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# Clinical nurse specialists and survival in patients with cancer: the UK National Cancer Experience Survey

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## ABSTRACT

**Objective** To examine whether having a better care experience with a clinical nurse specialist (CNS) is associated with better overall survival of patients with cancer in England.

**Methods** We identified 99 371 patients with colorectal, lung, breast and prostate cancer who reported their care experience with CNS from the National Cancer Patient Experience Survey (2010–2014) and English cancer registration linked dataset. We categorised patients' experiences into three groups (excellent, non-excellent and no CNS name was given), across three aspects of CNS care: the ease of contacting their CNS, feeling that a CNS had listened to them and the degree to which explanations given by a CNS were understandable. We used univariable and multivariable Cox proportional hazards regression analyses to estimate HRs with 95% CIs by patient experience for each cancer adjusting for patients' sociodemographic and disease stage at diagnosis.

**Results** Among the three compared groups, patients who reported not being given a CNS name had the lowest survival. In the adjusted Cox regression analysis, the results show that among those who reported not being given a CNS name, the highest risk of death was in those with colorectal, breast and prostate cancers only (colorectal HR: 1.40; 95% CI: 1.32 to 1.84; breast HR: 1.34; 95% CI: 1.25 to 1.44; prostate HR: 1.09; 95% CI: 0.99 to 1.13). However, this association seemed reversed among patients with lung cancer, although attenuated when accounting for potential confounders.

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

## INTRODUCTION

Cancer survival in the UK is low compared with several high-income countries with

## Key messages

### What is already known on this topic

- ▶ Improving patients' experiences of cancer care is a high priority in the national cancer strategy in England.
- ▶ The role of clinical nurse specialists (CNS) in improving experiences of patients with cancer is thought to be a positive one but has not yet been extensively researched.

### What this study adds

- ▶ In our population-based study, we used data collected mainly for the purpose of measuring experiences of patients with cancer at a national level.
- ▶ This study shows for the first time how being directed to a specific CNS is subsequently associated with better care experiences at an individual patient level and subsequent survival.

### How this study might affect research, practice or policy

- ▶ If this association is causal, this is new evidence of the vital contribution CNS may make to cancer survival.
- ▶ Future research should focus on determining what aspects of patients' experience with CNS play the most vital role in patients' assessment, treatment and their subsequent survival.

universal healthcare systems.<sup>1</sup> Variabilities in underlying health systems, cancer policy and clinical practice are known to be important drivers of cancer survival.<sup>1</sup> Patient experience is widely considered as a central pillar of cancer care quality and has also been shown to be associated with patient safety, care effectiveness and health outcomes in many care settings, including cancer.<sup>2–6</sup> Previous research in England and Europe has shown that hospital care quality and patients' experiences vary in relation to inpatient nurse

staffing and education, and improve with higher levels of each across many care settings.<sup>7–11</sup>

Clinical nurse specialists (CNS) play a key role in coordinating cancer care, contributing to the cancer multidisciplinary team, as well as in providing information and emotional support for individual patients during face-to-face and telephone contact.<sup>12–16</sup> Previous reports have shown variation in access to CNS by geography and by tumour site.<sup>17 18</sup> The National Cancer Patient Experience Survey (CPES) asks patients about a wide range of care aspects including their experiences with CNS.<sup>19</sup> CNS care has been shown to play a role in patients' receipt of anticancer therapy and in improving experiences of patients with cancer with other care aspects such as care coordination, involvement in treatment decisions and overall care experiences.<sup>18 20</sup> An important question is whether variation in care experiences of patients with cancer with CNS is also associated with their survival.

The linked CPES and English cancer registration data (CPES-National Cancer Registration and Analysis Service (NCRAS)) have enabled studies of the potential association between patients' experiences and cancer care outcomes.<sup>21</sup> Using the CPES-NCRAS linked dataset and focusing on the four most common cancers (colorectal, lung, breast and prostate cancers), this study aimed to examine whether having a better care experience of CNS care is associated with better overall survival of patients with cancer in England.

## METHODOLOGY

### Study design and participants

In this population-based study, we extracted data on all individuals with a primary, invasive tumour of the colorectum, lung, female breast and prostate from the CPES-NCRAS linked dataset focusing on patients who responded to the National CPES between 2010 and 2014. The survey sampling frame includes all adult patients with a primary diagnosis of cancer who have been discharged from a National Health Service hospital during a 3-month period in each year. Patients are invited to complete the survey by post, with two reminders being sent to non-responders. The response rate to the survey was stable (64%–68%) between

2010 and 2014. CPES contains around 70 questions covering many aspects of cancer care experience. Patients are asked in CPES to report their experiences on four aspects of CNS care. These are, as ordered in CPES: (1) being given a CNS name, (2) the ease of contacting their CNS, (3) feeling that a CNS had listened to them and (4) the degree to which explanations given by a CNS were understandable. Patients who reported not being given a CNS name were asked not to report their experiences in the subsequent three CNS experience questions in the survey. For the purposes of the analysis, we first identified the group of patients who were not given the name of a CNS. For patients who were given a CNS name and reported their experiences in the remaining three questions, we categorised their responses into two main categories: 'excellent' and 'non-excellent' experience in line with previous reports<sup>22–24</sup> (table 1).

### Procedures

A total number of 114 898 records were extracted from the CPES-NCRAS dataset. Some patients were surveyed more than once throughout the different iterations of CPES during 2010–2014. Therefore, we took the first survey record for each patient and removed additional responses (n=6293). In addition, we excluded cases with a missing socioeconomic deprivation score for their area of residence (n=174), and patients with a registered date of death before treatment and/or diagnosis dates (n=1230). We also excluded patients who did not indicate whether they had been given a CNS name, and those who did not report their experiences for at least one of the CNS questions, including patients who reported 'I do not know' or 'I did not ask questions' (n=7825) (figure 1).

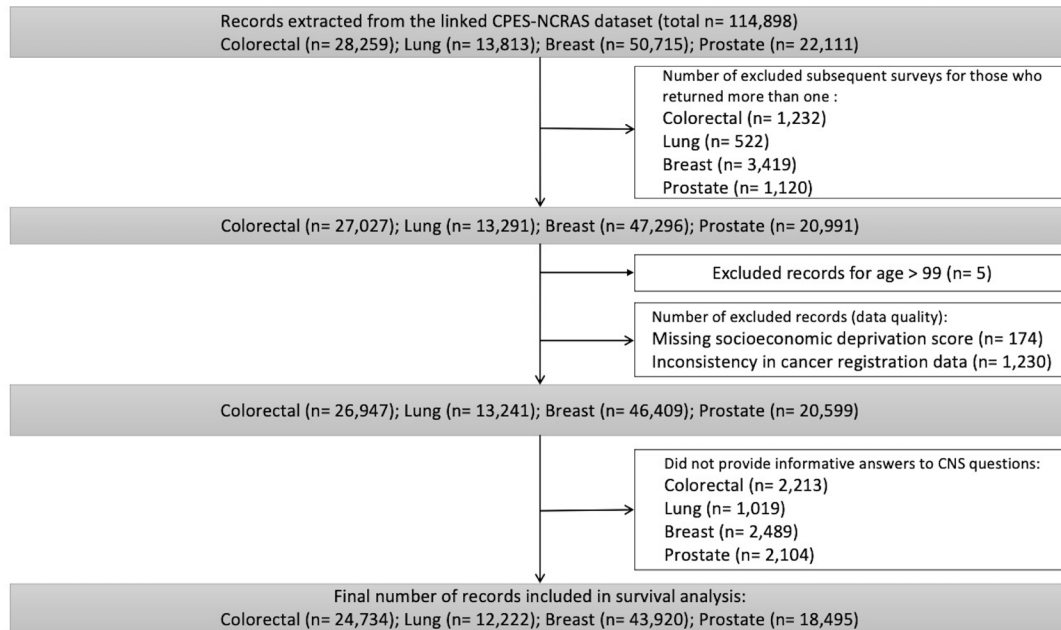
### Start of follow-up

To eliminate the possibility of 'immortal time' bias, which occurs when a person-time is counted when that person is not at risk of the outcome of interest,<sup>25</sup> we considered that in this study, those patients who completed the survey had, by definition, to be alive to receive, complete and return it. Ideally, we would have used the date at which patients completed their

