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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, nonexcellent 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



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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

		Experience categories base	d on CPES answers*
Cancer care aspects	Exact question in CPES	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
4 m 1 1 1 1 1 1 1			

\*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 analvsis 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





(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 their received. A potential way to assess the impact of this issue is to eliminate patients with the worst outcomes in a sensitivity analvsis.<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,

	CNS	name		Contact	ting CNS			Speal	king to CNS		1	Unde	rstanding CN	S
vel of care experience	Not given' (n=2388)	*	Excellent	(n=16 107) (78.6%)	Non-excellé (n=4392) (2	ent (1.4%)	Excellent (n=20 532	() (92.8%)	Non-exc (n=1585	ellent ) (7.2%)	Excellent (n=18 612)	) (92.1%)	Non-exce (n=1597)	ellent (7.9%)
riable	N	%	٩	%	۲	%	<u>ح</u>	%	z	%	٩	%	۲	%
×														
Male	1373	57.5	9720	60.3	2517	57.3	12 326	60.0	848	53.5	11 187	60.1	868	56.2
Female	1015	42.5	6387	39.7	1875	42.7	8206	40.0	737	46.5	7425	39.9	669	43.8
and p value*			χ2=17.5; μ	0<0.001			χ2=29.8; p	<0.001			χ2=3.8; p=	0.001		
e group														
<45	74	3.1	456	2.8	212	4.8	635	3.1	69	4.4	580	3.1	87	5.4
1559	448	18.8	2684	16.7	908	20.7	3468	16.9	374	23.6	3274	17.6	331	20.7
50-74	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
and p value			χ2=138.6;	: p<0.001			χ2=93.9; p	<0.001			χ2=82.7; p·	<0.001		
nicity														
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
Von-white	73	3.1	437	2.7	150	3.4	573	2.8	68	4.3	514	2.8	80	5.0
Jnknown	245	10.3	1450	9.0	437	9.9	1876	9.1	157	9.9	1692	9.1	151	9.5
and p value			χ2=13.5; μ	0<0.001			χ2=16.3; p	=0.003			$\chi^{2=30.0; p}$	<0.001		
33														
east Midlands	294	12.3	1506	9.3	397	9.0	1955	9.5	158	10.0	1768	9.5	154	9.6
iast of England	261	10.9	1962	12.2	544	12.4	2495	12.2	194	12.2	2270	12.2	190	11.9
ondon	191	8.0	1453	9.0	505	11.5	1909	9.3	188	11.9	1714	9.2	191	12.0
Vorth East	107	4.5	1142	7.1	189	4.3	1342	6.5	75	4.7	1223	6.6	83	5.2
Vorth West	247	10.3	2086	13.0	528	12.0	2589	12.6	185	11.7	2370	12.7	195	12.2
outh East	375	15.7	2442	15.2	846	19.3	3251	15.8	296	18.7	2937	15.8	275	17.2
outh West	232	9.7	2190	13.6	530	12.1	2741	13.3	168	10.6	2524	13.6	169	10.6
Vest Midlands	389	16.3	1754	10.9	482	11.0	2279	11.1	195	12.3	2043	11.0	197	12.3
orkshire & Humber	292	12.2	1572	9.8	371	8.4	1971	9.6	126	7.9	1763	9.5	143	9.0
and p value			$\chi^{2=260.9}$	; p<0.001			χ2=171.9;	p<0.001			$\chi^{2=167.5; \parallel}$	p<0.001		
0														
	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
~	507	21.2	3444	21.4	904	20.6	4351	21.2	342	21.6	3940	21.2	351	22.0
4	427	17.9	2815	17.5	756	17.2	3587	17.5	285	18.0	3237	17.4	309	19.3
5	340	14.2	2123	13.2	536	12.2	2650	12.9	232	14.6	2374	12.8	257	16.1
and p value			$\chi^{2=22.7; \mu}$	0<0.001			χ2=13.2; p	1=0.10			χ2=34.8; p·	<0.001		
ute to diagnosis														
-	000		1000	1		•							L C C	

