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

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

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

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

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

KEYWORDS
cancer, clinical nurse specialist, patient experience, survey

INTRODUCTION

Patient experience is widely considered to be an important aspect of cancer care quality (The Independent Cancer Taskforce, 2015; Wolf, 2018). Previous research in England and Europe has shown hospital care quality varies in relation to inpatient nurse staffing and education and improves with higher levels of each across many care settings (Aiken et al., 2012, 2014; Keogh, 2017; Rafferty et al., 2007). In cancer care, clinical nurse specialists (CNS) play a key role in ensuring that high-quality information is provided to patients, coordinating
their care, as well as assessing needs and providing emotional support (National Cancer Action Team, 2010; Stewart et al., 2020). Findings from the National Cancer Patient Experience Survey (CPES) 2010 show English cancer patients’ experiences of care coordination and emotional support are better in NHS hospitals with large numbers of CNS (Griffiths et al., 2013).

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

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

2 | METHODOLOGY

2.1 | Study population and data

In this population-based cohort study, we extracted data on all individuals with invasive colorectal (C18–20), lung (C33–34), female breast (C50) and prostate (C61) cancers (International Classification of Diseases [Version 10] [ICD-10]) who responded to CPES 2010–2014 from CPES-NCRAS dataset (n = 114,898). CPES has been conducted by Quality Health, on behalf of NHS England, for the years 2010–2019 and contains around 70 questions covering many aspects of cancer care experience. Patients who have been discharged from NHS inpatient and day-case admission for cancer are invited by post to complete the survey, with two reminders being sent to non-responders (Quality Health, 2019). The response rate was stable (64–68%) between 2010 and 2014 (Quality Health, 2019). The CPES-NCRAS dataset is linked based on patient NHS number and tumour site, using the ICD-10 3/4-digit code (Alessy, Lüchtenborg, & Davies, 2019b).

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

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

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

Data on sex, age, geographical region of residence, deprivation of area of residence and TNM disease stage were available in the cancer registry dataset for all patients with cancer. For lung cancer, we extracted additional stage information from the National Lung Cancer Audit (NLCA) (n = 2888), which includes more detailed clinical and multidisciplinary team data returned by the audit and extracted from hospital data feeds to NCRAS (Henson et al., 2019). Although ethnicity data are collected in CPES, the response categories were slightly different in each survey year. We therefore used self-assigned ethnicity information from cancer registration data which is derived from Hospital
Episode Statistics (HES) data (Henson et al., 2019). Due to the limited numbers in each ethnic category, we collapsed the 16-group classification into two categories: all White background (i.e., White British, Irish and other White background) and non-White.

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

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

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

**FIGURE 1** Study participant flow chart
Chi-squared tests were performed to estimate the differences between groups. To assess whether being given the name of a CNS influenced patients’ experiences of being involved in treatment decisions, their feeling about care coordination, being treated with respect and dignity and their overall care experience with NHS cancer care, we compared responses between patients who reported being given the name of a CNS and those who did not using univariable and multivariable logistic regression analyses. After adjusting for these variables in univariable and multivariable logistic regression analyses, being given the name of a CNS was strongly associated with reporting better experiences across all aspects of care (being involved in treatment decisions, perceiving care as more coordinated, reporting being treated with respect and dignity, and reporting a positive overall experience with NHS care) for all cancers (Table 4).

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

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

4 | DISCUSSION

4.1 | Summary of main findings

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

4.2 | Comparison with other findings

Few large population studies of the role of the CNS in cancer care have considered its possible influence across the cancer care pathway.
### TABLE 2  Demographic and cancer stage at diagnosis for CPES responders with colon, lung, breast and prostate cancers according to reporting been given the name of a CNS

