

## ORIGINAL ARTICLE

# Being assigned a clinical nurse specialist is associated with better experiences of cancer care: English population-based study using the linked National Cancer Patient Experience Survey and Cancer Registration Dataset

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## Abstract

**Objective:** This study aimed to examine whether being given the name of a clinical nurse specialist (CNS) is associated with better cancer patients' experiences across different points along their cancer care pathway.

**Methods:** We identified 100,885 colorectal, lung, breast and prostate cancer patients who responded to the National Cancer Patient Experience Survey between 2010 and 2014. We compared experiences of four key aspects of cancer care among patients who reported being given a CNS name with those who did not, adjusting for age, sex, socio-economic deprivation, ethnicity, route to diagnosis and disease stage.

**Results:** Across all cancers, patients who reported being given the name of a CNS reported better experiences with involvement in treatment decisions, care coordination, treatment with more respect and dignity, and overall care experience. Experience of being involved in treatment decisions was the aspect of care most strongly associated with being given a CNS name (colorectal: OR 2.69, 95% CI: 2.45–2.96; lung: OR 2.41, 95% CI: 2.07–2.78; breast: OR 2.68, 95% CI: 2.47–2.92; and prostate: OR 2.11, 95% CI: 1.92–2.32).

**Conclusion:** These findings may provide new evidence of the vital contribution CNS make to cancer care and suggest their input and support should be available to all patients after the diagnosis.

## KEYWORDS

cancer, clinical nurse specialist, patient experience, survey

## 1 | INTRODUCTION

Patient experience is widely considered to be an important aspect of cancer care quality (The Independent Cancer Taskforce, 2015; Wolf, 2018). Previous research in England and Europe has shown

hospital care quality varies in relation to inpatient nurse staffing and education and improves with higher levels of each across many care sittings (Aiken et al., 2012, 2014; Keogh, 2017; Rafferty et al., 2007). In cancer care, clinical nurse specialists (CNS) play a key role in ensuring that high-quality information is provided to patients, coordinating

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their care, as well as assessing needs and providing emotional support (National Cancer Action Team, 2010; Stewart et al., 2020). Findings from the National Cancer Patient Experience Survey (CPES) 2010 show English cancer patients' experiences of care coordination and emotional support are better in NHS hospitals with large numbers of CNS (Griffiths et al., 2013).

CPES has been conducted annually since 2010 with the aim of assessing and improving patients' experiences of NHS cancer care. The survey asks patients about a wide range of care aspects including whether they have been given the name of a CNS (Quality Health, 2019). Research using different years of CPES data has so far shown variation in cancer patients' experiences by socio-demographic and health system factors (Griffiths et al., 2013; Pinder et al., 2016; Salika et al., 2018). This variation includes patients' reports of being involved in decisions about treatment (El Turabi et al., 2013), their care coordination (Griffiths et al., 2013) of being treated with respect and dignity (Griffiths et al., 2013), and their overall care experience (Pinder et al., 2016). An important question is therefore whether being assigned a CNS has a direct impact on patients' care experiences at an individual level.

The National Cancer Registration and Analysis Service (NCRAS) recently linked the CPES dataset to the English population cancer registry to enable studies of the potential association between patients' experiences and aspects of their cancer diagnosis, treatment and outcomes (Alessy, Lüchtenborg, & Davies, 2019b). Using the CPES-NCRAS linked dataset and focusing on the four most common cancers—colorectal, lung, breast and prostate cancers—we aimed to (1) compare the characteristics of patients who reported being given the name of a CNS with those who did not and (2) examine whether being given the name of a CNS is associated with more positive reports of experiences in aspects of care where CNS play a key role. These are being involved in treatment decisions, perceiving care is more coordinated, reporting being treated with respect and dignity, and a more positive overall care experience. A more detailed understanding of the experiences of patients who have been assigned to CNS care can provide new evidence to support cancer policies and workforce planning.

## 2 | METHODOLOGY

### 2.1 | Study population and data

In this population-based cohort study, we extracted data on all individuals with invasive colorectal (C18–20), lung (C33–34), female breast (C50) and prostate (C61) cancers (International Classification of Diseases [Version 10] [ICD-10]) who responded to CPES 2010–2014 from CPES-NCRAS dataset ( $n = 114,898$ ). CPES has been conducted by Quality Health, on behalf of NHS England, for the years 2010–2019 and contains around 70 questions covering many aspects of cancer care experience. Patients who have been discharged from NHS inpatient and day-case admission for cancer are invited by post to complete the survey, with two reminders being sent to

