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National Cancer Intelligence Network

English National Cancer Patient Experience Surveys linked to cancer registration data

A descriptive overview of respondents' characteristics

Produced in partnership with Macmillan Cancer Support and Cancer Research UK

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The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

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The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

Contents

Executive summary

This report compares the characteristics of respondents to the English Cancer Patient Experience Surveys (CPES) with a relevant recently diagnosed cancer population which includes patients who were alive at the end of the survey periods.

As well as providing new insights, this work supports future analyses and interpretation of data from the national survey of cancer patients and from the new linked CPES and cancer registration datasets.

The main findings in this report are:

- the quality of the CPES datasets compared to registration is good, with high concurrence for age, date of birth, sex, ethnicity and postcode
- a small proportion (8%) of the respondents have responded to more than one of the three surveys, with more than 70% of these people responding about the same tumour each time
- overall, CPES distributions of patients by sex, region of residence and deprivation were similar to cancer registration data
- there were larger differences with regards to age distribution and ethnicity; this reflects a known bias in the survey responders
- patients with certain cancers were over-represented in CPES while some other cancers under-represented, compared to registration
- CPES had higher proportions of breast, bladder and haematological cancer patients and lower proportions of lung, prostate, head and neck and skin cancer patients

Much of what is described in this report has been made possible by data linkage undertaken by the National Cancer Intelligence Network (NCIN) in partnership with Macmillan Cancer Support and Cancer Research UK.

The linked CPES cancer registration datasets are available for use by analysts and researchers subject to appropriate information governance approvals. For all data access requests please visit the Office for Data Release (ODR) webpage at http://ncin.org.uk/collecting_and_using_data/odr.

Introduction

The National Cancer Patient Experience Survey (CPES), most recently commissioned by NHS England through Quality Health, is a survey sent to cancer patients who have been discharged within a specified period from one of the acute and specialist NHS trusts in England that provide adult cancer services. The survey aims to collect information from patients about their experience of their cancer journey from their initial GP or hospital visit prior to diagnosis, through diagnosis and treatment to the ongoing management of their cancer. Results from all iterations of the surveys are available separately and can be found here: www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey

The NCIN data briefing on the linkage of the English Cancer Patient Experience Survey to cancer registration data (www.ncin.org.uk/view?rid=3036) along with the technical report (www.ncin.org.uk/view?rid=3037) describe the processes involved in linking these datasets. The 2014 survey will be linked with registration data in due course.

This report describes characteristics of CPES respondents and compares those to a population of recently diagnosed cancer patients who were alive at the end of the survey period.

The aims of this report are

- to determine how many patients were surveyed multiple times
- to describe and compare the characteristics of the patients surveyed and to compare them to a cancer population-based dataset
- to support informed analyses of the linked dataset through better understanding of the representativeness of survey respondents

Datasets

The analyses in this report are based on the data from the National Cancer Patient Experience Survey (CPES) for 2010 (Wave 1), 2011/12 (Wave 2) and 2013 (Wave 3) linked to cancer registration data in PHE's Cancer Analysis System (CAS). The cancer registration dataset used in CAS is the snapshot of all cancer registrations taken as at February 2015.

CPES

In England, the CPES is sent to all adult patients (aged 16 and over) admitted to an NHS hospital for cancer either as inpatients or day-cases and discharged during a three month sampling period. Each completed survey contains the patient's answers to survey questions that cover a range of different topics, such as seeing the GP, diagnostic tests, support for people with cancer and cancer research, among other information.

This report relates to the English Cancer Patient Experience Survey – more recently similar surveys have been conducted or are in progress in other UK countries.

Cancer registration data

A snapshot of the cancer registration data in CAS is generated once a month. The table AV_tumour in the February 2015 snapshot (CAS1502) includes all cancers diagnosed up to 2013. It contains extensive data about English patients diagnosed with cancer, with multiple records for any individuals diagnosed with more than one tumour. There is also information on patient demographics, tumour characteristics and treatment events. This information was linked to the CPES datasets.

Methods

Initial Linkage

In this report, the three CPES datasets/surveys are referred to as Waves 1, 2 and 3.

Wave 1: the 2010 survey, sent to patients discharged between 1 January 2010 and 31 March 2010.

Wave 2: the 2011/12 survey, sent to patients discharged between 1 September 2011 and 30 November 2011.

Wave 3: the 2013 survey, sent to patients discharged between 1 September 2012 and 30 November 2012.

The 2014 survey will be linked to cancer registration data in due course.

Records of patients in the CPES datasets were matched to the cancer registration data first by the patients' NHS numbers and then by tumour type to identify the tumour records in CAS that corresponded to the correct CPES response.

The full methodology of the linkage including descriptions of the variables present in the linked datasets can be found in the technical report on the NCIN website (http://ncin.org.uk/cancer_information_tools/cancer_patient_experience).

Characteristics of survey respondents

The case-mix of respondents with respect to sex, age at time of survey, region of residence, ethnicity and socio-economic deprivation were used to describe the patients who responded to the surveys. Variable categories (eg age groups) were aligned to those used by Quality Health for public reporting of data from these surveys.

The geographic breakdown of respondents is presented at regional level to give an overview of the variation across England. Each patient was assigned to a socio-economic deprivation quintile based on their CPES postcode of residence and income domain of the Indices of Multiple Deprivation 2010, adjusted to align Income Domain scores with 2011 boundaries for Lower Layer Super Output Areas (LSOAs).

We examine and discuss here the characteristics of patients in Wave 2. Similar patterns exist when examining respondents in Waves 1 and 3 (results included in the appendix).

The majority of results presented in this report are based on analyses for all tumour sites combined. Detailed data by cancer site can be found in the accompanying 'Descriptive Report Workbook' on the NCIN website (http://ncin.org.uk/cancer_information_tools/cancer_patient_experience).

Comparison of the characteristics of CPES respondents with a relevant population of cancer patients

To allow comparison to the cancer registration data, we defined a comparative cohort of incident cases who were diagnosed within a year before and up to the end of the survey period, and were alive at the end of that period. This was defined as the comparator population of cancer patients.

For example, Wave 2 (1 September 2011 to 30 November 2011) respondents are compared to patients who were diagnosed with cancer between the 1 September 2010 and 30 November 2011 and were still alive on 30 November 2011. This comparator population is referred to as 'Cancer Registration 2011' in this report.

Both absolute and relative differences between respondents and the comparator population are tabulated.

