

## **Putting patients first:**

*Understanding what matters most to lung cancer patients and carers*



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## Foreword

Lung cancer is the UK's biggest cancer killer. It causes more than one in five of all cancer-related deaths<sup>1</sup>. In 2010, there were almost 35,000 deaths from lung cancer in the UK – more than twice as many deaths as the next ranked cancer<sup>2</sup>.

Unlike the majority of cancers, improvement in relative survival for lung cancer has been modest in recent years. In addition, cancer outcomes in England, including those for lung cancer, remain poor when compared with the best outcomes in the world. An estimated 1,300 deaths from lung cancer could be avoided each year if survival rates matched the best in Europe<sup>3</sup>.

Closing the gap in survival will require sustained and co-ordinated action by both policymakers and the NHS to help improve prevention, early diagnosis, access to the best possible treatments and provision of care and support for all lung cancer patients.

As well as the challenges in improving mortality and survival rates, the renewed focus on achieving better patient outcomes in the NHS also places a clear emphasis on ensuring those people living with a diagnosis of lung cancer have a positive experience of their care<sup>4</sup>.

In order to realise the ambition of providing all people with lung cancer with patient-centred care, there are a number of barriers that NHS services must tackle in order to improve the quality of care they deliver. These challenges include:

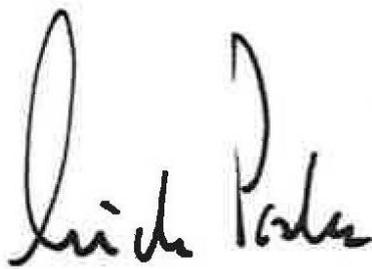
- **Delays in diagnosis** with 39% of lung cancer cases diagnosed through emergency presentation<sup>5</sup>
- **Inequalities in outcomes** of lung cancer patients linked to their age, gender and socio-economic background<sup>6, 7, 8</sup>
- **Responding to patients' full range of care and treatment needs** as a result of the physical, psychological, emotional, and practical impact of lung cancer
- **Managing the changing needs of patients at different stages in their cancer journey** – from diagnosis, to treatment, to end of life care

The United Kingdom Lung Cancer Coalition (UKLCC) is committed to providing a voice for lung cancer patients and carers, and ensuring that high quality, patient-centred services are readily accessible throughout the country.

We have undertaken a survey of patients and carers to learn more about the priorities of people affected by lung cancer when it comes to the treatment, care and support they receive.

The findings reveal worrying discrepancies between what really matters to people living with lung cancer and current national service targets, and the actual care and treatment patients receive. It also shows the clear need for action to address the general lack of support and information on lung cancer available to patients and their families, as well as the gaps in the public and professional awareness and understanding of lung cancer and its impact.

The insights we have gained and the priorities we have identified through this survey have highlighted the need to promote and embed a more patient-centred approach to lung cancer care. Our analysis and recommendations relate to the health and social care system in England, however we believe that many of these principles could be applied in Scotland, Wales and Northern Ireland to raise standards of care and improve lung cancer outcomes for patients across the whole of the UK.



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## About UKLCC

Established in November 2005, the UK Lung Cancer Coalition (UKLCC) is a coalition of the UK's leading lung cancer experts, senior NHS professionals, charities and healthcare companies.

The organisation's long-term vision is to double one year lung cancer survival by 2015 and five year survival by 2020. Such ambitions are underpinned by four key objectives:

- To raise political awareness of lung cancer
- To raise the general public's awareness of lung cancer – and especially encourage earlier presentation and symptom recognition
- To empower patients to take an active part in their care
- To improve lung cancer service in the UK

The UKLCC's full membership is set out below.

### ***Committee Members***

- Richard Steyn, Consultant Thoracic Surgeon, Birmingham Heartlands Hospital; National Cancer Advisor; Chair of the UKLCC
- Dr Mick Peake, Consultant Respiratory Physician, Glenfield Hospital; National Clinical Lead for Lung Cancer
- David Bellamy, Trainer for Education for Health
- Alison Bennett, Macmillan Lung Cancer Nurse Specialist, Barnsley District General Hospital
- Paula Chadwick, Chief Executive, Roy Castle Lung Cancer Foundation
- Frank Chinegwundoh, Clinical Director for Surgery and Anaesthesia, Newham University Hospital NHS Trust; Consultant Urological Surgeon
- Emma Gunby, Director of Marketing and PR, The Roy Castle Lung Cancer Foundation
- Naomi Horne, Macmillan Lead Lung Cancer Nurse, Llandough Hospital
- Babu Naidu, Cardio-Thoracic Surgeon at Heartlands Hospital
- Professor Stephen Spiro, Professor of Respiratory Medicine at UCL (Retired)
- Dr Andrea Williams, Representative, Primary Care Respiratory Society UK

### ***Patient advocacy organisations***

- British Lung Foundation
- Cancer Black Care
- Cancer Research UK
- Macmillan Cancer Support
- Marie Curie Cancer Care
- Roy Castle Lung Cancer Foundation

## ***Professional Groups***

- British Thoracic Society
- National Lung Cancer Forum for Nurses
- Primary Care Respiratory Society UK

## ***Healthcare companies***

- AstraZeneca
- Lilly & Co Limited
- Pfizer Limited
- Roche Products Limited

This survey and report have been developed by MHP Health, a specialist health policy consultancy, who provide communications and campaigning support to UKLCC.

