Public Health England

National Cancer Intelligence Network

Cancer and equality groups: key metrics

2014 report

About Public Health England

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The intelligence networks

Public Health England operates a number of intelligence networks, which work with partners to develop world-class population health intelligence to help improve local, national and international public health systems.

National Cancer Intelligence Network

Public Health England's National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

National Cardiovascular Intelligence Network

The National cardiovascular intelligence network (NCVIN) analyses information and data and turns it into meaningful timely health intelligence for commissioners, policy makers, clinicians and health professionals to improve services and outcomes.

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National End of Life Care Intelligence Network

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

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Foreword

In 2013, the National Cancer Equality Initiative (NCEI) and the National Cancer Intelligence Network (NCIN) published a baseline report on cancer and equality groups. The purpose was to establish a series of metrics relating to equality groups and cancer that would provide a basis to measure change, whether positive or negative. The rationale was simple: it is impossible to tackle inequalities without data to inform activity and scrutinise progress. The NCIN has pioneered the collection and analysis of meaningful cancer metrics, ensuring that data are routinely collected, analysed, interpreted and published for as many equality groups as viable.
The availability and quality of data is improving. Our knowledge of the disease and differences by equality groups is increasing. Our understanding of patient's experiences is evolving.

This follow up report brings together updated information and intelligence, and highlights where differences by equality groups exist so that we can work to reduce inequalities. It also shows what improved data quality will allow us to do in the future to improve our understanding further.

The metrics contained within the report provide an overview of national trends, providing insight for commissioners and providers alike and enable the NCEI to champion further action. The 10 chapters cover the spectrum of the cancer patient journey starting with basic epidemiological data such as incidence, mortality and one-year survival. Further chapters cover the completeness of data on ethnicity; the uptake of the cancer screening programmes; a breakdown of Routes of Diagnosis; reporting on patient experience; radical treatment; stage at diagnosis and patient reported outcomes.

This report illustrates that progress against these metrics is being made. Hospital trusts have made great improvements in recording ethnicity. This will enable us to have a far better understanding of cancer in relation to minority ethnic groups. Likewise, Public Health England's National Cancer Registration Service shows there has been a continued increase in the proportion of cancer registrations with a recorded stage of disease at diagnosis. This will significantly improve the assessment of variations in early diagnosis across all equality groups. Though these improvements are positive, some trusts still lag behind in the completeness of ethnicity recording whilst staging completeness remains below the benchmark of 70%.

Commissioners, clinicians, patients and local communities alike want to see continued progress across the pathway: from high quality data collection to intelligence on cancer by equality groups.

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Introduction

The National Cancer Intelligence Network (NCIN), working with the National Cancer Equalities Initiative, has brought together a selection of key cancer metrics into one central report. The metrics selected either provide background information by equality group or analysis of cancer in relation to equality groups.

This 2014 report brings together updated information on cancer by equality groups and builds on the baseline report published in 2013, making comparisons over time where data permit.

There are still some equality metrics where data either are not yet available, or have only just become available and where national analyses are planned for the coming year. A placeholder has been included where relevant as an indication that analysis will be undertaken once data are of good enough quality to produce meaningful results.

Every piece of national analysis on cancer that is undertaken within Public Health England (PHE) through the NCIN and its site specific clinical reference groups considers all equality groups when assessing which breakdowns of results can be produced. Where data are available and of good enough quality, analysis will be undertaken. Having high quality data linked to cancer registrations enables novel analyses, such as Routes to Diagnosis which combines five administrative datasets to assign a Route to all newly diagnosed malignant neoplasms and selected benign and in-situ tumours. The recently updated report on Routes to Diagnosis produced breakdowns by sex, age, deprivation and ethnicity for over 55 different cancer sites and groups.

One area that has seen improvements in recent years is the completeness of ethnicity recording in NHS Trusts. Completeness of ethnicity in episodes within Hospital Episode Statistics (HES) increased not just in Admitted Patient Care data but also for Outpatient and A&E data across 2010-2012.

Analysis of cancer by ethnic group, from differences in presentation to treatment and survival are reliant on the completeness of ethnicity in hospital datasets. Without complete recording, perceived differences will always be questioned as to the impact of the cases with unknown ethnicity. In England in 2008-2010, 91% of cancer registrations have been assigned to the White ethnic group, with 5.1% of newly diagnosed malignant neoplasms assigned to the unknown ethnic group. The number of registrations with an unknown ethnic group remains higher than the number of people assigned to the Asian, Black, Chinese and Mixed ethnic group combined (3.9%).

Completeness of staging data also continues to improve. Overall completeness for all malignant neoplasms (excluding non-melanoma skin cancer) has increased from 39.5% in 2010 to 51.2% in 2011 to 62% in 2012. These improvements see the National Cancer Registration Service (NCRS) making large strides towards their standard of having 70% of all cancers staged within the next few years. Stage completeness is above 70% for colon, rectum, lung, breast, malignant melanoma, endometrium, ovarian and prostate cancers.

Survey data undertaken by Quality Health through the Cancer Patient Experience Survey (CPES) collects information 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. The third Cancer Patient Experience Survey shows that differences in reported experiences have remained fairly stable since the first survey in 2010. The national report highlights many of these areas where improvements are required to reduce inequalities in patient experiences.

Data included in this report have been taken from a variety of different sources, including analysis produced within the NCIN, Cancer Research UK (CRUK) and the Office for National Statistics (ONS), 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.

NCIN continues its commitment to produce an updated report each year to keep monitoring where inequalities exist. By presenting these data together into one central report with links to further information, it is hoped that this report will provide a basis for further questions to be asked about cancer by equality groups, and to provide a platform to drive further analysis, especially in areas where the quality or completeness is improving.

This report mainly contains results for the four most common cancers in England. Due to the requirement of having sufficient number of cases in each study in order to draw conclusions, these sites present the most likely to be present in every study. 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. Please visit the site specific pages of the NCIN website for detailed specific studies covering many equality groups.

Further information can also be found form the NCIN's "What cancer statistics are available and where can I find them". This is a useful resource for further data on cancer statistics and is updated periodically.

Whilst this report is focussed mainly on data available in England, further data are available by equality groups in Scotland, Northern Ireland and Wales 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
(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. The number of cases for the four most common cancers increased by around 5,100 cases from 2011, with a similar increase seen for each sex. The 53% of all cancers that these four sites account for remains the same as in 2011. See section 1.4 for information on trends in cancer incidence by sex.

1.1.1. Newly diagnosed cases of cancer by site, England, 2012

Cancer Site	All persons Number	Change from 2011 % change	Males Number	ASR[1]	Females Number	ASR[1]
Breast	42,631	3.1%			42,631	129.6
Colorectal	34,510	1.7%	19,398	58.9	15,112	37.6
Lung	36,059	3.8%	19,643	58.5	16,416	41.3
Prostate	37,117	4.9%	37,117	113.3		
All cancers*	**283,087**	**3.8%**	**144,254**	**445.6**	**138,833**	**387.7**

* Excluding non-melanoma skin cancer (NMSC)
[1] Age-Standardised to the European Standard Population

Source: CASCADE, based on CAS snapshot CAS1403.

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 for 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

Different cancer sites affect different age groups. The data below provide basic information as to which ages are affected by the most common cancers. The groups used are an agreed standard set of age ranges which will be used for analyses by age group. Children (0-14) and teenagers and young adults (15-24) are also represented.

Table 1.2.1 shows that the most common cancers are not prevalent in children and teenage and young adults.

1.2.1. Newly diagnosed cases of cancer by site and age group, England, 2012

Cancer site	Age group					
	0-14	15-24	25-64	65-74	75-84	85+
Breast (f)	0	33	22,688	9,420	6,816	3,674
Colorectal (f)	14	71	3,928	3,943	4,580	2,576
Colorectal (m)	10	51	5,535	5,979	5,682	2,141
Lung (f)	1	9	3,931	5,226	4,948	2,301
Lung (m)	3	8	4,464	6,709	6,105	2,354
Prostate (m)	1	0	9,096	14,495	10,220	3,305
All cancers* (f)	**578**	**905**	**54,709**	**33,989**	**31,484**	**17,168**
All cancers* (m)	**652**	**899**	**43,108**	**45,820**	**39,229**	**14,546**

* Excluding non-melanoma skin cancer (NMSC)

Source: CASCADE, based on CAS snapshot CAS1403.

Where to go for further information

Further data are available from NCIN and PHE Knowledge and Intelligence teams. The Office for 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 any differences in the age structure of the populations are 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 1.3.1 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 one. 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 one.
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.

1.3.1. Age standardised rate ratios for non-sex specific cancers, UK, 2010
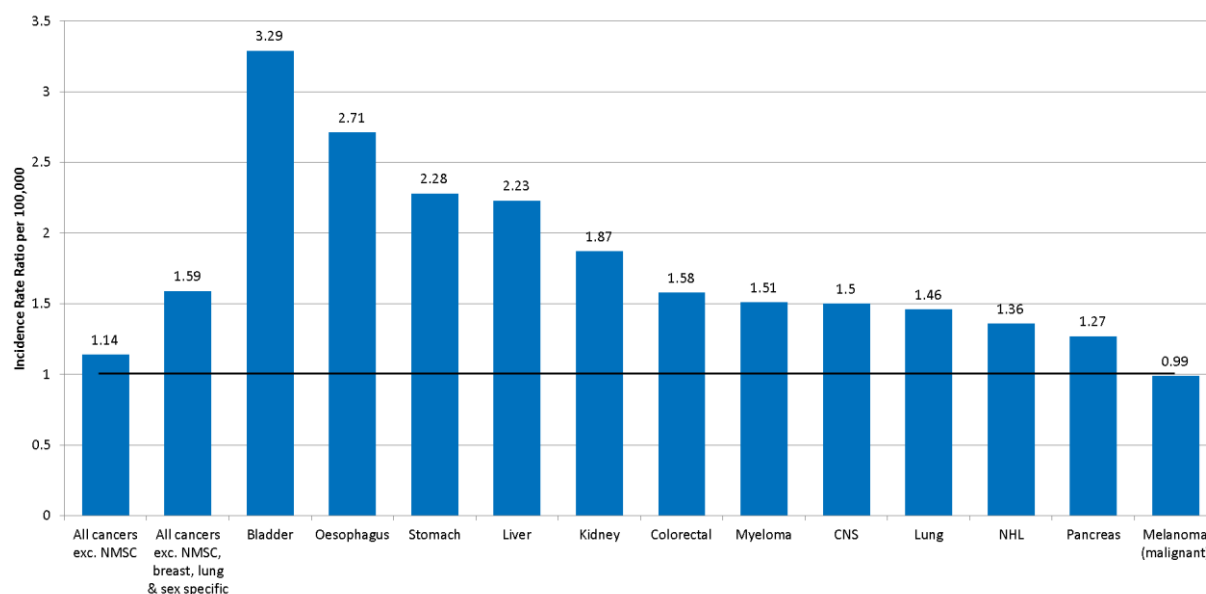
Source: "Excess Burden of cancer in Men", Cancer Research UK, NCIN and Men's Health Forum

Where to go for further information

A report on the excess burden of cancer in men 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 and to identify where progress is not being made. The number of cases per site per year provides the burden of disease, whereas age-standardised rates take into account differences in the age structure of the population over time. The trends below show incidence rates for the most common cancers over the last 10 years. The overall number of newly diagnosed cancers is increasing each year, however, the "all cancers" age-standardised rate has remained steady in recent years, with a slight fall seen for males. This reflects the ageing population in England as well as the population living longer. Individual sites show that lung cancer incidence has been falling in males and is remaining steady in females, reflecting the historic trend in smoking prevalence.

1.4.1. Trends in age standardised incidence rates, all cancers excluding NMSC[1], England, 2003-2012

Trends in age-standardised cancer incidence, all cancers excl NMSC[1], by sex, England, 2003 - 2012
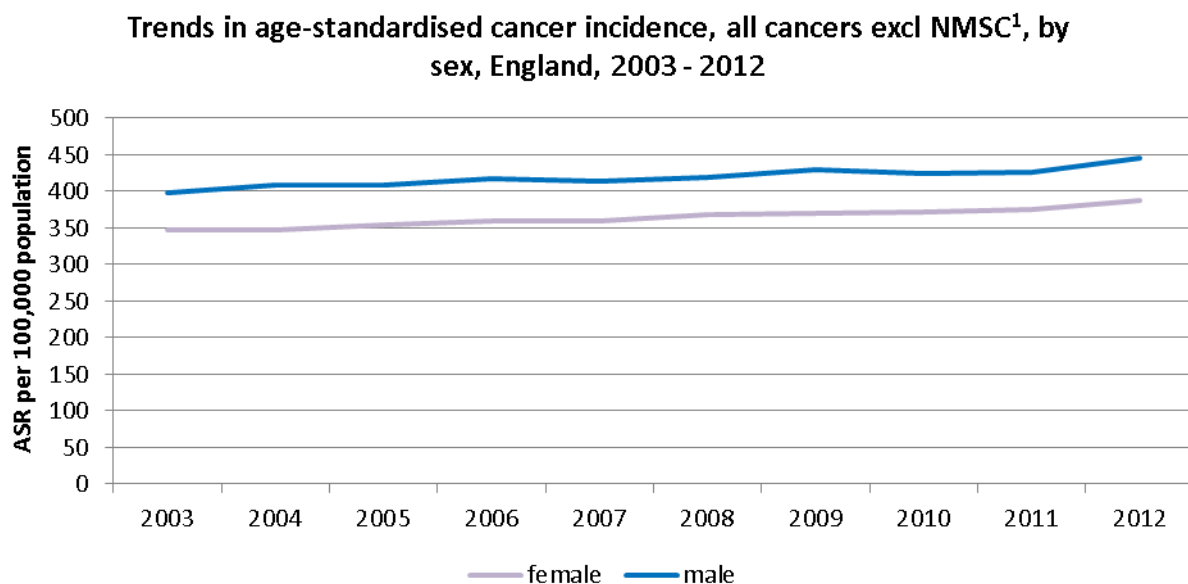
[1] Excluding non-melanoma skin cancer (NMSC)
ASR – Age-standardised rate

