Is the English Cancer Patient Experience Survey representative? A comparative analysis with the National Lung Cancer Audit

Yvonne Nartey[1], Iain Stewart[2], Aamir Khakwani[1], Vanessa Beattie[3], Andrew Wilcock[4], Ian Woolhouse[5], Paul Beckett[6], Richard B Hubbard[1], Laila J Tata[1]

1 Division of Epidemiology and Public Health, University of Nottingham, Clinical Science Building, Nottingham City Hospital, Nottingham, NG5 1PB, UK

2 Division of Respiratory Medicine, University of Nottingham, Clinical Science Building, Nottingham City Hospital, Nottingham, NG5 1PB, UK

3 Aintree University Hospital NHS Foundation Trust, Longmoor Lane, Liverpool, L9 7AL, UK

4 Hayward House, Nottingham University Hospitals and University of Nottingham, UK

5 Queen Elizabeth Hospital Birmingham, Mindelsohn Way, Edgbaston, Birmingham, B15 2GW, UK

6 University Hospitals of Derby and Burton NHS Foundation Trust, Uttoxeter Road, Derby, DE22 3NE, UK

Correspondence author:
Yvonne Nartey
University of Nottingham
Epidemiology and Public Health
School of Medicine
Clinical Sciences Building
Nottingham City Hospital
Nottingham
NG5 1PB, UK.
E-mail: yvonne.nartey@nottingham.ac.uk

Manuscript word count (I,M,R,D) = 3,543 (/5,000)

Abstract

Word count = 255 (/300)

Objectives: Healthcare systems increasingly recognise the importance of service users' perspectives for improving care organisation and delivery. The English Cancer Patient Experience Survey (CPES) is carried out annually, however, its representativeness within cancer types is unknown. We have explored if the CPES results are representative of people with lung cancer.

Materials and methods: We linked cancer registry data across multiple sources to assess how CPES represents sociodemographic and clinical characteristics of the National Lung Cancer Audit population, accounting for post-sampling mortality bias. Multivariable logistic regression was used to compare people included and not included in CPES.

Results: Of 240,375 people diagnosed (2009-2015), 15,967 (7%) were included in CPES. Gender and ethnicity were reasonably represented, as were sociodemographic and clinical groupings, although more received anti-cancer treatment (96% of CPES respondents vs. 56% of patients nationally; adjusted odds ratio=10.3, 95% confidence interval 9.4-11.2 for any anti-cancer treatment) with chemotherapy most over-represented, followed by surgery and then radiotherapy. CPES under-represented older, more socioeconomically deprived, and certain clinical groups, including those with worse performance status, multiple comorbidities, and diagnosis via emergency presentation.

Conclusion: CPES includes patients across the sociodemographic and clinical spectrum indicating its value for research and service planning. Unbalanced representation of incident lung cancer cases is a limitation that must be considered in context of using CPES findings to implement service changes. Although half the national lung cancer population who received no anti-cancer treatment do not have their experiences represented, the strength of this dataset is in providing detailed comparisons of patient experiences across different treatment groups.

Keywords: Patient experience, Patient view, CPES, Lung cancer, England

Abbreviations:

CPES: Cancer Patient Experience Survey

ICD: International Classification of Diseases

IMD: Index of Multiple Deprivation

LCNS: Lung Cancer Nurse Specialist

MDT: Multidisciplinary Team Discussion

NCRAS: National Cancer Registration and Analysis Service

NHS: National Health Service

NLCA: National Lung Cancer Audit

NSCLC: Non-small cell Lung Cancer

ONS: Office of National Statistics

PHE: Public Health England

SCLC: Small Cell Lung Cancer

SNOMED: Systematised Nomenclature of Medicine

TWW: Two Weeks Wait

1. Introduction

Survival after diagnosis of lung cancer appears to be lower in the UK compared with other western and European countries, despite recent improvements [1, 2]. Inequalities in the receipt of anti-cancer treatment have been reported with effective treatment under-utilised and uptake of active treatment lower in the UK compared with Scandinavian and North American countries who have better survival [3-6].

Recommendations have been made by the National Institute of Health and Care Excellence to improve the quality of cancer care in England including the training of specialist cancer nurses to help identify the needs of people diagnosed with cancer and provide support throughout the cancer pathway, and involving people in decisions that shape or reshape their own cancer care including anti-cancer treatment options [7]. There has been significant investment of resource in surveys measuring patient experience to provide information on the quality of healthcare directly from the service users' point of view [8]. The National Lung Cancer Audit (NLCA) is now a leading national audit and one of the largest and most detailed on lung cancer internationally, however it lacks a programme for patient reported outcome or experience measures.

For healthcare service providers, feedback from patient experience surveys helps to identify where cancer services can focus efforts to improve care [9, 10]. For service users, this helps in making choices about their care and for quality assurance. The English National Cancer Patient Experience Survey (CPES) was commissioned by the Department of Health for this purpose and is carried out annually by Quality Health. Feedback from similar patient experience surveys has been successful in informing healthcare service quality in outpatient departments and patient-doctor interaction in countries such as Australia, Finland and the USA [11-13]. For CPES to achieve its purpose, it is important to understand how patients responding to the survey represent people diagnosed with lung cancer in England. It

currently obtains responses from over 65,000 people with cancer each year, approximately 6% of whom have lung cancer; this representation relative to the incidence of lung cancer is lower than for many other tumour sites, particularly breast cancer [14, 15], which may partially reflect CPES's sampling frame of selecting people recently discharged from hospital treatment episodes. Post-sampling mortality and sociodemographic variation in survey response patterns in CPES has been assessed across all cancer types [16]. Assessment of how CPES respondents are representative of the whole incident cancer population, however, has not been conducted, which is arguably important for the application of CPES in changing cancer services that serve all people with cancer. To do this, a comprehensive assessment for each cancer type is required, that includes detailed comparisons between individuals' clinical and treatment pathways as well as their sociodemographic characteristics. This opportunity has only recently arisen through the individual patient linkage of CPES to national cancer registry data.

We used national cancer registry data (from the NLCA) linked across multiple sources including route to diagnosis, anti-cancer treatments and long-term follow up, to assess how people with incident diagnoses of lung cancer included in CPES represent the sociodemographic, clinical, treatment characteristics and survival of the whole incident lung cancer population in England.

2. Materials and methods

2.1 Study population and data sources

Information on all people in England with a new primary diagnosis of lung cancer (International Classification of Diseases (ICD-10) codes C34*) between 2009 and 2015 was obtained from the National Cancer Registration and Analysis Service (NCRAS) run by Public Health England (PHE). NCRAS forms the most complete source of information on all people diagnosed with incident cancer by obtaining information from across the National Health Service (NHS), which covers 98-99% of all hospital activity in England. The NLCA comprises those individuals in NCRAS with a lung cancer diagnosis. We also accessed linked survey results of those included in at least one wave of the national CPES between 2010 and 2015 (waves 1:2010, 2:2011, 3:2012, 4:2013, 5:2015).

2.1.1 The National Cancer Patient Experience Survey (CPES)

CPES collects self-reported information from people diagnosed with cancer about their experience of primary care pre-diagnosis, ongoing clinical management and longer-term support. It includes over 70 questions across 12 different domains. The survey is sent to all people in England aged 16 years and older with a primary diagnosis of cancer (identified using ICD-10 codes, excluding C44-other malignant neoplasms of the skin and C84-peripheral and cutaneous T-cell lymphomas) who have been admitted as an inpatient or day-case to hospital in relation to their cancer and discharged within the specified survey period each year (usually a three-month window, with some variation across waves). People are sent the survey by post, with two reminders for non-respondents; there are also options to complete wave 5 online or via telephone. All survey questions have undergone cognitive interview testing on samples of people with different types of cancer in different English regions [17].

2.1.2 NCRAS data linkages

For all lung cancer patients we used information on age, gender, ethnicity, lung cancer type, stage at diagnosis, and route to diagnosis from their NCRAS record. Lung cancer morphology was defined using recorded Systematised Nomenclature of Medicine (SNOMED) codes. People whose SNOMED codes were missing or coded as unknown were classified as non-small-cell lung cancer (NSCLC) based on the method used by the NLCA to define lung cancer [3].

NCRAS records for NLCA patients were also linked at individual-level to Hospital Episode Statistics (HES) data which included all hospital inpatient, outpatient and emergency admissions. We used all relevant ICD-coded conditions in these admissions up to the lung cancer diagnosis to calculate a comorbidity score for each patient (Charlson Index) [18]. To build patient profiles of surgical, radiotherapy and chemotherapy treatments, we used admissions for surgery, radiotherapy or chemotherapy related to their lung cancer in conjunction with individual linked treatment databases, the National Radiotherapy Dataset and Systemic Anti-cancer Therapy dataset, and treatments recorded in the core cancer registry data [19, 20]. In HES data, we identified Office of Population Census and Survey Classification of Intervention version 4 codes corresponding to surgical, chemotherapy and radiotherapy treatment. In line with methods used by the NLCA to define anti-cancer treatment related to lung cancer, we define surgical resection of lung cancer within a timeframe of 1 month before to 6 months after diagnosis of lung cancer, and relevant chemotherapy or radiotherapy rounds as 1 month before to 9 months after diagnosis [3]. Survival time was calculated from their diagnosis date to their date of death obtained from the Office of National Statistics (ONS) or follow-up was truncated at the date of ONS cross-check for death (28/01/2018). Household socioeconomic deprivation was measured as quintiles of the Index of Multiple Deprivation based on national census data and was linked to individuals' records based on their home postcode.

Although we had the NCRAS record across our whole study period, we also used pre-2015 NLCA data that was provided through a bespoke data collection system, called Lung Cancer Audit Data (LUCADA). Data entry in LUCADA was non-mandatory and showed some selection bias [21], however, they were entered by the multidisciplinary team (MDT) in NHS hospitals and included more detailed information on patient pathway including hospital-trust first seen, timing and method of Lung Cancer Nurse Specialist (LCNS) assessments and performance status (PS). This is the first time all of these linkages had been done collectively. PHE's Office for Data Release (PHE ODR) conducted all individual matching procedures for people diagnosed with lung cancer from the core cancer registry to CPES and other data sources using bespoke algorithms that included NHS number and tumour type, as described on their website (www.ncin.org.uk).

2.2 Statistical analysis

Data management and analyses were carried out using Stata 15 (StataCorp, College Station, TX, USA). We compared proportions of key variables, including age, gender, PS, lung cancer stage, anti-cancer treatment and clinical service factors between people in CPES and the whole NLCA population from NCRAS. We used multivariate logistic regression to calculate odds ratios (OR) to quantify the extent to which being in CPES varied by these key variables. For the subset of patients with a LUCADA record we repeated the main analyses using a multilevel logistic regression model fitting patient and hospital level factors, enabling us to assess whether trust size (number of new lung cancer patients seen annually) or trust treatment specialty were associated with inclusion in CPES.

We compared survival of those included and not included in CPES using the Kaplan–Meier method. To assess the potential effects of survival bias on our overall analyses, we conducted a subgroup analysis restricting the NCRAS study population to people who survived more

than 426 days after diagnosis, which was the 75th quartile of survival for people surveyed in CPES.

3. Results

3.1 Study population

The flow diagram (Figure 1) demonstrates how the study population was derived. From the whole NLCA population, we included only those with one primary lung cancer diagnosis (not multiple tumours) (N=244,957). We excluded individuals diagnosed before age 18 years or diagnosed upon or after their death (death certificate cases). From an initial 18,023 individuals with linked CPES questionnaires, we excluded 698 individuals whose CPES records were likely to be unrelated to their lung cancer diagnosis. The final study population was 240,375 people with primary lung cancer diagnosed between 2009 and 2015, 15,967 (6.6%) of whom had a linked CPES questionnaire. Of those in CPES; 2,761(17.9%), 3,327 (20.8%), 3,353 (21.0%), 3,185(20.0%) and 3,341 (20.9%) were from waves 1 to 5, respectively. Seventy percent (167,210) of the 240,375 people had linked LUCADA information.

