Are people with mesothelioma who respond to the English Cancer Patient Experience Survey representative of the national mesothelioma population? A data comparison with cancer registry patients from the National Lung Cancer Audit

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ABSTRACT

Introduction: More than 2,700 people are diagnosed with mesothelioma each year in the UK. Survival from mesothelioma is poor and to ensure service users' perspectives are incorporated in designing the most effective strategies to improve healthcare in England, the English Cancer Patient Experience Survey (CPES) is carried out annually in people diagnosed with cancer. We assessed whether the mesothelioma population responding to the English CPES is representative of the national mesothelioma population.

Method: Data from all people in England from the National Cancer Registry defined as having an incident mesothelioma diagnosis (2009–2015) were included. Data were linked across multiple sources including CPES. Using multivariable logistic regression, clinical and sociodemographic characteristics were compared between CPES respondents with mesothelioma and all people with mesothelioma in England.

Results: We identified 15,587 people diagnosed with mesothelioma, of which 1,597 (10.3%) were included in CPES. Adjusted odds ratios showed that representation in CPES decreased with older age, later stage, worse performance status, multiple comorbidities or emergency presentation at diagnosis. Gender was reasonably represented, although people with non-white ethnicity and from more deprived socioeconomic groups were underrepresented. lung cancer nurse specialist assessment was not associated with inclusion in CPES, however, having a lung cancer nurse specialist present at diagnosis was. Representation in CPES was highest for people who had chemo-radiotherapy (fully adjusted odds ratio 6.52 (95% confidence interval 5.34–7.96).

Conclusion: Responses were included across all sociodemographic and clinical groups, but there was unbalanced representation when compared with the national mesothelioma population. Patients who do not receive anti-cancer treatment are particularly under-represented. It is

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important to consider the impact of person characteristics on CPES representation when using cancer experiences to plan service management.

Contribution of the Paper:
What is already known:

- Surveys of patient-reported experiences of health care, such as the National Cancer Patient Experience Survey (CPES), are important for informing changes to practice and policy
- To be most useful, surveys should be representative of all service users
- CPES shows reasonable representation across most groups with lung cancer although the representation of people with mesothelioma in CPES has not been assessed

What this paper adds:

- Using CPES data linked to the National Cancer Registry, this is the largest study describing the characteristics of people with mesothelioma across England
- CPES respondents are broadly representative of the national mesothelioma population, however, people from non-white ethnic groups and more socioeconomically deprived areas are under-represented
- Considering the higher prevalence of mesothelioma in more socioeconomically deprived groups, this under-representation should be recognised when using CPES for modifying cancer care pathways.

1. Introduction

Mesothelioma is a type of thoracic cancer that is primarily caused by workplace exposures to asbestos and is thus largely preventable [Cancer Research UK 2018, UK M 2020, Royal College of Physicians 2018]. In the United Kingdom, about 2700 people are diagnosed with mesothelioma each year and the 5-year survival is 7% [Cancer Research UK 2018, UK M 2020, Royal College of Physicians 2018]. This is compared with a survival of 16% for all lung cancer [Royal College of Physicians 2018]. In England, over 6000 people were diagnosed with mesothelioma between 1 January 2016 and 31 December 2016 [Royal College of Physicians 2018].

Feedback from healthcare service users is increasingly recognised as one of the pillars for informing healthcare quality and policy to improve care, and surveys of the experience of patient are increasingly undertaken [Madden and Davies, 2010, The Kings Fund 2015]. In the United Kingdom, various surveys are conducted to collect information on people's experiences with a variety of National Health Service interactions, including with general practice and hospital care. For people with cancer, surveys of patient experience were first carried out in 2000 and 2004 for six cancer sites (breast, colorectal, ovarian, prostate, lung and non-Hodgkin's lymphoma) [Department of Health 2002, National Audit Office 2005]. In these two surveys of cancer patients' experiences, better experience of care was reported by people with breast cancer and poorer experience was reported by people with prostate cancer and lung cancer [Department of Health 2002, National Audit Office 2005]. A revised National Cancer Patient Experience Survey (CPES) including all cancers was undertaken in 2010 and is conducted annually. The English CPES is commissioned by the Department of Health and carried out annually by the Picker institute [Picker Institute 2021], obtaining responses from over 65,000 people with cancer [Public Health England 2015].