1.4.2. Trends in age standardised incidence rates, colorectal, England, 2003-2012

Trends in age-standardised cancer incidence, colorectal cancer, by sex, England, 2003 - 2012
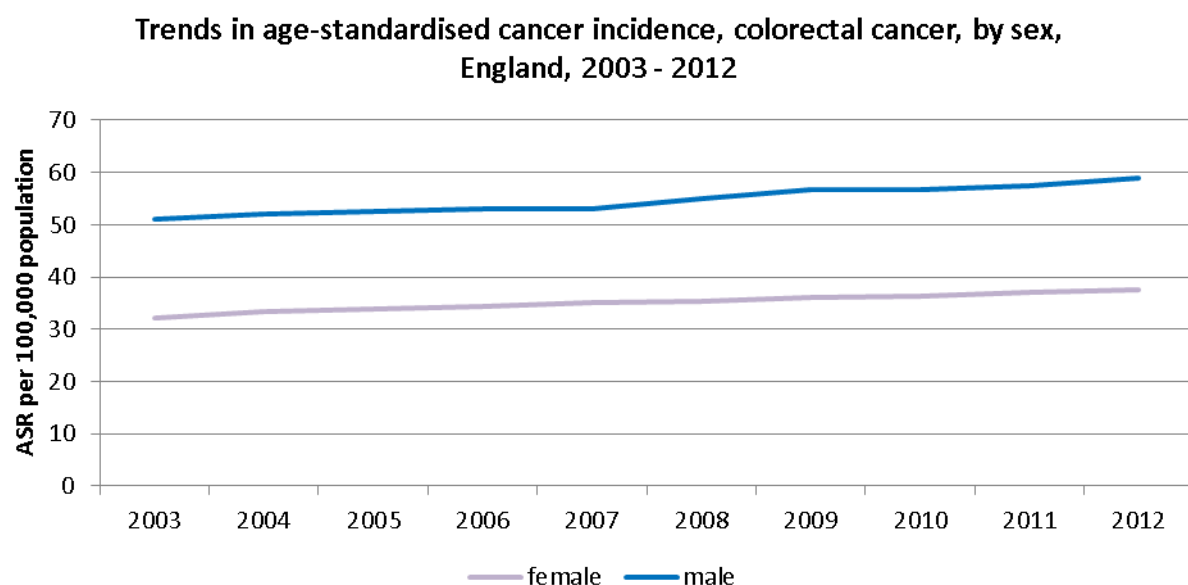
ASR = Age-standardised rate

1.4.3. Trends in age standardised rates, lung, England, 2003-2012

Trends in age-standardised cancer incidence, lung cancer, by sex, England, 2003 - 2012
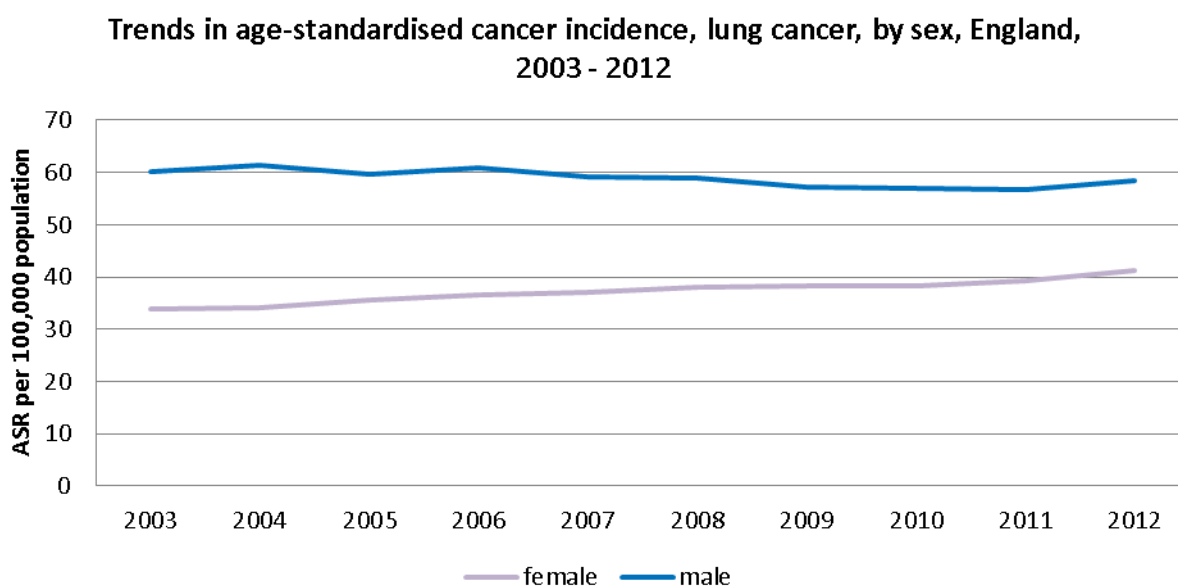
ASR = Age-standardised rate

1.4.4. Trends in age standardised rates, breast (females), prostate, England, 2003-2012

Trends in age-standardised cancer incidence, breast (f) and prostate, England, 2003 - 2012
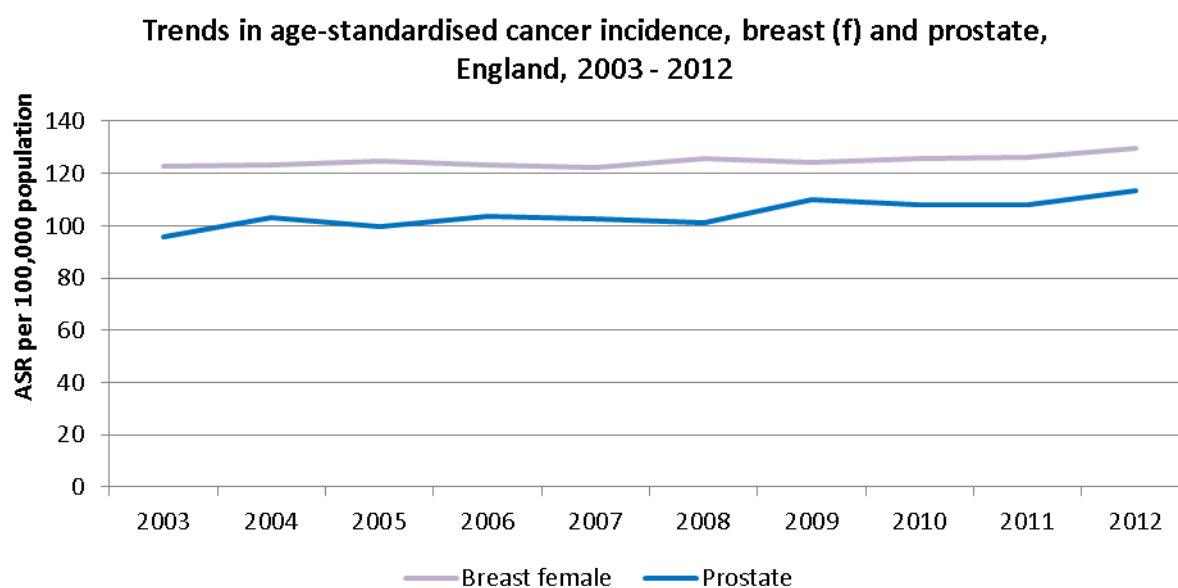
ASR = Age-standardised rate

Source: CASCADE, based on CAS snapshot CAS1403.

Where to go for further information

Further information on trends in cancer incidence is available from the NCIN and PHE Knowledge and Intelligence teams. Information is also 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)

A joint NCIN and Cancer Research UK report published in 2014 presented results for cancer incidence by deprivation quintile for all cancers combined (excluding NMSC) and for 38 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 2006-2010, oral cavity (m), larynx, liver (m) and lung cancer incidence rates in the most derived group were at least double that of the least deprived group. In addition, Incidence rates were higher for the most deprived compared to the least deprived group for oropharynx, oral cavity (f), oesophagus, stomach, pancreas, colorectal (m), anus, vulva, vagina, cervix, penis, kidney, bladder, cancer of unknown primary, Hodgkin lymphoma (m), NHL (f) and acute myeloid leukaemia (m). Differences for all these sites were statistically significant. For other sites, including central nervous system (f), breast (f), prostate, testis, malignant melanoma and acute lymphoblastic leukaemia (m) higher rates were seen for the least deprived compared to the most deprived. For breast and prostate cancer, this reflects the higher uptake of screening and PSA testing respectively in the least deprived quintile.

1.5.1. Age standardised rate ratios by deprivation group, selected sites, England, 2006-2010

	ASR least deprived	ASR most deprived	Incidence Rate Ratio
Breast (f)	132.0	113.2	**0.9**
Colorectal (m)	53.4	60.5	**1.1**
Colorectal (f)	35.6	36.3	**1.0**
Lung (m)	36.8	97.9	**2.7**
Lung (f)	23.3	63.6	**2.7**
Prostate	113.3	94.1	**0.8**
All cancers* (m)	**390.9**	**485**	**1.2**
All cancers* (f)	**349.7**	**395.5**	**1.1**

* Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network

Where to go for further information

The NCIN – CRUK partnership report on cancer incidence and mortality by deprivation 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 in the NHS by trusts and recorded in Hospital Episode Statistics (HES) (see section 4). The first national report on cancer incidence by ethnic group 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.

Better linkage of cancer registrations to HES and improved recording of ethnicity within HES (see section 4) has greatly increased the proportion of cancer registrations with an assigned ethnicity. Data shown below therefore shows the number of cases for each major ethnic group.

The improvement in recording of ethnicity in HES will allow us to produce more comprehensive analyses of cancer by ethnic group so that we can really understand the impact of different cancers on different ethnic groups in England. The NCIN commits to producing an updated report on cancer incidence by major ethnic group in 2014. This is dependent on the Office for National Statistics producing estimated populations by ethnic group. The methodologies for these are currently being reviewed with 2009 being the latest year where population estimates by ethnic group are available.

1.6.1. Number of cases by Major ethnic group (including unknown), selected cancer sites, England, 2006-2010

	White	Asian	Black	Chinese	Mixed	Other	Unknown	Total	Per cent unknown
Breast	180,702	4,381	2,944	450	694	1,594	9,649	200,414	**4.8%**
Colorectal (m)	82,886	1,217	944	188	204	461	3,409	89,309	**3.8%**
Colorectal (f)	66,263	831	859	129	139	397	3,490	72,108	**4.8%**
Lung (m)	85,452	1,213	879	159	160	595	5,833	94,291	**6.2%**
Lung (f)	66,721	433	373	108	110	407	4,629	72,781	**6.4%**
Prostate	149,549	2,308	4,905	177	511	959	7,927	166,336	**4.8%**
All cancers (m)	599,979	11,154	10,979	1,127	1,857	4,542	32,143	661,781	**4.9%**
All cancers (f)	584,157	11,992	8,516	1,372	1,904	4,860	33,449	646,250	**5.2%**

Source: National Cancer Intelligence Network, March 2014

Where to go for further information

For more information, please contact enquiries@ncin.org.uk. An older report on cancer incidence by major ethnic group is available from the NCIN website.

2. Cancer mortality 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 28% of all registered deaths in England and Wales[1], falling slightly from 29% in 2011. Mortality data are presented below to help understand cancer mortality by equality groups. Deaths from the 4 most common cancer sites account for 45% of all cancer deaths. The number of deaths from cancer rose by 1.5%, but it is important to consider the change in cancer types, and change in age distribution of the population. See section 2.4 for trends in age-standardised mortality rates.

2.1.1. Number of deaths, selected cancer sites, England and Wales, 2012

	All persons	Change from 2011	Males	Females
Breast	10,373	-0.2%	62	10,311
Colorectal	14,166	3.0%	7,733	6,433
Lung	30,273	0.4%	16,698	13,575
Prostate	9,698	0.3%	9,698	-
All cancers*	**142,107**	**1.5%**	**75,072**	**67,035**

Source: Office for National Statistics, Series DR

Where to go for further information

Further information on cancer mortality is available from a variety sources including the NCIN, Cancer Research UK and the Office for 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

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 over 200 deaths were caused by cancer in people aged 14 and under in 2012, none were caused by the most common cancer sites. Cancers of the central nervous system, certain leukaemias and lymphomas are more common cancers in children.

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[1] Office for National Statistics, Series DR

2.2.1. Number of deaths by age group, England and Wales, selected sites, 2012

Cancer site	Age group
	0-14	15-24	25-64	65-74	75-84	85+
Breast (f)	0	1	3,438	2,049	2,458	2,365
Colorectal (f)	0	5	1,116	1,259	2,016	2,037
Colorectal (m)	0	3	1,616	1,971	2,646	1,497
Lung (f)	0	1	2,785	3,998	4,420	2,371
Lung (m)	0	2	3,456	5,329	5,521	2,390
Prostate (m)	0	0	587	1,843	3,842	3,426
All cancers* (f)	**118**	**101**	**14,997**	**15,721**	**20,341**	**15,757**
All cancers* (m)	**117**	**143**	**15,151**	**20,360**	**25,126**	**14,175**

Source: Office for National Statistics, Series DR

Where to go for further information

The Office for National Statistics produces number of deaths by age group by ICD10 code in the DR series. Cancer Research UK produces charts and tables by age group for a wide variety of cancer sites. Further information is also available from Public Health England Knowledge and Intelligence Teams

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 2.3.1 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.

