

Cancer and Equality groups: Key metrics





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Foreword

Working together, the National Cancer Equality Initiative (NCEI) and the National Cancer Intelligence Network (NCIN) have compiled this report, which sets out for the first time alongside each other, a collection of cancer equality metrics. This meets the commitment made by NCEI, to establish a series of equality metrics to enable measurement of progress on issues where there is a proven link to inequality. As *Improving Outcomes: a strategy for Cancer* makes clear, it is impossible to tackle inequalities without data to inform activity and scrutinise progress.

NCIN and NCEI worked together to compile a list of metrics, based on data that could be routinely calculated. These metrics will ensure that we are able to track progress in improving cancer services and outcomes for *everyone* in England.

NCIN has pioneered the collection and analysis of meaningful data, ensuring that data are routinely collected, analysed and made available by equality group. This work has made people and their experiences visible, by asking the question *who* and not just what and where.

The equality metrics provide an overview of national trends, providing insight for commissioners and providers alike; and enabling the NCEI Implementation Advisory Group to champion further action. The next step is to make these data readily accessible and intelligible and to make similar progress in other diseases.

The metrics cover the spectrum of the cancer patient journey including incidence, mortality and one year survival; uptake of the three cancer screening programme; a breakdown of the routes to diagnosis; reporting on patient experience; radical treatment; stage at diagnosis and patient reported outcomes. The report shows that despite progress, the percentage of cancer patients who have their ethnicity reliably recorded is still only 86% and this is preventing in depth analysis of ethnicity as a variable in reaching best outcomes. Commissioners and local communities alike will want to see faster progress in coding for ethnicity.

Metrics are available for as many equality groups as the data currently allow, covering critical aspects of cancer but with the firm intention to improve data linkages and reporting over time. This first report provides the baseline for improvement in equality and cancer.

Professor Steve Field

Deputy National Medical Director, NHS England Co-chair of the National Cancer Equalities Initiative

Joanne Rule

Co-chair of the National Cancer Equalities Initiative

Introduction

The National Cancer Equality Initiative identified a selection of key cancer metrics which the NCIN have brought together into one central report. The metrics selected either provide background information by equality group or analysis of cancer in relation to equality groups. There are some equality metrics where data are not yet available. A placeholder has been put in as an indication that analysis will be undertaken once data are either available or of good enough quality to produce meaningful results.

Every piece of national analysis that is undertaken across the NCIN, through registries and site specific clinical reference groups, considers which equality groups results can be produced for. Where data are available and of good enough quality, analysis will be undertaken. The recently released report looking at "Routes to diagnosis" for example produced breakdowns by sex, age, deprivation and ethnicity for over 30 different cancer sites.

Survey data undertaken by Quality Health through the "Cancer Patient Experience Survey" and "Quality of life of cancer survivors in England" are able to collect data on a wider range of equality groups. By including questions regarding sexual orientation for example, more information in regard to cancer and equality groups is made available.

Data included in this report have been taken from a variety of different sources, including analysis produced within the NCIN, Cancer Research UK and the Office of National Statistics, with data from the Health and Social Care Information Centre, Cancer Patient Experience Survey and the Quality of life of cancer survivors in England. The value of bringing these data together presents an overall view of data on cancer and equalities. Some of the data highlight where differences within equality groups exist, whilst others show that differences between groups do not exist.

Basic epidemiology data are included to give background to how common cancer is with incidence, mortality and survival data presented for a range of indicators.

Other data shows how good, or bad, collection of certain data are. The report shows that for some indicators such as ethnicity and staging, completeness is improving. An NCIN report in 2008 used Hospital Episode Statistics (HES) data linked to cancer registrations in order to produce cancer incidence by ethnic group. This report showed that for cancers registered between 2004 and 2006, an ethnic group was assigned to 76% of registered cancers. For cancer registered between 2008 and 2010, the percentage of records with a valid ethnicity had increased to 86% of tumours. This reflects the improvements being made in the completeness of ethnicity in admitted care HES data.

Staging data is also improving. For patients registered in 2010, less than 40% of registrations in England had a stage recorded. This improved to over 50% of registrations having a stage recorded in 2011. This is a big improvement and sets the registries well on their way to having 70% of all cancers staged in the next few years.

By presenting these data together in one place, with a commitment to updating these data annually, it is hoped that these data will provide a basis for further questions to be asked about inequalities in cancer, and to provide a platform to drive further analysis, especially in areas where the quality or completeness is improving.

This report only presents results for a small number of cancers in order to produce a variety of metrics from which to assess overall progress in tackling inequalities and promoting equality. There is a vast amount of information available on inequalities in cancer for a wide range of cancer sites and each section has a link to where further information can be found.

This report does not include national analysis of individual site specific work, but much of this can be found from the <u>site specific pages of the NCIN website</u>.

The NCIN also present a document entitled "What cancer statistics are available and where can I find them". This is a useful resource for sourcing further data on cancer and is updated periodically.

Whilst this report is focussed mainly on data available in England, further data are available by equality groups in <u>Scotland</u>, <u>Northern Ireland</u> and <u>Wales</u> through their respective cancer centres.

If you have any questions regarding data included in this report, please contact equalities@ncin.org.uk.

1. Cancer incidence and incidence rates

1.1. Total number of new cases in England for all cancers combined and for the four most common cancers by sex

Breast, colorectal, lung and prostate cancers account for 53% of all newly diagnosed cancers in England. Understanding the burden of disease is the first step to being able to monitor differences between equality groups.

1.1 Newly diagnosed cases of cancer by site, England, 2010

Company City	All novemen		Males	Females		
Cancer Site	All persons	Number	Age standardised rate	Number	Age standardised rate	
Breast	41,612	353	1.1	41,259	125.7	
Colorectal	33,218	18,590	56.5	14,628	36.1	
Lung	33,818	18,756	56.0	15,062	38.0	
Prostate	34,892	34,892	106.4	-	-	
All cancers*	268,758	136,372	422.6	132,386	369.6	

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: Office of National Statistics, Series MB1

Where to go for further information

Further information on cancer incidence is available from a variety sources including the NCIN, Cancer Research UK statistical information team and the Office of National Statistics. The NCIN's document "What Cancer Statistics are available, and where can I find them?" details where to go for a wide variety of cancer data in the UK.

1.2. Total number of new cases by age (0-14, 15-24, 25-64, 65-74, 75-84, 85+)

Different cancers affect different age groups. The data below provide basic information as to which ages are affected by the most common cancers. The age groups used are an agreed set of age ranges to produce analysis by age group, with children (0-14) and teenagers and young adults (15-24) also being represented.

The table below shows that the most common cancers are not prevalent in children and teenage and young adults.

1.2 Newly diagnosed cases of cancer by site and age group, England, 2010

Ago group			Ma	les					Fem	ales		
Age group	0-14	15-24	25-64	65-74	75-84	85+	0-14	15-24	25-64	65-74	75-84	85+
Breast	0	0	115	106	95	37	1	24	22,725	8,439	6,565	3,505
Colorectal	7	24	5,278	6,050	5,346	1,885	1	35	3,709	3,875	4,520	2,488
Lung	0	8	4,531	6,174	5,956	2,087	1	14	3,831	4,531	4,659	2,026
Prostate	3	2	8,783	13,577	9,748	2,779	-	-	-	-	-	-
All cancers*	701	898	42,444	42,841	36,723	12,765	542	849	53,709	30,822	30,146	16,318

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: Office of National Statistics, Series MB1

Where to go for further information

The Office of National Statistics produces an annual series (MB1) which includes cancer incidence by cancer site. Cancer research UK produces charts and tables by age group for a wide variety of cancer sites.

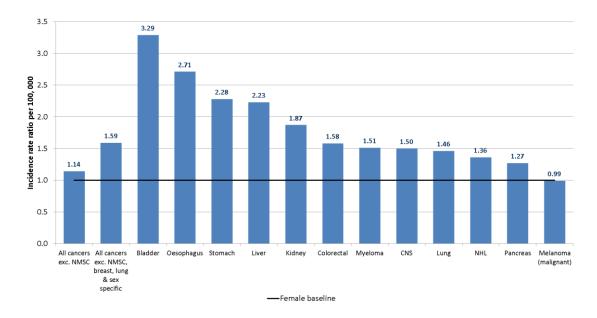
1.3. Age standardised rate ratios by sex for selected non-sex specific cancers

For the majority of common cancer sites, males have higher incidence rates than females when difference in the age structure of the populations is taken into account (age standardised). With certain causes of cancer being higher in males, such as smoking and exposure to asbestos, it is to be expected that lung, bladder and other smoking related cancers are also higher in males. However, higher rates for males are also seen in many other cancer sites. For all cancers combined (excl. NMSC), age standardised incidence rates are 14% higher for males compared to females. When breast, lung and sex-specific cancers are not included, age standardised incidence rates are 59% higher in males compared to females.

