

Protecting and improving the nation's health

# **National Cancer Intelligence Network**

Cancer and equality groups: key metrics

2015 report

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Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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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**

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

## **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.

#### **National Child and Maternal Health Intelligence Network**

The National Child and Maternal Health Intelligence Network provides information and intelligence to improve decision-making for high-quality, cost-effective services. Its work supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children's, young people's and maternal health.

# National Mental Health, Dementia and Neurology Intelligence Network

The National Mental Health Intelligence Networks (NMHDNIN) brings together the distinct National Mental Health Intelligence Network, the Dementia Intelligence Network and the Neurology Intelligence Network under a single programme. The Networks work in partnership with key stakeholder organisations. The Networks seeks to put information and intelligence into the hands of decision makers to improve mental health and wellbeing, support the reduction of risk and improve the lives of people living with dementia and improve neurology services.

# **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.

# **Foreword**

This is the third report published for the National Cancer Equality Initiative (NCEI) by the National Cancer Intelligence Network (NCIN) on cancer and equality groups. It builds on previous reports to give a clear picture of where there are differences between groups in aspects of cancer patients' diagnosis, care and outcomes. Although we are continuing to make gains in cancer survival, the 2015 report reminds us that there are still some stark health inequalities for people with cancer. For example for all cancers combined (excluding non-melanoma skin, breast, lung and sex specific) age standardised mortality for men is 70% higher than it is for women. Age standardised mortality in the most deprived populations is 50% higher than in the least deprived. Similarly emergency presentation – a marker of late diagnosis and worse prognosis – increases with age and has a clear socioeconomic gradient that worsens with deprivation. This evidence is even more valuable in light of one of the recommendations in the National Audit Office's report 'Progress in improving cancer services and outcomes in England' that the Department of Health, NHS England and Public Health England should further investigate the reasons for inequalities in outcomes and access to services between different groups of cancer patients. The information shown in the following chapters identifies where inequalities currently exist, and therefore where attention needs to be focused to understand and reduce these differences.

The report also highlights the importance of timely, good quality data collection. This includes linking different data sources to ensure the full picture is examined, from routinely collected 'basic' information, such as the number of people of people being diagnosed with cancer, through survey information to understand the patient experience, and patient reported outcome measures.

A notable improvement since previous reports is the National Cancer Registration Service (NCRS) exceeding their target of having 70% of all cancers staged. This impressive feat should enable future work to examine where different groups are more likely to be diagnosed with advanced stage, meaning they have more limited treatment options and poorer survival.

While information on some equality groups are available as standard, such as age and sex, others are less commonly collected. For example, important differences in patient experience are found between heterosexual and non-heterosexual groups, and patients with and without long-term conditions, however there is currently less evidence about these equality groups for other cancer metrics.

Commissioners and clinicians in local communities should use the information in this report to devise strategies to tackle all inequalities that are issues in their populations.

Cancer and equality groups: key metrics – 2015 report

Ensuring all cancer patients have the best quality care and experience remains a priority for all, and being able to examine the evidence provided within this report is a crucial part of achieving this.

## Mr Sean Duffy

National Clinical Director for Cancer, NHS England

#### **Professor John Newton**

Chief Knowledge Officer, Public Health England

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# Introduction

The National Cancer Intelligence Network (NCIN), working with the National Cancer Equality Initiative (NCEI), has brought together a selection of key cancer metrics into one central report. The metrics selected either provide background information or describe analysis on aspects of cancer care. This 2015 report brings together updated information on cancer by equality groups and builds on the two previous reports.

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. Analysis will be undertaken where data are available and of good enough quality.

This year's report is the first to include cancer prevalence, chemotherapy, radiotherapy and information from the colorectal, cervical, womb and ovarian cancer-specific patient reported outcome measures. These are significant steps in understanding the full picture for cancer patients by different equality groups.

Age, sex and deprivation are the most commonly reported equality metrics as they are routinely collected as part of the cancer registration process. Completeness of ethnicity information has been improving over recent years, and ethnic groups are now included more widely in analyses. Information on sexuality and long-term conditions have been examined in this report as part of the cancer patient experience survey; how to describe other cancer metrics for these groups will need consideration in the future.