**Table 1** CPES questions about patients' experiences with clinical nurse specialists (CNS) categorised into excellent and non-excellent experience

Cancer care aspects	Exact question in CPES	Experience categories based on CPES answers*	
		Excellent	Non-excellent
Ease of contacting a CNS	How easy is it for you to contact your CNS?	Easy	Sometimes easy, sometimes difficult Difficult
CNS listening carefully to patients	The last time you spoke to your CNS, did she/he listen carefully to you?	Yes definitely	Yes, to some extent No
Patients understanding answers from a CNS	When you have important questions to ask your CNS, how often do you get answers you can understand?	All or most of the time	Some of the time Rarely or never

\*Patients who reported that they did not try to ask or contact their CNS were excluded from the analysis.  
CPES, Cancer Patient Experience Survey.



**Figure 1** Study population flow chart. CNS, clinical nurse specialist; CPES, Cancer Patient Experience Survey; NCRAS, National Cancer Registration and Analysis Service.

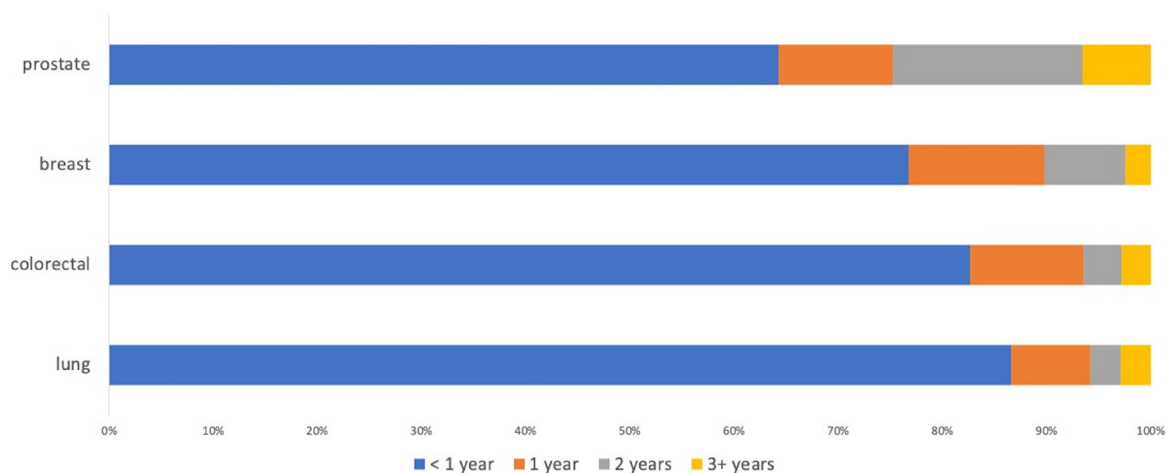
own survey. As this is not recorded, we moved the start of follow-up to the survey mail out date provided by Quality Health, that is, that patients were considered to be at risk of death from the survey mail out. We also calculated the ‘immortal time’ between the date of diagnosis and the point where the survival analysis started (survey mail out) in days to adjust for in the Cox proportional hazards modelling (figure 2). Patients who were still alive were censored on their vital status date in the cancer registration (updated between 5 and 10 February 2019).

#### Patients’ information and data analysis

Data on sex, age, geographical region of residence, deprivation of area of residence and the *TNM*

*Classification* of Malignant Tumours (*TNM*) disease stage are available in the cancer registry dataset for all patients with cancer. For lung cancer, we also extracted additional stage information from the National Lung Cancer Audit data (n=2888).<sup>26</sup> We used self-assigned ethnicity information from cancer registration data which is derived from the Hospital Episode Statistics (HES) data.<sup>26</sup> Due to the limited numbers in each ethnic category, we collapsed the 16-group classification into two categories: all white background (ie, white British, Irish and other white background) and non-white.

Socioeconomic deprivation is measured using the income domain of the Indices of Multiple Deprivation



**Figure 2** Time between date of cancer diagnosis and start of follow-up (CPES mail out) in the study population by cancer type. CPES, Cancer Patient Experience Survey.

(IMD) on the lower super output level. Individual patients are assigned a score of 1 (affluent) through 5 (most deprived) based on their postcode of residence at diagnosis. We applied the closest match of each patient's year of diagnosis to one of the four versions of IMD available in the cancer registry (2004, 2007, 2010, 2015). Route to diagnosis data is available for all cancer cases diagnosed in England since 2006 and is derived by linking HES data, Cancer Waiting Times data, cancer screening programmes data and cancer registration data.<sup>26</sup> The categories used are emergency presentation, general practice referral, screening, 2-week referral and elective referral.

We first tabulated the distribution of patient characteristics (age, sex, socioeconomic deprivation, ethnicity, geographical areas), tumour characteristics (disease stage at diagnosis) and route to diagnosis according to the reported experience with CNS: the ease of contacting their CNS, feeling that a CNS had listened to them and the degree to which explanations given by a CNS were understandable.  $\chi^2$  tests were obtained to test for differences between each CNS experience group according to age, sex, ethnicity, route to diagnosis and stage categories included in these tests.

We used the Kaplan-Meier survival function to compare overall patients' survival in relation to their experiences with CNS for all cancers and obtained the log-rank test to test for statistical significance. We used univariable and multivariable Cox proportional hazards regression analyses to estimate unadjusted and adjusted HRs with 95% CIs to assess the risk of death according to patients' experiences for each cancer. As previously explained, the three categories for patients' experiences were excellent, non-excellent and no CNS name was given, using the 'excellent' experience as the reference group. We included all three aspects of patients' experiences with CNS that are reported in CPES: the ease of contacting their CNS, feeling that a CNS had listened to them and the degree to which explanations given by a CNS were understandable. Based on previous literature, several factors were considered as potential confounders of the relationship between patient experience and survival. We included sex, age, socioeconomic deprivation, ethnicity, area of residence, route to diagnosis, time between date of diagnosis and survey mail out (in days), and stage at diagnosis in our modelling, as these factors have previously been linked to variation in patients' experiences,<sup>22–24 27</sup> and shown to be associated with cancer survival.<sup>28–30</sup> We evaluated the assumption of proportional hazards using Schoenfeld residuals.