Differences in representativeness [Nartey et al., 2020, Alessy et al., 2019] and care [Bone et al., 2014, El Turabi et al., 2013, Lyratzopoulos et al., 2012] by socio-demographic and clinical factors have been reported by studies conducted in the UK, with female, non-white ethnic groups, younger people and those with advanced disease being less likely to captured in patient experience surveys [Nartey et al., 2020, Alessy et al., 2019, Bone et al., 2014, El Turabi et al., 2013, Lyratzopoulos et al., 2012]. A study conducted on lung cancer from our group [Nartey et al., 2020] did not include mesothelioma, however, and because mesothelioma is different in presentation and pathway, it is important to assess representativeness in this condition separately. Whilst there are similarities with lung cancer overall, mesothelioma is much more common in men, tends to present with pleural effusion and is generally considered incurable, leading to a somewhat different diagnostic pathway reflected in clinical guidelines which differ in the United Kingdom between mesothelioma and lung cancer. Outcomes of healthcare are not only influenced by the care provided to patient but also external factors such as the severity of the condition [Abel et al., 2014]. Additionally, judgments about the quality of care may be influenced by differential response tendencies between different cancer patient groups [Abel et al., 2014].

Using national cancer registry data linked across multiple sources, we assessed how mesothelioma patients who responded to CPES represent the sociodemographic, clinical, treatment characteristics and survival of the whole mesothelioma population in the English National Lung Cancer Audit.

2. Materials and methods

2.1. Study population and data sources

The methods on which this study is based are previously described for a study conducted in all people with lung cancer [Nartey et al., 2020]. In brief, our study population comprised all people in England with a new primary diagnosis of mesothelioma (International classification of disease (ICD) −10 code C45*) between 2009 and 2015 who were obtained from the National Cancer Registration and Analysis Service (NCRAS) run by Public Health England. NCRAS gathers information from across the National Health Service, which covers 99% of all hospital activity in England, and is thus considered the most complete source of information on all people diagnosed with incident cancer. The National Lung Cancer Audit includes all people with lung cancer, including mesothelioma, from NCRAS. Up to 2014, the National Lung Cancer Audit also had a bespoke data collection system, called Lung Cancer Audit Data (LUCADA), which included more detailed information on the patient pathway, such as timing and method of Lung Cancer Nurse Specialist assessment and performance status. The National Lung Cancer Audit accounts for approximately 98% of the annual incidence of lung cancer and almost all of the cases presenting to secondary care [Abel et al., 2014]. We used all available clinical information for mesothelioma patients from NCRAS and LUCADA.

2.1.1. The National Cancer Patient Experience Survey (CPES) and data linkage

We accessed survey results for individuals with a diagnosis of mesothelioma who responded to at least one wave of CPES between 2010 and 2015 (wave 1 to wave 5). CPES is commissioned by the United Kingdom Department of Health and was carried out by Quality Health during this period, a specialist survey provider [Quality Health 2017]. The sampling frame included people aged 16 years and older with a primary cancer diagnosis, seen as inpatients or day cases in English National Health Service hospitals for cancer related treatment over a three-month period each year (the timing of which varied across waves). People were included if they had International Classification of Disease 10 (ICD-10) codes C00 to C99, excluding C44 (non-melanoma skin cancers) in their care records. After vital status checks, patients were sent the survey questionnaire by post, with up to two reminders for non-responders [Quality Health 2017]. Patients were asked a series of questions about their experience of healthcare from initial general practice appointment through to ongoing management and long-term care. This is obtained using over 70 questions across 12 different domains: seeing your general practitioner before diagnosis, diagnostics tests, finding out what was wrong, deciding treatment, Lung Cancer Nurse Specialist involvement, further support, operations, hospital staff, hospital care, outpatient and day case care, general practice care and overall care. Survey questions were developed and validated following standard cognitive testing techniques. There have been small changes in questions across waves mainly to avoid confusion and to make them consistent with other National Health Service patient experience surveys to allow comparison between them. There was no difference between the 2013 and 2014 questionnaires.

For all mesothelioma patients we used information on age, sex, ethnicity, stage and performance status at diagnosis from their NCRAS record. Due to the small number of people in CPES reporting their ethnicity in groups other than white, ethnicity was categorised into "white" and "other than white."