Figure 1.3 shows the rate ratios between male and female incidence rates. The rate ratio shows how the incidence rate for males compares to females by showing the female rate as 1 (the black line) and the male rate in comparison to this. For all cancers combined (excl. NMSC) the 14% higher rate in males is shown as the male rate ratio being 1.14 compared to the female rate of 1. If the age standardised rate for males was less than the age-standardised rate for females, it would be shown as a being less than 1.

Of the common cancer sites analysed, rates were higher for males compared to females for all sites with the exception of malignant melanoma. All differences between rates for these sites were statistically significant.

1.3 Age standardised rate ratios for non-sex specific cancers, UK, 2010



Source: "Excess Burden of cancer in Men", Cancer Research UK, NCIN and Men's Health Forum

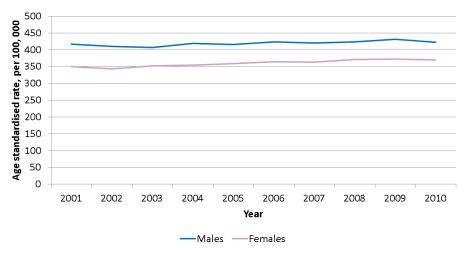
Where to go for further information

A report on the <u>excess burden of cancer in men</u> was jointly produced in January 2013 between the NCIN, Cancer Research UK and the Men's Health Forum.

1.4. Trends in incidence rates

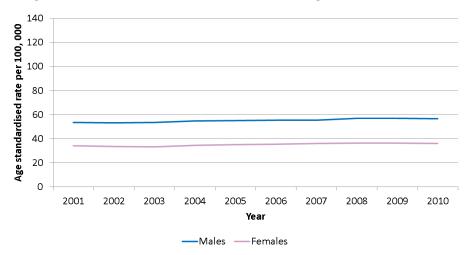
Trends in cancer incidence over time allow progress to be monitored or identify where progress is not being made. Looking at the number of cases only tells part of the story as the cases are determined by the age structure of the population. Age standardised rates therefore show us how the rates of cancer in the overall population are changing, after taking into account the differences in the age structure of the population for each year. The trends below show incidence rates for the most common cancers over the last 10 years.

1.4.1 Trends in age standardised incidence rates, all cancers excluding NMSC, England, 2001-2010

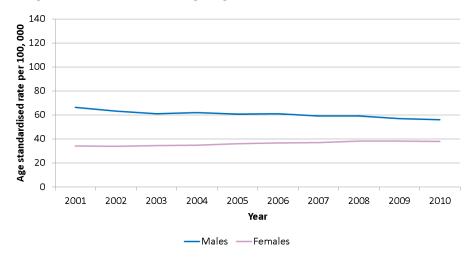


^{*} Excluding non-melanoma skin cancer (NMSC)

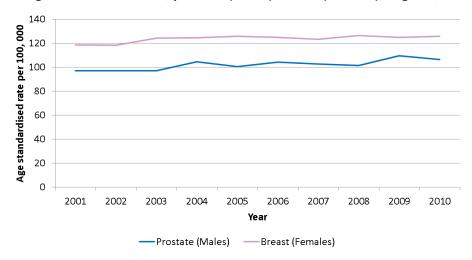
1.4.2 Trends in age standardised incidence rates, colorectal, England, 2001-2010



1.4.3 Trends in age standardised rates, lung, England, 2001-2010



1.4.4 Trends in age standardised rates, prostate (males), breast (females), England, 2001-2010



Source: Cancer Registration Statistics, England, 2010, ONS

Where to go for further information

Information on trends in cancer is available from the Cancer Research UK website.

1.5. Age standardised rate ratios by deprivation for all cancers combined and for the four most common cancers

An NCIN report published in 2008 presented results for cancer incidence by deprivation quintile for all cancers combined (excluding NMSC) and for 23 cancer sites or groups. Inequalities in cancer incidence in relation to socio-economic deprivation are one of the major concerns as it is known that risk factors for cancer, especially smoking, are strongly influenced by socio-economic determinants.

The report showed that for cancers diagnosed in 2000-2004, head and neck, stomach, liver, lung and cervical cancers showed incidence rates in the most derived group that were close to double that of the least deprived group. Incidence rates were statistically higher for the most deprived compared to the least deprived group for oesophageal, pancreatic, kidney and bladder cancer.

For other sites, including malignant melanoma, breast (f), prostate and testicular cancer, higher rates were seen for the least deprived compared to the most deprived.

Other sites such as colorectal (m), mesothelioma (f) showed a statistically significant correlation between incidence and deprivation whilst cancer of the central nervous system (CNS) (m), non-Hodgkin lymphoma (m) and myeloma (m) showed an inverse correlation. This was only true for the sexes indicated.

1.5 Age standardised rate ratios by deprivation group, England, 2000-2004

Cancer s	ite	Least deprive	d Most deprived
Breast (females)	ASR Rate ratio	127.2	104.3 0.8
Colorectal	ASR Rate ratio	41.2	43.8 1.1
Lung	ASR Rate ratio	29.8	75.2 2.5
Prostate	ASR Rate ratio	103.7	78.8 0.8
All cancers*	ASR Rate ratio	345	399 1.2

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network

Where to go for further information

The report on cancer incidence by deprivation, 1995-2004 is available from the NCIN website.

1.6. Total number of new cases by major ethnic group (for all cancers combined, breast, colorectal, lung and prostate)

A patient's ethnicity is collected by trusts and recorded in Hospital Episode Statistics (see section 4). The first national report on cancer incidence by ethnicity for multiple cancer sites was published in 2009 using HES data linked to cancer registrations. Whilst ethnicity recording was not complete for all registered cancers, results did show that some ethnic groups had higher incidence rates compared to the White ethnic group. For example, people from the Black ethnic group have higher rates of myeloma and stomach cancer and males from the Black ethnic group have higher rates of prostate cancer. Liver cancer is higher amongst people from the Asian ethnic group compared to the White ethnic group, as is mouth cancer in females and cervical cancer in the over 65's.

As Ethnicity data were not complete, it is not possible to say for certain how many cancers occurred for each ethnic group. Estimates of rates have therefore been made based on the data held for registrations with ethnicity assigned. Data shown below therefore show the expected range of rate ratios for certain cancers compared to the White ethnic group. The range is calculated by taking the lowest confidence interval of the lowest estimated rate and the highest confidence interval of the highest estimated rate. The corresponding range shows where the real rate is expected to lie, if we were to have ethnicity data for all newly diagnosed cancers.

1.6 Age standardised cancer incidence rate ratios by site and ethnic group, England, 2004-2006

Canacarcita		Ethnicity							
Cancer site	White	Asian	Black	Chinese	Mixed				
Breast (females)	1.0	0.5 - 0.8	0.6 - 0.9	0.4 - 0.6	0.4 - 0.7				
Colorectal (males)	1.0	0.4 - 0.5	0.6 - 0.8	0.5 - 0.9	0.4 - 0.6				
Colorectal (females)	1.0	0.3 - 0.5	0.6 - 0.9	0.5 - 0.8	0.4 - 0.8				
Lung (males)	1.0	0.4 - 0.6	0.5 - 0.8	0.4 - 0.8	0.4 - 0.7				
Lung (females)	1.0	0.2 - 0.3	0.3 - 0.4	0.3 - 0.7	0.3 - 0.5				
Prostate	1.0	0.3 - 0.6	1.2 - 2.6	0.2 - 0.5	0.5 - 1.1				
All cancers* (males)	1.0	0.4 - 0.6	0.8 - 1.2	0.4 - 0.7	0.4 - 0.7				
All cancers* (females)	1.0	0.5 - 0.7	0.6 - 0.9	0.4 - 0.7	0.5 - 0.7				

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network

Where to go for further information

The NCIN report on <u>cancer incidence by major ethnic group</u> is available from the NCIN website.