It should be noted that the choice of this comparator population was pragmatic; a range of relevant comparators (eg incident or prevalent cancer cases) exist, and future work could address such comparisons.

Concordance of attributes between CPES and comparator population

Data recorded on sex, date of birth, postcode and ethnicity were compared between data from CPES and from CAS to see how well the datasets were matched on key attributes.

Patients who responded to the survey multiple times

Patients who responded to the survey more than once across the three surveys were identified by their NHS number. A patient was considered to have responded multiple times if records of their responses appeared more than once across the three survey datasets.

Patients could be surveyed for the same tumour across the surveys or they could be asked about a different tumour for different surveys. The recorded ICD-10 codes in the CPES and cancer registration data were compared at three digit and ten digit levels. Patients were grouped as to whether they were surveyed in two surveys (Wave 1 and Wave 2, Wave 1 and Wave 3, Wave 2 and Wave 3) or all three surveys.

Distribution by selected cancer site

The distribution of respondents across the three waves has also been tabulated by selected cancer site to show variations across time. The sites were selected based on their occurrence in CPES. Sites with less than 1,000 cases in any year were grouped as ‘Other cancers’. Similarly, the distribution of cancer registrations by cancer site is also presented to aid comparisons between the two data sources.

Results

Concordance of attributes between CPES and comparator population

Table 1 shows the numbers and proportions of records where the information recorded in the CPES datasets was the same as that recorded in the cancer registration data. It shows that concordance of information for sex, postcode and date of birth were high across the three waves. The details on date of birth recorded in Wave 1 CPES were the same in around 78% of records but improved for Wave 2 and Wave 3.

Table 1. Concordance of attributes between CPES Waves 1, 2 and 3, and corresponding comparator population in 2011 to 2013

	Wave 1		Wave 2		Wave 3	
	n	% of total	n	% of total	n	% of total
Sex	54,691	100.0%	57,986	99.8%	56,092	100.0%
Date of birth	42,786	78.2%	57,894	99.6%	55,937	99.7%
Patient recorded ethnicity	40,756	74.5%	45,201	77.8%	41,940	74.7%
Postcode	52,861	96.6%	56,138	96.6%	54,345	96.9%

Patients who responded to the survey multiple times

The linked dataset gives us the opportunity to identify patients who responded to the survey multiple times across the three periods.

There are people surveyed multiple times in CPES over the three years. The proportions of those re-surveyed in a later wave were 6%, 10% and 10%, respectively for Wave 1, Wave 2 and Wave 3.

As shown in Table 2, around 78% of respondents who were surveyed in waves 1 and 2 had the same tumour type to level of 3 digits in ICD-10 code. Among those surveyed in consecutive waves, the proportions with the same tumour (measured by ICD-10 3 digits) is around 77% overall. This suggests that around 1,400 people who responded to the survey had been receiving treatment for the same cancer over at least the previous 2 years (there is a 26 month gap between the survey period of the first and last wave).

There were more people who responded to both waves 2 and 3 and there was a higher concordance of tumour types at 4 digits for this group. The time interval between the three different waves of the survey is likely to have influenced these figures. The number of people responding to multiple surveys with the higher figures between waves 2 and 3 is probably due to a shorter between-survey interval (9 months) compared to the between-survey interval between waves 1 and 2 (17 months).

Table 2. Patients who were surveyed multiple times across different waves*

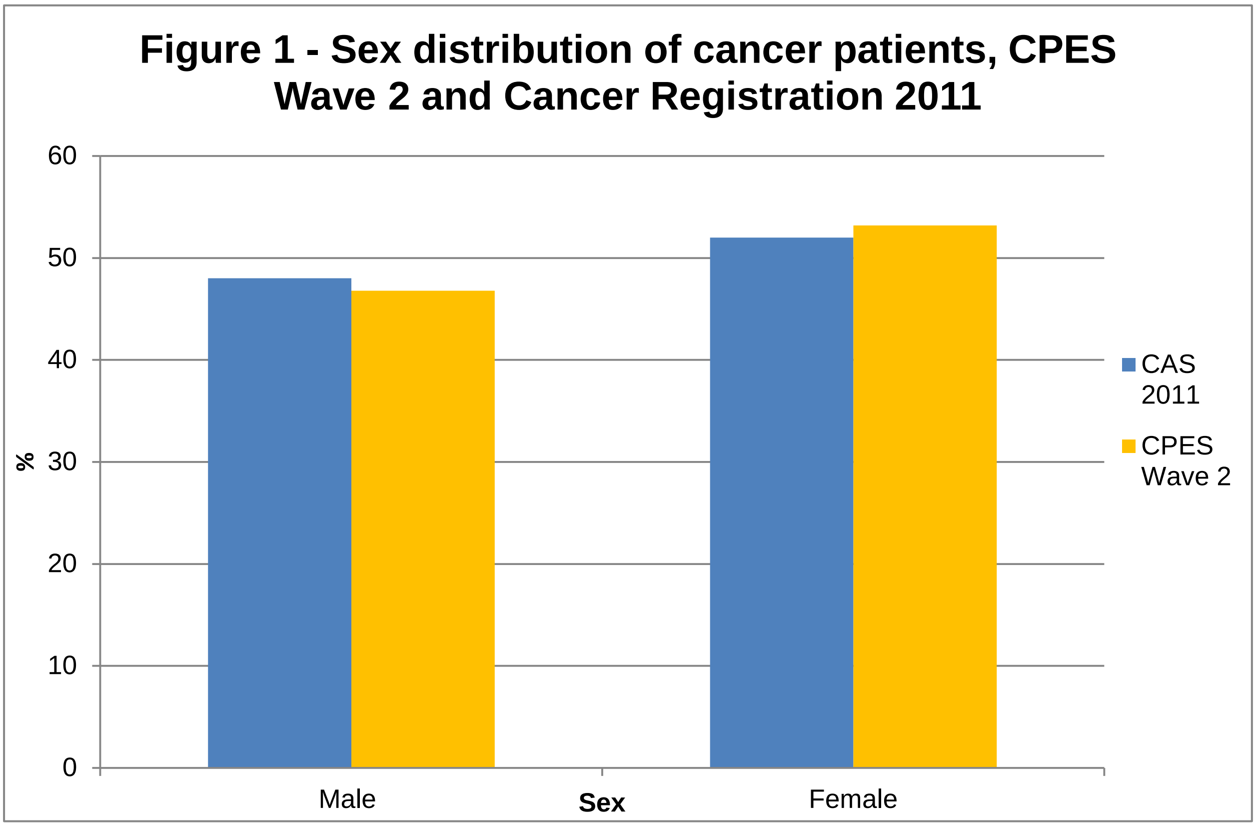
	Wave 1 and Wave 2	Wave 1 and Wave 3	Wave 2 and Wave 3	All Waves
	n	n	n	n
Patients surveyed in the specified waves (a)	3,773	1,620	6,936	1,408
Patients with same ICD10- 4 digits (% of a)	1,610 (42.7%)	582 (35.9%)	5,126 (73.9%)	583 (41.4%)
Patients with same ICD10- 3 digits (% of a)	2,950 (78.2%)	1,104 (68.2%)	5,752 (82.9%)	1,081 (76.8%)

*This table is based on all records with a valid NHS number.

