

# Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English Cancer Patient Experience Survey

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**Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English Cancer Patient Experience Survey**

Patient experience is a critical dimension of cancer care quality. Understanding variation in experience among patients with different cancers and characteristics is an important first step for designing targeted improvement interventions. We analysed data from the 2011/2012 English Cancer Patient Experience Survey ( $n = 69\,086$ ) using logistic regression to explore inequalities in care experience across 64 survey questions. We additionally calculated a summary measure of variation in patient experience by cancer, and explored inequalities between patients with cancers treated by the same specialist teams. We found that younger and very old, ethnic minority patients and women consistently reported worse experiences across questions. Patients with small intestine/rarer lower gastrointestinal, multiple myeloma and hepatobiliary cancers were most likely to report negative experiences whereas patients with breast, melanoma and testicular cancer were least likely (top-to-bottom odds ratio = 1.91,  $P < 0.0001$ ). There were also inequalities in experience among patients with cancers treated by the same specialty for five of nine services ( $P < 0.0001$ ). Specifically, patients with ovarian, multiple myeloma, anal, hepatobiliary and renal cancer reported notably worse experiences than patients with other gynaecological, haematological, gastrointestinal and urological malignancies respectively. Initiatives to improve cancer patient experience across oncology services may be suitably targeted on patients at higher risk of poorer experience.

**Keywords:** oncology service, hospital, quality of health care, healthcare inequalities, patient satisfaction, neoplasms.

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## INTRODUCTION

Patient experience is a central dimension of healthcare quality (IOM 2001; ASCO 2006; Ludwig *et al.* 2006; NHS 2013–2014). Consequently, measurement of patient experience in large nationwide samples of patients is becoming common practice in several countries. For example, in the United States, the Hospital Consumer Assessment of Healthcare Providers and Systems survey measures the experience of over a million hospital patients every year (Goldstein *et al.* 2005; Medicare.Gov 2014). A potential barrier in translating patient experience information into improvement actions is that data often relate to patients with a wide spectrum of conditions. Patients with cancer, in particular, have very different care pathways compared with other inpatients with non-neoplastic disease (e.g., elective surgery patients or those with exacerbations of a chronic disease). Therefore, experience surveys of patients with cancer are increasingly being considered in different countries (Iversen *et al.* 2012; Evensen *et al.* 2013; Garfinkel *et al.* 2013).

In England, a national programme of repeatable surveys specifically dedicated to the measurement of the experience of patients with cancer was introduced recently (Department of Health 2011–2012a). Cancer charities and consumer groups strongly support and engage with the dissemination of the results of these surveys, which cover a wide spectrum of items on different domains of experience (Macmillan Cancer Support 2012–2013). Because this survey encompasses patients with any type of cancer, it provides an opportunity to explore variation among patients with different diagnoses (including common, rarer and rare cancers; Department of Health 2011–2012a; Lyratzopoulos *et al.* 2012b; El Turabi *et al.* 2013).

Appreciating how patient experience varies among patients with different socio-demographic characteristics, and crucially, different cancers, is an important first step in helping to understand responsible mechanisms and the development of targeted interventions for improvement. Because large national surveys of the experience of patients with many different cancers are a recent development, our current understanding of variation in experience by cancer diagnosis is limited. The ease and speed by which a diagnosis can be established, the treatment burden and the prognosis of different cancers vary substantially. We would hypothesise that the experience of care will vary substantially among patients with different cancers; specifically, patients with prolonged diagnostic intervals, higher treatment burden and worse prognosis may provide more critical evaluations of their care. Although inequalities in reported experience among socio-demographic groups may

be driven by differential prior expectations of quality, variation in experience among patients with different cancers should be relatively robust to such confounding, more directly reflecting disease factors.

Further, as results for the Cancer Patient Experience Survey are reported publicly for each survey item, we were a priori interested in potential inequalities in respect of each survey item; and on the degree of consistency in patterns of variation across different research questions and aspects of experience.

With these prior considerations, we analysed data from the English Cancer Patient Experience Survey 2011/2012 to explore variation in the experience of care between patients with cancer for all survey questions. Specifically, our objective was to describe and summarise variation in patient experience by age, gender, deprivation, ethnicity and cancer diagnosis across all survey questions.

## METHODS

### Data

We used anonymous data from the Cancer Patient Experience Survey 2011/2012, a national postal survey of patients with cancer treated in English National Health Service hospitals commissioned by the UK Department of Health and undertaken by Quality Health (Chesterfield, UK), a specialist survey provider (Department of Health 2011–2012a). Patients were included in the survey sampling frame if cancer was recorded as the primary diagnosis in any hospital care record during September to November 2011. Primary data collection for the survey was approved by the Ethics and Confidentiality Committee of the National Information Governance Board (reference ECC 3-04(d)/2011; Department of Health 2011–2012a). Anonymous data from the survey are available for not-for-profit research from the UK Data Archive (<http://www.data-archive.ac.uk/>) – the source of data used in the present study (Department of Health 2011–2012b).

The survey questionnaire included evaluative questions that covered patient experience along the care pathway of patients with cancer, encompassing experience of presentation, diagnostic testing, treatment decisions, doctor and nurse communication, informational integration between hospital and community services after discharge, experience of chemotherapy and radiotherapy treatment, and outpatient follow-up care (Appendix 1). Cognitive testing of survey items was carried out by the survey provider in panels of volunteers identified by Macmillan Cancer Support, a national cancer charity (Department of Health 2011–2012a). The same postal methodology used for the final survey was used during cognitive testing, with

interview follow-up. Testing encompassed the assessment of patients' ability to complete the questionnaire, their understanding of questions and general exploration of patient views about the survey.

Most questions had four or five ordered (Likert) response options, ranging from *very positive* to *very negative* experience, although some report-type questions had a binary (Yes/No) format. For each survey question, public reporting is based on the proportion of patients who provided responses indicating 'good' or 'very good' experience (Department of Health 2011–2012a). As this is how the survey findings are used by clinicians and managers to inform quality improvement efforts, and also by members of the public when accessing information about the comparative performance of different English hospitals, in this analysis, we used the same binary categorisation of experience (positive/negative) as used in public reporting.

Hospital record recorded cancer diagnosis classified using the International Classification of Diseases 10th edition (ICD-10) diagnostic code, patient age and gender, and hospital of treatment were available for all respondents. Self-reported ethnic group information was used in the analysis (Office of National Statistics classification) as the gold-standard approach to ethnic group assignment (Saunders *et al.* 2013). Therefore, and in the context of highly complete information (96.3%), the analysis was restricted to survey respondents for whom information on self-reported ethnicity was available. Age was categorised into eight groups (16–24, 25–34 in 10 year groups to 75–84 and 85+). Socio-economic status information was not available in the 2011/2012 dataset; however, patients' deprivation score (Index of Multiple Deprivation 2007 score of lower super output area of residence) was available for the 2010 survey (Indices of Deprivation 2007; Department of Health 2010). Consequently, in supplementary analysis, we examined socio-economic inequalities in cancer patient experience using the latter dataset.

