is £5.3 billion per year.<sup>6</sup>

One of the main reasons for this is a lack of support from health professionals and a lack of specialist vocational rehabilitation support. We believe the NHS should routinely provide information and advice on work for people with long-term conditions, and signpost people to further support should they need it. We also believe that there needs to be improved access to specialist vocational rehabilitation support for people with complex problems.

We understand that the barrier to the development of this indicator, despite its inclusion in the NHS Outcomes Framework, is that the Labour Force Survey cannot be broken down beyond a regional level, to CCG, Local Authority or provider level. **We recommend that the Department for Health and NICE urgently work with partners to understand how these data problems can be overcome.** It is also vital that the data is able to provide a clear measure for employment rates for people with cancer – currently cancer is combined with other conditions like Multiple Sclerosis, HIV and Parkinson’s Disease.

We also urge the Department and NICE to consider other ways to measure the contribution that work makes to an improved quality of life for people with long-term conditions. For example, a work question is included in the 2013/14 Cancer Patient Experience Survey, which will give us valuable data about the extent to which health professionals are raising work issues with cancer patients and will allow us to compare provider performance.

### **Colorectal cancer**

While we were pleased to see that the consultation document includes indicators on breast and lung cancer (based on quality standards), we note that potential indicators for colorectal cancer were not included. Given that there is a quality standard for colorectal cancer and CCGs will also be responsible for commissioning these services, we would welcome clarification on when it is intended to include indicators in the CCG OIS to reflect the quality standard.

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<sup>3</sup> Maddams J et al, Cancer prevalence in the United Kingdom: estimates for 2008, *British Journal of Cancer*, 2009.

<sup>4</sup> Office for National Statistics. *Cancer Registration Statistics England*, 2009. Information Services Division Scotland, Cancer Incidence Scotland, 2009. Welsh Cancer Intelligence and Surveillance Unit, Cancer Incidence Wales, 2004-2008. Northern Ireland Cancer Registry, Cancer Incidence Northern Ireland, 2009.

<sup>5</sup> Department of Health report *Quality of Life of Cancer Survivors in England: report on a pilot survey using PROMS*, 2012

<sup>6</sup> The Cost of Cancer, Policy Exchange, 2010

## Proposed Indicators

### Domain 1: Preventing people from dying prematurely

#### Cancer

##### **1.9 Cancers diagnosed via emergency routes**

##### **1.10 Cancers stage at diagnosis**

##### **1.11 Cancers detected at stage 1 or 2**

In 2011 the All Party Parliamentary Group on Cancer published a report, *Effective cancer commissioning in the new NHS*, which put forward a series of recommendations as to how the NHS can improve outcomes for cancer patients. The report outlined that as new CCGs would be smaller in size than Primary Care Trusts (PCTs), indicators on stage of cancer at diagnosis and cancers diagnosed as an emergency admission, would provide a more accurate picture of how services are being delivered at ground level.<sup>7</sup>

Therefore, we support the inclusion of the indicators 1.9, 1.10 and 1.11: *cancers diagnosed via emergency routes*, *cancers stage at diagnosis* and *cancers diagnosed at stage 1 or 2*. We believe these indicators will encourage CCGs to contract services that improve early diagnosis of cancer.

#### Breast Cancer

##### **BC30 Breast cancer mortality rates.**

##### **BC32 Recurrence rates of breast cancer by site and type of primary surgery.**

We support the inclusion of the proposed breast cancer indicators. However, as stated above, we are concerned that they are narrowly focused on clinical aspects of care. We firmly believe this highlights the need for an indicator on patient experience of cancer services.

#### Lung Cancer

##### **LC02 Lung Cancer: 3-month and 1-year survival rates from diagnosis**

##### **LC03 Lung cancer: Stage at diagnosis**

##### **LC09 Of people with lung cancer, the proportion who have been seen by a lung cancer clinical nurse specialist**

##### **LC21 Resection rates**

##### **LC22 Of people with lung cancer, the proportion who receive assessment for multimodality treatment by a multidisciplinary team comprising all specialist core members**

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<sup>7</sup> Effective cancer commissioning in the new NHS, All Party Parliamentary Group on Cancer, <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/APPG/BritainAgainstCancer2011/EffectiveCancerCommissioningintheNewNHS.pdf>

We support the inclusion of the proposed lung cancer indicators. However, as stated above, we are concerned that they are narrowly focused on clinical aspects of care. We firmly believe this highlights the need for an indicator on patient experience of cancer services.

