

# Diagnostic route is associated with care satisfaction independently of tumour stage: Evidence from linked English Cancer Patient Experience Survey and cancer registration data

Tra My Pham<sup>a</sup>, Mayam Gomez-Cano<sup>b</sup>, Theodosia Salika<sup>a</sup>, Demian Jardel<sup>c</sup>, Gary A. Abel<sup>b</sup>, Georgios Lyratzopoulos<sup>a,d,\*</sup>

<sup>a</sup> Epidemiology of Cancer Healthcare and Outcomes (ECHO) Group, Department of Behavioural Science and Health, University College London, WC1E 7HB, London, UK

<sup>b</sup> University of Exeter Medical School (Primary Care), Smeall Building, St Luke's Campus, Exeter, EX1 2LU, UK

<sup>c</sup> Cancer Alliance Data, Evidence and Analysis Service (CADEAS), NHS England, Skipton House, 80 London Road, London, SE1 6LH, UK

<sup>d</sup> Cambridge Centre for Health Services Research, Institute of Public Health, University of Cambridge, Cambridge, CB2 0SR, UK

## ARTICLE INFO

**Keywords:**  
Cancer  
Disparities  
Patient  
Survey  
Diagnosis  
Stage

## ABSTRACT

**Background:** Whether diagnostic route (e.g. emergency presentation) is associated with cancer care experience independently of tumour stage is unknown.

**Methods:** We analysed data on 18 590 patients with breast, prostate, colon, lung, and rectal cancers who responded to the 2014 English Cancer Patient Experience Survey, linked to cancer registration data on diagnostic route and tumour stage at diagnosis. We estimated odds ratios (OR) of reporting a negative experience of overall cancer care by tumour stage and diagnostic route (crude and adjusted for patient characteristic and cancer site variables) and examined their interactions with cancer site.

**Results:** After adjustment, the likelihood of reporting a negative experience was highest for emergency presenters and lowest for screening-detected patients with breast, colon, and rectal cancers (OR versus two-week-wait 1.51, 95% confidence interval [CI] 1.24–1.83; 0.88, 95% CI 0.75–1.03, respectively). Patients with the most advanced stage were more likely to report a negative experience (OR stage IV versus I 1.37, 95% CI 1.15–1.62) with little confounding between stage and route, and no evidence for cancer-stage or cancer-route interactions.

**Conclusions:** Though the extent of disease is strongly associated with ratings of overall cancer care, diagnostic route (particularly emergency presentation or screening detection) exerts important independent effects.

## 1. Introduction

A positive experience of cancer care is increasingly understood to represent a key aspect of high quality cancer services. [1,2] In several countries, this realisation has led to initiatives supporting the measurement of the experience of cancer patients through patient surveys. [3–8] While those surveys chiefly focus on the public reporting of hospital scores of patients' satisfaction with cancer care, understanding person-level variation is also important.

Women, younger and very old, and ethnic minority patients report worse cancer care experiences. [9,10] Additionally, certain cancer sites, particularly those with generally poor survival such as lung cancer, are associated with worse than average experiences (and vice versa for cancer sites with good prognosis, such as breast cancer) [9]. In spite of

evidence on socio-demographic and cancer site variation in patient experience, there is little appreciation of how disease factors (including tumour stage at diagnosis) are associated with the experience of cancer care. Such influences are indeed plausible, as demonstrated by previous research showing that patients with different types of cancer reported variable experiences even when treated by the same specialty. [11] Diagnostic route [12,13], denoting whether the cancer was diagnosed thorough screening detection, or in an elective or emergency care context, has prognostic implications and may also be important for patient experience. Previously examined associations between diagnostic route and cancer care experience were confined to a single cancer (colorectal) and did not account for potential confounding of the examined associations by tumour stage. [14]

We therefore aimed to examine whether in patients with common

\* Corresponding author at: Professor of Cancer Epidemiology, Epidemiology of Cancer Healthcare and Outcomes (ECHO) Group, Department of Behavioural Science and Health, University College London, 1-19 Torrington Place, London, WC1E 7HB, UK.

E-mail address: [y.lyratzopoulos@ucl.ac.uk](mailto:y.lyratzopoulos@ucl.ac.uk) (G. Lyratzopoulos).

<https://doi.org/10.1016/j.canep.2019.04.011>

Received 29 October 2018; Received in revised form 8 March 2019; Accepted 26 April 2019

Available online 30 May 2019

1877-7821/ © 2019 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license

(<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

cancers diagnostic route and tumour stage at diagnosis are independently associated with differential evaluation of cancer care experience.

## 2. Methods

### 2.1. Data source

We analysed anonymous data from responders to the 2014 English Cancer Patient Experience Survey (CPES), [3] a postal survey of patients aged 16 years and older who were treated for cancer in English National Health Service (NHS) hospitals during the period September–November 2013. The survey was commissioned by NHS England and provided by Quality Health. Following vital status checks, patients were sent a survey questionnaire by post, with up to two reminders for non-responders. Of the 109 760 surveyed patients, 70 141 responded to the survey (response rate = 64%).

### 2.2. Variables

**Outcome.** We examined responses to the survey question 70: ‘Overall, how would you rate your care?’, with five possible informative response categories of ‘Excellent / Very good / Good / Fair / Poor’. Responses were dichotomised into two broad categories defined as ‘positive’ (Excellent - Very good) and ‘negative’ (all other response options) ratings, consistent with how this item is reported publicly. [3]

**Main exposures.** The exposures of primary interest were tumour stage at diagnosis and diagnostic route. Information on these two variables was provided by linkage of the 2014 CPES responders’ sample to the cancer registration data, carried out by the Public Health England National Cancer Registration and Analysis Services (PHE NCRAS). [15–17] Data were linked deterministically on the basis of matching NHS patient numbers and relevant International Classification of Disease (ICD)-10 diagnosis codes [18], taking into account relevant diagnosis time windows. [16]

Diagnostic route refers to care pathways leading to the diagnosis of cancer. It is derived algorithmically (by PHE NCRAS) linking together cancer registration, Hospital Episode Statistics, screening, and Cancer Waiting Times data. [12] We used a five-category definition of diagnostic route, comprising the following [12,14].