2. Number of cancer deaths and mortality rates

2.1. Total number of deaths in England for all cancers combined and for the four most common cancers

Cancer is a major cause of death accounting for 29% of all registered deaths in England and Walesⁱ. Mortality data are presented below to help understand cancer mortality by equality groups.

2.1 Number of deaths, England and Wales, 2011

Cancer Site	All persons	Males	Females
Breast	10,397	69	10,328
Colorectal	13,742	7,474	6,268
Lung	30,148	16,881	13,267
Prostate	9,671	9,671	-
Other cancers	75,993	39,614	36,379
All cancers	139,951	73,709	66,242

Source: Office of National Statistics, Series DR

Where to go for further information

Further information on cancer incidence is available from a variety sources including the NCIN, Cancer Research UK and the Office of National Statistics. The NCIN's document "What Cancer Statistics are available, and where can I find them?" details where to go for a wide variety of cancer data in the UK.

2.2. Total number of deaths by age (0-14, 15-24, 25-64, 65-74, 75-84, 85+)

The number of deaths by age group is important when focussing on addressing inequalities in mortality. These data allow us to focus on specific cancers for specific age-groups. Whilst just over 200 deaths were caused by cancer in 2011 in people aged 14 and under, only 2 (<1%) were caused by the most common cancers. Cancers of the central nervous system, certain leukaemias and lymphomas are more common cancers in children.

2.2 Number of deaths by age group, England and Wales, 2011

Ago group			Ma	les					Fem	ales		
Age group	0-14	15-24	25-64	65-74	75-84	85+	0-14	15-24	25-64	65-74	75-84	85+
Breast	0	0	14	19	26	10	0	2	3,570	1,966	2,447	2,343
Colorectal	0	7	1,494	1,999	2,544	1,430	0	2	996	1,240	2,039	1,991
Lung	1	2	3,571	5,386	5,626	2,295	0	0	2,837	3,966	4,179	2,285
Prostate	1	2	669	1,919	3,815	3,265	-	-	-	-	-	-
All cancers	133	154	15,430	20,093	24,548	13,351	82	115	15,173	15,340	20,030	15,502

Source: Office of National Statistics, Series DR

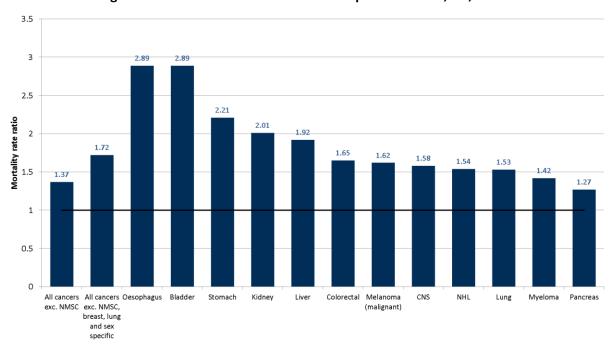
Where to go for further information

The <u>Office of National Statistics</u> produces number of cases by age group by ICD10 code in the DR series. <u>Cancer Research UK</u> produces charts and tables by age group for a wide variety of cancer sites.

2.3. Age standardised rate ratios by sex for selected non-sex specific cancers

For the majority of common cancer sites, males have higher cancer mortality rates than females. Similarly to cancer incidence, higher cancer mortality rates in males are seen across a broad range of cancer sites. For Oesophageal and bladder cancers, age-standardised cancer mortality rates were just under 3 times higher for males compared to females (rate ratio:2.89). For all cancers combined, age standardised mortality rates in males are 37% higher than females. This increases to being 72% higher when breast, lung and sex-specific cancers are excluded. Of the most common cancer sites analysed, all had significantly higher cancer mortality rates for males compared to females. Figure 2.3 shows male to female mortality rate ratio, where the rates for females are represented as 1 (the black line) as the comparator for the male mortality rates.

2.3 Male-female age standardised rate ratios for non-sex specific cancers, UK, 2010



Source: "Excess Burden of cancer in Men", Cancer Research UK

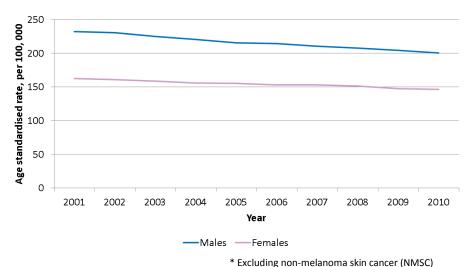
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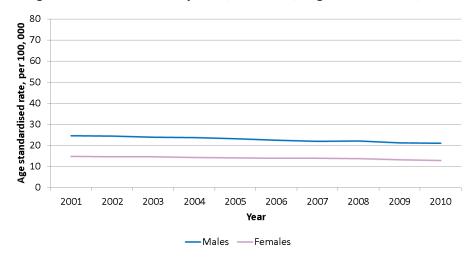
2.4. Trends in age standardised mortality rates (over previous 10 years)

Monitoring trends in mortality is important for measuring progress to improve outcomes from cancer. Like incidence, monitoring the number of cases doesn't show whether mortality is falling or not as it is very much dependent on the age structure of the population. Age standardised rates enable the monitoring of trends whilst taking into account changes in the age structure of the population.

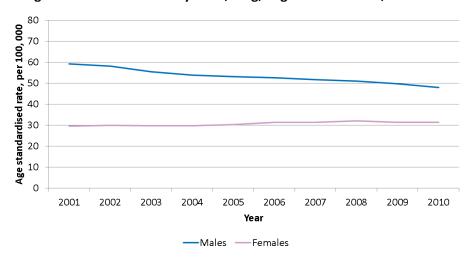
2.4.1 Trends in age standardised cancer mortality rates, all malignant neoplasms, England and Wales, 2001-2010



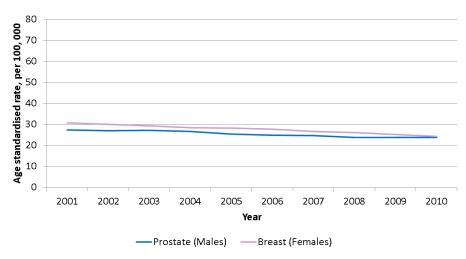
2.4.2 Trends in age standardised mortality rates, colorectal, England and Wales, 2001-2010



2.4.3 Trends in age standardised mortality rates, lung, England and Wales, 2001-2010



2.4.4 Trends in age standardised mortality rates, prostate (Males), breast (Females), England and Wales, 2001-2010



Source: Data extracted from UKCIS, accessed March 2013

Where to go for further information

<u>Cancer Research UK</u> produces trends by age group for a wide variety of cancer sites. Further data can also be obtained from the <u>UKCIS</u>.

2.5. Total number of deaths and age standardised rate ratios by deprivation

A report on cancer mortality by deprivation in England and Wales was published in 2006 by the office of national statistics for a selection of cancer sites. This publication analysed cancers diagnosed in 1999 and 2001-2003 and showed variation between mortality rates by deprivation for a number of sites, using the Carstairs score.

For each cancer site, mortality rates were calculated for 20 deprivation groups, with a ratio created between the age standardised mortality rate for the most deprived and that for the least deprived group. The study showed a particularly strong relationship between mortality and deprivation for lung cancer.

2.5 Cancer mortality ratio by deprivation, England and Wales, 1999-2003

Age	Cancer site	Least deprived 20 th	Most deprived 20 th	Ratio
	Breast (female)	30.6	29.1	1.0
	Colorectal (male)	21.8	25.3	1.2
ages	Colorectal (female)	14.4	14.6	1.0
Alla	Lung (male)	34.8	89	2.6
_	Lung (female)	17.1	44.6	2.6
	Prostate (male)	29.2	25.8	0.9
-74	All cancers aged (male)	109.1	185.9	1.7
0	All cancers aged (female)	92.9	131.4	1.4

Source: Office of National Statistics

Where to go for further information

The office of National Statistics report on Mortality by deprivation and cause of death in England and Wales, 1999-2003 is available from the ONS website.

2.6. Mortality by major ethnic group and unknown ethnicity

Cancer mortality by major ethnic group has not been calculated nationally for multiple cancer sites. Mortality from cancer could have been from a cancer diagnosed a number of years ago when there was poorer recording of ethnicity. Given the improvements in HES ethnicity completeness (see section 4) and long term survival for some cancer sites, the completeness of ethnic group for mortality is worse than for incidence. NCEI will continue to press for action on ethnicity recording and analysis.