Assessing health outcomes based on survey responses is problematic due to the possibility of reverse causation where the current patient's health status might influence their response to the outcome measured by the survey. This type of reverse causation has been warned against in the literature that investigated the association between patients' satisfaction and

their health outcomes.<sup>2</sup> In this study, it might well be argued that patients could rate their experiences with care based on their prognosis and/or extent of their current disease progression. Specifically, patients who have a worse cancer prognosis might rate their experience as negative based on their disease prognosis, how they feel about this, the treatment they have to undergo and the impact of both on their life in general, rather than on the actual care they received. A potential way to assess the impact of this issue is to eliminate patients with the worst outcomes in a sensitivity analysis.<sup>31 32</sup> Therefore, we reanalysed survival excluding patients with the worst outcomes (lowest 25th quartile of survival time: colorectal 731 days; lung 202 days; breast 1820 days; prostate 1340 days). All statistical analyses were carried out using Stata V.15.1 (Stata Corp, Texas, USA).

#### Patient involvement in this study

The study research team worked and shared methods and findings of this study with two patient representatives (MB and JR) at the National Cancer Research Institute. They themselves had conducted work on the CPES and were familiar with some of the data used in this study. The representative team members provided invaluable insight into aspects of the data analysis plan and assisted with the drafting of this paper.

#### RESULTS

The final study population included 99 371 patients (colorectal n=24 734; lung n=12 222; breast n=43 920; prostate n=18 495) who responded to CPES between 2010 and 2014. Overall, the proportions of patients reported being given the name of a CNS were 90% of patients with colorectal cancer, 92% of lung, 94% of breast and only 86% of patients with prostate cancer. According to cancer type, tables 2–5 show the distributions of patients' sex, age, ethnicity, socioeconomic deprivation, geography of residence, route to diagnosis and disease stage at diagnosis according to their reported experience with CNS. More than 89% of patients with colorectal, lung, breast and prostate cancer reported an excellent care experience with the two following care aspects: feeling that a CNS had listened to them and that the explanations given by CNS had made sense. However, the proportion of patients reporting excellent experience with ease of contacting their CNS varied between cancer types, from 72% for breast and prostate cancer to 78% for colorectal cancer. Tables 2–5 also show variation in patients' experiences by their demographic characteristics. Patients aged 45–59 years and those with non-white ethnicity backgrounds were more likely to report negative experiences across all cancers, while women were more likely to report negative care experiences compared with men among patients with colorectal and lung cancer. Reported care experiences also varied by patients' socioeconomic deprivation,



**Table 2** Characteristics of patients with colorectal cancer reporting their care experiences with cancer clinical nurse specialists (CNS)

Type of experience	CNS name		Contacting CNS		Speaking to CNS		Understanding CNS							
	Not given* (n=2388)	%	Excellent (n=16 107) (78.6%)	Non-excellent (n=4392) (21.4%)	Excellent (n=20 532) (92.8%)	Non-excellent (n=1585) (7.2%)	Excellent (n=18 612) (92.1%)	Non-excellent (n=1597) (7.9%)						
Level of care experience	N	%	n	%	n	%	n	%						
<b>Sex</b>														
Male	1373	57.5	9720	60.3	2517	57.3	12 326	60.0	848	53.5	11 187	60.1	898	56.2
Female	1015	42.5	6387	39.7	1875	42.7	8206	40.0	737	46.5	7425	39.9	699	43.8
$\chi^2$ and p value*			$\chi^2=17.5$ ; p<0.001		$\chi^2=29.8$ ; p<0.001		$\chi^2=3.8$ ; p=0.001							
<b>Age group</b>														
<45	74	3.1	456	2.8	212	4.8	635	3.1	69	4.4	580	3.1	87	5.4
45–59	448	18.8	2684	16.7	908	20.7	3468	16.9	374	23.6	3274	17.6	331	20.7
60–74	1123	47.0	8606	53.4	2280	51.9	10 897	53.1	794	50.1	9991	53.7	768	48.1
75–99	743	31.1	4361	27.1	992	22.6	5532	26.9	348	22.0	4767	25.6	411	25.7
$\chi^2$ and p value			$\chi^2=138.6$ ; p<0.001		$\chi^2=93.9$ ; p<0.001		$\chi^2=82.7$ ; p<0.001							
<b>Ethnicity</b>														
White	2070	86.7	14 220	88.3	3805	86.6	18 083	88.1	1360	85.8	16 406	88.1	1366	85.5
Non-white	73	3.1	437	2.7	150	3.4	573	2.8	68	4.3	514	2.8	80	5.0
Unknown	245	10.3	1450	9.0	437	9.9	1876	9.1	157	9.9	1692	9.1	151	9.5
$\chi^2$ and p value			$\chi^2=13.5$ ; p<0.001		$\chi^2=16.3$ ; p=0.003		$\chi^2=30.0$ ; p<0.001							
<b>Area</b>														
East Midlands	294	12.3	1506	9.3	397	9.0	1955	9.5	158	10.0	1768	9.5	154	9.6
East of England	261	10.9	1962	12.2	544	12.4	2495	12.2	194	12.2	2270	12.2	190	11.9
London	191	8.0	1453	9.0	505	11.5	1909	9.3	188	11.9	1714	9.2	191	12.0
North East	107	4.5	1142	7.1	189	4.3	1342	6.5	75	4.7	1223	6.6	83	5.2
North West	247	10.3	2086	13.0	528	12.0	2589	12.6	185	11.7	2370	12.7	195	12.2
South East	375	15.7	2442	15.2	846	19.3	3251	15.8	296	18.7	2937	15.8	275	17.2
South West	232	9.7	2190	13.6	530	12.1	2741	13.3	168	10.6	2524	13.6	169	10.6
West Midlands	389	16.3	1754	10.9	482	11.0	2279	11.1	195	12.3	2043	11.0	197	12.3
Yorkshire & Humber	292	12.2	1572	9.8	371	8.4	1971	9.6	126	7.9	1763	9.5	143	9.0
$\chi^2$ and p value			$\chi^2=260.9$ ; p<0.001		$\chi^2=171.9$ ; p<0.001		$\chi^2=167.5$ ; p<0.001							
<b>IMD</b>														
1—affluent	509	21.3	3692	22.9	1126	25.6	4847	23.6	356	22.5	4407	23.7	337	21.1
2	605	25.3	4033	25.0	1070	24.4	5097	24.8	370	23.3	4654	25.0	343	21.5
3	505	21.2	4444	21.4	904	20.6	4351	21.2	342	21.6	3940	21.2	351	22.0
4	427	17.9	815	17.5	756	17.2	587	17.5	285	18.0	3237	17.4	309	19.3
5—deprived	340	14.2	2123	13.2	536	12.2	2650	12.9	232	14.6	2374	12.8	257	16.1
$\chi^2$ and p value			$\chi^2=22.7$ ; p<0.001		$\chi^2=13.2$ ; p=0.10		$\chi^2=34.8$ ; p<0.001							
<b>Route to diagnosis</b>														
ER	609	25.5	1888	11.7	524	11.9	2421	11.8	212	13.4	2177	11.7	227	14.2

Continued

Table 2 Continued

Type of experience	CNS name		Contacting CNS		Speaking to CNS		Understanding CNS	
	Not given* (n=2388)	%	Excellent (n=16 107) (78.6%)	Non-excellent (n=4392) (21.4%)	Excellent (n=20 532) (92.8%)	Non-excellent (n=1585) (7.2%)	Excellent (n=18 612) (92.1%)	Non-excellent (n=1597) (7.9%)
Variable	N	%	n	n	n	N	n	n
GP	560	23.5	3933	1147	5052	430	4542	431
Screening	165	6.9	2445	566	3070	182	2852	169
Two-week referral	704	29.5	8869	1586	7473	569	6744	557
Elective referral	266	11.1	1733	483	2205	156	2000	178
Unknown	84	3.5	239	86	311	36	297	35
$\chi^2$ and p value			$\chi^2=495.7; p<0.001$		$\chi^2=497.5; p<0.001$		$\chi^2=501.5; p<0.001$	
<b>Stage</b>								
I	142	5.9	1437	322	1770	120	1615	113
II	332	13.9	8896	604	3632	209	3221	234
III	489	20.5	4037	1104	5143	397	4741	394
IV	465	19.5	1990	762	2679	294	2386	276
Unknown	960	40.2	7747	1600	3308	565	6649	580
$\chi^2$ and p value			$\chi^2=225.1; p<0.001$		$\chi^2=170; p<0.001$		$\chi^2=156.6; p<0.001$	

All  $\chi^2$  tested for differences between three groups (excellent, non-excellent and not having CNS) across all variables in the table.