- **Emergency presentation:** cancer diagnosis soon after any of emergency hospital admission, attendance at the Accident and Emergency department, emergency GP referral or emergency between-hospital transfer;
- **Urgent primary to secondary care referral for suspected cancer (also known as ‘two-week-wait’ referral):** patients are to be assessed by specialist hospital services within two weeks;
- **Elective primary to secondary care referral:** primary care referral other than through the two-week-wait route where patients attend routine (non-urgent) out-patient appointments;
- **Screening detection:** breast, or colon/rectal cancer diagnosis following participation in NHS screening programmes.
- **Other routes:** not described above.

Tumour stage at diagnosis is based on the relevant field of the English cancer registration system and is assigned by registrars based on information on clinical, pathology, and imaging records. For the analysis, tumour stage was defined as stages I (least advanced) to IV (most advanced)<sup>13</sup>. A small number of stage-0 patients were also treated as having stage-I tumours.

**Other covariates.** We also considered the responders’ age group (<55, 55–64, 65–74, 75+ years old), sex, and deprivation status

(quintiles 1 to 5, from least to most deprived), based on cancer registration data. For deprivation status, the population-weighted quintile of the income domain from the Indices of Multiple Deprivation (IMD) 2015 [19] was derived by assigning each patient to the deprivation category of their Lower Super Output Areas using the postcode of residence at the time of diagnosis. Patients’ cancer diagnoses were recorded using the ICD-10 diagnosis codes [18] based on cancer registration data.

### 2.3. Sample derivation

We a priori restricted our analyses to survey responders who indicated that they had been treated for cancer in the last year (using responses to question 76: ‘How long is it since you were first treated for this cancer?’), and patients with the five most common sites (breast, prostate, lung, colon, and rectal cancer). In the context of relatively high data completeness, we excluded from subsequent analyses responders with missing information on the outcome (response to question 70), tumour stage, diagnostic route, and patient characteristic variables.

### 2.4. Statistical analysis

We first calculated the crude proportions of reporting a negative experience of overall cancer care by diagnostic route and tumour stage. Subsequently, we used logistic regression models to examine the associations of overall cancer care rating with diagnostic route and tumour stage. We obtained (i) the unadjusted odds ratios (OR) of reporting a negative experience for diagnostic route or tumour stage; (ii) the adjusted ORs for either diagnostic route or tumour stage (in different models), conditional on patient characteristic and cancer site variables; and (iii) the adjusted ORs for both diagnostic route and tumour stage in the same model, conditional on patient characteristic and cancer site variables. In the final multivariable logistic regression model with both diagnostic route and tumour stage, we further examined pairwise interactions of each of these two variables with cancer site. All analyses were conducted in Stata v15.2 [20].

## 3. Results

In total, there were 21 934 patients with a diagnosis of one of the five studied cancers (breast, prostate, lung, colon, rectal) who had been treated in the last year. After exclusions due to missing data, the analysis sample comprised 18 590 responders (Fig. 1). Across cancer sites,

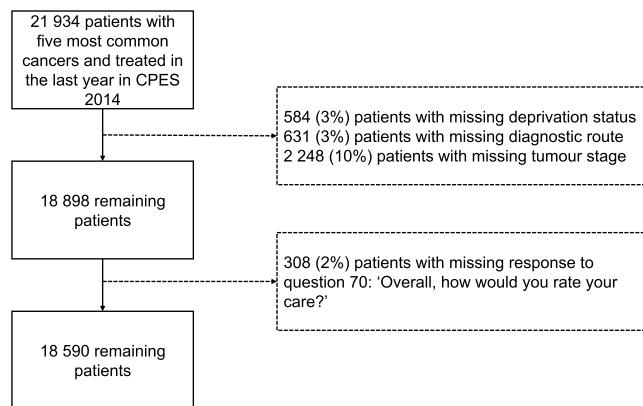


Fig. 1. Analysis sample derivation. CPES: Cancer Patient Experience Survey.

there were associations between tumour stage and diagnostic route, with stage IV being generally more frequent among emergency presenters and stage I among screening-detected patients (with breast, colon, and rectal cancer) (Appendix 1). There was large variation in both tumour stage and diagnostic route by patient characteristic variables and cancer site (Appendix 2).

The percentage of patients reporting a negative experience of overall cancer care was 10% (Table 1). Table 1 and Fig. 2 present the frequencies and percentages, as well as crude and adjusted odds ratios of a negative rating of overall cancer care by tumour stage and diagnostic route, as well as other patient characteristic and cancer site variables.

Overall, the younger and the very old patients, those living in more deprived areas, and those with prostate cancer were more likely to report a negative experience of cancer care (Table 1).

In fully adjusted analysis (including patient characteristic, cancer site, tumour stage, and diagnostic route variables) younger patients (OR < 55 vs 65–74 years old 1.58, 95% confidence interval [CI] 1.37–1.83); women (OR female vs male 1.51, 95% CI 1.29–1.76); and those living in more deprived areas (OR deprivation quintile 5 vs 1 1.50, 95% CI 1.28–1.77) had a higher likelihood of reporting a negative experience of overall care. There was some variation by cancer site, with breast cancer having the lowest and prostate cancer the highest likelihood of reporting a negative rating of overall care (Table 1, Fig. 2). Comparing the results from unadjusted and adjusted analyses we observed a similar overall pattern of variation, though this comparison indicated a substantial amount of confounding between sex and cancer site.