3.2 Sociodemographic and clinical features

Table 1 shows a multivariate logistic regression model assessing the odds of being included in CPES according to various characteristics. Inclusion increased over time, apart from a dip for people diagnosed in 2014 because CPES was not conducted that year. Overall, patients included in CPES had representation across every sociodemographic and clinical grouping, however, representativeness varied by feature and those in CPES were less likely to have missing information for stage, performance status, ethnicity and route to diagnosis. Women had a small increase in adjusted odds of being included in CPES compared with men. Adjusted odds of inclusion in CPES generally decreased with increasing age, PS, comorbidities and socioeconomic deprivation. Patients with a PS of 1-4, clinically recorded in their LUCADA record close to the time they were initially diagnosed, were less likely to be included in CPES compared with those recorded as PS0, clinically considered as fully

functional and asymptomatic (OR=0.79; 95% CI=0.39-0.16 for PS1-4 collectively compared with PS0). Compared with stage Sg1A, stages SgIB-IIIA were considerably more likely to be represented in CPES, whereas SgIV and missing stage were less likely to be represented. Ethnicity was not associated with the likelihood of inclusion in CPES, however, people in CPES were more likely to have complete information on ethnicity. All lung cancer types were included, with a small increase in representativeness of SCLC compared with NSCLC. Being diagnosed with lung cancer through the Two Week Wait NHS standard (an urgent referral requiring the person to be seen by a specialist within 14 days) was associated with a greater adjusted odds of inclusion in CPES, (OR=1.26; 95% CI=1.21-1.32), whilst emergency presentation was associated with a lower odds of inclusion (OR=0.52; 95% CI=0.49-0.55) compared with primary care referral.

People included in CPES had considerably longer survival from diagnosis; (median survival was 158 days for those not in CPES and 774 days for those included in CPES (Figure 2a). When the analysis was restricted to all NLCA patients who survived more than 426 days, the 75th quartile of survival for those in CPES, this did not result in the CPES population being more evenly representative despite similar survival (Figure 2b). Results across sociodemographic and clinical features were very similar to the original analysis, with the exception of gender, stage and ethnicity (Supplementary Table 1). Females, those with Asian ethnicity, and those with Carcinoid diagnosis were now slightly less represented in CPES, and those with high comorbidity scores or increasing stage were more represented in CPES.

3.3 Clinical service and treatment features

Recorded discussion at the MDT was not associated with CPES inclusion, although patients who were assessed by a LCNS or had a LCNS present when they received their diagnosis were 25% more likely to be included in CPES than those without these service factors (OR:1.25; 95% CI=1.18-1.32) (Table 2). Among those assessed by LCNS, the place of

assessment or whether they were assessed before or after their diagnosis was not associated with their odds of being in CPES.

Having received anti-cancer treatment was the strongest factor associated with being included in CPES. Compared with 56% of people receiving treatment in the whole NLCA population, 96% of people included in CPES had received some combination of radiotherapy, chemotherapy or surgery; the odds of inclusion in CPES after adjusting for sociodemographic and clinical features were 10 times higher for those receiving treatment compared with no anti-cancer treatment (OR=10.26; 95% CI=9.37-11.23 for any treatment). Patients receiving chemotherapy had the highest odds of being in CPES, followed by surgery and then radiotherapy. In our analysis restricted to all NLCA patients who survived more than 426 days (Figure 2b) associations between service and treatment features with inclusion in CPES were similar to the original analysis (Supplementary Table 2).

3.4 Multilevel model including hospital trust level factors

Results from a multilevel model incorporating hospital trust for the LUCADA population of 167,210 lung cancer patients (70% of the NLCA study population) showed little change in the representativeness across the sociodemographic, clinical, service and treatment features for inclusion in CPES (Supplementary Table 3), in comparison to the main analyses (Tables 1 and 2). The annual service size of the trust where the patient was first seen was not associated with inclusion in CPES, however, patients first seen in surgical or chemotherapy trusts were slightly more likely to be included in CPES, even after adjustment for their individual anti-cancer treatment receipt.

4. Discussion

4.1 Summary of main findings

Our study of over 240,000 people from the English NLCA showed that those with self-reported information on their clinical experience from CPES had representation across a wide number of sociodemographic, clinical, health service and anti-cancer treatment groups, however, balanced representation varied. After accounting for all factors together, we found CPES under-represented lung cancer patients who were older, from more socioeconomically deprived groups, had worse performance status, the most advanced stage of cancer, multiple comorbidities, or were diagnosed via emergency presentation. People diagnosed via the TWW standard, those with recorded LCNS assessment, and those with SCLC, compared with NSCLC, were slightly over-represented in CPES.

A clear difference was that 96% of people included in CPES had some form of anti-cancer treatment (compared with 56% of the overall lung cancer population); they were ten times more likely to have received anti-cancer treatment compared with people not in CPES. This likely relates to selection methods reported by CPES that include discharge following a treatment episode. Those included in CPES were even more likely to have chemotherapy treatment, for which multiple admissions are required, thus making them even more likely to have the opportunity to be sampled. Most findings were very similar after excluding lung cancer patients who died early from the disease, and thus may not have had the chance to respond to the survey or meet the inclusion criteria for being surveyed. This indicates that, despite accounting for likely survival bias, people included in CPES are still much more likely to have received anti-cancer treatment compared with the general lung cancer population. We also demonstrated that CPES includes patients across the sociodemographic and clinical spectrum, supporting its utility for research and service planning. However,

under-representation of socioeconomically deprived groups and certain ethnic minorities must be considered in the context of implementing changes based on its findings.

4.2 Strengths and limitations of the study

This is the first study to use linked patient level CPES responses and NCRAS records to assess cancer-specific representation within the survey, demonstrating the strengths of individual patient linkage across national data sources. Our findings support studies that have shown age and deprivation as factors influencing recruitment in patient experience surveys [16, 22]. By linking CPES with the NLCA cancer registry, HES hospital information, IMD socioeconomic deprivation and ONS deaths, we have been able to study multiple patient and NHS service characteristics in a large national sample that has provided considerable power. Our methods demonstrate that this could also be used for advancing patient experience research in other cancer types. Two UK studies have assessed response rates and method of response (postal versus online) to CPES [16, 23]. Although broad socio-demographics of CPES responders were compared with those sampled for all cancers [16], this has not been able to tell us if their cancer pathway is broadly representative of the whole cancer population, or if findings are applicable to specific cancer sites which vary widely in patient populations and clinical care models. Our study was the first to assess the likelihood of people with a specific incident cancer diagnosis in the population being included in CPES across the cancer pathway, and we identified under-representation of some important groups.

The opportunity to be selected as eligible for CPES and respond to the CPES questionnaire will be influenced by survival time, with a natural bias towards excluding those who die sooner following their lung cancer diagnosis, which is evident from our results. We made efforts to account for this selection bias by conducting a sensitivity analysis limiting to patients who had survived more than 426 days (the 75th quartile of survival for people

surveyed in CPES), which provided further insight to CPES representativeness for this group. Although post-sampling mortality is more evident in cancers with poor prognosis [16], such as lung cancer, our findings from the restricted analysis indicate lack of representation was more likely to be due to non-response and frequency of hospital use rather than post-sampling mortality. Variation in response has been reported for different groups of patients, with more socioeconomically deprived groups and people from ethnic minority backgrounds reporting to be less likely to respond to such surveys, and responding with less positive experience of cancer care [24-28]. It is possible that the variation reported may reflect different health, emotional and support needs of different groups of people with lung cancer. Older, more socioeconomically deprived people and those diagnosed through emergency presentation may be less likely to respond to surveys about their experience due to the overall severity of their health [29]. Alternatively, these groups may have less positive experiences of healthcare and may be less motivated to respond to CPES with those responding being more critical of their care [30, 31]. Furthermore, due to the severity of the disease in these groups, they may be more likely to be admitted to hospice care rather than hospitals and may thus have less chance of being sampled in CPES.

People who were assessed by a LCNS may have had positive experiences of healthcare providing more motivation to respond to CPES, or this could reflect people's more frequent hospital contact for treatment during which they had LCNS assessment, and thus higher likelihood of being included in CPES sampling. The positive association between anti-cancer treatment and the likelihood of being surveyed in CPES is likely explained by more frequent hospital use and the bias introduced through methodology of hospitals providing discharged patient lists as the initial step of inclusion for survey recruitment.

4.3 Implication for practice and policy

We provide estimates of the degree of under-representation in lung cancer patient experience according to clinical characteristics, age, socioeconomic deprivation and ethnicity, which can contribute to planning clinical service modifications. We have also shown that CPES largely represents people with lung cancer who receive anti-cancer treatment, most notably chemotherapy. In the recent national audit of lung cancer outcomes, 35% of people did not receive anti-cancer treatment [32], highlighting a need for lung cancer PROMs to also be representative of these individuals. The design of any PROMS for lung cancer would need to take short average survival into account and ensure sampling methods were designed to capture people soon after diagnosis in order to be representative. We advise that it is important to have patients' specific treatment types and pathways, available through data linkage, in order to most appropriately interpret individual patient experience responses in CPES for use in transforming services.

Our study also supports the continuing emphasis on issues associated with the sampling methods of CPES. Almost half of people with lung cancer nationally do not receive anti-cancer treatment, and thus CPES does not represent almost half of the national lung cancer service. It is not the intention of this paper to canvas this debate, but to note that the notion of a "one size fit all" method of recruitment is not straightforward. Policy makers need to be aware of the under-representatives of certain groups of lung cancer in CPES. We recommend modifications to survey methods be considered for cancers with poor prognosis, such as sending out invitations shortly after discharge or by other means that capture people not undergoing intensive anti-cancer treatment pathways. Although this may add additional cost to patient experience surveys, its cost-effectiveness needs to be evaluated. National surveys are expensive undertaking and should thus strive to ensure they are representative of the source population to influence policy. In trying to improve the quality of NHS services, data to support such improvement needs to be of great quality [33]. CPES demonstrates huge

potential in assessing how people receiving different types of lung cancer treatment may have different experiences of care and exploring their how their healthcare experience may relate to their longer-term health outcomes. Further study can assess whether experiences of cancer treatment decisions are associated with anti-cancer treatments received, informing strategies to increase rates of active treatment, or whether interactions with health service staff are associated with rates of unplanned hospital attendances, informing safe staffing policies and financial impact.

Ethical considerations

The data was obtained from PHE. Ethical approval was obtained by the researchers from the University of Nottingham Faculty of Medicine and Health Sciences Ethical Committee (reference no: 182-1710). We also obtained study approval from the NHS Health Research Authority (reference no: 18/LO/0110). A data sharing agreement to use the linked dataset was obtained from PHE (reference no: ODR1617_288). The study was performed in accordance with the Declaration of Helsinki.

Availability of data and materials

Because of the sensitive and potentially identifiable nature of the data used for this study, the researchers have been granted permission to conduct analyses based on their approved protocol and can only present aggregated data. All data used in this paper are available directly from the PHE ODR subject to appropriate study approval and data sharing agreements.

Funding

This study was funded by the Roy Castle Lung Cancer Foundation.

Authors' contribution

The conception of the study was done by LJT and IS with input on the design from RBH, AK and YN. YN acquired, managed and analysed the data from PHE. YN, LJT, IS and AK were involved in the core data interpretation and shaping of the analysis. YN and LJT wrote the core of the manuscript and all authors critically reviewed the manuscript and approved it prior to submission.