Table 2 Continued														
Type of experience	CNS	name		Contact	ing CNS			Speaki	ng to CNS			Unders	tanding CNS	
Level of care experience	Not given' (n=2388)	*	Excellent (	n=16 107) (78.6%)	Non-excellent (n=4392) (21. <sup>,</sup>	(%)	Excellent (n=20 532) (9	92.8%)	Non-excell (n=1585) (	lent 7.2%)	Excellent (n=18 612) (	92.1%)	Non-excelle (n=1597) (7	nt .9%)
Variable	z	%	c	%	٩	%	٩	%	z	%	۲	%	٩	%
GP	560	23.5	3933	24.4	1147	26.1	5052	24.6	430	27.1	4542	24.4	431	27.0
Screening	165	6.9	2445	15.2	566	12.9	3070	15.0	182	11.5	2852	15.3	169	10.6
Two-week referral	704	29.5	5869	36.4	1586	36.1	7473	36.4	569	35.9	6744	36.2	557	34.9
Elective referral	266	11.1	1733	10.8	483	11.0	2205	10.7	156	9.8	2000	10.7	178	11.1
Unknown	84	3.5	239	1.5	86	2.0	311	1.5	36	2.3	297	1.6	35	2.2
$\chi^2$ and p value			χ2=495.7;	p<0.001			χ2=497.5; p<	0.001			χ2=501.5; p<	0.001		
Stage														
_	142	5.9	1437	8.9	322	7.3	1770	8.6	120	7.6	1615	8.7	113	7.1
=	332	13.9	2896	18.0	604	13.8	3632	17.7	209	13.2	3221	17.3	234	14.7
=	489	20.5	4037	25.1	1104	25.1	5143	25.0	397	25.0	4741	25.5	394	24.7
N	465	19.5	1990	12.4	762	17.3	2679	13.0	294	18.5	2386	12.8	276	17.3
Unknown	960	40.2	5747	35.7	1600	36.4	7308	35.6	565	35.6	6649	35.7	580	36.3
$\chi^2$ and p value			$\chi^{2=225.1; +}$	p<0.001			χ2=170.; p<0	.001			χ2=156.6; p<	0.001		
All $\chi$ 2 tested for differences betwee *Patients who were not given a CN <sup>5</sup>	en three groups S name were as	(excellent, nor ked to not rep	n-excellent and r sort their experie	not having CNS) across all vinnee CN	ariables in the table. VS questions (contac	ting CNS, speaking	to CNS and unders	tanding CNS).						

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

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e of experience	CN	S name		Cor	Itacting CNS			Spea	iking to CNS			Unc	derstanding Ci	NS
el of care experience	Not giv∉ (n=966)⁺	u *	Excellent (n=7888)	t i (75.9%)	Non-exce (n=2510)	llent (24.1%)	Excellent (n=10 12	8) (91.0%)	Non-exc( (n=1000)	ellent \ (9.0%)	Excellent (n=8886)	(89.5%)	Non-exce (n=1040)	ellent (10.5.%)
able	u	%	ч	%	c	%	Ľ	%	Z	%	c	%	Ľ	%
ale	507	52.5	4356	55.2	1293	51.5	5541	54.7	476	47.6	4856	54.6	539	51.8
male	459	47.5	3532	44.8	1217	48.5	4587	45.3	524	52.4	4030	45.4	501	48.2
nd p value*			χ2=11.7;	p=0.003			$\chi^{2=19.4;}$	p<0.001			χ2=4.2; p·	<0.12		
group														
5	20	2.1	84	1.1	43	1.7	122	1.2	16	1.6	103	1.2	24	2.3
59	159	16.5	1272	16.1	523	20.8	1679	16.6	227	22.7	1528	17.2	208	20.0
-74	525	54.3	4821	61.1	1469	58.5	6150	60.7	561	56.1	5438	61.2	582	56.0
-66	262	27.1	1711	21.7	475	18.9	2177	21.5	196	19.6	1817	20.4	226	21.7
nd p value			χ2=65.6;	p<0.001			χ2=49.7;	p<0.001			$\chi^{2=46.5;}$	p<0.001		
icity														
lite	831	86.0	7122	90.3	2222	88.5	9107	89.9	890	89.0	8009	90.1	905	87.0
in-white	39	4.0	171	2.2	96	3.8	259	2.6	32	3.2	222	2.5	48	4.6
known	96	9.9	595	7.5	192	7.6	762	7.5	78	7.8	655	7.4	87	8.4
nd p value			χ2=35.0;	p<0.001			$\chi^{2=16.1;}$	p=0.003			$\chi^{2=30.6;}$	p<0.001		
st Midlands	101	10.5	714	9.1	243	9.7	963	9.5	95	9.5	809	9.1	104	10.0
st of England	102	10.6	878	11.1	292	11.6	1146	11.3	127	12.7	1008	11.3	115	11.1
nobr	121	12.5	733	9.3	320	12.7	666	9.8	126	12.6	861	9.7	141	13.6
rth East	46	4.8	747	9.5	133	5.3	873	8.6	75	7.5	782	8.8	78	7.5
rth West	163	16.9	1131	14.3	312	12.4	1392	13.7	126	12.6	1221	13.7	146	14.0
uth East	127	13.1	923	11.7	380	15.1	1246	12.3	144	14.4	1094	12.3	134	12.9
uth West	79	8.2	857	10.9	262	10.4	1084	10.7	103	10.3	953	10.7	96	9.2
est Midlands	129	13.4	837	10.6	224	8.9	1052	10.4	81	8.1	931	10.5	91	8.8
rkshire & Humber	98	10.1	1068	13.5	344	13.7	1379	13.6	123	12.3	1227	13.8	135	13.0
nd p value			χ2=141.6	i; p<0.001			χ2=70.1;	p<0.001			χ <sup>2=72.2;</sup>	p<0.001		
	168	17.4	1215	15.4	429	17.1	1599	15.8	148	14.8	1427	16.1	145	13.9
	174	18.0	1582	20.1	514	20.5	2030	20.0	211	21.1	1810	20.4	178	17.1
	196	20.3	1611	20.4	512	20.4	2084	20.6	210	21.0	1810	20.4	211	20.3
	205	21.2	1695	21.5	520	20.7	2152	21.2	214	21.4	1881	21.2	234	22.5
	223	23.1	1785	22.6	535	21.3	2263	22.3	217	21.7	1958	22.0	272	26.2
nd p value			χ <sup>2=9.2;</sup> μ	i=0.32			χ <sup>2=5.2;</sup> p	=0.73			$\chi^{2=18.6;}$	p=0.01		