We included patients with any cancer, using 36 diagnosis groups based on the ICD-10 classification (Table 1; Appendix 2). Of these, 31 were further nested within nine specialty groups (also called 'multidisciplinary team' or MDT groups in the United Kingdom and in other European countries, e.g., urological, gynaecological or haematological specialty groups) (European Partnership Action Against Cancer Consensus Group *et al.* 2014). Specialty groups encompass patients with cancers typically treated by the same oncology service and within shared premises (e.g., wards or outpatient clinics); these patients are also often treated by the same multidisciplinary group of oncologists, surgeons, nurses and other

**Table 1.** Socio-demographic and clinical characteristics of survey respondents

Age	All	%
16–24	355	0.5
25–34	954	1.4
35–44	2,999	4.3
45–54	8,911	12.9
55–64	16,970	24.6
65–74	22,749	32.9
75–84	13,564	19.6
85+	2,584	3.7
<b>Gender</b>		
Men	32,463	47.0
Women	36,623	53.0
<b>Ethnic group</b>		
White	66,421	96.1
Mixed	278	0.4
Asian	1,146	1.7
Black	949	1.4
Chinese	150	0.2
Other	142	0.2
<b>Deprivation</b>		
<i>Most affluent</i>	14,589	21.1
<i>2nd</i>	14,624	21.2
<i>3rd</i>	13,582	19.7
<i>4th</i>	11,566	16.7
<i>Most deprived</i>	9,409	13.6
<b>Cancer diagnosis</b>		
Anal	242	0.4
Bladder	6,503	9.4
Bone sarcoma	174	0.3
Brain	483	0.7
Breast	13,396	19.4
Cervical	405	0.6
Colon	5,054	7.3
Ductal carcinoma in situ	916	1.3
Endometrial	1,478	2.1
Gynaecological NOS	88	0.1
Hepato-biliary	568	0.8
Hodgkin lymphoma	487	0.7
Laryngeal	361	0.5
Leukaemia	2,479	3.6
Lung	3,698	5.4
Melanoma	1,546	2.2
Mesothelioma	392	0.6
Multiple myeloma	3,236	4.7
Non-Hodgkin lymphoma	4,290	6.2
Oesophageal	1,362	2
Ophthalmic and rarer CNS	59	0.1
Oropharyngeal	1,280	1.9
Ovarian	1,823	2.6
Pancreatic	673	1
Prostate	5,568	8.1
Rectal	3,541	5.1
Renal	950	1.4
Secondary	4,308	6.2
Small-intestine	215	0.3
Soft tissue sarcoma	575	0.8
Stomach	1,019	1.5
Testicular	256	0.4
Thyroid	493	0.7
Ureter and rarer urological	349	0.5
Vulval / vaginal	236	0.3
Any other cancer diagnosis	583	0.8

Ethnic group was defined using a six-group classification (White, Mixed, Asian or Asian British, Black or Black British, Chinese and Other). Deprivation quintile groups (for data from the 2010 survey only) were defined by applying national (England) quintile-defining points (8.257, 13.525, 20.741, and 33.511) to Index of multiple deprivation (IMD) scores. ICD-10 diagnostic codes. Anal C21; Bladder C67; Bone sarcoma C40, C41; Brain C71; Breast C50; Cervical C53; Colon C18; Ductal carcinoma in situ (DCIS) D05; Endometrial C54, C55; Gynaecological not otherwise specified (Gynaecological NOS) C57; Hepato-biliary C22, C23, C24; Hodgkin lymphoma C81; Laryngeal C32; Leukaemia C91, C92, C93, C94, C95; Lung C34, C33; Melanoma C43; Mesothelioma C45; Multiple myeloma C90; Non-Hodgkin lymphoma C82, C83, C85, C84; Oesophageal C15; Ophthalmic and rarer central nervous system (CNS) C47, C69, C70, C72; Oropharyngeal C00 – C14, C30, C31; Ovarian C56; Pancreatic C25; Prostate C61; Rectal C19, C20; Renal C64; Secondary C77, C78, C79; Small-intestine C17, C26; Soft tissue sarcoma C48, C49, C46; Stomach C16; Testicular C62; Thyroid C73; Ureter and rarer urological C60, C63, C65, C66, C68; Vulval / vaginal C51, C52; Any other cancer diagnosis C37, C38, C39, C74, C75, C76, C80, C97, C58, C88, C96.

healthcare professionals, specialising in the treatment of cancers of the same body system (Table 2; Appendix 2).

### Analysis

Initially, we calculated the unadjusted proportion of positive responses for each question and by each variable group. Then, for each (of 65) evaluative questions separately, we fitted a mixed-effect logistic regression model with positive/negative experience categories as the outcome, and adjusting for age group, sex, ethnicity and cancer diagnosis as categorical variables. A random effect for hospital of treatment was also included in these models, to account for potential confounding by differential concentration of patients with different characteristics (e.g., ethnic minority patients) in differentially performing hospitals. For one question (question 28, whether a patient was happy to be asked to take part in research) the model did not converge, and this question was excluded from further analyses; patient experience for this question was highly positive (95.5%).

We visually summarised patterns of inequality across all questions – similar approaches for visually summarising multiple observations across many cancer sites have been used previously (Moller *et al.* 2009). By survey question, for each variable we assigned ranks to each one of its categorical groups (i.e., among the 36 cancers, we assigned ranks of 1 and 36 to those cancers associated with the best and worst reported experience, respectively, and similarly for all other variable categories by question). We subsequently used a red-amber-green colour coding convention (red = most negative experience rank/group, green = most positive experience rank/group) to further visually summarise the findings across questions, reporting odds ratios (ORs) and a rank-based colour code. We used a joint (Wald) test to examine whether each variable improved the fit of model to the data, and where it did not we did not apply the colour coding.

Subsequently, as we observed overall consistent patterns of inequalities in patient experience by cancer, we estimated the average association between cancer diagnosis and patient experience across the entire survey. For this analysis we included all responses to all questions and adjusted for question to account for the fact that the proportion of patients reporting positive experience varies by question; and that some questions do not apply to all patients (see Appendix 1). We also adjusted for age, gender and ethnicity, and accounted for within-respondent correlation of responses using a linear regression within a generalised estimating equation approach. This approach increases power to explore within specialty group (i.e., within MDT) variation, enabling us to better distinguish inequalities even

between cancers with relatively small sample sizes. To explore whether there are inequalities in cancer patient experience among patients with cancers treated by the same specialty groups we tested the equality of ORs for diagnoses within each specialty group using a Wald test.

We chose the largest cancer diagnosis group with approximately balanced gender distribution (rectal) as the baseline, while for further analysis comparing cancer experience within specialty group, we chose the largest bi-gender cancer diagnosis in each group. All analyses were carried out using Stata 11.2 (StataCorp. 2009. Stata Statistical Software: Release 11. College Station, TX: StataCorp LP). Colour coding was applied using MS Excel 2010 (Microsoft Excel (2010) [computer software]).

### RESULTS

Of an initial total of 113 808 patients, 71 793 completed the survey (a response rate of 68%, after excluding patients who died soon after their inclusion in the sampling frame); 69 086 responses with valid self-reported ethnicity were included in the final analysis sample.

The sample characteristics and number of responses by survey question are shown in Table 1 and Appendix 1. The unadjusted proportion of patients reporting positive experience ranged from 24% (q68 – was the patient offered a written care plan) to 95% (q63 – correct patient records available at outpatient appointment).

Hereafter and unless otherwise noted, the adjusted ORs for reporting a more negative experience of care compared with the baseline group are presented for question 70 (overall rating of care, Table 2). The results for this question are a typical reflection of inequalities observed in respect of other survey questions (Tables 3 and 4 and Appendix 3).

Patients in the 65–74-year group reported a positive experience more often than any other age group, while younger patients, and also the very old, reported comparatively poorer experience. Patients from ethnic minorities and women were also more likely to report poor experience ( $P < 0.0001$  for all).