Mesothelioma stage was defined using Tumour Nodes and Metastases (TNM) version 7. Hospital Episode Statistics data individually linked to patients' NCRAS records were used to calculate a comorbidity score for each patient (Charlson Index) using diagnoses from inpatient and outpatient hospital admissions [Charlson et al., 1987]. We derived patient anti-cancer treatment profiles using information from Hospital Episode Statistics admissions in conjunction with the National Radiotherapy Dataset [Public Health England 2010], the Systemic Anti-cancer Therapy dataset [Public Health England 2011], and treatments recorded in the core NCRAS data. We identified Office of Population Census and Survey Classification of Intervention version 4 codes corresponding to surgical, chemotherapy and radiotherapy treatment in the Hospital Episode Statistics data. In line with methods used by the National Lung Cancer Audit to define anti-cancer treatment related to lung cancer, we defined 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 [Royal College of Physicians 2020]. NCRAS also provides individual linkages to the Routes to Diagnosis dataset for route to cancer diagnosis [Public Health England 2010], the Office of National Statistics for mortality data and Index of Multiple Deprivation to measure household socioeconomic deprivation. All individual matching procedures link to NCRAS mesothelioma diagnoses with CPES, LUCADA and other sources were performed by the Public Health England Office for Data Release [Public Health England 2021]. Public Health England's Office for Data Release 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 National Health Service number, other patient information, and tumour type, as described on their website (www.ncin.org.uk). Patients are then given an anonymised identification number for each study which is provided to the researchers to ensure patient anonymity is maintained.

2.2. Statistical analysis

All analyses were completed using Stata Version 16 (Stata Corp, TX, United States of America). We performed a descriptive analysis of the whole NCRAS population and of those who were included in CPES. We then conducted multiple logistic regression to estimate odds ratios (OR) with 95% confidence intervals (CI) to quantify the association of being included in CPES with a number of patient characteristics including age, cancer stage and performance status at diagnosis.

We compared survival of those included and not included in CPES using the Kaplan–Meier method. 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 mesothelioma diagnosis. To minimise the potential effects of survival bias on our overall analyses,

we conducted a subgroup analysis restricting our whole NCRAS study population to people who survived more than 405 days after diagnosis, as this was the 75th quartile of survival for people surveyed in CPES. On the subset of people with LUCADA records up to 2014, we additionally performed multi-level logistic regression to assess both patient and hospital level factors as we have previously found National Health Service Trust size (number of new lung cancer patients seen annually) and treatment speciality at a Trust can affect patient pathways. National Health Service Trusts typically include 1–2 hospitals in a local area in England.

3. Results

3.1. Participants

The flow diagram (Fig. 1) demonstrates how the final study population was derived resulting in 15,587 people with mesothelioma diagnosed across England between 2009 and 2015. Their median age at diagnosis was 74 years (interquartile range 67–80). The majority were male (82.9%) and of white ethnicity (86.6%) (Table 1). Stage and performance status were not recorded in 10,542 (67.6%) and 2125 (20.0%) people, respectively. Clinical information from LUCADA was available for 10,618 (68.1%) people and of these 8115 (76.4%) were documented as having been assessed by a Lung Cancer Nurse Specialist and 9839 (92.7%) were discussed at Multi-Disciplinary Team meetings.