lable 3 Continued															
Type of experience	CN	S name		Con	Itacting CNS			Spea	king to CNS			Unc	derstanding CN	IS	
Level of care experience	Not give (n=966)	en *	Excellent (n=7888)	(75.9%)	Non-exce (n=2510)	llent (24.1%)	Excellent (n=10 128	() (91.0%)	Non-exce (n=1000)	llent (9.0%)	Excellent (n=8886)	(89.5%)	Non-exce (n=1040)	llent (10.5.%)	
Variable	c	%	<u>-</u>	%		%	<b>_</b>	%	z	%	<u>د</u>	%	<u>ح</u>	%	
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			χ2=51.3; J	o<0.001			χ <sup>2=59.5;</sup> p	<0.001			χ2=49.8; p	0<001			
Stage															
_	262	27.1	1276	16.2	324	12.9	1582	15.6	168	16.8	1338	15.1	156	15.0	
=	112	11.6	1011	12.8	319	12.7	1284	12.7	149	14.9	1141	12.8	143	13.8	
=	208	21.5	2360	29.9	767	30.6	3010	29.7	303	30.3	2642	29.7	309	29.7	
2	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	66	9.5	
$\chi^2$ and p value			χ2=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 bet *Definition of a set of the set	ween three gro	ups (excellen	it, non-excellent	t and not havin	g CNS) across all	variables in the	table.	options to CNIC of	o doreto o dore						
FALIPTIS WITO WELP TO LOVELLA	AM ALLEL ON	THE ASKED TO DI	ol report their e	XDPLETCE WILL		CIND QUESTIONS (CL	The solution of the solution o								

"Patients who were not given a CNS name were asked to not report their experience with the other three CNS que ER, emergency room; GP, general practitioner; IMD, Indices of Multiple Deprivation.