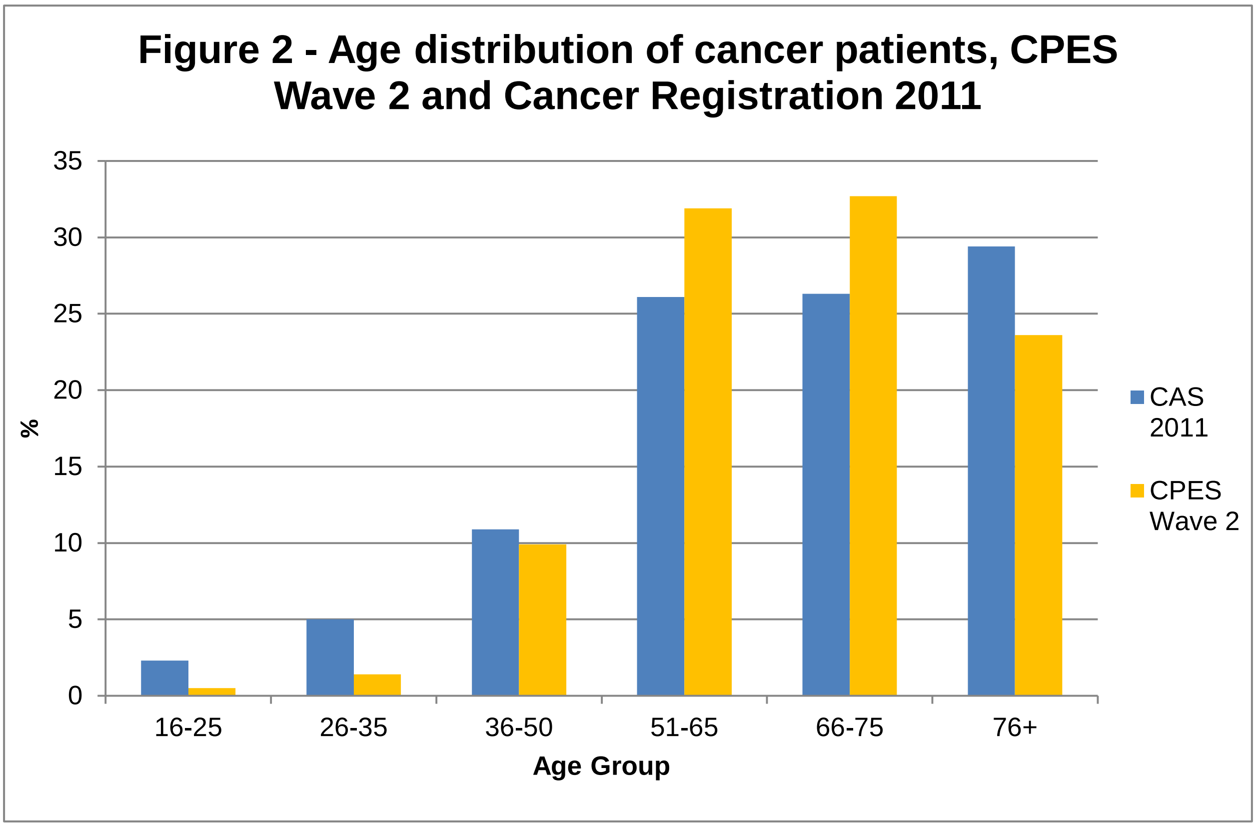
Patients' characteristics and comparison of CPES respondents to the English cancer population

Figures 1 to 5 show the distributions of Wave 2 CPES respondents by the case-mix variables and the relevant cancer population, in this case Cancer Registration 2011. The results for all Waves are presented in the appendix.

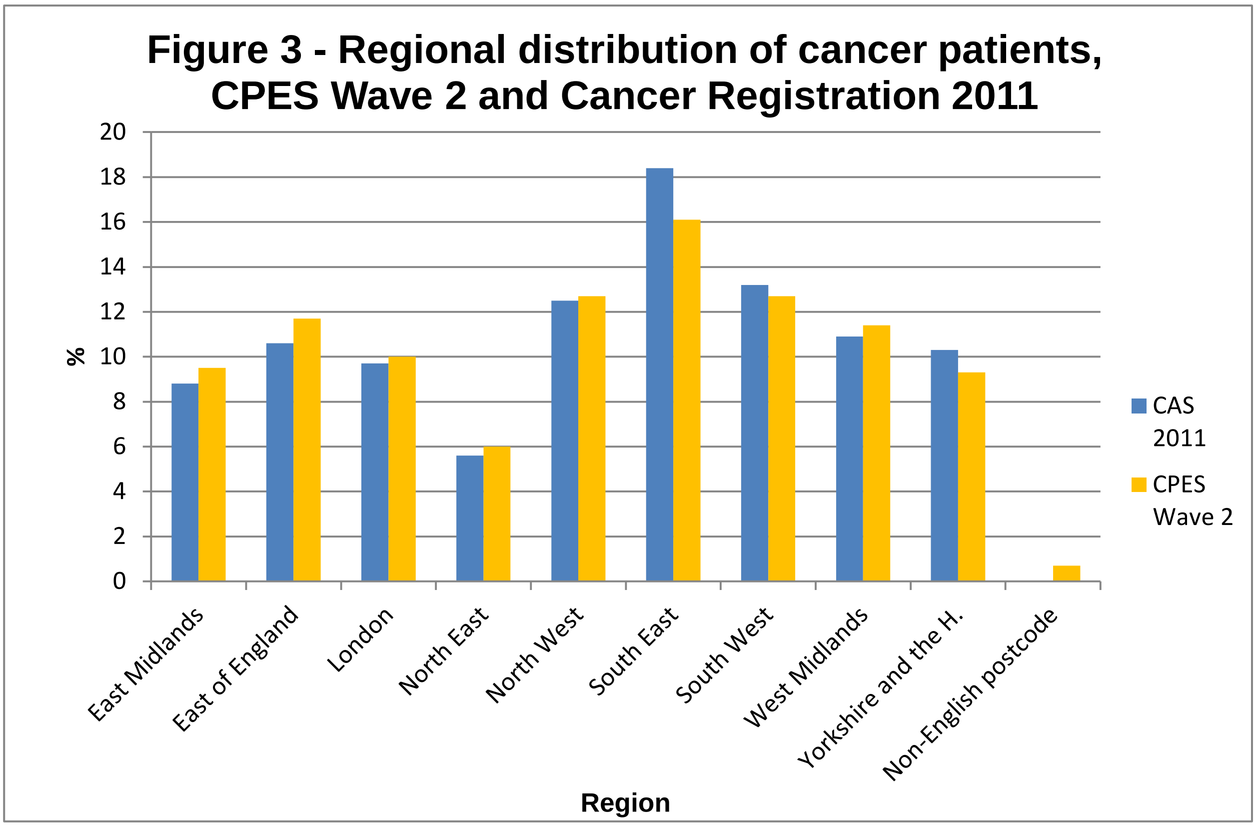
Figure 1 shows there were small differences in the proportion of patients of either sex between respondents and the comparator population.