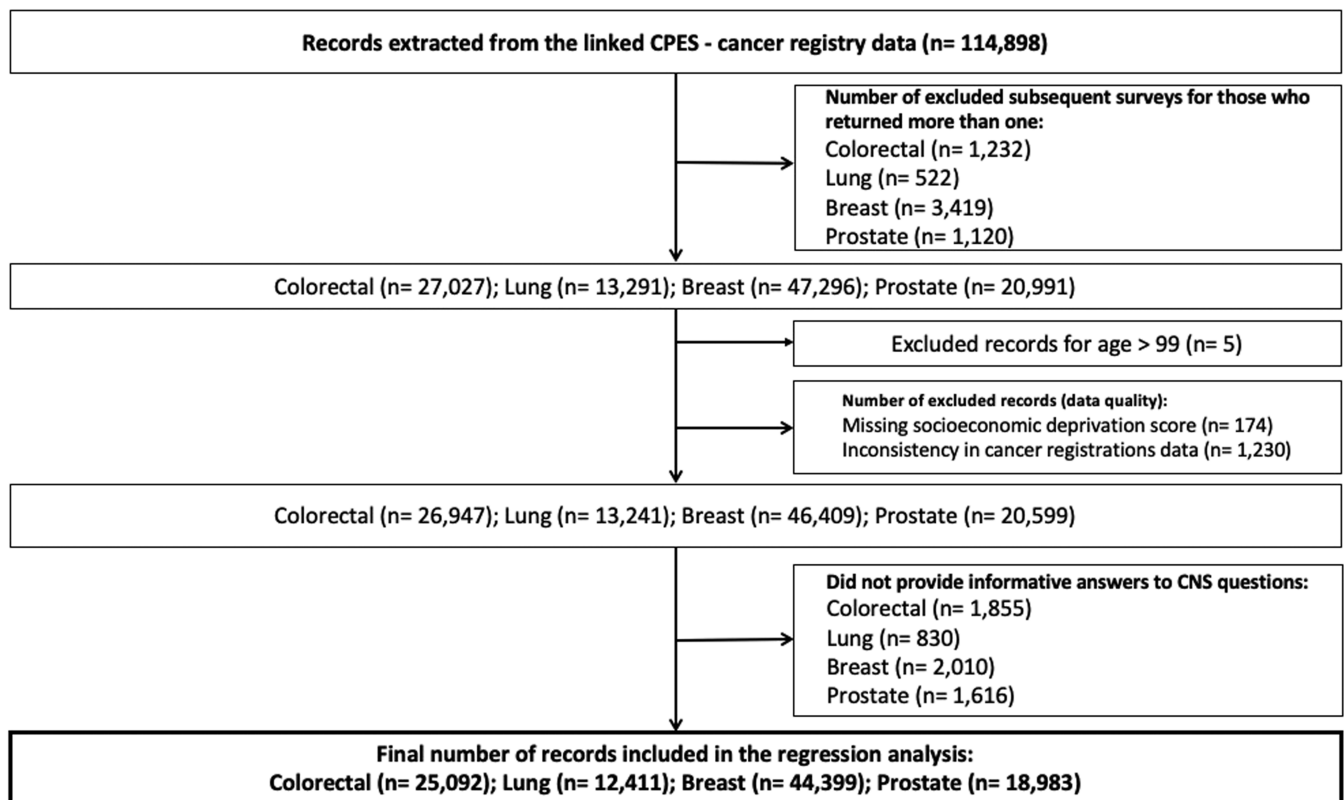
non-responders (Quality Health, 2019). The response rate was stable (64–68%) between 2010 and 2014 (Quality Health, 2019). The CPES-NCRAS dataset is linked based on patient NHS number and tumour site, using the ICD-10 3/4-digit code (Alessy, Lüchtenborg, & Davies, 2019b).

Some patients were surveyed more than once in different iterations of CPES. Therefore, we took the first survey record for each patient and removed additional responses ( $n = 6293$ ). We also excluded cases with a missing socio-economic deprivation score for area of residence ( $n = 174$ ) and inconsistent registration dates ( $n = 1230$ ). CPES contains four questions on aspects of CNS care. We focused our analysis on the survey question about patients being given the name of a CNS: 'Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?'. Patients' answers in CPES included 'Yes', 'No' or 'I do not know'. We excluded patients who did not respond or provide informative answers about whether they have been given a CNS name (i.e., 'I do not know') or who did not report their care experiences ( $n = 6311$ ) (Figure 1).