### Key findings

- Prompt referral to a hospital and quick access to appropriate tests were rated as the two most important determinants of high quality care
- Despite a large majority of respondents rating prompt access to tests as “very important”, only 54 per cent confirmed that this occurred through the care they, or the person they cared for, received. Only 64 per cent stated that they were referred in a timely manner
- Almost half (45 per cent) of those who completed the survey noted that they, or the person they cared for, had perceived delays at some point during the lung cancer care pathway
- 40 per cent of respondents indicated that compassionate and understanding care from the GP was not a consistent hallmark of the care given to them, or the person they cared for
- Rather than being informed about the stage of disease, almost two-fifths (38 per cent) of respondents confirmed that they had either simply been notified that their cancer had spread or were explicitly not told about the extent to which the cancer had spread
- Although three quarters of respondents described being given a care plan as “very important”, less than half (46 per cent) could confirm that they, or the person they cared for, had been offered a personalised plan with tailored treatment goals
- Almost a quarter (22 per cent) of respondents did not receive continuous support from a clinical nurse specialist or keyworker
- Four in ten respondents stated that awareness and understanding about lung cancer among the general population was low
- Based on their experiences, 40 per cent of respondents described the level of understanding of lung cancer demonstrated by their GP as “variable”, “not enough” or “not at all”
- Most respondents were happy with the overall standard of care they, or the person they cared for, received. Over half (52 per cent) rated the care as ‘excellent’, a further 23 per cent felt that it was ‘very good’

### Recommendations

- **Clinical commissioning groups (CCGs), and member GP practices, should work in partnership with patient groups and local Healthwatch bodies to host workshops with lung cancer patients and carers to design more patient-centred care and help to direct resources towards the interventions that matter most to patients**
- **Local hospital trusts providing lung cancer services should produce action plans setting out steps aimed at improving the experiences reported by patients. These measures could be included within the annual quality accounts which NHS trusts are required to publish**
- **Local commissioners should require evidence of compliance with all the statements set out in the lung cancer quality standard, including those central to patient-centred care, as part of the standard contract with providers**
- **NHS England should ensure that indicators in national frameworks reflect what is important to cancer patients and encourage continued improvements in care**
- **Providers should ensure that all lung cancer patients receive a personalised care plan, based on their individual needs and preferences, setting tailored treatment goals. These should be routinely reviewed and updated, and shared with the patients' GP.**
- **Using Patient Reported Outcome Measures (PROMs) to collect patient symptoms, concerns and quality of life data routinely from diagnosis onwards, will help focus on what really matters to patients.**
- **CCGs should work with local authorities to deliver targeted advertising campaigns, building on the key messages from the 'Be Clear on Cancer' programme**
- **Health and wellbeing boards should evaluate local lung cancer risk based on population demography and make recommendations within their JHWBS to ensure high quality commissioning based on local priorities**
- **Academic Health Science Networks should support CCGs to develop the workforce and equip health professionals with the appropriate communications and shared decision-making skills, and consider involving current and recovering patients in designing training**



## Survey methodology

The survey looked to gather the views of lung cancer patients and carers from across the UK on what constitutes high quality care for people affected by lung cancer and their beliefs about what more can be done to deliver more effective, patient-centred care.

The survey included 14 key questions on aspects of lung cancer provision, including awareness, diagnosis, treatment and support. A full list of the survey questions can be found in Annex 1.

To help gather qualitative information about patients' experiences a number of free text boxes were provided to afford respondents the opportunity to share any additional insights or examples from the care and treatment they experienced or observed.

The survey was available both online and in hard copy. In total, we received 432 responses from patients and their carers between 5 June and 19 July 2013. A breakdown of the characteristics of those who completed the survey has been set out below. These raw figures broadly reflect the profile of lung cancer patients with incidence rising significantly from around the age of 40.

### Profile of respondents

- 171 (40.1 per cent) of respondents were people living with lung cancer
- 63 (14.8 per cent) of respondents were people who had previously had lung cancer
- 164 (38.2 per cent) of respondents care, or had previously cared, for someone living with lung cancer
- 29 (6.8 per cent) of respondents indicated 'other'
- The age of respondents was distributed as follows:
  - 0-15: 4 (0.9 per cent)
  - 16-24: 5 (1.2 per cent)
  - 25-29: 6 (1.4 per cent)
  - 30-39: 27 (6.3 per cent)
  - 40-49: 42 (9.9 per cent)
  - 50-59: 80 (18.8 per cent)
  - 60-69: 147 (34.5 per cent)
  - 70-79: 83 (19.5 per cent)
  - 80-89: 23 (5.4 per cent)
  - 90+: 2 (0.5 per cent)
- 179 (42 per cent) of respondents were male
- 236 (55.4 per cent) of respondents were female
- 339 (79.6 per cent) of respondents indicated that they live in England
- 6 (1.4 per cent) of respondents indicated that they live in Northern Ireland
- 38 (8.9 per cent) of respondents indicated that they live in Scotland
- 43 (10.1 per cent) of respondents indicated that they live in Wales

### Making lung cancer services more patient-centred

Providing care based on the needs of individual service users is one of the fundamental principles of the NHS<sup>9</sup>. The provision of patient-centred care is now regarded as an integral part of efforts to improve the quality of services.

Efforts to improve the quality of NHS services are underpinned by the NHS Outcomes Framework which sets out the indicators for measuring health outcomes at a national and local level<sup>10</sup>. Table 1 sets out suggestions on how a patient-centred approach to lung cancer care could help the NHS to deliver against all five areas of the NHS Outcomes Framework.

**Table 1 – Suggested markers of patient-centred lung cancer services for each domain of the NHS Outcomes Framework<sup>11</sup>**

#### Domain 1: Preventing people from dying prematurely

- Awareness campaigns targeted at high-risk groups to encourage early diagnosis
- Provision of prompt diagnostic testing
- Identification of patients for urgent referral
- Access to high quality treatment

#### Domain 2: Enhancing quality of life

- Information and advice on self-management
- Prompt access to effective treatment, and better access to interventions for people with advanced disease
- Provision of emotional and psychological support
- Access to support networks and groups

#### Domain 3: Helping people recover from episodes of ill health

- Enhanced recovery approaches following surgery
- Continuity of care to support rehabilitation and recovery where appropriate
- Tailored community-based support

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

- Giving appropriate information to enable patients to be fully involved in decisions about their treatment and care
- Supporting patients to exercise choice about how and where they receive their care
- Patients treated as individuals - 'not a set of symptoms' - and with dignity and respect
- Continuity across the stages of a patient's care pathway

## Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

- Delivery of chemotherapy in line with safety protocols
- Provision of clear information about treatment options, including anticipated side effects
- Access to high quality acute oncology services

In lung cancer, there is a clear need to embed patient-centred care – an approach which ensures that all lung cancer patients are offered a co-ordinated package of advice, information, treatment and support, tailored to their ongoing needs and preferences.

