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Lung cancer diagnosed following an emergency admission: mixed methods study of the management, outcomes and needs and experiences of patients and carers

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Summary

Background: In the UK, although 40% of patients with lung cancer are diagnosed following an emergency admission (EA), data is limited on their needs and experiences as they progress through diagnostic and treatment pathways.

Methods: Prospective data collection using medical records, questionnaires and in-depth interviews. Multivariate logistic regression explored associations between diagnosis following EA and aspects of interest. Questionnaire responses with 95% confidence intervals were compared with local and national datasets. A grounded theory approach identified patient and carer themes.

Results: Of 401 patients, 154 (38%) were diagnosed following EA; 37 patients and six carers completed questionnaires and 13 patients and 10 carers were interviewed. Compared to those diagnosed electively, EA patients adjusted results found no difference in treatment recommendation, treatment intent or place of death. Time to diagnosis, review, or treatment was 7–14 days quicker but fewer EA patients had a lung cancer nurse present at diagnosis (37% vs. 62%). Palliative care needs were high (median [IQR] 21 [13–25] distressing or bothersome symptoms/issues) and various information and support needs unmet. Interviews highlighted in particular, perceived delays in obtaining investigations/specialist referral and factors influencing success or failure of the cough campaign.

Conclusions: Presentation as an EA does not appear to confer any inherent disadvantage regarding progress through lung cancer diagnostic and treatment pathways. However, given the frequent combination of advanced disease, poor performance status and prognosis, together with the high level of need and reported short-fall in care, we suggest that a specialist palliative care assessment is routinely offered.

KEYWORDS

Lung cancer; Non-small cell lung cancer; Palliative care; Small cell lung cancer

Introduction

In the UK, survival after a diagnosis of lung cancer appears lower compared to countries with similar healthcare systems.[1] In part, this is explained by differences in stage at presentation, with proportionally fewer diagnosed with early stage disease.[1] Diagnostic delay is also suggested by the fact that about 40% of patients with lung cancer in the UK are diagnosed after an emergency admission to hospital.[2] Analysis of a large dataset of patients with non-small cell lung cancer found, compared to patients diagnosed electively, that the most strongly associated clinical features in those diagnosed after an emergency admission were stage IV disease and a poor performance status (Eastern Cooperative Oncology Group 4), which contributed to a poorer prognosis (median survival 77 vs. 260 days, 1-year survival 17% vs. 41%).[3] Despite diagnosis after emergency admission being common and having such a poor outlook, there has been relatively little research focusing specifically on the needs of this group and their experiences as they go through the diagnostic and treatment pathways; they are unlikely to be captured by the National Cancer Patient Experience Survey which is biased toward fitter patients.[4]

This study used a mixed-methods approach to explore in detail the characteristics, outcomes, needs and experiences of a cohort of patients diagnosed with lung cancer following an emergency admission. The aim was to identify areas where there may be potential to improve the care provided so as to inform the need for further focused research. During part of the recruitment period, the English

Department of Health ran a lung cancer awareness ‘cough campaign’, which permitted capture of patient and carer views relating specifically to this.

Methods

Setting, participants and data collection

This was a prospective survey between 1st December 2012 and 31st November 2013 at Nottingham University Hospitals NHS Trust. All patients assigned a diagnosis of lung cancer at the lung cancer multidisciplinary team meeting (MDT) were identified and categorised as either diagnosed following an emergency admission or electively. Basic demographic and other data recorded included aspects defined as follows; socioeconomic status (Index of Multiple Deprivation Score based on postcode, separated into quintiles), investigations undertaken in secondary care (following emergency admission or the receipt of a referral letter from the general practitioner, until the date of the treatment recommendation of the lung cancer MDT), time taken to diagnosis (the number of days from the date of emergency admission or from receipt of a referral letter from the general practitioner, to either a histocytology report or assignment of a clinical diagnosis by the lung cancer MDT), cancer stage (International Association for the Study of Lung Cancer, TNM staging classifications, 7th edition) and best supportive care (a treatment recommendation of the lung cancer MDT when specific anticancer treatment is either inappropriate, e.g. due to a poor performance status, or not currently indicated, e.g. palliative radiotherapy).