2.3.1. Male-female age standardised rate ratios for non-sex specific cancers, UK, 2010
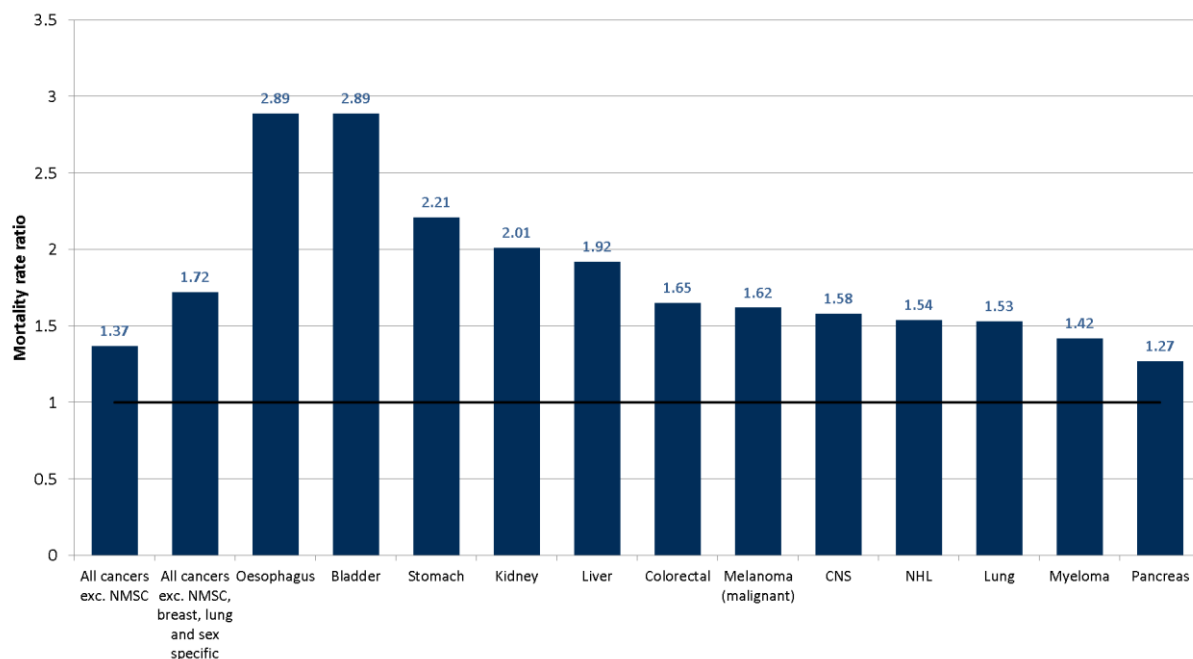
Source: "Excess Burden of cancer in Men", Cancer Research UK

Where to go for further information

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

2.4.   Trends in age standardised mortality rates (over previous ten 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. Whilst overall cancer mortality rates have been falling over the last 10 years, the last few years have seen little difference year on year.

2.4.1. Trends in age standardised cancer mortality rates, all malignant neoplasms, UK, 2002-2011

Trends in cancer mortality, all cancers, by sex, UK, 2002 - 2011
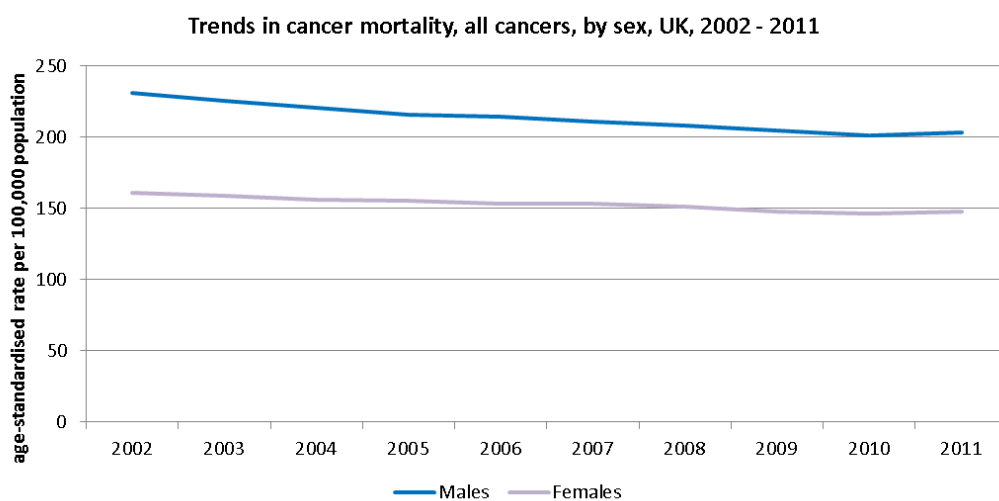
2.4.2. Trends in age standardised mortality rates, colorectal, UK, 2002-2011

Trends in cancer mortality, colorectal, by sex, UK, 2002 - 2011
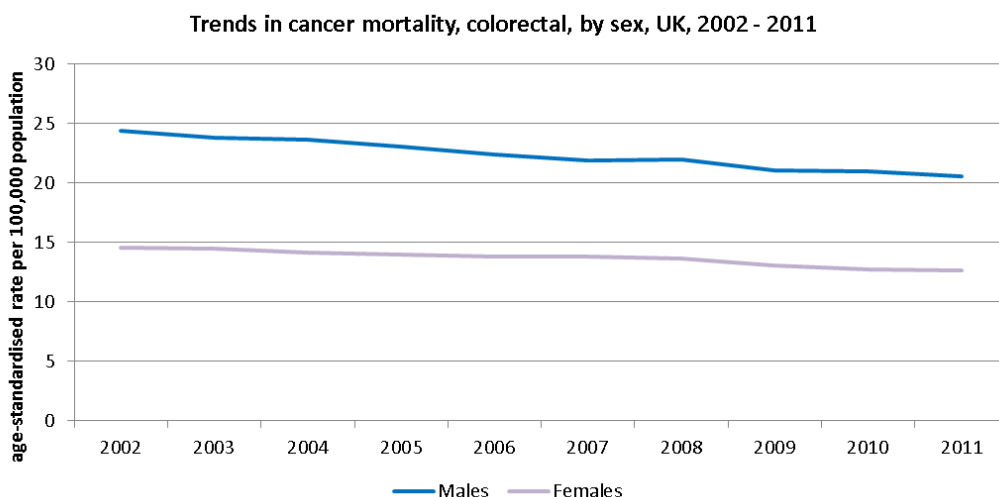
2.4.3. Trends in age standardised mortality rates, lung, UK, 2002-2011

Trends in cancer mortality, lung, by sex, UK, 2002 - 2011
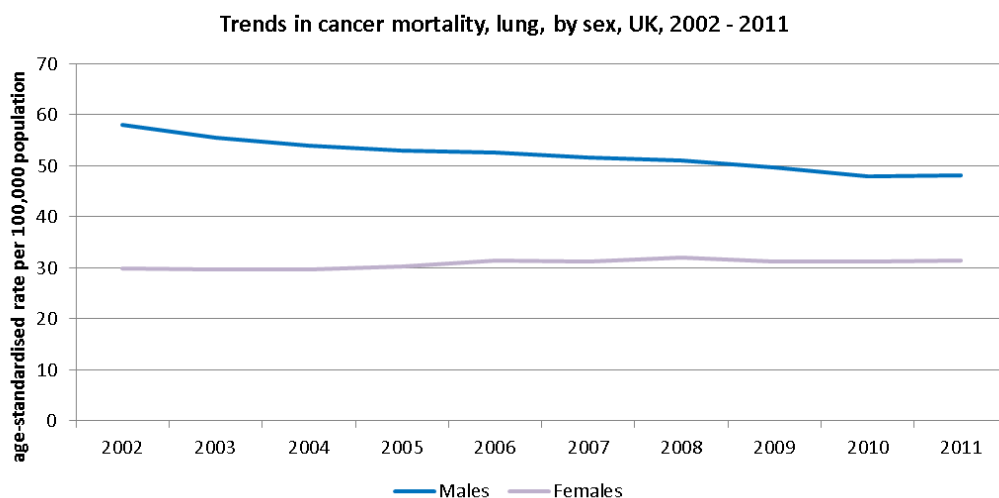
2.4.4. Trends in age standardised mortality rates, prostate (Males), breast (Females), UK, 2002-2011

Trends in cancer mortality, prostate and breast (f), UK, 2002 - 2011
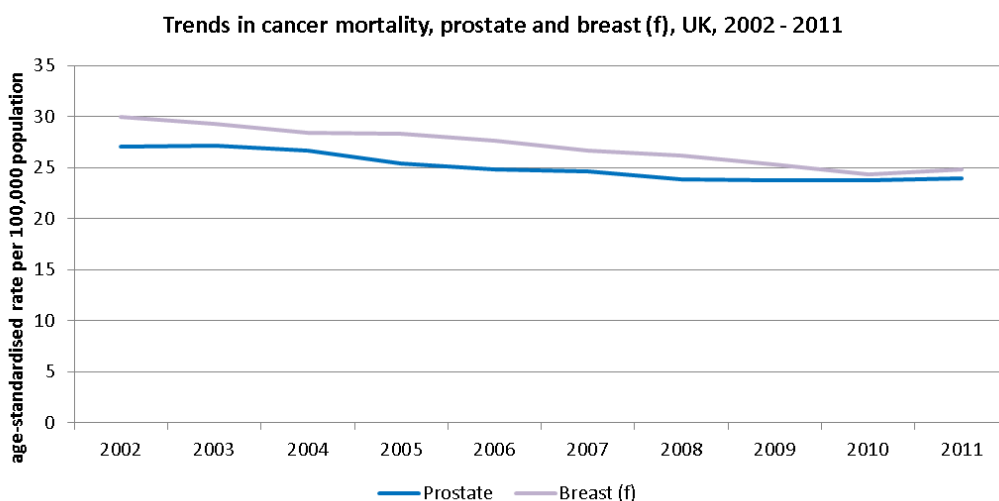
Source: Data extracted from UKCIS, accessed March 2014

Where to go for further information

NCIN and PHE Knowledge and Intelligence Teams can produce information on cancer incidence and mortality. Cancer Research UK produces trends by age group for a wide variety of cancer sites.

2.5. Age standardised cancer mortality rates by deprivation

A joint NCIN and Cancer Research UK report published in 2014 presented results for cancer mortality by deprivation quintile for all cancers combined (excluding NMSC) and for 38 cancer sites or groups. Inequalities in cancer mortality in relation to socio-economic deprivation are linked to differences in cancer incidence by deprivation (see section 1.5).

This national report on cancer incidence and mortality by deprivation showed that for deaths occurring in 2007-2011, cancers of the oropharynx, oral cavity (m), larynx (m), stomach, anus, lung, cervix and penis had mortality rates in the most derived group that were at least double that of the least deprived group. In addition, mortality rates were higher for the most deprived compared to the least deprived group for oral cavity (f), salivary glands (m), oesophagus, liver, pancreas, colorectal, breast, vulva, vagina, uterus, testis, kidney, bladder, cancer of unknown primary, Hodgkin lymphoma (m), NHL (f) and chronic myeloid leukaemia (m) and the difference was statistically significant.

Only malignant melanoma showed higher rates for the least deprived compared to the most deprived. Breast cancer incidence has an inverse relationship with deprivation, predominantly caused by screening uptake. Higher mortality in the most deprived for female breast cancer reflects the different nature of breast tumours being diagnosed between sexes.

2.5.1. Cancer mortality ratio by deprivation, selected sites, England, 2007-2011

	ASR least deprived	ASR most deprived	Rate Ratio
Breast (f)	24.6	26.1	**1.1**
Colorectal (m)	18.5	24.0	**1.3**
Colorectal (f)	12.1	14.0	**1.2**
Lung (m)	29.6	80.1	**2.7**
Lung (f)	18.6	51.3	**2.8**
Prostate	23.2	24.0	**1.0**
All cancers* (m)	164.1	262.0	**1.6**
All cancers* (f)	123.7	182.7	**1.5**

Source: NCIN and CRUK report on cancer incidence and mortality by deprivation quintile, 2014

Where to go for further information

The NCIN – CRUK partnership report on cancer incidence and mortality by deprivation is available from the NCIN website.

## 2.6. Mortality by major ethnic group and unknown ethnicity

Given the improved completeness of ethnicity coding for cancer registrations, NCIN will look at the feasibility of including cancer mortality by ethnic group alongside its commitment to producing an updated report on cancer incidence by ethnic group in 2014. Currently, national data on cancer mortality by ethnic group are not available.

3. One year relative survival from cancer (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.[2] 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.

3.1.1. Trends in one year relative survival, selected sites, England, 1996-2009, followed up to 2010.
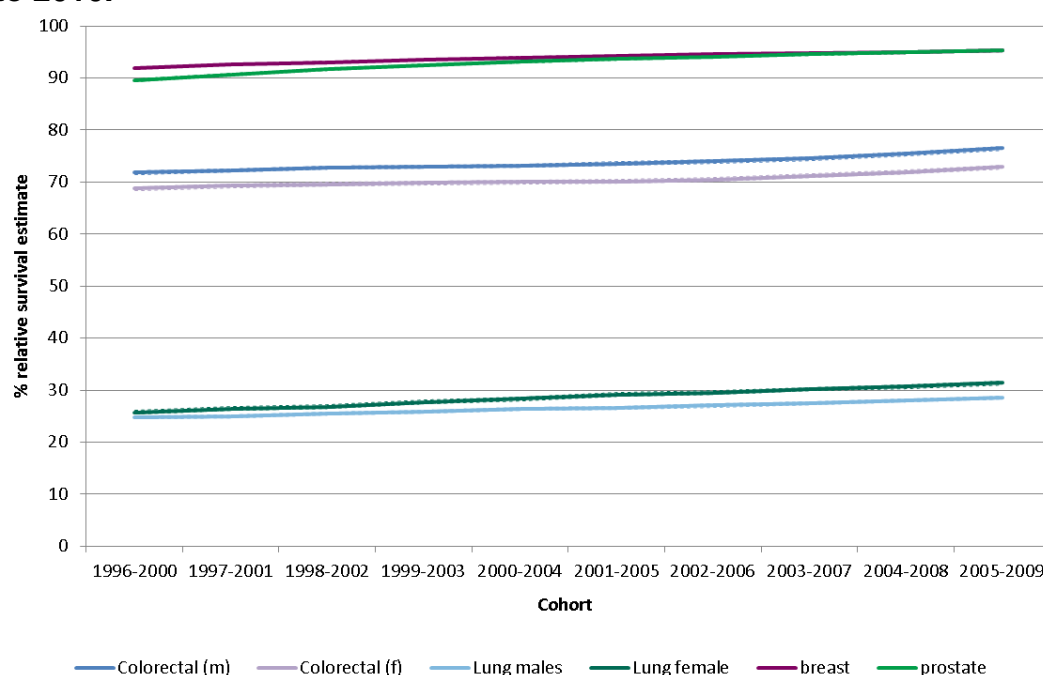
Source: Data extracted from UKCIS, accessed March 2014

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.