Acknowledgments

The authors would like to acknowledge the Roy Castle Lung Cancer Foundation who funded the study and Public Health England for providing the data. They would also like to thank the Palliative Research Team at Hayward House, Nottingham City Hospital (Cathann Manderson and Sarah Schofield) for helping with recruiting people with lung cancer for our Research Advisory Group, and all participants with lung cancer and their families who participated in the advisory group.

References

[1] Francisci S, Minicozzi P, Pierannunzio D, et al. Survival patterns in lung and pleural cancer in Europe 1999-2007: Results from the EUROCARE-5 study. *European journal of cancer (Oxford, England : 1990)* 2015;51(15):2242-53.

[2] De Angelis R, Sant M, Coleman MP, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE--5-a population-based study. *The Lancet Oncology* 2014;15(1):23-34.

[3] Royal College of Physicians. National Lung Cancer Audit Annual Report 2016 (for the audit period 2015). London: Royal College of Physicians, 2017.

[4] Forrest LF, Adams J, Wareham H, et al. Socioeconomic inequalities in lung cancer treatment: systematic review and meta-analysis. *PLoS medicine* 2013;10(2):e1001376.

[5] Khakwani A, Rich AL, Powell HA, et al. The impact of the 'hub and spoke' model of care for lung cancer and equitable access to surgery. *Thorax* 2015;70(2):146-51.

[6] Cusworth K, O'Dowd E, Hubbard R, et al. Variation in lung cancer resources and workload: results from the first national lung cancer organisational audit. *Thorax* 2015;70(10):1001-3.

[7] National Institute For Clinical Excellence. Supportive and Palliative Care Guidance. London: National Institute For Clinical Excellence, 2005.

[8] Department of Health and Social Care. NHS Outcomes Framework Indicators. London: Department of Health and Social Care, 2018.

[9] The Kings Fund. Patients' experince of using hospital services: An analysis of trends in inpatient serveys in NHS acute trusts in England, 2005 -13. London: The kings Fund, 2015.

[10] Madden PB, Davies EA. Reporting cancer patients' experiences of care for quality improvement: analysis of 2000 and 2004 survey results for South East England. *Journal of evaluation in clinical practice* 2010;16(4):776-83.

[11] Greco M, Brownlea A, McGovern J. Impact of patient feedback on the interpersonal skills of general practice registrars: results of a longitudinal study. *Medical education* 2001;35(8):748-56.

[12] Hiidenhovi H, Nojonen K, Laippala P. Measurement of outpatients' views of service quality in a Finnish university hospital. *Journal of advanced nursing* 2002;38(1):59-67.

[13] Davies E, Shaller D, Edgman-Levitan S, et al. Evaluating the use of a modified CAHPS survey to support improvements in patient-centred care: lessons from a quality improvement collaborative. *Health expectations : an international journal of public participation in health care and health policy* 2008;11(2):160-76.

[14] Quality Health. Cancer Patient Experince Survey. Chesterfield: Quality Health: Quality Health, 2017.

[15] PHE. National Cancer Intelligence Network: English Cancer Patient Experince Survey linked to cancer registration data, a descriptive overview of respondents' characteristics. London: Public Health England, 2015.

[16] Abel GA, Saunders CL, Lyratzopoulos G. Post-sampling mortality and non-response patterns in the English Cancer Patient Experience Survey: Implications for epidemiological studies based on surveys of cancer patients. *Cancer epidemiology* 2016;41:34-41.

[17] Quality Health. National Cancer Patient Experience Survey Programme: Cognitive Testing Report 2010. Chesterfield: Quality Health, 2010.

[18] Charlson ME, Pompei P, Ales KL, et al. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of chronic diseases* 1987;40(5):373-83.

[19] PHE. National Radiotherapy Datast (RTDS) 2010 [Available from: http://www.ncin.org.uk/collecting_and_using_data/rtds accessed 11/01/2019 2019.

[20] PHE. Systemic Anti-cancer Therapy London: Public Health England2011 [Available from: http://www.chemodataset.nhs.uk/home accessed 11/01/2019 2019.

[21] Khakwani A, Jack RH, Vernon S, et al. Apples and pears? A comparison of two sources of national lung cancer audit data in England. *ERJ open research* 2017;3(3)

[22] O'Cathain A, Knowles E, Nicholl J. Testing survey methodology to measure patients' experiences and views of the emergency and urgent care system: telephone versus postal survey. *BMC medical research methodology* 2010;10:52.

[23] Pham TM, Abel GA, Gomez-Cano M, et al. Predictors of Postal or Online Response Mode and Associations With Patient Experience and Satisfaction in the English Cancer Patient Experience Survey. *Journal of Medical Internet Research* 2019; 21(5) :e11855.

[24] Elliott MN, Edwards C, Angeles J, et al. Patterns of unit and item nonresponse in the CAHPS Hospital Survey. *Health services research* 2005;40(6 Pt 2):2096-119.

[25] Saunders CL, Abel GA, Lyratzopoulos G. Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from

respondents to the English Cancer Patient Experience Survey. *European journal of cancer care* 2015;24(1):85-98.

[26] Bone A, McGrath-Lone L, Day S, et al. Inequalities in the care experiences of patients with cancer: analysis of data from the National Cancer Patient Experience Survey 2011-2012. *BMJ open* 2014;4(2):e004567.

[27] Abel GA, Saunders CL, Lyratzopoulos G. Cancer patient experience, hospital performance and case mix: evidence from England. *Future oncology (London, England)* 2014;10(9):1589-98.

[28] Ayanian JZ, Zaslavsky AM, Guadagnoli E, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 2005;23(27):6576-86.

[29] Beckett P, Tata LJ, Hubbard RB. Risk factors and survival outcome for non-elective referral in non-small cell lung cancer patients--analysis based on the National Lung Cancer Audit. *Lung cancer (Amsterdam, Netherlands)* 2014;83(3):396-400.

[30] Pham TM, Gomez-Cano M, Salika T, et al. Diagnostic route is associated with care satisfaction independently of tumour stage: Evidence from linked English Cancer Patient Experience Survey and cancer registration data. *Cancer Epidemiology* 2019; 61:70-78.

[31] Salika T, Abel GA, Mendonca SC, et al. Associations between diagnostic pathways and care experience in colorectal cancer: evidence from patient-reported data. *Frontline gastroenterology* 2018;9(3):241-248

[32] Royal College of Physicians. National Lung Cancer Audit Annual Report 2018 (for the audit period 2017). London: Royal College of Physicians, 2018.

[33] The Health Foundation. Quality improvement made simple: What everyone should know about health care quality improvement, 2013.

Is the English Cancer Patient Experience Survey representative? A comparative analysis with the National Lung Cancer Audit

Yvonne Nartey[1], Iain Stewart[2], Aamir Khakwani[1], Vanessa Beattie[3], Andrew Wilcock[4], Ian Woolhouse[5], Paul Beckett[6], Richard B Hubbard[1], Laila J Tata[1]

1 Division of Epidemiology and Public Health, University of Nottingham, Clinical Science Building, Nottingham City Hospital, Nottingham, NG5 1PB, UK

2 Division of Respiratory Medicine, University of Nottingham, Clinical Science Building, Nottingham City Hospital, Nottingham, NG5 1PB, UK

3 Aintree University Hospital NHS Foundation Trust, Longmoor Lane, Liverpool, L9 7AL, UK

4 Hayward House, Nottingham University Hospitals and University of Nottingham, UK

5 Queen Elizabeth Hospital Birmingham, Mindelsohn Way, Edgbaston, Birmingham, B15 2GW, UK

6 University Hospitals of Derby and Burton NHS Foundation Trust, Uttoxeter Road, Derby, DE22 3NE, UK

Correspondence author:
Yvonne Nartey
University of Nottingham
Epidemiology and Public Health
School of Medicine
Clinical Sciences Building
Nottingham City Hospital
Nottingham
NG5 1PB, UK.
E-mail: yvonne.nartey@nottingham.ac.uk

Manuscript word count (I,M,R,D) = 3,543 (/5,000)

Abstract

Word count = 255 (/300)

Objectives: Healthcare systems increasingly recognise the importance of service users' perspectives for improving care organisation and delivery. The English Cancer Patient Experience Survey (CPES) is carried out annually, however, its representativeness within cancer types is unknown. We have explored if the CPES results are representative of people with lung cancer.

Materials and methods: We linked cancer registry data across multiple sources to assess how CPES represents sociodemographic and clinical characteristics of the National Lung Cancer Audit population, accounting for post-sampling mortality bias. Multivariable logistic regression was used to compare people included and not included in CPES.

Results: Of 240,375 people diagnosed (2009-2015), 15,967 (7%) were included in CPES. Gender and ethnicity were reasonably represented, as were sociodemographic and clinical groupings, although more received anti-cancer treatment (96% of CPES respondents vs. 56% of patients nationally; adjusted odds ratio=10.3, 95% confidence interval 9.4-11.2 for any anti-cancer treatment) with chemotherapy most over-represented, followed by surgery and then radiotherapy. CPES under-represented older, more socioeconomically deprived, and certain clinical groups, including those with worse performance status, multiple comorbidities, and diagnosis via emergency presentation.

Conclusion: CPES includes patients across the sociodemographic and clinical spectrum indicating its value for research and service planning. Unbalanced representation of incident lung cancer cases is a limitation that must be considered in context of using CPES findings to implement service changes. Although half the national lung cancer population who received no anti-cancer treatment do not have their experiences represented, the strength of this dataset is in providing detailed comparisons of patient experiences across different treatment groups.

Keywords: Patient experience, Patient view, CPES, Lung cancer, England

Abbreviations:

CPES: Cancer Patient Experience Survey

ICD: International Classification of Diseases

IMD: Index of Multiple Deprivation

LCNS: Lung Cancer Nurse Specialist

MDT: Multidisciplinary Team Discussion

NCRAS: National Cancer Registration and Analysis Service

NHS: National Health Service

NLCA: National Lung Cancer Audit

NSCLC: Non-small cell Lung Cancer

ONS: Office of National Statistics

PHE: Public Health England

SCLC: Small Cell Lung Cancer

SNOMED: Systematised Nomenclature of Medicine

TWW: Two Weeks Wait

1. Introduction

Survival after diagnosis of lung cancer appears to be lower in the UK compared with other western and European countries, despite recent improvements [1, 2]. Inequalities in the receipt of anti-cancer treatment have been reported with effective treatment under-utilised and uptake of active treatment lower in the UK compared with Scandinavian and North American countries who have better survival [3-6].

Recommendations have been made by the National Institute of Health and Care Excellence to improve the quality of cancer care in England including the training of specialist cancer nurses to help identify the needs of people diagnosed with cancer and provide support throughout the cancer pathway, and involving people in decisions that shape or reshape their own cancer care including anti-cancer treatment options [7]. There has been significant investment of resource in surveys measuring patient experience to provide information on the quality of healthcare directly from the service users' point of view [8]. The National Lung Cancer Audit (NLCA) is now a leading national audit and one of the largest and most detailed on lung cancer internationally, however it lacks a programme for patient reported outcome or experience measures.

For healthcare service providers, feedback from patient experience surveys helps to identify where cancer services can focus efforts to improve care [9, 10]. For service users, this helps in making choices about their care and for quality assurance. The English National Cancer Patient Experience Survey (CPES) was commissioned by the Department of Health for this purpose and is carried out annually by Quality Health. Feedback from similar patient experience surveys has been successful in informing healthcare service quality in outpatient departments and patient-doctor interaction in countries such as Australia, Finland and the USA [11-13]. For CPES to achieve its purpose, it is important to understand how patients responding to the survey represent people diagnosed with lung cancer in England. It

currently obtains responses from over 65,000 people with cancer each year, approximately 6% of whom have lung cancer; this representation relative to the incidence of lung cancer is lower than for many other tumour sites, particularly breast cancer [14, 15], which may partially reflect CPES's sampling frame of selecting people recently discharged from hospital treatment episodes. Post-sampling mortality and sociodemographic variation in survey response patterns in CPES has been assessed across all cancer types [16]. Assessment of how CPES respondents are representative of the whole incident cancer population, however, has not been conducted, which is arguably important for the application of CPES in changing cancer services that serve all people with cancer. To do this, a comprehensive assessment for each cancer type is required, that includes detailed comparisons between individuals' clinical and treatment pathways as well as their sociodemographic characteristics. This opportunity has only recently arisen through the individual patient linkage of CPES to national cancer registry data.