All patients diagnosed with lung cancer following an emergency admission were potentially eligible to complete the questionnaires: Eastern Co-operative Oncology Group (ECOG) performance status, Charlson co-morbidities index,[5] Sheffield Profile for Assessment and Referral to Care (SPARC©) holistic needs questionnaire[6–8] and the 2012 National Cancer Patient Experiences Survey.[9] The latter was modified by removing irrelevant questions and those relating to information already collected. If the patient was unable to participate, an adult informal carer was approached to act as a proxy. Exclusion criteria were the presence of severe distress, a lack of capacity to consent, a lack of awareness of the diagnosis of lung cancer or an inability to communicate in English.

Following completion of the questionnaires, patients and their carers were invited to take part in more in-depth interviews, undertaken as detailed in Appendix 1S.

Written informed consent was obtained for the questionnaire and interview elements of the study; it was not required for collection of quasi-anonymised data, similar to that gathered for the National Lung Cancer Audit. The National Research Ethics Service Committee East Midlands – Nottingham 1 (12/EM/0305) approved the study and it was adopted onto the UK NIHR portfolio (12993).

Data handling and analysis

After an initial descriptive analysis, gender, age, deprivation, performance status, diagnosis and stage were assessed by univariate analysis to determine whether there were any differences in presenting characteristics for those diagnosed following emergency admission or electively. A multivariate model was then fitted including all of these variables. We investigated whether a diagnosis following emergency admission resulted in a difference in investigations undertaken, treatment recommendation, treatment intent and place of death, with these multivariate models adjusted for gender, age, performance status, diagnosis and stage. Survival was assessed using survival rate, Kaplan-Meier method and a Cox proportional hazards model, adjusted for gender, age, performance status, diagnosis and stage. The start date was the date of diagnosis and the end date was the date of death or 1st March 2014, with all survivors confirmed alive on this date. Mann-Whitney U and Pearson Chi-squared tests were used to compare time taken to reach key points in the diagnostic pathway, presence of a lung cancer clinical nurse specialist and receipt of an active oncological treatment.

Proportions with 95% confidence intervals (CI) were calculated for responses to the SPARC© questionnaire and compared to a historical dataset of patients diagnosed electively generated locally at the time of assessment for a rehabilitation service, generally within 4 weeks of diagnosis. Similarly, responses from the modified National Cancer Patient Experiences Survey were compared with those obtained in the National Cancer Patient Experiences Survey 2012–13 both nationally and locally, noting instances where the 95% CI did not encompass the latter. The National Cancer Patient Experiences Survey 2012–13 responses are in the public domain (www.quality-health.co.uk); they were obtained from patients who had received inpatient or day case treatment between 1st September 2012 and 30th November 2012 and are not limited to those with a recent diagnosis.

For the in-depth interviews, a grounded theory[10] approach was used to identify themes likely to be typical for patients diagnosed following emergency admission and their carers. Interviews were recorded, transcribed and entered into a qualitative data management package. Coding and thematic analysis were undertaken by two researchers (GC, JS) to check validity. Interviews continued until data saturation was achieved. Standard procedures for evaluating rigour in qualitative research were employed.[11]

All calculations were performed using Statistical Package for the Social Sciences version 20.

Results

Over one year, 401 patients received a diagnosis of lung cancer, of which 154 (38%) were following emergency admission. Emergency admissions were mostly via the accident and emergency department (63%); those via the GP were either direct (24%), or via an urgent outpatient referral (6%). The remaining 7% were emergency transfers from another hospital, care home or nursing home. Emergency admissions utilized 1,856 hospital bed days, a median [IQR] of 9 [3–16] per patient. Seventeen (11%) patients died during the emergency admission, with 122 (79%) discharged home, 10 (6%) transferred to a hospice and 5 (3%) to a residential/nursing home or other hospital.