\*Patients who were not given a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS and understanding CNS).

ER, emergency room; GP, general practitioner; IMD, Indices of Multiple Deprivation.

**Table 3** Characteristics of patients with lung cancer reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	CNS name		Contacting CNS		Speaking to CNS		Understanding CNS	
	Not given (n=966)*	%	Excellent (n=7888) (75.9%)	Non-excellent (n=2510) (24.1%)	Excellent (n=10 128) (91.0%)	Non-excellent (n=1000) (9.0%)	Excellent (n=8886) (89.5%)	Non-excellent (n=1040) (10.5.%)
Level of care experience	n	%	n	%	n	%	n	%
<b>Sex</b>								
Male	507	52.5	4356	55.2	5541	54.7	4856	54.6
Female	459	47.5	3532	44.8	4587	45.3	4030	45.4
$\chi^2$ and p value*			$\chi^2=11.7$ ; p=0.003		$\chi^2=19.4$ ; p<0.001		$\chi^2=4.2$ ; p<0.12	
<b>Age group</b>								
<45	20	2.1	84	1.1	122	1.2	103	1.2
45–59	159	16.5	1272	16.1	1679	16.6	1528	17.2
60–74	525	54.3	4821	61.1	6150	60.7	5438	61.2
75–99	262	27.1	1711	21.7	2177	21.5	1817	20.4
$\chi^2$ and p value			$\chi^2=65.6$ ; p<0.001		$\chi^2=49.7$ ; p<0.001		$\chi^2=46.5$ ; p<0.001	
<b>Ethnicity</b>								
White	831	86.0	7122	90.3	9107	89.9	8009	90.1
Non-white	39	4.0	171	2.2	259	2.6	222	2.5
Unknown	96	9.9	595	7.5	762	7.5	655	7.4
$\chi^2$ and p value			$\chi^2=35.0$ ; p<0.001		$\chi^2=16.1$ ; p=0.003		$\chi^2=30.6$ ; p<0.001	
<b>Area</b>								
East Midlands	101	10.5	714	9.1	963	9.5	809	9.1
East of England	102	10.6	878	11.1	1146	11.3	1008	11.3
London	121	12.5	733	9.3	993	9.8	861	9.7
North East	46	4.8	747	9.5	873	8.6	782	8.8
North West	163	16.9	1131	14.3	1392	13.7	1221	13.7
South East	127	13.1	923	11.7	1246	12.3	1094	12.3
South West	79	8.2	857	10.9	1084	10.7	953	10.7
West Midlands	129	13.4	837	10.6	1052	10.4	931	10.5
Yorkshire & Humber	98	10.1	1068	13.5	1379	13.6	1227	13.8
$\chi^2$ and p value			$\chi^2=141.6$ ; p<0.001		$\chi^2=70.1$ ; p<0.001		$\chi^2=72.2$ ; p<0.001	
<b>IMD</b>								
1—affluent	168	17.4	1215	15.4	1599	15.8	1427	16.1
2	171	17.7	1251	16.1	1630	16.1	1477	16.7
3	161	16.7	1191	15.2	1584	15.6	1427	16.1
4	205	21.2	1495	19.1	1952	19.1	1727	19.5
5—deprived	223	23.1	1785	22.6	2263	22.3	1958	22.0
$\chi^2$ and p value			$\chi^2=9.2$ ; p=0.32		$\chi^2=5.2$ ; p=0.73		$\chi^2=18.6$ ; p=0.01	
<b>Route to diagnosis</b>								
1	145	14.9	1042	13.3	1379	13.3	1227	13.8
2	178	18.4	1251	16.1	1630	16.1	1477	16.7
3	211	21.7	1584	20.0	2084	20.6	1810	20.4
4	234	24.0	1727	22.0	2263	22.3	1958	22.0
5	272	28.1	2084	26.6	2630	26.6	2263	26.6
$\chi^2$ and p value			$\chi^2=141.6$ ; p<0.001		$\chi^2=70.1$ ; p<0.001		$\chi^2=72.2$ ; p<0.001	

Continued



**Table 3** Continued

Type of experience	CNS name		Contacting CNS				Speaking to CNS				Understanding CNS			
	Not given (n=966)*	%	Excellent (n=7888) (75.9%)	Non-excellent (n=2510) (24.1%)	Excellent (n=10 128) (91.0%)	Non-excellent (n=1000) (9.0%)	Excellent (n=8886) (89.5%)	Non-excellent (n=1040) (10.5%)						
Variable	n	%	n	%	n	%	n	%	n	%	n	%		
ER	126	13.0	978	12.4	327	13.0	1256	12.4	145	14.5	1124	12.6	142	13.7
GP	265	27.4	1944	24.6	689	27.5	2512	24.8	298	29.8	2213	24.9	297	28.6
Screening	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Two-week referral	359	37.2	3667	46.5	1113	44.3	4710	46.5	415	41.5	4123	46.4	449	43.2
Elective referral	195	20.2	1206	15.3	344	13.7	1522	15.0	128	12.8	1313	14.8	142	13.7
Unknown	21	2.2	93	1.2	37	1.5	128	1.3	14	1.4	113	1.3	10	1.0
$\chi^2$ and p value			$\chi^2=51.3$ ; p<0.001		$\chi^2=59.5$ ; p<0.001		$\chi^2=49.8$ ; p<0.001							
<b>Stage</b>														
I	262	27.1	1276	16.2	324	12.9	1582	15.6	168	16.8	1338	15.1	156	15.0
II	112	11.6	1011	12.8	319	12.7	1284	12.7	149	14.9	1141	12.8	143	13.8
III	208	21.5	2360	29.9	767	30.6	3010	29.7	303	30.3	2642	29.7	309	29.7
IV	239	24.7	2568	32.6	881	35.1	3383	33.4	296	29.6	3010	33.9	333	32.0
Unknown	145	15.0	673	8.5	219	8.7	869	8.6	84	8.4	755	8.5	99	9.5
$\chi^2$ and p value			$\chi^2=173.2$ ; p<0.001		$\chi^2=159.4$ ; p<0.001		$\chi^2=164.6$ ; p<0.001							

All  $\chi^2$  tested for differences between three groups (excellent, non-excellent and not having CNS) across all variables in the table.

\*Patients who were not given a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS and understanding CNS).

ER, emergency room; GP, general practitioner; IMD, Indices of Multiple Deprivation.