There was also evidence ( $P < 0.0001$ ) of considerable inequalities in experience across cancer diagnoses, with patients with ductal carcinoma in situ and breast cancer being the most likely to report positive experiences and patients with thyroid and hepatobiliary cancer the least likely to do so [OR for negative experience compared with rectal cancer; ductal carcinoma in situ OR = 0.40 (95% confidence interval 0.31–0.53), breast OR = 0.55 (0.48–0.62), thyroid OR = 1.44 (1.12–1.84), hepatobiliary cancer OR = 1.46 (1.14–1.87)]. There was evidence ( $P < 0.05$ ) of inequalities within cancer specialty for four of the nine specialty

**Table 2.** Survey question 70: Overall rating of care. Clinical and socio-demographic variation

	Comparison of experience by socio-demographic characteristic			Comparison of experience by cancer			Comparison of experience between patients treated by the same speciality		
	Odds ratio [95% CI]	Joint P-value	Cancer diagnosis	Odds ratio [95% CI]	Joint P-value	Specialty team	Cancer diagnosis (comparisons within MDT)	Within MDT odds ratio [95% CI]	Within group P-value
Age (years)									
16-24	1.77 (1.29-2.44)	<0.0001	Ductal carcinoma in situ	0.40 (0.31-0.53)	<0.0001	Breast	Breast	Baseline	0.021
25-34	1.66 (1.37-2.01)		Breast	0.55 (0.48-0.62)			Ductal carcinoma in situ	0.74 (0.57-0.96)	
35-44	1.73 (1.54-1.94)		Non-Hodgkin lymphoma	0.58 (0.50-0.68)		Gynaecology	Ovarian	Baseline	0.396
45-54	1.42 (1.32-1.54)		Leukaemia	0.59 (0.5-0.71)			Endometrial	0.90 (0.73-1.11)	
55-64	1.31 (1.23-1.40)		Hodgkin lymphoma	0.6 (0.44-0.82)			Cervical	0.90 (0.65-1.24)	
65-74	Reference		Testicular	0.70 (0.46-1.06)			Vulval/vaginal	1.19 (0.80-1.76)	
75-84	1.10 (1.03-1.18)		Melanoma	0.71 (0.58-0.86)		Head and neck	Gynaecological NOS	1.40 (0.78-2.50)	0.0002
85+	1.47 (1.31-1.66)		Bone sarcoma	0.74 (0.45-1.21)			Thyroid	Baseline	
Gender			Laryngeal	0.74 (0.51-1.08)			Laryngeal	0.51 (0.34-0.79)	
Men	Reference	<0.0001	Cervical	0.76 (0.56-1.04)			Oropharyngeal	0.57 (0.43-0.76)	
Women	1.34 (1.26-1.42)		Endometrial	0.76 (0.63-0.93)		Haematology	Non-Hodgkin lymphoma	Baseline	<0.0001
Ethnic group			Mesothelioma	0.79 (0.55-1.14)			Multiple myeloma	1.56 (1.34-1.82)	
White	Reference	<0.0001	Oropharyngeal	0.82 (0.67-1.01)			Leukaemia	1.02 (0.85-1.22)	
Mixed	1.50 (1.08-2.09)		Any other cancer diagnosis	0.83 (0.63-1.10)			Hodgkin lymphoma	1.03 (0.75-1.42)	
Asian	2.67 (2.32-3.07)		Ovarian	0.85 (0.71-1.01)		Lower gastrointestinal	Rectal	Baseline	0.753
Black	2.03 (1.96-2.70)		Multiple myeloma	0.91 (0.78-1.05)			Colon	0.99 (0.87-1.13)	
Chinese	3.49 (2.45-4.97)		Lung	0.95 (0.82-1.10)			Anal	1.21 (0.84-1.74)	
Other	2.30 (1.55-3.42)		Colon	0.99 (0.87-1.13)			Small-intestine	1.06 (0.71-1.59)	0.321
			Rectal	Baseline			Lung	Baseline	
			Vulval/vaginal	1.01 (0.69-1.48)			Mesothelioma	0.83 (0.57-1.20)	0.914
			Soft-tissue sarcoma	1.02 (0.78-1.33)		Neurology	Brain	Baseline	
			Oesophageal	1.03 (0.85-1.25)			Ophthalmic and rarer CNS	1.04 (0.50-2.17)	
			Small-intestine	1.06 (0.71-1.59)		Upper gastrointestinal	Oesophageal	Baseline	0.064
			Bladder	1.18 (1.05-1.34)			Stomach	1.23 (0.97-1.57)	
			Gynaecological NOS	1.19 (0.67-2.11)			Pancreatic	1.28 (0.98-1.67)	
			Secondary	1.19 (1.04-1.36)			Hepatobiliary	1.42 (1.07-1.88)	0.038
			Anal	1.21 (0.84-1.74)			Bladder	Baseline	
			Prostate	1.21 (1.06-1.37)			Prostate	1.02 (0.91-1.14)	
			Brain	1.25 (0.96-1.62)			Renal	1.18 (0.97-1.42)	
			Stomach	1.27 (1.03-1.55)			Testicular	0.59 (0.39-0.89)	
			Ophthalmic and rarer CNS	1.30 (0.64-2.62)			Ureter and rarer urological	1.11 (0.82-1.51)	
			Ureter and rarer urological	1.31 (0.96-1.80)					
			Pancreatic	1.32 (1.04-1.66)					
			Renal	1.39 (1.14-1.70)					
			Thyroid	1.44 (1.12-1.84)					
			Hepatobiliary	1.46 (1.14-1.87)					

CI, confidence interval; Ophthalmic and rarer CNS, ophthalmic and rarer central nervous system; Gynaecological NOS, gynaecological not otherwise specified; MDT, multidisciplinary team.



