



## Barriers to delivering advanced cancer nursing: A workload analysis of specialist nurse practice linked to the English National Lung Cancer Audit

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### ARTICLE INFO

#### Keywords:

Case management  
Clinical audit  
Lung neoplasms  
Nurse specialists  
Survey  
Workload

### ABSTRACT

**Purpose:** Health services across the world utilise advanced practice in cancer care. In the UK, lung cancer nurse specialists (LCNS) are recognised as key components of quality care in national guidelines, yet access to LCNS contact is unequal and some responsibilities are reportedly left undone. We assess whether any variation in working practices of LCNS is attributable to factors of the lung cancer service at the hospital trust.

**Method:** Nationwide workload analysis of LCNS working practices in England, linked at trust level to patient data from the National Lung Cancer Audit. Chi-squared tests were performed to assess whether patient contact, workload, involvement in multidisciplinary teams (MDT), and provision of key interventions were related to 1) the trust's lung cancer service size, 2) LCNS caseload, 3) anti-cancer treatment facilities and 4) lung cancer patient survival.

**Results:** Unpaid overtime was substantial for over 60% of nurses and not associated with particular service factors assessed; lack of administrative support was associated with large caseloads and chemotherapy facilities. LCNS at trusts with no specialty were more likely to challenge all MDT members (80%) compared with those at surgical (53%) or chemotherapy (58%) trusts. The most frequent specialist nursing intervention to not be routinely offered was proactive case management.

**Conclusion:** Working practices of LCNS vary according to service factors, most frequently associated with trust anti-cancer treatment facilities. High workload pressures and limited ability to provide key interventions should be addressed across all services to ensure patients have access to recommended standards of care.

### 1. Introduction

The unmatched skillset of nurses in advanced practice is increasingly recognised internationally (de Bont et al., 2016; Steinke et al., 2017). In the UK, clinical nurse specialists are linked to better outcomes for both patients and the local health economies as experienced practitioners providing quality care, leadership and enabling safe release of consultant time (NCAT, 2010; Read and Waters, 2015). Cancer care represents a significant specialist area: particularly lung cancer which accounts for 22% of all cancer deaths in the UK (CRUK, 2014), and studies have shown poor five-year relative survival rates compared with other European countries (De Angelis et al., 2014; Francisci et al., 2015).

Patients and their families gain enormous value from the crucial role lung cancer nurse specialists (LCNS) have throughout the clinical pathway, from breaking significant news to meeting information needs, advocating patient wishes and offering a continuity of care (McPhillips et al., 2014; Mishelmovich et al., 2016; Tod et al., 2015; White, 2013). As financial pressures on health services continue, there have been gains in productivity and cost-effectiveness resulting from LCNS working with people to proactively manage their condition in limiting the progression of disease burden (Baxter and Leary, 2011; Leary and Baxter, 2014).

The Department of Health (England) recommends that specialist nurses should be available throughout the cancer journey and the National Cancer Action Team (NCAT) recognised the unique insight

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LCNS can provide in multi-disciplinary teams (MDT) (NCAT, 2013). As such, the LUCADA dataset of the National Lung Cancer Audit (NLCA) includes non-mandatory records of initial contact and timing of assessments by LCNS, though data completeness varied between 2007 and 2011; assessment records were missing for 32% and 10% of people, respectively (Khakwani et al., 2016).

With limitations to LCNS metrics considered, the NLCA reports inequalities in access to LCNS workforces between services and that hospital trusts do not always meet the standard of at least 80% of patients seen by a LCNS (RCP, 2015). National audit data has also shown that people diagnosed in trusts with high annual numbers of new patients are less likely to have an initial LCNS assessment whereas those with early stage lung cancer are more likely to be assessed (Khakwani et al., 2016). Whilst there is some recognition for the local cultures and practices that seek to minimise such differences, a recent census of the cancer nurse specialist workforce identified variability in vacancies and caseload (Macmillan, 2017), potentially impacting on the depth and quality of subsequent contact. A survey of 78 LCNS indicated that the majority felt that important work, most often proactive case management, was left undone against best practice (Leary et al., 2014).

We linked insights provided by a nationwide workload survey of 230 LCNS in England to data from the NCAT workforce census and NLCA data from over 125,000 patients diagnosed between 2007 and 2011 to build a comprehensive view of specialist cancer nurse experiences according to factors that described the lung cancer service in which they work. Our aim was to assess whether LCNS workforce, workload, MDT activity and the ability to provide key advanced nursing interventions varied according to the service size, caseload, onsite provision of anti-cancer treatments, and patient survival. Where we identify gaps and barriers to delivering the LCNS role, we highlight strategies to improve resource allocation.