Completeness of staging data also continues to improve. Overall completeness for all malignant neoplasms (excluding non-melanoma skin cancer) has increased from 62% in 2012 to 71% in 2013. There have been particular improvements since 2012 for non-Hodgkin lymphoma, kidney, rectum, and urinary bladder cancers. The National Cancer Registration Service (NCRS) have now met their standard of having 70% of all cancers staged.

Data included in this report have been taken from a variety of different sources, including analysis produced within the NCIN, PHE Knowledge and Intelligence Teams, Cancer Research UK (CRUK), Macmillan Cancer Support, and the Office for National Statistics (ONS), with data from the Health and Social Care Information Centre, NHS Cancer Screening Programme, and the Cancer Patient Experience Survey. The value of bringing these data together presents an overall view of data on cancer and equalities. Some of the data highlight where there are differences between equality groups, while others show that differences do not exist.

NCIN continues its commitment to produce an updated report each year to keep monitoring where inequalities exist, and hopefully where they have been reduced or eliminated. By presenting these data together in one central document 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, or where new datasets become available.

This report mainly contains results for the four most common cancers in England – lung, colorectal, prostate, and female breast cancer. Due to the requirement of having sufficient number of cases in each study in order to draw conclusions, these cancers are the most likely to be present in every study. There is a vast amount of information available on important inequalities in cancer for a wide range of cancer types 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 for data on cancer statistics can also be found in the NCIN's 'Cancer statistics: availability and location' document. This is a useful resource and is updated periodically.

While this report is focused mainly on England, further data are available by equality groups in Scotland, Northern Ireland and Wales through their respective cancer registries.

A glossary with definitions of abbreviations and key terms used is at the end of the report.

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

# 2. Cancer incidence and incidence rates

# 1.1. Total number of new cases in England

Understanding the burden of disease is the first step to being able to monitor differences between equality groups. In 2013, there were nearly 300,000 people newly diagnosed with cancer in England (Table 1.1.1). Just over half (53%) of these cancers were lung, colorectal, prostate and female breast cancer. While the total number of cancers diagnosed increased by 1% (around 3,000 cases) compared with 2012, different patterns are seen for the most common cancers individually. The number of female breast cancers and prostate cancers both increased, while colorectal and lung cancer numbers decreased.

Table 1.1.1. Newly diagnosed cases of cancer by type and sex, England, 2013

Cancer type	All persons	trom		Males		es
	Number	% change	Number	ASR <sup>†</sup>	Number	ASR <sup>†</sup>
Breast	44,504	3.4%			44,504	169.6
Colorectal	33,676	-4.3%	18,778	86.5	14,898	56.1
Lung	36,295	-2.0%	19,625	91.4	16,670	63.8
Prostate	40,228	5.9%	40,228	185.0		
All cancers*	291,847	1.0%	149,234	680.3	142,613	541.3

<sup>\*</sup> Excluding non-melanoma skin cancer (NMSC)

#### Where to go for further information

Further information on cancer incidence is available from a variety sources including the NCIN, the Cancer Research UK statistical information team and the Office for National Statistics. The NCIN's document 'Cancer statistics: availability and location' 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 types affect different age groups. The data in Table 1.2.1 provide basic information as to which ages are affected by the most common cancers. Children (0 to 14) and teenagers and young adults (15 to 24) are also represented, although the most common cancers are not prevalent in these groups. The large numbers of women diagnosed with breast cancer in the 25 to 64 age group is partly due to the breast

<sup>&</sup>lt;sup>†</sup> Age standardised to the 2013 European Standard Population Source: CASCADE, based on CAS February 2015 snapshot.

cancer screening programme in England (see section 6.2 for analysis on uptake in this programme by different age groups).

Table 1.2.1. Newly diagnosed cases of cancer by type, sex and age, England, 2013

Cancer type	Age group					
	0-14	15-24	25-64	65-74	75-84	85+
Breast (F)	1	29	23,546	10,154	7,018	3,756
Colorectal (M)	4	45	5,338	5,841	5,464	2,086
Colorectal (F)	17	78	3,860	3,717	4,560	2,666
Lung (M)	0	5	4,331	6,632	6,361	2,296
Lung (F)	1	11	3,892	5,320	5,083	2,363
Prostate (M)	1	0	9,599	16,271	10,948	3,409
All cancers* (M)	690	890	43,982	48,197	40,685	14,790
All cancers* (F)	609	963	56,064	35,258	32,164	17,555

<sup>\*</sup> Excluding non-melanoma skin cancer (NMSC) Source: CASCADE, based on CAS February 2015 snapshot.