In the same adjusted model, tumour stage and diagnostic route were (independently of each other) associated with satisfaction ratings of overall cancer care. Patients diagnosed with stage IV tumours were most likely to report an overall negative experience of their care (OR stage IV vs stage I 1.37, 95% CI 1.15–1.62), as were those diagnosed through an emergency presentation (OR emergency vs two-week-wait referral 1.51, 95% CI 1.24–1.83). Patients diagnosed through an elective (*i.e.* not two-week-wait) referral were also more likely to report a negative experience than those diagnosed through screening or two-week-wait referral (OR elective vs two-week-wait referral 1.24, 95% CI 1.09–1.43). Screening detected patients (with breast, colon, and rectal cancers) had a lower risk of reporting a negative experience of their care than those diagnosed via other routes (OR screening vs two-week-wait 0.88, 95% CI 0.75–1.03). Comparing the fully adjusted model to the one which excludes diagnostic route shows that there was only minor attenuation of the effect associated with tumour stage at diagnosis when adjusting for diagnostic route (*e.g.* OR for stage IV vs I decreased from 1.44 to 1.37). Similarly, there was only a small attenuation in the effect of diagnostic route when adjusting for stage (*e.g.* OR for emergency presentation vs two-week-wait referral decreased from 1.60 to 1.51).

In additional analyses, there was no evidence for pairwise interactions between cancer site and either tumour stage (*p*-value = 0.117), or diagnostic route (*p*-value = 0.628) (Appendix 3). In other words, there was no evidence that the associations between ratings of overall cancer care and either tumour stage or diagnostic route varied between patients with the studied cancers.

## 4. Discussion

### 4.1. Summary of findings

Among patients with breast, prostate, lung, colon, and rectal cancers, emergency presentation, elective referral route and stage-IV tumours at diagnosis were associated with a higher likelihood of reporting a negative experience of overall care, after adjusting for other patient characteristic and cancer site variables. Although there was evidence that some of the effect of stage at diagnosis operated through diagnostic route and vice-versa, the magnitude of this mediation was

small and the two variables are associated with ratings of overall care independently of each other.

### 4.2. Strengths and limitations

Our analyses were based on data from a large nationwide sample of cancer patients with high response rate – representing the largest available collection of patient experience data in cancer patients. Information on tumour stage and diagnostic route was provided by linkage to population-based datasets, which enabled us to examine their associations with overall cancer care experience ratings. We were able to adjust our principal findings (with regard to associations with tumour stage and diagnostic route) for a range of patient factors, including age group, sex, deprivation, and cancer site, which are known to be associated with patient experience. [9,21,22] The overall completeness of the outcome and exposure variables in our analysis sample was high.

The survey (CPES) responders were patients recently treated for cancer in NHS hospitals, a patient population with certain compositional differences compared with incident or prevalent cancer cases. [23] These compositional differences arise from differences in survival in patient groups with different prognosis, both regarding patients with different cancers (*e.g.* resulting in a relative ‘deficit’ of responders with lung or pancreatic cancers, compared with a relative ‘excess’ of responders with breast cancer or melanoma) or between patient subgroups with the same cancer. Further, differential non-response (with men, younger and very old patients, more deprived, and ethnic minority patients being less likely to respond), and differential treatment patterns and duration also result in compositional differences between patient survey responders and other populations of cancer patients [23]. Relatedly, as patients diagnosed at advanced stages or through an emergency presentation had a higher risk of early mortality [24], they were under-represented in patient surveys. While these considerations may suggest that our analyses have underestimated the overall prevalence of negative ratings of care, such differences are unlikely to have substantially biased the estimates of associations. Additionally, the fact that CPES responders consisted of a special population (cancer survivors with recent hospital treatment) needs to be borne in mind when interpreting the findings.

Given the public reporting conventions for this survey, we dichotomised the outcome (*i.e.* overall satisfaction with care) in our analysis. Future work may explore alternative parameterisations for analysing this item.

### 4.3. Comparisons with existing evidence

We were not aware of previous studies that characterise associations between reported patient experience of cancer care and both tumour stage at diagnosis and diagnostic route considered together. With regard to examining associations between cancer patient experience and tumour stage, a recent Dutch study assessed the level of satisfaction with hospital care among patients with advanced cancer and found no evidence for an association between a surrogate of stage (estimated life expectancy in months) and general satisfaction with care. [10] Similarly, a US study on ratings of quality of cancer care among a sample of lung and colorectal cancer patients indicated no association between tumour stage and overall ratings of cancer care in the adjusted analysis. [26] It is worth noting that the first of these studies had a very small sample size (*N* = 105) and that both studies adjusted for health status which is likely to mediate the effect of tumour stage at diagnosis.

With regard to examining associations between cancer patient experience and diagnostic route, a previous study [14] examined the impact of diagnostic route (without adjustment for stage at diagnosis) on reported experience of key aspects of cancer care (not including satisfaction with overall cancer care) among colorectal cancer patients who responded to the 2010 CPES; screen-detected patients were found

**Table 1**  
Frequency and percentage, crude and adjusted odds ratio of reporting a negative experience of overall cancer care for key exposures (tumour stage at diagnosis and diagnostic route), patient characteristic and cancer site variables, N = 18 590.

