

## UNITED KINGDOM LUNG CANCER COALITION BRIEFING

### EXECUTIVE SUMMARY

The UKLCC has been campaigning to increase NHS Hospital and Foundation Trusts' participation in the National Lung Cancer Audit (NLCA). Participation rates are improving year on year, but the NLCA also highlights significant and worrying variations in lung cancer services, most notably:

- Overall, only 51% of patients receive any kind of active treatment. In some Trusts less than 10% of patients receive active treatment, compared to 70% of patients in others
- Only 10% of patients have surgery – which still provides the best hope of a cure. In some Trusts less than 5% of patients have surgery, compared to 25% in others
- Not all patients have access to a specialist nurse; specialist nurses are a vital source of information and support for patients and their families

**The figures above must be improved if we are to increase the survival rate from lung cancer. The UKLCC has written to low performing Trusts to encourage them to participate fully in the next Audit and to complete Local Action Plans to identify how they can improve.**

### THE IMPORTANCE OF FIRST-CLASS DATA COLLECTION

**Understanding what is happening in clinical practice and how this is affecting patient outcomes depends on having first-class data collection.**

Participation in national comparative audits such as the National Lung Cancer Audit (NLCA) is integral to improving the standard of treatment and care across the country, and to achieving better patient outcomes.

Data collection is one of twelve areas identified for action in the UKLCC's Lung Cancer Plan. The importance of accurate and comprehensive data collection is also reinforced in the *Cancer Reform Strategy* (December 2007) which highlighted the NLCA and stated that "better information on cancer services and outcomes will enhance patient choice, drive up service quality and underpin stronger commissioning."

The UKLCC is campaigning for all NHS and Foundation Hospital Trusts to participate in data collection for national audits and believes they should be held to account if they fail to submit their data. Improved data capture for NLCA, both in terms of submission rates and quality of data, would enable better mapping of services and performance management, and make an important contribution towards improving lung cancer survival.

### THE NATIONAL LUNG CANCER AUDIT (NLCA)

Audit is the essential first step in efforts to improve services, enabling managers and clinicians to assess the quality of care and the patient outcomes delivered by their teams. NLCA, currently in its third year, was one of the first national comparative audits of cancer services.

It is commissioned by the Healthcare Commission, and managed by the NHS Information Centre in partnership with the Royal College of Physicians.

The NLCA collects information on referral, diagnosis, treatment and outcome for people diagnosed with lung cancer or mesothelioma. The audit aims to understand the incidence of lung cancer within the UK, describe the range of treatments utilised and explore regional variations in treatments and outcomes. Using data that has been risk-adjusted for casemix, the audit has the potential to explain some of the wide variations found in lung cancer outcomes. The data currently collected in NLCA is already providing valuable insights into regional and national performance and will, in time, provide the basis for much of what patients will need to know about their local services.

The third major NLCA report was published at the end of April 2009. Hospital participation is improving (from 44% of Trusts participating in 2005, to 66% participating in 2006, and rising to 75% in 2007). Trusts submitted data on more than 22,600 lung cancer cases, which is around 75% of the expected number. However, despite the improvements that have been made over the last three years there are still a number of Trusts that fail to submit any data at all and this seriously hampers efforts to fully understand the reasons for variations in care and to take the steps necessary to tackle it. The UKLCC is writing to all Trusts that have never submitted data or are low respondents to encourage them to contribute to the National Lung Cancer Audit 2008, the deadline for which is 26 June 2009.

**The 2007 audit recommends that all Trusts participate and that they should submit all relevant data on all patients. The UKLCC supports this recommendation and calls on all Trusts to participate fully.**

## HIGHLIGHTING VARIATIONS

Importantly, the NCLA is now providing important insights into lung cancer service delivery.

### Key findings: treatment

There is considerable variation in the proportion of lung cancer patients receiving surgery or any form of active treatment between different parts of the UK. Unfortunately there will always be some patients for whom active treatment is not an option because they are diagnosed at a late stage. However, we believe that the overall level of active treatment is too low and that the variations between Trusts in terms of access to treatment are too wide.

Overall, only 51% of patients receive any form of active treatment. This varies from only 10% of patients receiving active treatment in the lowest performing Trusts, to more than 70% in the highest performing ones.

In surgery – the treatment which still offers best hope of a cure from lung cancer – considerable variation exists too. Overall, only 10% of patients have surgery, but this varies from only 5% of patients receiving surgery in some Trusts to 25% in others. Around 25% of lung cancer and mesothelioma patients receive chemotherapy, and 22% receive radiotherapy. For small cell lung cancer (SCLC) chemotherapy is usually suggested over surgery. However only 62% of SCLC patients received chemotherapy. As before, these averages mask large variations between Trusts.

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As part of the UKLCC's *Lung Cancer Plan*, the UKLCC called for more lung cancer patients to be considered for active treatment, with all Trusts learning from those where innovative and aggressive cancer management is bringing about better patient outcomes. Expanding access to active treatment is a major way by which we can ultimately improve the UK's lung cancer survival rates.

### **Key findings: service organisation**

The proportion of patients discussed at a multidisciplinary team (MDT) meeting is 87.2%. This is far short of the national target of 100%, but also short of the 95% generally agreed to be a realistic but acceptable level. MDT discussion is central to the planning and co-ordination of lung cancer treatment, and must be improved so that patients receive the right treatment.

Specialist nurses are a vital source of information and support for patients and their families throughout the cancer pathway. Of the patient records entered, only 35% of patients were recorded as having definitely seen a specialist nurse, while 12% definitely didn't see a nurse. The remainder was either unknown or unrecorded. The Audit has set a target of 60% of patients to be seen by a specialist nurse, with 40% of patients having a nurse present at the point of diagnosis. However these figures are low and that the aim should be considerably higher. Trusts with low figures for specialist nurse support should review staffing levels.

While issues such as data collection may still impact in particular Trusts, it is important that those achieving less than the national mean investigate the reasons for this. Those Trusts not achieving acceptable service delivery levels should complete a Local Action Plan, to help them examine where they may be falling short and how they can improve.

The Audit 'red-flagged' a number of Trusts which were identified as of concern. The UKLCC has written to these Trusts and their Cancer Networks to encourage Trusts to complete and act on their Local Action Plans. In this way, we hope to drive up the quality of lung cancer services to the benefit of patient care.

## **ABOUT THE UKLCC**

The United Kingdom Lung Cancer Coalition (UKLCC) is a powerful partnership of the leading lung cancer charities, clinicians, healthcare professionals and healthcare companies with a commitment to lung cancer issues. The UKLCC is the nation's largest multi-interest group in lung cancer, working to bring lung cancer out of the shadow.

Lung cancer is the country's biggest cancer killer. In the UK, someone dies from lung cancer every 15 minutes. Despite some recent improvements in service provision, there are still wide variations in standards across the country, including diagnosis, treatment and care for lung cancer patients. The UKLCC believes that more can be done to reduce the terrible death toll caused by lung cancer. Our vision is to double lung cancer survival.

## **FURTHER INFORMATION**

The UKLCC would be happy to provide further information. Please do not hesitate to contact us via our secretariat (c/o the British Lung Foundation):

Email: [uklcc@bif-uk.org](mailto:uklcc@bif-uk.org) or tel. 020 7688 5555.

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