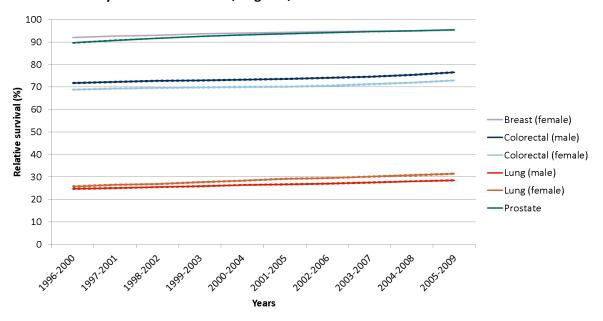
As and when results for age standardised mortality groups are available, they will be included within this report.

3. One year relative survival from cancer (for breast, colorectal, lung and prostate cancers)

3.1. Trends in one year relative survival from cancer

Cancer survival in the UK is lower than for many other European countries. However, relative survival estimates are improving over time. Trends in cancer survival estimates show that it has been improving for many cancers over the last ten years, with a small difference between observed survival estimates for males and females for colorectal and lung cancer. The survival estimates in this section show crude relative survival estimates as age-standardised relative survival are not routinely calculated. Section 3.3 shows comparisons between age-standardised survival estimates which should be used when comparing the rates between males and females.

3.1 Trends in one year relative survival, England, 1996-2009



Source: Data extracted from UKCIS, accessed March 2013

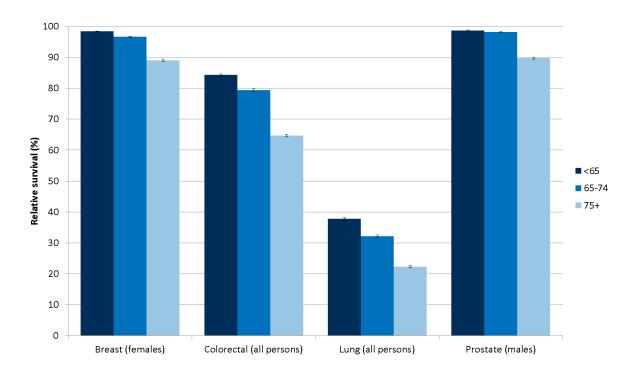
Where to go for further information

Cancer survival estimates for England are available from a variety of sources, see "What Cancer Statistics are available, and where can I find them?" for more details.

3.2. One year relative survival by age (<65, 65-74, 75+)

Relative survival by age highlights the poorer relative survival rates for older cancer patients. Those aged 75 or over have significantly poorer survival rates than younger age-groups. For some cancer sites such as lung and colorectal cancer, a drop off in survival rates by age are seen in the 65-74 age group.

3.2 One year relative survival estimates by age group, 2005-2009, England



Source: Data extracted from UKCIS, accessed March 2013

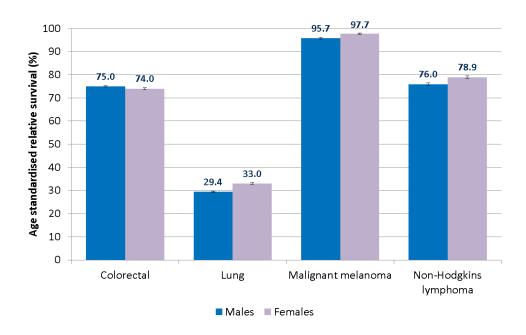
Where to go for further information

Cancer survival estimates for England are available from a variety of sources, see "What Cancer Statistics are available, and where can I find them?" for more details.

3.3. One year relative survival by sex for selected non-sex specific cancers

Relative survival estimates by sex show where inequalities in cancer survival exist. The survival estimates below are age standardised to allow for the differences in age-structures between the male and female populations. The data show for a selection of cancers the one year age standardised relative survival estimates by sex.

3.3 One year age standardised relative survival by sex, selected sites, 2005-2009, England



Source: Office of National Statistics

Where to go for further information

Age standardised relative survival estimates are available from the <u>ONS website</u>. Other cancer survival estimates for England are available from a variety of sources, see "<u>What Cancer Statistics are</u> available, and where can I find them?" for more details.

3.4. One year relative survival by deprivation

A comprehensive publication of survival by deprivation was published in the British Journal of Cancer, volume 99, supplement 1 on 23 September 2008ⁱⁱⁱ. This supplement contains relative survival estimates for 20 cancer sites in England and Wales and contains clinical commentaries.

For each site, a deprivation gap is provided showing the difference between relative survival estimates for the most deprived quintile compared to the least deprived. All figures are statistically significant with the exception of female lung cancer (bold). Table 3.4 shows the difference between the most deprived quintile compared to the least deprived quintile. This shows, for example, that the one year relative survival estimate for breast cancer was 2.7 percentage points lower for the most deprived quintile compared to the least deprived quintile.

A more recent study by Thames cancer registry looked at excess deaths caused by deprivation. This study analysed patients diagnosed with the 14 most common cancers from 1999 to 2007 and looked at the difference in survival by deprivation quintile. This showed higher survival for all cancer sites in the least deprived quintile. Over 2,600 premature deaths from these cancer sites could be avoided if all patients had the same survival as the least deprived quintile. iv

- 3.4 Deprivation gap in one-year and five-year relative survival, England and Wales, 2001 estimates
- A comparison of the most deprived and least deprived quintiles

Cancer site	Relative survival				
Calicel Site	1 year	5 years			
Breast (female)	-2.7%	-5.2%			
Colon (male)	-7.8%	-6.0%			
Colon (female)	-6.8%	-7.2%			
Rectum (male)	-9.7%	-9.8%			
Rectum (female)	-5.7%	-9.4%			
Lung (male)	-3.2%	-1.5%			
Lung (female)	-1. 2 %	-0.6%			
Prostate	-4.4%	-7.3%			

All differences were statistically significant at the 95% level, with the exception of lung cancer in females.

Where to go for further information

The British Journal of Cancer volume 99, Supplement 1 "Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001: population-based analyses and clinical commentaries" contains an extensive study into survival by deprivation quintile.

3.5. One year relative survival by ethnicity (White, non-White, not recorded)

As we do not have 100% complete ethnicity coding in Hospital Episode Statistics (HES), relative survival estimates by ethnic group do not tell a complete picture. Whilst it is possible to calculate survival estimates for patients with known ethnicity, survival for patients with unknown ethnicity has to be calculated separately.

The NCIN publication on <u>cancer incidence by major ethnic group</u> did include relative survival estimates for breast, colorectal, lung and prostate cancer but caution is advised in interpreting these results due to the number of cases with unknown ethnicity. If the ethnicity of the patients from the Unknown Ethnic group were to be available, relative survival estimates by Ethnic group could potentially change and therefore it is currently difficult to draw any conclusions from these estimates.

4. Ethnicity coding compliance

4.1. The proportion of cancer patients who have an ethnicity record

The completeness of ethnicity coding is vital to understanding more about the impact of cancer on different ethnic groups. Some differences in incidence rates between groups, such as in colorectal cancer, are linked to genetic factors, whilst others may be linked to lifestyle and diet. In order to understand more about differences between ethnic groups and to be able to look at survival by ethnic group with more confidence, we need to ensure that the recording of ethnicity improves within trusts.

Ethnicity recording has been improving. For newly diagnosed cancers diagnosed in 2002-2006, 76% had an ethnicity derived from HES. For tumours diagnosed in 2008-2010, this had risen to 86% of records having an ethnic group assigned from HES. Ethnicity is assigned by linking cancer registrations with admitted care HES data. Not all cancer patients have an inpatient or day case attendance therefore it is not possible to assign ethnicity to all cases. Some cancer sites, such as prostate and melanoma, have a lower percentage of records with a known ethnic group due to being treated in a primary care or in an outpatient setting.

4.1 Proportion of newly diagnosed cases of cancer with an ethnic group recorded, England, 2008-2010

Cancer site		Total cases		
Califer Site	White	Non-White	Unknown	Total cases
Breast	80.6%	4.8%	14.6%	123,245
Colorectal	88.2%	3.3%	8.5%	98,958
Lung	85.0%	2.6%	12.4%	101,310
Prostate	68.9%	4.0%	27.1%	102,344
Other cancers*	82.6%	4.5%	12.9%	374,140
All cancers*	81.5%	4.1%	14.4%	799,997

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: NCIN, calculated from the NCDR 2010

Where to go for further information

These data are calculated from the <u>National Cancer Data Repository</u> (NCDR) for this report. More information can be requested by contacting the NCIN.