Since CNS are actively involved with patients across the cancer care pathway, we selected four questions from CPES representing different aspects of patients' experiences of cancer services where CNS are involved. We hypothesised a priori that patients who have been given a CNS name would report better experiences in response to questions on (1) involvement in treatment decision, (2) treatment with respect and dignity, (3) overall care coordination and (4) overall care experience. For the purposes of the analysis, we categorised patients' responses into two main categories: 'excellent' and 'non-excellent' experience in line with other reports (see Table 1) (El Turabi et al., 2013; Pinder et al., 2016; Salika et al., 2018). An additional sensitivity analysis was undertaken for the effect of (1) adding the response 'most of the time' to the 'excellent' experience category in treatment with respect and dignity aspect and (2) for adding the response 'very good' to 'excellent' experience category in overall care experience aspect.

For all patients, we included information on demographic and tumour characteristics at diagnosis that previous research has linked to variation in reported experiences of care (El Turabi et al., 2013; Pinder et al., 2016; Salika et al., 2018) or shown to be associated with variation in being given a CNS name (Royal College of Physicians, 2019). These include sex, age, socio-economic deprivation of area of residence, ethnicity, geographical region of residence in England, route to diagnosis and disease stage.

Data on sex, age, geographical region of residence, deprivation of area of residence and TNM disease stage were available in the cancer registry dataset for all patients with cancer. For lung cancer, we extracted additional stage information from the National Lung Cancer Audit (NLCA) ( $n = 2888$ ), which includes more detailed clinical and multidisciplinary team data returned by the audit and extracted from hospital data feeds to NCRAS (Henson et al., 2019). Although ethnicity data are collected in CPES, the response categories were slightly different in each survey year. We therefore used self-assigned ethnicity information from cancer registration data which is derived from Hospital



**FIGURE 1** Study participant flow chart

**TABLE 1** CPES questions on aspects of cancer care categorised into excellent and non-excellent experience

Cancer care aspects	Question as phrased in CPES	Experience categories based on CPES answers		Notes
		Excellent	Non-excellent	
Involvement in treatment decision	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely	Yes, to some extent No, but I would like to have been more involved	We excluded patients who did not provide informative answers: 'There was only one treatment option' or 'Not sure/cannot remember'
Treatment with respect and dignity	Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Always	Most of the time Some of the time Never	'Most of the time' was categorised as an excellent experience in the sensitivity analysis
Overall care coordination	Sometimes people with cancer feel they are treated as 'a set of cancer symptoms', rather than a whole person. In your NHS care over the last year did you feel like that?	No	Yes, often Yes, sometimes	—
Overall care experience	Overall, how would you rate your care?	Excellent	Very good Good Fair Poor	This question is only available in CPES 2012–2014; 'very good' was categorised as an excellent experience in the sensitivity analysis

Episode Statistics (HES) data (Henson et al., 2019). Due to the limited numbers in each ethnic category, we collapsed the 16-group classification into two categories: all White background (i.e., White British, Irish and other White background) and non-White.

Socio-economic deprivation is measured using the income domain of the indices of multiple deprivation (IMD). The geographical area used is the lower super output area (LSOA, around 1500 persons) based on post code of residence at diagnosis (Office for

National Statistics, 2015). Individual patients are assigned a score of 1 (least deprived) through 5 (most deprived) based on the quintile of distribution that their LSOA falls within. Four versions of IMD were available (2004, 2007, 2010 and 2015), and we applied the closest match of IMD to each patient's year of diagnosis (IMD 2004 for diagnosis years 1998 to 2002; IMD 2007 for diagnosis years 2003 to 2006; IMD 2010 for diagnosis years 2007 to 2009; and IMD 2015 for diagnosis years 2010 to 2013). Route to diagnosis data is available for all cancer cases diagnosed in England since 2006 and are derived by linking HES data, Cancer Waiting Times data, cancer screening programmes data and cancer registration data (Henson et al., 2019). The categories used are emergency presentation, general practice referral, screening, 2-week referral and elective referral.

## 2.2 | Data analysis

A total number of 100,885 cases were included in the analysis (colorectal  $n = 25,092$ ; lung  $n = 12,411$ ; breast  $n = 44,399$ ; and prostate  $n = 18,983$ ). We tabulated the distribution of patient characteristics (age, sex, socio-economic deprivation, ethnicity and geographical areas) and disease stage at diagnosis between patients reporting that they were given the name of a CNS and those who did not (Table 2). Chi-squared tests were performed to estimate the  $p$  values for differences between groups. To assess whether being given the name of a CNS influenced patients' experiences of being involved in treatment decisions, their feeling about care coordination, being treated with respect and dignity and their overall care experience with NHS cancer care, we compared responses between patients who reported being given the name of a CNS and those who did not using univariable and multivariable logistic regression. Finally, Cohen's kappa coefficient test was used to assess the interrater reliability of lung cancer patients' reports of being given the name of a CNS in CPES with the clinical data from the NLCA on whether or not they had been assigned a CNS. All analyses were performed using Stata Software, Version 15.1 (StataCorp, Texas, USA).