Demographics

Patients diagnosed following emergency admission or electively were similar with regard to gender (60% vs. 56% male), age (72 (11) vs. 72 (9) years), ethnicity (96% vs. 97% white British) and deprivation (Table 1S). However, the group diagnosed following emergency admission had a greater proportion of patients with a poor performance status (30% vs. 13% ECOG 3–4), a clinical diagnosis (25% vs. 9%) and more advanced stage disease (81% vs. 51% stage IIIB/IV). In the univariate model and after mutual adjustment in multivariate analysis, ECOG 4, a clinical diagnosis and stage IV were strongly associated with diagnosis following emergency admission (Table 1S).

Diagnosis, treatment, survival and place of death

Investigations undertaken in secondary care: The adjusted multivariate model found that patients diagnosed following an emergency admission were more likely to have had a chest x-ray (adjusted OR 6.95, 95% CI 4.01–12.09) or a MRI (adjusted OR 3.20, 95% CI 1.40–7.29) and less likely to have PET CT (adjusted OR 0.29, 95% CI 0.12–0.73) as compared to an elective admission (Table 1).

Time to diagnosis: In those diagnosed following emergency admission the median time to either diagnosis or discussion at the lung cancer MDT was 14 days less at 9 vs. 23 days and 11 vs. 25 days respectively (p<0.001 for both). Fewer patients diagnosed following emergency admission had a lung cancer clinical nurse specialist present at the time of diagnosis (37% vs. 62%, p<0.001) (Table 1).

Treatment recommendation: Compared to those diagnosed electively, the proportion of patients diagnosed following emergency admission recommended by the lung cancer MDT for surgery was lower (5% vs. 22%) and for best supportive care higher (50% vs. 19%); consequently, for a higher proportion the treatment intent was palliative (95% vs. 72%), with a smaller proportion receiving an 'active' oncological intervention (46% vs. 79%, p<0.001) (Table 2). After adjusting for confounders, there were no significant differences in treatment recommendations between the two groups (Table 1).

Time taken to treatment commencement: Those diagnosed following an emergency admission were treated more quickly, with the median time from lung cancer MDT treatment recommendation to commencement of an 'active' oncological treatment seven days less (6 vs. 13 days, p<0.001), as compared to those diagnosed electively (Table 1).

Survival and place of death: Median duration of follow-up was the same for patients diagnosed electively and after emergency admission (233 vs. 232 days). Three and

12-month survival rates were lower for patients diagnosed following emergency admission at 47% vs. 85% and 17% vs. 40% respectively ($p<0.001$ for both), as was median [IQR] survival (67 [33–100] vs. 405 [208–523] days, $p<0.001$; Table 1, Fig. 1S). The hazard ratio for death, adjusted for gender, age, performance status, diagnosis and stage, was also higher in patients diagnosed following emergency admission compared to those diagnosed electively (HR 1.68, 95% CI 1.23–2.28, $p=0.001$).

Place of death was similar for patients diagnosed electively or following emergency admission, with about 40% dying either in hospital or home, with the remainder in a hospice/palliative care unit (16–19%) or a nursing/residential home (2–3%); univariate and multivariate analyses revealed no significant differences (Table 1).

Holistic needs assessment and patient experience

Forty-three participants (37 patients and 6 carer proxies) completed the questionnaires, representing 28% of patients diagnosed following emergency admission (for study flow, see Fig. 2S). Participants and non-participants were similar with regard to mean age (71 vs. 72 years), sex (63 vs. 60% male), metastatic (stage IV) cancer (74 vs. 66%) and median [IQR] ECOG performance status (1 [1–3] vs. 2 [1–3]). Participants Charlson co-morbidities index score was 9 [8–12] with common comorbidities COPD (23%), diabetes mellitus (16%) and prior myocardial infarction (12%).