In contrast, Figure 2 shows that there was a relative over-representation of cancer patients in the middle age groups (51-75) and a relative under-representation of patients in the younger (<50) and older (76+) age groups within CPES Wave 2 compared to the comparator population.



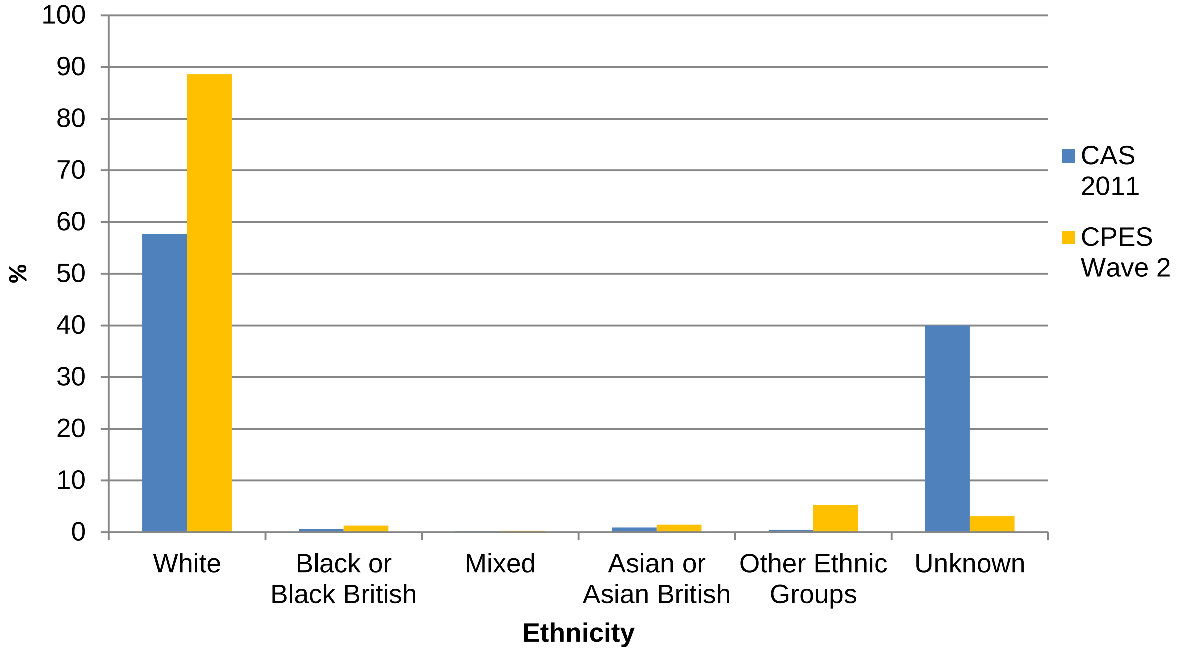
Regarding how cancer patients were regionally distributed, Figure 3 shows those proportions. There is a slightly lower proportion from the South East among CPES respondents.



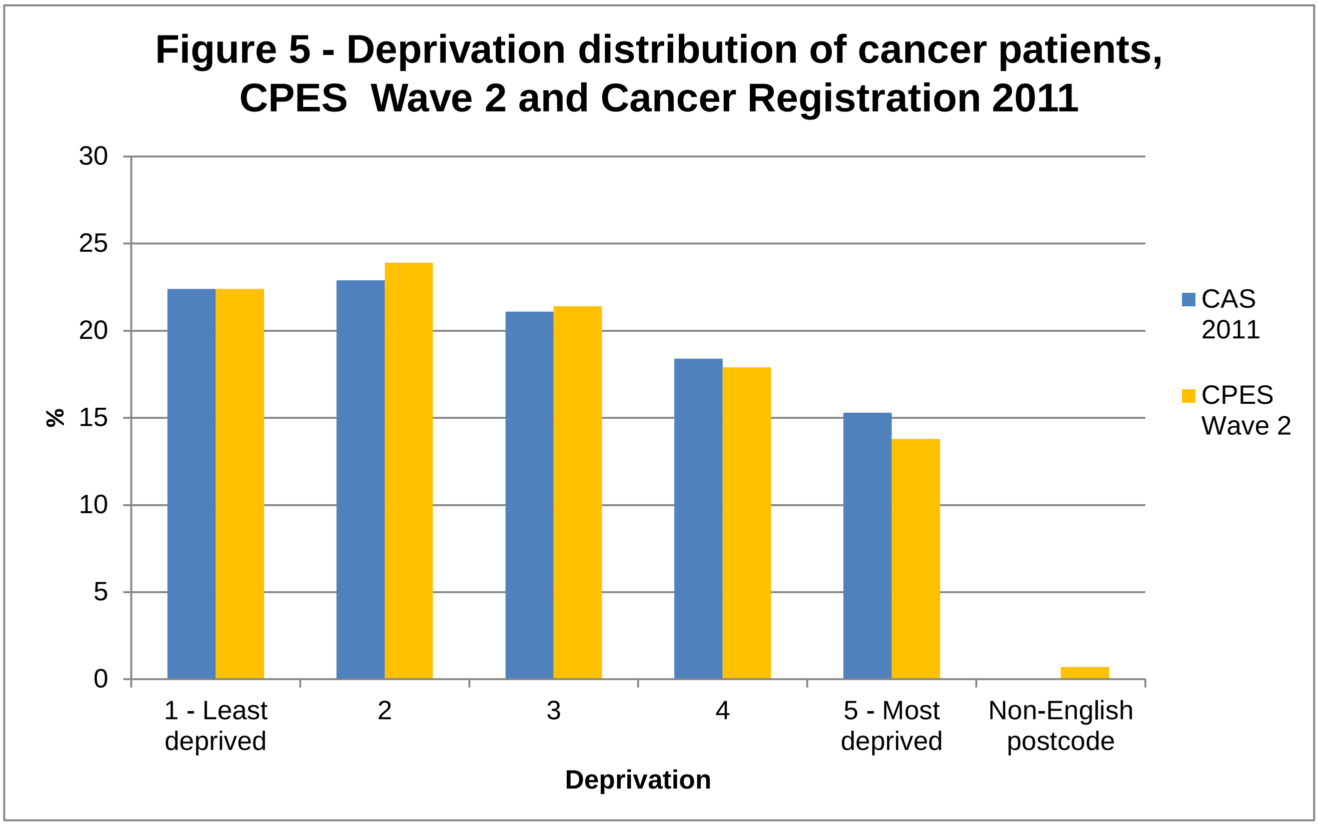
Note: 409 people responding to CPES in Wave 2 had a non-English postcode.