**Table 3.** Association between patient socio-demographic characteristics and cancer patient experience

		Age							Sex		Ethnicity					Deprivation						
		16-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	Men	Women	White	Mixed	Asian	Black	Chinese	Other	Affluent	2nd	3rd	4th	Deprived
1	Saw GP once/twice before being told had to go to hospital	2.1	1.7	1.6	1.4	1.3	ref	0.9	0.9	ref	1.3	ref	1.4	2.2	1.9	1.6	1.8	ref	1.0	1.0	1.0	1.1
2	Patient thought they were seen as soon as necessary	2.1	2.6	2.0	1.5	1.3	ref	0.9	0.8	ref	1.1	ref	1.3	2.2	1.3	1.8	3.2	ref	1.0	1.0	0.9	0.9
3	% saw a hospital doctor in less than 3 months	2.1	2.1	1.6	1.4	1.2	ref	1.0	1.0	ref	1.2	ref	1.3	1.6	1.4	1.6	1.7	ref	1.0	1.0	1.1	1.1
4	Patient's health got better or remained about the same while waiting	2.2	2.0	1.9	1.6	1.3	ref	0.9	0.9	ref	1.1	ref	1.2	1.8	1.4	1.7	1.7	ref	1.0	1.0	1.1	1.3
6	Staff gave complete explanation of purpose of test(s)	1.6	1.4	1.4	1.2	1.0	ref	1.2	1.8	ref	1.2	ref	1.5	1.2	1.6	1.8	1.0	ref	0.9	1.0	1.0	0.9
7	Staff explained completely what would be done during test	2.0	1.5	1.6	1.3	1.1	ref	1.2	1.8	ref	1.2	ref	1.5	1.3	1.6	2.2	1.4	ref	0.9	1.0	1.0	1.0
8	Given easy to understand written information about test	1.4	1.1	1.2	1.0	1.0	ref	1.4	2.0	ref	1.0	ref	1.5	1.6	1.7	2.7	1.8	ref	1.0	1.1	1.2	1.2
9	Given complete explanation of test results in understandable way	1.7	2.0	1.6	1.6	1.2	ref	1.1	1.3	ref	1.0	ref	1.2	1.3	1.8	2.6	1.8	ref	1.0	1.1	1.0	1.0
11	Patient told they could bring a friend when first told they had cancer	0.9	1.4	1.9	1.6	1.4	ref	0.8	0.8	ref	1.3	ref	0.8	0.8	1.1	0.6	0.8	ref	1.0	0.9	0.8	0.7
12	Patient felt they were told sensitively that they had cancer	1.7	1.5	1.5	1.6	1.3	ref	0.7	0.6	ref	1.3	ref	1.0	1.2	0.9	0.8	1.2	ref	1.0	0.9	0.9	0.8
13	Patient completely understood the explanation of what was wrong	2.9	2.5	2.2	1.7	1.3	ref	0.9	1.2	ref	1.1	ref	1.1	1.0	1.4	1.6	1.3	ref	1.1	1.1	1.0	1.1
14	Patient given written information about the type of cancer they had	1.1	1.1	1.3	1.2	1.1	ref	1.2	1.6	ref	1.2	ref	1.2	1.2	1.5	1.9	1.4	ref	1.0	1.0	1.0	1.0
15	Patient given a choice of different types of treatment	1.0	1.2	1.5	1.3	1.1	ref	1.1	1.1	ref	1.1	ref	1.5	1.1	1.3	2.3	1.4	ref	1.0	1.1	1.1	1.1
16	Patient thinks their views were taken into account when discussing	1.5	1.5	1.4	1.4	1.2	ref	1.0	1.1	ref	1.0	ref	1.2	1.1	1.3	1.7	1.2					
17	Possible side effects explained in an understandable way	1.0	0.9	1.0	1.0	1.0	ref	1.2	1.6	ref	1.1	ref	1.4	1.1	1.4	1.7	1.0	ref	1.0	1.0	1.0	1.0
18	Patient given written information about side effects	0.7	0.7	0.6	0.7	0.8	ref	1.6	3.2	ref	1.1	ref	1.7	1.3	1.4	1.6	1.4	ref	1.0	1.0	1.1	1.2
19	Patient definitely involved in decisions about which treatment	1.7	1.6	1.5	1.4	1.2	ref	1.0	1.2	ref	1.1	ref	1.4	1.2	1.7	1.8	1.5	ref	1.0	1.1	1.0	1.0
20	Patient given the name of the CNS in charge of their care	0.6	0.9	1.1	1.0	1.0	ref	1.4	2.2	ref	1.0	ref	1.0	1.2	0.9	1.4	1.3	ref	1.0	1.0	1.0	0.9
21	Patient finds it easy to contact their CNS	1.3	1.4	1.4	1.3	1.2	ref	0.9	0.8	ref	1.1	ref	1.1	1.3	1.1	1.5	1.3	ref	1.0	1.0	0.9	0.9
22	CNS definitely listened carefully the last time spoken to	1.3	1.7	1.5	1.5	1.3	ref	0.9	1.1	ref	1.2	ref	1.0	1.4	1.2	2.0	1.4	ref	1.0	1.1	1.0	1.0
23	Get understandable answers to important questions all/most of the time	1.2	1.6	1.5	1.3	1.1	ref	1.1	1.2	ref	1.0	ref	1.3	2.2	1.5	3.5	1.0	ref	1.1	1.1	1.2	1.4
24	Hospital staff gave information about support groups	0.7	1.2	1.2	1.2	1.1	ref	1.1	1.7	ref	1.6	ref	1.0	1.2	1.2	1.3	1.0	ref	1.0	1.0	1.0	1.1
25	Hospital staff gave information on getting financial help	0.2	0.6	0.8	0.8	0.9	ref	1.1	1.3	ref	1.2	ref	0.9	1.1	0.9	1.3	1.0	ref	1.0	1.0	1.0	0.9
26	Hospital staff told patient they could get free prescriptions	2.6	3.0	3.4	3.7	3.1	ref	0.8	0.7	ref	1.4	ref	1.0	0.9	1.1	0.9	0.9	ref	1.0	0.9	0.8	0.8
27	Patient asked if they would like to take part in cancer research	0.7	0.7	0.9	0.8	0.8	ref	1.7	3.2	ref	1.2	ref	0.8	0.9	0.8	1.2	0.9					
29	Patient would have liked to have been asked	0.5	0.2	0.3	0.4	0.6	ref	1.6	2.5	ref	1.2	ref	0.9	1.2	1.0	1.8	1.1					
31	Admission date not changed by hospital	1.2	1.1	1.0	1.0	0.9	ref	1.1	1.4	ref	0.9	ref	1.8	1.6	1.2	0.5	1.8	ref	1.0	1.1	1.1	1.1
32	Staff gave complete explanation of what would be done	1.5	1.1	1.2	1.1	1.1	ref	1.2	1.7	ref	1.3	ref	0.9	1.0	1.3	1.2	2.8	ref	1.0	1.1	1.0	1.1
33	Patient given written information about the operation	1.1	0.7	0.8	0.9	1.0	ref	1.4	2.1	ref	1.2	ref	1.0	1.1	0.7	1.4	1.2	ref	1.0	1.0	1.0	1.0
34	Staff explained how operation had gone in understandable way	1.5	1.5	1.5	1.5	1.3	ref	1.1	1.4	ref	1.2	ref	1.3	1.3	1.3	2.0	2.1	ref	1.0	1.0	1.0	1.0
36	Got understandable answers to important questions all/most of the time	2.0	1.9	1.7	1.5	1.2	ref	1.2	1.4	ref	1.0	ref	1.4	1.6	1.6	2.2	1.8	ref	1.0	1.1	1.1	1.3
37	Patient had confidence and trust in all doctors treating them	2.5	2.1	2.0	1.6	1.4	ref	0.9	0.8	ref	1.3	ref	1.3	1.3	1.6	2.0	2.0	ref	0.9	0.9	0.9	0.9
38	Doctors did not talk in front of patient as if they were not there	1.6	1.6	1.4	1.3	1.1	ref	1.2	1.5	ref	0.9	ref	1.2	2.4	1.3	1.5	1.5	ref	1.0	1.1	1.2	1.3
39	Patient's family definitely had opportunity to talk to doctor	1.4	2.4	2.0	1.9	1.4	ref	0.9	1.0	ref	1.1	ref	0.8	0.8	0.7	0.8	1.2	ref	0.9	1.0	0.9	0.9
40	Got understandable answers to important questions all/most of the time	1.7	1.6	1.5	1.4	1.2	ref	1.1	1.4	ref	1.2	ref	1.6	1.6	1.4	2.0	1.7	ref	1.0	1.0	1.1	1.1
41	Patient had confidence and trust in all ward nurses	1.7	1.6	1.6	1.4	1.2	ref	0.9	1.0	ref	1.4	ref	1.3	1.2	1.3	1.4	1.3	ref	1.0	1.0	0.9	0.7
42	Nurses did not talk in front of patient as if they were not there	1.5	1.6	1.5	1.4	1.1	ref	1.2	1.6	ref	1.0	ref	1.8	2.9	1.5	2.0	2.4	ref	1.0	1.1	1.1	1.2
43	Always / nearly always enough nurses on duty	2.2	1.8	1.8	1.6	1.3	ref	0.8	0.9	ref	1.3	ref	1.1	1.1	1.0	1.2	1.3	ref	1.1	1.0	1.0	0.9
44	Patient did not think hospital staff deliberately misinformed them	2.4	2.0	1.9	1.6	1.3	ref	1.1	1.6	ref	1.0	ref	2.3	2.5	2.5	2.4	2.7	ref	1.1	1.2	1.3	1.4
45	Patient never thought they were given conflicting information	2.7	2.2	2.2	1.8	1.4	ref	0.9	0.9	ref	1.1	ref	1.2	1.1	1.0	0.8	0.9	ref	1.0	1.0	1.0	1.0
46	Hospital staff asked what name the patient preferred to be called by	1.5	2.0	1.9	1.8	1.4	ref	0.8	0.8	ref	1.4	ref	1.4	1.2	1.4	0.9	1.7					
47	Always given enough privacy when discussing condition/treatment	2.3	2.0	2.0	2.0	1.6	ref	0.8	0.8	ref	1.5	ref	1.2	1.1	1.2	1.0	1.1	ref	1.0	1.0	0.9	0.9
48	Always given enough privacy when being examined or treated	3.2	2.7	2.5	2.1	1.5	ref	0.8	1.2	ref	1.2	ref	1.1	1.0	1.1	1.3	0.7	ref	1.0	0.9	0.9	0.9
49	Patient was able to discuss worries and fears with staff	1.6	1.8	1.8	1.7	1.3	ref	1.1	1.2	ref	1.5	ref	1.3	1.6	1.3	1.7	2.6					
50	Hospital staff did everything to help control pain all of the time	3.1	2.4	2.2	1.9	1.4	ref	1.0	1.3	ref	1.2	ref	1.5	1.7	1.1	1.1	1.2	ref	1.0	1.0	1.0	1.0
51	Always treated with respect and dignity by staff	1.8	2.0	1.5	1.6	1.2	ref	0.9	1.1	ref	1.3	ref	1.2	1.4	1.1	1.7	1.3	ref	1.0	0.9	0.9	0.9
52	Given clear written information about what should / should not do post	0.9	1.8	1.3	1.3	1.2	ref	1.0	1.3	ref	1.3	ref	0.9	0.8	0.8	1.1	1.6	ref	0.9	0.9	0.8	0.8
53	Staff told patient who to contact if worried post discharge	0.9	1.7	1.4	1.2	1.1	ref	1.1	1.8	ref	1.4	ref	0.5	0.9	0.9	1.3	1.1	ref	1.1	1.1	1.0	1.1
54	Family definitely given all information needed to help care at home	0.9	1.8	1.8	1.6	1.3	ref	0.9	0.9	ref	1.5	ref	1.0	0.7	0.9	1.1	1.2	ref	1.0	0.9	0.9	0.8
55	Patient definitely given enough care from health or social services	1.0	1.8	1.6	1.4	1.2	ref	1.0	1.1	ref	1.3	ref	1.5	1.5	1.3	1.6	1.8	ref	1.0	1.1	1.1	1.1
56	Staff definitely did everything to control side effects of radiotherapy	1.6	1.6	1.2	1.1	1.0	ref	1.1	1.1	ref	1.2	ref	1.4	1.6	1.8	2.2	1.0	ref	0.9	0.9	0.9	0.8
57	Staff definitely did everything to control side effects of chemotherapy	1.3	1.4	1.3	1.1	1.1	ref	1.1	1.6	ref	1.1	ref	1.2	1.8	1.5	1.5	1.8					
58	Staff definitely did everything they could to help control pain	1.7	1.5	1.3	1.2	1.1	ref	1.2	1.5	ref	1.2	ref	1.3	1.7	1.5	1.6	1.6	ref	0.9	1.0	0.9	0.9
59	Hospital staff definitely gave patient enough emotional support	1.6	2.0	2.0	1.9	1.5	ref	0.9	0.9	ref	1.3	ref	1.2	1.3	1.4	1.4	1.4	ref	1.0	0.9	0.9	0.9
61	Waited no longer than 30 minutes for OPD appointment to start	1.5	1.8	1.9	1.4	1.2	ref	0.9	0.8	ref	1.1	ref	1.4	1.1	0.9	1.4	1.4	ref	1.0	0.9	0.9	0.8
62	Patient thought doctor spent about the right amount of time with them	2.1	2.4	2.4	1.8	1.4	ref	1.0	1.1	ref	1.2	ref	0.6	1.9	1.5	1.6	1.3	ref	1.0	1.1	1.1	1.2
63	Doctor had the right notes and other documentation with them	1.7	2.1	1.6	1.5	1.4	ref	0.8	0.6	ref	0.9	ref	0.5	1.1	0.7	0.9	1.5	ref	0.9	0.9	0.9	0.9
64	GP given enough information about patient's condition and treatment	2.6	2.5	1.9	1.6	1.4	ref	0.8	1.0	ref	1.2	ref	1.5	2.1	1.3	3.5	3.0	ref	1.0	1.1	1.1	1.4
65	Practice staff definitely did everything they could to support patient	1.9	1.7	1.4	1.3	1.2	ref	0.9	1.0	ref	1.2	ref	1.4	1.3	1.3	1.8	1.8	ref	1.0	1.0	1.1	1.2
66	Hospital and community staff always worked well together	2.0	2.2	1.9	1.7	1.4	ref	0.9	1.0	ref	1.2	ref	1.1	1.6	1.3	1.5	2.1	ref	0.9	0.9	0.9	0.8
67	Given the right amount of information about condition and treatment	1.4	1.9	1.9	1.7	1.3	ref	1.0	1.3	ref	1.2	ref	1.5	1.2	1.4	2.3	1.7	ref	1.0	1.1	1.1	1.2
68	Patient was offered a written care plan	1.2	1.8	1.8	1.5	1.2	ref	0.9	1.0	ref	1.1	ref	0.8	0.5	0.5	0.8	0.7					
69	Patient did not feel that they were treated as a set of cancer symptoms	1.6																				