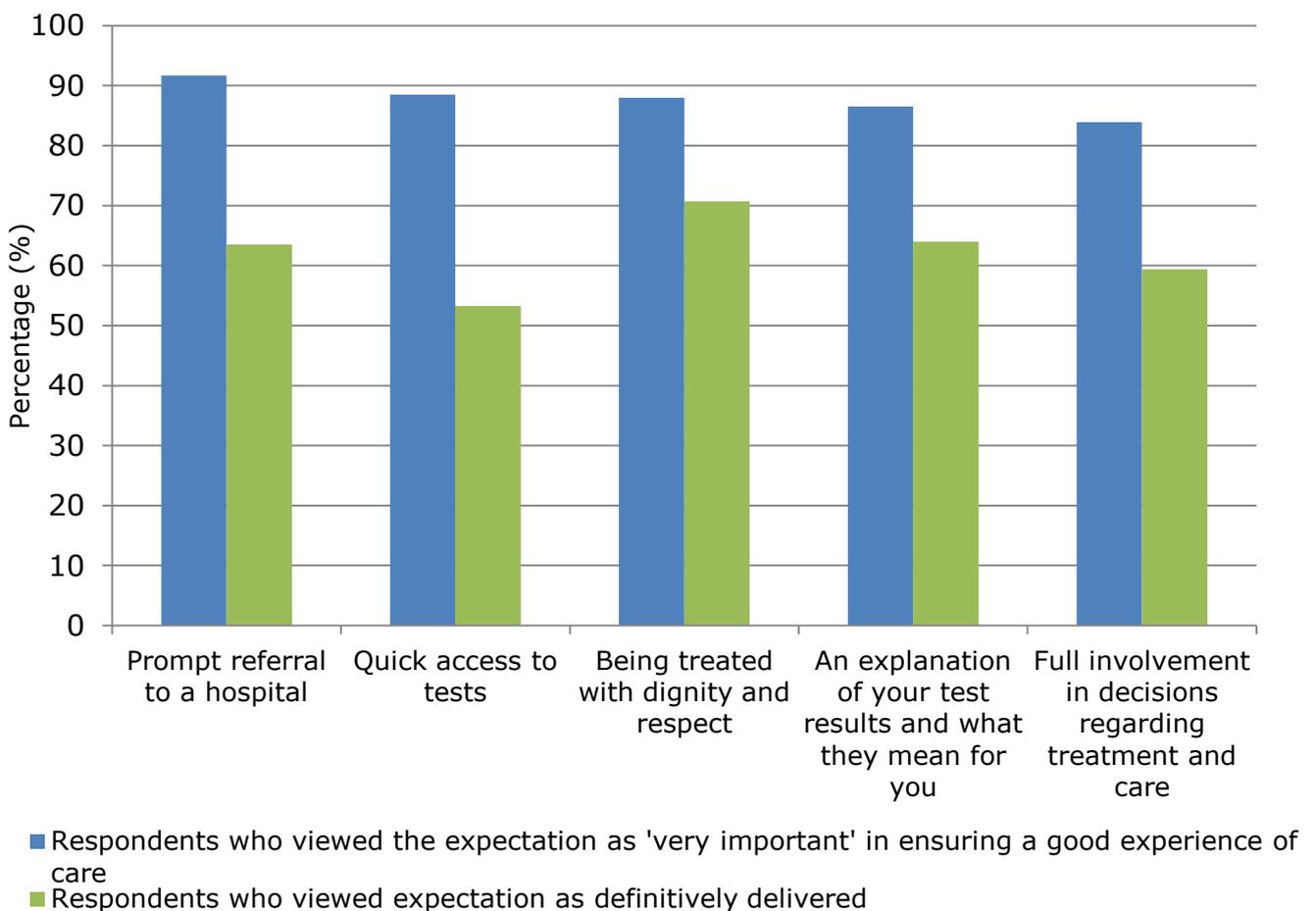
## Understanding what matters most to people affected by lung cancer

Patient experience has become an important way of measuring the quality of NHS services. Gathering feedback on the quality of care across the whole patient pathway, from those with firsthand experience of using NHS services, is crucial to informing changes in the way that care is organised and provided. For example, the *National Cancer Patient Experience Survey*<sup>12</sup> has been established in England as a means of tracking how effective national and local lung cancer services are in delivering patient-centred care, based on the views of patients themselves.

*What do people expect from lung cancer services?*

Through our survey, we asked respondents to rate the importance they attached to a series of statements associated with different aspects of care, and separately specify whether the care they received delivered fully, partly or wholly against these statements. A comparison of these scores for those aspects of care they prioritised most is set out in Figure 1 below.

**Figure 1 – Comparison of expectations and experiences of people affected by lung cancer on key aspects of care**



Prompt referral to a hospital (92 per cent) and quick access to tests (88 per cent) were rated as “very important” markers of a good experience of care. It is concerning therefore that only 64 per cent of respondents stated that they, or the person they cared for, felt that they received a prompt referral.

There was also a significant gap between the proportion of people prioritising quick access to tests as “very important” (88 per cent) and the percentage reporting that this was definitely delivered (54 per cent). A further 26 per cent claimed that this was only true “to some extent”.

It is imperative that people with suspected lung cancer are referred to hospital in a timely manner for the appropriate tests to investigate the type and stage of their disease, in line with national waiting time targets. This will also pose the least risk to the patient. The lung cancer quality standard makes clear that people reporting one or more symptoms suggesting lung cancer are referred within one week of presentation for a chest X-ray, or directly to a chest physician who is a core member of the lung cancer multidisciplinary (MDT) team<sup>13</sup>.

### *Problems and delays*

Separately, we asked respondents to indicate whether they, or the person that they cared for, encountered any delays throughout their care. Of those who responded, 45 per cent experienced perceived delays, with a number of specific examples of delays cited during the diagnostic phase of their care. Some of these problems encountered are set out in the box below.