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

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.

3.2.1. One year relative survival estimates by age group, selected sites, 2005-2009, England

Source: Data extracted from UKCIS, accessed March 2014

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.

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

Source: Office for National Statistics

Where to go for further information

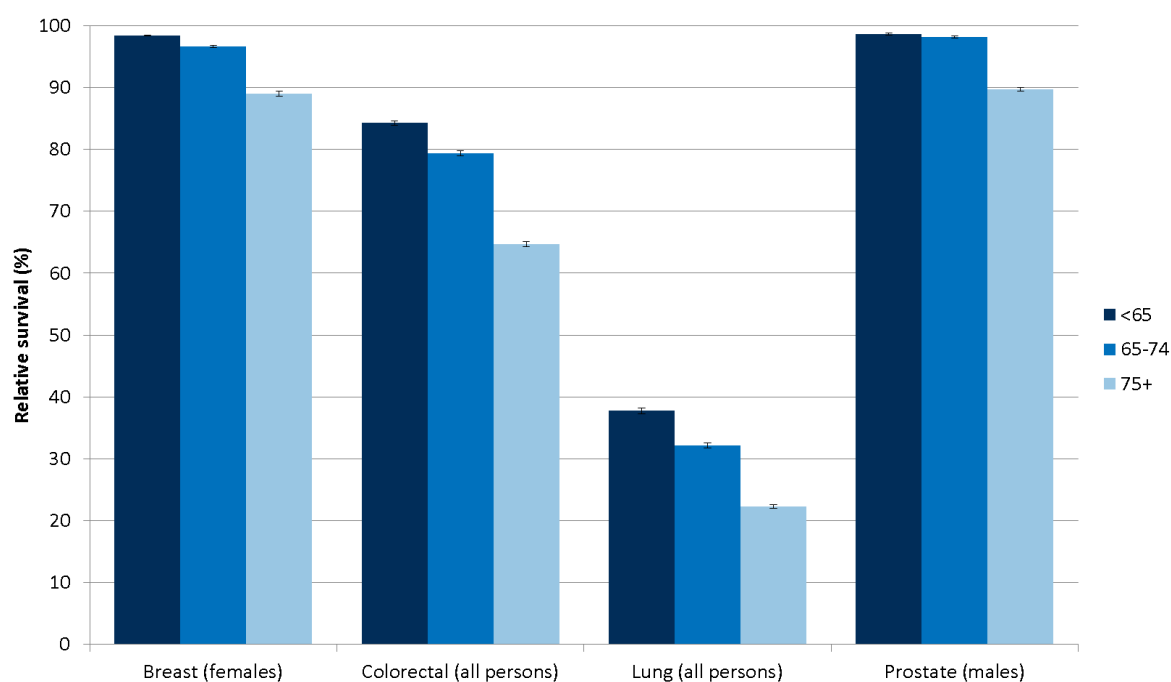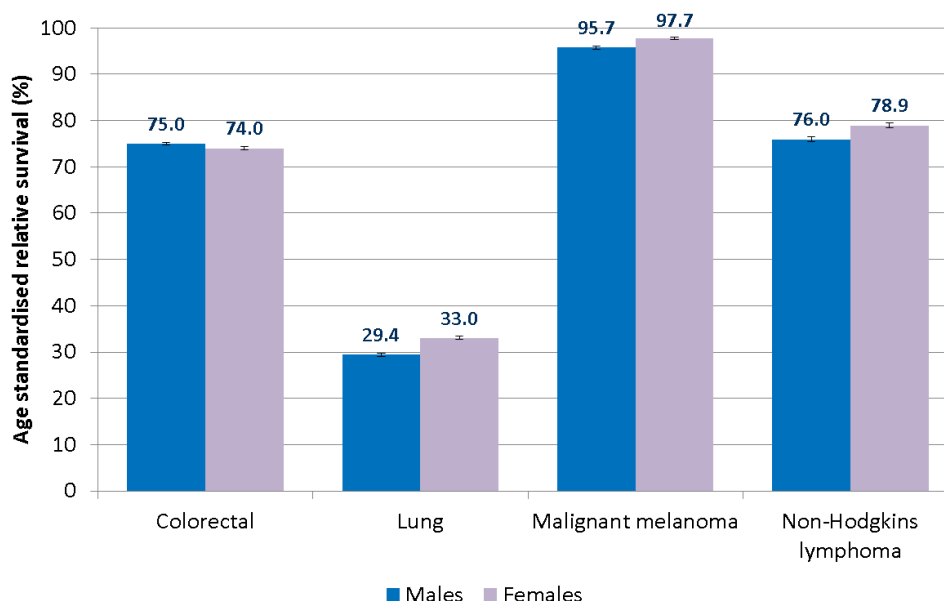Age standardised relative survival estimates are available from the ONS website. Other cancer survival estimates for England are available from a variety of sources, see "What Cancer Statistics are available, and where can I find them?" for more details.

3.4. 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 2008[3]. 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

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[3] 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.

figures are statistically significant with the exception of female lung cancer (bold). Table 3.4.1 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[4]

3.4.1. 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	
	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%

Source: British Journal of Cancer volume 99, Supplement 1

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.

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[4] 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

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 cancer incidence by major ethnic group 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 initially risen to 86% of records having an ethnic group assigned from HES. In 2013, the process for obtaining HES data to link to cancer registrations changed, with agreement from the Confidentiality Advisory Group. As a result, the proportion of registrations with an assigned ethnicity is now 95%. Ethnicity is assigned by linking cancer registrations with admitted care HES, Outpatient HES, A&E HES and also from information collected for cancer registration purposes. Of the proportion of records with no ethnic group assigned, the majority are caused by ethnicity not being recorded in HES rather than not being linked to a hospital episode.

4.1.1. Proportion of newly diagnosed cases of cancer with an ethnic group recorded, selected sites, England, 2008-2010

	White	Asian	Black	Chinese	Mixed	OtherEth	Unknown
Breast	90.2%	2.2%	1.5%	0.2%	0.3%	0.8%	4.8%
Colorectal (m)	92.8%	1.4%	1.1%	0.2%	0.2%	0.5%	3.8%
Colorectal (f)	91.9%	1.2%	1.2%	0.2%	0.2%	0.6%	4.8%
Lung (m)	90.6%	1.3%	0.9%	0.2%	0.2%	0.6%	6.2%
Lung (f)	91.7%	0.6%	0.5%	0.1%	0.2%	0.6%	6.4%
Prostate	89.9%	1.4%	2.9%	0.1%	0.3%	0.6%	4.8%
All cancers* (m)	**90.7%**	**1.7%**	**1.7%**	**0.2%**	**0.3%**	**0.7%**	**4.9%**
All cancers* (f)	**90.4%**	**1.9%**	**1.3%**	**0.2%**	**0.3%**	**0.8%**	**5.2%**

Excluding non-melanoma skin cancer (NMSC)

Source: NCIN, calculated March 2014

Where to go for further information

These data are calculated from the National Cancer Data Repository (NCDR) for this report. More information can be requested by contacting enquiries@ncin.org.uk

4.2. Completeness of ethnicity in HES data linked to cancer registrations

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 five year period.
For HES data linked to cancer registrations (a subset of HES), a similar improvement has been seen in the completeness of Ethnicity. The completeness of Outpatient HES has also improved greatly from 2010 to 2012. Complete coding of Ethnicity in HES enables us to produce national analyses by Ethnic group. The lack of complete ethnicity coding has prevented analysis by this equality group historically, but improvements are leading to us being able to understand how different cancers affect different ethnic groups so that relevant messages can be conveyed to the right populations.

4.2.1. HES Admitted Patient Care episodes with known or unknown ethnicity, England, 2012

	White	Mixed	Asian	Black	Chinese	Other	Unknown
2012 Episodes	86.8%	0.5%	2.8%	2.4%	0.2%	1.0%	6.3%

See also table 4.3.1 for completeness of Ethnicity by Trust for episodes in 2012.

Source: NCIN, reproduced with permission from the Health and Social care information centre

4.2.2. Completeness of ethnicity recording in Outpatient HES records linked to cancer registrations, England, 2010-2012

	2010	2011	2012
Ethnicity Completeness per episode	38.3%	72.8%	93.7%

Source: NCIN, reproduced with permission from the Health and Social Care Information Centre

Outpatient data were linked to cancer registrations for the first time in 2013. The table above shows the improvement of ethnicity coding in Outpatient data over the last three years for which data were available. This improved completeness contributes greatly to an ethnicity being able to be assigned to a cancer registration and enhances the opportunity for ethnic group to be standard reporting group for all cancer analyses.

4.2.3. Completeness of ethnicity recording in Accident and Emergency HES records linked to cancer registrations, England, 2010-2012

	2010	2011	2012
Ethnicity Completeness per episode	31.5%	64.8%	85.5%

Source: NCIN, reproduced with permission from the Health and Social Care Information Centre

Accident and Emergency data were linked to cancer registrations for the first time in 2013. The table above shows the improvement of ethnicity coding in A&E data over the last three years for which data were available. This improved completeness contributes greatly to an ethnicity being able to be assigned to a cancer registration and enhances the opportunity for ethnic group to be standard reporting group for all cancer analyses.

Where to go for further information

Contact the NCIN if you have further enquiries regarding cancer and ethnicity. The Information Centre's report on ethnic coding in Admitted Care HES is available from HES online, produced by the Health and Social Care information centre and contains further breakdowns by ethnic group.

4.3. Completeness of ethnicity in HES data linked to cancer registrations by trust

For cancer registrations, Hospital Episode Statistics are received for both people with a registered tumour and for people in HES with a diagnosis code of a neoplasm. The latest complete year available to cancer registration is for 2012. The proportion of episodes with a complete ethnicity recording in 2012 varies greatly by trust, with six trusts having a completeness of less than 50% (marked as outliers in figure 4.3.1). This excludes any trust with less than ten episodes submitted (six trusts). The median completeness is 95.2%.

4.3.1. Completeness of ethnicity recording by Trust, England, Admitted Patient Care HES data for cancer registrations or people with a diagnosis of a neoplasm within HES, England, 2012

% completeness of ethnicity recording across episodes
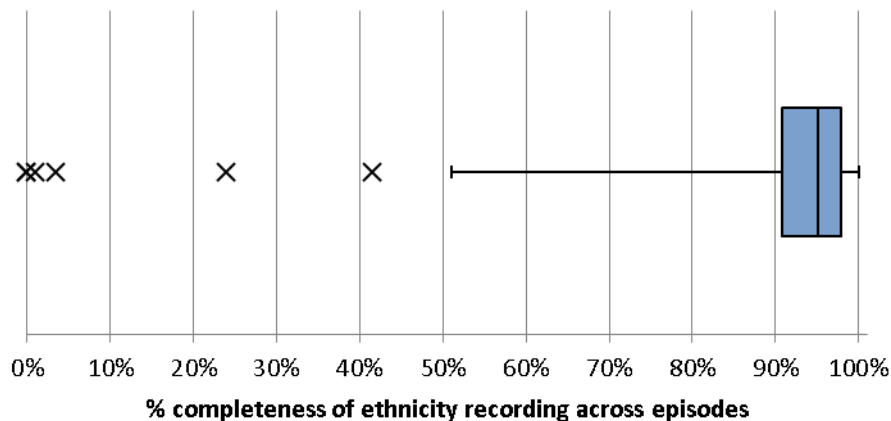
X represents trusts with <50% recording but more than 10 episodes

Due to the variability of ethnicity completeness by trust, the NCIN will be working with the HSCIC to produce a report on ethnicity completeness to feed back to trusts. With 90% of trusts attaining at least 83% completeness and with 75% of trusts attaining at least 91% of their episodes having a non-unknown ethnic group, there needs to be a strong push to get the bottom quartile of trusts to improve their coding completeness. We will not be able to fully understand the impact of different cancers on different ethnic groups until we have fully recorded ethnicity information in HES.
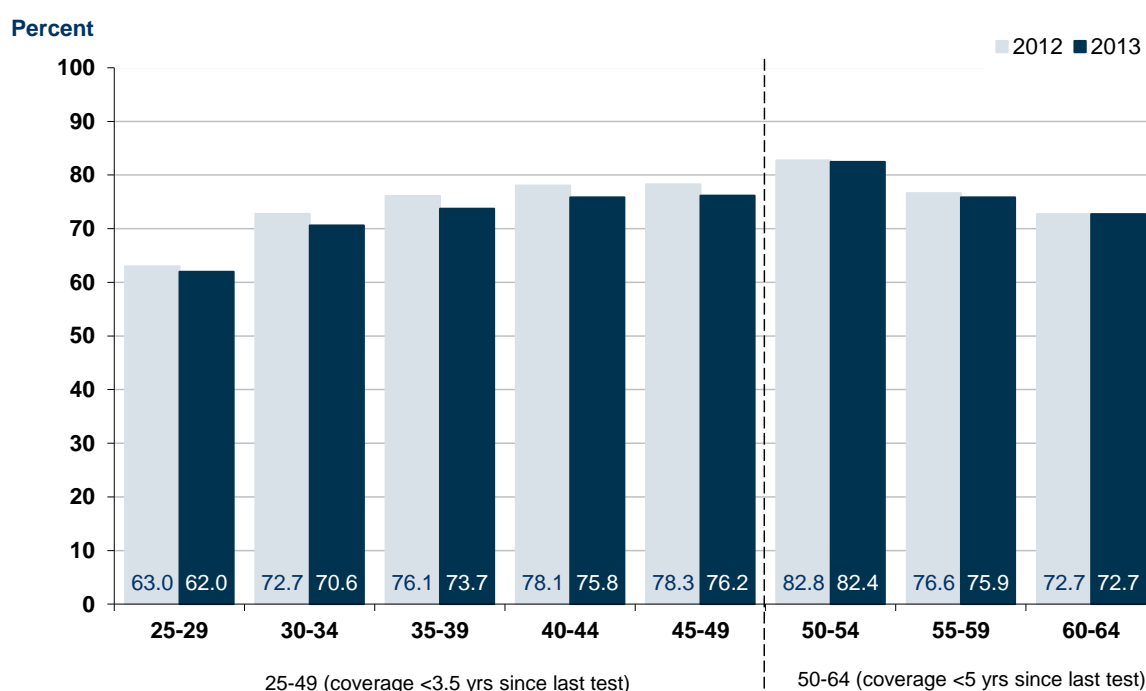
5. Cancer screening programme

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[5].