Table 4. Association between cancer diagnosis and patient experience

Diagnosis	Text	DCIS	Breast	Melanoma	Endometrial	Testicular	Cervical	Hodgkin lymphoma	Leukemia	Colon	Non-Hodgkin lymphoma	Laryngeal	Oropharyngeal	Lung	Mesothelioma	Ovarian	Rectal	Bone sarcoma	Prostate	Uteral/vaginal	Stomach	Any other soft tissue sarcoma	Gynaecological NOS	Thyroid	Bladder	Secondary myeloma	Brain	Other Ophthalmic and rarer CNS	Anal	Pancreatic	Renal	Hepatobiliary						
1	Saw GP once/twice before being told had to go to hospital	0.2	0.3	0.5	0.9	1.8	1.0	1.6	1.5	1.2	1.2	1.2	1.7	1.4	1.4	1.4	1.4	1.9	1.9	1.5	1.6	1.0	0.7	0.8	1.3	3.2	1.6	1.3	1.1	2.4	1.0	2.2	1.4	1.3				
2	Patient thought they were seen as soon as necessary	0.1	0.4	0.5	0.6	0.9	1.0	1.1	1.2	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0			
3	% saw a hospital doctor in less than 3 months	0.2	0.6	0.5	0.6	0.9	0.8	1.2	0.9	0.8	1.2	0.9	0.8	0.7	0.7	0.7	0.7	1.1	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9	0.9		
4	Patient's health got better or remained about the same while waiting	0.1	0.2	0.2	0.7	1.0	1.1	1.5	1.9	1.6	1.0	1.1	1.4	2.3	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6	2.6		
5	Staff gave complete explanation of purpose of tests	0.4	0.7	1.2	0.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
6	Staff explained completely what would be done during test	0.6	0.8	1.1	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
7	Given easy to understand written information about test	0.6	1.3	1.5	1.5	1.6	1.1	1.5	2.1	1.1	1.3	1.7	1.6	2.0	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		
8	Given complete explanation of test results in understandable way	0.6	0.8	0.7	0.9	1.1	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
9	Patient told they could bring a friend when first told they had cancer	0.3	0.6	0.8	0.8	0.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
10	Patient felt they were told sensitively that they had cancer	0.3	0.6	0.8	0.8	0.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
11	Patient completely understood the explanation of what was wrong	0.9	0.8	1.0	0.7	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	
12	Patient given written information about the type of cancer they had	0.3	0.7	0.6	0.8	0.7	0.8	0.6	0.9	1.0	0.8	1.2	1.7	1.0	1.4	0.6	1.4	2.3	0.7	1.2	1.2	1.8	2.2	1.6	1.3	1.0	1.8	2.0	2.2	1.3	2.6	2.1	1.6	2.1	2.2	2.2		
13	Patient given a choice of different types of treatment	0.4	0.5	0.6	0.7	0.4	1.2	1.3	0.8	1.3	0.5	1.0	0.8	1.0	0.8	1.0	0.8	1.0	0.8	1.0	0.8	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
14	Patient thinks their views were taken into account when discussing treatment	0.5	0.8	0.7	0.7	0.9	0.8	0.8	1.0	0.8	0.8	1.0	0.8	0.9	1.1	0.9	0.9	1.1	0.9	0.9	1.1	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
15	Possible side effects explained in an understandable way	0.8	0.9	1.2	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
16	Patient given written information about side effects	0.8	0.6	1.1	1.2	0.8	1.5	1.1	0.9	1.8	2.4	0.9	1.0	0.9	0.8	2.7	1.2	1.9	1.3	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4	1.4		
17	Patient definitely involved in decisions about which treatment	0.5	0.7	0.6	0.8	0.8	0.9	0.8	0.9	1.0	1.1	0.9	0.9	1.0	1.1	0.9	0.9	1.0	0.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
18	Patient given the name of the CNS in charge of their care	0.5	0.7	0.6	0.8	1.4	0.7	1.2	2.2	0.9	1.4	1.2	1.5	0.6	0.8	0.6	0.9	1.8	1.6	0.7	1.8	1.0	0.7	2.1	1.5	3.2	2.3	2.3	1.4	3.3	1.4	3.3	2.1	3.3	2.1	3.3		
19	Patient finds it easy to contact their CNS	0.9	1.0	0.6	0.9	1.0	0.8	0.9	0.9	1.1	1.1	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
20	CNS definitely listened carefully the last time spoken to	0.8	1.0	0.6	1.1	0.9	1.4	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
21	Get understandable answers to important questions all/most of the time (CNS)	0.8	0.9	0.7	0.8	1.3	0.6	1.0	0.9	1.2	1.1	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	0.9	1.3	
22	Get understandable answers to important questions all/most of the time (doctor)	0.4	0.4	0.7	0.9	0.6	0.6	1.2	1.0	0.9	0.6	0.9	0.8	0.7	0.6	0.8	0.7	1.1	0.9	0.8	1.1	0.9	0.8	1.1	0.9	0.8	1.1	0.9	0.8	1.1	0.9	0.8	1.1	0.9	0.8	1.1	0.9	0.8
23	Hospital staff gave information about support groups	0.1	0.7	1.1	0.8	0.9	0.6	0.6	0.9	1.1	0.9	0.6	0.7	0.8	0.4	0.1	0.7	0.5	1.7	0.7	0.8	0.8	0.7	0.8	0.7	0.8	0.7	0.8	0.7	0.8	0.7	0.8	0.7	0.8	0.7	0.8	0.7	
24	Hospital staff gave information on getting financial help	2.1	0.9	3.7	1.5	2.1	0.7	1.0	1.5	1.1	0.8	1.1	0.8	1.1	0.9	0.7	1.2	1.6	2.4	1.6	1.1	1.5	1.1	1.5	1.1	1.5	1.1	1.5	1.1	1.5	1.1	1.5	1.1	1.5	1.1	1.5		
25	Hospital staff told patient they could get free prescriptions	1.3	0.8	1.6	2.3	2.3	0.5	0.7	0.9	1.9	2.8	2.2	1.0	1.1	0.9	0.7	0.8	0.9	1.0	4.4	0.8	2.6	1.7	1.4	2.0	3.5	1.0	0.9	1.0	0.4	0.8	0.7	0.8	0.9	1.0	1.0		
26	Patient would have liked to have been asked	0.8	0.6	0.9	1.2	1.3	0.7	1.3	0.9	0.7	0.6	1.0	1.4	1.5	1.4	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		
27	Admission date not changed by hospital	0.6	0.7	0.6	1.0	1.0	1.3	0.8	1.0	0.8	1.1	0.9	1.1	1.0	0.8	1.1	1.0	0.8	0.9	1.3	0.8	0.9	1.0	1.4	1.5	1.3	1.4	1.0	1.4	1.0	1.4	1.0	1.4	1.0	1.4	1.0		
28	Staff gave complete explanation of what would be done	0.5	0.6	1.4	0.5	1.3	0.8	2.2	1.5	1.9	1.2	1.8	0.8	1.3	1.2	1.1	2.9	0.8	1.6	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		
29	Patient given written information about the operation	0.8	0.9	0.7	1.5	0.8	1.3	0.8	0.9	1.1	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
30	Staff explained how operation had gone in understandable way	0.6	0.7	0.5	0.6	0.8	0.9	0.9	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1		
31	Got understandable answers to important questions all/most of the time (doctor)	0.5	0.7	0.5	0.7	0.8	0.9	0.9	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	1.1	0.8	
32	Doctors did not talk in front of patient as if they were not there	0.3	0.5	0.6	0.4	0.5	0.9	0.8	1.0	0.7	1.2	0.9	0.9	1.0	0.9	0.8	0.9	0.8	0.9	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	
33	Patients family definitely had opportunity to talk to doctor	0.5	0.6	0.5	0.7	0.6	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7	0.7		
34	Got understandable answers to important questions all/most of the time (nurse)	0.6	0.7	0.5	0.6	0.8	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0		
35	Patient had confidence and trust in all ward nurses	0.5	0.6	0.4	0.6	0.4	0.7	0.6	0.7	0.9	0.6	0.6	0.8	0.8	0.7																							