Lung cancer carer, Yorkshire and Humber:

***"The lung cancer was missed by the local doctors and only diagnosed in hospital even though X-rays were taken."***

Lung cancer carer, South West:

***"Once my mother was admitted to hospital the care was excellent. The diagnosis and not being taken seriously by the GP and locums were the problem."***

Male lung cancer patient, 50-59 years old, North West:

***"Took ages to get a proper biopsy done."***

Lung cancer carer, East of England:

***"Took too long for the cancer to be diagnosed, they were reluctant to give an MRI scan, we had to pay for one."***

Male lung cancer patient, 50-59 years old, Yorkshire & Humber:

***"The diagnosis, evaluation, tests and commencement of treatment was extremely prompt. I have nothing but praise for all staff."***

As the gatekeepers to investigation and referral, GPs have a key role to play in helping to detect lung cancer at an early stage. However, this task is made difficult as a GP would typically expect to encounter a new lung cancer approximately once every 8 months, and so recognising new symptoms can be particularly difficult with a patient who has an established respiratory disease. This is reflected in data from the *National Cancer Patient Experience Survey* for 2012/13, which revealed that almost a third (32%) of lung cancer patients had to see their GP more than twice before being referred to hospital<sup>14</sup>.

One of the most revealing findings from our survey questions, looking at the expectations and experiences of people affected by lung cancer, was the proportion of respondents who stated that they, or the person they cared for, had an understanding and compassionate GP. Recognised by 82 per cent of respondents as being a "very important" facet of high quality care, over 40 per cent of those who answered stated that this was not the case either at all, or some of the time, during their care.

We also asked those surveyed to rate the overall quality of care that they, or the person they care for, received. Positively, three in four of those surveyed considered the care they had as 'excellent' (52 per cent) and 'very good' (23 per cent).

### Recommendations:

- **Clinical commissioning groups (CCGs), and member GP practices, should work in partnership with patient groups and local Healthwatch bodies to host workshops with lung cancer patients and carers to design more patient-centred care and help to direct resources towards the interventions that matter most to patients**
- **Local hospital trusts providing lung cancer services should produce action plans setting out steps aimed at improving the experiences reported by patients. These measures could be included within the annual quality accounts which NHS trusts are required to publish**
- **Local commissioners should require evidence of compliance with all the statements set out in the lung cancer quality standard, including those central to patient-centred care, as part of the standard contract with providers**
- **NHS England should ensure that indicators in national frameworks reflect what is important to cancer patients and encourage continued improvements in care.**

### **Addressing the information and support needs of lung cancer patients**

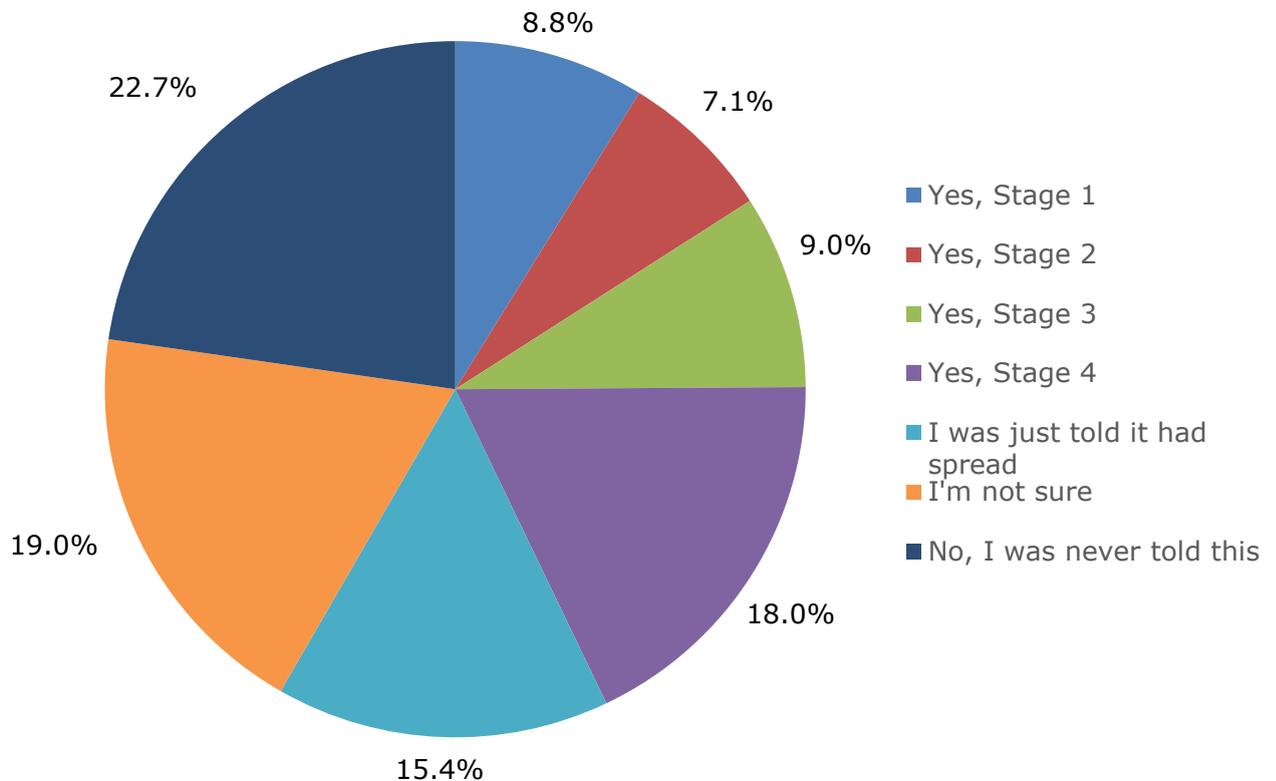
Tailored information and regular support should be key elements of the care available to lung cancer patients and their families. These elements help to provide clarity and understanding about the nature of their condition and how it can be managed. It is also vital in helping patients and their families to make informed choices about their care and treatment during what can be a very difficult time following diagnosis.

#### *Information on lung cancer patients on their condition*

The *National Cancer Patient Experience Survey* revealed that only 65 per cent of lung cancer patients received appropriate written information about their condition – less than the average across all cancer types. Furthermore, only three out of four lung cancer patients indicated that they fully understood the explanation of what was wrong with them<sup>15</sup>.