## 2.3 | Patient and public involvement

The research members of the team worked transparently throughout, sharing methods and findings with two patient representative members (M. B. and J. R.) who themselves had conducted work on the CPES and were familiar with that component of the data. The representative members provided invaluable insight into aspects of these data and assisted with the drafting of this paper.

## 3 | RESULTS

Patients' demographic and cancer stage characteristics are shown in Table 2. Overall, 90.5% of colorectal, 92.2% of lung and 93.9% of

breast cancer patients reported being given the name of a CNS compared to only 86.4% of prostate cancer patients. There were slight variations by demographic and cancer stage characteristics across all cancers between patients who reported being given the name of a CNS compared with those who did not (Table 2).

Patients' reported experiences with four aspects of cancer care according to having been given the name of a CNS are shown in (Table 3). After adjusting for these variables in univariable and multivariable logistic regression analyses, being given the name of a CNS was strongly associated with reporting better experiences across all aspects of care (being involved in treatment decisions, perceiving care as more coordinated, reporting being treated with respect and dignity, and reporting a positive overall experience with NHS care) for all cancers (Table 4).

Experience of being involved in the treatment decision was the aspect of care most improved (rated excellent) if patients reported being given the name of a CNS (colorectal: adjusted OR 2.69, 95% CI: 2.45–2.96; lung: adjusted OR 2.41, 95% CI: 2.07–2.78; breast: adjusted OR 2.68, 95% CI: 2.47–2.92; and prostate: adjusted OR 2.11, 95% CI: 1.92–2.32) (Table 4). Across all cancers, this was followed by overall care experience, care coordination, and being treated with respect and dignity (Table 4). In a sensitivity analysis, the association between having been given the name of a CNS and having excellent care experiences was stronger across all cancers for the respect and dignity and overall care experience aspects (Table 4).

Table 5 shows the number of lung cancer patients who reported being given the name of a CNS in comparison to the assignment of a CNS recorded by NLCA. Most of patients who reported having been given the name of a CNS were also recorded as having been allocated a CNS ( $\kappa = 0.80$ ; very good agreement;  $p$  value  $<0.001$ ; 95% CI: 0.79–0.82).

## 4 | DISCUSSION

### 4.1 | Summary of main findings

This study used 4 years of linked CPES and cancer registration data for 100,885 patients to examine whether being given the name of a CNS is associated with reporting more positive care experiences for patients with breast, colorectal, lung and prostate cancers. A strong association emerged between being given the name of a CNS and reporting being more involved in treatment decisions, perceiving care as more coordinated, being treated with dignity and respect and better overall experiences with NHS cancer care across all four cancer types.

### 4.2 | Comparison with other findings

Few large population studies of the role of the CNS in cancer care have considered its possible influence across the cancer care pathway.

**TABLE 2** Demographic and cancer stage at diagnosis for CPES responders with colon, lung, breast and prostate cancers according to reporting been given the name of a CNS

