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# Which patients are assessed by Lung Cancer Nurse Specialists? A National Lung Cancer Audit study of over 128,000 patients across England

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# Abstract

**Background:** Lung cancer nurse specialists (LCNS) are integral to the multidisciplinary clinical team, providing personalised physical and psycho-social interventions, and care management for people with lung cancer. The National Institute of Health and Care Excellence (NICE) recommend that all patients have access to a LCNS. We conducted a national study assessing whether there is variation in access to and timing of LCNS assessment.

**Methods:** The National Cancer Action Team's LCNS workforce census in England was linked with patient and hospital Trust data from the English National Lung Cancer Audit. Multivariate logistic regression was used to assess features associated with LCNS assessment.

**Results:** 128,124 lung cancer patients were seen from 2007-2011. LCNS assessment confirmation was 'yes' in 62%, 'no' in 6% and 'missing' in 32%. Where (in clinic versus ward) and when (before versus after diagnosis) patients were assessed by a LCNS also varied. Older patients with poor performance status, early cancer stage, and comorbidities were less likely to be assessed; there was no difference with sex or socioeconomic group. Patients receiving any anti-cancer treatment were more likely to be assessed. Assessment was lower in Trusts with high annual patient numbers (odds ratio=0.58, 95% confidence interval 0.37-0.91) and where LCNS caseload >250 (0.69, 0.41-1.16, although not statistically significant), but increased where workload was conducted mostly by band 8 nurses (2.22, 1.22-4.02).

**Conclusion:** LCNS assessment varied by patient and Trust features, which may indicate unmet need for some patients. The current workforce needs to expand as well as retain experienced LCNSs.

# Introduction

Lung cancer (LC) is the second most common cancer in the United Kingdom (UK) with 39,000 new cases annually in England [1 2]. Recent National Institute for Health and Care Excellence (NICE) guidelines recommend that every person diagnosed with LC has direct personal access to a Lung Cancer Nurse Specialist (LCNS) in their local hospital who they can meet with and be supported by throughout the cancer pathway [1 3]. LCNSs are now integral to the multidisciplinary team (MDT) within which they contribute to decisions on their patients' treatment and care [4]. Previous research has shown the effectiveness of tailored nursing care and proactive LCNS case management in reducing unnecessary hospital admissions and doctor consultations, symptom control, emotional functioning and patient-reported satisfaction for early and metastatic LC [5-8]. A 2002 randomised control trial by Moore and colleagues of 203 patients showed that LCNS led follow-up was also cost-effective when compared with conventional medical follow-up [8].

Although LC is the second commonest cancer in the UK [9], LCNSs comprise only 11% of the Cancer Nurse Specialists (CNSs) in England, compared with breast (20%), colorectal (14%) and urology (12%) CNSs [10]. A recent Macmillan report highlighted that on average, there is one LCNS for every 161 people diagnosed with LC, compared with 117 people diagnosed with breast cancer [11]. According to the 2013 National Lung Cancer Audit (NLCA) annual report, approximately 80% of all patients are now assessed by a LCNS, but there is variation by Trust and only 30% of LC patients are assessed in some Trusts [12].

In this study we linked individual clinical information from the NLCA, the English Hospital Episode Statistics (HES) and Office of National Statistics (ONS) deaths with the National Cancer Action Team (NCAT) census on the LCNS workforce. We assessed whether, when and where patients are assessed by a LCNS and how clinical, demographic, socioeconomic status (SES) of patients and National Health Services (NHS) Trust characteristics including Trust size, LCNS salary bands and caseload affected their assessment.

## Methods

The NLCA collects key clinical information on all new patients presenting with a diagnosis of LC in the UK. In this study data from the NLCA was linked with HES, which includes all inpatient admissions in England, ONS mortality data to provide nationally registered dates of death, and NCAT, a census of the entire cancer specialist nurse workforce in England which provided details on the LCNS workforce.

We included all patients in the NLCA who were first seen in England between January 1st, 2007 and December 31st, 2011 across 150 NHS Trusts in England. We used the latest NCAT census carried out in 2011 to map the workforce of 321 LCNS to NHS Trusts. Trusts without LCNS workforce information from the NCAT (n=4) were dropped leaving 146 Trusts for analysis. Patients diagnosed with LC through death certificate and those with mesothelioma or carcinoid were excluded.