Patients reported a median [IQR] overall total of 21 [13–25] symptoms or issues causing distress or bother, the most common being ‘feeling tired’, ‘feeling sleepy in the day’, ‘feeling weak’ and ‘worrying about the effect your illness is having on other people’ (Table 2; for full responses see Table 2S). By comparison, in the larger historical dataset, patients diagnosed electively reported a lower median [IQR] overall total of 15 [10–21] symptoms or issues. Although the order varied, seven out of the top 10 symptoms or issues were the same. There were higher proportions of patients diagnosed following emergency admission reporting ‘feeling sleepy during the day’, ‘feeling weak’, ‘feeling everything is an effort’ and ‘worrying about the effect your illness was having on other people’.

Most responses to the modified National Cancer Patient Experiences Survey were similar to those obtained nationally and locally in the 2012–13 National Cancer Patient Experiences Survey (for full responses see Table 3S). However, for several questions, the responses from patients diagnosed following emergency admission were suggestive of a potential shortfall in care, with the 95% CI falling outside of the national and/or local Nottingham University Hospitals results (Table 3). Compared to the local results, patients diagnosed following emergency admission appeared to be more likely to have seen their GP five or more times (13, 30%) and to highlight an apparent lack of sufficient information and a desire for more information in relation to diagnostic tests and about the type of cancer they had (Tables 3 and 3S). Conversely, in the overall NHS care summary question, more patients diagnosed following emergency admission reported that they had received ‘too much’ information about their condition and treatment (Table 3); however, the gap between the 95% CI and the national response was small, i.e. 12% [2–22] vs. 1%. Fewer were given the name of a Lung Cancer Nurse Specialist (Table 4), although a higher proportion contacting the Lung Cancer Nurse Specialist found it easy to do so (Table 3S). Regarding inpatient care, more thought there were insufficient nurses on duty. On leaving hospital, fewer reported being given written information about what to do and not do and who to contact if worried after discharge. This extended to lower levels of information provided by doctors and nurses as required by family/informal carers to help care for those diagnosed following emergency admission at home. Fewer patients diagnosed following emergency admission felt they received enough care from health and social care services (Tables 3 and 3S)

Themes arising from qualitative interviews

Interviews were conducted with 13 patients (7 female) and 10 carers, reflecting on the experiences of 20 patients. The interviews included three interview dyads (two wives with their husbands, one daughter and her mother), four carers alone (three daughters and one daughter-in-law) and three bereaved carers (two widows and one stepson). The mean (range) age of patients was 71 (48–91) years. Similar issues emerged across the interviews, suggesting data saturation was achieved. Six themes were identified summarized below. For a detailed overview, with additional illustrative comments, see Appendix 2S.

Experiences prior to hospital admission

Not all had seen their GP prior to admission. For those who had, some considered they had received prompt and effective care. Others felt it had taken too long to obtain tests or referral to secondary care, with several seeing their GP multiple times before a referral was made. Some felt this was due to the GP attributing their symptoms to another cause:

> *Oh, I went to the doctor's but she told me I was depressed so I went in the walk-in centre… they did a blood test which showed that there was white cells in my blood, and in my water. And there was also blood in my water. So…she phoned the doctor's and made an appointment, so I went back to the doctor's and then she took another blood test and then we waited and then it came back as low sodium, and that's how I was admitted to hospital* (49 year old female).

Delay in seeking help

Generally, patients were aware that they should go to their GP if they had a cough for three or more weeks, either because of the cough campaign, knowing someone with lung cancer, or ‘common sense’, and four of seven patients with a cough did so. The three that did not attributed the cough to another cause (e.g. smoking, a drug side effect) or did not ‘believe’ the cough campaign adverts. Those without a cough also reported attributing their symptoms to other causes (e.g. tiredness because of ‘old age’) or a pre-existing condition (e.g. increasing breathlessness due to asthma).

Cough campaign awareness

Awareness of the cough campaign was not universal, but it had directly led some to see their GP, with carers using the campaign message to encourage this. However, others considered the adverts unhelpful, choosing to ignore the message or because carer encouragement had the unintended opposite effect:

> *And it don’t matter how many adverts you put on telly…they don’t work. You know that one where they had where the cigarette was burning, it showed you all these mutating cells…Laugh, just laugh at it. Nobody takes the blindest bit of notice* (61 year old female patient with cough).
>
> *And you see, also, there were a lot of adverts on the telly round about that time as well about coughing. And I used to make snide remarks to him, [laughter] about it.* (female carer of 69 year old male patient who had a cough) *Which has the reverse effect on me, because, yeah, my back goes up, you see* (69 year old male patient with cough).