We used national cancer registry data (from the NLCA) linked across multiple sources including route to diagnosis, anti-cancer treatments and long-term follow up, to assess how people with incident diagnoses of lung cancer included in CPES represent the sociodemographic, clinical, treatment characteristics and survival of the whole incident lung cancer population in England.

2. Materials and methods

2.1 Study population and data sources

Information on all people in England with a new primary diagnosis of lung cancer (International Classification of Diseases (ICD-10) codes C34*) between 2009 and 2015 was obtained from the National Cancer Registration and Analysis Service (NCRAS) run by Public Health England (PHE). NCRAS forms the most complete source of information on all people diagnosed with incident cancer by obtaining information from across the National Health Service (NHS), which covers 98-99% of all hospital activity in England. The NLCA comprises those individuals in NCRAS with a lung cancer diagnosis. We also accessed linked survey results of those included in at least one wave of the national CPES between 2010 and 2015 (waves 1:2010, 2:2011, 3:2012, 4:2013, 5:2015).

2.1.1 The National Cancer Patient Experience Survey (CPES)

CPES collects self-reported information from people diagnosed with cancer about their experience of primary care pre-diagnosis, ongoing clinical management and longer-term support. It includes over 70 questions across 12 different domains. The survey is sent to all people in England aged 16 years and older with a primary diagnosis of cancer (identified using ICD-10 codes, excluding C44-other malignant neoplasms of the skin and C84-peripheral and cutaneous T-cell lymphomas) who have been admitted as an inpatient or day-case to hospital in relation to their cancer and discharged within the specified survey period each year (usually a three-month window, with some variation across waves). People are sent the survey by post, with two reminders for non-respondents; there are also options to complete wave 5 online or via telephone. All survey questions have undergone cognitive interview testing on samples of people with different types of cancer in different English regions [17].

2.1.2 NCRAS data linkages

For all lung cancer patients we used information on age, gender, ethnicity, lung cancer type, stage at diagnosis, and route to diagnosis from their NCRAS record. Lung cancer morphology was defined using recorded Systematised Nomenclature of Medicine (SNOMED) codes. People whose SNOMED codes were missing or coded as unknown were classified as non-small-cell lung cancer (NSCLC) based on the method used by the NLCA to define lung cancer [3].

NCRAS records for NLCA patients were also linked at individual-level to Hospital Episode Statistics (HES) data which included all hospital inpatient, outpatient and emergency admissions. We used all relevant ICD-coded conditions in these admissions up to the lung cancer diagnosis to calculate a comorbidity score for each patient (Charlson Index) [18]. To build patient profiles of surgical, radiotherapy and chemotherapy treatments, we used admissions for surgery, radiotherapy or chemotherapy related to their lung cancer in conjunction with individual linked treatment databases, the National Radiotherapy Dataset and Systemic Anti-cancer Therapy dataset, and treatments recorded in the core cancer registry data [19, 20]. In HES data, we identified Office of Population Census and Survey Classification of Intervention version 4 codes corresponding to surgical, chemotherapy and radiotherapy treatment. In line with methods used by the NLCA to define anti-cancer treatment related to lung cancer, we define surgical resection of lung cancer within a timeframe of 1 month before to 6 months after diagnosis of lung cancer, and relevant chemotherapy or radiotherapy rounds as 1 month before to 9 months after diagnosis [3]. Survival time was calculated from their diagnosis date to their date of death obtained from the Office of National Statistics (ONS) or follow-up was truncated at the date of ONS cross-check for death (28/01/2018). Household socioeconomic deprivation was measured as quintiles of the Index of Multiple Deprivation based on national census data and was linked to individuals' records based on their home postcode.

Although we had the NCRAS record across our whole study period, we also used pre-2015 NLCA data that was provided through a bespoke data collection system, called Lung Cancer Audit Data (LUCADA). Data entry in LUCADA was non-mandatory and showed some selection bias [21], however, they were entered by the multidisciplinary team (MDT) in NHS hospitals and included more detailed information on patient pathway including hospital-trust first seen, timing and method of Lung Cancer Nurse Specialist (LCNS) assessments and performance status (PS). This is the first time all of these linkages had been done collectively. PHE's Office for Data Release (PHE ODR) conducted all individual matching procedures for people diagnosed with lung cancer from the core cancer registry to CPES and other data sources using bespoke algorithms that included NHS number and tumour type, as described on their website (www.ncin.org.uk).

2.2 Statistical analysis

Data management and analyses were carried out using Stata 15 (StataCorp, College Station, TX, USA). We compared proportions of key variables, including age, gender, PS, lung cancer stage, anti-cancer treatment and clinical service factors between people in CPES and the whole NLCA population from NCRAS. We used multivariate logistic regression to calculate odds ratios (OR) to quantify the extent to which being in CPES varied by these key variables. For the subset of patients with a LUCADA record we repeated the main analyses using a multilevel logistic regression model fitting patient and hospital level factors, enabling us to assess whether trust size (number of new lung cancer patients seen annually) or trust treatment specialty were associated with inclusion in CPES.

We compared survival of those included and not included in CPES using the Kaplan–Meier method. To assess the potential effects of survival bias on our overall analyses, we conducted a subgroup analysis restricting the NCRAS study population to people who survived more

than 426 days after diagnosis, which was the 75th quartile of survival for people surveyed in CPES.

3. Results

3.1 Study population

The flow diagram (Figure 1) demonstrates how the study population was derived. From the whole NLCA population, we included only those with one primary lung cancer diagnosis (not multiple tumours) (N=244,957). We excluded individuals diagnosed before age 18 years or diagnosed upon or after their death (death certificate cases). From an initial 18,023 individuals with linked CPES questionnaires, we excluded 698 individuals whose CPES records were likely to be unrelated to their lung cancer diagnosis. The final study population was 240,375 people with primary lung cancer diagnosed between 2009 and 2015, 15,967 (6.6%) of whom had a linked CPES questionnaire. Of those in CPES; 2,761(17.9%), 3,327 (20.8%), 3,353 (21.0%), 3,185(20.0%) and 3,341 (20.9%) were from waves 1 to 5, respectively. Seventy percent (167,210) of the 240,375 people had linked LUCADA information.

3.2 Sociodemographic and clinical features

Table 1 shows a multivariate logistic regression model assessing the odds of being included in CPES according to various characteristics. Inclusion increased over time, apart from a dip for people diagnosed in 2014 because CPES was not conducted that year. Overall, patients included in CPES had representation across every sociodemographic and clinical grouping, however, representativeness varied by feature and those in CPES were less likely to have missing information for stage, performance status, ethnicity and route to diagnosis. Women had a small increase in adjusted odds of being included in CPES compared with men. Adjusted odds of inclusion in CPES generally decreased with increasing age, PS, comorbidities and socioeconomic deprivation. Patients with a PS of 1-4, clinically recorded in their LUCADA record close to the time they were initially diagnosed, were less likely to be included in CPES compared with those recorded as PS0, clinically considered as fully

functional and asymptomatic (OR=0.79; 95% CI=0.39-0.16 for PS1-4 collectively compared with PS0). Compared with stage Sg1A, stages SgIB-IIIA were considerably more likely to be represented in CPES, whereas SgIV and missing stage were less likely to be represented. Ethnicity was not associated with the likelihood of inclusion in CPES, however, people in CPES were more likely to have complete information on ethnicity. All lung cancer types were included, with a small increase in representativeness of SCLC compared with NSCLC. Being diagnosed with lung cancer through the Two Week Wait NHS standard (an urgent referral requiring the person to be seen by a specialist within 14 days) was associated with a greater adjusted odds of inclusion in CPES, (OR=1.26; 95% CI=1.21-1.32), whilst emergency presentation was associated with a lower odds of inclusion (OR=0.52; 95% CI=0.49-0.55) compared with primary care referral.

People included in CPES had considerably longer survival from diagnosis; (median survival was 158 days for those not in CPES and 774 days for those included in CPES (Figure 2a). When the analysis was restricted to all NLCA patients who survived more than 426 days, the 75th quartile of survival for those in CPES, this did not result in the CPES population being more evenly representative despite similar survival (Figure 2b). Results across sociodemographic and clinical features were very similar to the original analysis, with the exception of gender, stage and ethnicity (Supplementary Table 1). Females, those with Asian ethnicity, and those with Carcinoid diagnosis were now slightly less represented in CPES, and those with high comorbidity scores or increasing stage were more represented in CPES.

3.3 Clinical service and treatment features

Recorded discussion at the MDT was not associated with CPES inclusion, although patients who were assessed by a LCNS or had a LCNS present when they received their diagnosis were 25% more likely to be included in CPES than those without these service factors (OR:1.25; 95% CI=1.18-1.32) (Table 2). Among those assessed by LCNS, the place of

assessment or whether they were assessed before or after their diagnosis was not associated with their odds of being in CPES.

Having received anti-cancer treatment was the strongest factor associated with being included in CPES. Compared with 56% of people receiving treatment in the whole NLCA population, 96% of people included in CPES had received some combination of radiotherapy, chemotherapy or surgery; the odds of inclusion in CPES after adjusting for sociodemographic and clinical features were 10 times higher for those receiving treatment compared with no anti-cancer treatment (OR=10.26; 95% CI=9.37-11.23 for any treatment). Patients receiving chemotherapy had the highest odds of being in CPES, followed by surgery and then radiotherapy. In our analysis restricted to all NLCA patients who survived more than 426 days (Figure 2b) associations between service and treatment features with inclusion in CPES were similar to the original analysis (Supplementary Table 2).

3.4 Multilevel model including hospital trust level factors

Results from a multilevel model incorporating hospital trust for the LUCADA population of 167,210 lung cancer patients (70% of the NLCA study population) showed little change in the representativeness across the sociodemographic, clinical, service and treatment features for inclusion in CPES (Supplementary Table 3), in comparison to the main analyses (Tables 1 and 2). The annual service size of the trust where the patient was first seen was not associated with inclusion in CPES, however, patients first seen in surgical or chemotherapy trusts were slightly more likely to be included in CPES, even after adjustment for their individual anti-cancer treatment receipt.

4. Discussion

4.1 Summary of main findings

Our study of over 240,000 people from the English NLCA showed that those with self-reported information on their clinical experience from CPES had representation across a wide number of sociodemographic, clinical, health service and anti-cancer treatment groups, however, balanced representation varied. After accounting for all factors together, we found CPES under-represented lung cancer patients who were older, from more socioeconomically deprived groups, had worse performance status, the most advanced stage of cancer, multiple comorbidities, or were diagnosed via emergency presentation. People diagnosed via the TWW standard, those with recorded LCNS assessment, and those with SCLC, compared with NSCLC, were slightly over-represented in CPES.

A clear difference was that 96% of people included in CPES had some form of anti-cancer treatment (compared with 56% of the overall lung cancer population); they were ten times more likely to have received anti-cancer treatment compared with people not in CPES. This likely relates to selection methods reported by CPES that include discharge following a treatment episode. Those included in CPES were even more likely to have chemotherapy treatment, for which multiple admissions are required, thus making them even more likely to have the opportunity to be sampled. Most findings were very similar after excluding lung cancer patients who died early from the disease, and thus may not have had the chance to respond to the survey or meet the inclusion criteria for being surveyed. This indicates that, despite accounting for likely survival bias, people included in CPES are still much more likely to have received anti-cancer treatment compared with the general lung cancer population. We also demonstrated that CPES includes patients across the sociodemographic and clinical spectrum, supporting its utility for research and service planning. However,

under-representation of socioeconomically deprived groups and certain ethnic minorities must be considered in the context of implementing changes based on its findings.