#### Where to go for further information

Further data are available from the NCIN and Public Health England Knowledge and Intelligence Teams. The Office for National Statistics produces an annual series (MB1) which includes cancer incidence by cancer type. Cancer Research UK produces charts and tables by age group for a wide variety of cancer types.

# 1.3. Age standardised incidence rate ratios by sex

For the majority of common cancer types, males have higher incidence rates than females when any differences in the age structure of the populations are taken into account (the rates have been '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 for many other cancer types.

Figure 1.3.1 shows the ratios between male and female incidence rates for the UK in 2010 and England in 2013. The rate ratio shows how the incidence rate for males compares with the female rate for each cancer type, by showing the female rate as the baseline at one and the male rate in comparison to this. Bars above one mean that men have a higher incidence rate than women, and bars below show a higher incidence rate in women compared with men.

The incidence rate ratios generally follow a similar pattern for the UK in 2010 and England in 2013. Incidence rates for all cancers (excluding non-melanoma skin cancer (NMSC), breast, lung, and sex specific cancers) are more than 50% higher in men than women. Cancers of the bladder, oesophagus, stomach, and liver all had incidence rates more than twice as high in men than women.

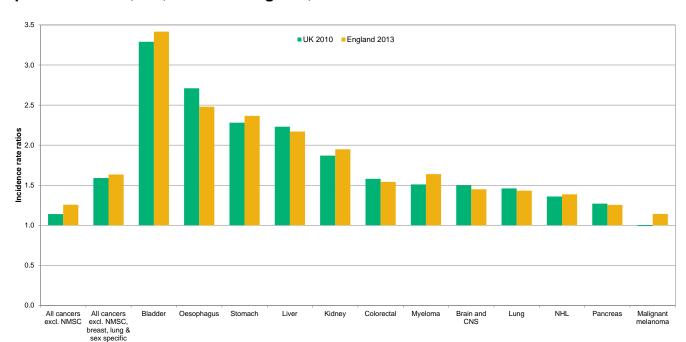


Figure 1.3.1. Male to female age standardised incidence rate ratios, selected non-sex specific cancers, UK, 2010 and England, 2013

Sources: Cancer Research UK, NCIN, Leeds Metropolitan University and the Men's Health Forum, Excess Burden of Cancer in Men (UK data); CASCADE, based on CAS February 2015 snapshot (England data).

## 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, Leeds Metropolitan University and the Men's Health Forum.

# 1.4. Age standardised incidence rate ratios by deprivation

A joint NCIN and Cancer Research UK report published in 2014 presented results for cancer incidence by deprivation quintile for all cancers combined (excluding non-melanoma skin cancer) and for 38 cancer types or groups. Inequalities in cancer incidence in relation to socioeconomic deprivation are one of the major concerns, as it is known that some risk factors for cancer, especially smoking, are strongly influenced by socioeconomic determinants.

The report showed that for cancers diagnosed in 2006 to 2010, oral cavity (in males), larynx, liver (in males) 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 with the least deprived group for cancers of the oropharynx, oral cavity (in females), oesophagus, stomach, pancreas, colorectal (in males), anus, vulva, vagina, cervix, penis, kidney, bladder, unknown primary, Hodgkin lymphoma (in males), non-Hodgkin lymphoma (in females), and acute myeloid leukaemia (in males). Differences for all these cancers were statistically significant.

For other cancers, including central nervous system (in females), breast (in females), prostate, testis, malignant melanoma, and acute lymphoblastic leukaemia (in males) higher rates were seen for the least deprived compared to the most deprived groups. For breast and prostate cancer, this is partially due the higher uptake of screening and PSA testing respectively in the least deprived group.

Table 1.4.1. Age standardised incidence rates and rate ratios by deprivation and sex, selected cancer types, England, 2006 to 2010

Cancer type	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	485.0	1.2
All cancers* (F)	349.7	395.5	1.1

<sup>\*</sup> Excluding non-melanoma skin cancer (NMSC)

Source: NCIN-CRUK, Cancer by Deprivation in England.