The NLCA records whether the patient is assessed by a LCNS (yes, no), date of assessment, timing of assessment in the cancer pathway and location of the first assessment. We categorised the timing of assessment as before/at diagnosis versus after diagnosis and the location of assessment as in clinic versus ward or other location (i.e. home visit, telephone or other). For each of the three variables, where no information was entered they were separately categorised as missing.

Age at diagnosis, sex, SES, source of referral to a LC physician, performance status (classified according to WHO definition) and stage of disease (Union for International Cancer Control definition) were identified from NLCA. Data on active treatment were obtained from a combination of the NLCA and HES using methods as previously described [13-15] and categorised as no treatment, surgery, chemotherapy and radiotherapy, chemotherapy alone or radiotherapy alone. We used HES to calculate a patient's composite score of co-morbidity (Charlson Index).

We used the NLCA to calculate the number of new LC patients seen annually in each Trust using our established methods [14]. We estimated each Trust's caseload per whole time equivalent (WTE) LCNS using the number of new cases first seen in 2011 plus the number of patients surviving since 2004, divided by the number of WTE LCNSs employed at the Trust. We assumed that the patients initially seen in a particular Trust were equally divided between the LCNSs employed by that Trust and that patients followed the LC pathway in that same Trust. Using NCAT information on salary bands of WTE LCNSs, we assessed the composition of the LCNS team at each trust. We also estimated which LCNS salary band conducted the majority of the work based on WTE employment at each Trust (e.g. Trust A was categorised at Band 7 if more than 50% of the total WTE LCNSs were on salary band 7).

## Statistical analysis

All data analyses were performed using Stata MP12. Initially we plotted the percentage of patients recorded as having been assessed by a LCNS by the Trust size (average number of patients seen annually) and calculated the Pearson's correlation coefficient to quantify the relationship. We used multinomial logistic regression analyses, to estimate the relative risk ratio (RRRs) of being assessed by a LCNS by patient and NHS Trust features. For all patients who had information on having been assessed, we also performed separate analyses to estimate the RRRs of being assessed after diagnosis versus before/at diagnosis and being assessed in clinic versus being assessed on wards. The unadjusted and adjusted RRR were clustered by NHS Trust to account for the hierarchical grouping of patient observations. A separate analysis was carried out for patients with missing data and a sensitivity analyses was conducted excluding all patients who died within 30 days of diagnosis to account for immortal time bias.

# Results

There were a total of 128,124 people with LC who were first seen between 1 January 2007 and 31 December 2011, of whom 80,113 (63%) were seen by a LCNS, 7,544 (6%) were not seen and 40,467 (31%) had missing data. The proportion of patients assessed increased over the study period (6,216 (31%) in 2007 to 23,045 (80%) in 2011), mainly driven by a decrease in the missing data. From those who were assessed, 3,809 (5%) had missing information on the timing of first assessment and 8,317 (10%) on the location. We observed a borderline moderate negative correlation between the number of new cases seen at a Trust and the proportion of patients assessed by a LCNS (Figure 1 - Pearson's correlation coefficient= -0.305).

## Who is assessed by LCNS

Table 1 shows results for being assessed by a LCNS by patient features. The RRR of being assessed by a LCNS was 6% higher for men compared with women, but this association was accounted for when we adjusted for other patient features and Trust/LCNS features (RRR 1.02, 95% CI 0.96 -1.07). There was a clear association seen with age with patients >75 years less likely to be assessed. Patients with worse performance status (PS) and with comorbidities were also less likely to have been assessed. Patients with LC stage other than stage IA-IB and stage IV had a higher RRR of being assessed by a LCNS. The association with stage IV patients was not seen when we carried out a sensitivity analysis and restricted our analyses to patients who survived more than 30-days after diagnosis (Supplemental table 1).There was no difference by SES. We analysed missing data separately and that the RRR of missing data compared with patients not assessed revealed that there was no difference in being recorded as not seen between patients with stage IA-IB and stage IV. The amount of missing data was similar between patients from different SES (Supplemental table 2).

Patients admitted through an emergency route were 57% less likely to have been assessed compared with those who were referred by a GP. Active treatment was also associated with assessment. Patients who had surgery were twice as likely to be assessed (RRR 2.04), while patients who receive chemotherapy alone or radiotherapy alone were three times as likely to be assessed (RRR 3.42 & 2.51

respectively). However, the strongest association was seen in patients who receive chemotherapy and radiotherapy, who were four times as likely to be assessed (RRR 3.93, 95% CI 3.10 – 4.98). This association was also present in patients surviving more than 30-days post diagnosis.