3.2. Likelihood of being included in CPES by baseline and clinical features

Of the 15,587 people with mesothelioma, 1597 (10.2%) were in CPES. CPES respondents were reasonably distributed across waves 1–5 (290 (18.2%), 362 (22.7%), 360 (22.5%), 317(19.8%), and 268 (16.8%) from waves 1–5, respectively). Table 1 shows the adjusted ORs for being included in CPES by sociodemographic and clinical characteristics. As age, stage, performance status, number of comorbidities and socioeconomic deprivation level increased, the likelihood of being included in CPES decreased. People with ethnic backgrounds other than white were less likely to be represented in CPES compared with white ethnicity (OR 0.11, 95% CI: 0.07–0.15). Sex was not associated with the likelihood of being included in CPES. Compared with diagnosis via usual general practice referral, people diagnosed with mesothelioma through the Two Week Wait referral (urgent referral from a general practice) were more likely to be included in CPES (OR 1.30; 95% CI:1.13 - 1.50) whereas those diagnosed following emergency admission were less likely to be included (OR 0.76, 95%CI 0.65–0.88). Patterns were similar after we restricted the analysis to people who survived more than 405
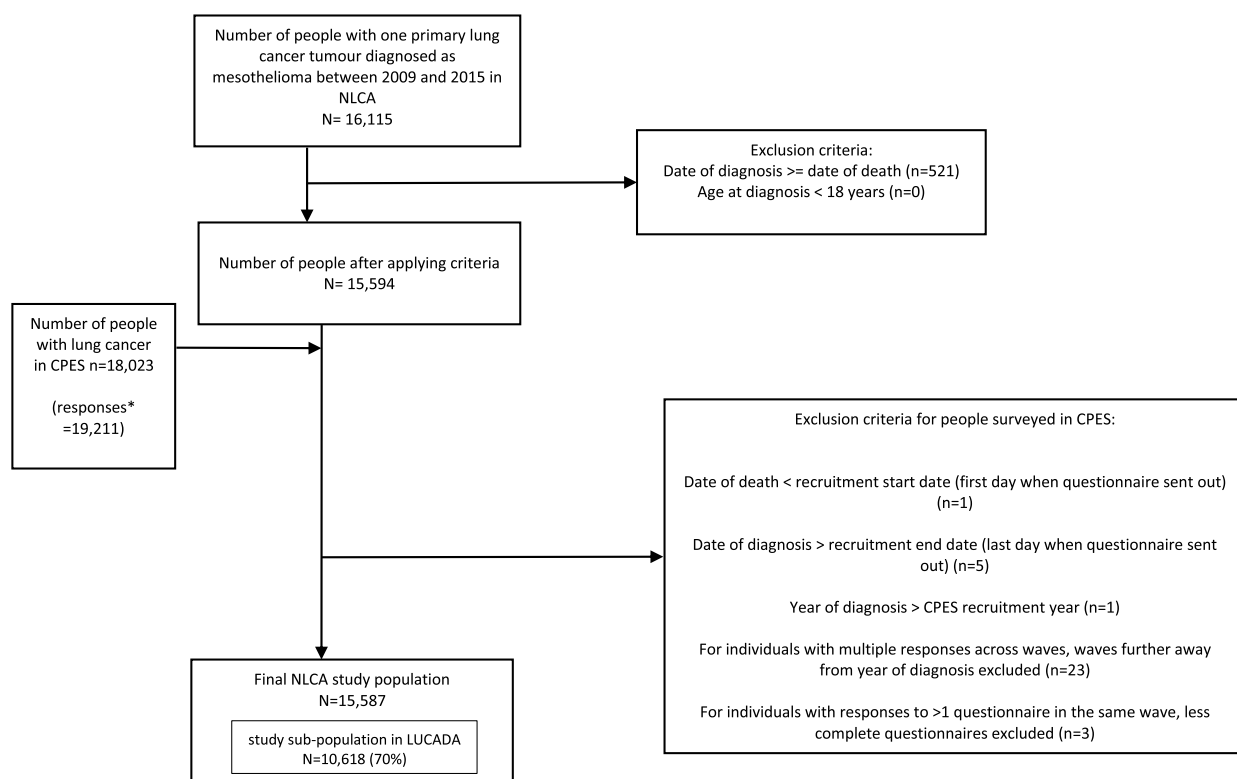

Fig. 1. Flow chart of study population derivation: people with mesothelioma in the English national cancer register. CPES: Cancer Patient Experience Survey; NLCA: National Lung Cancer Audit; LUCADA: Lung Cancer Audit Data. *People participating in CPES may have responded to more than one annual wave of the CPES questionnaire.

Table 1

Baseline and clinical characteristics and their association with participation in the Cancer Patient Experience Survey