#### Where to go for further information

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

## 1.5. Total number of new cases by ethnicity

A patient's ethnicity is collected in the NHS by trusts and recorded in the Hospital Episode Statistics (HES) dataset (see section 5). The first national report on cancer incidence by ethnic group for multiple cancer types was published in 2009 using HES data linked to cancer registrations. While ethnicity recording was not complete for all registered cancers, results did show that some ethnic groups had higher incidence rates compared with 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 with the white ethnic group, as are mouth cancer in females and cervical cancer in the over 65s.

Better linkage of cancer registrations to HES and improved recording of ethnicity within HES (see section 5) have greatly increased the proportion of cancer registrations with an assigned ethnicity. Data shown in Table 1.5.1 therefore show the number of cases for each major ethnic group. This table gives an idea of the burden of cancer for different ethnic groups, but does not take into account the different age structures. As

many of the ethnic groups have ageing populations, the number of patients being diagnosed with cancer is likely to rise in the future.

Table 1.5.1. Number of cases by ethnicity and sex, selected cancer types, England, 2006 to 2010

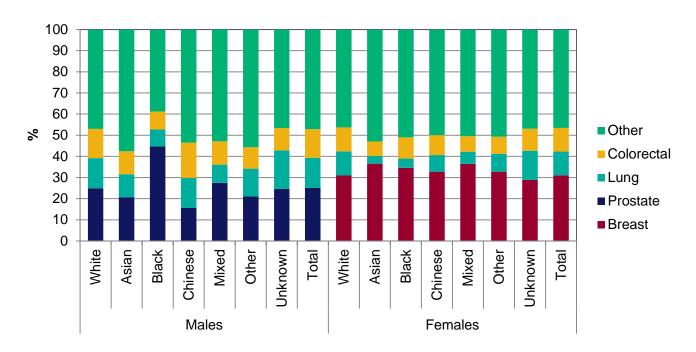
Ethnic	Breast	Cold	Colorectal		Lung		All ca	ncers*
group	Females	Males	Females	Males	Females	Males	Males	Females
White	180,702	82,886	66,263	85,452	66,721	149,549	599,979	584,157
Asian	4,381	1,217	831	1,213	433	2,308	11,154	11,992
Black	2,944	944	859	879	373	4,905	10,979	8,516
Chinese	450	188	129	159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

<sup>\*</sup> Excluding non-melanoma skin cancer (NMSC) Source: NCIN, March 2014.

Figure 1.5.1 shows the proportion of all cancers (excluding non-melanoma skin cancer) made up by the main cancer types (breast, lung, colorectal and prostate) for males and females in each ethnic group. Some of the variation between groups will be due to the different age structures. Prostate cancer makes up over 40% of Black men's cancer,

compared with around 15% of Chinese men, and 25% of all men.

Figure 1.5.1. Proportion of main cancer types by ethnicity and sex, England, 2006 to 2010



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Source: NCIN, March 2014.

# Where to go for further information

For more information, please contact enquiries@ncin.org.uk. A previous report on cancer incidence by major ethnic group including patients diagnosed between 2002 and 2006 is available from the NCIN website.

# 2. Cancer mortality and mortality rates

# 2.1. Total number of cancer deaths in England

Cancer is a major cause of death accounting for 29% of all registered deaths in England and Wales in 2013<sup>1</sup>, similar to 2012 (28%) and 2011 (29%). Mortality data are presented below to help understand cancer mortality by equality groups. Deaths from the four most common cancer types account for 45% of all cancer deaths. There was a small decrease (0.1%) in the number of deaths compared with 2012, but it is important to consider the change in cancer types, and in age distribution of the population. Of the main cancers, female breast and colorectal cancer deaths also decreased, while lung and prostate cancer deaths slightly increased.

Table 2.1.1. Number of cancer deaths by type and sex, England and Wales, 2013

Cancer type	All persons	Change from 2012	Males	Females
Breast	10,144	-1.6%	-	10,144
Colorectal	13,939	-1.6%	7,557	6,382
Lung	30,437	0.5%	16,818	13,619
Prostate	9,726	0.3%	9,726	-
All cancers	141,909	-0.1%	75,227	66,682

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, the Cancer Research UK statistical information team and the Office for National Statistics' DR series. The NCIN's document 'Cancer statistics: availability and location' details where to go for a wide variety of cancer data in the UK.