There was notable over-representation of White patients among CPES respondents, with substantial under-representation of the 'Unknown' group, as shown in Figure 4.

Figure 4 - Ethnicity distribution of cancer patients, CPES Wave 2 and Cancer Registration 2011



There were small differences in the distribution of patients by deprivation between CPES respondents and the comparator population, as shown in Figure 5.

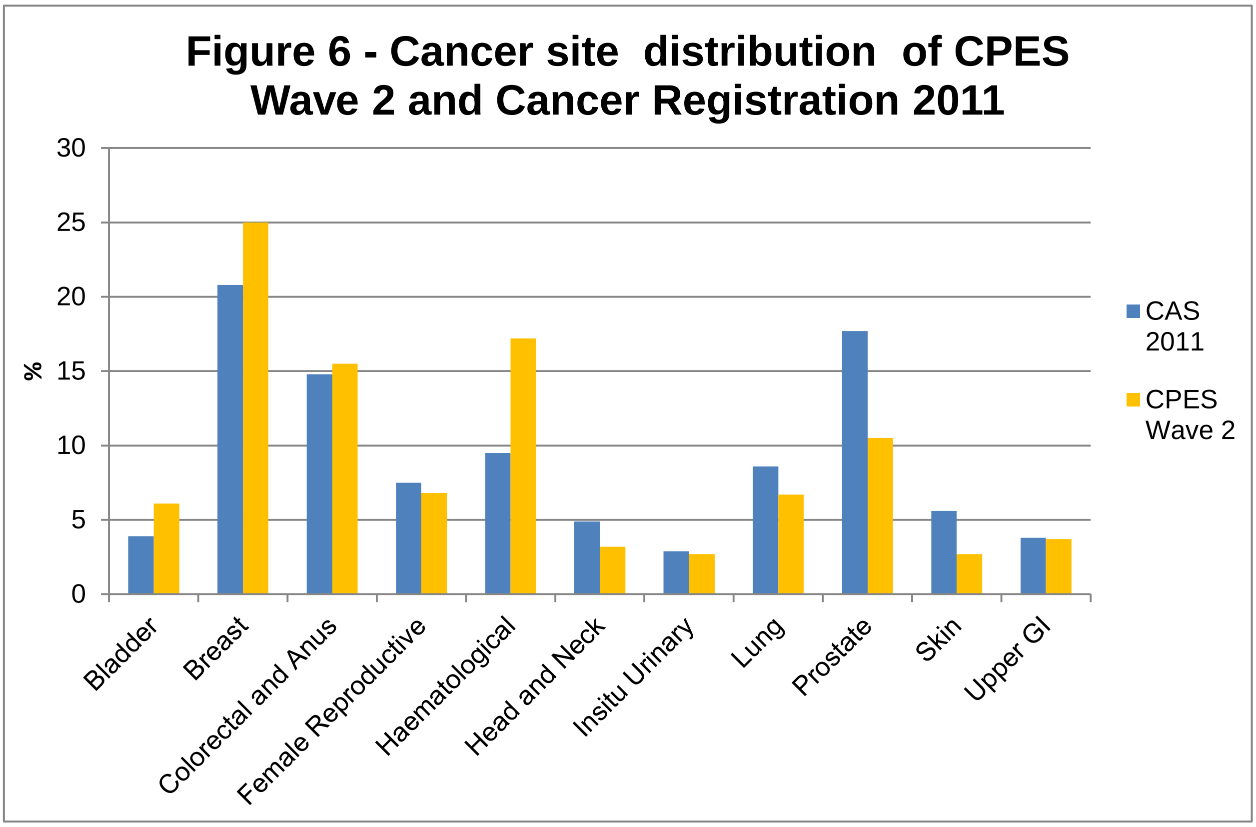


Note: 409 people responding to CPES Wave 2 had a non-English postcode.

In a sensitivity analysis we restricted the sample of CPES respondents to those diagnosed in the previous year before responding to the survey, making them more similar to the comparator population. This analysis resulted in similar results for region and deprivation, but accentuated age and ethnic group differences, and reversed sex proportions (with men predominating, possibly due to the change in the distribution of cancer sites).

Distribution by cancer site

Figure 6 shows the distributions of patients in CPES Wave 2 and also the comparator population of the cancer registrations by selected cancer sites. There were more patients diagnosed with breast, colorectal and haematological cancers across the three surveys compared with other cancer sites.



*Note: Cancer sites under 1,000 patients in CPES respondents are grouped under 'Other cancers' in both CPES and the comparator. Those account for about 10% of all cases in CPES and 50% in CAS. Given this skewness, they were not included in the calculation of the cancer proportions presented above.

In comparison to the population-based cohort of recently diagnosed cancer survivors (cancer registrations), CPES respondents are more likely to have breast, bladder and haematological tumours and less likely to have lung, prostate, head and neck and skin tumours. However, the proportions of patients with upper GI, female reproductive and insitu urinary tumours appear to be similar (discounting 'Other cancers').