Table 4 Characteristi	cs of patie	ints with t	oreast cance	ir reporting tr	והון רמוה ביאנ	נוובוורב אוווו ו	מוורבו רוווורי	al liuise speci	לכאור) כוכוום					
Type of experience	S	IS name		Con	tacting CNS			Spea	king to CNS			Unde	erstanding CNS	
Level of care experience	Not give (n=2721)	* -	Excellent (n=27 740)	(72.1%)	Non-excelle (n=10 736)	ent (28.9%)	Excellent (n=37 056)	(%)0.6%)	Non-excel. (n=3852) (	ent 9.4%)	Excellent (n=34 898)	(91.4%)	Non-excel (n=3303) (	ent 8.6%)
Variable	u	%	=	%	٤	%	z	%	z	%	٤	%	-	%
Age group														
<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	1 000	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			χ2=515.5; μ	<0.001			χ2=257.8; p	<0.001			χ2=166.4; p	<0.001		
Ethnicity														
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			χ2=84.4; p<	±0.001			χ <sup>2=37.2; p&lt;</sup>	:0.001			χ2=147.7; p	<0.001		
Area														
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			χ2=751.5; μ	i<0.001			χ <sup>2=568.8; p</sup>	≤0.001			χ2=550.4; p	<0.001		
DIMI														
1affluent	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
m	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	0609	17.5	630	19.1
5	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			χ2=24.0; p=	=0.02			χ2=20.8; p=	=0.008			χ2=78.5; p<	0.001		
Route to diagnosis														
ER	67	2.5	323	1.2	118	1.1	439	1.2	40	1.0	393	1.1	42	1.3
GP	286	10.5	1857	6.7	871	8.1	2578	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			χ2=649.2; p	<0.001			χ2=626.4; p	<0.001			χ2=637.3; p	<0.001		
														Continue

Table 4 Continued														
Type of experience	C	VS name		Cont	acting CNS			Speak	ing to CNS			Unders	standing CNS	
Level of care experience	Not give. (n=2721)	, u	Excellent (n=27 740) (	(72.1%)	Non-exceller. (n=10 736) (2	nt 28.9%)	Excellent (n=37 056) (9	0.6%)	Non-exceller (n=3852) (9.	nt 4%)	Excellent (n=34 898) ( <u>5</u>	1.4%)	Non-excelle (n=3303) (8	nt 6%)
Variable	c	%	٩	%	5	%	z	%	z	%	=	%	=	%
Stage														
_	560	20.6	7923	28.6	2663	24.8	10 549	28.5	940	24.4	9821	28.1	773	23.4
_	791	29.1	9012	32.5	3394	31.6	11 879	32.1	1195	31.0	11 355	32.5	978	29.6
=	237	8.7	2503	9.0	1025	9.5	3353	0.6	323	8.4	3142	9.0	343	10.4
N	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			χ2=281.8; p<	<0.001			χ2=260.8; p <c< td=""><td>0.001</td><td></td><td></td><td>χ2=290.4; p&lt;</td><td>0.001</td><td></td><td></td></c<>	0.001			χ2=290.4; p<	0.001		
All $\chi 2$ tested for differences between thr *Patients who were not given a CNS nar	ree groups (exce ne were asked t	ellent, non-excelle to not report thei	ent and not having C ir experience with th	CNS) across all variable e other three CNS que	les in the table. estions (contacting CN	S, speaking to CNS a	nd understanding CNS	5).						
ER, emergency room; GP, general practiti	ioner; IMD, Indic	ces of Multiple De	eprivation.											