Reporting being given a CNS name Variable	Colorectal cancer			Lung cancer			Breast cancer			Prostate cancer		
	Yes N	% <sup>a</sup>	No N	Yes N	%	No N	Yes N	%	No N	Yes N	%	No N
Sex												
Male	13,514	59.5	1367	6178	57.5	505	—	—	—	16,405	100	2578
Female	9202	40.5	1009	5271	42.5	457	41,681	100	2718	—	—	—
$\chi^2$ and <i>p</i> value	$\chi^2 = 3.4; p = 0.06$			$\chi^2 = 0.7; p = 0.3$			—			—		
Age group												
<45	707	3.1	74	138	3.1	20	5690	13.7	470	17.3	30	4
45–59	3924	17.3	448	1932	18.9	159	16,494	39.6	1188	43.7	2517	333
60–74	11,966	52.7	1118	6918	47.1	525	15,402	37.0	811	29.8	11,093	1564
75–99	6119	26.9	736	2461	31.0	258	4095	9.8	249	9.2	2765	677
$\chi^2$ and <i>p</i> value	$\chi^2 = 28.9; p < 0.001$			$\chi^2 = 21.9; p < 0.001$			$\chi^2 = 71.8; p < 0.001$			$\chi^2 = 133.6; p < 0.001$		
Ethnicity												
White	19,969	87.9	2059	10,290	86.7	827	34,759	83.4	2265	83.3	13,978	2163
Non-White	650	2.9	73	299	3.1	39	2038	4.9	162	6.0	635	116
Unknown	2097	9.2	244	860	10.3	96	4884	11.7	291	10.7	1792	299
$\chi^2$ and <i>p</i> value	$\chi^2 = 3.1; p = 0.2$			$\chi^2 = 15.3; p < 0.001$			$\chi^2 = 8.1; p = 0.01$			$\chi^2 = 3.5; p = 0.1$		
Area												
East Midlands	2176	9.6	292	1089	12.3	100	3755	9.0	445	16.4	1478	355
East of England	2763	12.2	260	1318	10.9	102	4957	11.9	236	8.7	1975	248
London	2140	9.4	190	1143	8.0	121	4732	11.4	311	11.4	1480	322
North East	1431	6.3	107	973	4.5	46	2417	5.8	71	2.6	837	88
North West	2833	12.5	246	1554	10.4	163	4693	11.3	181	6.7	3159	347
South East	3658	16.1	374	1437	15.7	127	6600	15.8	504	18.5	2296	337
South West	2998	13.2	229	1228	9.6	79	5077	12.2	398	14.6	2170	353
West Midlands	2549	11.2	387	1162	16.3	127	4819	11.6	428	15.7	1730	303
Yorkshire and the Humber	2168	9.5	291	1545	12.2	97	4631	11.1	144	5.3	1280	225
$\chi^2$ and <i>p</i> value	$\chi^2 = 127.2; p < 0.001$			$\chi^2 = 50.8; p < 0.001$			$\chi^2 = 406.3; p < 0.001$			$\chi^2 = 152.4; p < 0.001$		

(Continues)

TABLE 2 (Continued)

Reporting being given a CNS name Variable	Colorectal cancer			Lung cancer			Breast cancer			Prostate cancer		
	Yes N	% <sup>a</sup>	No N	Yes N	%	No N	Yes N	%	No N	Yes N	%	No N
IMD												
1 (most affluent)	5356	23.6	508	1789	15.6	168	9630	23.1	692	4230	25.8	664
2	5622	24.7	600	2318	20.2	174	10,033	24.1	620	4204	25.6	659
3	4822	21.2	505	2363	20.6	195	8984	21.6	577	3360	20.5	503
4	3962	17.4	426	2436	21.3	204	7362	17.7	503	2571	15.7	455
5 (most deprived)	2954	13.0	337	2543	22.2	221	5672	13.6	326	2040	12.4	297
$\chi^2$ and p value	$\chi^2 = 7.2; p = 0.1$			$\chi^2 = 4.2; p = 0.3$			$\chi^2 = 13.8; p = 0.008$			$\chi^2 = 8.0; p = 0.09$		
Route to diagnosis												
ER	2709	11.9	607	1442	12.6	125	493	1.2	67	553	3.4	146
GP	5638	24.8	558	2883	25.2	263	2931	7.0	286	6868	41.9	917
Screening	3322	14.6	164	—	—	—	12,457	29.9	609	—	—	—
2-week referral	8263	36.4	700	5272	46.0	358	22,867	54.9	1277	6381	38.9	723
Elective referral	2427	10.7	265	1707	14.9	195	852	2.0	79	1545	9.4	282
Unknown	357	1.6	82	145	1.3	21	2081	5.0	400	1058	6.4	510
$\chi^2$ and p value	$\chi^2 = 468.5; p < 0.001$			$\chi^2 = 39.2; p < 0.001$			$\chi^2 = 594.6; p < 0.001$			$\chi^2 = 608.2; p < 0.001$		
Stage												
I	1945	8.6	142	1823	15.9	262	11,760	28.2	559	2499	15.2	305
II	3958	17.4	330	1478	12.9	112	13,258	31.8	790	2624	16.0	237
III	5677	25.0	489	3396	29.7	206	3727	8.9	237	2012	12.3	154
IV	3076	13.5	465	3777	33.0	237	1221	2.9	169	1690	10.3	280
Unknown	8060	35.5	950	975	8.5	145	11,715	28.1	963	7580	46.2	1602
$\chi^2$ and p value	$\chi^2 = 117.6; p < 0.001$			$\chi^2 = 150.9; p < 0.001$			$\chi^2 = 196.0; p < 0.001$			$\chi^2 = 280.7; p < 0.001$		

Abbreviations: CNS, clinical nurse specialist; ER, emergency presentation; GP, general practitioner; IMD, indices of multiple deprivation;  $\chi^2$ , chi-squared test, with unknown ethnicity, route to diagnosis and stage as a category.