Table 4 Characteristics of patients with breast cancer reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	CNS name				Contacting CNS				Speaking to CNS				Understanding CNS			
	Not given* (n=2721)		Excellent (n=27 740) (72.1%)		Non-excellent (n=10 736) (28.9%)		Excellent (n=37 056) (90.6%)		Non-excellent (n=3852) (9.4%)		Excellent (n=34 898) (91.4%)		Non-excellent (n=3303) (8.6%)			
Variable	n	%	n	%	n	%	N	%	N	%	n	%	n	%		
<b>Age group</b>																
<45	470	17.3	3506	12.6	1894	17.6	4960	13.4	680	17.7	4786	13.7	640	19.4		
45–59	1189	43.7	10 574	38.1	4761	44.3	14 494	39.1	1774	46.1	13 978	40.1	1397	42.3		
60–74	812	29.8	10 687	38.5	3369	31.4	13 857	37.4	1155	30.0	12 857	36.8	1000	30.3		
75–99	250	9.2	2973	10.7	712	6.6	3745	10.1	243	6.3	3277	9.4	266	8.1		
$\chi^2$ and p value																
							$\chi^2=515.5$ ; p<0.001							$\chi^2=166.4$ ; p<0.001		
<b>Ethnicity</b>																
White	2268	83.4	23 244	83.8	8774	81.7	30 910	83.4	3162	82.1	29 159	83.6	2617	79.2		
Non-white	162	6.0	1219	4.4	707	6.6	1764	4.8	260	6.7	1622	4.6	311	9.4		
Unknown	291	10.7	3277	11.8	1255	11.7	4382	11.8	430	11.2	4117	11.8	375	11.4		
$\chi^2$ and p value							$\chi^2=84.4$ ; p<0.001							$\chi^2=147.7$ ; p<0.001		
<b>Area</b>																
East Midlands	446	16.4	2374	8.6	932	8.7	3259	8.8	373	9.7	3002	8.6	323	9.8		
East of England	236	8.7	3321	12.0	1239	11.5	4412	11.9	439	11.4	4154	11.9	393	11.9		
London	312	11.5	2841	10.2	1607	15.0	4025	10.9	645	16.7	3839	11.0	537	16.3		
North East	71	2.6	1860	6.7	428	4.0	2244	6.1	155	4.0	2129	6.1	132	4.0		
North West	181	6.7	3284	11.8	1119	10.4	4198	11.3	417	10.8	3974	11.4	334	10.1		
South East	504	18.5	4202	15.1	1869	17.4	5876	15.9	607	15.8	5459	15.6	529	16.0		
South West	398	14.6	3387	12.2	1229	11.4	4535	12.2	422	11.0	4300	12.3	340	10.3		
West Midlands	429	15.8	3297	11.9	1126	10.5	4347	11.7	383	9.9	4072	11.7	353	10.7		
Yorkshire & Humber	144	5.3	3174	11.4	1187	11.1	4160	11.2	411	10.7	3969	11.4	362	11.0		
$\chi^2$ and p value							$\chi^2=751.5$ ; p<0.001							$\chi^2=550.4$ ; p<0.001		
<b>IMD</b>																
1—affluent	692	25.4	6329	22.8	2536	23.6	8489	22.9	903	23.4	8106	23.2	679	20.6		
2	620	22.8	6673	24.1	2565	23.9	8958	24.2	897	23.3	8474	24.3	750	22.7		
3	579	21.3	5948	21.4	2388	22.2	8033	21.7	797	20.7	7577	21.7	660	20.0		
4	504	18.5	4952	17.9	1846	17.2	6532	17.6	696	18.1	6090	17.5	630	19.1		
5—deprived	326	12.0	3838	13.8	1401	13.0	5044	13.6	559	14.5	4651	13.3	584	17.7		
$\chi^2$ and p value							$\chi^2=24.0$ ; p=0.02							$\chi^2=78.5$ ; p<0.001		
<b>Route to diagnosis</b>																
ER	69	2.5	323	1.2	118	1.1	439	1.2	40	1.0	393	1.1	42	1.3		
GP	882	10.5	1857	6.7	718	8.1	8572	7.0	316	8.2	2427	7.0	280	8.5		
Screening	609	22.4	8317	30.0	2935	27.3	11 102	30.0	1051	27.3	10 389	29.8	846	25.6		
Two-week referral	1277	46.9	15 295	55.1	6061	56.5	20 366	55.0	2153	55.9	19 270	55.2	1867	56.5		
Elective referral	79	2.9	597	2.2	200	1.9	757	2.0	78	2.0	725	2.1	71	2.1		
Unknown	403	14.8	1351	4.9	551	5.1	1814	4.9	214	5.6	1694	4.9	197	6.0		
$\chi^2$ and p value							$\chi^2=637.3$ ; p<0.001							$\chi^2=637.3$ ; p<0.001		

Continued

Type of experience		CNS name		Contacting CNS		Speaking to CNS		Understanding CNS							
		Not given* (n=2721)	%	Excellent (n=27 740) (72.1%)	%	Excellent (n=37 056) (90.6%)	%	Excellent (n=34 898) (91.4%)	%	Non-excellent (n=3303) (8.6%)	%				
Level of care experience		n	%	n	%	n	%	n	%	n	%				
Variable		n	%	n	%	n	%	n	%	n	%				
<b>Stage</b>															
I		560	20.6	7923	28.6	2663	24.8	10 549	28.5	940	24.4	9821	28.1	773	23.4
II		791	29.1	9012	32.5	3394	31.6	11 879	32.1	1195	31.0	11 355	32.5	978	29.6
III		237	8.7	2503	9.0	1025	9.5	3353	9.0	323	8.4	3142	9.0	343	10.4
IV		170	6.2	779	2.8	318	3.0	1042	2.8	140	3.6	931	2.7	139	4.2
Unknown		963	35.4	7523	27.1	3336	31.1	10 233	27.6	1254	32.6	9649	27.6	1070	32.4
$\chi^2$ and p value															

All  $\chi^2$  tested for differences between three groups (excellent, non-excellent and not having CNS) across all variables in the table.

\*Patients who were not given a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS and understanding CNS).

ER, emergency room; GP, general practitioner; IMD, Indices of Multiple Deprivation.

area of residence, route to diagnosis and stage to diagnosis, but these variations were not consistent across all cancers.

Overall, the Kaplan-Meier survival curves showed variation in patient survival according to their reported communication experiences with CNS between the three compared groups (excellent experience, non-excellent experience and no CNS name given) (figures 3 and 4). Patients who reported not being given a CNS name had the lowest survival among the three compared groups across colorectal, breast and prostate cancers. Notably, this association was in the opposite direction for patients with lung cancer. Differences in survival were also observed between the patients with excellent and non-excellent experience among all cancers and were more pronounced among patients with colorectal cancer. The differences were all statistically significant (all log-rank tests  $p < 0.001$ ).

Table 6 shows the results of the different Cox proportional hazards regression models for analysis of the association between patient experience and survival. After adjusting for age and sex in model 1, the results show that among those who reported not being given a CNS name, the highest risk of death was in those with colorectal, breast and prostate cancers (colorectal HR: 1.78; 95% CI: 1.68 to 1.88; breast HR: 1.94; 95% CI: 1.82 to 2.08; prostate HR: 1.58; 95% CI: 1.48 to 1.69). These estimates were slightly attenuated by further adjustment for stage of disease (model 2). The association, however, was more clearly attenuated when fully adjusted for all covariables (model 3). The association remained strong among colorectal and breast cancers only (colorectal HR: 1.40; 95% CI: 1.32 to 1.84; breast HR: 1.34; 95% CI: 1.25 to 1.44). Among patients with lung cancer, however, the picture differed. Those who reported not being given a CNS name had a lower risk of death compared with other groups, but this association was attenuated when adjusted for stage, and in the fully adjusted model (HR: 0.92; 95% CI: 0.84 to 0.98).