| Variable                  | Colorectal cancer | Lung cancer | Breast cancer | Prostate cancer |
|---------------------------|-------------------|-------------|---------------|-----------------|
| Reporting被 given a CNS name | Yes | % | No | % | Yes | % | No | % | Yes | % | No | % | Yes | % | No | % | Yes | % | No | % |
| N | 22,716 | 90.5 | 2376 | 9.5 | 11,449 | 92.2 | 962 | 7.8 | 41,681 | 93.9 | 2718 | 6.1 | 16,405 | 86.4 | 2578 | 13.6 |
| Sex                      | Male | 13,514 | 59.5 | 1367 | 57.5 | 6178 | 54.0 | 505 | 52.5 | – | – | – | – | 16,405 | 100 | 2578 | 100 |
|                          | Female | 9202 | 40.5 | 1009 | 42.5 | 5271 | 46.0 | 457 | 47.5 | 41,681 | 100 | 2718 | 100 | – | – | – |
| Age group                | <45 | 707 | 3.1 | 74 | 3.1 | 138 | 1.2 | 20 | 2.1 | 5690 | 13.7 | 470 | 17.3 | 30 | 0.2 | 4 | 0.2 |
|                          | 45–59 | 3924 | 17.3 | 448 | 18.9 | 1932 | 16.9 | 159 | 16.5 | 16,494 | 39.6 | 1188 | 43.7 | 2517 | 15.3 | 333 | 12.9 |
|                          | 60–74 | 11,966 | 52.7 | 1118 | 47.1 | 6918 | 60.4 | 525 | 54.6 | 15,402 | 37.0 | 811 | 29.8 | 11,093 | 67.6 | 333 | 12.9 |
|                          | 75–99 | 6119 | 26.9 | 736 | 31.0 | 2461 | 21.5 | 258 | 26.8 | 4095 | 9.8 | 249 | 9.2 | 2765 | 16.9 | 677 | 26.3 |
| Ethnicity                | White | 19,969 | 87.9 | 2059 | 86.7 | 10,290 | 89.9 | 827 | 86.0 | 34,759 | 83.4 | 2265 | 83.3 | 13,978 | 85.2 | 2163 | 83.9 |
|                          | Non-White | 650 | 2.9 | 73 | 3.1 | 299 | 2.6 | 39 | 4.1 | 2038 | 4.9 | 162 | 6.0 | 635 | 3.9 | 116 | 4.5 |
|                          | Unknown | 2097 | 9.2 | 244 | 10.3 | 860 | 7.5 | 96 | 10.0 | 4884 | 11.7 | 291 | 10.7 | 1792 | 10.9 | 299 | 11.6 |
| Area                     | East Midlands | 2176 | 9.6 | 292 | 12.3 | 1089 | 9.5 | 100 | 10.4 | 3755 | 9.0 | 445 | 16.4 | 1478 | 9.0 | 355 | 13.8 |
|                          | East of England | 2763 | 12.2 | 260 | 10.9 | 1318 | 11.5 | 102 | 10.6 | 4957 | 11.9 | 236 | 8.7 | 1975 | 12.0 | 248 | 9.6 |
|                          | London | 2140 | 9.4 | 190 | 8.0 | 1143 | 10.0 | 121 | 12.6 | 4732 | 11.4 | 311 | 11.4 | 1480 | 9.0 | 322 | 12.5 |
|                          | North East | 1431 | 6.3 | 107 | 4.5 | 973 | 8.5 | 46 | 4.8 | 2417 | 5.8 | 71 | 2.6 | 837 | 5.1 | 88 | 3.4 |
|                          | North West | 2833 | 12.5 | 246 | 10.4 | 1554 | 13.6 | 163 | 16.9 | 4693 | 11.3 | 181 | 6.7 | 3159 | 19.3 | 347 | 13.5 |
|                          | South East | 3658 | 16.1 | 374 | 15.7 | 1437 | 12.6 | 127 | 13.2 | 6600 | 15.8 | 504 | 18.5 | 2296 | 14.0 | 337 | 13.1 |
|                          | South West | 2998 | 13.2 | 229 | 9.6 | 1228 | 10.7 | 79 | 8.2 | 5077 | 12.2 | 398 | 14.6 | 2170 | 13.2 | 353 | 13.7 |
|                          | West Midlands | 2549 | 11.2 | 387 | 16.3 | 1162 | 10.1 | 127 | 13.2 | 4819 | 11.6 | 428 | 15.7 | 1730 | 10.5 | 303 | 11.8 |
|                          | Yorkshire and the Humber | 2168 | 9.5 | 291 | 12.2 | 1545 | 13.5 | 97 | 10.1 | 4631 | 11.1 | 144 | 5.3 | 1280 | 7.8 | 225 | 8.7 |

χ² and p value

- Colorectal cancer: χ² = 34; p = 0.06
- Lung cancer: χ² = 0.7; p = 0.3
- Breast cancer: χ² = 71.8; p < 0.001
- Prostate cancer: χ² = 133.6; p < 0.001