## 2. Methods

### 2.1. Study population and data sources

We used linked data to capture information on people with lung cancer in England and the LCNS workforce across English National Health Service (NHS) trusts (i.e. all hospitals providing lung cancer services across the country). To obtain details of LCNS (including thoracic nurse specialist) working practices across the patient care pathway, we designed a survey disseminated via the National Lung Cancer Forum for Nurses (NLCFN) using Survey Monkey in 2014 (Appendix A). Using the NHS hospital trust code where the LCNS worked, survey data was linked with clinical information from the English NLCA according to hospital where patients first seen, Hospital Episode Statistics (HES) in-patient data, Office for National Statistics (ONS) mortality data, and with the 2011 NCAT LCNS workforce census in England (NCAT, 2012).

We categorised each trust according to size, LCNS caseload, anti-cancer treatment facilities and survival of its lung cancer patient population. Trust size was measured using NLCA data between 2007 and 2011 to calculate the average number of new lung cancer patients seen annually in each trust, as previously described (Khakwani et al., 2016). Size category of hospital trust was defined: small (< 175), medium (175–264), large ( $\geq 265$ ). Patients first seen in 2011 plus surviving patients since 2004 were divided by the number of whole time equivalent (WTE) LCNS at a trust to estimate each trust's total caseload per LCNS (Khakwani et al., 2016). Caseload was calculated using the assumption that patients first seen in a particular trust were equally divided between the trust's LCNS team, and remained at that trust throughout the pathway. Trusts were divided into 2 groups based on whether or not they were above the median caseload of 188 patients per LCNS. NLCA and HES data were used to classify trusts according to whether surgery was available (with or without chemotherapy), only chemotherapy was available, or neither treatment facilities were

available onsite. A chemotherapy trust was defined by at least 75% of patients receiving an anti-cancer drug at a trust also being first seen there (Powell et al., 2014). To categorise trusts based on the survival of their lung cancer patient population we used median survival information based on ONS date of death for patients first seen in a trust in 2014 (RCP, 2015). The hazard ratio for death following diagnosis was calculated for each trust's patient population compared with the national lung cancer population, adjusting for sex, age, stage, performance status and socioeconomic group. Trusts were categorised as having either average/higher (hazard ratio  $\leq 1$ ) or lower (hazard ratio  $> 1$ ) survival compared with the national English lung cancer population.

We used salary and WTE information from the linked NCAT census to calculate the composition of each trust's LCNS team, categorising each LCNS as band 6, 7 or 8. Detailed information on workload and working practices of the hospital trusts LCNS workforce were then obtained from the NLCFN survey. The workload survey requested contractual and estimated weekly overtime hours which we used to calculate the proportion of WTE hours working overtime. Hours of weekly administrative support as reported by the LCNS were grouped as no support, up to 10 h, or  $> 10$  h. The survey requested each LCNS to report the point on the patient care pathway at which they first see more than 60% of patients, with answers summarised as before/at or after the lung cancer diagnosis. An estimation of the proportion of new patients seen as emergency presentations was also requested as this is often indicative of a greater severity of disease manifestation. LCNS are considered core members of the lung cancer MDT (NCAT, 2013; NICE, 2011), so the survey ascertained whether they actively attended the MDT, whether they were prepared to challenge all other members of the MDT, and whether they felt uncomfortable or intimidated within the MDT setting. The survey also captured LCNS ability to provide key interventions that are accepted as part of the LCNS role (Baxter and Leary, 2011; Leary and Baxter, 2014; Tod et al., 2015; White, 2013). Respondents were asked which interventions they were routinely able to offer (i.e. to more than 70% of their patients) at each of the following points of the clinical care pathway: before diagnosis, at diagnosis, post diagnosis, treatment, end of treatment, follow-up, disease progression, and end of life care.

### 2.2. Statistical analyses

We assessed how representative the trusts included in our study were of all English trusts by comparing their treatment facilities, LCNS salary band composition and caseload size. Survey responses regarding LCNS workforce, patient contact, workloads and MDT experience were described as proportions of LCNS survey responses (i.e. the English LCNS workforce captured by the NLCFN survey). Responses on the ability to offer key interventions were aggregated to trust level using the rationale that one affirmation of provision was sufficient to indicate it as being offered by the trust's LCNS team. Variations in reported provision between LCNS at a trust may also be influenced by individual patient-contact patterns across the pathway; trust-level aggregation provided the best description of key interventions available to the patient population. Provision was assessed at any point of the pathway and then specifically at diagnosis, follow-up (stable disease), and disease progression based on the relative importance of a LCNS offering interventions at these times, compared with other specialist nurses who may be involved at different pathway points (Gardiner et al., 2011; NCAT, 2010; NICE, 2004).

Chi-squared tests were performed to determine whether differences in LCNS patient contact, workload, experience of MDT meetings and capacity to routinely offer interventions were associated with trust size, LCNS caseload, anti-cancer treatment facilities or one-year survival. To assess potential response bias we used chi-squared tests to assess whether missing data on survey responses was related to the four trust factors. A level of 0.05 for statistical significance was used throughout. Data analyses were performed using Stata SE14.

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