groups. For example, among patients with haematological cancers, patients with multiple myeloma were most likely to report poor experience (OR compared with non-Hodgkin lymphoma patients 1.56, 95% confidence interval 1.34–1.82) and within the urology group, compared with patients with bladder cancer, patients with testicular cancer had substantially lower odds of reporting a negative overall experience (OR = 0.59, 95% confidence interval 0.39–0.89) – noting that this difference was adjusted for age.

To aid interpretation, the full crude and case-mix adjusted proportions of patients reporting a negative experience by variable category (age group, gender, ethnic group and cancer diagnosis) for question 70 are shown in Appendix 4. For example, the case-mix adjusted proportion of participants reporting a negative experience was 6% and 8% for patients with ductal carcinoma in situ or breast cancer, whereas it was 18% and 19% for patients with thyroid and hepatobiliary cancer respectively.

Visual summaries of inequalities in patient experience by age, gender, deprivation, ethnic group and cancer diagnosis across survey questions is provided by Tables 3 and 4 and Appendix 3. A brief summary is presented in Box 1. Questions are grouped by domain of care (full details in Appendix 1).

Lastly, given overall consistent inequalities across questions, we examined the average experience of patients across the whole survey. We found significant variation in patient experience by socio-demographic characteristics ( $P < 0.0001$  for all), cancer diagnosis (Fig. 1,  $P < 0.0001$ ) and within cancer specialty group (Fig. 2,  $P < 0.0001$  for five of nine specialty groups, Appendix 5–7). On average, patients with ductal carcinoma in situ, breast cancer and melanoma report the most positive patient experience and those with anal, hepatobiliary, multiple myeloma and small-intestine cancers the least positive, overall consistent with the patterns observed across individual questions. Regarding inequalities within cancer specialty groups, patients with endometrial cancer tended to report more positive experience than patients with ovarian cancer [OR for reporting a poor experience = 0.81 (0.75–0.86),  $P < 0.0001$ ]. There was also heterogeneity in experience among patients with haematological malignancies ( $P < 0.0001$ ), with patients with multiple myeloma reporting the poorest experience [OR for reporting a poorer experience = 1.25 (1.19–1.31) compared with patients with non-Hodgkin lymphoma]. Patients with anal, hepatobiliary and renal cancer also tended to report notably worse experiences compared with patients with other gastrointestinal and urological cancers respectively ( $P < 0.001$ ).

## DISCUSSION

Using data from a large nationwide survey with a relatively high response rate, we describe overall consistent inequalities in the experience of patients with cancer across different survey items. Younger and very old patients and those belonging to ethnic minorities tended to evaluate their care experience more critically across the great majority of questions; to a lesser degree, this is also true for women. There were overall consistent differences in experience among patients with different cancers. For example, among patients with 36 distinct diagnostic groups, patients with melanoma and breast cancer tended to most often report positive experiences and those with hepatobiliary cancer and multiple myeloma were more likely to report negative experiences. Further, there were also substantial differences among patients with different cancers treated by the same clinical specialties, and therefore, within the same MDT service environments. Specifically, patients with ovarian, multiple myeloma, anal, hepatobiliary and renal cancer tended to report worse experiences compared with patients with other gynaecological, haematological, upper gastrointestinal and urological cancers respectively.

The observed socio-demographic differences in experience are concordant with other patient survey evidence (note: not necessarily from patients with cancer) generally suggesting that younger and ethnic minority patients and women provide more critical evaluations of their care (Campbell *et al.* 2001; Weech-Maldonado *et al.* 2003; Mead & Roland 2009; Goldstein *et al.* 2010; Elliott *et al.* 2012; Lyratzopoulos *et al.* 2012a). There are only few previous reports of experience surveys specific to patients with cancer. A US study of the experience of patients with lung and colorectal cancer also indicates worse experiences by ethnic minority patients (Ayanian *et al.* 2010). Using data from the English Cancer Patient Experience surveys, inequalities in the experience of promptness of diagnostic suspicion in primary care, shared decision making and ‘overall’ evaluation of care have been previously reported (Lyratzopoulos *et al.* 2012b; El Turabi *et al.* 2013; Bone *et al.* 2014). The present study substantially amplifies these previous analyses as it explores variation in experience across every survey question and all experience domains (including the experience of diagnosis, treatment and community care, across 64 items). In spite of the observed inequalities among different patient groups, hospital performance in respect of cancer patient experience scores is only marginally affected by patient case-mix; this finding principally reflects the homogeneity of patient case-mix among most English hospitals (Abel *et al.* 2014).