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

Jertical problem         Jertical problem         Jertical problem         Jertical problem         Jertical problem           deficie deficience         jertical problem         Jerical problem<	Iype or experience Level of care experience					0000			1				the second se								
Motionality conditionality conditality conditionality conditionality conditionality cond	Level of care experience	CN	s name		Conta	icting CNS			speak	ing to CNS			Understa	anding CNS							
(i)         (i) <th></th> <th>Not given* (n=2600)</th> <th></th> <th>Excellent (n=10 271) (</th> <th>72.0%)</th> <th>Non-excell (n=3991) (;</th> <th>ent 28.0%)</th> <th>Excellent (n=14 279) (</th> <th>(91.2%)</th> <th>Non-exce (n=1370)</th> <th>ellent (8.8%)</th> <th>Excellent (n=12 587)</th> <th>(%8.06) (</th> <th>Non-exo (n=1278</th> <th>cellent 3) (9.2%)</th>		Not given* (n=2600)		Excellent (n=10 271) (	72.0%)	Non-excell (n=3991) (;	ent 28.0%)	Excellent (n=14 279) (	(91.2%)	Non-exce (n=1370)	ellent (8.8%)	Excellent (n=12 587)	(%8.06) (	Non-exo (n=1278	cellent 3) (9.2%)						
Perton         Image         Image <t< th=""><th>variable</th><th>۲</th><th>%</th><th></th><th>%</th><th></th><th>%</th><th>z</th><th>%</th><th>  z</th><th>%</th><th></th><th>%</th><th></th><th>%</th></t<>	variable	۲	%		%		%	z	%	z	%		%		%						
(4)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1)         (1) <td>Age group</td> <td></td>	Age group																				
(5)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3)         (3) <td>&lt;45</td> <td>4</td> <td>0.2</td> <td>17</td> <td>0.2</td> <td>10</td> <td>0.3</td> <td>29</td> <td>0.2</td> <td>-</td> <td>0.1</td> <td>25</td> <td>0.2</td> <td>£</td> <td>0.2</td>	<45	4	0.2	17	0.2	10	0.3	29	0.2	-	0.1	25	0.2	£	0.2						
	45-59	333	12.8	1529	14.9	713	17.9	2185	15.3	245	17.9	2002	15.9	231	18.1						
3-94         0         1         1         2         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         3         1         1         3         1         3         1         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3         3	60–74	1572	60.5	6946	67.6	2752	69.0	9677	67.8	920	67.2	8596	68.3	825	64.6						
	75–99	691	26.6	1779	17.3	516	12.9	2388	16.7	204	14.9	1964	15.6	219	17.1						
MotionMotion10102020201020102020201010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010101010	2 and p value			χ2=217.4; p<	:0.001			χ2=161.9; p<	<0.001			χ2=188.6; p	p<0.001								
(bit)         (28)         (30)         (31)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32)         (32) <t< td=""><td>thnicity</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></t<>	thnicity																				
One-online         18         35         37         16         42         54         13         13         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37         37	White	2182	83.9	8770	85.4	3392	85.0	12 194	85.4	1143	83.4	10 723	85.2	1084	84.8						
Undention300115116103633634634634634634634634614635614635634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634634 <td>Non-white</td> <td>118</td> <td>4.5</td> <td>385</td> <td>3.7</td> <td>166</td> <td>4.2</td> <td>540</td> <td>3.8</td> <td>71</td> <td>5.2</td> <td>471</td> <td>3.7</td> <td>72</td> <td>5.6</td>	Non-white	118	4.5	385	3.7	166	4.2	540	3.8	71	5.2	471	3.7	72	5.6						
24-5 tipe 10.6         2-6 tipe 10.6         2-6 tipe 10.6         2-6 tipe 10.6         2-6 tipe 10.6           Reference         3         2         2         2-6 tipe 10.6         2-6 tipe 10.6           Reference         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38         38 <th <="" colspan="6" t<="" td=""><td>Unknown</td><td>300</td><td>11.5</td><td>1116</td><td>10.9</td><td>433</td><td>10.8</td><td>1545</td><td>10.8</td><td>156</td><td>11.4</td><td>1393</td><td>11.1</td><td>122</td><td>9.5</td></th>	<td>Unknown</td> <td>300</td> <td>11.5</td> <td>1116</td> <td>10.9</td> <td>433</td> <td>10.8</td> <td>1545</td> <td>10.8</td> <td>156</td> <td>11.4</td> <td>1393</td> <td>11.1</td> <td>122</td> <td>9.5</td>						Unknown	300	11.5	1116	10.9	433	10.8	1545	10.8	156	11.4	1393	11.1	122	9.5
Anticipated         Set         Set <th< td=""><td>2 and p value</td><td></td><td></td><td><math>\chi^{2=5.1; p=0.}</math></td><td>26</td><td></td><td></td><td><math>\chi^{2=10.6; p=1}</math></td><td>0.03</td><td></td><td></td><td>χ2=16.0; p•</td><td>&lt;0.001</td><td></td><td></td></th<>	2 and p value			$\chi^{2=5.1; p=0.}$	26			$\chi^{2=10.6; p=1}$	0.03			χ2=16.0; p•	<0.001								
Exertimation381388998908834834610610510686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686868686 <th< td=""><td>Irea</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></th<>	Irea																				
Ext of regiated223971.20011.75161.2018.711.816412.716.917.716.613.0Methoding32432432553535413353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353535353 </td <td>East Midlands</td> <td>358</td> <td>13.8</td> <td>899</td> <td>8.8</td> <td>358</td> <td>9.0</td> <td>1255</td> <td>8.8</td> <td>146</td> <td>10.7</td> <td>1086</td> <td>8.6</td> <td>138</td> <td>10.8</td>	East Midlands	358	13.8	899	8.8	358	9.0	1255	8.8	146	10.7	1086	8.6	138	10.8						