4.2. The proportion of all inpatient and day case episodes with a recorded ethnicity

In 2004/2005, around 24% of finished consultant episodes in admitted care HES (Inpatient and day cases) had an unknown ethnic group. For finished consultant episodes in 2009/10 this had fallen to less than 9% of episodes not having an ethnicity code recorded, a big improvement over the 5 year period.

4.2 HES Inpatient records with known or unknown ethnicity, England, 2009/2010

	Plutabani.	HES Inpatient							
Data provided by	Finished consultant episodes	Known	Total Unknown	Unknown:	Unknown:				
				Not Known	Not stated				
NHS Trusts	16,347,807	91.6%	8.4%	1.9%	6.5%				
PCT	237,269	88.0%	12.0%	3.6%	8.3%				
Independent providers	217,746	76.4%	23.6%	1.2%	22.4%				
Care trusts	11,565	96.8%	3.2%	1.7%	1.5%				
Overall	16,814,387	91.4%	8.6%	1.9%	6.7%				

Source: Health and Social care information centre

Where to go for further information

The Information Centre's report on ethnic coding in Admitted Care HES is available from HES online, produced by the <u>Health and Social Care information centre</u> and contains further breakdowns by ethnic group.

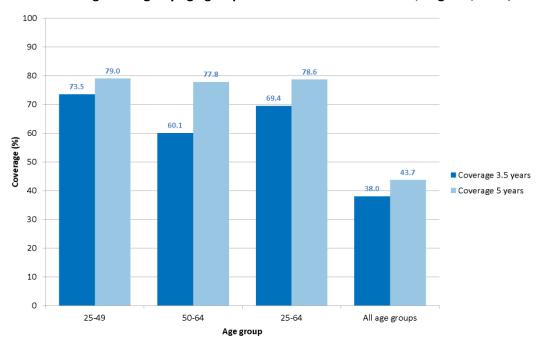
5. Cancer screening programme

5.1. Cervical screening coverage by age

Cervical screening is an important way of preventing cancers as well as catching them at an early stage. The Routes to Diagnosis project (see section 6) showed that cervical tumours diagnosed through the screening route had better survival at one year than tumours diagnosed through any other Route^v.

Cervical screening is therefore extremely important. Currently, five year coverage is very similar for both the 25-49 and the 50-64 age groups. Higher three and a half year coverage is seen in females aged 25-49 and reflects the frequency with which females are invited for screening. Females aged 25-49 are invited every three years whilst females aged 50-64 are invited every five years.

5.1 Cervical screening coverage by age group and time since last screened, England, 2011/2012



Source: The NHS Information Centre for health and social care, Cervical Screening Programme - England, 2011-12

Where to go for further information

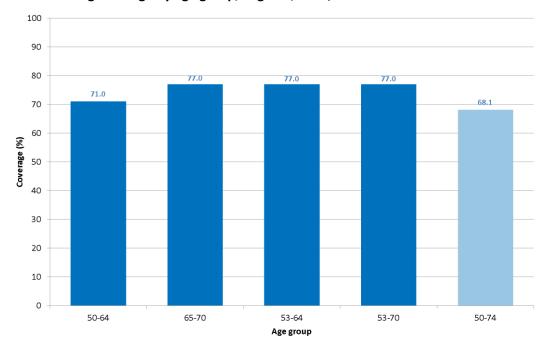
Further information on cervical screening is also available from the <u>NHS Cervical cancer screening</u> programme and the Health and Social Care information centre.

5.2. Breast cancer screening coverage by age

Women aged 50 and over are offered free breast screening every three years. Currently, an extension is being phased into the screening programme that will extend the age range to people aged between 47 and 73. Women aged over the age limit are encouraged to make their own appointments.

Screening coverage is lower for the 50-64 age group. As women are invited every three years, a woman may not receive her first invitation until the age of 53. This is changing as a result of the extended age range and by 2016, the coverage of women aged 50-64 could be expected to be similar to the 65-70 age range.

5.2 Breast screening coverage by age group, England, 2011/12



Source: The NHS Information Centre for health and social care, Breast Screening Programme - England, 2011-12

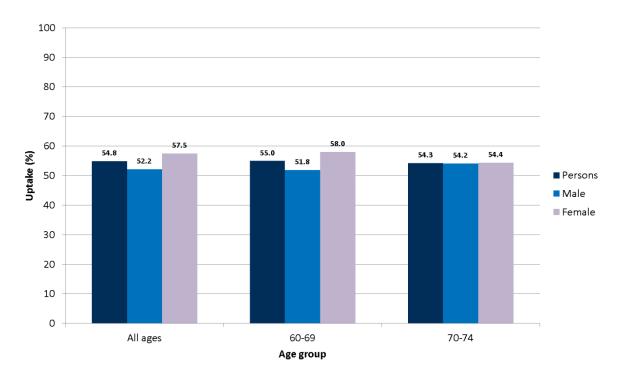
Where to go for further information

The <u>Breast cancer screening website</u> contains information and usage statistics of the breast cancer screening programme, along with the <u>Health and Social Care information centre</u>.

5.3. Bowel screening uptake by age and sex

Bowel cancer screening is offered to people aged 60-69. Currently, screening uptake is higher amongst females than for males. The Routes to Diagnosis project showed that for patients diagnosed in 2006-2008, one year relative survival estimate for patients presenting through the screened Route was higher than for any other Route and the difference was statistically significant.

5.3 Bowel cancer screening uptake by age group and sex, 2011/2012



Source: Bowel Cancer Screening Programme National Office

Where to go for further information

Further information on the bowel cancer screening programme is available from the <u>Bowel Cancer screening programme website</u>. The programme National Office can be contacted via <u>info@cancerscreening.nhs.uk</u>.

6. Routes to Diagnosis (for all cancers combined and for the four most common cancers)

6.1. Proportion of emergency presentations by age (0-14, 15-24, 25-64, 65-74, 75-84, 85+)

The Routes to Diagnosis project determined how each patient presented to secondary care on their way to being diagnosed with cancer. Results were presented for eight distinct routes for 36 cancer sites and for all cancers combined (excl. NMSC), with relative survival estimates produced for each Route. The worst survival was for patients diagnosed through the Emergency Presentation Route.

The breakdown of Emergency Presentations by age shows that for all cancer sites the highest proportion of emergencies was seen in older patients.

6.1 Proportion of emergency presentations by age group, England, 2008

	Age group																				
Cancer site	Under 50 50-59		60-69		70-79		80-84		85+			All ages									
	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI
Breast	2%	2%	2%	2%	1%	2%	3%	2%	3%	6%	5%	7%	12%	11%	13%	18%	17%	20%	5%	5%	5%
Colorectal	24%	22%	26%	20%	19%	22%	19%	16%	18%	23%	23%	24%	31%	29%	32%	42%	41%	44%	25%	24%	25%
Lung	31%	29%	35%	30%	29%	32%	31%	30%	32%	38%	37%	39%	45%	44%	47%	57%	55%	59%	38%	38%	39%
Prostate	4%	2%	7%	4%	3%	4%	4%	4%	5%	7%	7%	8%	18%	16%	19%	32%	30%	34%	9%	9%	10%
All cancers*	15%	15%	15%	15%	15%	15%	17%	17%	17%	24%	24%	24%	33%	33%	34%	43%	43%	44%	23%	23%	23%

* Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network, Routes to Diagnosis

Where to go for further information

The NCIN report on Routes to Diagnosis is available from the NCIN website.

6.2. Proportion of Emergency Presentations by sex for selected non-sex specific cancers

The Routes to Diagnosis project presents results by sex for each site. For the majority of sites, there were no statistically significant differences observed in the proportion of emergency presentations between sexes. Any differences that were seen were due to differences in the proportion of cases diagnosed within each age group for these cancers.

For example, for colorectal cancer the proportion of emergencies for females was six percentage points higher than for males. An inspection of the proportion of colorectal cases by age shows that around 17% of female cases occur in the 85 or over age group compared to only 9% of male cases. With a higher proportion of emergency presentations observed in older age, it is therefore expected that the proportion of emergency presentations for females would be higher than for males.