Patients first seen in a Trust with an annual LC caseload of >=265 patients were less likely to be assessed compared with smaller Trusts (adjusted RRR 0.58), but we found no association with increasing annual LCNS caseload. There was a higher likelihood of being assessed in Trust where the LCNS were on salary band 7 or 8 (RRR 1.59), however clustering by NHS Trusts widened the confidence interval and made the association non-significant. Patients first seen in Trusts where the majority of work was done by band 8 nurses were twice as likely to have been assessed compared 7 band Trusts (RRR 2.22, 95%CI 1.22 – 4.02), while trusts where majority of work is done by a band 6 LCNS were less likely to have been assessed (RRR 0.71, 95% CI 0.47 – 1.07).

## Point of lung cancer pathway where the patient is first assessed

Table 2 shows results for the point at which the patient was first assessed by a LCNS (n=80,113). Patients with age >75 years, worsening PS and stage, other than stage IV, were less likely to be assessed before/at diagnosis but we found no difference with sex. Patients with a comorbidity score of higher than 4 were slightly more likely to be assessed before diagnosis than after diagnosis, while there was no difference with SES. Patients admitted through emergency were less likely to have been assessed before diagnosis; however those who were referred from another consultant were 76% more likely to have been assessed before receiving their lung cancer diagnosis. Patients having surgical treatment were almost twice more likely to have been assessed before/ at diagnosis than after diagnosis while significant association for patients receiving chemotherapy and radiotherapy was only present in patients surviving 30-days post LC diagnosis (Supplemental table 1). There was no association seen with the likelihood of being assessed before/ at diagnosis than after diagnosis with either increasing annual trust size or annual WTE LCNS caseload. LCNS on salary grade 7 or 8 were more likely to assess a patient before/at diagnosis than LCNS on a lower salary grade while there was no association seen with trusts were majority of work is done by either band 6, 7 or 8.

### Where the patient is first assessed?

Table 3 presents an overview of unadjusted and adjusted RRR of where the patients are first assessed by a LCNS. Over the years, the proportion of patients being assessed in clinics versus the proportion being assessed in wards has remained the same. Males and young people were 9% less likely to have been first assessed in a ward than in a clinic. The strongest association was seen with PS. Patients with PS 4 were almost 7 times more likely to have been first seen in a ward than in clinic. People with advanced stage and comorbidity were also associated with patients being more likely to have been first assessed in the ward. There was no difference in where the patient is first seen by SES, increasing annual WTE LCNS caseload or LCNS salary grade/majority work. Patients who receive any treatment are less likely to have their first assessment by a LCNS in wards than in clinic (RRR 0.48 surgery, 0.47 chemotherapy and radiotherapy, 0.51 chemotherapy alone and 0.64 radiotherapy alone).

## Discussion

Our results demonstrate an increase in the absolute proportion of patients assessed in recent years which is mainly driven by improvements in data completeness. However, the data reveals that older patients, with poorer PS, and those admitted through an emergency route are less likely to be assessed, which was still present in patients surviving more than 30-days after diagnosis, highlighting unmet need. However, it is possible that some patients are appropriately being referred to supportive and palliative care nurses, and that the LCNS is instrumental in making this happen. In contrast to research which indicates a more active approach to treatment in larger Trust, we found borderline moderate negative association between assessment and Trust size.

Overall 32% of patients in our data had missing data. Even though the ascertainment of this information has improved in recent years, our results may be an underestimate of the true proportion of patients assessed by a LCNS.

As reported previously, there is a strong association between assessment by a LCNS and active anticancer treatment [4]. We observed a higher likelihood of being assessed before diagnosis by a LCNS on a higher salary grade (i.e. 7 or 8) and a higher likelihood of being assessed where majority of work is done by band 8 nurses. This may be linked to a better leadership qualities and an active involvement in MDT clinics by senior nurses. While patients diagnosed in a Trust with an annual Trust size of >265 were less likely to have been assessed, the effect of increasing caseload per WTE LCNS on the likelihood of being assessed was not present even when adjusted for several patient and Trust features. This may be due to differences in access to a LCNS, which were not examined in this study.