Characteristic	Total number of people N = 15587 (%)	Number of people surveyed N = 1597 (%)	% of total number of people	Unadjusted OR of being surveyed (95% CI)	Adjusted OR of being surveyed (95% CI)	p-value
Year of diagnosis						
2009	2061(13.2)	191(12.0)	9.3	reference	reference	
2010	2123(13.6)	200(12.5)	9.4	1.02(0.83 - 1.25)	1.06(0.85 - 1.31)	
2011	2195(14.1)	331(20.7)	15.1	1.74(1.44 - 2.10)	1.78(1.46 - 2.17)	
2012	2350(15.1)	345(21.6)	14.7	1.68(1.40 - 2.03)	1.40(1.15 - 1.70)	
2013	2230(14.3)	287(18.0)	12.9	1.45(1.19 - 1.76)	1.20(0.98 - 1.47)	
2014	2316(14.9)	72(4.5)	3.1	0.31(0.24 - 0.41)	0.25(0.19 - 0.33)	
2015	2312(14.8)	171(10.7)	7.4	0.78(0.63 - 0.97)	0.60(0.48 - 0.76)	<0.001*
Sex						
Male	12914(82.9)	1332(83.4)	10.3	reference	reference	
Female	2673(17.2)	265(16.6)	9.9	0.96(0.83 - 1.10)	0.93(0.81 - 1.08)	0.34
Age (years)						
<65	2510(16.1)	401(25.1)	16.0	reference	reference	
65–80	9407(60.4)	1077(67.4)	11.4	0.68(0.60 - 0.77)	0.70(0.61 - 0.80)	
>80	3670(23.6)	119(7.5)	3.2	0.18(0.14 - 0.22)	0.21(0.17 - 0.26)	<0.001*
Stage						
Stage IA-IB	1190(7.6)	163(10.2)	13.7	reference	reference	
Stage IIA-IIB	677(4.3)	86(5.4)	12.7	0.92(0.69 - 1.21)	0.88(0.66 - 1.18)	
Stage IIIA-IIIB	1739(11.2)	192(12.0)	11.0	0.78(0.63 - 0.98)	0.74(0.58 - 0.93)	
Stage IV	1439(9.2)	113(7.1)	7.9	0.54(0.42 - 0.69)	0.52(0.40 - 0.68)	0.015*
Unknown	10542(67.6)	1043(65.3)	9.9	0.69(0.58 - 0.83)	0.65(0.53 - 0.78)	
Performance status						
0	1810(17.1)	395(31.1)	21.8	reference	reference	
1	3633(34.2)	538(42.3)	14.8	0.62(0.54 - 0.72)	0.73(0.63 - 0.85)	
2	1456(13.7)	100(7.9)	6.9	0.26(0.21 - 0.33)	0.39(0.31 - 0.50)	
3–4	1594(15.0)	51(4.0)	3.2	0.12(0.09 - 0.16)	0.26(0.19 - 0.35)	<0.001*
Missing	2125(20.0)	187(14.7)	8.8	0.35(0.29 - 0.42)	0.63(0.51 - 0.77)	
Ethnicity						
White	13501(86.6)	1565(98.0)	11.6	reference	reference	
Other than white	2086(13.4)	32(2.0)	1.5	0.12(0.08 - 0.17)	0.11(0.07 - 0.15)	<0.001
Deprivation						
1-least deprived	3435(22.0)	394(24.7)	11.5	reference	reference	
2	3673(23.6)	424(26.6)	11.5	1.01(0.87 - 1.17)	0.97(0.83 - 1.13)	
3	3291(21.1)	320(20.0)	9.7	0.83(0.71 - 0.97)	0.82(0.70 - 0.96)	
4	2815(18.1)	272(17.0)	9.7	0.83(0.70 - 0.97)	0.88(0.74 - 1.04)	
5-most deprived	2373(15.2)	187(11.7)	7.9	0.66(0.55 - 0.79)	0.68(0.56 - 0.82)	<0.001*
Charlson index						
0	7784(49.9)	949(59.4)	12.2	reference	reference	
1	2844(18.3)	282(17.7)	9.9	0.79(0.69 - 0.91)	0.84(0.72 - 0.97)	
02-Mar	2713(17.4)	233(14.6)	8.6	0.68(0.58 - 0.79)	0.80(0.69 - 0.94)	
4+	2246(14.4)	133(8.3)	5.9	0.45(0.38 - 0.55)	0.58(0.48 - 0.71)	<0.001*
Route to diagnosis						
General Practice referral	4014(25.8)	434(27.2)	10.8	reference	reference	
Emergency presentation	4894(31.4)	339(21.2)	6.9	0.61(0.53 - 0.71)	0.76(0.65 - 0.88)	
Inpatient elective	289(1.9)	31(1.9)	10.7	0.99(0.67 - 1.46)	0.94(0.63 - 1.39)	
Other outpatient	2421(15.5)	255(16.0)	10.5	0.97(0.82 - 1.14)	0.95(0.81 - 1.13)	
Two-week Wait	3668(23.5)	521(32.6)	14.2	1.37(1.19 - 1.56)	1.30(1.13 - 1.50)	<0.001
Missing	301(1.9)	17(1.1)	5.6	0.49(0.30 - 0.81)	0.59(0.35 - 0.98)	

Abbreviations: OR: odds ratio; CI: confidence interval

Notes: Logistic regression model with ORs adjusted for all other variables in the table excluding trust variables.

The reference category has an odds ratio of 1.00

Missing values for characteristics were not included in p-values for tests for trend or chi2 tests

Performance status only available for patients in the Lung Cancer Audit Data (LUCADA) sub-population (N = 10618)

*P-values for test for trend; otherwise, p-values are for chi2 test

days after diagnosis to account for potential survival bias (Fig. 2, Supplementary Table 1), however, only year of diagnosis, age, ethnicity other than white, socioeconomic deprivation and route to diagnosis via Two Week Wait remained statistically significant. In this restricted analysis, females with mesothelioma (OR 0.84; 95% CI: 0.70 - 0.99) were less likely to be represented in CPES compared with males.