In our survey, we asked respondents to indicate if they, or the person they cared for, were notified about the stage of their lung cancer at the time of diagnosis (figure 2). Tellingly, almost two-fifths (38 per cent) of respondents confirmed that they had either simply notified that their cancer had spread or were explicitly not told about the extent to which the cancer had spread. A further 19 per cent stated that they were 'unsure' or 'unable to recall' this information.

**Figure 2 – Were you told the stage of the lung cancer when you/the person you care for were diagnosed?**



### *Patient involvement in their care and treatment*

All lung cancer patients should be actively involved in decisions about how their condition is managed. Assisting and enabling patients and their carers to understand the specifics of their own condition and the implications of their prognosis is crucial to helping patients to play an active role in discussions about their care and treatment.

To make shared decision-making a reality in lung cancer, patients must be supported by healthcare professionals to make fully-informed, meaningful choices about investigations, treatment and care that reflect what is important to them<sup>16</sup>.

Greater patient involvement and shared decision-making extends to enabling patients to set realistic care and treatment goals in partnership with their clinicians. Following their diagnosis, people with lung cancer should receive a written assessment and tailored care plan, based on their individual needs and preferences. These should be routinely reviewed and updated, and shared with the patients' GP.

75 per cent of the respondents to our survey described being given a care plan as “very important”, although less than half (46 per cent) could confirm that they, or the person they cared for, had been offered a care plan. This mirrors the same gap in provision of care plans highlighted in the *National Cancer Patient Experience Survey*<sup>17</sup>.

The care plan should be reviewed at each key stage of care to monitor the holistic needs of patients with input from doctors, nurses and allied health professionals where appropriate, assessing whether a referral to a specialist service is appropriate. A more personalised approach should also include exploring the potential for tailored outcome goals through Patient Reported Outcome Measures (PROMs). These would be developed by patients in partnership with clinicians, to focus on those aspects of care that matter most to them.

### *Patient support and advice*

Clinical guidance makes clear that the care of every person diagnosed with lung cancer should be managed and discussed by a multidisciplinary team (MDT) consisting of healthcare professionals with skills, knowledge and experience in the diagnosis, treatment and care of a person with lung cancer. Membership of an MDT should include a trained clinical nurse specialist (CNS) to provide support and information for patients and their families<sup>18</sup>.

Access to a CNS has been shown to play a vital role in the delivery of high quality, patient-centred care and treatment to people with cancer<sup>19</sup>. As well as those patients allocated a CNS being more positive about the experience of their care, access to a CNS has also been identified as increasing the chances of a patient receiving chemotherapy<sup>20</sup> and helping to reduce emergency admissions and inpatient stays<sup>21</sup>.

It is concerning, therefore, that our survey revealed that almost a quarter (22 per cent) of respondents did not receive continuous support from a CNS or keyworker and there is evidence of significant variation in the number of full-time CNSs available in local areas<sup>22</sup>. When clinical resources are stretched it will often be to the detriment of patient care, as a number of comments below indicate.

#### **Female lung cancer patient, North West:**

*"I was dependent on the nurses who already have a heavy workload..."*

#### **Lung cancer carer, 50-59, South West:**

*"I understand that the nurses are under pressure but we would have liked more honesty and counselling/support..."*

It is imperative that the allocation of a CNS must not be seen as an end in itself. Lung cancer patients should have meaningful and regular access to a CNS in order to: help meet their individual care needs; understand their treatment options; and identify emerging issues associated with treatment side effects that might require medical attention.

### Recommendations:

- **Providers should ensure that all lung cancer patients receive a personalised care plan, based on their individual needs and preferences, setting tailored treatment goals. These should be routinely reviewed and updated, and shared with the patients' GP**
- **Using PROMs to collect patient symptoms, concerns and quality of life data routinely from diagnosis onwards, will help focus on what really matters to patients**

### Driving better awareness and understanding of lung cancer

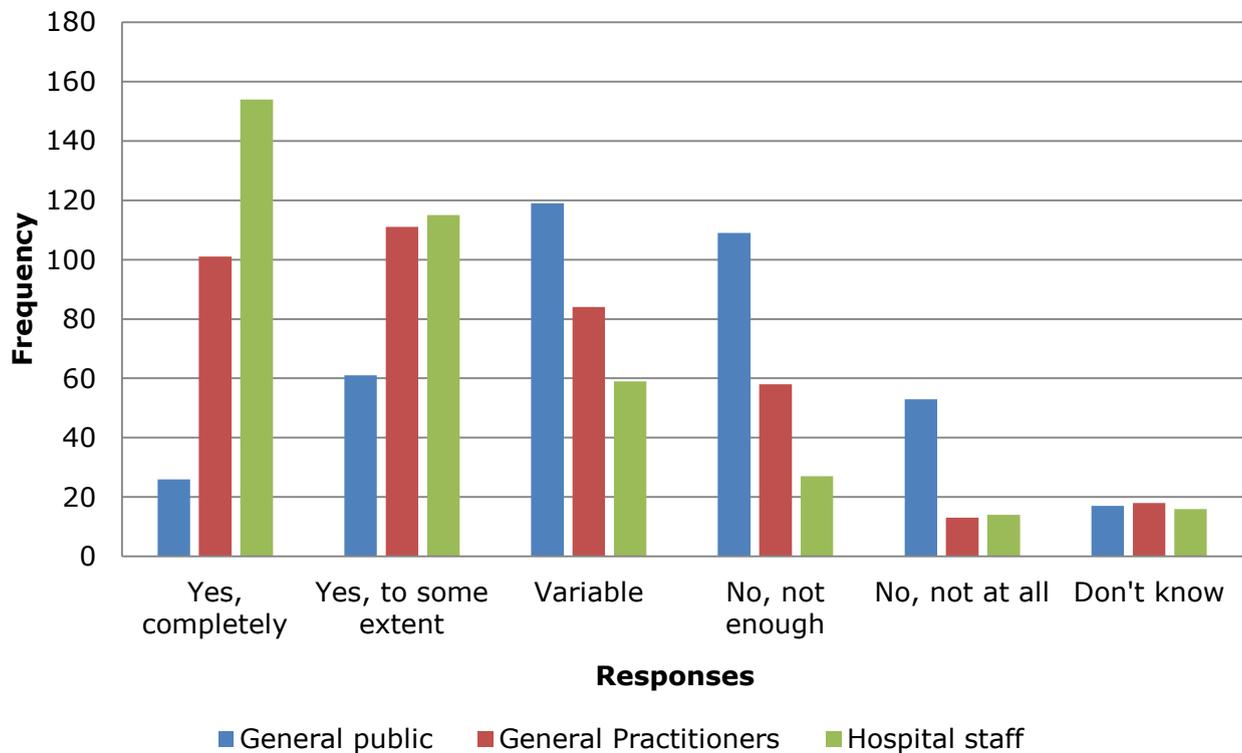
Survival rates for lung cancer in the UK are poorer than in several other European countries. Statistics show that around 70% of lung cancer patients in England are diagnosed with late stage disease – when the cancer has already spread and curative treatment is not an option. In contrast, only around 15% of cases are diagnosed at the earliest stage, when treatment is most likely to be successful<sup>23</sup>.