Experiences of inpatient care

Although descriptions of hospital care were mostly positive, most identified areas for improvement. These included general issues such as increasing staffing levels and improving the quality of the food, to more specific suggestions to automatically obtain support from Macmillan Cancer Support at diagnosis.

Receiving the diagnosis

This was a significant event for patients and carers and experiences varied. Some reported a poor experience in how the news was relayed (e.g. bluntly, lack of privacy) with others feeling that the professional handled the encounter well. Some wanted to know about prognosis, but noted that the topic did not arise as part of the diagnosis interview. Information requirements varied between some patients and their carers, e.g. regarding prognosis, what to expect in the future.

Experiences of outpatient/community care

Some patients reported outpatient treatment such as chemotherapy as a positive experience, in part because of the regular follow-up and that something was ‘being done’. Others were critical of some aspects, e.g. long waits and treatment times involved. Family and friends were a common source of support for patients but there was variation in professional support; some felt well supported, e.g. by their general practitioner, Macmillan nurse, lung cancer nurse specialist or research nurse, but others less so, e.g. because of no contact from the general practitioner, or a lack of practical help:

> *And [laughs] my God, there was so much help to die and no help to live, is what we found. But all the help to die wasn’t practical help. A great deal of it was all about, to my mum, How are you? How are you? And my mum doesn’t want that* (female carer of 78 year old male patient).

Discussion

The main novel findings of this study are that a diagnosis of lung cancer following an emergency admission *per se* does not appear to influence treatment recommendation, treatment intent or place of death. This suggests that this mode of presentation does not specifically disadvantage patients in how they progress through the diagnostic and treatment pathways. On the contrary, the time taken to diagnosis, discussion at the lung cancer MDT and commencement of an 'active' oncological treatment was a median of 1–2 weeks quicker than those diagnosed electively. This most likely reflects the additional time taken for elective referrals to be seen in secondary care, along with those diagnosed following an emergency admission being more likely to present with situations that require urgent treatment, e.g. radiotherapy for spinal cord compression.

Like others, we have found that patients diagnosed following an emergency admission are more likely to have a poor performance status (ECOG 4), a clinical diagnosis, advanced disease (stage IV) and a reduced survival.[2,3] These features are likely to mostly explain the differences found between patients diagnosed following an emergency admission or electively in relation to the proportions receiving specific treatment recommendations (e.g. best supportive care 50% vs. 19%) and treatment intent (palliative in 95% vs. 72%) and, in part, the differences seen in some investigations undertaken in secondary care, i.e. those diagnosed following emergency admission were more likely to have had a chest x-ray and MRI, and less likely to have had a PET CT. The most likely explanations are that patients admitted as an emergency often present with symptoms which warrant a chest x-ray, e.g. increasing breathlessness; conversely, those diagnosed electively are likely to have had a chest x-ray undertaken in primary care. MRI is mostly undertaken for suspected spinal cord compression, which generally presents as an emergency.

Finally, PET CT is mostly undertaken in patients with early stage disease potentially suitable for curative treatment.

The SPARC© holistic assessment questionnaire revealed that patients diagnosed following emergency admission had a median of 21 wide-ranging symptoms or issues, with 8 causing ‘very much’ or ‘quite a bit’ of distress or bother. This compares to 15 and 5 respectively, in our local SPARC© dataset of patients with lung cancer diagnosed electively (n=538, unpublished data). Although seven of the 10 most common issues were similar, ‘feeling sleepy during the day’, ‘feeling weak’, ‘feeling everything is an effort’ and ‘worrying about the effect your illness was having on other people’ appeared more common in patients diagnosed following emergency admission, which may reflect a more advanced disease stage and more ‘urgent’ nature of the situation. Use of different scales limits direct comparison with previous work, but our findings are in keeping with the high symptom burden of lung cancer reported by others.[12]