**Box 1.** Summary of disparities in the experience of patients with cancer by cancer diagnosis and socio-demographic characteristics (full visual summary of results in Tables 3 and 4 and Appendix 3).

**Age:** Poor experience across the cancer patient journey is consistently more common among younger ages than older groups, and decreases in older age groups. This is particularly consistent for questions relating to experience of inpatient hospital care. However, there are some notable exceptions.

- Very old patients (i.e., aged 85+) tend to report slightly poorer experience than 75–84-year-olds.
- Younger patients more often report a positive experience for questions relating to provision of information or explanation than older patients, for example regarding treatment side effects (questions 17–18). They also report more positive experience of being offered financial support (question 25) and experience of cancer research (questions 27–29).

**Gender:** Women consistently report poor cancer patient experience more often than men. After adjustment for age, ethnicity and cancer, this gender inequality becomes more apparent than it could be appreciated by simply observing crude patterns of variation. This is partly explained by the overall positive experience of women with breast cancer, masking the poorer experience of female patients with cancer overall.

**Ethnic group:** Patients from White ethnic groups report more positive experiences than patients from ethnic minority groups. The only question where patients from all ethnic minority groups had a more positive experience was for the provision of a written care plan (question 68). Chinese ethnic group patients report the worst experience across most questions.

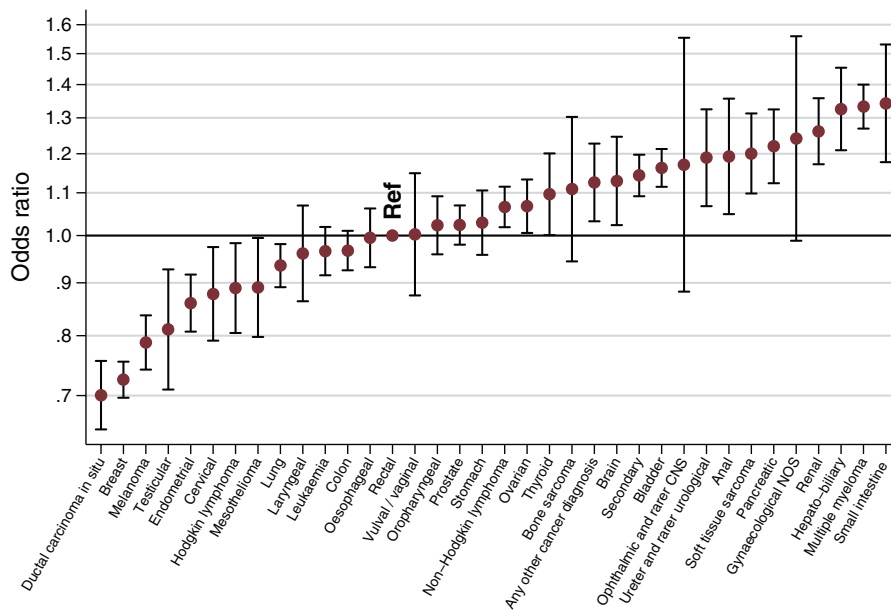
**Deprivation:** There was evidence of (relatively small) disparities in patient experience by socio-economic group for about half the survey items; however, there is no consistent pattern in the direction of this effect.

**Cancer diagnosis:** Positive experiences are most often reported among patients with ductal carcinoma in situ, breast, melanoma, endometrial, cervical and testicular cancers. It should be noted that in crude analysis, two of these cancers (cervical and testicular) are associated with relatively poor reported experience, before adjustment is made for age and other variables (Appendix 5). On the other hand, positive experience was least often reported by patients with anal, pancreatic, renal and hepatobiliary/gall bladder cancers and multiple myeloma.

- There are disparities among specialty groups, for example we note particularly that overall inpatient experience (questions 31–54) among patients with gynaecological cancers is more often positive than for patients with lower gastrointestinal cancers.
- There are also substantial disparities within cancer specialty groups, consistent across questions.
- Finally, there are a few notable associations for individual questions, for example, patients with mesothelioma are very likely to report positive experiences of information about financial support (question 25), reflecting established statutory compensation schemes for this occupational cancer.
- There are only a few questions where the overall patterns of inequality in experience by cancer differ from the general trend. Experience of cancer research (question 27) is one of these; this is perhaps explained by patients with common cancers (such as breast cancer) being less likely to be invited to take part in research than patients with rarer cancers, where the pool of potential research participants is smaller. Experience of outpatient waiting times (question 61) is a further question where inequalities do not follow the general pattern of variation by cancer, but overall variation in experience of outpatient waiting times is not strongly associated with any particular diagnosis.

Strengths of our study include its high (for a postal patient survey) response rate; its nationwide sample; its large population; the inclusion of patients with any type of cancer; and the relatively high completeness of information on exposure variables. Certain limitations ought to also be borne in mind in interpretation. We had no infor-

mation on a range of variables that may influence experience, for example, on health performance status, or the influence of the actual treatments and care experienced by the patients (Ayanian *et al.* 2010). It should also be noted that the proportion of patients in active treatment or in remission (under surveillance) will vary across cancers.



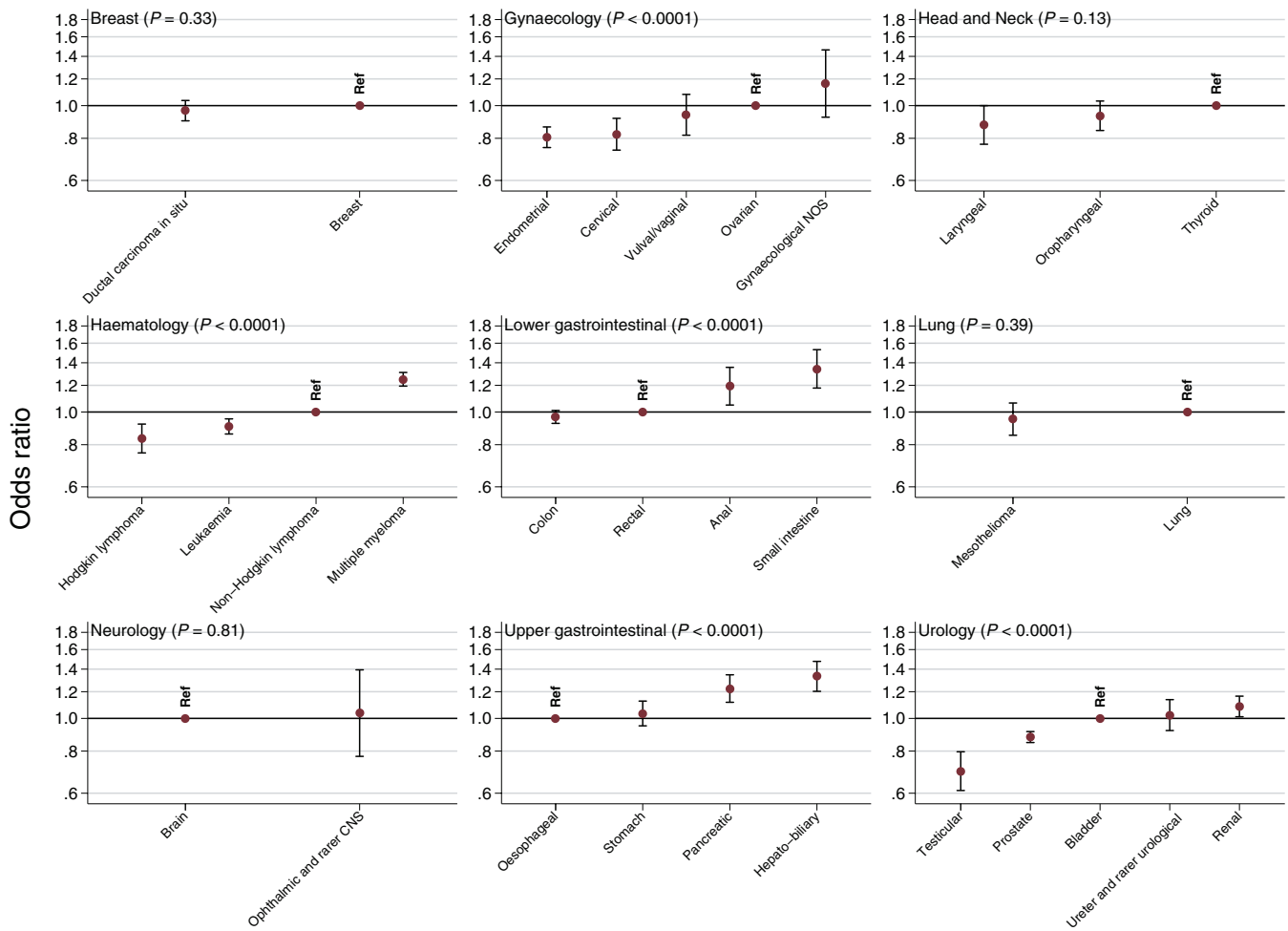
**Figure 1.** Association between cancer diagnosis and overall patient experience (average) across the survey/patient journey. Results are compared with the experience of patients with rectal cancer as a baseline, with a lower odds ratio indicating more positive experiences. Ophthalmic and rarer CNS, ophthalmic and rarer central nervous system; Gynaecological NOS, gynaecological not otherwise specified.