6.2 Proportion of Emergency Presentations by sex for selected non-sex specific sites, England, 2008

		Male		Female					
Cancer site	%	LCI	UCI	%	LCI	UCI			
Colorectal	22%	22%	23%	28%	28%	29%			
Lung	37%	37%	38%	40%	39%	41%			
Melanoma	3%	2%	3%	3%	2%	3%			
NHL	28%	27%	29%	25%	24%	27%			
All cancers*	24%	24%	24%	23%	22%	23%			

Source: National Cancer Intelligence Network, Routes to Diagnosis

Where to go for further information

The NCIN report on Routes to Diagnosis is available from the NCIN website.

6.3. Proportion of emergency presentations by deprivation

For many cancer sites, differences were also observed by deprivation quintile with a higher proportion of emergencies in the most deprived quintile. Further work is needed to understand the underlying cause behind these differences.

6.3 Proportion of emergency presentations by deprivation quintile, England, 2006-2008

Cancer site	1 (least deprived)			2			3			4			5 (most deprived)			
	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	
Breast	4%	4%	4%	4%	4%	5%	5%	5%	5%	6%	5%	6%	6%	6%	7%	
Colorectal	22%	22%	23%	24%	24%	25%	26%	25%	26%	28%	27%	28%	32%	31%	33%	
Lung	35%	34%	36%	37%	36%	37%	38%	37%	39%	40%	39%	41%	41%	41%	42%	
Prostate	8%	7%	8%	9%	9%	9%	10%	10%	11%	11%	11%	12%	13%	13%	14%	
All cancers*	19%	19%	19%	21%	21%	22%	24%	23%	24%	26%	26%	26%	29%	29%	30%	

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network, Routes to Diagnosis

Where to go for further information

The NCIN report on Routes to Diagnosis is available from the NCIN website.

6.4. Proportion of emergency presentations by ethnicity (White, non-White, unknown)

Whilst the proportion of cancer patients by Route and ethnic group have been produced, the large proportion of patients with unknown ethnicity means that we need to be cautious as to how we interpret the results. Despite this, there were no statistically significant differences between the Non-White group and White group for any of the main cancer sites.

^{*} Excluding NMSC

6.4 Proportion of emergency presentations by Ethnic group, England, 2006-2008

		Wh	ite			Non W	hite		Unknown					
Cancer site	Cases	%	LCI	UCI	Cases	%	LCI	UCI	Cases	%	LCI	UCI		
Breast	86,139	5%	5%	5%	4,624	4%	3%	4.56%	19,410	5%	4.63%	5%		
Colorectal	78,948	26%	25%	26%	2,626	26%	24%	28%	9,842	28%	27%	29%		
Lung	80,042	39 %	39%	39%	2,169	38%	36%	40%	14,524	37 %	36%	38%		
Prostate	61,563	12 %	12%	12%	3,222	11%	10%	12%	28,137	5%	5%	6%		
All cancers*	587,640	25%	25%	25%	26,440	24%	24%	25%	125,587	19%	19%	19%		

^{*} Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network, Routes to Diagnosis

Where to go for further information

The NCIN report on Routes to Diagnosis is available from the NCIN website.

7. Cancer patient experience

The National Cancer Patient Experience Survey (CPES) provides an insight into the care experienced by cancer patients across England. The data collected in the survey enables analysis to be produced by a range of equality groups. The survey comprises of around 70 questions which cover a wide range of issues including information provision, communications and quality of service. This section provides example key messages and findings from the survey. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

It is important to note throughout this section that many of the CPES findings by equality groups are similar to that found from official NHS national surveys of mental health service users, patients in primary care, and hospital inpatients. It appears that there may be aspects of NHS provision generally that affect the experiences across equality groups. However, the level of detail offered by CPES enables cancer specific action.

What are the latest data available?

The latest national cancer patient experience survey is for 2011/12. It covered inpatient and day case cancer patients treated between 1st September and 30th November 2011. 160 NHS Trusts providing cancer services identified patients and nearly 72,000 patients chose to respond.

Where to go for further information

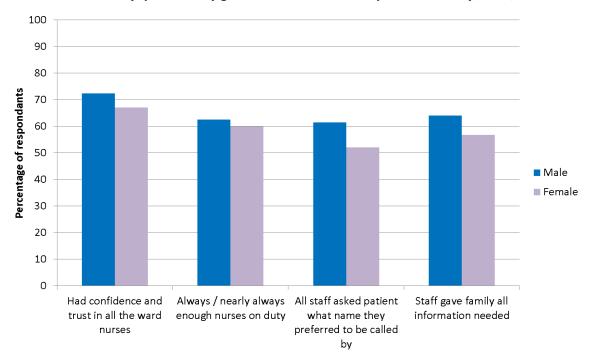
A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website

7.1. Patient experience by sex

Differences in the views of patients related to their gender tend to be of smaller scale than some of the other demographic factors, where they exist. Overall, women were more likely to report a poorer experience of care. In the 2011/12 CPES there were 46 out of the 70 questions on which there were significant differences of view between men and women, with men being more positive on 31 questions and women more positive on 11 questions.

Men reported a better experience compared to women regarding staff and staff working well together; privacy, being given respect and dignity, being told enough about their condition and treatment, about being treated as a person rather than as a set of symptoms, and discharge and post discharge arrangements. A higher proportion of men also reported that they received written information on types of cancer, and on free prescriptions. Figure 7.1.1 provides a gender comparison for four selected survey questions where male respondents indicated a better patient experience.

7.1.1 Selected survey questions by gender, Cancer Patient Experience Survey, 2011/12

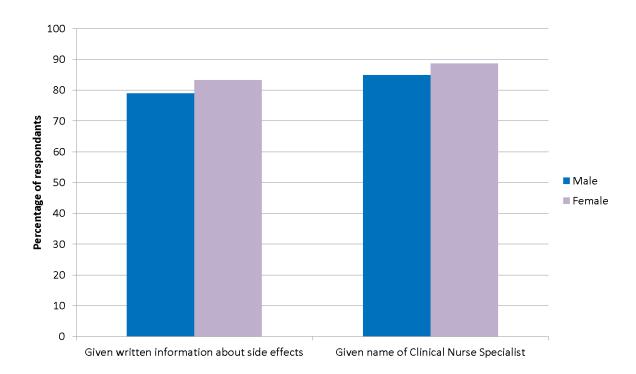


There were also a number of questions where women showed a better patient experience than men. Women were more likely than men to say that they saw their GP only once or twice before being referred on to hospital, were more likely to say that their health stayed the same in the waiting period before seeing a hospital doctor, that the side effects of treatment were explained in an understandable manner that they were given written information about the side effects of their treatment and more likely to be given the name of a Clinical Nurse Specialist

Women also reported that they were given easy to understand written information about their operation, that ward nurses did not talk in front of them as if they were not there, more likely to say that staff did not deliberately fail to tell them things, that they were given clear written information about what to do after they left hospital

Figure 7.1.2 provides a gender comparison for two survey questions, where the female respondents showed a more positive patient experience than males.

7.1.2 Example survey questions by gender, Cancer Patient Experience Survey, 2011/12



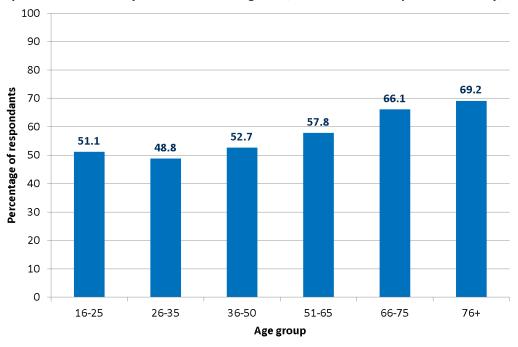
Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

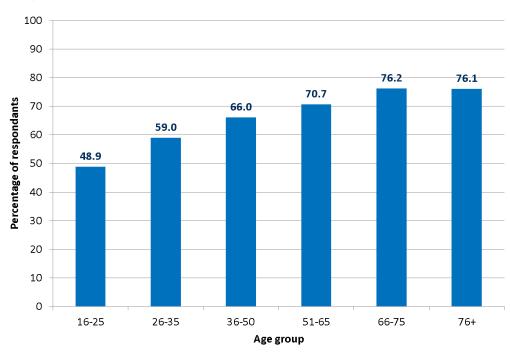
7.2. Patient experience by age

There were large differences in reported patient experience by age group from the 2011/12 CPES. On most issues measured in the CPES the youngest age cohort (16-25) reported a patient experience that wasn't as positive as for other ages.