Discussion at Multi-Disciplinary Team meetings was associated with slightly lower likelihood of being included in CPES, whereas and Lung Cancer Nurse Specialist assessment was not associated with being included in CPES (Table 2). For people assessed by a Lung
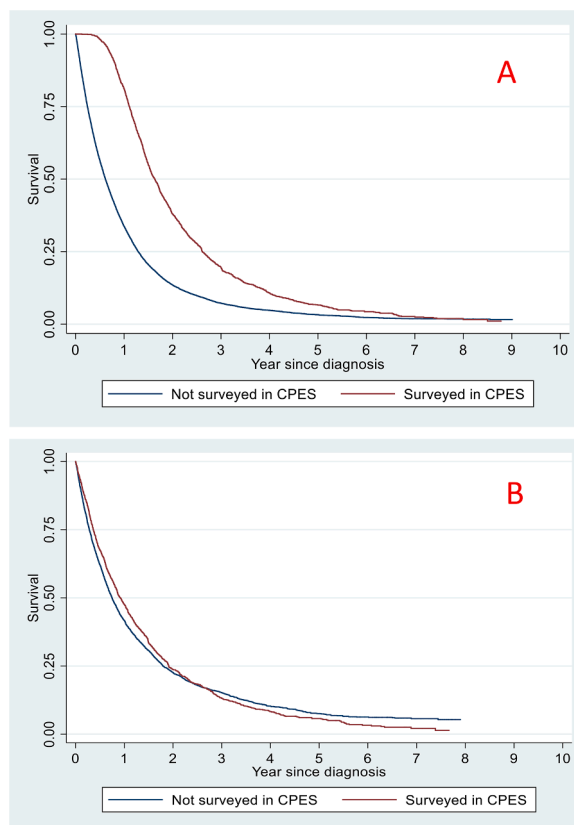
Fig. 2. Kaplan-Meier survival curves of survival from mesothelioma diagnosis comparing people included and not included in the Cancer Patient Experience Survey (CPES) A: Whole National Lung Cancer Audit population (N = 15,587) B: National Lung Cancer Audit population surviving more than 405 days after diagnosis (N = 5424)

Cancer Nurse Specialist, the timing and place of Lung Cancer Nurse Specialist assessment were not associated with being included in CPES, however, they were more likely to be included in CPES if the Lung Cancer Nurse Specialist was present at diagnosis (OR: 1.22; 95% CI: 1.03 – 1.45). Treatment was associated with being included in CPES; people who had chemotherapy with radiotherapy were more likely to be included compared with no treatment (OR 6.52, 95%CI 5.34–7.96). After restricting the analysis to people who survived more than 405 days from diagnosis, a clear variation with treatment remained (Fig. 2, Supplementary Table 2).

3.4. Survival of CPES respondents and all people with mesothelioma in NCRAS

Kaplan-Meier curves showed more than 75% of CPES respondents with mesothelioma survived to one year, compared with 25% surviving to one year for people who were not CPES respondents (Fig. 2). For people who were included, the median survival was 598 days compared with 225 days for those who were not included in CPES. There was little difference in survival for people who were included and not included in CPES when we limited the analysis to those who survived more than 405 days. However, after 3 years, people who were not included survived longer than those who were included in CPES.

3.5. Multilevel model including hospital trust level factors

The multilevel model incorporating National Health Service Trust for the LUCADA sub-population of 10,618 mesothelioma patients (68.1% of the NCRAS study population) showed similar representativeness across the sociodemographic, clinical, service and treatment features (Supplementary Table 3), in comparison to the main analyses (Tables 1 and 2). Trust size and treatment were not associated with representation in CPES, even after adjustment for the individual anti-cancer treatment received by the patient.

4. Discussion

4.1. Main findings

Amongst people diagnosed with mesothelioma, we found inclusion in CPES is influenced by patients' demographic and clinical

Table 2

Health service and treatment characteristics and their association with participation in the Cancer Patient Experience Survey