# 2.2. Total number of cancer deaths by age

The number of deaths by age group is important to examine when addressing inequalities in mortality. Table 2.2.1 shows the number of cancer deaths for the main four cancers in England in 2013 by different age groups. These data allow us to focus on specific cancers for specific age groups. There were over 200 cancer deaths in people aged 14 and under in 2013, however none were caused by the most common cancer types. Cancers of the central nervous system, certain leukaemias and

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<sup>&</sup>lt;sup>1</sup> Office for National Statistics, Series DR

lymphomas are more common cancers in children. The majority of cancer deaths occurred in the 75 to 84 age group for both males and females.

Table 2.2.1. Number of cancer deaths, by type, sex and age, England and Wales, 2013

Cancer type	Age group						
	0-14	15-24	25-64	65-74	75-84	85+	
Breast (F)	0	4	3,320	2,035	2,420	2,365	
Colorectal (M)	0	2	1,497	1,996	2,553	1,509	
Colorectal (F)	0	3	1,035	1,293	2,018	2,033	
Lung (M)	0	0	3,372	5,451	5,590	2,405	
Lung (F)	0	1	2,680	4,142	4,414	2,382	
Prostate	0	0	579	1,823	3,805	3,519	
All cancers (M)	126	121	14,921	20,695	24,915	14,449	
All cancers (F)	101	114	14,330	16,138	20,350	15,649	

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 cancer type in the DR series. Cancer Research UK produces charts and tables by age group for a wide variety of cancer types. Further information is also available from Public Health England Knowledge and Intelligence Teams

# 2.3. Age standardised mortality rate ratios by sex

For the majority of common cancer types, males have higher cancer mortality rates than females, similar to cancer incidence (see section 1.3). Figure 2.3.1 shows the rate ratios between male and female mortality rates for the UK in 2010 and England in 2013. The rate ratio shows how the mortality rate for males compares with the female rate for each cancer type, by showing the female rate as baseline at one and the male rate in comparison to this. Bars above one mean that men have a higher mortality rate than women, and bars below would show a higher mortality rate in women compared with men. For all cancer types examined here, men had higher mortality rates.

For bladder and oesophageal cancers, age standardised cancer mortality rates were more than two and a half times higher for males compared with females. For all cancers combined (excluding non-melanoma skin cancer (NMSC), breast, lung and sex specific cancers), the age standardised mortality rate in males is around 70% higher than females.

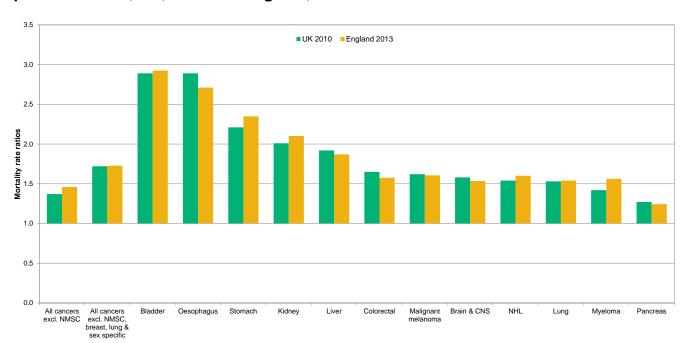


Figure 2.3.1. Male to female age standardised mortality rate ratios, selected non-sex specific cancers, UK, 2010 and England, 2013

Sources: Cancer Research UK, NCIN, Leeds Metropolitan University and the Men's Health Forum, Excess Burden of Cancer in Men (UK data); CASCADE, based on CAS February 2015 snapshot (England data).

#### 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, Leeds Metropolitan University and the Men's Health Forum.

# 2.4. Age standardised mortality rate ratios 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 non-melanoma skin cancer) and for 38 cancer types or groups. Inequalities in cancer mortality in relation to socioeconomic deprivation are linked to differences in cancer incidence by deprivation (see section 1.4).

This national report on cancer incidence and mortality by deprivation showed that for deaths occurring in 2007 to 2011, cancers of the oropharynx, oral cavity (in males), larynx (in males), stomach (in males), anus (in males), lung, cervix, and penis had mortality rates in the most deprived group that were at least double that of the least deprived group. In addition, mortality rates were higher for the most deprived compared with the least deprived group for cancers of the stomach (in females), anus (in females), oral cavity (in females), salivary glands (in males), oesophagus, liver, pancreas, colorectal, breast, vulva, vagina, uterus, testis, kidney, bladder, cancer of unknown

primary, Hodgkin lymphoma (in males), non-Hodgkin lymphoma (in females), and chronic myeloid leukaemia (in males). These differences were all statistically significant.