<sup>a</sup>Column percentage.



**TABLE 3** Level of reported patients' experiences with four aspects of cancer care for CPES responders with colon, lung, breast and prostate cancers according to reporting been given the name of a CNS

Care aspect Level of experience Reporting being given a CNS name	Involvement in treatment decision			Treatment with respect and dignity			Overall care coordination			Overall care experience				
	Non-excellent N <sup>a</sup>	% <sup>b</sup>	Excellent N	Non-excellent N	%	Excellent N	Non-excellent N	%	Excellent N	Non-excellent N	%	Excellent N	Non-excellent N	%
Colorectal cancer	5688	25.0	17,036	3729	18.6	16,313	4061	16.9	19,925	83.1	8052	44.3	10,143	55.7
No	951	45.7	1128	488	29.8	1152	660	29.2	1602	70.8	1041	63.1	609	36.9
Yes	4737	22.9	15,908	3241	17.6	15,161	3401	15.7	18,323	84.3	7011	42.4	9534	57.6
$\chi^2$ and p value <sup>b</sup>	$\chi^2 = 523.1; p < 0.001$			$\chi^2 = 146.6; p < 0.001$			$\chi^2 = 266.3; p < 0.001$			$\chi^2 = 260.9; p < 0.001$				
Lung cancer	3057	26.9	8289	1112	16.4	5672	2510	21.1	9396	78.9	4071	43.9	5204	56.1
No	367	44.3	462	134	23.3	440	291	31.9	622	68.1	398	61.5	249	38.5
Yes	2690	25.6	7827	978	15.7	5232	2219	20.2	8774	79.8	3673	42.6	4955	57.4
$\chi^2$ and p value	$\chi^2 = 136.4; p < 0.001$			$\chi^2 = 22.1; p < 0.001$			$\chi^2 = 69.2; p < 0.001$			$\chi^2 = 87.7; p < 0.001$				
Breast cancer	10,850	26.1	30,653	5603	15.7	29,974	9297	21.5	33,881	78.5	13,119	40.5	19,277	59.5
No	1201	48.4	1282	486	27.7	1268	1006	38.2	1630	61.8	1236	64.2	688	35.8
Yes	9649	24.7	29,371	5117	15.1	28,706	8291	20.5	32,251	79.5	11,883	39.0	18,589	61.0
$\chi^2$ and p value	$\chi^2 = 675.7; p < 0.001$			$\chi^2 = 198.8; p < 0.001$			$\chi^2 = 459.6; p < 0.001$			$\chi^2 = 478.6; p < 0.001$				
Prostate cancer	4374	24.5	13,477	1320	15.0	7489	3142	17.4	14,911	82.6	6512	46.2	7588	53.8
No	935	40.1	1399	202	20.5	785	594	24.3	1854	75.7	1068	61.0	682	39.0
Yes	3439	22.2	12,078	1118	14.3	6704	2548	16.3	13,057	83.7	5444	44.1	6906	55.9
$\chi^2$ and p value	$\chi^2 = 351.2; p < 0.001$			$\chi^2 = 26.2; p < 0.001$			$\chi^2 = 92.7; p < 0.001$			$\chi^2 = 177.1; p < 0.001$				

Abbreviation:  $\chi^2$ , chi-squared test.

<sup>a</sup>The total responses across the different questions are not the same because patients did not respond to all four questions. Further description on this can be found in Section 2.

<sup>b</sup>Row percentage.

**TABLE 4** Odds ratio of having excellent care experiences according to reporting been given the name of a CNS

Cancer care aspects	Colorectal cancer			Lung cancer			Breast cancer			Prostate cancer						
	Univariable		Multivariable	Univariable		Multivariable	Univariable		Multivariable	Univariable		Multivariable				
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI				
Involvement in treatment decision	2.83	2.58–3.10	2.69	2.45–2.96	2.31	2.00–2.66	2.41	2.07–2.78	2.85	2.62–3.09	2.68	2.47–2.92	2.34	2.14–2.57	2.11	1.92–2.32
Treatment with respect and dignity	1.98	1.77–2.21	1.93	1.72–2.17	1.62	1.33–2.01	1.68	1.36–2.08	2.15	1.92–2.39	2.03	1.80–2.27	1.54	1.30–1.82	1.51	1.26–1.78
Overall care coordination	2.21	2.01–2.44	2.12	1.92–2.35	1.88	1.59–2.14	1.91	1.63–2.21	2.40	2.21–2.60	2.24	2.06–2.44	1.64	1.48–1.81	1.57	1.41–1.75
Overall care experience	2.32	2.09–2.58	2.19	1.96–2.43	2.15	1.83–2.54	2.15	1.81–2.53	2.81	2.55–3.09	2.63	2.39–2.90	1.98	1.79–2.20	1.86	1.68–2.07
Sensitivity analysis <sup>a</sup>																
Treatment with respect and dignity	2.88	2.34–3.56	2.88	2.31–3.58	2.09	1.42–3.09	2.19	1.47–3.27	2.56	2.07–3.16	2.36	1.90–2.92	2.65	1.86–3.77	2.82	1.95–4.09
Overall care experience	3.02	2.68–3.42	2.83	2.49–3.21	2.93	2.42–3.54	2.87	2.37–3.49	3.51	3.14–3.92	3.26	2.91–3.66	2.51	2.21–2.83	2.42	2.13–2.75