Variable	Summary			Unadjusted			Adjusted for tumour stage and socio-demographic variables <sup>a</sup>			Adjusted for diagnostic route and socio-demographic variables <sup>b</sup>			Adjusted for tumour stage, diagnostic route, and socio-demographic variables <sup>c</sup>		
	Frequency of negative rating	%	Frequency total	OR <sup>d</sup>	95% CI <sup>e</sup>	p <sup>f</sup>	OR <sup>d</sup>	95% CI <sup>e</sup>	p <sup>f</sup>	OR <sup>d</sup>	95% CI <sup>e</sup>	p <sup>f</sup>	OR <sup>d</sup>	95% CI <sup>e</sup>	p <sup>f</sup>
Age group															
<55	467	26	4 064	22	1.41	1.23 – 1.60	<0.001	1.64	1.42 – 1.89	<0.001	1.58	1.37 – 1.83	1.58	1.37 – 1.83	<0.001
55–64	442	25	4 765	26	1.11	0.97 – 1.26		1.16	1.01 – 1.33		1.16	1.01 – 1.33	1.16	1.01 – 1.33	
65–74	531	30	6 278	34	1		1	1			1		1		
75+ Sex	343	19	3 483	19	1.18	1.03 – 1.36		1.21	1.05 – 1.40		1.17	1.01 – 1.35	1.18	1.02 – 1.36	
Male	700	39	7 273	39	1		0.901	1			1		1		<0.001
Female	1 083	61	11 317	61	0.99	0.90 – 1.10		1.52	1.30 – 1.77		1.5	1.29 – 1.75	1.51	1.29 – 1.76	
Deprivation score															
Quintile 1 (least deprived)	359	20	4 293	23	1		<0.001	1		<0.001	1		1		<0.001
Quintile 2	411	23	4 399	24	1.13	0.97 – 1.31		1.13	0.97 – 1.31		1.12	0.96 – 1.30	1.12	0.97 – 1.30	
Quintile 3	398	22	4 044	22	1.20	1.03 – 1.39		1.19	1.02 – 1.38		1.19	1.02 – 1.38	1.19	1.02 – 1.38	
Quintile 4	302	17	3 327	18	1.09	0.93 – 1.28		1.09	0.92 – 1.28		1.08	0.92 – 1.27	1.08	0.92 – 1.27	
Quintile 5 (most deprived)	313	18	2 527	14	1.55	1.32 – 1.82		1.50	1.28 – 1.77		1.51	1.28 – 1.77	1.50	1.28 – 1.77	
Cancer site															
Breast	692	39	8 127	44	0.81	0.69 – 0.96	<0.001	0.64	0.52 – 0.78	<0.001	0.63	0.51 – 0.77	0.69	0.56 – 0.85	<0.001
Prostate	345	19	3 016	16	1.13	0.93 – 1.36		1.48	1.21 – 1.81		1.33	1.09 – 1.63	1.39	1.13 – 1.70	
Colon	304	17	3 191	17	0.92	0.76 – 1.11		0.90	0.74 – 1.09		0.84	0.69 – 1.02	0.85	0.70 – 1.04	
Lung	254	14	2 428	13	1.02	0.84 – 1.24		0.92	0.75 – 1.13		0.92	0.75 – 1.13	0.88	0.72 – 1.09	
Rectal	188	11	1 828	10	1		1	1			1		1		
Tumour stage at diagnosis															
I	481	27	5 475	29	1		<0.001	1		<0.001	1		1		<0.001
II	531	30	6 211	33	0.97	0.85 – 1.10		0.95	0.83 – 1.08		0.93	0.81 – 1.06	0.93	0.81 – 1.06	
III	461	26	4 475	24	1.19	1.04 – 1.36		1.14	0.98 – 1.31		1.11	0.96 – 1.28	1.11	0.96 – 1.28	
IV	310	17	2 429	13	1.52	1.31 – 1.77		1.44	1.22 – 1.70		1.37	1.15 – 1.62	1.37	1.15 – 1.62	
Diagnostic route															
Two-week-wait	843	47	9 071	49	1		<0.001	1		<0.001	1		1		<0.001
Emergency presentation	160	9	1 146	6	1.58	1.32 – 1.90		1.60	1.32 – 1.94		1.51	1.24 – 1.83	1.51	1.24 – 1.83	
Elective referral	396	22	3 412	18	1.28	1.13 – 1.45		1.23	1.07 – 1.40		1.24	1.09 – 1.43	1.24	1.09 – 1.43	
Screening	272	15	3 765	20	0.76	0.66 – 0.88		0.87	0.74 – 1.01		0.88	0.75 – 1.03	0.88	0.75 – 1.03	
Other routes	112	6	1 196	6	1.01	0.82 – 1.24		0.98	0.79 – 1.21		0.99	0.80 – 1.22	0.99	0.80 – 1.22	
Rating of overall care															
Negative			1 783	10											
Positive			16 807	90											
Total			18 590	100											

<sup>a</sup> Tumour stage, case-mix adjusted: multivariable logistic regression model, conditional on age group, sex, deprivation status, cancer site, and tumour stage at diagnosis.