The modified National Cancer Patient Experiences Survey suggests that patients diagnosed following emergency admission are more likely to have visited the GP five or more times prior to diagnosis. Multiple visits to the GP before diagnosis have been well described,[13] with the frequency 4–12 months preceding diagnosis independently predictive of a diagnosis of lung cancer.[14] Patients diagnosed following emergency admission also appear less likely to have their information and support needs met. Some of these issues may be specific to Nottingham University Hospitals. A notable difference was that compared to those diagnosed electively, fewer patients diagnosed following emergency admission had a lung cancer nurse specialist present specifically at the time of diagnosis, as recommend by national and specialty guidelines.[15,16] This probably reflects the fact that the lung cancer nurses are based on a different hospital site to the one which deals with emergency admissions. Nonetheless, this discrepancy should be explored further in other centres. Others issues are probably more generic, varying between simple to correct, e.g. providing written information to patients regarding investigations undertaken as an inpatient, as sent routinely with appointments for outpatient investigations, or forming part of a longer term strategy, e.g. improved communication skills training.

The qualitative interviews identified several themes similar to those previously identified as important to patients with lung cancer and their carers.[17,18] Although most were satisfied with the care they received, some specific criticisms, e.g. time taken for tests or referral to secondary care, have also been noted by others.[17] Although some patients saw their GP as a direct consequence of the cough campaign, others chose to ignore its message or attributed their cough to other causes; such misattribution of cough or other symptoms is a recognised factor in delayed diagnosis.[19–22] Our data highlights the challenges the cough campaign faces in trying to change both knowledge and behaviour, and also the limitations of focusing on one symptom. Although, cough is quoted as the most common presenting symptom,[23] in this study, and in our larger local dataset (n=538), based on causing any degree of distress or bother, cough was ranked 7th and 3rd. Deficiencies in health and social care support in the community is also a previously identified theme.[17]

There is limited previous work which has exclusively studied patients diagnosed with lung cancer following emergency admission and a particular strength of this study is the overall depth of detail it provides. Our cohort is likely to be reflective of those presenting to other centres in the UK, with the proportion diagnosed following an emergency admission (38%) and the association with advanced disease, poor performance status and reduced survival typical of that reported in larger UK data sets.[2,3]

The main limitations of this study are being a single centre with a relatively small sample size and scope for self-selection bias. This probably explains why, unlike others, we found no association between diagnosis following emergency admission and deprivation, gender or age.[3,24,25] Nonetheless, we calculated the precision to which we could estimate descriptive data values at a population level (6–8%; Appendix 1S). Further, participants completing questionnaires appeared representative of the overall group. It is possible that there were some patients with lung cancer who were not referred to the lung cancer MDT. However, this is unlikely to represent a significant number; a local 'rad alert' system is in operation which sends a copy of any chest x-ray report suspicious of lung cancer to the lung cancer MDT and previous comparisons with local cancer registry data indicate that the lung cancer MDT captures all but a few patients with lung cancer (Professor David Baldwin, personal communication). We did not record investigations undertaken in primary care, which would have aided more definite interpretation of our data relating to chest x-rays, nor if the patient saw the lung cancer nurse specialist subsequent to the time of diagnosis, which was the specific focus of our interest, or the specialist palliative care team, although referrals are made ad hoc rather than routinely. Having anticipated the potential difficulties of recruiting this group to the questionnaire element, we, like others, included the provision for informal carers to act as proxies.[26] Carers appear able to reliably report on patients' observable symptoms and experiences of care delivery, although possibly less so for more subjective aspects of patients' experiences, like pain and anxiety.[27] The qualitative interviews involved numbers of participants typical of previous work.[18,19] Participants were a balanced mix of patients and carers, gender and ages, and data achieved saturation. Similar themes emerged as reported by others,[17,19] suggesting a degree of generalizability, but this requires appropriate caution. Interviews were undertaken once, relatively soon after diagnosis, aiding recall of events, but themes are known to vary over time.[17]