Indention3241256618443811012588146107112589137137NorthEat3433535714937756535064535353NorthEat3401313397361437577565350645353SouthEat34013133973373514973273149734732143SouthEat3561337321431031461426473143734143SouthEat356133732143103143143143143143SouthEat236133732143103143143143143SouthEat237234103103103103103104103VectoRidends238731397313973134134133SouthEat2332543332543332645923143Job13206132012442442441011152Job14244242424242424124126Job14242424242424242424Job255233233242424	East of England	252	9.7	1200	11.7	516	12.9	1687	11.8	164	12.0	1469	11.7	166	13.0						
North field         34         595         57         149         37         756         53         50         55         52         63         52         63         52         63         52         63         53           North field         340         133         1389         136         133         138         136         133         138         143         139         134         139         134         139         134         139         134         136         134         138         143         136         143         136         143         134         134         136         134         136         134         136         134         136         134         136         134         136         134         136         134         136         134         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136         136 <td>London</td> <td>324</td> <td>12.5</td> <td>861</td> <td>8.4</td> <td>438</td> <td>11.0</td> <td>1262</td> <td>8.8</td> <td>146</td> <td>10.7</td> <td>1125</td> <td>8.9</td> <td>137</td> <td>10.7</td>	London	324	12.5	861	8.4	438	11.0	1262	8.8	146	10.7	1125	8.9	137	10.7						
Nontweat         347         133         035         198         706         171         2771         194         225         184         248         194         224         173           Southweat         360         131         1393         135         644         156         1961         139         147         173         143         143         123           Southweat         360         138         149         102         149         103         149         133         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         143         144         143	North East	88	3.4	585	5.7	149	3.7	756	5.3	50	3.6	654	5.2	68	5.3						
South feat34013113891356241561891130147173814.2163103South Mest358138146114.2142143143143143143143143South Mest356118104910.2144143143143143143143South Mest356118104910.2144143143143143143Vots Mest Member23814310.2144103113143143143South Mest356132102143103153154133144143143South Mest235143103152144105153154133143143143South Mest669557253253253253253253254254254154154South Mest669557253253253253253253253253253253253254254254254South Mest669557253253253253253253253253253253254254254South Mest3001531532541561561561561561561571541532541541541541541541	North West	347	13.3	2035	19.8	206	17.7	2777	19.4	252	18.4	2438	19.4	224	17.5						
SouthWest         38         146         142         468         117         192         137         138         101         1734         138         101         1734         138         101         110           West Midlands         306         118         009         02         449         109         110         724         126         149         149         169         113         104         149         149         149         149         169         116         126         116         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126         126	South East	340	13.1	1389	13.5	624	15.6	1981	13.9	201	14.7	1788	14.2	163	12.8						
Wet Midands         306         11.8         1049         10.2         4.3         10.9         10.7         10.5         13.0         10.4         14.7         11.5           Vackine & Hunber         227         87         72         74         2.23444; pc.001         7.2         2.444; pc.001         7.2         2.446; pc.001         7.2         2.466; pc.001         7.2         2.466; pc.001         7.2         2.47         2.47         2.46         2.47         2.47         2.46         2.47         2.46         2.47         2.46         2.46         2.47         2.46         2.47         2.46         2.47         2.46         2.47         2.46         2.47         2.46         2.47         2.46         2.44         2.41         2.44         2.44         2.44         2.44         2.44 <td< td=""><td>South West</td><td>358</td><td>13.8</td><td>1461</td><td>14.2</td><td>468</td><td>11.7</td><td>1962</td><td>13.7</td><td>138</td><td>10.1</td><td>1734</td><td>13.8</td><td>140</td><td>11.0</td></td<>	South West	358	13.8	1461	14.2	468	11.7	1962	13.7	138	10.1	1734	13.8	140	11.0						
Volchine R Humber         217         87         722         173         288         7.5         102         7.7         114         8.3         8.3         7.8         55         7.4           2 and p value $\chi = 2344$ , pc.001	West Midlands	306	11.8	1049	10.2	434	10.9	1497	10.5	159	11.6	1310	10.4	147	11.5						
2 and p due $\chi^2 = 344$ ; $p = 0.01$ $\chi^2 = 344$ ; $p = 0.01$ $\chi^2 = 1765$ ; $p = 0.01$ $\chi^2 = 1765$ ; $p = 0.01$ No $\chi^2 = 2344$ ; $p = 0.01$ $\chi^2 = 3363$ $\chi^2 = 332$ $\chi^2 = 1765$ ; $p = 0.01$ $\chi^2 = 333$ $\chi^2 = 333$ $\chi^2 = 333$ $\chi^2 = 7$ $\chi^2 = 7$ 1 - affluent       669 $\chi^2 = 7$ $\chi^2 = 333$ $\chi^2 = 7$ $\chi^2 = 7$ 2 $\chi^2 = 10$	Yorkshire & Humber	227	8.7	792	7.7	298	7.5	1102	7.7	114	8.3	983	7.8	95	7.4						