The differences found are likely to reflect a range of factors, including:

- different site-specific patterns of short-term mortality
- variable non-response between patients with different cancers (possibly mediated by disease severity)

- variable (by cancer site) inpatient or day-case care patterns, resulting in patients with some tumours (eg bladder and haematological tumours) having a higher chance of being surveyed in any given sampling period due to multiple hospital care episodes compared with patients with other tumours

Strengths and limitations

The CPES datasets provide vast potential as resources on cancer patients' appraisal of their experience and self-reported characteristics. The linkage to cancer registration data increases that potential by enabling comparison with clinical information and outcomes. Comparisons of the characteristics of respondents with other relevant populations of cancer patients could better inform the design and interpretation of further analysis using data from such surveys.

This descriptive overview compares people responding to the CPES with a comparator population drawn from CAS. Notably the CPES respondents are from a population of people recently discharged following inpatient or day-case activity, while the comparator cancer population is a group of recently diagnosed survivors. The representation of certain cancers may be particularly affected by these different frames – for example:

- people with a poor prognosis cancer, such as lung cancer, may die or be too ill and not receive or complete a survey within the survey follow up period
- people with cancers which may be managed outside of the hospital setting, such as some men with prostate cancer on watch and wait, would be less likely to receive a survey

For the purpose of this descriptive report, patients who were successfully matched by NHS number and tumour site between CPES and the cancer registration data were included in most of the analyses. The analyses presented here exclude approximately 15% of respondents in each of the survey years due to the lack of a tumour match to the cancer registration data. The lack of a match for both NHS number and tumour site could be related to various factors, for example registration limitations including missing information or invalid NHS number.

There were 399, 409 and 386 respondents in Waves 1, 2 and 3, respectively, that did not have a valid English postcode. They were patients from other UK countries, such as Wales and Scotland, receiving treatment in England. Given the lack of an English postcode, no deprivation code or region could be assigned to them. They are shown under the category 'Unknown' on the tables.

Information on ethnicity used for the comparison was based on the cancer registration data and could be improved by using the ethnicity information derived from Hospital Episodes System (HES).

Conclusions

This report establishes some basic characteristics of the cohorts of respondents from the Cancer Patient Experience Survey compared with a population of recently diagnosed cancer patients who were alive at the end of the survey period.

The main findings in this report indicate that there is:

- some skewness in the age, ethnicity and cancer site distribution of respondents to the surveys compared with recently diagnosed cancer survivors
- a high concordance of basic patient characteristics in the two datasets
- a noteworthy proportion of patients who responded to multiple surveys

The observed patterns of variation should be interpreted in conjunction with evidence about early mortality and non-response patterns. There will also be differences in the use of hospital services for different cancers.

Further work can support interpretation of findings from the surveys and the new linked dataset and inform future analyses.

Project Team and Acknowledgements

This report was prepared by Isabella Carneiro and Anna Fry who are CRUK-NCIN partnership analysts and James Charnock, who is a Macmillan-NCIN partnership analyst.

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Special thanks to the CPES Consortium that provided support, guidance and resources for this project, and to the patients who have responded to the surveys.

We would like to acknowledge the essential work of the National Cancer Registration Service and Quality Health, without whom we would not have any cancer registration or CPES data.

Appendix

Table 1 shows the characteristics of those that were not matched by NHS number to the cancer registration dataset. As can be seen, there is an over representation of males, older age groups, residents of London and White respondents.

Tables 2, 3 and 4 present the socio-demographic characteristics of CPES respondents compared with the comparator population by cancer sites in 2010, 2011 and 2013, respectively.

Table 1. Characteristics of the CPES respondents that were not matched to cancer registry data via an NHS number

	Wave 1		Wave 2		Wave 3	
	n	%	n	%	n	%
Sex						
Male	572	50.1%	322	58.4%	363	54.9%
Female	570	49.9%	229	41.6%	298	45.1%
Age group*						
16 – 25	8	0.7%	4	0.7%	11	1.7%
26 - 35	23	2.0%	9	1.6%	17	2.6%
36 - 50	160	14.0%	62	11.3%	63	9.5%
51 - 65	378	33.1%	177	32.1%	225	34.0%
66 - 75	335	29.3%	162	29.4%	189	28.6%
76 +	238	20.8%	137	24.9%	156	23.6%
Region						
East Midlands	49	4.3%	25	4.5%	31	4.7%
East of England	44	3.9%	38	6.9%	15	2.3%
London	163	14.3%	117	21.2%	208	31.5%
North East	27	2.4%	35	6.4%	34	5.1%
North West	54	4.7%	93	16.9%	66	10.0%
South East	156	13.7%	72	13.1%	114	17.2%
South West	421	36.9%	15	2.7%	8	1.2%
West Midlands	155	13.6%	82	14.9%	87	13.2%
Yorkshire and the Humber	34	3.0%	34	6.2%	36	5.4%
Unknown	39	3.4%	40	7.3%	62	9.4%
Ethnicity						
White	981	85.9%	449	81.5%	509	77.0%
Black or black British	18	1.6%	17	3.1%	26	3.9%
Mixed	5	0.4%	6	1.1%	1	0.2%
Asian or Asian British	30	2.6%	11	2.0%	24	3.6%
Other ethnic groups	14	1.2%	10	1.8%	14	2.1%
Unknown	94	8.2%	58	10.5%	87	13.2%
Deprivation						
1 - Least deprived	178	15.6%	95	17.2%	129	19.5%
2	238	20.8%	115	20.9%	128	19.4%
3	277	24.3%	99	18.0%	106	16.0%
4	236	20.7%	109	19.8%	127	19.2%
5 - Most deprived	174	15.2%	93	16.9%	109	16.5%
Non-English postcode	39	3.4%	40	7.3%	62	9.4%
Total	1,142	100%	551	100%	661	100%

Table 2. Population socio-demographic characteristics, Wave 1 of CPES and comparator population cohort in 2010