4.2 Strengths and limitations of the study

This is the first study to use linked patient level CPES responses and NCRAS records to assess cancer-specific representation within the survey, demonstrating the strengths of individual patient linkage across national data sources. Our findings support studies that have shown age and deprivation as factors influencing recruitment in patient experience surveys [16, 22]. By linking CPES with the NLCA cancer registry, HES hospital information, IMD socioeconomic deprivation and ONS deaths, we have been able to study multiple patient and NHS service characteristics in a large national sample that has provided considerable power. Our methods demonstrate that this could also be used for advancing patient experience research in other cancer types. Two UK studies have assessed response rates and method of response (postal versus online) to CPES [16, 23]. Although broad socio-demographics of CPES responders were compared with those sampled for all cancers [16], this has not been able to tell us if their cancer pathway is broadly representative of the whole cancer population, or if findings are applicable to specific cancer sites which vary widely in patient populations and clinical care models. Our study was the first to assess the likelihood of people with a specific incident cancer diagnosis in the population being included in CPES across the cancer pathway, and we identified under-representation of some important groups.

The opportunity to be selected as eligible for CPES and respond to the CPES questionnaire will be influenced by survival time, with a natural bias towards excluding those who die sooner following their lung cancer diagnosis, which is evident from our results. We made efforts to account for this selection bias by conducting a sensitivity analysis limiting to patients who had survived more than 426 days (the 75th quartile of survival for people

surveyed in CPES), which provided further insight to CPES representativeness for this group. Although post-sampling mortality is more evident in cancers with poor prognosis [16], such as lung cancer, our findings from the restricted analysis indicate lack of representation was more likely to be due to non-response and frequency of hospital use rather than post-sampling mortality. Variation in response has been reported for different groups of patients, with more socioeconomically deprived groups and people from ethnic minority backgrounds reporting to be less likely to respond to such surveys, and responding with less positive experience of cancer care [24-28]. It is possible that the variation reported may reflect different health, emotional and support needs of different groups of people with lung cancer. Older, more socioeconomically deprived people and those diagnosed through emergency presentation may be less likely to respond to surveys about their experience due to the overall severity of their health [29]. Alternatively, these groups may have less positive experiences of healthcare and may be less motivated to respond to CPES with those responding being more critical of their care [30, 31]. Furthermore, due to the severity of the disease in these groups, they may be more likely to be admitted to hospice care rather than hospitals and may thus have less chance of being sampled in CPES.

People who were assessed by a LCNS may have had positive experiences of healthcare providing more motivation to respond to CPES, or this could reflect people's more frequent hospital contact for treatment during which they had LCNS assessment, and thus higher likelihood of being included in CPES sampling. The positive association between anti-cancer treatment and the likelihood of being surveyed in CPES is likely explained by more frequent hospital use and the bias introduced through methodology of hospitals providing discharged patient lists as the initial step of inclusion for survey recruitment.

4.3 Implication for practice and policy

We provide estimates of the degree of under-representation in lung cancer patient experience according to clinical characteristics, age, socioeconomic deprivation and ethnicity, which can contribute to planning clinical service modifications. We have also shown that CPES largely represents people with lung cancer who receive anti-cancer treatment, most notably chemotherapy. In the recent national audit of lung cancer outcomes, 35% of people did not receive anti-cancer treatment [32], highlighting a need for lung cancer PROMs to also be representative of these individuals. The design of any PROMS for lung cancer would need to take short average survival into account and ensure sampling methods were designed to capture people soon after diagnosis in order to be representative. We advise that it is important to have patients' specific treatment types and pathways, available through data linkage, in order to most appropriately interpret individual patient experience responses in CPES for use in transforming services.

Our study also supports the continuing emphasis on issues associated with the sampling methods of CPES. Almost half of people with lung cancer nationally do not receive anti-cancer treatment, and thus CPES does not represent almost half of the national lung cancer service. It is not the intention of this paper to canvas this debate, but to note that the notion of a "one size fit all" method of recruitment is not straightforward. Policy makers need to be aware of the under-representatives of certain groups of lung cancer in CPES. We recommend modifications to survey methods be considered for cancers with poor prognosis, such as sending out invitations shortly after discharge or by other means that capture people not undergoing intensive anti-cancer treatment pathways. Although this may add additional cost to patient experience surveys, its cost-effectiveness needs to be evaluated. National surveys are expensive undertaking and should thus strive to ensure they are representative of the source population to influence policy. In trying to improve the quality of NHS services, data to support such improvement needs to be of great quality [33]. CPES demonstrates huge

potential in assessing how people receiving different types of lung cancer treatment may have different experiences of care and exploring their how their healthcare experience may relate to their longer-term health outcomes. Further study can assess whether experiences of cancer treatment decisions are associated with anti-cancer treatments received, informing strategies to increase rates of active treatment, or whether interactions with health service staff are associated with rates of unplanned hospital attendances, informing safe staffing policies and financial impact.

Ethical considerations

The data was obtained from PHE. Ethical approval was obtained by the researchers from the University of Nottingham Faculty of Medicine and Health Sciences Ethical Committee (reference no: 182-1710). We also obtained study approval from the NHS Health Research Authority (reference no: 18/LO/0110). A data sharing agreement to use the linked dataset was obtained from PHE (reference no: ODR1617_288). The study was performed in accordance with the Declaration of Helsinki.

Availability of data and materials

Because of the sensitive and potentially identifiable nature of the data used for this study, the researchers have been granted permission to conduct analyses based on their approved protocol and can only present aggregated data. All data used in this paper are available directly from the PHE ODR subject to appropriate study approval and data sharing agreements.

Funding

This study was funded by the Roy Castle Lung Cancer Foundation.

Authors' contribution

The conception of the study was done by LJT and IS with input on the design from RBH, AK and YN. YN acquired, managed and analysed the data from PHE. YN, LJT, IS and AK were involved in the core data interpretation and shaping of the analysis. YN and LJT wrote the core of the manuscript and all authors critically reviewed the manuscript and approved it prior to submission.

Acknowledgments

The authors would like to acknowledge the Roy Castle Lung Cancer Foundation who funded the study and Public Health England for providing the data. They would also like to thank the Palliative Research Team at Hayward House, Nottingham City Hospital (Cathann Manderson and Sarah Schofield) for helping with recruiting people with lung cancer for our Research Advisory Group, and all participants with lung cancer and their families who participated in the advisory group.

References

[1] Francisci S, Minicozzi P, Pierannunzio D, et al. Survival patterns in lung and pleural cancer in Europe 1999-2007: Results from the EUROCARE-5 study. *European journal of cancer (Oxford, England : 1990)* 2015;51(15):2242-53.

[2] De Angelis R, Sant M, Coleman MP, et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE--5-a population-based study. *The Lancet Oncology* 2014;15(1):23-34.

[3] Royal College of Physicians. National Lung Cancer Audit Annual Report 2016 (for the audit period 2015). London: Royal College of Physicians, 2017.

[4] Forrest LF, Adams J, Wareham H, et al. Socioeconomic inequalities in lung cancer treatment: systematic review and meta-analysis. *PLoS medicine* 2013;10(2):e1001376.

[5] Khakwani A, Rich AL, Powell HA, et al. The impact of the 'hub and spoke' model of care for lung cancer and equitable access to surgery. *Thorax* 2015;70(2):146-51.

[6] Cusworth K, O'Dowd E, Hubbard R, et al. Variation in lung cancer resources and workload: results from the first national lung cancer organisational audit. *Thorax* 2015;70(10):1001-3.

[7] National Institute For Clinical Excellence. Supportive and Palliative Care Guidance. London: National Institute For Clinical Excellence, 2005.

[8] Department of Health and Social Care. NHS Outcomes Framework Indicators. London: Department of Health and Social Care, 2018.

[9] The Kings Fund. Patients' experince of using hospital services: An analysis of trends in inpatient serveys in NHS acute trusts in England, 2005 -13. London: The kings Fund, 2015.

[10] Madden PB, Davies EA. Reporting cancer patients' experiences of care for quality improvement: analysis of 2000 and 2004 survey results for South East England. *Journal of evaluation in clinical practice* 2010;16(4):776-83.

[11] Greco M, Brownlea A, McGovern J. Impact of patient feedback on the interpersonal skills of general practice registrars: results of a longitudinal study. *Medical education* 2001;35(8):748-56.

[12] Hiidenhovi H, Nojonen K, Laippala P. Measurement of outpatients' views of service quality in a Finnish university hospital. *Journal of advanced nursing* 2002;38(1):59-67.

[13] Davies E, Shaller D, Edgman-Levitan S, et al. Evaluating the use of a modified CAHPS survey to support improvements in patient-centred care: lessons from a quality improvement collaborative. *Health expectations : an international journal of public participation in health care and health policy* 2008;11(2):160-76.

[14] Quality Health. Cancer Patient Experince Survey. Chesterfield: Quality Health: Quality Health, 2017.

[15] PHE. National Cancer Intelligence Network: English Cancer Patient Experince Survey linked to cancer registration data, a descriptive overview of respondents' characteristics. London: Public Health England, 2015.

[16] Abel GA, Saunders CL, Lyratzopoulos G. Post-sampling mortality and non-response patterns in the English Cancer Patient Experience Survey: Implications for epidemiological studies based on surveys of cancer patients. *Cancer epidemiology* 2016;41:34-41.

[17] Quality Health. National Cancer Patient Experience Survey Programme: Cognitive Testing Report 2010. Chesterfield: Quality Health, 2010.

[18] Charlson ME, Pompei P, Ales KL, et al. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of chronic diseases* 1987;40(5):373-83.

[19] PHE. National Radiotherapy Datast (RTDS) 2010 [Available from: http://www.ncin.org.uk/collecting_and_using_data/rtds accessed 11/01/2019 2019.

[20] PHE. Systemic Anti-cancer Therapy London: Public Health England2011 [Available from: http://www.chemodataset.nhs.uk/home accessed 11/01/2019 2019.

[21] Khakwani A, Jack RH, Vernon S, et al. Apples and pears? A comparison of two sources of national lung cancer audit data in England. *ERJ open research* 2017;3(3)

[22] O'Cathain A, Knowles E, Nicholl J. Testing survey methodology to measure patients' experiences and views of the emergency and urgent care system: telephone versus postal survey. *BMC medical research methodology* 2010;10:52.

[23] Pham TM, Abel GA, Gomez-Cano M, et al. Predictors of Postal or Online Response Mode and Associations With Patient Experience and Satisfaction in the English Cancer Patient Experience Survey. *Journal of Medical Internet Research* 2019; 21(5) :e11855.

[24] Elliott MN, Edwards C, Angeles J, et al. Patterns of unit and item nonresponse in the CAHPS Hospital Survey. *Health services research* 2005;40(6 Pt 2):2096-119.

[25] Saunders CL, Abel GA, Lyratzopoulos G. Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from

respondents to the English Cancer Patient Experience Survey. *European journal of cancer care* 2015;24(1):85-98.

[26] Bone A, McGrath-Lone L, Day S, et al. Inequalities in the care experiences of patients with cancer: analysis of data from the National Cancer Patient Experience Survey 2011-2012. *BMJ open* 2014;4(2):e004567.

[27] Abel GA, Saunders CL, Lyratzopoulos G. Cancer patient experience, hospital performance and case mix: evidence from England. *Future oncology (London, England)* 2014;10(9):1589-98.