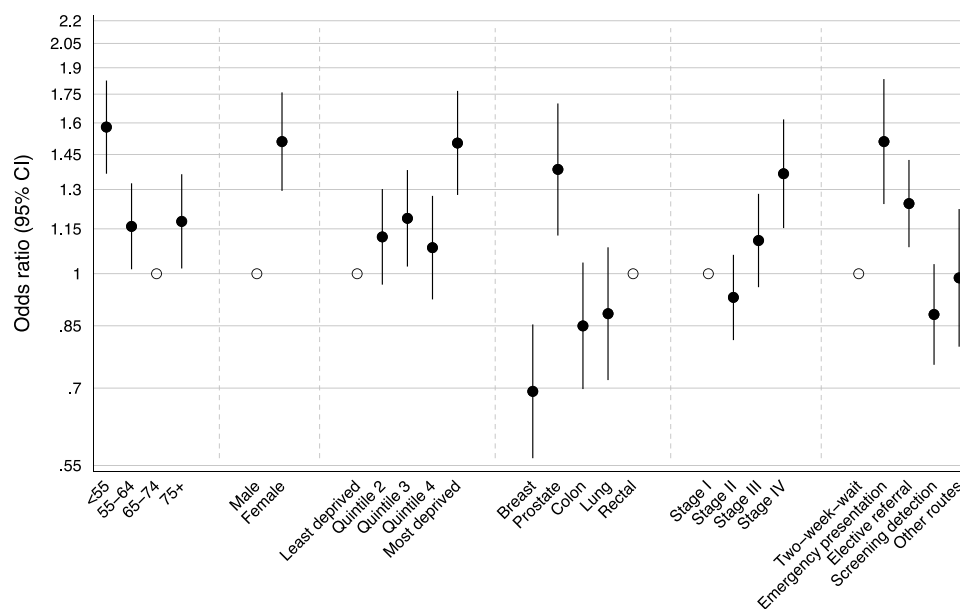
<sup>b</sup> Diagnostic route, case-mix adjusted: multivariable logistic regression model, conditional on age group, sex, deprivation status, cancer site, and diagnostic route.

<sup>c</sup> Tumour stage, diagnostic route, case-mix adjusted: multivariable logistic regression model, conditional on age group, sex, deprivation status, cancer site, tumour stage at diagnosis, and diagnostic route.

<sup>d</sup> OR: odds ratios from univariable and multivariable logistic regression models for reporting a negative rating of overall cancer care.

<sup>e</sup> 95% CI: 95% confidence intervals for odds ratios.

<sup>f</sup> p: p-values from joint Wald tests.



**Fig. 2.** Adjusted odds ratios of reporting a negative experience of overall cancer care for tumour stage at diagnosis and diagnostic route, as well as patient characteristic and cancer site variables, N = 18 590. CI: confidence interval.

to be associated with the best and emergency presenters the worst experience of cancer care. In addition, two recent Danish studies reported that cancer patients managed through ‘fast-track’ referrals (similar to the two-week-wait route) were less likely to be dissatisfied with the length of waiting times and more likely to be satisfied with their subsequent cancer care, compared with those referred electively. [27,28] Our study cannot explain the reasons for the observed variation in care satisfaction by diagnostic route. The fact that emergency presenters were found to be the least satisfied with their care may reflect the negative psychological impact of being diagnosed in an emergency context. Similarly, electively referred patients may rate their care more negatively if they feel that their diagnosis could have been more timely had they been ‘fast-tracked’ through a two-week-wait referral, as perceived diagnostic delay is associated with distress. [29] These are plausible and intuitive hypotheses which should be examined empirically by further research. These previous studies however were not able to adjust for the likely influence of stage at diagnosis on the diagnostic pathways. In contrast, in our study we were able to examine the influence of both diagnostic route and stage at diagnosis, with the adjusted analysis indicating that both could be influencing care experience independently of each other.

#### 4.4. Implications

The finding that emergency presenters and patients with the most advanced tumour stage were more likely to report a negative experience of overall cancer care highlights the need for service improvement targeting these groups of patients. There may be opportunities to improve the availability of services (e.g. in the context of emergency presentations) or the management of patients with advanced tumour stages, though how this can be achieved should be addressed in future research. Continued efforts to improve timely diagnosis of cancer and to reduce the number of emergency presenters will also likely lead to a reduction in the number of patients who are not satisfied with the quality of their care.

The results also suggest that after adjusting for tumour stage and diagnostic route, sociodemographic inequalities (by age, sex, and social deprivation) prevailed. Therefore, disease severity does not appear to fully explain these disparities. Whether these disparities reflected differential norms in expectations of care quality or actually worse care cannot be answered by our findings. Future empirical research, such as

using standardised encounters (e.g. ‘vignettes’) may be helpful. [30]

When cancer patient survey data are used for epidemiological research, potential compositional differences between the analysis sample (which represents recently treated cancer survivors) and other populations of prior interest (e.g. incident or prevalent cases) might limit the external validity of findings. Therefore, in addition to the variation in reported experience by patient characteristic and cancer site variables, [9] associations between diagnostic route, tumour stage at diagnosis, and reported experience need to be considered when applying methods for dealing with sample distortions, such as the inclusion of these variables in deriving post-stratification weights. [25]

#### 4.5. Conclusions

In conclusion, we report variation in experience of overall care among cancer patients with different tumour stages at diagnosis, diagnostic routes, and other characteristics. These associations need to be borne in mind when using patient experience survey data for epidemiological research. A reduction in the proportion of patients who are diagnosed with cancer as an emergency, greater availability and uptake of screening interventions, and reduction in the incidence of late-stage diseases may contribute to improvements in care experience. The findings could guide improvement efforts in the care of patients diagnosed via emergency presentation and those with advanced-stage disease, who are also higher-risk groups of reporting poorer experience of cancer care.

#### Ethics approval

The research is a secondary analysis of anonymous data, thus requiring no ethics approval.

#### Availability of data and materials

Data used are made available through an Open Government Licence, published by Public Health England (PHE) Office for Data Release (ODR) <https://data.gov.uk/dataset/7675d4a3-7aeb-47a6-b753-869cfe736e9/cancer-registration-national-cancer-patient-experience-survey-wave-4-by-patient-characteristics-and-route-to-diagnosis>.

**Conflict of interest statement**

All authors declare no conflict of interest.

**Funding**

This work is supported by Macmillan Cancer Support grant 5995414 for which GAA and GL are joint principal investigators. GL is supported by a Cancer Research UK Advanced Clinician Scientist Fellowship Award (C18081/A18180). The views expressed in this publication are those of the authors and not necessarily those of any funder or any other organisation or institution.