<b>10 10</b> 1-affluent       669       257       2641       257       1041       261       363       353       332       262       253       305       233         2       663       255       2533       253       1057       261       267       363       55       353       253       253       305       253       305       253       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       305       30	2 and p value			χ2=234.4; p<	c0.001			χ2=186.9; p<	<0.001			χ2=176.5; μ	p<0.001								
	DN																				
2 $663$ $25,5$ $253$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $16,7$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,6$ $20,7$ $20,7$ $4$ $40$ $17,7$ $161,7$ $15,7$ $20,1$ $20,6$ $20,6$ $20,4$ $20,6$ $20,4$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$ $20,7$	1—affluent	669	25.7	2641	25.7	1041	26.1	3691	25.8	319	23.3	3302	26.2	252	19.7						
3         508         19.5         2131         20.7         801         20.1         29.4         20.6         26.6         20.4         26.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.4         20.	2	663	25.5	2593	25.2	1067	26.7	3633	25.4	354	25.8	3264	25.9	305	23.9						
4         460         17.7         1613         15.7         629         15.8         24.3         15.7         219         16.0         19.1         15.2         250         19.6           5deprived         300         11.5         1293         12.6         453         11.4         1768         12.4         209         15.3         15.4         12.3         207         16.2           2 - deprived         300         11.5         1293         12.6         453         11.4         1768         12.4         209         15.3         15.4         12.3         207         16.2           2 and value         2         2         348         3.4         122         3.1         460         3.2         69         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5         5.5 <td>З</td> <td>508</td> <td>19.5</td> <td>2131</td> <td>20.7</td> <td>801</td> <td>20.1</td> <td>2944</td> <td>20.6</td> <td>269</td> <td>19.6</td> <td>2566</td> <td>20.4</td> <td>264</td> <td>20.7</td>	З	508	19.5	2131	20.7	801	20.1	2944	20.6	269	19.6	2566	20.4	264	20.7						
5-deprind         30         11.5         12.4         23         12.4         20         15.3         15.4         12.3         207         16.2           2 and value         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2         2 </td <td>4</td> <td>460</td> <td>17.7</td> <td>1613</td> <td>15.7</td> <td>629</td> <td>15.8</td> <td>2243</td> <td>15.7</td> <td>219</td> <td>16.0</td> <td>1911</td> <td>15.2</td> <td>250</td> <td>19.6</td>	4	460	17.7	1613	15.7	629	15.8	2243	15.7	219	16.0	1911	15.2	250	19.6						
2 and p value       2 and p value<	5	300	11.5	1293	12.6	453	11.4	1768	12.4	209	15.3	1544	12.3	207	16.2						
oute to diagnosis           R         146         5.6         3.4         122         3.1         460         3.2         62         4.5         409         3.2         66         5.3           P         931         35.8         1498         40.9         1804         45.2         5977         41.9         602         4.3         5296         4.1         541         42.3           R         0         0.0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0	2 and p value			χ2=14.3; p<0	.07			$\chi^{2=20.7; p=0}$	0.008			χ2=58.6; p<	<0.001								
R         146         5.6         348         3.4         122         3.1         460         3.2         62         4.5         409         3.2         66         5.3           P         931         35.8         4198         40.9         1804         45.2         5977         41.9         602         43.9         5296         42.1         541         42.3           Gening         0         0.0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0	loute to diagnosis																				
IP         931         35.8         4198         40.9         1804         45.2         5971         41.9         602         43.9         5296         42.1         541         42.3           orening         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0	R	146	5.6	348	3.4	122	3.1	460	3.2	62	4.5	409	3.2	99	5.2						
αcening         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0.0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0         0	- E	931	35.8	4198	40.9	1804	45.2	5977	41.9	602	43.9	5296	42.1	541	42.3						
wo-week referral 725 27.9 4115 40.1 1415 35.5 5578 39.1 492 35.9 4884 38.8 453 35.4 Elective referral 288 11.1 970 9.4 364 9.1 1355 9.5 115 8.4 1184 9.4 109 8.5	icreening	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0						
Elective referral         288         11.1         970         9.4         364         9.1         1355         9.5         115         8.4         1184         9.4         109         8.5	wo-week referral	725	27.9	4115	40.1	1415	35.5	5578	39.1	492	35.9	4884	38.8	453	35.4						
	Elective referral	288	11.1	970	9.4	364	9.1	1355	9.5	115	8.4	1184	9.4	109	8.5						