[28] Ayanian JZ, Zaslavsky AM, Guadagnoli E, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 2005;23(27):6576-86.

[29] Beckett P, Tata LJ, Hubbard RB. Risk factors and survival outcome for non-elective referral in non-small cell lung cancer patients--analysis based on the National Lung Cancer Audit. *Lung cancer (Amsterdam, Netherlands)* 2014;83(3):396-400.

[30] Pham TM, Gomez-Cano M, Salika T, et al. Diagnostic route is associated with care satisfaction independently of tumour stage: Evidence from linked English Cancer Patient Experience Survey and cancer registration data. *Cancer Epidemiology* 2019; 61:70-78.

[31] Salika T, Abel GA, Mendonca SC, et al. Associations between diagnostic pathways and care experience in colorectal cancer: evidence from patient-reported data. *Frontline gastroenterology* 2018;9(3):241-248

[32] Royal College of Physicians. National Lung Cancer Audit Annual Report 2018 (for the audit period 2017). London: Royal College of Physicians, 2018.

[33] The Health Foundation. Quality improvement made simple: What everyone should know about health care quality improvement, 2013.

*Conflict of Interest Statement (Word document)

Competing interests

The University of Nottingham has received payment to analyse data for the NLCA annual reports since 2009. RBH is the academic clinical lead for the analyses and LJT and AK have been the data analysts for the annual reports. PB is the clinical lead for the NLCA. IW has previously been the senior clinical lead of the NLCA and then Clinical Director of the Care Quality Improvement Department at the Royal College of Physicians.

Figure

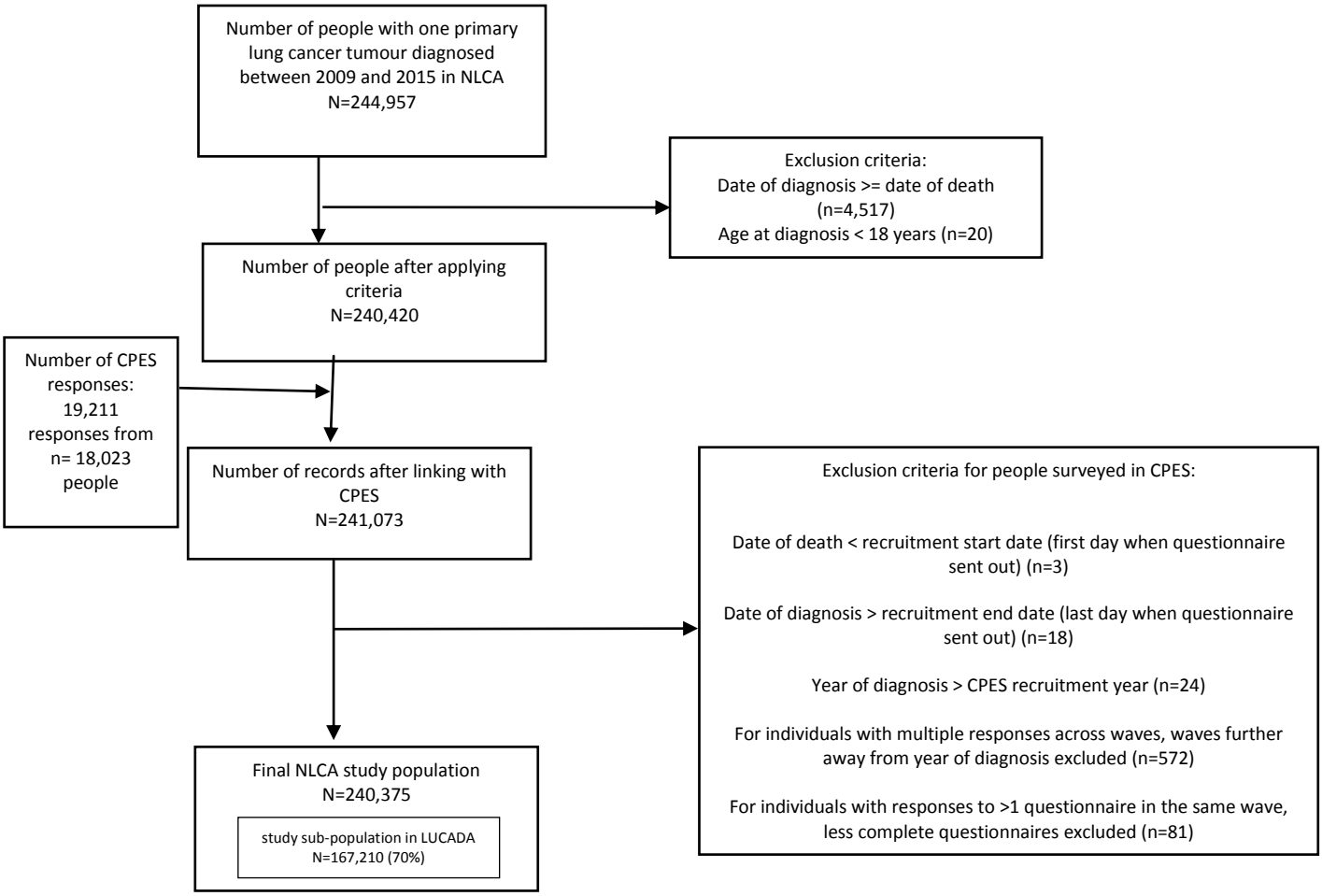
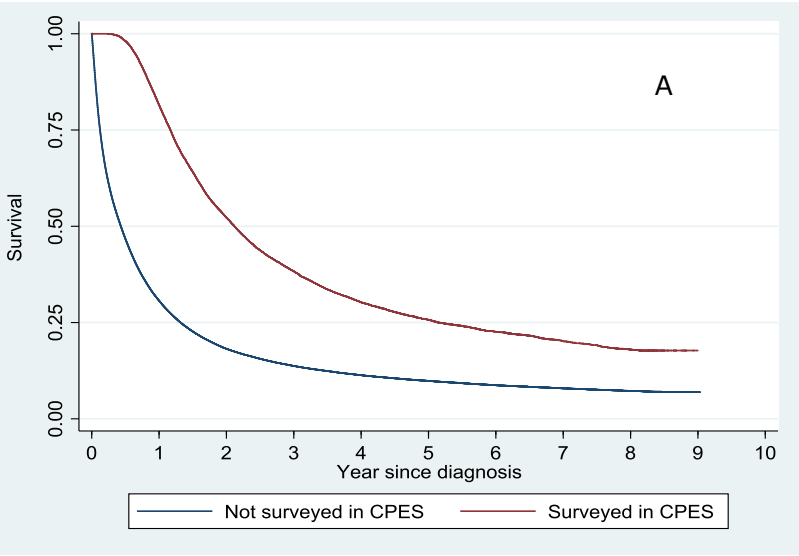


Figure 1: Flow chart of study population derivation: people with primary lung cancers in the English national cancer register

CPES: Cancer Patient Experience Survey; NLCA: National Lung Cancer Audit; LUCADA: Lung Cancer Audit Data

Figure



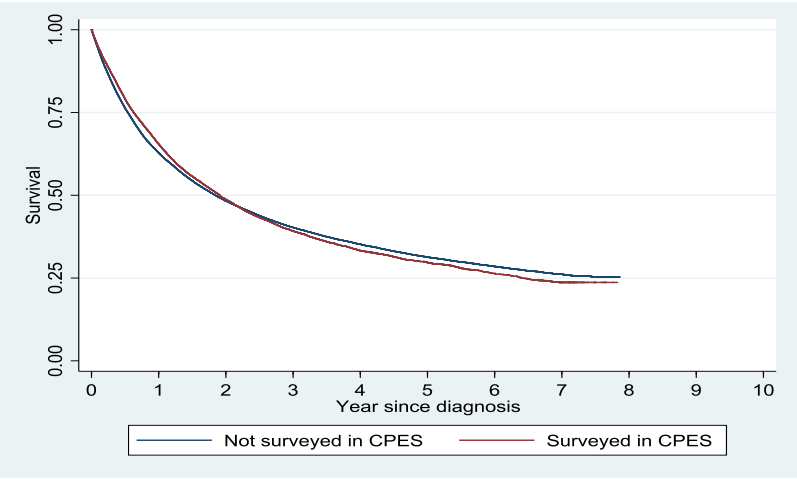


Figure 2. Kaplan-Meier survival curves of survival from lung cancer diagnosis comparing people included and not included in CPES.
A: Whole NLCA population (N=240,375); B: NLCA population surviving more than 426 days after diagnosis (N=73,500)

Table 1 - resubmission following reviewer suggestion

Table 1: Comparison of baseline and clinical characteristics for all lung cancer patients in NLCA with those in CPES

Characteristic	Total number of people (N=240,375) n (%)	Number of people in CPES (N=15,967) n (%)	Unadjusted OR of being surveyed (95% CI)	Adjusted OR of being in CPES (95% CI)	p-value	Test for trend
Year of diagnosis						
2009	31893(13.3)	1490(9.3)	1	1		
2010	32594(13.6)	1790(11.2)	1.19(1.10 - 1.27)	1.09(1.01 - 1.17)		
2011	33671(14.0)	3212(20.1)	2.15(2.02 - 2.29)	1.93(1.80 - 2.07)		
2012	34714(14.4)	3302(20.7)	2.14(2.01 - 2.28)	1.60(1.49 - 1.72)		
2013	35041(14.6)	3028(19.0)	1.93(1.81 - 2.06)	1.48(1.38 - 1.59)		
2014	36165(15.1)	631(4.0)	0.36(0.33 - 0.40)	0.34(0.31 - 0.38)		
2015	36297(15.1)	2514(15.7)	1.52(1.42 - 1.62)	2.08(1.88 - 2.30)	<0.001	<0.001
Gender						
Male	130804(54.6)	8561(53.6)	1	1		
Female	109571(45.5)	7406(46.4)	1.04(1.00 - 1.07)	1.06(1.02 - 1.09)	0.001	
Age (years)						
<65	56737(23.6)	5442(34.1)	1	1		
65-80	126872(52.8)	9394(58.8)	0.75(0.73 - 0.78)	0.84(0.81 - 0.87)		
>80	56766(23.6)	1131(7.1)	0.19(0.18 - 0.20)	0.31(0.29 - 0.33)	<0.001	<0.001
Stage						
SgIA	16902(7.0)	1418(8.9)	1	1		
SgIB	13745(5.7)	1466(9.2)	1.30(1.21 - 1.41)	1.29(1.19 - 1.40)		
SgIIA	7569(3.2)	1076(6.7)	1.81(1.66 - 1.97)	1.68(1.54 - 1.84)		
SgIIB	7259(3.0)	854(5.4)	1.46(1.33 - 1.59)	1.49(1.36 - 1.64)		
SgIIIA	25091(10.4)	2783(17.4)	1.36(1.27 - 1.46)	1.34(1.25 - 1.44)		
SgIIIB	19037(7.9)	1764(11.1)	1.12(1.04 - 1.20)	1.03(0.95 - 1.11)		
SgIV	102323(42.6)	4843(30.3)	0.54(0.51 - 0.58)	0.69(0.64 - 0.73)	<0.001	<0.001
Missing	48449(20.2)	1763(11.0)	0.41(0.38 - 0.44)	0.69(0.64 - 0.75)		
Performance status*						
0	25464(10.6)	4354(27.3)	1	1		
1	46805(19.5)	5328(33.4)	0.62(0.60 - 0.65)	0.79(0.75 - 0.82)		
2	27056(11.3)	1304(8.2)	0.25(0.23 - 0.26)	0.39(0.36 - 0.42)		
3	30491(12.7)	415(2.6)	0.07(0.06 - 0.07)	0.16(0.14 - 0.18)		
4	8115(3.4)	18(0.1)	0.01(0.01 - 0.02)	0.03(0.02 - 0.05)	<0.001	<0.001
Missing	29279(12.2)	1194(7.5)	0.21(0.19 - 0.22)	0.49(0.45 - 0.52)		
Ethnicity						
White	200615(83.5)	14504(90.8)	1	1		
Black	1772(0.7)	122(0.8)	0.95(0.79 - 1.14)	1.03(0.85 - 1.24)		
Asian	3018(1.3)	187(1.2)	0.85(0.73 - 0.98)	0.89(0.76 - 1.04)		
Mixed	442(0.2)	32(0.2)	1.00(0.70 - 1.44)	0.98(0.67 - 1.43)		
Other	1473(0.6)	102(0.6)	0.95(0.78 - 1.17)	0.95(0.77 - 1.18)	0.275	
Missing	33055(13.8)	1020(6.4)	0.41(0.38 - 0.44)	0.49(0.45 - 0.52)		
Socioeconomic deprivation quintile						
1-least deprived	33715(14.0)	2557(16.0)	1	1		
2	43094(17.9)	3222(20.2)	0.98(0.93 - 1.04)	0.96(0.91 - 1.02)		
3	47549(19.8)	3297(20.7)	0.91(0.86 - 0.96)	0.90(0.85 - 0.96)		
4	53048(22.1)	3354(21.0)	0.82(0.78 - 0.87)	0.81(0.77 - 0.86)		
5-most deprived	62969(26.2)	3537(22.2)	0.73(0.69 - 0.76)	0.70(0.67 - 0.74)	<0.001	<0.001
Comorbidity (Charlson index)						
0	76055(31.6)	6589(41.3)	1	1		
1	41235(17.2)	3473(21.8)	0.97(0.93 - 1.01)	1.09(1.04 - 1.14)		
2-3	39738(16.5)	2428(15.2)	0.69(0.65 - 0.72)	0.93(0.88 - 0.98)		
4+	83347(34.7)	3477(21.8)	0.46(0.44 - 0.48)	0.86(0.82 - 0.90)	<0.001	<0.001
Route to diagnosis						
GP referral	52649(21.9)	4062(25.4)	1	1		
Emergency presentation	85116(35.4)	2012(12.6)	0.29(0.27 - 0.31)	0.52(0.49 - 0.55)		
Inpatient elective	4007(1.7)	287(1.8)	0.92(0.81 - 1.04)	0.96(0.84 - 1.09)		
Other outpatient	26425(11.0)	2161(13.5)	1.07(1.01 - 1.12)	1.00(0.95 - 1.06)		
TWW	66887(27.8)	7318(45.8)	1.47(1.41 - 1.53)	1.26(1.21 - 1.32)	<0.001	
Missing	5291(2.2)	127(0.8)	0.29(0.25 - 0.35)	0.45(0.38 - 0.55)		
Lung cancer type						
NSCLC	211265(87.9)	13268(83.1)	1	1		
Carcinoid	2408(1.0)	273(1.7)	1.91(1.68 - 2.17)	1.09(0.95 - 1.25)		
SCLC	26702(11.1)	2426(15.2)	1.49(1.43 - 1.56)	1.51(1.44 - 1.59)	<0.001	