Characteristic	Total number of people $N = 15587$ (%)	Number of people surveyed $N = 1597$ (%)	% of total number of people	Unadjusted OR of being surveyed (95% CI)	Adjusted OR of being surveyed (95% CI)	p-value
Multi-Disciplinary Team discussion						
No	779(7.3)	94(7.4)	12.1	reference	reference	
Yes	9839(92.7)	1177(92.6)	12.0	0.99(0.79 - 1.24)	0.76(0.59 - 0.98)	0.04
Assessed by Lung Cancer Nurse Specialist						
No	2503(23.6)	261(20.5)	10.4	reference	reference	
Yes	8115(76.4)	1010(79.5)	12.4	1.22(1.06 - 1.41)	0.97(0.83 - 1.14)	0.73
First Lung Cancer Nurse Specialist assessment						
After diagnosis	6255(77.1)	807(79.9)	12.9	reference	reference	
At diagnosis only	1549(19.1)	164(16.2)	10.6	0.80(0.67 - 0.96)	0.86(0.71 - 1.03)	0.09
Missing	311(3.8)	39(3.9)	12.5	0.97(0.69 - 1.36)	0.96(0.67 - 1.38)	
Place of Lung Cancer Nurse Specialist assessment						
In clinic	5394(66.5)	748(74.1)	13.9	reference	reference	
Home visit	96(1.2)	6(0.6)	6.3	0.41(0.18 - 0.95)	0.45(0.19 - 1.06)	
Ward visit	1224(15.1)	94(9.3)	7.7	0.52(0.41 - 0.65)	0.78(0.62 - 1.00)	
Telephone	753(9.3)	98(9.7)	13.0	0.93(0.74 - 1.16)	0.99(0.78 - 1.25)	
Other	199(2.5)	18(1.8)	9.0	0.62(0.38 - 1.01)	0.93(0.56 - 1.56)	0.28
Missing	449(5.5)	46(4.6)	10.2	0.71(0.52 - 0.97)	0.76(0.55 - 1.06)	
Lung Cancer Nurse Specialist present at diagnosis						
No	1958(24.1)	207(20.5)	10.6	reference	reference	
Yes	5873(72.4)	769(76.1)	13.1	1.27(1.08 - 1.50)	1.22(1.03 - 1.45)	0.02
Missing	284(3.5)	34(3.4)	12.0	1.15(0.78 - 1.69)	1.32(0.88 - 1.99)	
Anti-cancer treatment modality						
No treatment	7146(45.9)	187(11.7)	2.6	reference	reference	
Surgery	432(2.8)	74(4.6)	17.1	7.69(5.76 - 10.27)	5.27(3.88 - 7.16)	
Chemo and radio	1947(12.5)	437(27.4)	22.4	10.77(9.00 - 12.89)	6.52(5.34 - 7.96)	
Chemotherapy alone	3641(23.4)	714(44.7)	19.6	9.08(7.68 - 10.72)	6.37(5.30 - 7.64)	
Radiotherapy only	2421(15.5)	185(11.6)	7.6	3.08(2.50 - 3.79)	2.28(1.84 - 2.84)	<0.001

Abbreviations: OR: odds ratio; CI: confidence interval.
Notes: Logistic regression model with ORs adjusted for gender, age, performance status, stage of cancer at diagnosis,.
ethnicity, socioeconomic deprivation, Charlson Index of comorbidity, route to diagnosis and year of diagnosis.
The reference category has an odds ratio of 1.00.
Missing values for characteristics were not included in p-values for tests for trend or chi2 tests.
Multi-Disciplinary Team discussion, Lung Cancer Nurse Specialist assessment, method and timing only available for patients in Lung Cancer Audit Data (LUCADA) sub-population ($N = 10618$).
*P-values for test for trend; otherwise, p-values are for chi2 test.

features such as age, ethnicity, stage at diagnosis, performance status, comorbidity, socioeconomic deprivation and route to diagnosis. People included in CPES were much more likely to receive anti-cancer treatment and had better survival than those not included. After accounting for survival bias in analyses and adjusting for receipt of anti-cancer treatment, certain groups remained under-represented, namely older age groups, those with ethnicity other than white, and those with higher socioeconomic deprivation. Whilst over-representation of those receiving treatment is likely due to the original CPES survey methodology, under-representation of certain groups requires careful consideration when using CPES data for understanding the care of people with mesothelioma.

4.2. Strengths and limitations of the study

The main strength of our study is the linkage of CPES with the National Lung Cancer Audit cancer registry data and other datasets such as the Index of Multiple Deprivation. This allowed us to explore the influence of multiple predictors including assessment by a Lung Cancer Nurse Specialist, level of socioeconomic deprivation, stage of cancer at diagnosis and type of treatment received for a large sample size ($N = 15,587$) of mesothelioma patients. To our knowledge this study is the largest of its kind on mesothelioma that provides information on the clinical and sociodemographic distribution of mesothelioma across the country other than the National Lung Cancer Audit reports.