Detecting lung cancer cases earlier will be vital to the NHS in delivering against the aim of saving 5,000 lives each year by 2014/15 as set out in *Improving outcomes: a strategy for cancer*<sup>24</sup>. To support this goal, Public Health England, working in partnership with the Department of Health and NHS England, launched a national lung cancer symptom awareness campaign in July and August 2013 as part of its 'Be Clear on Cancer' initiative<sup>25</sup>. The national campaign was targeted at men and women, over the age of 50 from lower socioeconomic groups, to encourage them to see their GP if a cough persists for three weeks or more.

Through our survey, we asked respondents for their general views on the extent to which the general public, GPs and hospital staff understand the effect of lung cancer on an individual patient and their families. The findings highlighted a belief that there is a clear lack of awareness of lung cancer among the wider population. A previous academic survey which asked people to list possible warning signs of lung cancer exposed the scale of this knowledge gap with only 5 per cent of a 1,500 sample identifying a persistent cough as a potential indicator<sup>26</sup>.

Figure 3 below also points to a need to improve GP awareness of lung cancer and its impact on patients. Based on their experiences, 40 per cent of respondents to our survey described the level of understanding demonstrated by their GP as "variable", "not enough" or "not at all". Overall, the results revealed a perception of mixed levels of understanding and awareness among the public and primary care professionals. Those surveyed were more positive about the levels of understanding demonstrated by hospital staff, although there was still clear variation between areas.

**Figure 3 – To what extent do you feel there is enough understanding of the impact of lung cancer on patients and their families among key groups?**



Female lung cancer patient, 60-69 years old, West Midlands:

***"The stigma of lung cancer and smoking still determines people's perception and acceptance..."***

Lung cancer carer, West Midlands:

***"Hospital staff who deal with this illness have a great understanding. Other hospital staff may not be as compassionate..."***

Female lung cancer patient, 50-59 years old:

***"Most people think lung cancer is your own doing... Greater awareness is needed so we are supported in the same way as other cancer sufferers..."***

A range of resources were developed at a national level to support GP practices, pharmacy teams and local community volunteers throughout the 'Be Clear on Cancer' campaign for lung cancer. Local commissioners in areas of high mortality rates should consider implementing targeted public awareness campaigns coordinated to promote understanding about the symptoms and signs of lung cancer to help encourage early presentation, building on the key messages from the 'Be Clear on Cancer' programme.

In order to improve understanding about lung cancer among the wider population, tackling system and cultural barriers to early presentation within the NHS, and primary care in particular, is also important. The results of our survey and some of the patient testimonies demonstrate that GPs need to be better supported through education and training on the consequences of being diagnosed with lung cancer and undergoing treatment.

As we previously indicated, people affected by lung cancer value greatly having an understanding and compassionate GP who is sensitive to their individual needs and preferences. This relationship will then ensure that they will be able to consider when it is appropriate to refer or signpost a patient for specialist advice and care.

Commissioners and providers of lung cancer services are required to consider how best to ensure that their clinicians have the necessary skills to communicate effectively with patients<sup>27</sup>. Academic Health Science Networks (AHSNs) have been established to help align education, training and healthcare delivery. As part of their remit, AHSNs have a key role in supporting the development of NHS staff through education and training to enhance the capacity and capability of personnel<sup>28</sup>. This should include supporting CCGs to develop the workforce and equip health professionals with appropriate communications and shared decision-making skills.

### **Recommendations:**

- **CCGs should work with local authorities to deliver targeted advertising campaigns, building on the key messages from the 'Be Clear on Cancer' programme.**
- **Health and wellbeing boards should evaluate local lung cancer risk based on population demography and make recommendations within their JHWBS to ensure high quality commissioning based on local priorities.**
- **Academic Health Science Networks should support CCGs to develop the workforce and equip health professionals with the appropriate communications and shared decision-making skills, and consider involving current and recovering patients in designing training.**

### Conclusion

The factors which affect the quality of care and support that lung cancer patients receive are complex and wide ranging. Gathering feedback on the standard of care and support available to those with firsthand experience of using NHS services is crucial to informing improvements in the way that care is organised and delivered.

As the findings of our survey highlight, there are still significant challenges in improving access to patient-centred care for people affected by lung cancer. Developments such as the publication of the NICE quality standard for lung cancer and updates to the NHS Mandate and NHS Constitution represent welcome steps forward in clearly articulating patients' rights and promoting more patient-focussed outcomes.

To translate these resources and principles into the right interventions for lung cancer patients, commissioners and providers of services should look to work in partnership with a range of other organisations and sectors within the health and social care system to achieve this goal.

Our recommendations for decision-makers within the restructured health system are intended to help ensure that patient-centred care is routinely available to every person diagnosed with lung cancer throughout the country. We hope to work in partnership with policy-makers, the NHS nationally and locally, so that all lung cancer patients in the UK can expect to receive the care and treatment that will make the biggest difference for them and their families.