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.

5.1.1. Cervical screening coverage by age group and time since last screened, England, 2012 and 2013

Percent

Age group	2012	2013
25-29	63.0	62.0
30-34	72.7	70.6
35-39	76.1	73.7
40-44	78.1	75.8
45-49	78.3	76.2
50-54	82.8	82.4
55-59	76.6	75.9
60-64	72.7	72.7

25-49 (coverage <3.5 yrs since last test)   50-64 (coverage <5 yrs since last test)

Reproduced directly from the Health and Social Care Information Centre (Source: KC53, Health and Social Care Information Centre.) Graphs available from Cervical Screening Programme, England – 2012-13:Graphs.ppt

Where to go for further information

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

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[5] Routes to diagnosis http://www.ncin.org.uk/publications/routes_to_diagnosis

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.

5.2.1. Breast screening coverage by age group, England, 2011/12
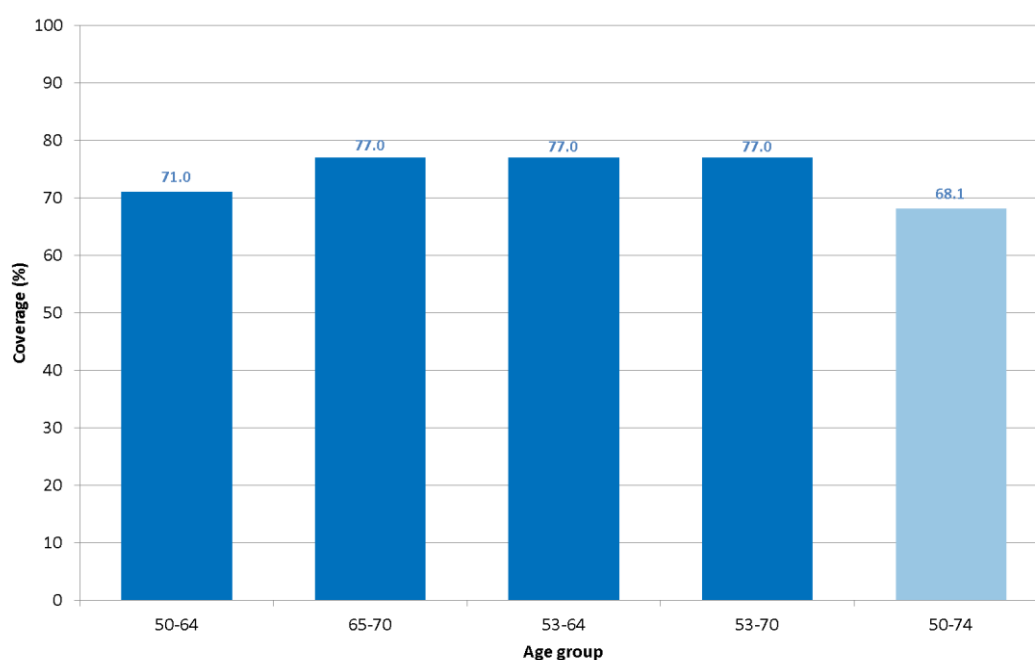
Source: The Health and Social Care Information Centre, Breast Screening Programme - England, 2011-12

Where to go for further information

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

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 2006-2010, 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].

5.3.1. Bowel cancer screening uptake by age group and sex, 2011/2012
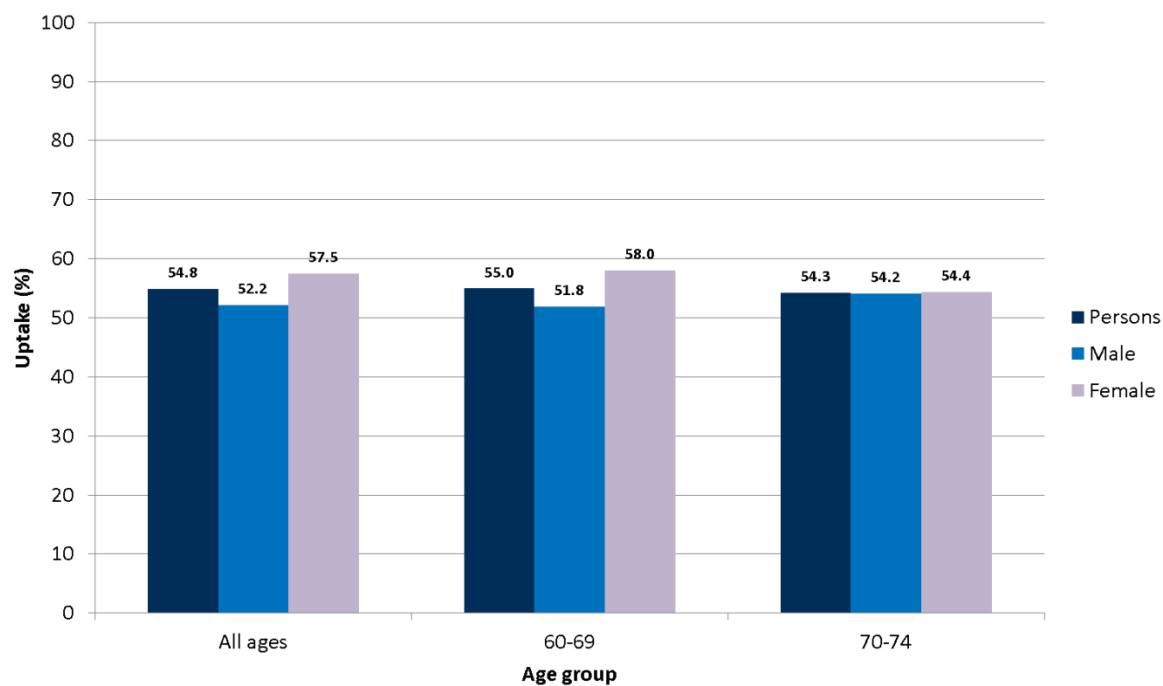
Source: Bowel Cancer Screening Programme National Office

Where to go for further information

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

6. Routes to Diagnosis (for all cancers combined and for the four most common cancers)
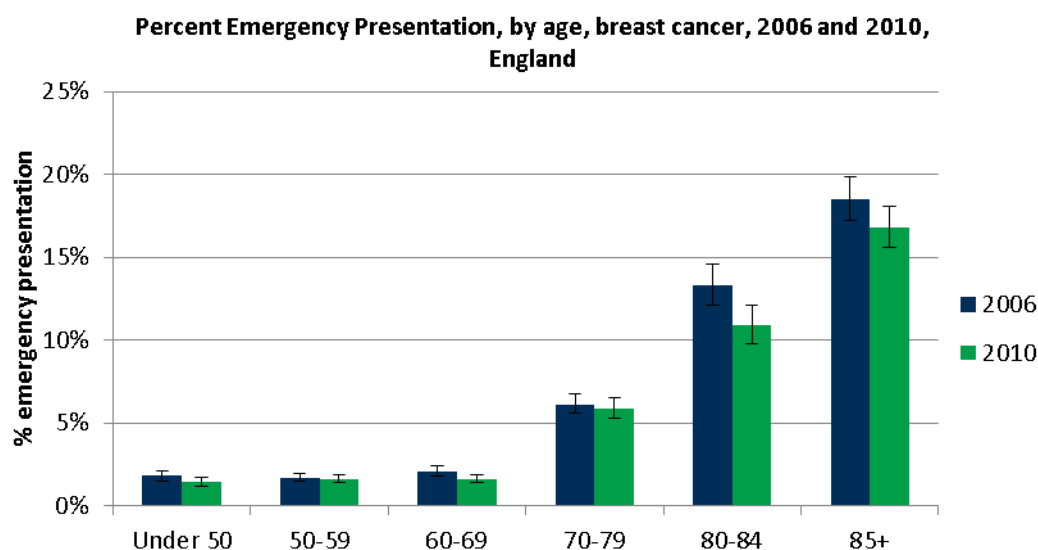
6.1. Proportion of emergency presentations by age

The Routes to Diagnosis project determined how each patient presented to secondary care on their way to being diagnosed with cancer. Results are available for 55 sites, including selected benign and in-situ sites, as well as for all cancers combined (excl. NMSC). Relative survival estimates are also available. The poorest survival is seen 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. Changes in the proportion of Emergency Presentations over time can also be influenced by changes to other Routes such as the introduction of screening or changes to TWW referral guidelines. It is therefore important to look at all Routes when assessing any changes in the proportion of emergencies.

The NCIN are committed to producing a short report on Routes to Diagnosis by sex and age group in 2014 which will also be available from the Routes to Diagnosis pages on the website.

6.1.1. Proportion of emergency presentations by age group, breast cancer, females, England, 2006 and 2010

Percent Emergency Presentation, by age, breast cancer, 2006 and 2010, England

In breast cancer (f), there is no difference between the percentage of emergency presentations for any age group that is statisically significant. The proportion of emergency presentations is low for breast cancer, however, high rates of emergency presentations are seen in the elderly age groups.

6.1.2. Proportion of emergency presentations by age group, colorectal cancer, England, 2006 and 2010

Percent Emergency Presentation, by age, colorectal cancer, 2006 and 2010, England
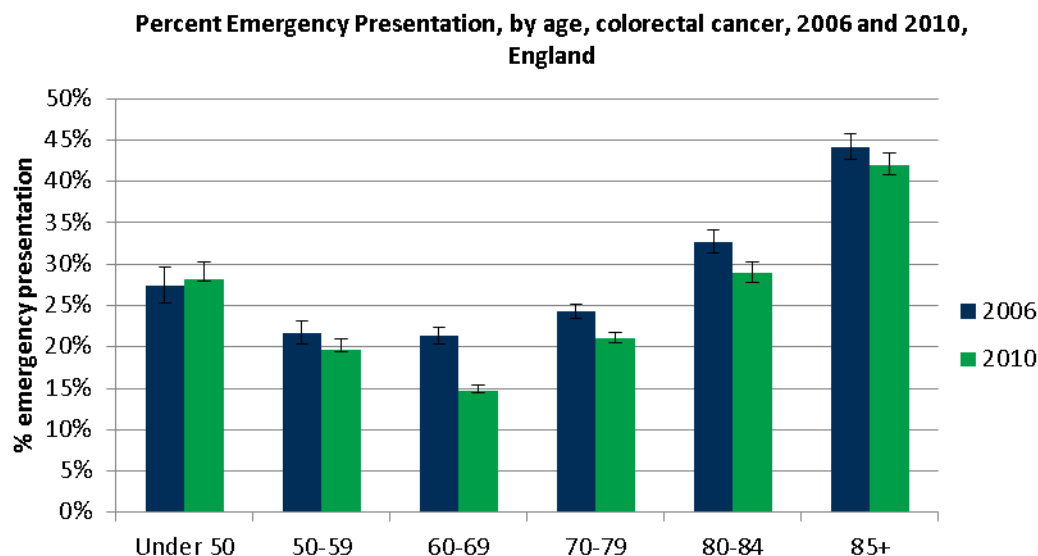
For colorectal cancer, the proportion of Emergency Presentations has fallen greatly in the 60-69 age group. This has predominantly been caused by an increase in the number of colorectal cancers diagnosed in the 60-69 year age group following the introduction of cancer screening for colorectal cancer in 2006. In the 60-69 yr age group, the number of newly diagnosed cases of colocrectal cancer rose by 10% from 2006 to 2007 and by 12% from 2007 to 2008 with small increases of 2% and 1% respectively from 2008 to 2009 and 2009 to 2010.

From 2008 to 2010, the proportion of Emergency Presentations in the 60-69 year age group decreased slightly from 23% to 21%. Whilst the age range for screening over the time period is 60-69, people aged 70 and over could request to be screened. In 2010, 7% of newly diagnosed tumours were assigned to the screening Route for the 70-79 yr age group which also affects the proportion of patients assigned to the emergency Route.

6.1.3. Proportion of emergency presentations by age group, lung cancer, England, 2006 and 2010

Percent Emergency Presentation, by age, lung cancer, 2006 and 2010, England
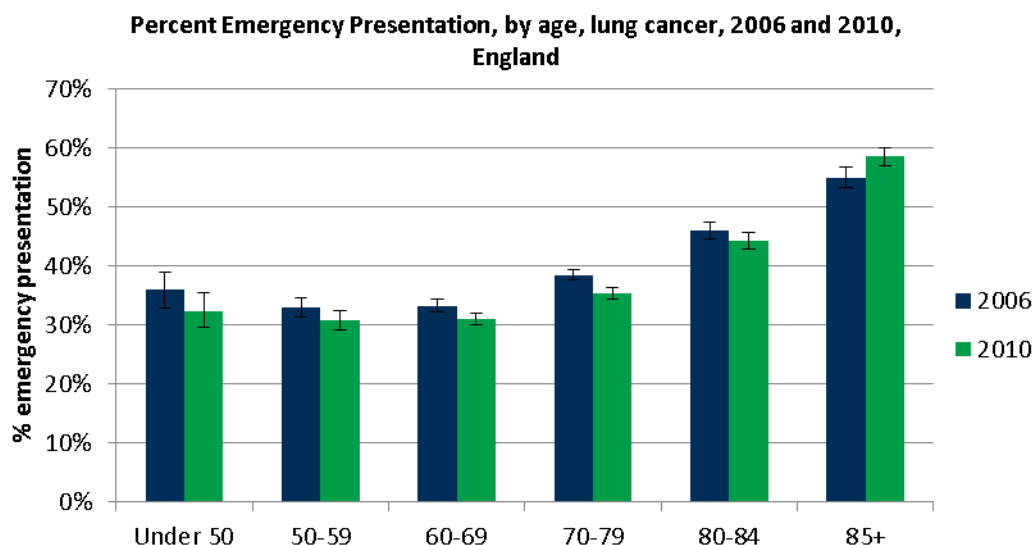
The difference in proportions of emergencies between 2006 and 2010 is statistically significant for the 70-79 age group. This decrease has also seen an increase for newly diagnosed tumours assigned to the Two Week Wait Route for this age range.