Patients' experience with the degree to which explanations given by a CNS were understandable was the aspect of CNS communication most strongly associated with the risk of death, followed by the experience of feeling that a CNS had listened to them (table 6). Among colorectal, breast and prostate cancers, those patients who reported non-excellent experiences with understanding CNS explanations had higher risk of death compared with those who reported excellent experiences (colorectal HR: 1.22; 95% CI: 1.12 to 1.30; breast HR: 1.23; 95% CI: 1.14 to 1.31; prostate HR: 1.26; 95% CI: 1.15 to 1.39, model 3).

In the sensitivity analysis (table 6, model 4), we excluded patients in the lowest 25% quartile of survival time to investigate whether the association between patients' experiences and their survival might be prone to reverse causation. Our hypothesis being that patients with better cancer prognosis might be

**Table 5** Characteristics of patients with prostate cancer reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	CNS name		Contacting CNS		Speaking to CNS		Understanding CNS	
	n	%	Excellent (n=10 271) (72.0%)	Non-excellent (n=3991) (28.0%)	Excellent (n=14 279) (91.2%)	Non-excellent (n=1370) (8.8%)	Excellent (n=12 587) (90.8%)	Non-excellent (n=1278) (9.2%)
<b>Level of care experience</b>								
<b>Variable</b>	n	%	n	%	N	%	n	%
<b>Age group</b>								
<45	4	0.2	17	0.2	29	0.2	25	0.2
45–59	333	12.8	1529	14.9	2185	15.3	2002	15.9
60–74	1572	60.5	6946	67.6	9677	67.8	8596	68.3
75–99	691	26.6	1779	17.3	2388	16.7	1964	15.6
$\chi^2$ and p value			$\chi^2=217.4; p<0.001$		$\chi^2=161.9; p<0.001$		$\chi^2=188.6; p<0.001$	
<b>Ethnicity</b>								
White	2182	83.9	8770	85.4	12 194	85.4	10 723	85.2
Non-white	118	4.5	385	3.7	540	3.8	471	3.7
Unknown	300	11.5	1116	10.9	1545	11.4	1393	11.1
$\chi^2$ and p value			$\chi^2=5.1; p=0.26$		$\chi^2=10.6; p=0.03$		$\chi^2=16.0; p<0.001$	
<b>Area</b>								
East Midlands	358	13.8	899	8.8	1255	8.8	1086	8.6
East of England	252	9.7	1200	11.7	1687	11.8	1469	11.7
London	324	12.5	861	8.4	1262	8.8	1125	8.9
North East	88	3.4	585	5.7	756	5.3	654	5.2
North West	347	13.3	2035	19.8	2777	19.4	2438	19.4
South East	340	13.1	1389	13.5	1981	13.9	1788	14.2
South West	358	13.8	1461	14.2	1962	13.7	1734	13.8
West Midlands	306	11.8	1049	10.2	1497	10.5	1310	10.4
Yorkshire & Humber	227	8.7	792	7.7	1102	7.7	983	7.8
$\chi^2$ and p value			$\chi^2=234.4; p<0.001$		$\chi^2=186.9; p<0.001$		$\chi^2=176.5; p<0.001$	
<b>IMD</b>								
1—affluent	669	25.7	2641	25.7	3691	25.8	3302	26.2
2	663	25.5	2593	25.2	3633	25.4	3264	25.9
3	508	19.5	2131	20.7	2944	20.6	2566	20.4
4	460	17.7	1613	15.7	2243	15.7	1911	15.2
5—deprived	300	11.5	1293	12.6	1768	12.4	1544	12.3
$\chi^2$ and p value			$\chi^2=14.3; p<0.07$		$\chi^2=20.7; p=0.008$		$\chi^2=58.6; p<0.001$	
<b>Route to diagnosis</b>								
ER	146	5.6	48	3.4	460	3.2	409	3.2
GP	931	35.8	198	40.9	5977	41.9	5296	42.1
Screening	0	0.0	0	0.0	0	0.0	0	0.0
Two-week referral	725	27.9	4115	40.1	5578	39.1	4884	38.8
Elective referral	288	11.1	970	9.4	1355	9.5	1184	9.4

Continued

Table 5 Continued

Type of experience	CNS name		Contacting CNS		Speaking to CNS		Understanding CNS	
	Not given* (n=2600)	%	Excellent (n=10 271) (72.0%)	Non-excellent (n=3991) (28.0%)	Excellent (n=14 279) (91.2%)	Non-excellent (n=1370) (8.8%)	Excellent (n=12 587) (90.8%)	Non-excellent (n=1278) (9.2%)
Level of care experience	n	%	n	%	N	%	n	%
Variable								
Unknown	510	19.6	640	6.2	909	6.4	814	6.5
$\chi^2$ and p value			$\chi^2=608.9; p<0.001$		$\chi^2=608.7; p<0.001$		$\chi^2=566.6; p<0.001$	
<b>Stage</b>								
I	310	11.9	1554	15.1	2152	15.1	1848	14.7
II	239	9.2	1635	15.9	2326	16.3	2076	16.5
III	154	5.9	1273	12.4	1777	12.4	1579	12.5
IV	281	10.8	1085	10.6	1443	10.1	1286	10.2
Unknown	1616	62.2	4724	46.0	6581	46.1	5798	46.1
$\chi^2$ and p value			$\chi^2=290.4; p<0.001$		$\chi^2=298.4; p<0.001$		$\chi^2=297.7; p<0.001$	

All  $\chi^2$  tested for differences between three groups (excellent, non-excellent and not having CNS) across all variables in the table.

\*Patients who were not given a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS and understanding CNS). ER, emergency room; GP, general practitioner; IMD, Indices of Multiple Deprivation.

more likely to be assigned to a CNS, and those with the poorest prognosis might be more likely to be referred initially to a palliative care nurse. The association was only sensitive to this adjustment among patients with breast cancer who reported not being given a CNS name (HR: 1.05; 95% CI: 0.85 to 1.09).