## Domain 2: Enhancing quality of life for people with long term conditions

### Carers

Macmillan welcomes the inclusion of the improvement area 'enhancing quality of life for carers' in the CCG OIS that focuses on measuring activities linked to identifying and supporting unpaid carers. There are 1.1 million carers of people with cancer in the UK and we know that half of these carers get no support at all.<sup>8</sup> Identifying a carer is the first step in helping them access the support and information they need to maintain their own wellbeing, and do their best for the person they care for. There is a range of support that can be provided to improve the quality of life for a carer including providing opportunities for respite, accessible support services, information, care for their own health, and emotional support. Due to their unique relationship and interaction with patients and their carers, GPs (and other health professionals) have the opportunity to provide carers with information at an early stage, refer or signpost carers to local support services, or the local authority for a carer's assessment.

#### 2.19 Carers identified on practice registers

We strongly support the inclusion of an indicator to measure the identification of carers by GP practices. A study by Macmillan with carers of people with cancer suggests that the most common source of formal support received by carers is from a GP or other health professional (20%). However, less than half of carers receive any support at all, meaning there is a chronic lack of recognition of carers by the NHS<sup>9</sup>. We also know that only 5% of cancer carers receive a Carers Assessment from the local authority. Without identification by a GP or other health professional (only a minority of carers consider themselves to be 'carers', meaning self-identification is low), it is much less likely that a carer will be either referred to their local authority for a carer's assessment, or signposted to the support they may require.

However, it is not clear how performance or year on year improvement, on the identification of carers is reflected in this indicator. Carers Trust estimates that only 1 in 10 carers are currently being identified by their GP practice<sup>10</sup>. We believe the number of carers identified as a proportion of the total CCG population should be compared to the estimated/expected proportion of carers in the CCG population. This data would be available from the census or the latest Carers' Survey, and would provide CCGs with an indication of how well they are doing in identifying carers within their population, which may drive further system improvements.

We understand the management indicator included in the Quality and Outcomes Framework (QOF) that provides an incentive for practices to have a protocol for the identification of carers and to develop mechanisms for the referral of carers for social

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<sup>8</sup> Macmillan Cancer Support (2011): More than a million. Understanding the UK's carers of people with cancer.

<sup>9</sup> Supra note 1.

<sup>10</sup> Carers Trust (2013)

services assessment, is being considered for removal. If this indicator were to be removed from the QOF, there would be a concerning lack of incentives for GPs to record carers on a GP carer register, or even maintain a register such as this. We would not support this removal and believe it would detract from the welcome focus placed on identifying and supporting carers within the CCG OIS.

## **2.21 Number of information prescriptions for carers**

We also support the inclusion of an indicator on the number of information prescriptions provided to carers. An information prescription should enhance a carer's ability to provide care, and can include Macmillan information specifically for cancer carers that link the carer to local carer support services and/or the local authority.

However, it is important to recognise the provision of information prescriptions should be part of a comprehensive package of support available to a carer as this indicator on its own will not adequately drive improvements in quality of life for carers. For instance, the data collected for this indicator will not provide information on whether carers are accessing the services that they may have been signposted to, or whether the carer's quality of life has improved as a result.

Therefore, while we support the inclusion of this indicator as a useful incentive for health professionals to provide carers with some form of support, it will be important to view this indicator alongside measures that incentivise local authorities to ensure carers' needs are assessed and effectively addressed. Ultimately, while they're important, information prescriptions will only be effective if they result in better uptake of services for carers, contact with local authorities and improvements in quality of life/health of carers.

## **Domain 4: Ensuring that people have a positive experience of care**

### **End of Life**

#### **ELC05 Of people who have stated their preferred place of death, the proportion who died in their preferred place of death**

Macmillan firmly supports the inclusion of the indicator, *ELC05 Of people who have stated their preferred place of death, the proportion who died in their preferred place of death*. We believe this will incentivise CCGs to improve end of life care and prioritise delivering choice to patients about where they are cared for and die. We agree with the CCG OIS Advisory Committee that *'this indicator is useful in determining high quality end of life care as it reflects whether good services are in place across the pathway and refers to patient care plans and whether these are being delivered'*.<sup>11</sup>

The NHS Mandate now includes an ambition for the NHS to be recognised as a global leader in care for people at the end of life. We know that a fundamental part of excellent end of life care is ensuring that people approaching the end of life are able to choose where they want to be cared for and die. This is clearly set out in the End of Life Care Strategy and the End of Life Care Quality Standard. Despite this focus, only 29% of people with