6.1.4. Proportion of emergency presentations by age group, prostate cancer, England, 2006 and 2010

Percent Emergency Presentation, by age, prostate cancer, 2006 and 2010, England
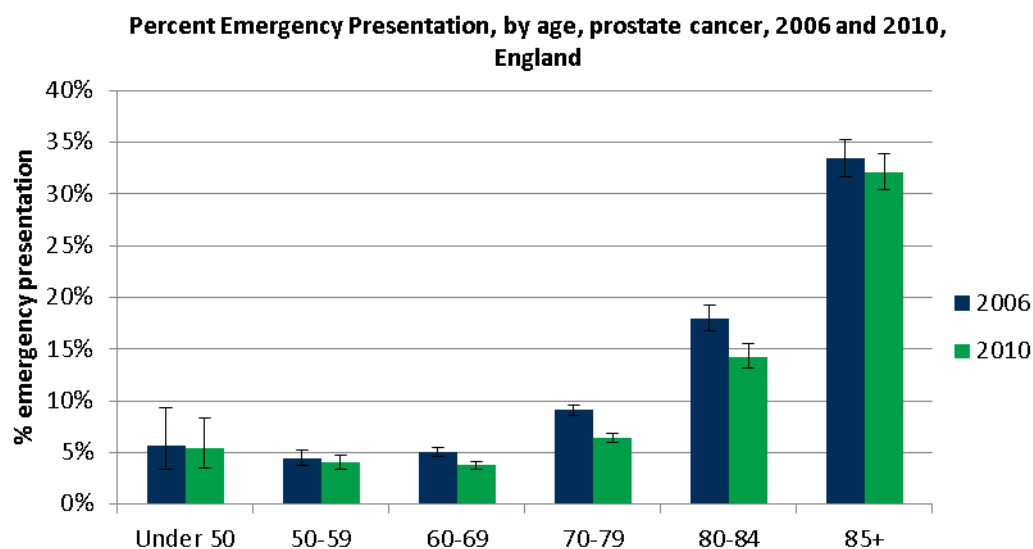
Between 2006 and 2010, there has been a large increase in the proportion of patients assigned to the TWW referral Route for prostate cancer. The proportion of TWW tumours increased from 23% to 33% for 60-69 years, 27% to 37% for 70-79 years and 24% to 38% for 80-84 year age group between 2006 and 2010.

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 for all ages.

The tables below present the proportion of emergencies by sex for a selection of non-sex specific sites. It is important to consider the differences in the proportion of cases for each age group as the proportion of emergencies increases for all cancer sites with increasing age.

The NCIN are committed to producing a short report on Routes to Diagnosis by sex and age group in 2014 which will also be available from the Routes to Diagnosis pages on the website.

6.2.1. Proportion of Emergency Presentations by sex for selected non-sex specific sites, England, 2010

Site	Sex	Emergency Presentation	LCI	UCI
Melanoma	male	3%	2%	3%
	female	2%	2%	2%
Hodgkin lymphoma	male	17%	15%	20%
	female	13%	11%	16%
Non-Hodgkin lymphoma	male	27%	26%	28%
	female	25%	24%	26%
Oesophagus	male	20%	18%	21%
	female	24%	22%	26%
Stomach	male	30%	28%	31%
	female	36%	34%	38%
Bladder	male	15%	14%	16%
	female	24%	22%	26%
Central nervous system (incl brain) malignant	male	60%	58%	62%
	female	62%	60%	65%
Head and neck – thyroid	male	9%	7%	11%
	female	6%	5%	7%
Leukaemia: acute myeloid	male	52%	49%	55%
	female	57%	54%	60%
Leukaemia: chronic lymphocytic	male	21%	19%	23%
	female	25%	22%	28%

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. As these percentages do not take into account the varying age structures between the populations, further work is required to understand the underlying cause behind these differences.

6.3.1. Proportion of emergency presentations by deprivation quintile, England, 2006-2010

	1 (least deprived)			2			3			4			5 (most deprived)		
	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI	%	LCI	UCI
Breast (f)	3%	3%	4%	4%	4%	4%	5%	4%	5%	5%	5%	6%	6%	6%	7%
Colorectal	22%	21%	22%	23%	23%	24%	25%	24%	25%	27%	27%	28%	30%	30%	31%
Lung	35%	34%	35%	37%	36%	37%	38%	37%	38%	39%	39%	40%	41%	41%	42%
Prostate	7%	7%	8%	8%	8%	9%	10%	9%	10%	11%	10%	11%	12%	12%	13%
All cancers*	19%	18%	19%	21%	21%	21%	23%	22%	23%	25%	25%	25%	28%	28%	29%

* 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 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, Cancer Patient Experience Survey 2012/13.

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.

The latest national cancer patient experience survey is for 2012/13. It covered inpatient and day case cancer patients treated between 1 September and 30 November 2012. 155 NHS Trusts providing cancer services identified patients and nearly 69,000 patients chose to respond. This was very similar to the previous survey which was undertaken at the same time in 2011, involved 160 NHS Trusts and covered nearly 72,000 patients.

Where to go for further information

Quality Health provide a range of publications and breakdowns by the old Strategic Health Authoritys.

A range of information on the Cancer Patient Experience Survey can also be found on the Patient experience 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. Results in 2013 were broadly similar to results from both the 2011 and 2012 surveys[6]. Overall, women were more likely to report a poorer experience of care. In the 2012/13 CPES survey, 45 questions showed significant differences in views between men and women, with men being more positive on 30 questions and women more positive on 15 questions. In the 2011/12 survey, this applied to 46 of the 70 questions, with men being more positive on 35 and women on 11.

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[6] Quality health http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-exerience-survey (page 14)

For each question in the 2013 CPES, comparisons with previous surveys are made, where questions were consistent, so that it is clear to see questions which have consistently shown a more or less positive patient experience for males or females. Of the 15 questions in which women were more positive than men, 11 were also apparent in the 2012 survey.

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. These overall results have remained consistent from 2010 through 2013 indicating a lack of progress of reducing perceived inequalities in patient experience by sex. These results should be used to try and understand how to improve the patient experience for women so that they have as positive experience of their care as their male counterparts.

Other areas are also worth further exploration. Overall, a lower proportion of males (16%) reported not seeing their GP before going to hospital compared to females (23%). Certain differences between sexes may well be influenced by the distribution of tumours between sexes, with 36.5% of breast cancer patients reporting not seeing their GP before going to Hospital, compared to 9.9% of prostate cancer patients.

A higher proportion of males felt that their health got worse whilst waiting for their first appointment with a hospital doctor compared to females.

7.1.1. Selected survey questions by gender, Cancer Patient Experience Survey, 2012/13
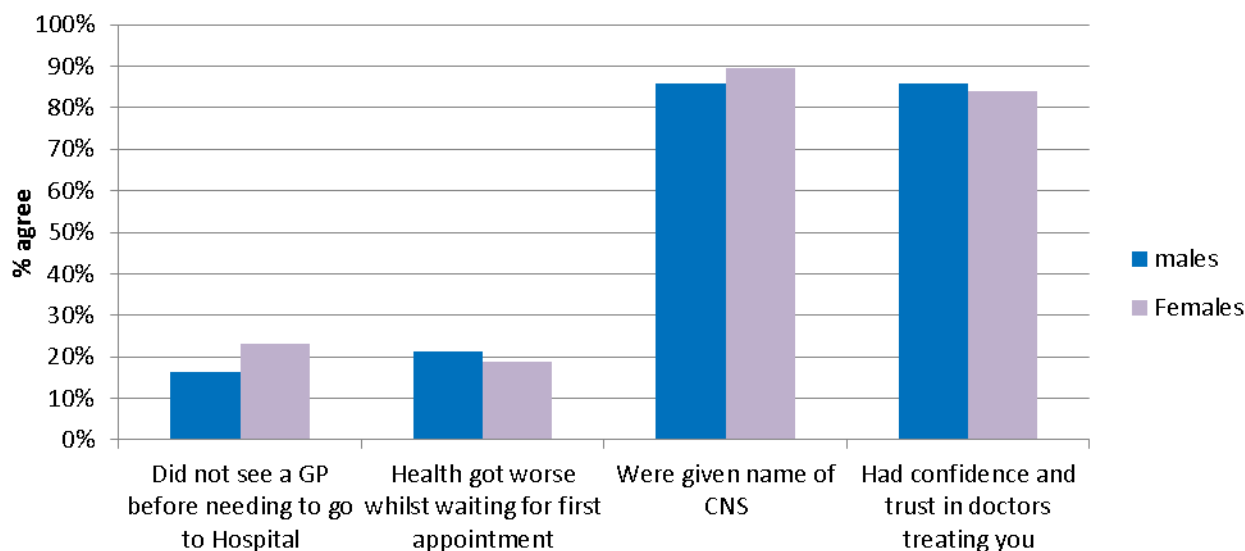
Source: Reproduced from Cancer Patient Experience Survey 2013 (p110), National Report, 30 August 2013

Of the questions where women reported a better experience than men, certain questions showed a more positive experience for women than for men in 2013 that hadn't been evident in previous surveys. This included women being more likely to say results of tests were explained in an understandable way, more likely to say they had been given information on getting financial help that they may be entitled to, more likely to say they got answers they could understand from doctors and more likely to say that family or someone close to them could speak to a doctor if they needed to.

Where to go for further information

For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13. A breakdown of results by gender is available from page 109 of the national report.
A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website. As of March 2014, this related to the 2012 CPES.

7.2. Patient experience by age

The Cancer Patient Experience Survey 2013 National Report also presents comparisons across CPES surveys by age groups. The number of questions which shows differences across age bands which were statistically significant remained steady across the years with 42 such questions in 2010, 43 in 2012 and 41 in 2013. Across all surveys, the youngest age band generally was the least positive about their patient experience. This is shown in the question regarding whether they completely understood the explanation as to what was wrong with them with less than 50% of the youngest age group answering positively to this question in both 2012 and 2013, compared to over 75% of the eldest age group in both years. Responses to this question indicate a need for easier to understand information for patients across all age groups, and especially amongst younger cancer patients.

7.2.1. Completely understood explanation of what was wrong, Cancer Patient Experience Survey, 2012 and 2013
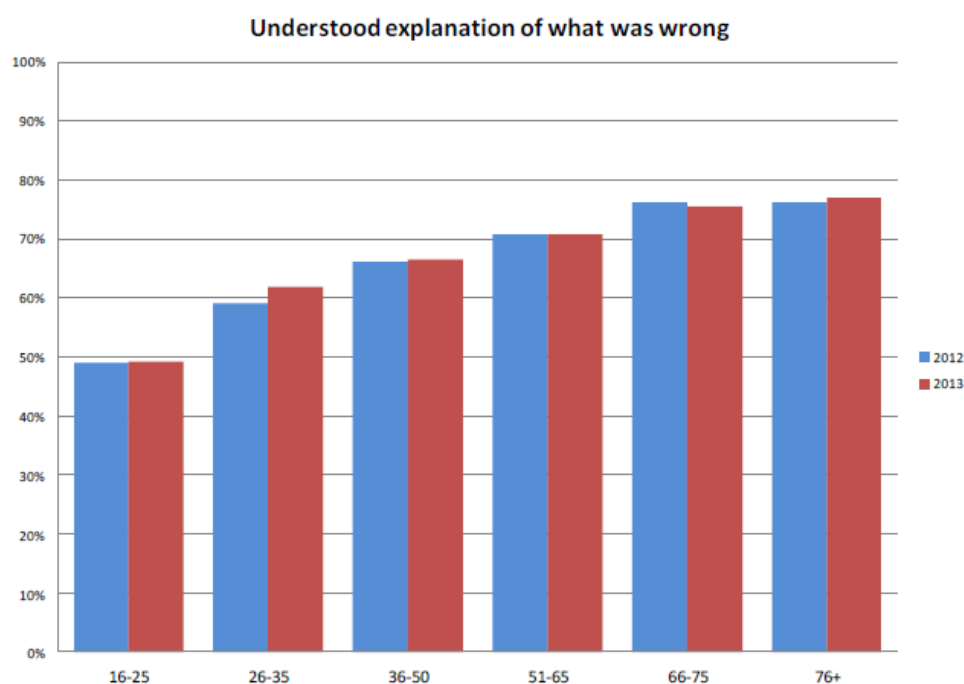

Conversely, the opposite picture is seen for some questions, including whether the patient is "given information on financial help". Over 80% of the youngest age group answered positively to this compared to over 50% of the eldest age group. There was also a large drop between respondents from the 16-25 age group and the 26-35 age group. Consistency across the 2012 and 2013 surveys again highlights a need for improving the information available to patients across all ages.