	CPES Wave 1 (N= 55,941)		Cancer registration ref (N=440,171)		Absolute difference	Relative diff. to cancer registration
	n	(%) (a)	n	(%) (b)	(a-b).	(a-b)/b
Sex						
Men	25,894	46.3%	207,802	47.2%	-0.9	-1.9
Women	30,047	53.7%	232,369	52.8%	0.9	1.7
Age group						
16-25	361	0.6%	9,473	2.2%	-1.6	-72.7
26-35	928	1.7%	27,178	6.2%	-4.5	-72.6
36-50	6,202	11.1%	50,291	11.4%	-0.3	-2.6
51-65	19,071	34.1%	115,004	26.1%	8.0	30.7
66-75	17,401	31.1%	111,737	25.4%	5.7	22.4
76+	11,978	21.4%	126,488	28.7%	-7.3	-25.4
Region						
East Midlands	5,554	9.9%	39,938	9.1%	0.8	8.8
East of England	6,691	12.0%	52,168	11.9%	0.1	0.8
London	6,070	10.9%	42,210	9.6%	1.3	13.5
North East	3,194	5.7%	22,992	5.2%	0.5	9.6
North West	6,700	12.0%	58,552	13.3%	-1.3	-9.8
South East	8,203	14.7%	75,354	17.1%	-2.4	-14.0
South West	6,778	12.1%	58,857	13.4%	-1.3	-9.7
West Midlands	6,306	11.3%	45,576	10.4%	0.9	8.7
Yorkshire and the Humber	6,046	10.8%	44,524	10.1%	0.7	6.9
Unknown	399	0.7%	0	0%	0.7	na
Ethnicity						
White	49,214	88.0%	261,273	59.4%	28.6	48.1
Black or black British	709	1.3%	3,172	0.7%	0.6	85.7
Mixed	165	0.3%	774	0.2%	0.1	50.0
Asian/Asian British	842	1.5%	4,065	0.9%	0.6	66.7
Other ethnic groups	444	0.8%	2,101	0.5%	0.3	60.0
Unknown	4,567	8.2%	168,786	38.3%	-30.1	-78.6
Deprivation						
1 - Least deprived	12,307	22.0%	97,762	22.2%	-0.2	-0.9
2	13,187	23.6%	100,456	22.8%	0.8	3.5
3	12,063	21.6%	93,193	21.2%	0.4	1.9
4	10,110	18.1%	81,025	18.4%	-0.3	-1.6
5- Most deprived	7,875	14.1%	67,735	15.4%	-1.3	-8.4
Non-English postcode	399	0.7%	0	0.0%	0.7	na

Table 3. Population socio-demographic characteristics, Wave 2 of CPES and comparator population cohort in 2011

	CPES Wave 2 (N= 59,919)		Cancer registration ref (N=447,072)		Absolute difference	Relative diff. to cancer registration
	n	(%) (a)	n	(%) (b)	(a-b).	(a-b)/b
Sex						
Men	28,048	46.8%	214,680	48.0%	-1.2	-2.5
Women	31,871	53.2%	232,392	52.0%	1.2	2.3
Age group						
16-25	303	0.5%	10,330	2.3%	-1.8	-78.3
26-35	849	1.4%	22,492	5.0%	-3.6	-72.0
36-50	5,903	9.9%	48,586	10.9%	-1.0	-9.2
51-65	19,107	31.9%	116,683	26.1%	5.8	22.2
66-75	19,607	32.7%	117,669	26.3%	6.4	24.3
76+	14,150	23.6%	131,312	29.4%	-5.8	-19.7
Region						
East Midlands	5,685	9.5%	39,416	8.8%	0.7	8.0
East of England	6,989	11.7%	47,467	10.6%	1.1	10.4
London	5,987	10%	43,372	9.7%	0.3	3.1
North East	3,599	6%	24,904	5.6%	0.4	7.1
North West	7,618	12.7%	55,852	12.5%	0.2	1.6
South East	9,623	16.1%	82,220	18.4%	-2.3	-12.5
South West	7,635	12.7%	59,233	13.2%	-0.5	-3.8
West Midlands	6,809	11.4%	48,537	10.9%	0.5	4.6
Yorkshire and the Humber	5,565	9.3%	46,071	10.3%	-1.0	-9.7
Unknown	409	0.7%	0	0.0%	0.7	n/a
Ethnicity						
White	53,075	88.6%	257,930	57.7%	30.9	53.6
Black or black British	770	1.3%	3,160	0.7%	0.6	85.7
Mixed	162	0.3%	744	0.2%	0.1	50.0
Asian/Asian British	888	1.5%	4,108	0.9%	0.6	66.7
Other ethnic groups	542	0.9%	2,259	0.5%	0.4	80.0
Unknown	4,482	7.5%	178,871	40%	-32.5	-81.3
Deprivation						
1 - Least deprived	13,398	22.4	100,057	22.4%	0.0	0.0
2	14,329	23.9	102,325	22.9%	1.0	4.4
3	12,808	21.4	94,275	21.1%	0.3	1.4
4	10,699	17.9	82,155	18.4%	-0.5	-2.7
5- Most deprived	8,276	13.8	68,260	15.3%	-1.5	-9.8
Non-English postcode	409	0.7%	0	0.0%	0.7	n/a

Table 4. Population socio-demographic characteristics, Wave 3 of CPES and comparator population cohort in 2013

	CPES Wave 3 (N= 57,906)		Cancer registration ref (N=445,663)		Absolute difference	Relative diff. from cancer registration
	n	(%) (a)	n	(%) (b)	(a-b)	(a-b)/b
Sex						
Men	26,896	46.4%	213,040	47.8%	-1.4	-3.0
Women	31,010	53.6%	232,623	52.2%	1.4	2.6
Age group						
16-25	237	0.4%	10,578	2.4%	-2.0	-83.3
26-35	813	1.4%	23,813	5.3%	-3.9	-73.6
36-50	5,509	9.5%	48,559	10.9%	-1.4	-12.8
51-65	17,751	30.7%	115,150	25.8%	4.9	19.0
66-75	19,756	34.1%	117,520	26.4%	7.7	29.2
76+	13,840	23.9%	130,043	29.2%	-5.3	-18.2
Region						
East Midlands	5,459	9.4%	37,026	8.3%	1.1	13.3
East of England	6,917	11.9%	49,137	11.0%	0.9	8.2
London	5,888	10.2%	43,791	9.8%	0.4	4.1
North East	3,370	5.8%	24,242	5.4%	0.4	7.4
North West	7,439	12.8%	55,740	12.5%	0.3	2.4
South East	9,158	15.8%	80,958	18.2%	-2.4	-13.2
South West	7,058	12.2%	60,475	13.6%	-1.4	-10.3
West Midlands	6,320	10.9%	50,957	11.4%	-0.5	-4.4
Yorkshire and the Humber	5,911	10.2%	43,337	9.7%	0.5	5.2
Unknown	386	0.7%	0	0.0%	0.7	na
Ethnicity						
White	50,093	86.5%	239,996	53.9%	32.6	60.5
Black or black British	748	1.3%	3,146	0.7%	0.6	85.7
Mixed	205	0.4%	714	0.2%	0.2	100.0
Asian/Asian British	941	1.6%	4,032	0.9%	0.7	77.8
Other ethnic groups	602	1.0%	2,652	0.6%	0.4	66.7
Unknown	5,317	9.2%	195,123	43.8%	-34.6	-79.0
Deprivation						
1 - Least deprived	13,397	23.1%	98,615	22.1%	1.0	4.5
2	13,826	23.9%	101,878	22.9%	1.0	4.4
3	12,439	21.5%	94,531	21.2%	0.3	1.4
4	10,094	17.4%	81,956	18.4%	-1.0	-5.4
5- Most deprived	7,764	13.4%	68,683	15.4%	-2.0	-13.0
Unknown	386	0.7%	0	0.0%	0.7	na

Tables 5, 6 and 7 present the comparison of CPES respondents with the comparator population by cancer sites in 2010, 2012 and 2013, respectively.