Even in the context of a survey with a relatively high response rate, there is potential for non-response bias. Specifically regarding the overall summary analysis of inequalities by cancer type, it should be noted that it is based on a linear regression model, which essentially represents the adjusted mean variation by cancer across all survey questions. These mean-reported values are therefore susceptible to the influence of outliers and for some cancers, the mean variation in experience may not be the same as the typical variation (e.g., as observed for patients with mesothelioma). In order to characterise variation across all survey questions, it was necessary to consider a large number of models (i.e., for each outcome). We have made no attempt to correct for multiple testing as this concern is inapplicable. Standard corrections for multiple testing are designed to avoid undue attention being given to a small number of significant results that are observed when a large number of tests are considered (often also assuming that tests are independent). This consideration does not apply here as almost all associations presented are statistically significant, which strongly argues against chance findings. Length of time since diagnosis may also differentially influence recall of care experiences; however, previous work found minimal differences in overall patterns of variation by cancer when restricting the analysis to patients diagnosed within the last year (Lyrtzopoulos *et al.* 2012b).

Being diagnosed with cancer in a young age is associated with particular practical and psychological difficulties (NICE 2005; Harrison *et al.* 2009; IOM 2013). It is therefore plausible that younger patients have greater needs for information about their tests, condition and treatment, and com-

munication with their providers. Our findings would indicate that these needs are on the whole not currently being fully met. It is, however, encouraging that, against the overall pattern of differences in experience by age, younger patients reported better experiences in respect of information about their treatment, access to a specialist nurse, information about access to peer and financial support, and participation in cancer research (questions 15, 20, 24, 25 and 27 respectively), concordant with national guidance supporting access to key workers and participation to clinical trials for young patients with cancer (NICE 2005).

Inequalities in experience among different socio-demographic groups, and particularly among patients of different ethnicity, may reflect either variation in actual provision of care or differences in expectations of quality (the so-called 'same care worse experience' hypothesis) (Mead & Roland 2009; Lyrtzopoulos *et al.* 2012a). Understanding the proportion of inequalities that is due to either of these two potential sources of variation is evidently critical for helping to inform appropriate improvement strategies. Distinguishing among differences in expectations of quality and actual differences in delivered care is, however, challenging, and it is likely that ethnic differences in patient experience may be the result of both differences in expectations of care quality and the care that is actually delivered (Mead & Roland 2009; Weinick *et al.* 2011; Lyrtzopoulos *et al.* 2012a; Saunders *et al.* 2014). Communication difficulties, either because of differences in socio-cultural norms of medical consultation or language barriers, can commonly result in poorer experience. Use of translators for patients with limited



**Figure 2.** Association between cancer diagnosis and overall patient experience across the patient journey. Results are presented making comparisons in experience among cancer diagnoses within cancer specialty group. A lower odds ratio indicates more positive experiences. *P*-values are presented, and are a Wald test of whether odds ratios vary within cancer specialty group. Ophthalmic and rarer CNS, ophthalmic and rarer central nervous system; Gynaecological NOS, gynaecological not otherwise specified.

English language skills can help to improve communication and satisfaction with care (Karlner *et al.* 2007). Hospitals with higher levels of 'cultural competency' scores have lower levels of ethnic disparity in patient experience (Weech-Maldonado *et al.* 2012).

We observed substantial inequalities in experience among patients with different cancer diagnoses. It would be unreasonable to assume that, after adjusting for age, gender and ethnicity, patients with different cancers have different prior expectations of care quality. It is theoretically possible that some of the differences may relate to inequalities in the quality of care provided by different specialist services (e.g., haematology compared with urology). However, notable inequalities in experience are observed even between patients with different cancers treated by the same clinical specialty and MDT service environments. Therefore, the observed differences in experience among

patients with different cancers are likely to chiefly reflect disease-specific factors; differences in the promptness of diagnosis, treatment burden and prognosis are likely to be important contributors. For example, among patients with haematological cancers, those with multiple myeloma report the most critical experience, and they are also the patients who are likely to have experienced a greater number of pre-referral consultations with a general practitioner with relevant symptoms (Lyrtzopoulos *et al.* 2012b, 2013). Similarly, among patients with lower gastrointestinal tract cancers, those with anal cancer tend to report the most critical experiences, possibly a reflection of associated treatment burden, as (compared with patients with colon cancer). Appreciation of worse prognosis may also be a factor, as advanced stage is associated with poorer experience of cancer care (Ayanian *et al.* 2010). Independent of their exact causes (in respect of the precise influence

of promptness of diagnosis, treatment burden and prognosis), large within specialty group variations in experience should be considered as indicators of different healthcare needs of patients with different diagnoses. Specialty teams may therefore be able to prioritise interventions to improve the experience of their patients specifically targeting those patients within their specialty with greater needs for patient-centred care. Such interventions can, for example, include the provision of additional information and emotional or peer-support, or additional access and time for communication with nurses or doctors, for patients with diagnoses that confer a higher risk of poorer experience. Although the findings are broadly consistent across the survey, appreciation of patterns of variation in respect of each question (Tables 3 and 4) may help to identify priorities for improving specific aspects of experience for different patient groups. Given the findings, oncology teams specialising in gynaecological, haematological, gastrointestinal and urological cancers could prioritise the development and evaluation of interventions to improve the experience of patients with ovarian, multiple myeloma, anal, hepatobiliary and renal cancer respectively.

In conclusion, we report inequalities in experience among patients with cancer with different characteristics and diagnosis. The findings could guide improvement

efforts targeting patients with cancer who are at greater risk of poorer experience of care. Specialty teams may be able to provide additional (targeted and tailored) support to improve the experience of patients with those cancers associated with greater care needs. Data from the English Cancer Patient Experience Survey provide an example of how nationwide surveys can provide intelligence to help inform and motivate both national and local initiatives to improve the care experience of patients with cancer. Identifying patterns of variation that we describe in other country populations and healthcare settings will be particularly useful.

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## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

**Appendix 1.** Questions, item response and score for all questions.

**Appendix 2.** Cancer ICD-10 codes, diagnosis groups and MDT classifications.

**Appendix 3.** Association between cancer diagnosis and patient experience. Cancers arranged in specialty groups, and sorted within specialty by ranked experience.

**Appendix 4.** Adjusted percentage of patients reporting a negative experience of care (question 70) results come from the model for which odds ratios are presented in Table 2.

**Appendix 5.** Unadjusted and adjusted association between patient socio-demographic characteristics and experience (average measure across all survey questions/the whole patient journey).

**Appendix 6.** Unadjusted and adjusted association between patient cancer diagnosis and experience (average measure across all survey questions/the whole patient journey).

**Appendix 7.** Adjusted ORs for 'overall' experience by cancer diagnosis (average measure across all survey questions/the whole patient journey).