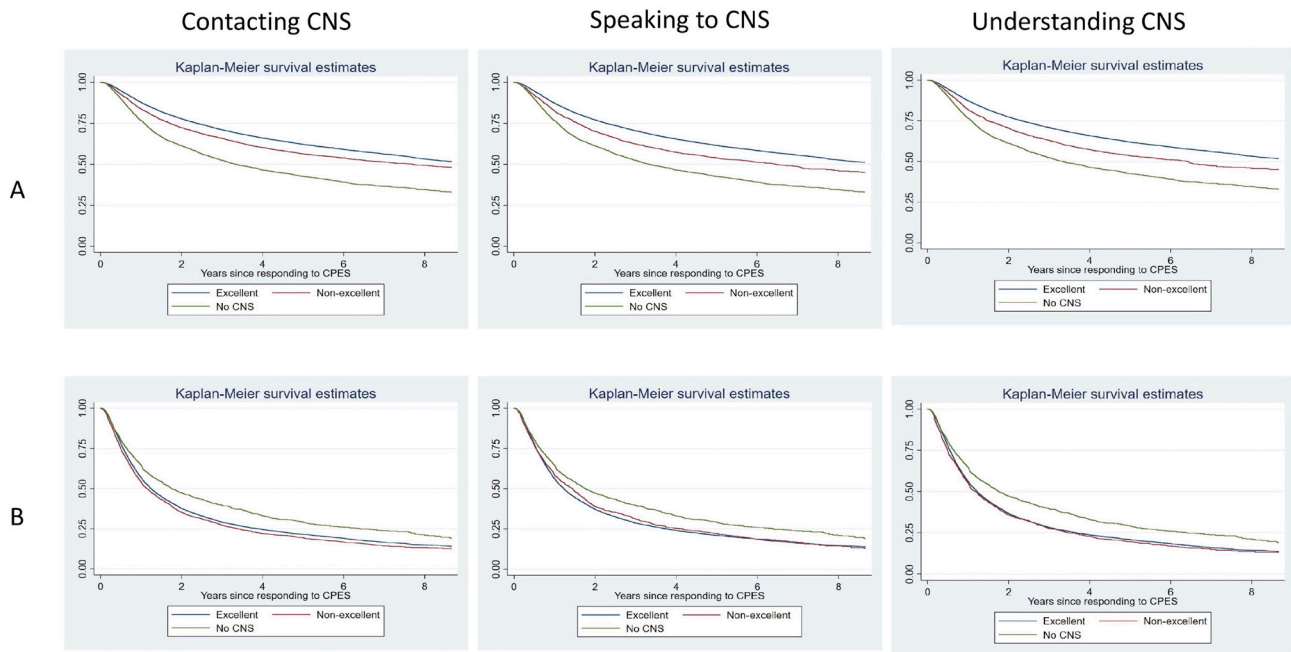
DISCUSSION

Measuring experiences with care of patients with cancer is vital to assess, monitor and deliver better care.<sup>33</sup> This study examined whether having a better care experience with a CNS is associated with better cancer survival in England. Overall, survival of patients with cancer varied in relation to their reported communication experiences with a CNS between the three groups compared (excellent experience, non-excellent experience and no CNS name given). Patients who reported not being given a CNS name had the lowest survival and those who reported excellent experience had the highest survival for colorectal, breast and prostate cancers. Adjustment for potential confounders attenuated these associations, but significant associations remained.

To our knowledge, this study is the first to use linked cancer experience and cancer registration data to examine the association between patients' experiences and their survival in England. Our study is particularly important as it has shown that better care experiences are associated with better patient outcomes. There are several explanations for our findings. One way of interpreting is that better experiences with CNS enable a trusted relationship to grow more quickly in the initial period after diagnosis, which therefore promote continuity of care and help patients to navigate the cancer care pathway. This could prevent or offset the effect of seeing different clinicians at subsequent appointments and of needing to re-explain concerns, which patients often describe as a frustrating experience. The lack of a trusting relationship is therefore expected to lead to less adherence with CNS instructions, less seeking of CNS help or advice from the CNS, especially around treatment decision-making.

The importance of CNS in cancer care has been shown in our previous analysis, where we showed that those who reported being given a CNS name had better experiences with care coordination, involvement in treatment decisions, and the overall care experience across colorectal, lung, breast, and prostate cancers.<sup>18</sup> In addition, the CNS is a direct access point for getting help and support from the whole cancer team when it is needed.<sup>15 34</sup> In particular, when patients have new or developing symptoms, they may contact the CNS who will then speak to the oncology team or allied health professionals. In cases where a CNS is not able to manage a patient's symptoms, they arrange for them to see the oncology team. From a patient's perspective, that process is seamless and timely, and without a CNS,

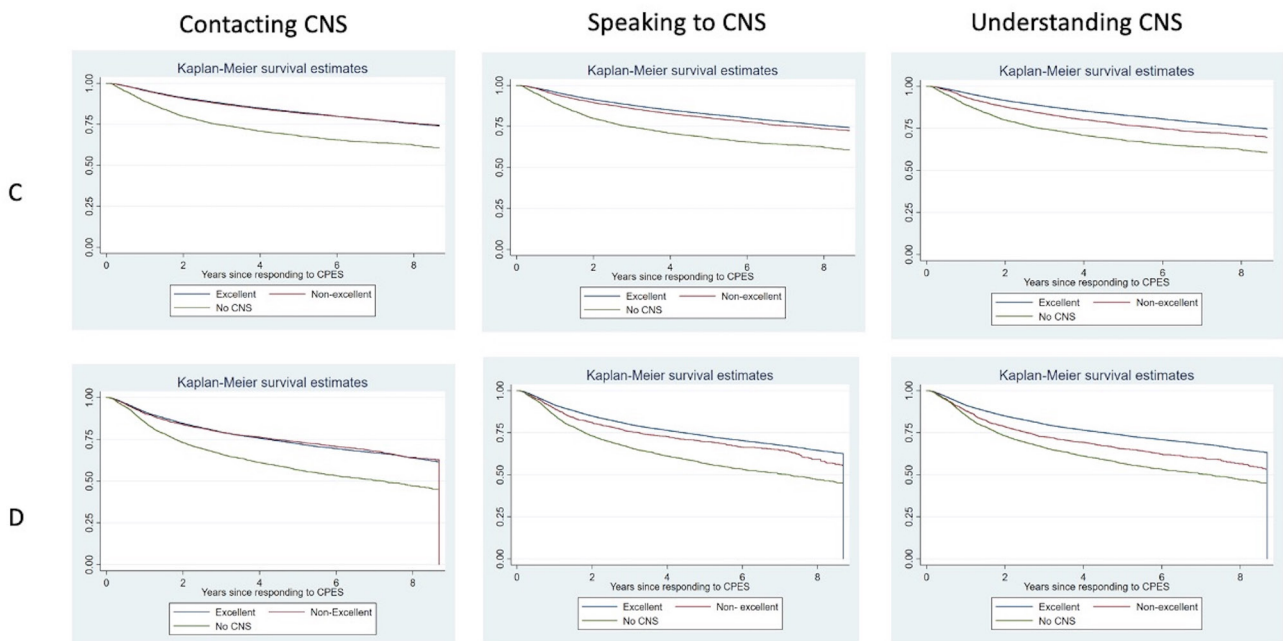




**Figure 3** Kaplan-Meier survival estimates of death from any cause in (A) patients with colorectal and (B) patients with lung cancer, in relation to their care experience with CNS. CNS, clinical nurses specialist; CPES, Cancer Patient Experience Survey,

it is very hard to access the oncology team meaning that a lot of time can potentially be wasted resulting in symptoms not being dealt with in a timely fashion. Previous research has shown that patients report more positive experiences of care coordination in Trusts where there are more CNS per patient.<sup>11</sup> Future research should focus on 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 and outcomes. Our results showed some variation but limited association between patients' experiences of CNS care and outcomes. The association between patients' experiences with CNS and their survival was attenuated after we adjusted for differences in patient mix and additional covariables. While our findings do not prove causality, they suggest that the CNS role is



**Figure 4** Kaplan-Meier survival estimates of death from any cause in (C) patients with breast and (D) prostate cancer, in relation to their care experience with CNS. CNS, clinical nurses specialist; CPES, Cancer Patient Experience Survey,



**Table 6** HR of death for all patients with cancer according to their care experience with cancer clinical nurse specialists (CNS)