Note: Univariable model = having been given the name of a CNS is the exposure and having an excellent care experience is the outcome. Multivariable model = adjusted for sex (only in lung and colorectal cancers), age, ethnicity (missing as a covariate), area, socio-economic deprivation, route to diagnosis (missing as a covariate) and stage (missing as a covariate).

<sup>a</sup>Sensitivity analysis = excellent care experience with being treated with respect and dignity = 'always' and 'most of the time' versus all other categories and excellent overall experience with care = 'excellent' and 'very good' versus all other categories.

A previous study using 2010 CPES data alone revealed that numbers of CNS per NHS hospital trust varied across England (Griffiths et al., 2013). It also showed that patients' experiences of care coordination and emotional support were better in hospital trusts that had higher numbers of CNS. While we have not assessed the relationship of experience to the numbers in each trust, our case-mix adjusted analysis shows better patient experiences with involvement in treatment decisions, perceived care coordination, being treated with dignity and respect, and overall care experience with NHS cancer care when patients report being given the name of a CNS. A recent Swedish study found that the implementation of a new oncology nursing role led to improvements in patients' perceptions of health-related information, supportive care resources and care coordination of care (Westman et al., 2019). In addition, a recent review showed that studies from several countries other than the United Kingdom, including Ireland, the Netherlands, Australia, New Zealand and South Korea, found that the CNS role was important in improving patient satisfaction, symptom management, meeting information needs and improving subsequent care outcomes (Kerr et al., 2021). Our findings are therefore consistent and suggest that it is the presence of a CNS that is important in leading to patients' reports of better experiences.

Furthermore, previous research highlighted variation in access to a CNS both by region of residence and by cancer type (Leary et al., 2011; Trevatt et al., 2008). Our study also revealed variation in being given the name of a CNS by cancer type and geographical region. Although among CPES responders 92% of lung cancer patients reported being given a named CNS, only around 71% of lung cancer patients overall in England were assessed by a lung CNS in 2017 (Royal College of Physicians, 2019). While this could not be verified for the other cancers, due to the lack of detailed data on the assignment of CNS, the difference for lung cancer may reflect the fact that the survey data are less representative of all lung cancer patients than for the other three cancers (Alessy, Davies, et al., 2019).

### 4.3 | Strengths and limitations of the study

To our knowledge, this study is the first to use linked cancer experience and cancer registration data to examine the impact the role of the CNS makes on patients' experiences across many aspects of cancer care. One strength of our study is the large sample size and the different cancer types studied. This allowed for detailed case-mix assessment of the role of the CNS across different aspects of cancer care in a diverse cancer population.

We recognise our study has some limitations. First, studies using survey data are prone to recall bias. Some patients in this study may have reported not being given the name of a CNS when they had been, or they may have mis-identified a ward nurse or a palliative care nurse as a CNS. This therefore might lead to an assumption that being given a CNS name, which is the independent variable in this study and reported by patients in CPES, is not an actual exposure to CNS allocation to cancer patients. Indeed, we had hypothesised that the CNS



**TABLE 5** Comparison of the agreement between reporting been given the name of a CNS in CPES and indication of being assigned a CNS in the cancer registry data for lung cancer patients

Reporting being given a CNS name in CPES	Being allocated a CNS from cancer registry data				Kappa <sup>a</sup>
	No	Yes	Missing	Total	
No	50	631	281	962	Kappa = 0.80 <sup>b</sup> p value = <0.001 95% CI = 0.79–0.82
Yes	174	9506	1769	11,449	
Total	224	10,137	2050	12,411	

<sup>a</sup>Kappa test did not include missing data.