7.2.2. Given information on financial help/benefits by staff, Cancer Patient Experience Survey, 2011/12 and 2012/13

Given information on how to get financial help
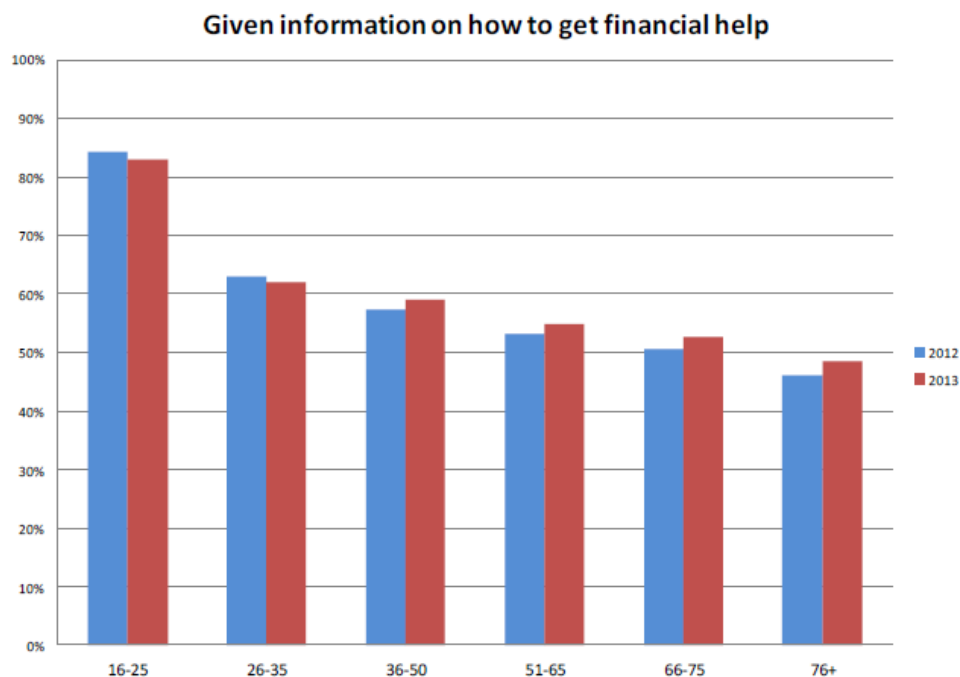
Not all questions produce large differences in responses between age groups. Graph 7.2.3 shows that on the question of whether a patient was given the name of a CNS, results are not just relatively consistent across age groups but also across surveys. The high positive response across the age groups reflects the importance of patients having a CNS and perhaps reflects a good way of being able to increase the information to patients to eradicate the inequalities in responses as shown in figures 7.2.1 and 7.2.2

7.2.3. Given name of Clinical Nurse Specialist, Cancer Patient Experience Survey, 2011/12 and 2012/13
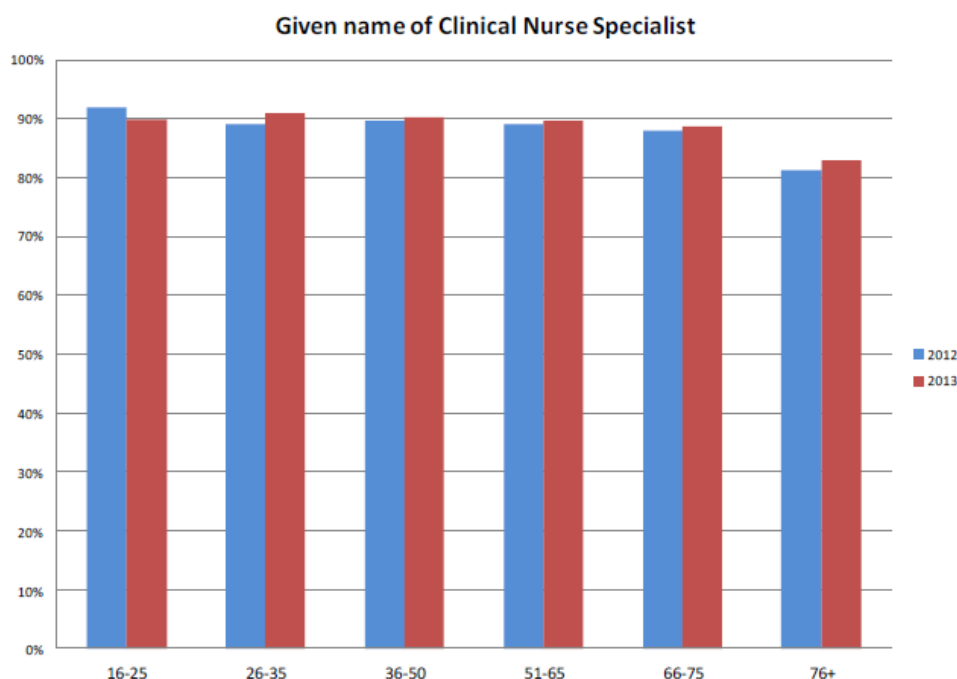
Source: Cancer Patient Experience Survey, Quality Health.

Where to go for further information

For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13.
A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website.

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

The proportion of patients by Route has been calculated for all cancer sites. This overall percentage gives an indication of how different ethnic groups present. This overall percentage doesn't take into account age and sex differences by Ethnic group therefore further work is required to fully understand the differences in presentation Routes by ethnic group.

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

	White				Asian				Black			
	Total cases	% EP	LCI	UCI	Total cases	% EP	LCI	UCI	Total cases	% EP	LCI	UCI
Breast (f)	172,111	5%	5%	5%	4,223	3%	3%	4%	2,831	4%	4%	5%
Colorectal	144,091	25%	25%	25%	1,990	23%	21%	25%	1,744	28%	26%	30%
Lung	148,503	39%	38%	39%	1,608	38%	36%	41%	1,220	42%	40%	45%
Prostate	147,165	10%	9%	10%	2,283	9%	8%	11%	4,865	8%	8%	9%
All cancers*	1,151,004	23%	23%	23%	22,602	23%	23%	24%	19,042	22%	22%	23%

	Chinese, Mixed and Other				Unknown			
	Total cases	% EP	LCI	UCI	Total cases	% EP	LCI	UCI
Breast (f)	2,647	4%	3%	5%	9,308	6%	5%	6%
Colorectal	1,480	27%	24%	29%	6,752	26%	25%	27%
Lung	1,508	38%	36%	41%	10,337	35%	34%	35%
Prostate	1,623	10%	8%	11%	7,866	7%	6%	7%
All cancers*	15,310	23%	23%	24%	64,488	22%	22%	23%

* Excluding non-melanoma skin cancer (NMSC)

Source: National Cancer Intelligence Network, Routes to Diagnosis
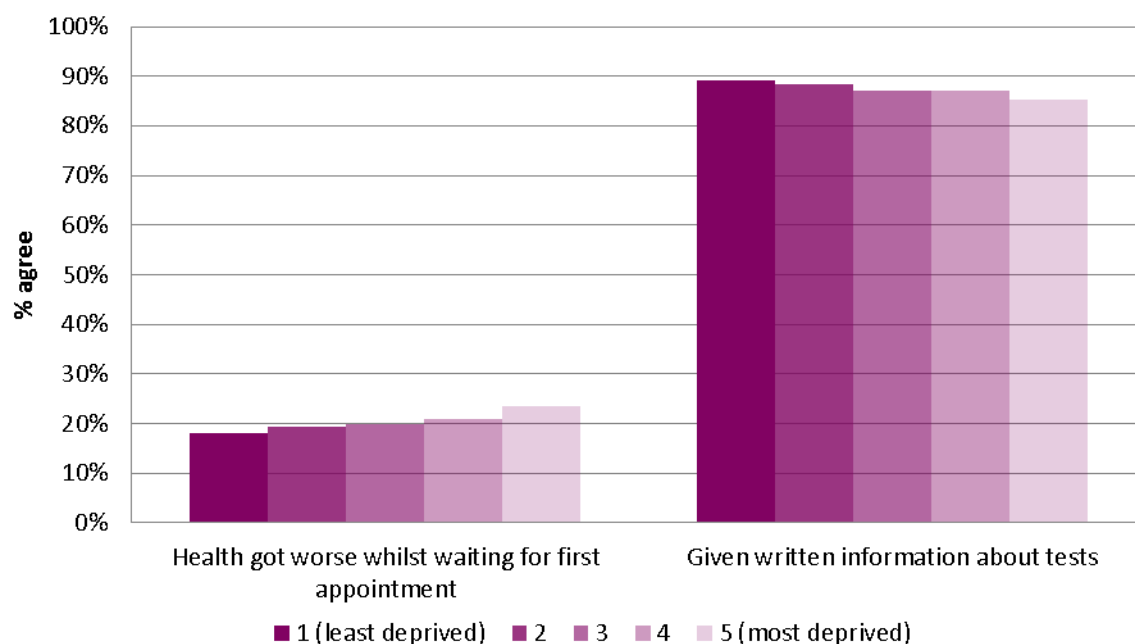
Where to go for further information

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

7.4. Patient experience by deprivation

For the 2013 survey, questions have been analysed by deprivation quintiles. 31 questions showed differences between the least and most deprived quintiles that were statistically significant.

44 questions showed a difference between the least deprived and most deprived quintiles that were statistically significant. This is in contrast to only three questions which showed differences between each quintile that was statistically significant. For 15 of the 44 questions that showed differences that were statistically significant, the most deprived quintile reported a better experience that the least deprived quintile. 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 quintile also reported a better experience for questions relating to finance and information regarding free prescriptions, but also that they had confidence and trust in ward nurses, were treated with dignity and respect and felt that people caring for them worked well to give them the best possible care. Conversely, patients in the least deprived quintile were more likely to report a better patient experience for 25 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 side effects of treatment and given easy to understand written information about tests beforehand. The least deprived quintile also were less likely to report that their health got worse whilst waiting for their first appointment. A full list of all these questions is available from the Cancer Patient Experience Survey National Report. Many questions regarding deprivation, when analysed as quintiles in 2013 or deciles in 2010 and 2012, show a similar pattern, indicating differences in experience still exist by deprivation quintile.

7.4.1. Cancer Patient Experience Survey by deprivation quintile, selected questions, England

Where to go for further information

For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13
A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website.
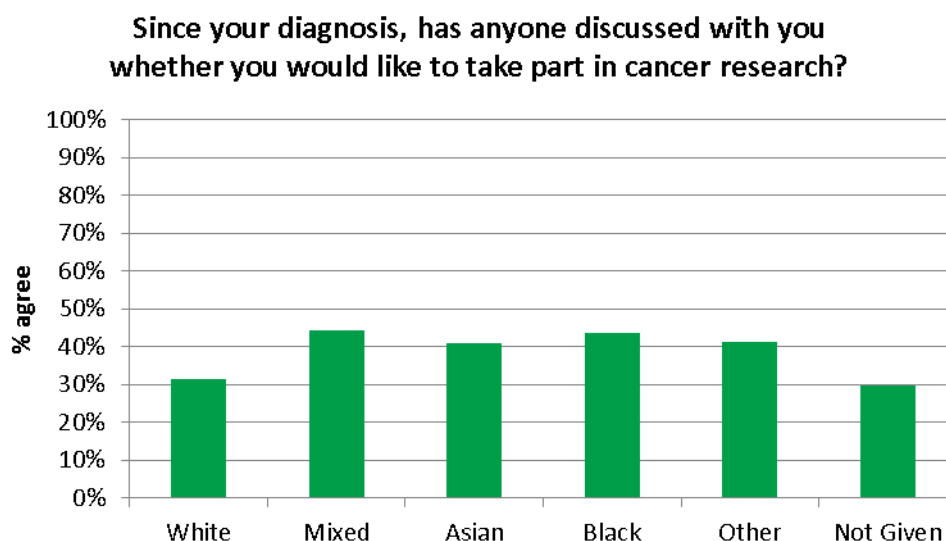
7.5.   Patient experience by ethnic group

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 and 2,713 in 2012/13. As a result, differences between ethnic groups were hard to identify due to the small number of respondents for each group.
The CPES national report highlights the questions which showed differences by Ethnic group. On questions regarding being asked to take part in cancer research and being given a written assessment and care plan, the White ethnic group had the lowest percentage agreeing. This was consistent with the 2012 survey.
Figures 7.4.1 and 7.4.2 show the survey results by ethnic group for two example survey questions. 7.4.1 shows differences by ethnic group for the 2013 for whether the patient was asked to take part in cancer research, whilst 7.4.2 shows results for whether staff worked well together in the 2012 and the 2013 survey.
A further 20 questions showed differences that were statistically significant between the White ethnic group and a least one non-White ethnic group where responses for the White ethnic group were more positive. Experiences for patients from the non-White ethnic group.

7.5.1. Example CPES question by ethnic group, Cancer Patient Experience Survey, 2012/13

Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?

7.5.2. Example CPES question by ethnic group, Cancer Patient Experience Survey, 2012/13

GP, Hospital and community staff worked well together
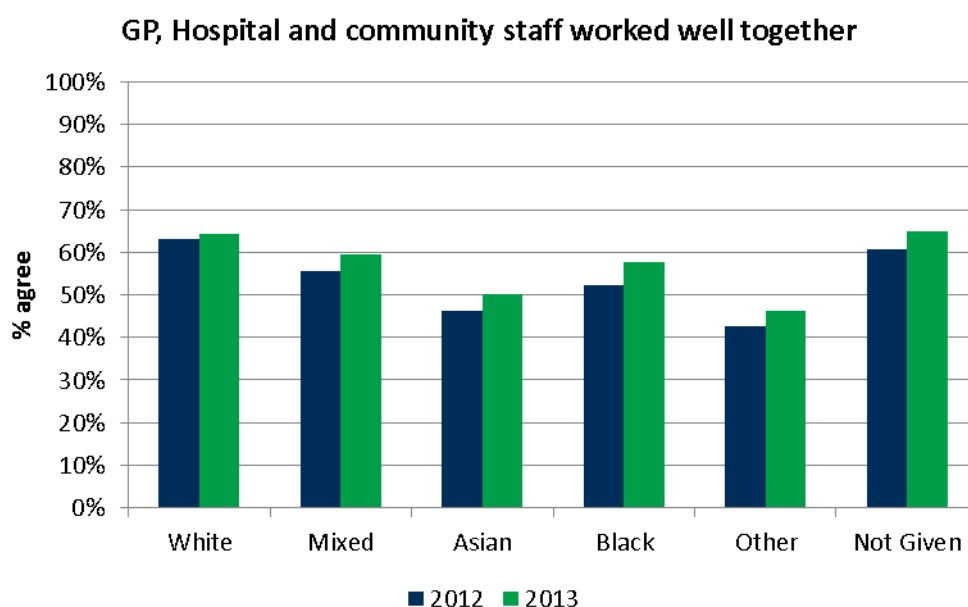
7.4.2 shows an increase in a positive response to this question across ethnic groups from 2012 to 2013, although similar trend in differences was seen across different ethnic groups. Other questions that have shown less positive responses from non-White ethnic groups include not being as satisfied with their care as the White ethnic group. In 2013, 89% of White respondents rated their care as excellent or very good, with positive responses much lower for BME patients; Mixed - 79.6%, Black – 78%, Other 74.6% and Asian – 73.3%. Differences in reported satisfaction of care from previous surveys also showed less positive experience for BME patients. Other questions where BME patients showed a worse experience than patients from the White ethnic group included

questions on being able to understand results of any tests and less likely to receive written information on tests before undergoing them. In addition, non-White patients were less likely to feel involved in decisions about their treatment. Differences remain between ethnic groups in their perception of their experience and care.