7.2.1 Hospital and community staff work well together, Cancer Patient Experience Survey, 2011/12

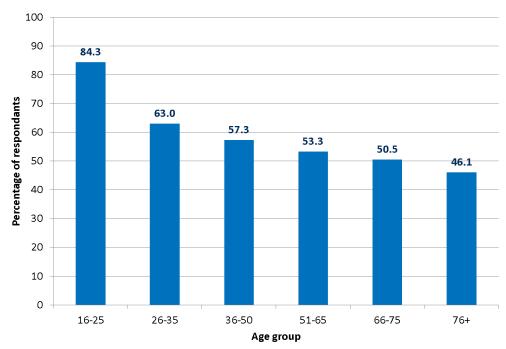


7.2.2 Completely understood explanation of what was wrong, Cancer Patient Experience Survey, 2011/12



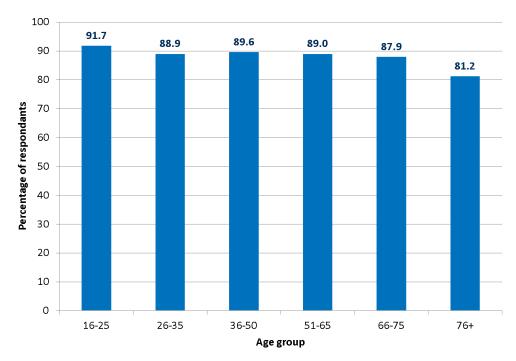
Analysis by age shows that both the youngest and oldest age patient groups are likely to receive different levels of information (depending on the issue concerned), which in some cases is not at optimum levels. The survey showed that younger patients are more likely to be given information about financial help or any benefits they may be entitled to. The difference reported between the youngest age group and the oldest is shown in chart 7.2.3

7.2.3 Given information on financial help/benefits by staff, Cancer Patient Experience Survey, 2011/12



It is not always younger patients who report a worse patient experience for cancer. Older people were least likely to say that they had been given the name of a CNS. Older people also reported that they were less likely to receive information about financial help or benefits they may be entitled to.

7.2.4 Given name of Clinical Nurse Specialist, Cancer Patient Experience Survey, 2011/12



Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

7.3. Patient experience by deprivation

In the survey for 2011/12, differences in responses between the least deprived decile and the most deprived decile showed a number of differences.

For 18 of the questions asked, responses for the more deprived patients reported a better patient experience than the least deprived. Examples of these include that they more likely to be told sensitively that they had cancer, that their views were taken into account when clinical team discussing which treatment they should have, that possible side effects of treatment explained in a way they could understand, that they were given the name of a Clinical Nurse Specialist and that it was easy to contact their CNS. The most deprived patients reported delayed diagnosis, less likely to receive understandable information or explanations and more likely to feel as if they were treated as a "set of cancer symptoms."

Patients in the least deprived quintile were more likely to report a better patient experience for 24 questions. These included being more likely to report an overall rating of care excellent / very good, given right amount of information about their condition and treatment, given understandable answers to questions by ward nurses all or most of the time, given easy to understand information about the type of cancer they had and given easy to understand written information about tests beforehand. A list of all these questions is available from the Cancer Patient Experience Survey National Report.

Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

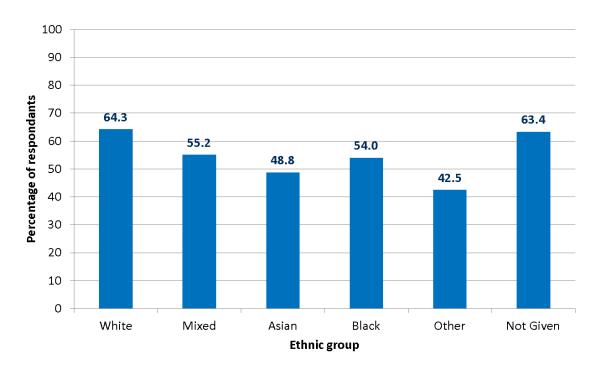
7.4. Patient experience by ethnic group

The number of respondents to the Cancer Patient Experience Survey from non-White ethnic groups is low, with only 2,665 non-White respondents in 2011/12. As a result, differences between ethnic groups were hard to identify due to the small number of respondents for each group. In order to have greater confidence about the results, NCEI requested analysis of two years' BME data and these verified the findings. For the 2011/12 survey, answers for 25 questions showed a difference between certain ethnic groups.

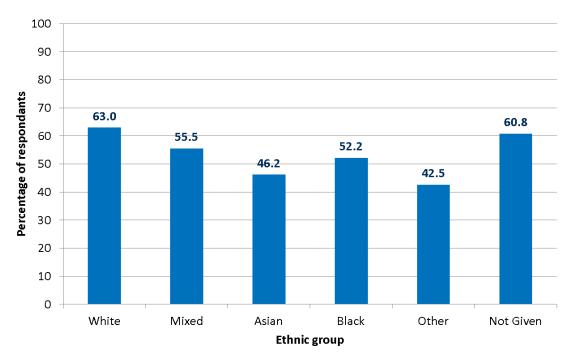
These 25 questions cover are a wide range of issues, ranging from communication that they received, confidence and trust in nurses, the control of pain, assessment of effectiveness of primary care support, and on the overall rating of care.

Figures 7.4.1 and 7.4.2 show the survey results by ethnic group for two example survey questions.

7.4.1 Patient able to discuss worries/fears with staff as much as wanted, Cancer Patient Experience Survey, 2011/12



7.4.2 Hospital and community staff work well together, Cancer Patient Experience Survey, 2011/12



From the 2010 Survey, the National Cancer Equalities Initiative identified key questions where patient from BME reported a worse experience compared to the White ethnic group. This included BME patients being more likely to report not receiving understandable answers to their questions, and less likely to receive written information on tests and procedures; BME patients having lower levels of confidence in their care and are less satisfied with communication about their care; BME patients, in particular black patients, less likely to feel involved in decisions about their treatment; BME patients less likely to feel they were given enough care and help from health and social services, once leaving hospital; While being treated as an outpatient or day case, BME patients less likely to feel they were given enough emotional support; BME patients, in particular Asian patients, more likely to feel like they were treated as a 'set of cancer symptoms'.

Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

7.5. Patient experience by sexuality

CPES respondents were asked if they were heterosexual, bisexual, gay or lesbian, or were of other sexual orientation. Due to the small number of respondents for any of these individual groups, responses were aggregated into one non-heterosexual group and compared to responses for the heterosexual group.

Of the 70 questions asked, 19 showed significant differences of opinion between heterosexual and non-heterosexual cancer patients. In these cases the differences demonstrate a less positive experience by non-heterosexuals. Responses showed that non-heterosexual respondents were less likely to feel that they were treated with dignity and respect, were not as positive about their

experience of communication, were less likely to feel that they were given enough emotional support and more likely to feel treated as 'a set of cancer symptoms'

Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

7.6. Patient experience by comorbidities

The CPES identifies respondents with long term conditions, or multiple conditions, other than cancer. The long term conditions (LTCs) identified in the survey were deafness / severe hearing impairment, blindness / partially sighted, long standing physical condition, learning disability, mental health conditions, long standing illness, e.g. HIV, diabetes, chronic heart disease, or epilepsy.

Responses were analysed by comparing the group of patients who had one or more of the long term conditions with the group who said they did not have a long term condition. Patients with long term conditions are rather less likely to be positive about their cancer care than patients without such conditions, and this less positive assessment is present across a wide range of issues measured in the survey.

For patients with long term conditions such as deafness and physical conditions, the differences are, in most cases, quite small. However, patients with mental health conditions and learning disabilities were far less likely to be positive, for example, more likely to say that they felt treated as 'a set of cancer symptoms' rather than a person.

Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the <u>Patient</u> <u>experience</u> section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, <u>Cancer Patient Experience Survey 2011/12</u>.