<sup>b</sup>Very good agreement.

name question is an indication of CNS allocation, as it shows an important aspect of cancer care from the patients' perspective. Data on whether lung cancer patients were allocated and assessed by a CNS for the population cohort in this study were collected by the National Lung Cancer Audit (LUCADA) and currently set within NLCA database within NCRAS (Rich et al., 2011). We were therefore able to validate the survey reports in the case of lung cancer patients by using the more detailed clinical data collected and extracted for the NLCA. A large percentage (83%) of patients who reported having been given a CNS name had also been recorded as being assigned to one according to the NLCA.

Second, although CPES had a good response rate (64–68%) between 2010 and 2014, it needs to be borne in mind that the survey only samples a section of the wider cancer population and studies have shown that patients with the poorest diagnosis are not always well represented (S. A. Alessy, Davies, et al., 2019). CPES is one of the most comprehensive and largest cancer patients' experience survey in the world. Although the 4-year attritions of CPES (2010–2014) might appear as outdated now, these CPES data are the most updated series currently linked to the cancer registry. In addition, these 4 years had consistent questions across the years, giving rise to sufficient power to undertake this study. More recent surveys have undergone changes to the questions, which impedes combining the data. Future linked data may need to be used to assess whether recent years CPES rounds confirm the consistency of our findings. In addition, although NCRAS data completeness for stage and ethnicity has improved since 2012 (Henson et al., 2019), a proportion of patients had missing information on disease stage, ethnicity and route to diagnosis. For lung cancer stage, missing information was supplemented using information available from the NLCA. Finally, a small percentage of patients had unknown route to diagnosis data, and this varied between cancers as already shown (Elliss-Brookes et al., 2012).

#### 4.4 | Study implications

Improving patients' experiences of cancer care has been a high priority in the NHS cancer strategy. CNS play a vital role in cancer patients' care pathways by eliciting and managing their concerns, promoting their well-being, providing physical and emotional support,

coordinating care services, and informing and advising them (Macmillan Cancer Support, 2014). There is, however, currently concern about the challenges facing CNS in cancer care because of restrictions on funding and an ageing workforce (Whittaker et al., 2017). Whilst the CNS workforce is continuing to grow, more are now employed on lower salary scales than in previous years, suggesting they are less experienced and skilled, which might impact on the quality of care and hence patients' experiences (Macmillan Cancer Support, 2017). Moreover, some variability still exists in the number of CNS vacancy posts across England (Macmillan Cancer Support, 2017). This variability will therefore require careful workforce planning to ensure recruitment and retention to the CNS workforce in order to maintain the level of patient experience reported in this study. Moreover, given that cancer patients are predicted to suffer delays in diagnosis and treatment due to the impact of the COVID-19 pandemic on NHS capacity (Maringe et al., 2020), the role of CNS in maintaining remote consultation and support will be even more vital.

Our study showed that CNS play a crucial role in improving patients' experiences in several important aspects across the cancer care pathway. These findings are particularly important as excellent experiences have been shown to benefit patient safety and outcomes (Alessy, Lüchtenborg, & Davies, 2019a; Doyle et al., 2013). One way of interpreting our findings is that giving patients a named CNS enables a trusted relationship to grow more quickly in the initial period after diagnosis. This could prevent or offset the effect of seeing different clinicians at subsequent appointments and re-explaining concerns, which patients often describe as a frustrating experience. Future research should focus on how well CPES captures experiences of the work done by CNS, the extent of equity in access to care, and on determining whether it is CNS availability, the size of the cancer centre or its ability to foster organisational cultures that empower both CNS and the whole cancer team that lead to the improved experiences of care. Moreover, while these findings might be applicable to other countries, CNS responsibilities and working practices within cancer care can vary between different cancer care settings (Cooper et al., 2019). For example, an advanced nurse practitioner (ANP) in different countries may fulfil the same role that CNS undertake within the NHS, while some countries might not have specialist nurses employed in cancer care (Challinor et al., 2020).

## 5 | CONCLUSION

This study demonstrates evidence of the positive impact of a CNS on patients' experiences across several important aspects of the cancer care pathway. These findings can be used by cancer policymakers, charities, cancer services and patient representatives as evidence of the significant role CNS play in cancer care. Future research should focus on determining where and how CNS play the most vital role, as reflected in improved patient experiences, and how to ensure equity of access to their care.

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### CONFLICT OF INTERESTS

The authors declare no conflicts of interest. All authors have completed the ICMJE uniform disclosure form at [http://www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare no support from any organisation for the submitted work, no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years, and no other relationships or activities that could appear to have influenced the submitted work.

### DATA AVAILABILITY STATEMENT

Data for this study are collated, owned, maintained and quality assured by the National Cancer Registration and Analysis Service within Public Health England. The authors do not own these data and therefore are not permitted to share or provide these data other than in scientific communication format.

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