(Continues)
| Reporting being given a CNS name | Colorectal cancer | Lung cancer | Breast cancer | Prostate cancer |
|---------------------------------|-------------------|-------------|---------------|----------------|
| Variable                        | Yes    | %     | No    | %     | Yes    | %     | No    | %     | Yes    | %     | No    | %     | Yes    | %     | No    | %     |
| IMD                             |        |       |       |       |        |       |       |       |        |       |       |       |        |       |       |       |
| 1 (most affluent)               | 5356   | 23.6  | 508   | 21.4  | 1789   | 15.6  | 168   | 17.5  | 9630   | 23.1  | 692   | 25.5  | 4230   | 25.8  | 664   | 25.8  |
| 2                               | 5622   | 24.7  | 600   | 25.3  | 2318   | 20.2  | 174   | 18.1  | 10,033 | 24.1  | 620   | 22.8  | 4204   | 25.6  | 659   | 25.6  |
| 3                               | 4822   | 21.2  | 505   | 21.3  | 2363   | 20.6  | 195   | 20.3  | 8984   | 21.6  | 577   | 21.2  | 3360   | 20.5  | 503   | 19.5  |
| 4                               | 3962   | 17.4  | 426   | 17.9  | 2436   | 21.3  | 204   | 21.2  | 7362   | 17.7  | 503   | 18.5  | 2571   | 15.7  | 455   | 17.6  |
| 5 (most deprived)              | 2954   | 13.0  | 337   | 14.2  | 2543   | 22.2  | 221   | 23.0  | 5672   | 13.6  | 326   | 12.0  | 2040   | 12.4  | 297   | 11.5  |

**χ² and p value**

| Route to diagnosis | Colorectal cancer | Lung cancer | Breast cancer | Prostate cancer |
|--------------------|-------------------|-------------|---------------|----------------|
| ER                 | 2709   | 11.9  | 607   | 25.5  | 1422   | 12.6  | 125   | 13.0  | 493    | 1.2   | 67    | 2.5   | 553    | 3.4   | 146   | 5.7   |
| GP                 | 5638   | 24.8  | 558   | 23.5  | 2883   | 25.2  | 263   | 27.3  | 2931   | 7.0   | 286   | 10.5  | 6868   | 41.9  | 917   | 35.6  |
| Screening          | 3322   | 14.6  | 164   | 6.9   | –      | –     | –     | –     | 12,457 | 29.9  | 609   | 22.4  | –      | –     | –     | –     |
| 2-week referral   | 8263   | 36.4  | 700   | 29.5  | 5272   | 46.0  | 358   | 37.2  | 22,867 | 54.9  | 1277  | 47.0  | 6381   | 38.9  | 723   | 28.0  |
| Elective referral | 2427   | 10.7  | 265   | 11.2  | 1707   | 14.9  | 195   | 20.3  | 852    | 2.0   | 79    | 2.9   | 1545   | 9.4   | 282   | 10.9  |
| Unknown            | 357    | 1.6   | 82    | 3.5   | 145    | 1.3   | 21    | 2.2   | 2081   | 5.0   | 400   | 14.7  | 1058   | 6.4   | 510   | 19.8  |

**χ² and p value**

| Stage | Colorectal cancer | Lung cancer | Breast cancer | Prostate cancer |
|-------|-------------------|-------------|---------------|----------------|
| I     | 1945   | 8.6   | 142   | 6.0   | 1823   | 15.9  | 262   | 27.2  | 11,760 | 28.2  | 559   | 20.6  | 2499   | 15.2  | 305   | 11.8  |
| II    | 3958   | 17.4  | 330   | 13.9  | 1478   | 12.9  | 112   | 11.6  | 13,258 | 31.8  | 790   | 29.1  | 2624   | 16.0  | 237   | 9.2   |
| III   | 5677   | 25.0  | 489   | 20.6  | 3396   | 29.7  | 206   | 21.4  | 3727   | 8.9   | 237   | 8.7   | 2012   | 12.3  | 154   | 6.0   |
| IV    | 3076   | 13.5  | 465   | 19.6  | 3777   | 33.0  | 237   | 24.6  | 1221   | 2.9   | 169   | 6.2   | 1690   | 10.3  | 280   | 10.9  |
| Unknown| 8060   | 35.5  | 950   | 40.0  | 975    | 8.5   | 145   | 15.1  | 11,715 | 28.1  | 963   | 35.4  | 7580   | 46.2  | 1602  | 62.1  |

**χ² and p value**

**Abbreviations:** CNS, clinical nurse specialist; ER, emergency presentation; GP, general practitioner; IMD, indices of multiple deprivation; χ², chi-squared test, with unknown ethnicity, route to diagnosis and stage as a category.