Experience type	Adjustments	Model 1		Model 2		Model 3		Sensitivity analysis*	
		Age and sex		Age, sex and stage		All covariables		All covariables	
Colorectal cancer	Experience level	HR	95% CI	HR	95% CI	HR	95% CI	HR	95% CI
CNS name	Not given	1.78	1.68 to 1.88	1.60	1.51 to 1.69	1.40	1.32 to 1.84	1.37	1.05 to 1.62
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.22	1.16 to 1.28	1.12	1.07 to 1.19	1.13	1.07 to 1.18	1.07	1.00 to 1.16
CNS listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.31	1.21 to 1.41	1.24	1.15 to 1.34	1.21	1.14 to 1.31	1.19	1.06 to 1.33
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.30	1.21 to 1.41	1.24	1.15 to 1.33	1.22	1.12 to 1.30	1.18	1.05 to 1.32
<b>Lung cancer</b>									
CNS name	Not given	0.79	0.74 to 0.86	0.91	0.84 to 0.98	0.92	0.84 to 0.99	0.87	0.79 to 0.95
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.09	1.04 to 1.14	1.04	0.99 to 1.09	1.05	1.00 to 1.10	1.00	0.95 to 1.07
CNS listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	0.98	0.91 to 1.06	1.03	0.96 to 1.11	1.04	0.97 to 1.12	1.01	0.92 to 1.10
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.04	0.98 to 1.12	1.04	0.98 to 1.12	1.04	0.97 to 1.12	0.98	0.89 to 1.06
<b>Breast cancer</b>									
CNS name	Not given	1.94	1.82 to 2.08	1.72	1.61 to 1.84	1.34	1.25 to 1.44	1.05	0.85 to 1.09
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.06	1.01 to 1.11	1.02	0.97 to 1.07	1.03	0.98 to 1.08	0.96	0.85 to 1.09
CNS listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.19	1.11 to 1.28	1.12	1.10 to 1.27	1.15	1.07 to 1.23	1.15	0.97 to 1.37
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.36	1.26 to 1.46	1.25	1.16 to 1.34	1.23	1.14 to 1.31	1.06	0.87 to 1.28
<b>Prostate cancer</b>									
CNS name	Not given	1.58	1.48 to 1.69	1.42	1.33 to 1.51	1.09	0.99 to 1.13	1.09	0.88 to 1.24
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.01	0.94 to 1.07	1.02	0.95 to 1.09	1.05	0.95 to 1.07	0.99	0.87 to 1.28
CNS listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.21	1.09 to 1.32	1.14	0.04 to 1.25	1.11	1.00 to 1.20	1.03	0.86 to 1.25
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.35	1.23 to 1.49	1.30	1.13 to 1.42	1.26	1.15 to 1.39	1.23	1.01 to 1.49

Model 1: excellent experience as a reference and adjusting sex (for patients with lung and colorectal cancer) and age; model 2: excellent experience as a reference and adjusting sex, age and stage; model 3: excellent experience as a reference and adjusting sex, age, ethnicity, areas, deprivation, route to diagnosis (unknown as a category), stage at diagnosis (unknown as a category) and time since diagnosis in days.

\*Sensitivity analysis: same as model 3 but eliminating patients with the worst outcomes based on the least 25% quartile of survival time (in days).

having an influence on both experiences of patients with cancer and their subsequent survival.

Previous studies found that patients with lung cancer who were assessed early by CNS were more likely to have an increased treatment uptake,<sup>20</sup> a lower hazard of death (HR=0.83, 95% CI: 0.73 to 0.94) or hospital unplanned admissions.<sup>12</sup> Among patients with lung cancer, the association between experience with CNS and survival almost disappeared after adjusting for stage in model 2. Most patients with lung cancer who are seen by a CNS have late-stage disease, which may explain the lack of a clear association once confounding by stage is accounted for. A recent study from the USA assessed the association between patients' experiences with

several care aspects and their survival from the 10 most common cancers in the USA.<sup>35</sup> Patients who reported lower overall care experiences also had a higher risk of death, but the association was attenuated after adjusting for several possible confounders including patients' demographic factors and their healthcare utilisation.<sup>35</sup> While this pattern has been shown in our study, it also raises an important question about the complexity of factors affecting patients' survival throughout the care pathway and the possibility of residual confounding in this association. For example, a recent review has highlighted the positive effectiveness of early palliative care on improving quality of life and increases the survival of patients with cancer.<sup>36</sup> After adjusting

for all covariables (model 3), patients' experience with the degree to which explanations given by a CNS were understandable was the aspect of CNS care that appeared to be most strongly associated with a decreased risk of death for the patient. It is of interest for future research to investigate the sensitivity of all the CNS questions in CPES in capturing patients' experiences.

Our results show that the highest risk of death was in those with colorectal, breast and prostate cancers, but this association seemed reversed among patients with lung cancer, although attenuated when accounting for potential confounders. It is possible that the remaining association can be explained by residual confounding. We assume that observed variations in survival in relation to patients' experiences between the four main cancers might be explained by the fact that CPES only samples a section of the wider population with cancer. Two studies have shown that patients with the poorest prognosis are not always well represented, and this pattern was more pronounced among patients with lung cancer,<sup>37 38</sup> making the patients with lung cancer responding to CPES the least representative of all patients with lung cancer. Although this does not explain the findings in this study, it does warrant caution as to the interpretation of the findings regarding the care experiences of the wider population of patients with lung cancer. It is possible that patients with better prognosis are more likely to be referred to a CNS in lung cancer. A previous study focused on patients with lung cancer between 2007 and 2011 showed that older patients with poor performance status, patients receiving any anti-cancer treatment and patients with comorbidities were less likely to be assessed by a CNS.<sup>39</sup>

One strength of our study is the large sample size and the different cancer types studied. NCRAS is considered one of the most comprehensive cancer registration systems in the world. This allowed for detailed case-mix adjustment of this association using a large sample and diverse population with cancer. In addition, there is a gap in the literature on research assessing the possible influence of care experiences on outcomes. This study begins to fill this gap in the literature and adds new knowledge that can be used for designing studies in this area.

However, we recognise that our study has some limitations. First, NCRAS data completeness for stage and ethnicity has improved since 2012, while routes to diagnosis data became available in England after 2006.<sup>26</sup> Therefore, a proportion of patients had missing information on disease stage, ethnicity and route to diagnosis.<sup>40</sup> In addition, treatment episodes are important in experiences and survival of patients with cancer, and a potential confounder when assessing the association between patients' experiences and their subsequent survival.

Treatment data, however, are not recorded in great detail in the cancer registry for the patient cohort in this study—patients who were diagnosed prior to 2013. We, therefore, did not account for treatment in the survival models and recommend future studies assess the feasibility of linking recent CPES rounds to link new treatment datasets within NCRAS<sup>26 41</sup> and so assess the impact of different types of treatment episodes on patients' experiences. Additionally, patient experience surveys are prone to high reporting of excellent experiences, giving rise to relatively low contrast and there is a possibility that patients who reported contacting a CNS were more likely to be more health literate or actively involved in their own cancer care. Finally, although the CPES 4-year iterations of CPES (2010–2014) included in this study might appear as outdated now, this CPES dataset is the most updated series currently linked to the cancer registry, and this linkage has also allowed for long-term follow-up of patients.

## CONCLUSION

This study demonstrates evidence of limited association between patients' experiences with a CNS and their subsequent outcomes. Our 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 what aspects of patients' experience with CNS play the most vital role in patients' assessment, treatment and their subsequent survival. Future research might build on this work and focus on more than one aspect of care experience and thus assess whether these results are consistent across other relevant aspects of experience and the full range of all other cancers.

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**Data availability statement** Data may be obtained from a third party and are not publicly available. The data that support the findings of this study are available from NHS Digital but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. 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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