There is seasonal variation in the use of healthcare services. Consultation for respiratory and flu-like symptoms and pressures on hospital beds, increase enormously in the winter period [O'Cathain et al., 2010]. Because the CPES data collection is restricted to a few-months each year, this might introduce selection bias into CPES. Patients with less aggressive disease and those who have survived

for a longer time were more likely to be surveyed and to respond to CPES which introduced selection and immortal time bias, respectively. Adjusting for potential confounders and restricting the analysis to patients who survived more than 405 may have addressed this. Furthermore, we studied people with mesothelioma, so our findings might not be generalizable to other cancer sites such as breast cancer which has a good prognosis.

4.3. Comparison with other findings

Our findings concerning the representativeness of CPES in people with mesothelioma are consistent with previous studies assessing lung cancer overall and other cancer types [Madden and Davies, 2010, Nartey et al., 2020, Alessy et al., 2019, Abel et al., 2016]. In our study on lung cancer (which did not include mesothelioma), we found people included in CPES were younger, from less socioeconomically deprived areas, were less likely to be diagnosed at late stage, and more likely to survive longer [Nartey et al., 2020], similar to our current findings for mesothelioma. These patients were more likely to have died in the 2 to 3 month period between the initial sampling and the mailing out of the questionnaire [Abel et al., 2016] but may also represent patients who received the questionnaire but were too ill to complete and return it [Alessy et al., 2019]. People included in CPES were more likely to survive longer than those not included. The study by Abel et al. [Abel et al., 2016] is important when assessing the internal representativeness of CPES. Additionally, the study by Alessy et al. [Alessy et al., 2019] assessed representativeness by cancer types. However, their study did not have information on treatment and other important variables such as assessment by Lung Cancer Nurse Specialist. Our study aims to address the question of how representative the people included in CPES are to the national mesothelioma population, and also assess the influence of treatment and other cancer related features.

We found that people who received treatment were more likely to be included in CPES compared with those who did not receive treatment. This may reflect a higher intensity of treatment through which they were more likely to be included in the sampling frame [Alessy et al., 2019]. It is of interest that mesothelioma patients with white ethnic background were more likely to be included in CPES than other ethnic groups. Minority ethnic groups have been reported to be less likely to report to such surveys and also report less positive experiences [Bone et al., 2014, Abel et al., 2014, Elliott et al., 2005, Saunders et al., 2015, Ayanian et al., 2005]. Communication has been identified as a barrier to effective healthcare use amongst minority ethnic groups [Pinder et al., 2016]. Although there is the option for patients to call a helpline and provide their answers to CPES questions in their own language, some may not feel comfortable to do so, and as a result, may not fill in the questionnaire.

4.4. Implication for practice and policy

The linking of CPES to cancer registry data and other datasets enables researchers to explore more complex questions. As we have shown, the representativeness of CPES in people with mesothelioma is limited, similar to what we and others previously reported in lung and other cancers [Nartey et al., 2020, Alessy et al., 2019, Abel et al., 2016]. Policy makers and healthcare providers should be aware of the limitations of CPES when using the survey. Most of the people included were diagnosed close to the survey sampling period due to the recruitment of patients recently treated in hospital for their cancer as eligible cases [Alessy et al., 2019]. Secondly, patients responding to the survey were more likely to be diagnosed with earlier stage diseases and survive longer. Furthermore, the experiences of people with greater healthcare needs such as people with poor prognosis may not be captured [Alessy et al., 2019]. A national mesothelioma audit has reported improvement in survival, the use of clinical nurse specialists and multidisciplinary team discussion [Royal College of Physicians 2018]. However, it will be important to assess whether these improvements affect a balanced representation of all patient subgroups.

It is therefore important to recruit patients to CPES with poor prognosis such as mesothelioma and lung cancer for their cancer care to be designed based on their experience [Alessy et al., 2019]. This may include additional surveys that capture experiences in the early stages of the patient cancer pathway such as during the referral, investigation and diagnosis [Nartey et al., 2020, Alessy et al., 2019]. Exposure to asbestos is the cause of most mesothelioma and this occurs primarily from occupation, mostly manual work. The under-representation in CPES of people who are from more socioeconomically deprived areas is therefore an even more important issue to consider in changing the focus of CPES recruitment moving forward.

Ethical considerations

The data was obtained from Public Health England's Office for Data Release. 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 Public Health England's Office for Data Release (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 Public Health England's Office for Data Release subject to appropriate study approval and data sharing agreements.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnsa.2022.100077.

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