Table 5 Continued														
Type of experience	5	VS name		Conta	Icting CNS			Speakin	ig to CNS			Understar	nding CNS	
Level of care experience	Not given* (n=2600)		Excellent (n=10 271) (7)	2.0%)	Non-excelle (n=3991) (2	nt 8.0%)	Excellent (n=14 279) (9	91.2%)	Non-excel (n=1370)	lent (8.8%)	Excellent (n=12 587)	(90.8%)	Non-exce (n=1278)	llent (9.2%)
Variable	c	%		%		%	z	%	z	%	=	%	_	%
Unknown	510	19.6	640	6.2	286	7.2	606	6.4	66	7.2	814	6.5	109	8.5
$\chi^2$ and p value			χ2=608.9; p<0	.001			χ2=608.7; p<	0.001			χ2=566.6; p	<0.001		
Stage														
_	310	11.9	1554	15.1	581	14.6	2152	15.1	196	14.3	1848	14.7	155	12.1
=	239	9.2	1635	15.9	682	17.1	2326	16.3	197	14.4	2076	16.5	195	15.3
=	154	5.9	1273	12.4	495	12.4	1777	12.4	151	11.0	1579	12.5	143	11.2
N	281	10.8	1085	10.6	404	10.1	1443	10.1	177	12.9	1286	10.2	168	13.1
Unknown	1616	62.2	4724	46.0	1829	45.8	6581	46.1	649	47.4	5798	46.1	617	48.3
$\chi 2$ and p value			χ2=290.4; p<0	.001			χ2=298.4; p<	0.001			χ2=297.7; p	<0.001		
All $\chi^2$ tested for differences betw *Patients who were not given a C	een three groups (e .NS name were aske	excellent, non-excelle	ent and not having CN experience with the c	S) across all variabl other three CNS que	es in the table. stions (contacting C	NS, speaking to CN	S and understanding	CNS).						
FR amargancy room. GP ganaral i	nractitioner-IMD In	victors of Multiple De	nrivation											

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 6HR of deal	ath for all patients w	ith cance	er according to t	heir care	experience with	cancer o	linical nurse spe	ecialists (	CNS)
		Mode	1	Model	2	Mode	3	Sensit	ivity analysis*
Experience type	Adjustments	Age a	nd sex	Age, s	ex and stage	All co	variables	All cov	variables
Colorectal cancer	Experience level	HR	95% <b>CI</b>	HR	95% <b>CI</b>	HR	95% <b>CI</b>	HR	95% <b>CI</b>
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
Lung cancer									
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
Breast cancer									
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
Prostate cancer									
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 anticancer 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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**Contributors** SAA, ML and ED designed the study and decided the analytical approach. SAA was responsible for extracting and analysing the data. All authors (SAA, ML, JR, MB and ED) contributed to the interpretation of the results and the writing of this manuscript. SAA is the the guarantor, and accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish

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carry out surveillance using the data they collect on all patients with cancer under section 251 of the NHS Act 2006. SAA (the lead author) was a PhD student at King's College London and has been guaranteed a studentship agreement with the National Cancer Registration and Analysis Service at Public Health England, and therefore, separate ethical approval was not required for this study. All methods were carried out in accordance with relevant guidelines and regulations.

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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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