## Annex 1: Survey results

An overview of the findings from the UKLCC's patient and carers' survey is set out below. Free text answers have been omitted from this summary:

<b>1. Which of the following statements most closely describes you?</b>	
<i>Answered question</i>	426
I am living with lung cancer	40.1%
I have had lung cancer	14.8%
I care for someone living with lung cancer	13.1%
I cared for someone with lung cancer who has now passed away	25.1%
Other	6.8%

<b>2. In which age bracket are you? If you are or were a carer, please tick the age of the person you care or cared for.</b>	
<i>Answered question</i>	426
0-15	0.9%
16-24	1.2%
25-29	1.4%
30-39	6.3%
40-49	9.9%
50-59	18.8%
60-69	34.5%
70-79	19.5%
80-89	5.4%
90+	0.5%
Rather not say	1.6%

<b>3. Which gender are you? If you are a carer, please tick the gender of the person you care or cared for.</b>	
<i>Answered question</i>	426
Male	42.0%
Female	55.4%
Rather not say	2.6%

<b>4. Which ethnicity are you? If you are a carer, please tick the ethnicity of the person you care or cared for.</b>	
<i>Answered question</i>	426
White (British, Irish or other white)	95.1%
Asian or Asian British	1.2%
Black or Black British	0.5%
Mixed background	0.2%
Other	0.7%
Rather not say	2.3%

<b>5. In which part of the UK do you live?</b>	
<i>Answered question</i>	426
<b>East Midlands</b> (Derbyshire, Leicestershire, Nottinghamshire, Northamptonshire, Rutland)	6.6%
<b>East of England</b> (Bedfordshire, Cambridge, Essex, Hertfordshire, Norfolk, Suffolk)	5.4%
<b>Greater London</b>	5.4%
<b>North East</b> (County Durham, Northumberland, Teesside, Tyne & Wear)	7.0%
<b>North West</b> (Cumbria, Lancashire, Greater Manchester, Cheshire, Merseyside)	12.4%
<b>South East</b> (Berkshire, Buckinghamshire, Hampshire, Isle of Wight, Kent, Oxfordshire, Surrey, Sussex)	9.4%
<b>South West</b> (Bristol, Cornwall, Devon, Dorset, Gloucestershire, Somerset, Wiltshire)	9.4%
<b>West Midlands</b> (Birmingham and West Midlands, Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire)	8.0%
<b>Yorkshire and the Humber</b> (North Yorkshire, West Yorkshire, South Yorkshire, East Riding and Humberside)	16.0%
<b>Northern Ireland</b>	1.4%
<b>Scotland</b>	8.9%
<b>Wales</b>	10.1%

<b>6. How long have you/the person you care for been diagnosed with cancer? If you are answering for someone who has passed away, please tick the box that indicates how long they lived with lung cancer from their diagnosis)</b>	
<i>Answered question</i>	423
Less than 3 months	18.4%
3-6 months	18.0%
6-12 months	17.0%
12-24 months	20.3%
24 months-5 years	15.1%
More than 5 years	5.7%
More than 10 years	1.2%
Don't know	4.3%

<b>7. The 'stage' of a cancer tells you how large the tumour is and whether it has spread to other parts of the body. Were you told the stage of the lung cancer when you/the person you care for were diagnosed?</b>	
<i>Answered question</i>	422
Yes, Stage 1	8.8%
Yes, Stage 2	7.1%
Yes, Stage 3	9.0%
Yes, Stage 4	18.0%
I was just told that it had spread	15.4%
I'm not sure	19.0%
No, I was never told this	22.7%

<b>8. Which of the following types of diagnostic tests did you/the person you care for receive?</b>			
<i>Answered question</i>			417
	<b>Yes</b>	<b>No</b>	<b>Not sure</b>
Chest x-ray	96.4%	1.3%	2.3%
Biopsy (where a small sample of tissue is taken)	87.1%	8.6%	4.3%
Bronchoscopy (a procedure used to view a patient's lungs and airway)	75.0%	15.5%	9.9%
PET CT scan (state of the art imaging tool to pinpoint a patients cancer before treatment)	86.8%	9.0%	4.9%
Other	74.0%	12.3%	15.1%

<b>9. The way that lung cancer is treated will depend on the diagnosis. Which of the following types of treatment did you/the person you care for receive?</b>			
<i>Answered question</i>			412
	<b>Yes</b>	<b>No</b>	<b>Not sure</b>
Surgery	50.6%	45.9%	3.5%
Chemotherapy	81.3%	14.8%	3.9%
Radiotherapy	61.4%	30.3%	8.2%
Supportive care	63.7%	27.9%	8.4%
Other	49.4%	42.0%	8.6%

## Putting patients first

**10. Here are a number of statements that describe possible experiences of care. Thinking about the GP practice and hospital at which you received most of your treatment and care, please tick in the box you think describes your experience/the experience of the person you care for.**

<i>Answered question</i>				396
	<b>Yes</b>	<b>Yes, to some extent</b>	<b>No</b>	<b>Did not need</b>
An understanding and compassionate GP	56.3%	25.8%	14.4%	3.5%
Prompt referral to a hospital	63.1%	12.6%	20.7%	2.5%
Information about the disease	55.8%	26.5%	14.1%	3.5%
Quick access to tests	53.3%	25.5%	17.2%	4.0%
An explanation of your test results and what they meant for your treatment	64.4%	24.5%	8.8%	2.3%
Full involvement in decisions regarding treatment and care	59.6%	23.0%	14.1%	3.3%
Information about your treatment options including potential side effects	63.4%	21.5%	11.6%	3.5%
A clear care plan setting out the different steps in your care	45.7%	23.5%	25.3%	5.6%
Continuous support from a clinical nurse specialist or keyworkers	51.5%	22.7%	21.5%	4.3%
Access to your consultant throughout the course of your treatment	53.8	27.8%	13.6%	4.8%
Treatment at a hospital near where you live	71.0%	14.1%	10.9%	4.0%
Offered financial information and support	40.7%	16.9%	31.3%	11.1%
Being treated with dignity and respect	71.0%	19.2%	7.6%	2.3%
Being able to return home after your treatment	79.0%	9.8%	4.3%	6.8%
Information about patient groups and support networks and how to get in touch with them	39.4%	21.7%	32.6%	6.3%
Emotional and psychological support	31.1%	28.0%	32.1%	8.8%
Advice and support for your family and friends	35.4%	27.0%	30.1%	7.6%
Ability to continue everyday tasks after treatment	33.3%	36.1%	23.0%	7.6%

## Putting patients first

### 11. Which of the following do you/the person you care for think are most important in ensuring that patients have a good experience of treatment and care?