Only malignant melanoma showed higher mortality rates for the least deprived compared with the most deprived group. Breast cancer incidence has an inverse relationship with deprivation, predominantly caused by screening uptake. Higher mortality in the most deprived group for female breast cancer may reflect differences in stage of disease, curative treatment received, and types of breast tumours being diagnosed in different deprivation groups.

Table 2.4.1. Age standardised mortality rates and rate ratios by deprivation and sex, selected cancer types, England, 2007 to 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

<sup>\*</sup> Excluding non-melanoma skin cancer (NMSC) Source: NCIN-CRUK, Cancer by Deprivation in England.

#### Where to go for further information

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

#### 2.5. Mortality by ethnicity

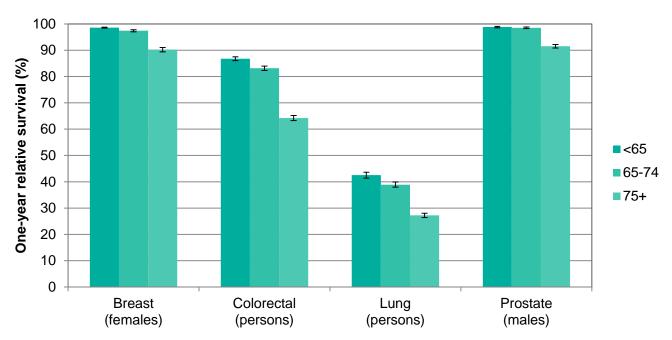
Given the improved completeness of ethnicity coding for cancer registrations, NCIN will look at the feasibility of including cancer mortality by ethnic group in the future. Currently, national data on cancer mortality by ethnic group are not available.

# 3. One-year relative survival

## 3.1. One-year relative survival by age

Relative survival by age group highlights the poorer relative survival rates for older cancer patients. Figure 3.1.1 shows one-year relative survival for the four main cancers by age group. Those aged 75 or over have significantly poorer survival rates than younger age groups. For some cancer types, such as lung and colorectal cancer, there is also a drop off in survival rates in the 65 to 74 age group.

Figure 3.1.1. One-year relative survival estimates by age, selected cancer types, England, 2012



Source: West Midlands Knowledge and Intelligence Team, based on CAS February 2015 snapshot.

#### Where to go for further information

Cancer survival estimates for England are available from a variety of sources, see 'Cancer statistics: availability and location' for more details.

# 3.2. One-year relative survival by sex

Survival estimates by sex show where inequalities in cancer survival exist. One-year relative survival estimates for a selection of cancer types are shown in Figure 3.2.1. The data show that survival is higher for females than males with lung cancer and malignant melanoma, while male colorectal cancer patients have a better survival than their female counterparts. There was little difference between the sexes in one-year relative survival for patients with non-Hodgkin lymphoma.

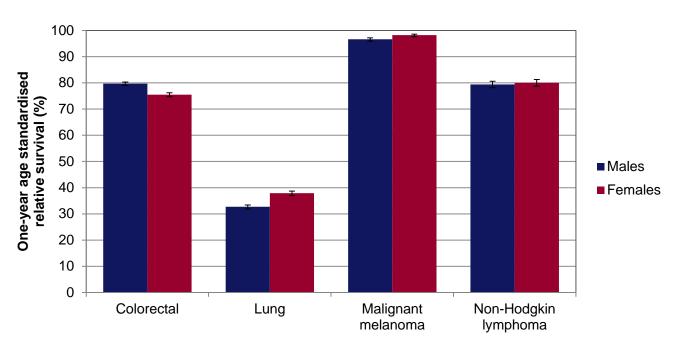


Figure 3.2.1. One-year age standardised relative survival by sex, selected cancer types, England, 2008 to 2012

Source: West Midlands Knowledge and Intelligence Team, based on CAS February 2015 snapshot.

#### Where to go for further information

Cancer survival estimates for England are available from a variety of sources, see 'Cancer statistics: availability and location' for more details.