**Authorship**

The study was originally conceived by GL and GAA, but research questions and methods employed to answer them were substantially enriched by both TMP and MGC. Methods development, data

interpretation, and writing were done collaboratively by all authors (TMP, MGC, TS, DJ, GAA, GL). The principal analyst was TMP, who also wrote the first draft of the manuscript. DJ linked CPES data to cancer registration data on diagnostic route and tumour stage at diagnosis. All authors gave final approval of the version to be published.

**Acknowledgements**

Data for this study is based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data is collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE). We thank the Department of Health as the principal investigator of the 2014 Cancer Patient Experience Survey, Quality Health as the survey provider and data collector, and all NHS Acute Trusts in England for provision of data samples. We are grateful to all patients who participated in the survey.

**Appendix**

Appendix 1 Frequency of tumour stage at diagnosis and diagnostic route by the five most common cancers, N = 18 590

Cancer site	Tumour stage at diagnosis	Two-week-wait	Emergency presentation	Elective referral	Screening detection	Other routes	Total	p <sup>a</sup>
Breast	1	1 316	9	168	1 808	66	3 367	< 0.001
	Row %	39	0	5	54	2	100	
	Col %	29	11	40	61	66	41	
	2	2 374	30	180	954	18	3 556	
	Row %	67	1	5	27	1	100	
	Col %	52	35	43	32	18	44	
	3	718	19	46	194	11	988	
	Row %	73	2	5	20	1	100	
	Col %	16	22	11	7	11	12	
	4	141	27	21	22	5	216	
	Row %	65	13	10	10	2	100	
	Col %	3	32	5	1	5	3	
	Total	4 549	85	415	2 978	100	8 127	
	Row %	56	1	5	37	1	100	
Col %	100	100	100	100	100	100		
Prostate	1	345	27	460	108	108	940	< 0.001
	Row %	37	3	49	11	11	100	
	Col %	25	26	35	45	31	880	
	2	377	12	437	54	6	100	
	Row %	43	1	50	6	100		
	Col %	28	12	33	22	29	779	
	3	397	9	326	47	6	100	
	Row %	51	1	42	6	19	26	
	Col %	29	9	25	19	26	417	
	4	236	54	94	33	8	100	
	Row %	57	13	23	8	14	14	
	Col %	17	53	7	14	14	3 016	
	Total	1 355	102	1 317	242	8	100	
	Row %	45	3	44	8	100	100	
Col %	100	100	100	100	100	100		
Colon	1	111	9	81	118	33	352	< 0.001
	Row %	32	3	23	34	9	100	
	Col %	10	2	12	24	10	11	
	2	392	145	242	149	118	1 046	
	Row %	37	14	23	14	11	100	
	Col %	35	26	35	30	37	33	
	3	393	226	239	195	107	1 160	
	Row %	34	19	21	17	9	100	
	Col %	35	40	34	39	33	36	
	4	216	182	135	38	62	633	
	Row %	34	29	21	6	10	100	
	Col %	19	32	19	8	19	20	
	Total	1 112	562	697	500	320	3 191	
	Row %	35	18	22	16	10	100	
Col %	100	100	100	100	100	100		

Lung	1	199	45	139	99	482	< 0.001
	Row %	41	9	29	21	100	
	Col %	17	15	25	26	20	
	2	184	36	94	57	371	
	Row %	50	10	25	15	100	
	Col %	16	12	17	15	15	
	3	379	76	149	115	719	
	Row %	53	11	21	16	100	
	Col %	32	25	27	30	30	
	4	412	149	178	117	856	
Row %	48	17	21	14	100		
Col %	35	49	32	30	35		
Total	1174	306	560	388	2 428		
Row %	48	13	23	16	100		
Col %	100	100	100	100	100		
Rectal	1	127	9	78	82	334	< 0.001
	Row %	38	3	23	25	100	
	Col %	14	10	18	29	18	
	2	169	23	76	63	358	
	Row %	47	6	21	18	100	
	Col %	19	25	18	22	20	
	3	418	32	200	119	829	
	Row %	50	4	24	14	100	
	Col %	47	35	47	41	45	
	4	167	27	69	23	307	
	Row %	54	9	22	7	100	
	Col %	19	30	16	8	17	
	Total	881	91	423	287	1 828	
	Row %	48	5	23	16	100	
	Col %	100	100	100	100	100	

<sup>a</sup>p-values from Chi-squared tests of associations.

Appendix 2 Associations between key exposures (tumour stage at diagnosis, diagnostic route) and patient characteristic and cancer site variables, N = 18 590