This study uses a large representative dataset reflects real life LC care in England. Although the data entry in the NLCA is non-mandatory, the linked database has been validated [16]. The ascertainment of cases and data completeness has improved annually with recent audit result reports ascertainment closer to 100% [17]. We had a large proportion of patients with missing data on LCNS input; but the decreasing missing information in recent years associated with no change in the proportion of assessed vs not assessed in the database suggests that this was not deliberate (Supplemental table 2). This is the first time a snapshot of the LCNS workforce together with the patient level data was used to create an approximate patient caseload per WTE LCNS. Although we used the most recent data from the NCAT, the number of employed LCNS has remained relatively stable since 2007 (301 total LCNS in 2010 & 321 in 2011). Our results could be influenced by bias as patients with aggressive disease and short survival time may not have the opportunity to be assessed, however we conducted a sensitivity analysis limiting to all those patients who have survived for more than 30 days after diagnosis and observed the same association (Supplemental table 1). It could be argued for some patients opting for palliative treatment, a palliative care specialist nurse would be more effective at attending to patient’s needs, but we believe that the skills and expertise of the LCNS are complementary and should still be available.

We created two variables to measure the effectiveness of LCNS based on their salary grade and the amount of work performed by them and observed a relationship of patients being assessed more and before diagnosis with Trusts where more senior nurses on higher salary bands are hired. With recent downgrading of nurses to band 6, our study highlights evidence of hiring more experienced nurses. It is very likely that many patients during the course of their treatment change nurses (for e.g. from

LCNS to specialist oncology nurse) and not all patients visit a LCNS each year survived after their diagnosis, however we believe that the number would be sufficiently small because of the poor survival rates [18] of LC and majority of the caseload for each LCNS comprised of new patients. Additionally, the surviving patients can still contact or can be referred to a LCNS from other CNSs.

We assumed that being assessed in a clinic represented best practice as it signified patients contact with the LCNS during the initial LC pathways. This may not be the true for patients suffering from aggressive LC where they are first presented in emergency rather than visit to their GP. This would not make much difference as only 13% of the total LC population are referred to a lung physician in emergency, while around 50% are referred from GPs and other consultants [14 19 20].

The NICE guidelines have stated that every patient diagnosed with LC should have an access to a LCNS [1] while the NLCA audit suggesting that 80% of patients in each Trust should be assessed by a LCNS [12] and our results do provide evidence that most Trusts are now achieving this benchmark. In addition, there is also the presence of variation in caseload per WTE LCNS which is also observed in the NLCA annual audit reports [12 17].

We used a combination of database and survey to plot LCNS activities in NHS Trusts in England, and found that contact with LCNS was associated with increased likelihood of having received chemotherapy, radiotherapy and surgery. These results, except for surgery, are similar to results presented by Beckett and colleagues [4] who analysed patients in the NLCA in 2009. However, due to the retrospective analysis nature of the study and limited data on determining at which point in the LC pathway these patients were assessed, it is difficult to establish temporal relationship between being assessed and receiving anti-cancer therapy. Our results indicate that Trusts with low annual patient Trust size or with low per WTE LCNS caseload were more likely to assess patients which is similar to the Royal College of Physicians report [21], which found that multidisciplinary teams with low caseload per LCNS more likely to meet targets for outcomes.

## Conclusion

LCNS provide a valued service for patients suffering from LC however we found wide variations between patient features, annual Trust workload, LCNS caseload and who are assessed by a LCNS in between Trusts across England suggesting an unmet need of some patients with LC. To meet the needs of all people with LC and the clear targets set out by NICE, we need to expand the current LCNS workforce and ensure that we retain experienced nurses as LCNS are an integral part of the LC team and provide help to people with LC.

### Conflict of Interest

PB, AT, AL, DB & JW have no conflict of interest. LJT has conducted the statistical analyses for the National Lung Cancer Audit annual reports from 2009 to 2013, which was funded by the NHS Information Centre, while AK has been involved in audit analysis for past 2 year including analysis for this year. LJT and AK have not received any personal earnings from the NHS HSCIC for this work. RBH has a grant provided by the British Lung Foundation chair of respiratory epidemiology. RAS was employed by the HSCIC as the Project Manager for the NLCA database until October 2013.

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