Table 5 . Distribution of Wave 1 of CPES and comparator population cohort in 2010 by selected cancer sites*

	CPES Wave 1 (N= 5,941)		Cancer registration ref (N=439,350)		Absolute difference	Relative diff. to cancer registration
	n	(%) (a)	n	(%) (b)	(a-b).	(a-b)/b
Colorectal and anus	7,823	15.5%	33,165	14.6%	0.9	0.1
Lung	3,131	6.2%	18,777	8.3%	-2.1	-0.3
Breast	13,129	26.0%	47,734	21.0%	5.0	0.2
Prostate	5,080	10.0%	41,369	18.2%	-8.1	-0.4
Head and neck	1,656	3.3%	10,827	4.8%	-1.5	-0.3
Upper GI	1,965	3.9%	8,841	3.9%	0.0	0.0
Bladder	3,397	6.7%	9,019	4.0%	2.7	0.7
Haematological	8,372	16.5%	21,795	9.6%	7.0	0.7
Skin	1,174	2.3%	11,855	5.2%	-2.9	-0.6
Female reproductive	3,428	6.8%	17,356	7.6%	-0.9	-0.1
Insitu urinary	1,433	2.8%	6,714	3.0%	-0.1	0.0
Sub-total (a)*	50,588	100%	227,452	100%	na	na
Other cancers (b)	5,353	na	211,898	na	na	na
Total (a+b)	55,941	na	439,350	na	na	na

*Note: Cancer sites under 1,000 patients in CPES are under 'Other cancers' in both CPES and the comparator. Those account for about 10% of all cases in CPES and 50% in CAS.
Given this skewness, they were not included in the calculation of the cancer proportions presented above.

Table 6 . Distribution of Wave 2 of CPES and comparator population cohort in 2011 by selected cancer sites*

	CPES Wave 2 (N= 59,919)		Cancer registration ref (N=446,789)		Absolute difference	Relative diff. to cancer registration
	n	(%) (a)	n	(%) (b)	(a-b).	(a-b)/b
Colorectal and anus	8,420	15.5%	35,063	14.8%	0.8	0.1
Lung	3,624	6.7%	20,440	8.6%	-1.9	-0.2
Breast	13,553	25.0%	49,449	20.8%	4.2	0.2
Prostate	5,676	10.5%	42,063	17.7%	-7.2	-0.4
Head and neck	1,735	3.2%	11,756	4.9%	-1.7	-0.4
Upper GI	2,009	3.7%	8,967	3.8%	-0.1	0.0
Bladder	3,284	6.1%	9,189	3.9%	2.2	0.6
Haematological	9,349	17.2%	22,682	9.5%	7.7	0.8
Skin	1,452	2.7%	13,214	5.6%	-2.9	-0.5
Female reproductive	3,669	6.8%	17,935	7.5%	-0.8	-0.1
Insitu urinary	1,455	2.7%	6,929	2.9%	-0.2	-0.1
Sub-total (a)*	54,226	100%	237,687	100%	na	na
Other cancers (b)	5,693	na	209,102	na	na	na
Total (a+b)	59,919	na	446,789	na	na	na

*Note: Cancer sites under 1,000 patients in CPES are under ‘Other cancers’ in both CPES and the comparator. Those account for about 10% of all cases in CPES and 50% in CAS.

Given this skewness, they were not included in the calculation of the cancer proportions presented above.

Table 7 . Distribution of Wave 3 of CPES and comparator population cohort in 2013 by selected cancer sites*

	CPES Wave 3 (N= 57,906)		Cancer registration ref (N=445,635)		Absolute difference	Relative diff. to cancer registration
	n	(%) (a)	n	(%) (b)	(a-b).	(a-b)/b
Colorectal and anus	7,969	15.1%	35,754	14.6%	0.6	0.0
Lung	3,714	7.1%	21,760	8.9%	-1.8	-0.2
Breast	12,808	24.3%	50,696	20.7%	3.7	0.2
Prostate	5,481	10.4%	43,131	17.6%	-7.2	-0.4
Head and neck	1,792	3.4%	12,478	5.1%	-1.7	-0.3
Upper GI	1,982	3.8%	9,321	3.8%	0.0	0.0
Bladder	2,788	5.3%	9,146	3.7%	1.6	0.4
Haematological	9,817	18.7%	23,093	9.4%	9.2	1.0
Skin	1,594	3.0%	13,572	5.5%	-2.5	-0.5
Female reproductive	3,461	6.6%	18,367	7.5%	-0.9	-0.1
Insitu urinary	1,228	2.3%	7,953	3.2%	-0.9	-0.3
Sub-total (a)*	52,634	100%	245,271	100%	na	na
Other cancers (b)	5,272	na	200,364	na	na	na
Total (a+b)	57,906	na	445,635	na	na	na

*Note: Cancer sites under 1,000 patients in CPES are under ‘Other cancers’ in both CPES and the comparator. Those account for about 10% of all cases in CPES and 50% in CAS.

Given this skewness, they were not included in the calculation of the cancer proportions presented above.

Table 8. The following ICD10 groups were used for the cancer groups contained in this report

Grouping	ICD-10 3 digit code
Colorectal and anus	C18-C21
Lung	C33, C34
Breast	C50
Prostate	C61
Head and neck	C00-C14, C30-C32, C73
Upper GI	C15-C16
Bladder	C66-C67, C68
Haematological	C81-C85, C88, C90-C96
Skin	C43
Female reproductive	C51, C52, C53, C54-C55, C56-C57
Insitu urinary	D41
Other cancers	Remaining C and D codes