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

| Care aspect | Level of experience | Reporting being given a CNS name | Involvement in treatment decision | Treatment with respect and dignity | Overall care coordination | Overall care experience |
|-------------|---------------------|---------------------------------|----------------------------------|-----------------------------------|--------------------------|------------------------|
|             | Non-excellent       | Excellent                       | Non-excellent                    | Excellent                         | Non-excellent            | Excellent              |
|             | N       | %     | N   | %    | N   | %     | N   | %    | N   | %    |
| Colorectal cancer | 5688 25.0 | 17,036 75.0 | 3729 18.6 | 16,313 81.4 | 4061 16.9 | 19,925 83.1 | 8052 44.3 | 10,143 55.7 |
| No | 951 45.7 | 1128 54.3 | 488 29.8 | 1152 70.2 | 660 29.2 | 1602 70.8 | 1041 63.1 | 609 36.9 |
| Yes | 4737 22.9 | 15,908 77.1 | 3241 17.6 | 15,161 82.4 | 3401 15.7 | 18,323 84.3 | 7011 42.4 | 9534 57.6 |
| *χ² and p value* | *χ² = 523.1; p < 0.001* | *χ² = 146.6; p < 0.001* | *χ² = 266.3; p < 0.001* | *χ² = 260.9; p < 0.001* |
| Lung cancer | 3057 26.9 | 8289 73.1 | 1112 16.4 | 5672 83.6 | 2510 21.1 | 9396 78.9 | 4071 43.9 | 5204 56.1 |
| No | 367 44.3 | 462 55.7 | 134 23.3 | 440 76.7 | 291 31.9 | 682 68.1 | 398 61.5 | 249 38.5 |
| Yes | 2690 25.6 | 7827 74.4 | 978 15.7 | 5232 84.3 | 2219 20.2 | 8774 79.8 | 3673 42.6 | 4955 57.4 |
| *χ² and p value* | *χ² = 136.4; p < 0.001* | *χ² = 22.1; p < 0.001* | *χ² = 69.2; p < 0.001* | *χ² = 87.7; p < 0.001* |
| Breast cancer | 10,850 26.1 | 30,653 73.9 | 5603 15.7 | 29,974 84.3 | 9297 21.5 | 33,881 78.5 | 13,119 40.5 | 19,277 59.5 |
| No | 1201 48.4 | 1282 51.6 | 486 27.7 | 1268 72.3 | 1006 38.2 | 1630 61.8 | 1236 64.2 | 688 35.8 |
| Yes | 9649 24.7 | 29,371 75.3 | 917 15.1 | 28706 84.9 | 8291 20.5 | 32,251 79.5 | 11,883 39.0 | 18,589 61.0 |
| *χ² and p value* | *χ² = 675.7; p < 0.001* | *χ² = 198.8; p < 0.001* | *χ² = 459.6; p < 0.001* | *χ² = 478.6; p < 0.001* |
| Prostate cancer | 4374 24.5 | 13,477 75.5 | 1320 15.0 | 7489 85.0 | 3142 17.4 | 14,911 82.6 | 6512 46.2 | 7588 53.8 |
| No | 935 40.1 | 1399 59.9 | 202 20.5 | 785 79.5 | 594 24.3 | 1854 75.7 | 1068 61.0 | 682 39.0 |
| Yes | 3439 22.2 | 12,078 77.8 | 1118 14.3 | 6704 85.7 | 2548 16.3 | 13,057 83.7 | 5444 44.1 | 6906 55.9 |
| *χ² and p value* | *χ² = 351.2; p < 0.001* | *χ² = 26.2; p < 0.001* | *χ² = 92.7; p < 0.001* | *χ² = 177.1; p < 0.001* |

Abbreviation: *χ²*, chi-squared test.

aThe total responses across the different questions are not the same because patients did not respond to all four questions. Further description on this can be found in Section 2.

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

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

### 4.3 | Strengths and limitations of the study

To our knowledge, this study is the first to use linked cancer experience and cancer registration data to examine the impact the role of the CNS makes on patients’ experiences across many aspects of cancer care. One strength of our study is the large sample size and the different cancer types studied. This allowed for detailed case-mix assessment of the role of the CNS across different aspects of cancer care in a diverse cancer population. We recognise our study has some limitations. First, studies using survey data are prone to recall bias. Some patients in this study may have reported not being given the name of a CNS when they had, or they may have mis-identified a ward nurse or a palliative care nurse as a CNS. This therefore might lead to an assumption that being given a CNS name, which is the independent variable in this study and reported by patients in CPES, is not an actual exposure to CNS allocation to cancer patients. Indeed, we had hypothesised that the CNS...
Comparison of the agreement between reporting been given the name of a CNS in CPES and indication of being assigned a CNS in the cancer registry data for lung cancer patients

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

*Kappa test did not include missing data.

*Very good agreement.

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

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

4.4 | Study implications

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

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

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

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CONFLICT OF INTERESTS

The authors declare no conflicts of interest. All authors have completed the ICMJE uniform disclosure form at http://www.icmje.org/doiDisclosure.pdf and declare no support from any organisation for coi_disclosure.pdf and declare no support from any organisation for completing the ICMJE uniform disclosure form at http://www.icmje.org/doiDisclosure.pdf and declare no support from any organisation for

DATA AVAILABILITY STATEMENT

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

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