Answered question				388
	Very important	Important	Less important	Not important
An understanding and compassionate GP	81.7%	11.9%	1.8%	4.6%
Prompt referral to a hospital	91.8%	3.6%	0.0%	4.6%
Information about the disease	79.4	14.9%	1.3%	4.4%
Quick access to tests	88.4%	5.9%	0.3%	5.4%
An explanation of your test results and what they meant for your treatment	86.3%	8.5%	1.0	4.1%
Full involvement in decisions regarding treatment and care	83.8%	8.8%	1.3%	6.2%
Information about your treatment options including potential side effects	83.0%	10.3%	0.8%	5.9%
A clear care plan setting out the different steps in your care	75.0%	17.8%	0.8%	6.4%
Continuous support from a clinical nurse specialist or keyworker	75.3%	18.0%	2.1%	4.6%
Access to your consultant throughout the course of your treatment	69.8%	22.2%	2.8%	5.2%
Treatment at a hospital near where you live	70.4%	20.4%	3.9%	5.4%
Offered financial information and support	52.6%	28.6%	9.8%	9.0%
Being treated with dignity and respect	87.6%	7.0%	0.3%	5.2%
Being able to return home after your treatment	71.9%	19.8%	3.1%	5.2%
Information about patient groups and support networks and how to get in touch with them	45.9%	37.9%	9.3%	7.0%
Emotional and psychological support	63.1%	23.2%	5.9%	7.7%
Advice and support for your family and friends	59.3%	27.3%	6.4%	7.0%
Ability to continue everyday tasks after treatment	57.5%	33.8%	3.4%	5.4%

### 12. Did you/the person you care for encounter any delays or difficulties during your experience? Please provide additional information using the available text box below.

Answered question		387
Yes	45.5%	176
No	47.8%	185
Don't know	6.7%	26

## References

- <sup>1</sup> Cancer Research UK, *Lung cancer mortality statistics*, April 2012. Webpage accessed 6 November 2013 via <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/lung/mortality/>
- <sup>2</sup> Cancer Research UK, *Lung cancer mortality statistics*, April 2012. Webpage accessed 6 November 2013 via <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/lung/mortality/>
- <sup>3</sup> Department of Health, Campaigns to promote earlier diagnosis of cancer (Gateway Ref: 16390), August 2011. Webpage accessed via: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215493/dh\\_128972.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215493/dh_128972.pdf)
- <sup>4</sup> Department of Health, *Equity and excellence: Liberating the NHS*, July 2010
- <sup>5</sup> National Cancer Intelligence Network (NCIN), *Routes to Diagnosis*, November 2010
- <sup>6</sup> Department of Health, *Improving Outcomes: A Strategy for Cancer*, January 2011
- <sup>7</sup> Health and Social Care Information Centre, *National Lung Cancer Audit*, December 2012
- <sup>8</sup> Cancer Research UK, *Lung cancer survival statistics*, June 2012. Webpage accessed 6 November 2013 via <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/lung/survival/#age>
- <sup>9</sup> Department of Health, *A consultation on strengthening the NHS Constitution*, November 2012
- <sup>10</sup> Department of Health, *The NHS Outcomes Framework 2013/14*, November 2012
- <sup>11</sup> Department of Health, *The NHS Outcomes Framework 2013/14*, November 2012
- <sup>12</sup> Quality Health, *National Cancer Patient Experience Survey 2012-13 National Report*, August 2013
- <sup>13</sup> National Institute for Health and Care Excellence (NICE), *Quality standard for lung cancer*, March 2012
- <sup>14</sup> Quality Health, *National Cancer Patient Experience Survey 2012-13 National Report*, August 2013
- <sup>15</sup> Quality Health, *National Cancer Patient Experience Survey 2012-13 National Report*, August 2013
- <sup>16</sup> National Institute for Health and Care Excellence (NICE), *QS15: Quality standard for patient experience in adult NHS services*, February 2012
- <sup>17</sup> Quality Health, *National Cancer Patient Experience Survey 2012-13 National Report*, August 2013
- <sup>18</sup> UKLCC, *The Dream MDT for lung cancer: Delivering high quality lung cancer care and outcomes*, November 2012
- <sup>19</sup> Quality Health, *National Cancer Patient Experience Survey 2012-13 National Report*, August 2013
- <sup>20</sup> IMS Health, *Bridging the Gap: Why some people are not offered the medicines that NICE recommends*, November 2012
- <sup>21</sup> National Cancer Action Team (NCAT) and Macmillan Cancer Support, *Excellence in Cancer Care: The Contribution of the Clinical Nurse Specialist*, 2010
- <sup>22</sup> National Cancer Action Team (NCAT), *2011 Census of Cancer Specialist Nurses in England*, May 2012
- <sup>23</sup> Health and Social Care Information Centre (HSCIC), *National Lung Cancer Audit Report 2012*
- <sup>24</sup> Department of Health, *Improving outcomes: a strategy for cancer*, January 2011
- <sup>25</sup> Public Health England, *Be Clear on Cancer National reminder lung cancer campaign*, June 2013
- <sup>26</sup> Simon, A., Juszczyk, D., Smyth, N., Power, E., Hiom, S., Peake, M., & Wardle, J., 'Knowledge of lung cancer symptoms and risk factors in the UK: development of a measure and results from a population-based survey', *Thorax*, 67 (5), 2012. 426-432
- <sup>27</sup> Department of Health, *Improving Outcomes: A strategy for cancer*, January 2011
- <sup>28</sup> Department of Health, Innovation and Service Improvement, *Innovation Health and Wealth, Accelerating Adoption and Diffusion in the NHS*, December 2011