Conclusions

Presentation as an emergency admission does not appear to confer any inherent disadvantage regarding progress through lung cancer diagnostic and treatment pathways in a busy cancer centre. However, this group often has a poor performance status and advanced disease which often results in treatment limited to best supportive care and a poor prognosis. In this regard, the themes from the interviews highlighting delay in referral to secondary care and factors influencing the success or failure of the cough campaign, are particularly relevant. Fewer have a lung cancer nurse specialist present at the time of diagnosis which is of potential concern given that there are high levels of supportive and palliative care needs and a reported short-fall in care. Further research is required to explore how these are best met; in the meantime, we suggest that all patients diagnosed following emergency admission should be routinely offered a specialist palliative care assessment.

Conflicts of interest: none.

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Supplementary material

The supplementary material associated with this article can be found, in the online version, at

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Table 1 Data relating to diagnostic and treatment pathways and survival along with odds ratios for diagnosis after emergency admission compared with elective diagnosis for selected outcomes. Number (%) unless specified otherwise.

	Diagnosed following emergency admission (n = 154)	*Elective diagnosis (n = 247)*	*Univariate*	*Multivariate*[e]	
			OR	*OR [95% CI]*	*P value*
Investigations undertaken[a]					
Chest x-ray	95 (62)	65 (26)	4.51	6.95 [4.01–12.09]	<0.001
CT	145 (94)	219 (89)	2.06	2.60 [0.98–6.93]	0.055
Biopsy (radiologically guided)	35 (23)	94 (38)	0.48	0.77 [0.45–1.33]	0.345
Biopsy (other)	28 (18)	45 (18)	1.00	0.86 [0.47–1.58]	0.635
Bronchoscopy	50 (33)	79 (32)	1.02	1.57 [0.94–2.63]	0.087
MRI	25 (16)	12 (5)	3.80	3.20 [1.40–7.29]	0.006
PET CT	7 (5)	71 (29)	0.12	0.29 [0.12–0.73]	0.009
Ultrasound	11 (7)	7 (3)	2.64	2.03 [0.67–6.13]	0.212
Median [IQR] days from referral/EA to diagnosis	9 [6–16]	23 [15–35]			<0.001
Lung cancer CNS present at diagnosis	57 (37)	152 (62)			<0.001
Median [IQR] days from referral/EA to LC-MDT[b]	11 [8–16]	25 [16–35]			<0.001
Treatment recommendation of lung cancer MDT[b]					
Surgery	8 (5)	54 (22)	1	1	0.208
Chemotherapy + radiotherapy	7 (5)	16 (6)	2.95	0.93 [0.25–3.49]	
Chemotherapy	35 (23)	72 (29)	3.28	1.13 [0.42–3.06]	
Radiotherapy	23 (15)	54 (22)	2.88	1.47 [0.53–4.09]	
Best supportive care only	75 (50)	46 (19)	11.01	2.56 [0.92–7.13]	
Active monitoring	2 (1)	5 (2)	2.70	1.02 [0.13–7.82]	
Treatment intent					
Curative	7 (5)	69 (28)	1	1	0.430

Palliative	143 (95)	178 (72)	7.92	1.55 [0.52–4.59]	
Received oncological treatment[c]	65 (46)	187 (79)			
Median [IQR] days from lung cancer MDT recommendation to start of treatment[c]	6 [2–14]	13 [6–25]			<0.001
Survival					
At 3-months	72 (47)	209 (85)			<0.001
At 12-months[d]	9 (17)	23 (40)			<0.001
Median [IQR] days	67 [33–100]	405 [208–523]			<0.001
Place of death					
Home	44 (40)	39 (40)	1	1	0.787
Hospital	46 (41)	38 (39)	1.07	0.85 [0.41–1.74]	
Hospice/Palliative care unit	18 (16)	19 (19)	0.84	0.64 [0.25–1.67]	
Nursing/ Residential home	3 (3)	2 (2)	1.33	0.49 [0.04–6.06]	

a. excludes three from total who had no investigations

b. four patients diagnosed following emergency admission died before the lung cancer MDT

c. excludes best supportive care and active monitoring, also 17 patients who declined treatment (two diagnosed electively), or died before treatment could commence (eight diagnosed following emergency admission, seven diagnosed electively)

d. based on 58 and 54 patients diagnosed following emergency admission and electively respectively followed up for a minimum of 12 months

e. adjusted for gender, age, performance status, diagnosis and stage.