Variable	Tumour stage at diagnosis					Diagnostic route					Total	p <sup>a</sup>	
	I	II	III	IV	p <sup>a</sup>	Two-week-wait	Emergency presentation	Elective referral	Screening detection	Other routes			
Age group													
<55	1 221	1 743	774	326	<0.001	2 465	173	502	753	171	4 064	<0.001	
	22	28	17	13		27	15	15	20	14	22		
55-64	1 501	1 505	1 173	586		1 984	261	823	1 415	282	4 765		
	27	24	26	24		22	23	24	38	24	26		
65-74	1 880	1 799	1 672	927		2 635	399	1 325	1 485	434	6 278		
	34	29	37	38		29	35	39	39	36	34		
75+	873	1 164	856	590		1 987	313	762	112	309	3 483		
	16	19	19	24		22	27	22	3	26	19		
Sex													
Male	1 616	1 900	2 312	1 445	<0.001	3 175	620	2 254	519	705	7 273	<0.001	
	30	31	52	59		35	54	66	14	59	39		
Female	3 859	4 311	2 163	984		5 896	526	1 158	3 246	491	11 317		
	70	69	48	41		65	46	34	86	41	61		
Deprivation score													
Quintile 1 (least deprived)	1 311	1 430	1 026	526	<0.001	2 060	238	808	916	271	4 293	0.079	
	24	23	23	22		23	21	24	24	23	23		
Quintile 2	1 323	1 525	992	559		2 149	272	817	896	265	4 399		
	24	25	22	23		24	24	24	24	22	24		
Quintile 3	1 139	1 399	957	549		1 996	239	746	795	268	4 044		
	21	23	21	23		22	21	22	21	22	22		
Quintile 4	991	1 090	826	420		1 611	217	595	697	207	3 327		
	18	18	18	17		18	19	17	19	17	18		
Quintile 5 (most deprived)	711	767	674	375		1 255	180	446	461	185	2 527		
	13	12	15	15		14	16	13	12	15	14		
Cancer site													
Breast	3 367	3 556	988	216	<0.001	4 549	85	415	2 978	100	8 127	<0.001	
	62	57	22	9		50	7	12	79	8	44		
Prostate	940	880	779	417		1 355	102	1 317	0	242	3 016		
	17	14	17	17		15	9	39	0	20	16		
Colon	352	1 046	1 160	633		1 112	562	697	500	320	3 191		
	6	17	26	26		12	49	20	13	27	17		

Lung	482	371	719	856	1 174	306	560	0	388	2 428
	9	6	16	35	13	27	16	0	32	13
Rectal	334	358	829	307	881	91	423	287	146	1 828
	6	6	19	13	10	8	12	8	12	10
Total	5 475	6 211	4 475	2 429	9 071	1 146	3 412	3 765	1 196	18 590
	100	100	100	100	100	100	100	100	100	100

<sup>a</sup>p-values from Chi-square tests of associations.

Note: values displayed as frequency (top of cell) and percentage (bottom of cell).

Appendix 3 Adjusted odds ratios of reporting a negative experience of overall cancer care, N = 18 590

Variable	Odds ratio <sup>a</sup>	95% confidence interval	p <sup>b</sup>
Age group			
< 55	1.59	1.37 – 1.84	< 0.001
55-64	1.16	1.01 – 1.32	
65-74	1		
75 +	1.16	1.00 – 1.34	
Sex			
Male	1		< 0.001
Female	1.51	1.30 – 1.76	
Deprivation score			
Quintile 1 (least deprived)	1		< 0.001
Quintile 2	1.12	0.96 – 1.30	
Quintile 3	1.18	1.02 – 1.38	
Quintile 4	1.08	0.92 – 1.26	
Quintile 5 (most deprived)	1.49	1.26 – 1.75	
Cancer site			
Breast	0.62	0.39 – 0.99	0.003
Prostate	1.12	0.68 – 1.85	
Colon	1.14	0.64 – 2.03	
Lung	0.74	0.42 – 1.29	
Rectal	1		
Tumour stage at diagnosis			
I	1		0.717
II	1.26	0.76 – 2.08	
III	1.08	0.69 – 1.70	
IV	0.96	0.56 – 1.66	
Diagnostic route			
Two-week-wait	1		0.034
Emergency presentation	1.82	1.01 – 3.27	
Elective referral	1.13	0.78 – 1.63	
Screening detection	0.54	0.30 – 0.95	
Other routes	0.93	0.51 – 1.69	
Cancer site & stage interaction			
Breast#stage I	1		0.117
Breast#stage II	0.73	0.43 – 1.26	
Breast#stage III	1.14	0.69 – 1.91	
Breast#stage IV	1.88	0.95 – 3.73	
Prostate#stage I	1		
Prostate#stage II	0.79	0.44 – 1.42	
Prostate#stage III	0.97	0.56 – 1.67	
Prostate#stage IV	1.61	0.84 – 3.07	
Colon#stage I	1		
Colon#stage II	0.48	0.25 – 0.93	
Colon#stage III	0.74	0.40 – 1.35	
Colon#stage IV	1.19	0.60 – 2.39	
Lung#stage I	1		
Lung#stage II	0.93	0.47 – 1.84	
Lung#stage III	1.16	0.64 – 2.11	
Lung#stage IV	1.35	0.70 – 2.63	
Cancer site & route interaction			
Breast#Two-week-wait	1		0.628
Breast#Emergency presentation	0.73	0.31 – 1.75	
Breast#Elective referral	0.86	0.52 – 1.43	
Breast#Screening detection	1.71	0.94 – 3.10	
Breast#Other routes	0.79	0.30 – 2.11	
Prostate#Two-week-wait	1		
Prostate#Emergency presentation	1.16	0.52 – 2.55	
Prostate#Elective referral	1.28	0.82 – 1.99	
Prostate#Screening detection	1		
Prostate#Other routes	1.30	0.62 – 2.73	
Colon#Two-week-wait			
Colon#Emergency presentation	0.70	0.36 – 1.37	



Colon#Elective referral	0.97	0.60 – 1.58
Colon#Screening detection	1.40	0.69 – 2.83
Colon#Other routes	1.00	0.48 – 2.10
Lung#Two-week-wait	1	
Lung#Emergency presentation	0.85	0.42 – 1.71
Lung#Elective referral	1.29	0.79 – 2.10
Lung#Screening detection	1	
Lung#Other routes	1.07	0.52 – 2.20

<sup>a</sup>Odds ratios from multivariable logistic regression model, conditional on tumour stage, diagnostic route, patient characteristic and cancer site variables, as well as pairwise interactions between cancer site and tumour stage or diagnostic route.

<sup>b</sup>p-values from joint Wald tests.