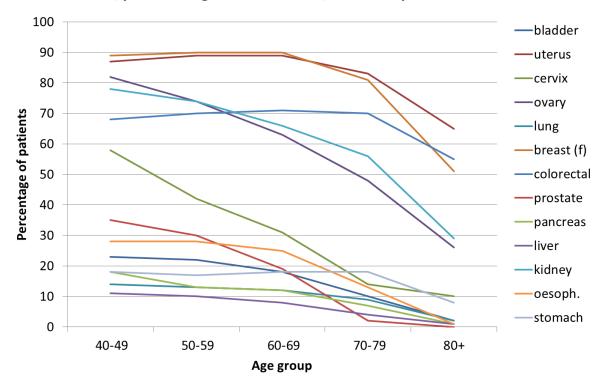
8. Radical treatment

8.1. Major resections by age

By linking Hospital Episode Statistics to cancer registrations, it is possible to look at the proportion of patients who receive a major resection in the NHS as part of their cancer treatment.

A study for patients diagnosed in England in 2004-2006 showed that for the majority of the 13 cancer sites analysed, there was a steep drop off with age in the proportion of patients who received a major resection as part of their treatment. Whilst this is apparent for patients from the age of 40, it is especially noticeable for patients aged 80 or over.

Percentage of patients with a record of a major resection, by age and cancer site, patients diagnosed 2004-2006, followed up to 2007



Source: National Cancer Intelligence Network, Major Surgical Resections

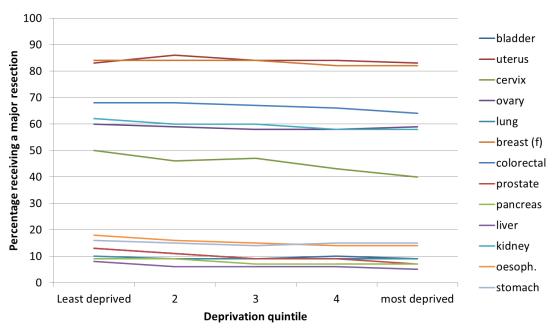
Where to go for further information

A <u>data briefing</u> and a <u>full report</u> are both available from the NCIN website.

8.2. Major resections by deprivation

Analysis of major resection rates by deprivation quintile showed little difference between deprivation groups. Cervical cancer showed the biggest difference between major resection rates for the most deprived and least deprived quintiles, with 50% of the least deprived NHS treated patients having a record of a major resection compared to 40% of the most deprived.

Percentage of patients with a record of a major resection, by cancer site and deprivation quintile, patients diagnosed 2004-2006, followed up to 2007



Source: National Cancer Intelligence Network, Major Surgical Resections

Where to go for further information

A data briefing and a full report are both available from the NCIN website.

8.3. Radiotherapy and chemotherapy

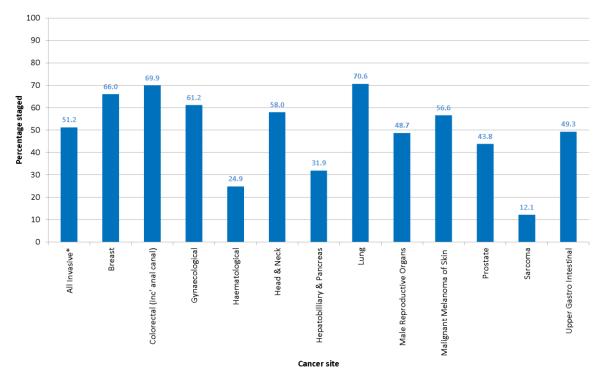
Analysis of cancer patients who receive radiotherapy and chemotherapy will be undertaken once these data become available. In 2013, the Radiotherapy dataset will be linked to cancer registrations enabling analysis of cancer patients who receive a major resection and those who receive radical radiotherapy.

9. Stage at diagnosis

9.1. The percentage of staging data recorded at diagnosis

The proportion of cancer patients with recorded stage is increasing. Data quality reports produced by cancer registries showed that for 2010 cancer registrations, 39.5% of all cancers (Excl. NMSC) diagnosed in England had a recorded stage. For 2011 registrations, this had increased to 51.2%. There are differences by Registry, but these are expected to become smaller over the coming years.

9.1 Proportion of cancers staged by cancer site, cancers registered in 2011, England



* Excluding non-melanoma skin cancer (NMSC)

Source: UKACR Data quality report for 2011 registrations

Where to go for further information

Data quality reports compiled by the cancer registries are available from the <u>UKACR website</u>.

9.2. Completeness of stage at diagnosis by age, sex, deprivation and ethnicity

Due to the incompleteness of staging data, breakdowns by different equalities groups have not been produced. Completeness by stage is improving as shown in section 9.1. Once staging data for sites are of a high enough completeness, breakdowns by different equality groups will be undertaken and reported in future reports.

10. Patient reported outcome measures (PROMS)

10.1. Cancer patient reported outcome measures by age

The first report on the <u>Quality of life of cancer survivors in England</u> used a pilot to determine the feasibility of collecting patient recorded outcome measures (PROMS) for a number of cancer sites. Patients were identified by three cancer registries and 3,300 questionnaires were sent to people registered as having been diagnosed with breast, colorectal, non-Hodgkin lymphoma or prostate cancers with an overall response rate of 68%.

During 2013, pilot surveys will be run covering cervical, ovarian, uterine and bladder cancers. The colorectal survey will also be scaled up from a pilot into a full survey.

From the pilots, differences by age were evident for a number of questions including that the oldest age group was the least positive on a question regarding mobility and the most positive on the question relating to fears that their cancer would come back¹.

The surveys noted that younger patients had more concern about death or dying, whereas older patients were more concerned about mobility and doing their domestic chores.²

Due to the small number of respondents to the pilots, specific differences are difficult to identify. When full cancer PROMS are collected for cancer sites, further analysis by equality groups will be included.

Where to go for further information

The <u>Quality of life of cancer survivors in England</u> report is available from the Department of Health's website

10.2. Cancer patient reported outcome measures by sex

The association of responses by sex showed that overall, men were more positive than women. This was true for 28 of the 43 common questions across all three sites applicable to both sexes. Women were more positive than men on only three of the questions; they were more likely to report their cancer had responded to treatment, more likely to report having no difficulty on sexual matters and more likely to report having a named nurse who they can contact³

Due to the small number of respondents to the pilots, specific differences are difficult to identify. When full cancer PROMS are collected for cancer sites, further analysis by equality groups will be included.

Where to go for further information

The <u>Quality of life of cancer survivors in England</u> report is available from the Department of Health's website

¹ Quality of life of cancer survivors in England section 11.2

² Quality of life of cancer survivors in England section 11.9

³ Quality of life of cancer survivors in England section 10.3

10.3. Cancer patient reported outcome measures by deprivation

On 39 of the 43 scored common questions asked of patients in all tumour groups, there were statistically significant differences by deprivation with patients in the least deprived quintile being more positive on every question than patients in the most deprived quintile. The remaining four questions didn't show any differences in responses that were statistically significant.

Breakdowns by cancer site were less conclusive given the smaller number of patients within each group, however differences that were statistically significant were apparent by site for between 16 of the 43 questions (breast cancer) and 25 of the 43 questions (non-Hodgkin lymphoma).

When full cancer PROMS are collected for cancer sites, further analysis by equality groups will be included.

Where to go for further information

The <u>Quality of life of cancer survivors in England</u> report is available from the Department of Health's website

10.4. Cancer patient reported outcome measures by self-reported ethnicity

Due to the limited number of cancer survivors contacted for this pilot, it was not possible to draw conclusions on differences by ethnic group. Cancer Proms will collect information regarding ethnicity and therefore breakdowns by ethnic group will be reported when these data are available.

References

ⁱ Office of National Statistics, Series DR

Eurocare study, http://www.eurocare.it/Results/tabid/79/Default.aspx

Br J Cancer, "Trends and inequalities in survival for 20 cancers in England and Wales 1986-2001: population-based analyses and clinical commentaries", Volume 99, Supplement 1, 23 September 2008.

^{iv} Lüchtenborg et al, "The impact of socio-economic deprivation on cancer survival in England" http://www.ncin.org.uk/view.aspx?rid=777, http://www.ncin.org.uk/view.aspx?rid=662

v Routes to diagnosis http://www.ncin.org.uk/publications/routes to diagnosis

National Cancer Intelligence Network 18th Floor, Portland House Bressenden Place London, SW1E 5RS

enquiries@ncin.org.uk

www.ncin.org.uk