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<sup>11</sup> <http://www.nice.org.uk/media/278/A7/UnconfirmedCOFACMinutes24092012.pdf>

cancer are able to die at home,<sup>12</sup> although almost three quarters (73%) would prefer to with the right support.<sup>13</sup>

Information from the National Bereavement Survey (VOICES), 2011 and information from death certification shows there is significant variation across England regarding whether people are able to die in their place of choice. For instance, only 16% of people with cancer who died in Waltham Forest in 2011 died at home, whereas the figure for Corby was 49%.<sup>14</sup>

For choice at the end of life to improve and for the ambition set out in the Mandate to be realised, it is vital that CCGs are encouraged to commission services – such as 24/7 community nursing and electronic end of life care registers – that help ensure more people's end of life preferences are met. These services can help prevent the fragmentation of end of life care provision which results in inappropriate A&E admissions and delayed discharge.

Without this focus we fear that people will continue to be admitted to and die in hospital against their wishes and at unnecessary cost to the NHS. A report by the National End of Life Intelligence Network highlights that 89% of those who die in hospital do so following an emergency admission, with the price of an inpatient admission in the last year of life that ends in death estimated to range from £2,352 - £3,779. Around 9.4 million bed days are occupied by people in the last year of life who have emergency admissions.<sup>15</sup> The estimated cost for a day of community care at the end of life is £145 compared with the cost of £425 per day for specialist palliative care in hospital. Changing the setting of end of life care can reduce the costs of care by £280 per day.<sup>16</sup>

The suggested data source for this indicator is the VOICES survey, which asks the bereaved whether their loved one expressed a preference about where they wanted to die and, if they did, where they stated they wanted to die. While we agree the survey is a useful data source for this indicator on an interim basis in the longer term we believe the data should come from Electronic Palliative Care Coordination Systems (EPaCCS) as they are rolled out nationally. EPaCCS would provide a more robust measure of whether choice has been delivered, as they record end of life preferences as indicated by the deceased as opposed to the recollection of their bereaved loved one.

We also understand that the NHS Information Centre is exploring whether the VOICES survey provides a robust enough sample for the data to be used reliably at a CCG level. Should the Information Centre conclude following testing that the VOICES survey did not provide a reliable sample on which to measure CCGs, we would urge NICE to consider alternative data sources, such as the death certification data collected by the Office of National Statistics (ONS). Although this data cannot be used to assess whether individual preferences were met, it does provide robust data as to where people died, broken down by home, hospital, hospice and care home. Given we know that a significant proportion of

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<sup>12</sup> Cancer deaths in own home by local authority, England, 2011. Office for national statistics personal communication.

<sup>13</sup> Macmillan Feb 2010 online survey of 1,019 people living with cancer. Survey results are unweighted. UK wide survey

<sup>14</sup> Cancer deaths in own home by local authority, England, 2011. Office for national statistics personal communication

<sup>15</sup> National End of Life Intelligence Network (2012) What do we know now that we didn't know a year ago? New intelligence on end of life care in England

<sup>16</sup> Marie Curie, (2012), Care Understanding the cost of end of life care in different settings

people would prefer to die at home this data source can act as a useful proxy measure for the delivery of patient choice at the end of life. Clearly, such a measure should only be used until alternative data, such as a larger VOICES survey sample or EPaCCS, is available.

**ELC28 Of people closely affected by a death, the proportion who report a satisfactory experience of:**

- **Communication**
- **Information**
- **Co-ordination of care**
- **Addressing their own needs**
- **Care around the time of death**
- **Bereavement care**
- **Pain management**

We are also pleased that in addition to an indicator relating to the delivery of choice at the end of life, an indicator that measures experience in regard to specific aspects of end of life care is also being considered. Clearly, while it is vital that choice is delivered at the end of life it is also crucial that patients receive high quality care, no matter where they choose to be cared for. We also welcome that the experiences of the bereaved in their own right are being measured by looking at how well their own needs were addressed or their experience of bereavement support.

However, we believe this indicator would be improved by breaking the results down by care setting (providing the sample is large enough) as we know there is significant variation depending on where people are cared for at the end of life. For instance, the VOICES survey shows that experiences of coordination of care for people cared for in hospital were significantly worse than for people cared for at home with 32% compared to 14% respectively reporting that services did not work well together.<sup>17</sup>

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<sup>17</sup> ONS. National Bereavement Survey (VOICES) 2011. <http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html> (accessed February 2013)