Abbreviations: CI: confidence interval; CPES: Cancer Patient Experience Survey; GP: general practice; NLCA: National Lung Cancer Audit; NSCLC: non-small cell lung cancer; OR: odds ratio; SCLC: small cell lung cancer; TWW: Two-week wait

Notes: Logistic regression model with ORs adjusted for all other variables in the table. Missing not included in p-values.

***Performance status only available for patients in Lung Cancer Audit Data (LUCADA) sub-population (N=167,210)**

Table

Table 2: Comparison of health service and treatment characteristics for all lung cancer patients in NLCA with those included in CPES

Characteristic	Total number of people (N=240,375) n (%)	Number of people in CPES (N=15,967) n (%)	Adjusted OR of being in CPES (95% CI)	p-value	Test for trend
MDT discussion*					
No	8908(5.3)	423(3.4)	1		
Yes	158302(94.7)	12190(96.7)	0.97(0.87 - 1.08)	0.549	
LCNS assessed*					
No	43614(26.1)	1936(15.4)	1		
Yes	123596(73.9)	10677(84.7)	1.25(1.18 - 1.32)	<0.001	
First LCNS assessment*					
After diagnosis	92205(74.6)	8046(75.4)	1.00		
Before/at diagnosis	26432(21.4)	2251(21.1)	0.99(0.94-1.04)	0.871	
Missing	4959(4.0)	380(3.6)	0.86(0.77-0.96)		
Place of LCNS assessment*					
In clinic	80159(64.9)	8126(76.1)	1		
Home visit	1035(0.8)	82(0.8)	1.06(0.84 - 1.34)		
Ward visit	23492(19.0)	732(6.9)	0.64(0.59 - 0.70)		
Telephone	9171(7.4)	941(8.8)	1.07(0.99 - 1.15)		
Other	2908(2.4)	221(2.1)	0.97(0.84 - 1.13)	0.002	
Missing	6831(5.5)	575(5.4)	0.89(0.81 - 0.98)		
LCNS present at diagnosis*					
No	28013(22.7)	1980(18.5)	1		
Yes	91476(74.0)	8408(78.8)	1.15(1.09 - 1.21)	<0.001	
Missing	4107(3.3)	289(2.7)	1.05(0.92 - 1.20)		
Anti-cancer treatment modality (all patients)					
No treatment	101276(44.1)	537(4.0)	1		
Surgery	22298(9.7)	2738(20.4)	10.23(9.16 - 11.42)		
Chemo and radio	36650(16.0)	5680(42.3)	19.64(17.80 - 21.68)		
Chemotherapy alone	27755(12.1)	3085(23.0)	15.16(13.72 - 16.75)		
Radiotherapy only	41758(18.2)	1393(10.4)	4.35(3.92 - 4.82)	<0.001	
NSCLC patients only:					
No treatment	93908(46.7)	496(4.6)	1		
Surgery	20389(10.1)	2516(23.2)	10.26(9.14 - 11.52)		
Chemo and radio	25699(12.8)	3750(34.6)	18.03(16.23 - 20.02)		
Chemotherapy alone	21374(10.6)	2769(25.6)	17.78(16.00 - 19.76)		
Radiotherapy only	39744(19.8)	1308(12.1)	4.26(3.83 - 4.75)	<0.001	
SCLC patients only:					
No treatment	6956(26.5)	21(0.9)	1		
Surgery	141(0.5)	9(0.4)	9.80(4.22 - 22.76)		
Chemo and radio	10,913(41.5)	1921(82.3)	42.21(27.23 - 65.44)		
Chemotherapy alone	6,310(24.0)	302(12.9)	11.46(7.32 - 17.92)		
Radiotherapy only	1,959(7.5)	80(3.4)	10.45(6.43 - 16.99)	<0.001	

Abbreviations: CI: confidence interval; CPES: Cancer Patient Experience Survey; LCNS: lung cancer nurse specialist; MDT: multidisciplinary discussion; NLCA: National Lung Cancer Audit; NSCLC: non-small cell lung cancer; OR: odd ratio; SCLC: small cell lung cancer; TWW: Two-week wait
Notes: Logistic regression model with ORs adjusted for all for gender, age, performance status, stage of cancer at diagnosis, ethnicity, socioeconomic deprivation, Charlson Index of comorbidity, route to diagnosis, lung cancer type and year of diagnosis. Missing not included in p-values.
***MDT discussion, LCNS assessment, method and timing only available for patients in Lung Cancer Audit Data (LUCADA) sub-population (N=167,210)**

Supplementary Table 1: Comparison of baseline and clinical characteristics for all lung cancer patients in NLCA with those included in CPES who survived more than 426 days after diagnosis

Characteristic	Total number of people (N=73,500) n (%)	Number of people in CPES(N=11,980) N (%)	Adjusted OR of being in CPES (95% CI)	p-value	Test for trend
Year of diagnosis					
2009	8423(11.5)	1198(10.0)	1		
2010	8978(12.2)	1241(10.4)	0.89(0.82 - 0.98)		
2011	9608(13.1)	2279(19.0)	1.74(1.59 - 1.89)		
2012	10899(14.8)	2409(20.1)	1.45(1.33 - 1.58)		
2013	11177(15.2)	2273(19.0)	1.35(1.24 - 1.47)		
2014	11905(16.2)	608(5.1)	0.34(0.30 - 0.38)		
2015	12510(17.0)	1972(16.5)	1.60(1.43 - 1.81)	<0.001	<0.001
Gender					
Male	36564(49.8)	6223(51.9)	1		
Female	36936(50.3)	5757(48.1)	0.94(0.91 - 0.98)	0.006	
Age (years)					
<65	21817(29.7)	4186(34.9)	1		
65-80	40421(55.0)	7040(58.8)	0.93(0.89 - 0.98)		
>80	11262(15.3)	754(6.3)	0.38(0.35 - 0.42)	<0.001	<0.001
Stage					
SgIA	13773(18.7)	1359(11.3)	1		
SgIB	10055(13.7)	1362(11.4)	1.36(1.25 - 1.48)		
SgIIA	5015(6.8)	972(8.1)	1.93(1.76 - 2.12)		
SgIIB	3950(5.4)	738(6.2)	1.90(1.71 - 2.10)		
SgIIIA	10923(14.9)	2204(18.4)	1.97(1.83 - 2.13)		
SgIIIB	5562(7.6)	1214(10.1)	1.98(1.81 - 2.17)		
SgIV	13801(18.8)	2858(23.9)	2.08(1.93 - 2.24)	<0.001	<0.001
Missing	10421(14.2)	1273(10.6)	1.39(1.27 - 1.52)		
Performance status*					
0	14507(19.7)	3512(29.3)	1		
1	19569(26.6)	3835(32.0)	0.87(0.82 - 0.92)		
2	5830(7.9)	781(6.5)	0.58(0.53 - 0.63)		
3	5102(6.9)	286(2.4)	0.39(0.34 - 0.44)		
4	324(0.4)	8(0.1)	0.12(0.06 - 0.25)	<0.001	<0.001
Missing	7731(10.5)	937(7.8)	0.71(0.66 - 0.77)		
Ethnicity					
White	64193(87.3)	10937(91.3)	1		
Black	701(1.0)	101(0.8)	0.88(0.71 - 1.10)		
Asian	1277(1.7)	156(1.3)	0.70(0.59 - 0.83)		
Mixed	168(0.2)	22(0.2)	0.77(0.48 - 1.22)		
Other	567(0.8)	87(0.7)	0.86(0.68 - 1.09)	<0.001	
Missing	6594(9.0)	677(5.7)	0.62(0.57 - 0.67)		
Socioeconomic deprivation quintile					
1-least deprived	11062(15.1)	1949(16.3)	1.00		
2	13504(18.4)	2376(19.8)	0.97(0.91 - 1.04)		
3	14380(19.6)	2488(20.8)	0.95(0.89 - 1.02)		
4	15863(21.6)	2521(21.0)	0.85(0.80 - 0.91)		
5-most deprived	18691(25.4)	2646(22.1)	0.74(0.69 - 0.79)	<0.001	<0.001
Comorbidity (Charlson Index)					
0	29457(40.1)	5033(42.0)	1		
1	16070(21.9)	2682(22.4)	1.10(1.04 - 1.16)		
2-3	14054(19.1)	1912(16.0)	1.00(0.94 - 1.06)		
4+	13919(18.9)	2353(19.6)	1.12(1.05 - 1.18)	0.002	<0.001
Route to diagnosis					
GP referral	21360(29.1)	3174(26.5)	1		
Emergency presentation	10866(14.8)	1322(11.0)	0.86(0.80 - 0.92)		
Inpatient elective	1147(1.6)	194(1.6)	1.04(0.88 - 1.23)		
Other outpatient	12198(16.6)	1749(14.6)	0.97(0.90 - 1.03)		
TWW	26236(35.7)	5448(45.5)	1.28(1.22 - 1.35)		
Missing	1693(2.3)	93(0.8)	0.43(0.34 - 0.53)	<0.001	
Lung cancer type					
NSCLC	65450(89.1)	10301(86.0)	1		
Carcinoid	2234(3.0)	267(2.2)	0.86(0.75 - 0.98)		
SCLC	5816(7.9)	1412(11.8)	1.38(1.29 - 1.48)	<0.001	