#, interaction.

## References

- [1] The Independent Cancer Taskforce, *Achieving World-class Cancer Outcomes: a Strategy for England 2015-2020*, (2015).
- [2] National Institute for Health and Care Excellence, *Patient Experience in Adult NHS Services: Improving the Experience of Care for People Using Adult NHS Services*, (2012).
- [3] Quality Health. National Cancer Patient Experience Survey. Available at: <http://www.ncpes.co.uk/>.
- [4] Scottish Government, *Scottish Cancer Patient Experience Survey 2015/16*, Available at: (2016) <http://www.gov.scot/Publications/2016/06/3957>.
- [5] R. Wagland, et al., Development and testing of a text-mining approach to analyse patients' comments on their experiences of colorectal cancer care, *BMJ Qual. Saf.* 25 (2016) 604–614.
- [6] K. Lacey, et al., Presentations to general practice before a cancer diagnosis in Victoria: a cross-sectional survey, *Med. J. Aust.* 205 (2016) 66–71.
- [7] M. Leonhardt, K. Aschenbrenner, M.E. Kreis, J.C. Lauscher, Exploring the characteristics and potential disparities of non-migrant and migrant colorectal cancer patients regarding their satisfaction and subjective perception of care - a cross-sectional study, *BMC Health Serv. Res.* 18 (2018) 423.
- [8] Agency for Healthcare Research and Quality, *CAHPS Cancer Care Survey*, Available at: <https://www.ahrq.gov/cahps/surveys-guidance/cancer/index.html>.
- [9] C.L. Saunders, G.A. Abel, G. Lyratzopoulos, Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English cancer patient experience survey, *Eur. J. Cancer Care (Engl)* 24 (2015) 85–98.
- [10] M. Engel, A. Brinkman-Stoppelenburg, D. Nieboer, A. van der Heide, Satisfaction with care of hospitalised patients with advanced cancer in the Netherlands, *Eur. J. Cancer Care (Engl)* (2018) e12874, <https://doi.org/10.1111/ecc.12874>.
- [11] A. El Turabi, G.A. Abel, M. Roland, G. Lyratzopoulos, Variation in reported experience of involvement in cancer treatment decision making: evidence from the National Cancer Patient Experience Survey, *Br. J. Cancer* 109 (2013) 780–787.
- [12] L. Elliss-Brookes, et al., Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets, *Br. J. Cancer* 107 (2012) 1220–1226.
- [13] S. McPhail, S. Johnson, D. Greenberg, M. Peake, B. Rous, Stage at diagnosis and early mortality from cancer in England, *Br. J. Cancer* 112 (2015) S108–S115.
- [14] T. Salika, et al., Associations between diagnostic pathways and care experience in colorectal cancer: evidence from patient-reported data, *Front. Gastroenterol* 0 (2018) 1–8.
- [15] National Cancer Registration and Analysis Service, *Routes to Diagnosis*, Available at: [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis).
- [16] Public Health England, National Cancer Intelligence Network, *Linking English Cancer Patient Experience Surveys 2010, 2011/12 and 2013 with cancer registration data. A technical summary*, (2015).
- [17] Public Health England, The National Cancer Registration and Analysis Service, Available at: <http://ncin.org.uk/home>.
- [18] World Health Organization, *ICD-10 Version:2010*, Available at: (2010) <http://apps.who.int/classifications/icd10/browse/2010/en>.
- [19] Department for Communities and Local Government, *English Indices of Deprivation 2015*, Available at: (2015) <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2015>.
- [20] StataCorp, *Stata Statistical Software: Release 15*, (2017).
- [21] G. Lyratzopoulos, et al., Understanding ethnic and other socio-demographic differences in patient experience of primary care: evidence from the English general practice patient survey, *BMJ Qual. Saf.* 21 (2012) 21–29.
- [22] C. Paddison, et al., Should measures of patient experience in primary care be adjusted for case mix? Evidence from the English General Practice Patient Survey, *BMJ Qual. Saf.* 21 (2012) 634–640.
- [23] G.A. Abel, C.L. Saunders, G. Lyratzopoulos, Post-sampling mortality and non-response patterns in the English Cancer Patient Experience Survey: Implications for epidemiological studies based on surveys of cancer patients, *Cancer Epidemiol.* 41 (2016) 34–41.
- [24] S. Mcphail, et al., Emergency presentation of cancer and short-term mortality, *Br. J. Cancer* 109 (2013) 2027–2034.
- [25] G.A. Abel, et al., Emergency diagnosis of cancer and previous general practice consultations: insights from linked patient survey data, *Br. J. Gen. Pract.* 67 (2017) e377–e387.
- [26] J.Z. Ayanian, et al., Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium, *J. Clin. Oncol.* 28 (2010) 4154–4161.
- [27] T.L. Dahl, P. Vedsted, H. Jensen, The effect of standardised cancer pathways on Danish cancer patients' dissatisfaction with waiting time, *Dan. Med. J.* 64 (2017).
- [28] M. Sandager, H. Jensen, H. Lipczak, C.D. Sperling, P. Vedsted, Cancer patients' experiences with urgent referrals to cancer patient pathways, *Eur. J. Cancer Care (Engl)* (2018) 1–11, <https://doi.org/10.1111/ecc.12927>.
- [29] A. Miles, et al., Perceived diagnostic delay and cancer-related distress: a cross-sectional study of patients with colorectal cancer, *Psychooncology* 26 (1) (2017) 29–36, <https://doi.org/10.1002/pon.4093>.
- [30] J. Burt, et al., Understanding negative feedback from South Asian patients: an experimental vignette study, *BMJ Open* 6 (2016) e011256, <https://doi.org/10.1136/bmjopen-2016-011256>.