Where to go for further information

For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13
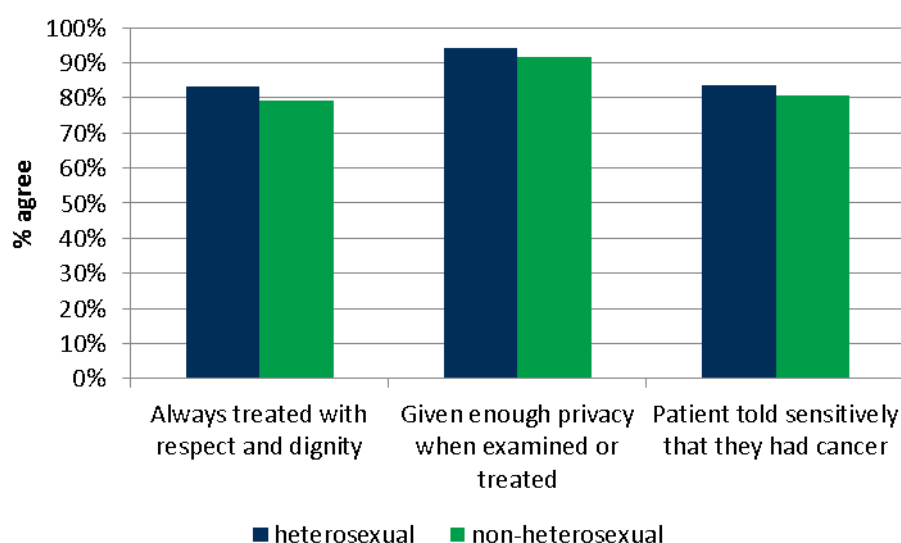A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website.

7.6.   Patient experience by sexuality

CPES respondents were asked if they were heterosexual, bisexual, gay or lesbian, or were of other sexual orientation. Over 3% of respondents chose not to answer the question. 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, 16 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 told sensitively that they had cancer, were not as positive about their experience of communication, were less likely to feel that they were given enough privacy either when examined, treated or when having their condition and treatment discussed with them and more likely to feel treated as 'a set of cancer symptoms'

7.6.1. Differences in responses for heterosexual and non-heterosexual patients, CPES, 2013
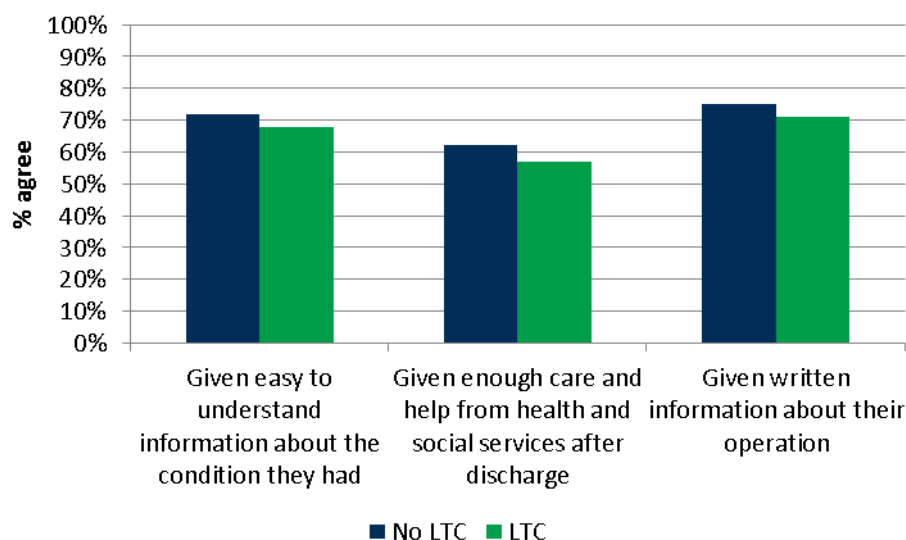
Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13.

7.7. 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 and long standing illness eg 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. In 50 of the questions, patients with long term conditions were 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.

7.7.1. Reported differences in patients without long term conditions (LTC) and with LTC, CPES, 2013

Where to go for further information

A range of information on the Cancer Patient Experience Survey can be found on the Patient experience section on the NCIN website. For detailed information on the survey results please refer to the Department of Health's national report, Cancer Patient Experience Survey 2012/13.

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.

8.1.1. Percentage of patients with a record of a major resection, by age and cancer site, patients diagnosed 2004-2006, followed up to 2007
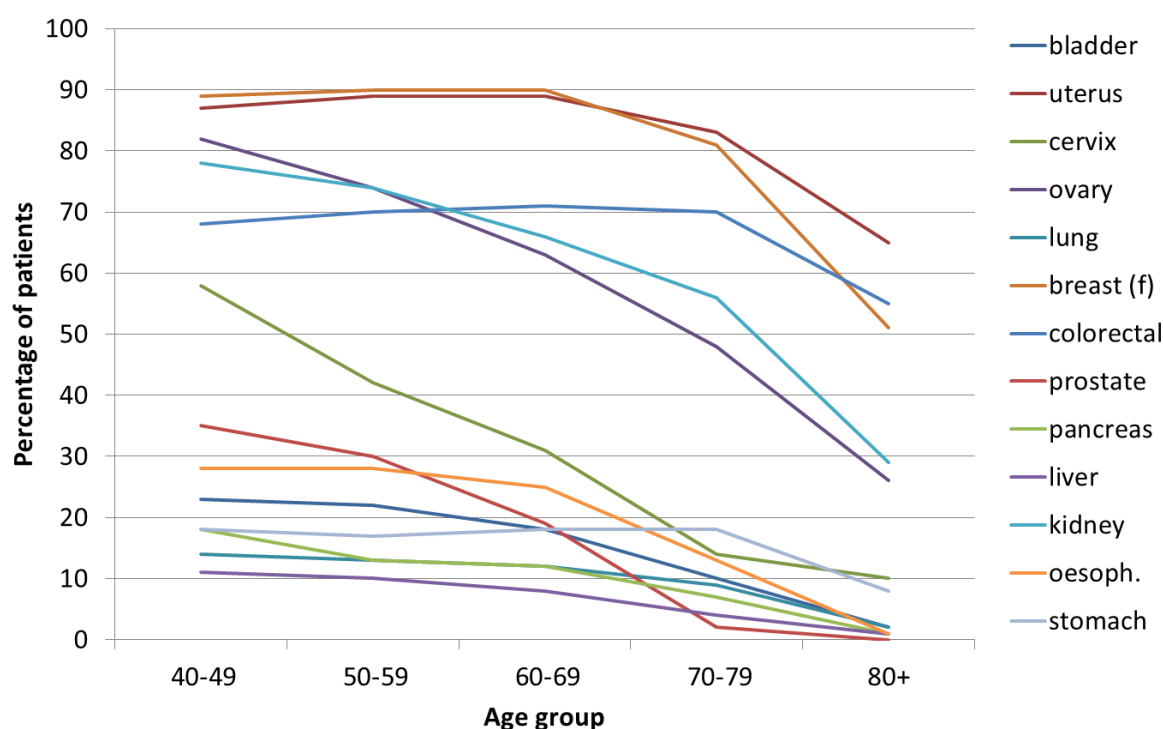
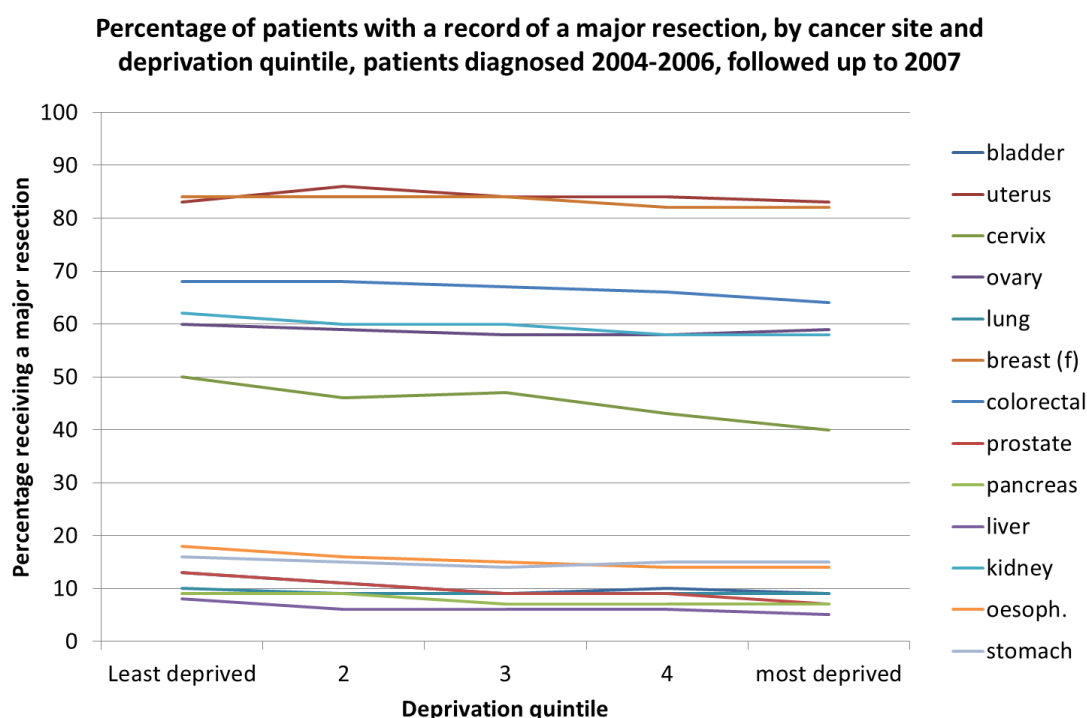Source: National Cancer Intelligence Network, Major Surgical Resections

Where to go for further information

A data briefing and a full report 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.

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

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. The radiotherapy summary dataset was linked to cancer registrations in 2013. With only 21 months of registrations with radiotherapy summary data available, a further linkage in spring 2014 will link registrations from 2009-2012 to radiotherapy data. This will hopefully allow site specific analysis on major treatment to be undertaken.

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 the National Cancer Registration Service 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%.and the most recent data for 2012 registrations show a similar increase to 62%. There are large differences by cancer sites with colon, rectum, breast and lung cancers having the most complete staging data.

9.1.1. Proportion of cancers staged by cancer site, cancers registered in 2012, selected sites (most common), England
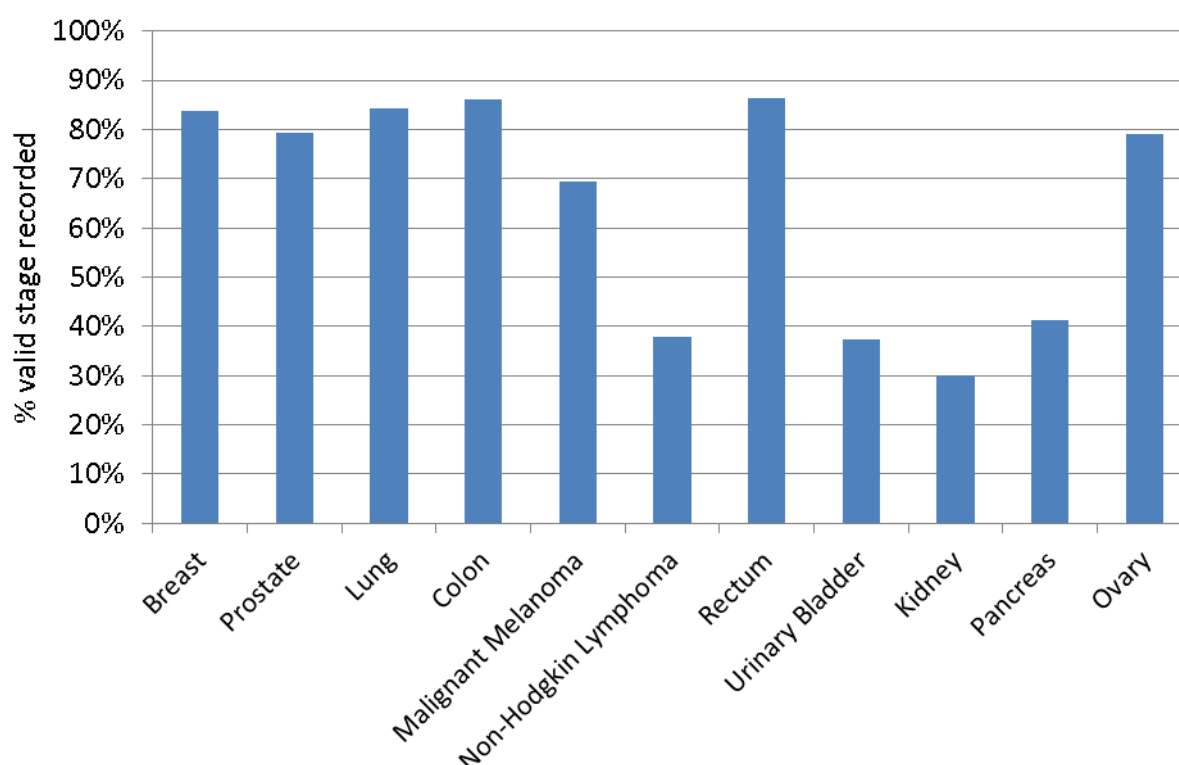
Source: NCRS Data quality report for 2012 registrations

Where to go for further information

Data quality reports compiled by the cancer registries are available from the National Cancer Registration Service

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 Quality of life of cancer survivors in England 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%.

Pilot gynaecological proms pilots have started in February 2014 and will run for 12 weeks. Results are expected to be available later in 2014. The gynaecological PROMs will cover cervical, ovarian, uterine cancers.

From the earlier 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 back[7].

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.[8]

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 Quality of life of cancer survivors in England 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,

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[7] Quality of life of cancer survivors in England section 11.2
[8] Quality of life of cancer survivors in England section 11.9

more likely to report having no difficulty on sexual matters and more likely to report having a named nurse who they can contact[9].

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 Quality of life of cancer survivors in England report is available from the Department of Health's website.

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 Quality of life of cancer survivors in England 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.

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[9] Quality of life of cancer survivors in England section 10.3