CNS = clinical nurse specialist; CT = computerised tomography; MDT = multidisciplinary team; MRI = magnetic resonance imaging; PET = positron emission tomography

Table 2 Most frequent symptoms or issues identified by the SPARC© questionnaire causing any degree of distress or bother for patients diagnosed following emergency admission compared to a historical dataset of patients diagnosed electively; * indicates items where the 95% CI fail to overlap

Symptom or issue	Patients diagnosed following EA (n=43) Percentage [95% CI]	Patients diagnosed electively (historical dataset, n=538) Percentage [95% CI] and rank
Feeling tired	91 [82–100]	79 [76–82], 1
Feeling sleepy during the day*	86 [75–96]	68 [64–72], 4
Feeling weak*	84 [73–95]	55 [51–59], 11
Worrying about the effect your illness is having on other people*	84 [73–95]	65 [61–69], 6
Shortness of breath	74 [61–87]	78 [75–82], 2
Feeling everything is an effort*	74 [61–87]	54 [50–58], 12
Cough	72 [58–85]	66 [62–70], 3
Loss of appetite	70 [56–84]	59 [55–63], 9
Changes in your weight	70 [56–84]	73 [69–77], 5
Dry mouth	67 [53–81]	52 [48–56], 14

EA = emergency admission

Table 3 Questions in the modified National Cancer Patient Experience Survey where the 95% CI of one or more of the responses from patients diagnosed following emergency admission did not encompass the local and/or national 2012–13 results (indicated by *) suggesting a shortfall in care. For full results see on-line Appendix B.

Question	*Response*	*Diagnosed following EA* (n=43)		*Lung (NUH)*[a] (n=145)	*Lung (national)* (n=5,018)
		% (n)	95% CI	%	%
Seeing your GP					
How many times did you see your GP (family doctor) about the health problem that ultimately led to your urgent admission to hospital?	I saw my GP 5 or more times	30 (13)	[16–44]		11*
Diagnostic tests					
Beforehand, did a member of staff explain the purpose of the test(s)?	Yes, completely	62 (23)	[46–78]	90*	84*
Beforehand, did a member of staff explain what would be done during the test procedure(s)?	Yes completely	69 (27)	[54–84]	92*	88*
Beforehand, were you given written information about your test(s)?	Yes, and it was easy to understand	44 (11)	[25–63]	94*	87*
Finding out what was wrong with you					
When you were told you had cancer, were you given written information about the type of cancer you had?	Yes, and it was easy to understand	44 (16)	[28–60]	68*	65*
Clinical nurse specialist					
Were you given the name of a Lung Clinical Nurse Specialist who would be in charge of your care?	Yes	66 (25)	[51–81]	85*	91*

Ward nurses					
In your opinion, are there enough nurses on duty to care for you in hospital?	There were always or nearly always enough on duty	48 (20)	[33–63]	71*	63
Information given to you before you left hospital					
Were you given clear written information about what you should or should not do after leaving hospital?	Yes	43 (10)	[25–61]	77*	81*
Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	Yes	62 (16)	[44–80]	88*	91*
Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	Yes, definitely	31 (8)	[13–49]	60*	61*
Arranging home support					
After leaving hospital, were you given enough care and help from health or social services (For example, district nurses, home helps or physiotherapists)?	Yes, definitely	31 (5)	[8–54]	51	57*
Your overall NHS care					
How much information were you given about your condition and treatment?	The right amount	69 (29)	[55–83]	93*	88*
	Too much	12 (5)	[2–22]		1*

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a. only responses to ‘key’ questions are available at an individual trust level.

CI = confidence interval; EA = emergency admission; NUH = Nottingham University Hospitals NHS Trust