Abbreviations: CI: confidence interval; CPES: Cancer Patient Experience Survey; GP: general practice; NLCA: National Lung Cancer Audit; NSCLC: non-small cell lung cancer; OR: odds ratio; SCLC: small cell lung cancer; TWW: Two-week wait
Notes: Logistic regression model with ORs adjusted for all other variables in the table. Missing not included in p-values.
***Performance status only available for patients in Lung Cancer Audit Data (LUCADA) sub-population (N=53,063)**

Supplementary Table 2: Comparison of health service and treatment characteristics for all lung cancer patients in NLCA with those included in CPES who survived more than 426 days after diagnosis

Characteristic	Total number of people(N=73,500) n (%)	Number of people in CPES(N=11,980) n (%)	Adjusted OR of being in CPES(95% CI)	p-value	Test for trend
MDT discussion*					
No	2888(5.4)	335(3.6)	1.00		
Yes	50175(94.6)	9024(96.4)	1.03(0.91 - 1.18)	0.603	
Assessed by LCNS*					
No	11713(22.1)	1513(16.2)	1.00		
Yes	41350(77.9)	7846(83.8)	1.17(1.10 - 1.25)	<0.001	
First LCNS assessment*					
After diagnosis	30680(74.2)	5825(74.2)	1.00		
Before/at diagnosis	9187(22.2)	1749(22.3)	1.08(1.01-1.15)	0.038	
Missing	1483(3.6)	272(3.5)	0.95(0.83-1.10)		
Place of LCNS assessment*					
In clinic	31095(75.2)	5993(76.4)	1.00		
Home visit	276(0.7)	49(0.6)	0.98(0.71 - 1.36)		
Ward visit	2776(6.7)	466(5.9)	0.95(0.85 - 1.06)		
Telephone	3784(9.2)	739(9.4)	1.10(1.00 - 1.20)		
Other	1043(2.5)	167(2.1)	1.00(0.84 - 1.20)	0.227	
Missing	2376(5.8)	432(5.5)	0.96(0.86 - 1.08)		
LCNS present at diagnosis*					
No	8935(21.6)	1510(19.3)	1.00		
Yes	31119(75.3)	6117(78.0)	1.13(1.06 - 1.20)	<0.001	
Missing	1296(3.1)	219(2.8)	1.06(0.90 - 1.24)		
Anti-cancer treatment modality (all patients)					
No treatment	12297(18.9)	328(3.4)	1.00		
Surgery	19148(29.4)	2616(27.1)	4.65(4.09 - 5.29)		
Chemo and radio	14677(22.5)	3685(38.2)	8.01(7.04 - 9.11)		
Chemotherapy alone	8268(12.7)	2138(22.2)	8.64(7.58 - 9.85)		
Radiotherapy only	10790(16.6)	885(9.2)	2.67(2.34 - 3.05)	<0.001	
NSCLC patients only:					
No treatment	11779(20.5)	301(3.7)	1.00		
Surgery	17326(30.1)	2396(29.7)	4.87(4.25 - 5.58)		
Chemo and radio	10274(17.9)	2521(31.3)	8.08(7.05 - 9.25)		
Chemotherapy alone	7606(13.2)	2001(24.8)	9.17(7.99 - 10.53)		
Radiotherapy only	10501(18.3)	847(10.5)	2.73(2.38 - 3.14)	<0.001	
SCLC patients only:					
No treatment	187(3.4)	7(0.5)	1.00		
Surgery	89(1.6)	8(0.6)	2.27(0.77 - 6.69)		
Chemo and radio	4376(79.3)	1157(86.9)	7.96(3.67 - 17.27)		
Chemotherapy alone	616(11.2)	125(9.4)	5.33(2.41 - 11.79)		
Radiotherapy only	253(4.6)	34(2.6)	3.58(1.54 - 8.37)	0.432	

Abbreviations: CI: confidence interval; CPES: Cancer Patient Experience Survey; LCNS: lung cancer nurse specialist; MDT: multidisciplinary discussion; NLCA: National Lung Cancer Audit; NSCLC: non-small cell lung cancer; OR: odd ratio; SCLC: small cell lung cancer; TWW: Two-week wait
Notes: Logistic regression model with ORs adjusted for all for gender, age, performance status, stage of cancer at diagnosis, ethnicity, socioeconomic deprivation, Charlson Index of comorbidity, route to diagnosis, lung cancer type and year of diagnosis. Missing not included in p-values.
***MDT discussion, LCNS assessment, method and timing only available for patients in Lung Cancer Audit Data (LUCADA) sub-population (N=53,063)**

Supplementary Table 3: Multi-level logistic regression model of baseline, clinical, treatment and service characteristics comparing lung cancer patients included and not included in CPES

Characteristic	Total number of people(N=167,210) n (%)	Number of people in CPES (N=12,613) n (%)	Adjusted OR of being in CPES (95% CI)	p-value
Year of diagnosis				
2009	25671(15.4)	1385(11.0)	1.00	
2010	26481(15.8)	1621(12.9)	1.18(1.09 - 1.28)	
2011	27712(16.6)	3020(23.9)	2.19(2.03 - 2.36)	
2012	29329(17.5)	3149(25.0)	1.91(1.77 - 2.07)	
2013	29422(17.6)	2856(22.6)	1.72(1.59 - 1.86)	
2014	28058(16.8)	534(4.2)	0.34(0.31 - 0.38)	
2015	537(0.3)	48(0.4)	1.48(1.08 - 2.03)	<0.001
Gender				
Male	91882(55.0)	6796(53.9)	1.00	
Female	75328(45.1)	5817(46.1)	1.06(1.02 - 1.10)	0.003
Age (years)				
<65	41541(24.8)	4445(35.2)	1.00	
65-80	90087(53.9)	7326(58.1)	1.01(0.97 - 1.06)	
>80	35582(21.3)	842(6.7)	0.76(0.70 - 0.83)	0.103
Stage				
SgIA	11002(6.6)	970(7.7)	1.00	
SgIB	10101(6.0)	1122(8.9)	1.28(1.16 - 1.41)	
SgIIA	5642(3.4)	837(6.6)	1.68(1.52 - 1.87)	
SgIIB	5370(3.2)	682(5.4)	1.57(1.41 - 1.76)	
SgIIIA	19104(11.4)	2241(17.8)	1.50(1.37 - 1.64)	
SgIIIB	14551(8.7)	1399(11.1)	1.15(1.04 - 1.28)	
SgIV	71519(42.8)	3856(30.6)	0.91(0.83 - 1.00)	<0.001
Missing	29921(17.9)	1506(11.9)	1.04(0.94 - 1.16)	
Performance status				
0	25464(15.2)	4354(34.5)	1.00	
1	46805(28.0)	5328(42.2)	0.86(0.82 - 0.90)	
2	27056(16.2)	1304(10.3)	0.60(0.56 - 0.65)	
3	30491(18.2)	415(3.3)	0.38(0.34 - 0.42)	
4	8115(4.9)	18(0.1)	0.12(0.08 - 0.19)	<0.001
Missing	29279(17.5)	1194(9.5)	0.68(0.63 - 0.73)	
Ethnicity				
White	139419(83.4)	11404(90.4)	1.00	
Black	1169(0.7)	88(0.7)	0.90(0.72 - 1.14)	
Asian	1977(1.2)	142(1.1)	0.86(0.72 - 1.04)	
Mixed	268(0.2)	23(0.2)	0.96(0.61 - 1.52)	
Other	939(0.6)	83(0.7)	1.02(0.80 - 1.30)	0.385
Missing	23438(14.0)	873(6.9)	0.60(0.56 - 0.65)	
Socioeconomic deprivation quintile				
1-least deprived	22872(13.7)	1989(15.8)	1.00	
2	29596(17.7)	2525(20.0)	0.97(0.91 - 1.04)	
3	32934(19.7)	2590(20.5)	0.94(0.88 - 1.00)	
4	37148(22.2)	2650(21.0)	0.86(0.81 - 0.92)	
5-most deprived	44660(26.7)	2859(22.7)	0.79(0.74 - 0.84)	<0.001
Comorbidity (Charlson index)				
0	49643(29.7)	5208(41.3)	1.00	
1	32024(19.2)	2845(22.6)	0.98(0.93 - 1.04)	
2-3	28670(17.2)	1874(14.9)	0.88(0.83 - 0.93)	
4+	56873(34.0)	2686(21.3)	0.83(0.79 - 0.88)	<0.001
Route to diagnosis				
GP referral	36496(21.8)	3112(24.7)	1.00	
Emergency presentation	53796(32.2)	1584(12.6)	0.73(0.68 - 0.78)	
Inpatient elective	2754(1.7)	214(1.7)	0.97(0.83 - 1.13)	
Other outpatient	18474(11.1)	1665(13.2)	0.96(0.90 - 1.03)	
TWW	53632(32.1)	5954(47.2)	1.08(1.03 - 1.14)	<0.001
Missing	2058(1.2)	84(0.7)	0.72(0.57 - 0.91)	
Lung cancer type				
NSCLC	145408(87.0)	10467(83.0)	1.00	
Carcinoid	1298(0.8)	159(1.3)	0.84(0.70 - 1.00)	
SCLC	20504(12.3)	1987(15.8)	1.04(0.98 - 1.10)	0.032

Supplementary table 3 continued:

Characteristic	Total number of people (%)	Number of people in CPES (%)	Adjusted OR of being in CPES (95% CI)	p-value
Anti-cancer treatment modality				
No treatment	60841(36.4)	391(3.1)	1.00	
Surgery	24544(14.7)	4036(32.0)	12.54(11.13 - 14.13)	
Chemo and radio	29066(17.4)	4610(36.6)	14.50(12.94 - 16.25)	
Chemotherapy alone	20962(12.5)	2466(19.6)	11.56(10.31 - 12.98)	
Radiotherapy only	31797(19.0)	1110(8.8)	3.69(3.27 - 4.15)	<0.001
Trust annual service size				
<150 new LC patients seen	47144(28.2)	3612(28.6)	1.00	
150-224	50742(30.4)	3741(29.7)	0.94(0.85 - 1.05)	
≥225	68473(41.0)	5240(41.5)	0.98(0.88 - 1.10)	0.641
unknown/missing	851(0.5)	20(0.2)	0.51(0.27 - 0.98)	
Trust treatment specialty				
No specialty	31229(18.7)	1989(15.8)	1.00	
Surgical trust	42600(25.5)	3583(28.4)	1.24(1.08 - 1.43)	
Chemotherapy trust	93381(55.9)	7041(55.8)	1.14(1.02 - 1.28)	0.002

Abbreviations: CI: confidence interval; CPES: Cancer Patient Experience Survey; GP: general practice; NLCA: National Lung Cancer Audit; NSCLC: non-small cell lung cancer; OR: odds ratio; SCLC: small cell lung cancer; TWW: Two-week wait

Notes: Logistic regression model with ORs adjusted for all other variables in the table. Missing not included in p-values.

Authors' contribution

The conception of the study was done by LJT and IS with input on the design from RBH, AK and YN. YN acquired, managed and analysed the data from PHE. YN, LJT, IS and AK were involved in the core data interpretation and shaping of the analysis. YN and LJT wrote the core of the manuscript and all authors critically reviewed the manuscript and approved it prior to submission.