# 3.3. One-year relative survival by deprivation

One-year relative survival for different deprivation groups are shown for the four main cancers plus ovarian cancer in Figure 3.3.1. Patients resident in more deprived areas have worse survival for colorectal, lung and ovarian cancer, with small differences between the deprivation groups for breast and prostate cancer.

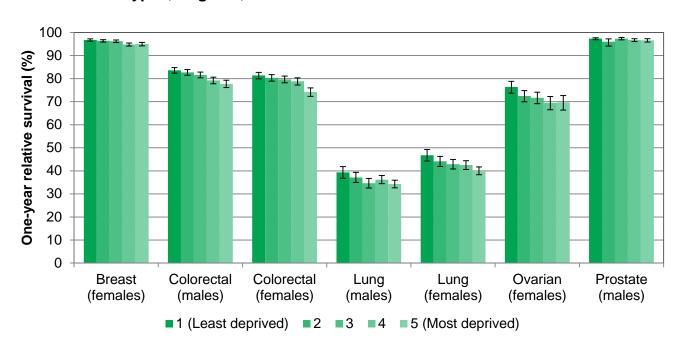


Figure 3.3.1. One-year age standardised relative survival by deprivation and sex, selected cancer types, England, 2012

Source: NCIN, Cancer Survival in England by Stage 2012 - Non-imputed workbook.

#### Where to go for further information

More information on the Cancer Survival in England by Stage project can be found on the NCIN website. Other cancer survival estimates for England are available from a variety of sources, see 'Cancer statistics: availability and location' for more details.

## 3.4. Survival by ethnicity

As we do not have complete ethnicity coding for cancer registrations, survival estimates by ethnic group do not tell a complete picture. While 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. Cancer prevalence

The Macmillan-NCIN UK Cancer Prevalence Project aims to break down, or 'segment', information on the UK cancer survivor population so that there is a more granular understanding of them. The first phase of the project provided information on all malignant cancers combined by: time since diagnosis, age, sex, for the UK and constituent countries, Strategic Clinical Networks (England only) and deprivation (England only). The next phases of the project include segmenting the data by other parameters and by cancer type.

#### Where to go for further information

More information on the project, including posters and datasets, can be found on the UK Cancer Prevalence Project section of the NCIN website.

# 4.1. Cancer prevalence in the UK

Cancer prevalence, defined in this section as the number of people diagnosed with cancer in the period specified who were alive at the end of 2010, is another measure of the burden of cancer. Variations in cancer prevalence can help to identify possible inequalities. Table 4.1.1 shows the number of people living with and beyond a diagnosis of cancer in different countries within the UK. At the end of 2010 there were over 1.8 million people alive who had been diagnosed with cancer in the previous 20 years. Over a million of these were women.

Table 4.1.1. 20-year all cancer (excluding non-melanoma skin cancer) prevalence of those alive at end of 2010 by country and sex, UK, 1991 to 2010

UK country	Males	Females	Total
England	660,616	851,862	1,512,478
Northern Ireland*	19,653	25,612	45,265
Scotland	66,288	92,129	158,417
Wales	43,096	52,535	95,631
Total	789,653	1,022,138	1,811,791

<sup>\*</sup>Northern Ireland data for 1993 to 2010

Source: Macmillan-NCIN, Segmenting the cancer survivor population.

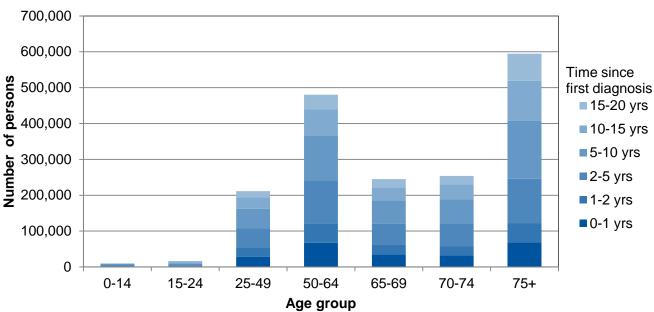
#### Where to go for further information

More information on the UK Cancer Prevalence Project can be found on the NCIN website. The Phase One Cancer Prevalence workbook shows the number of people living with and beyond a diagnosis of cancer for all cancers combined (excluding non-melanoma skin cancer) in the UK.

#### 4.2. Cancer prevalence by age

When examining cancer prevalence by age, it is possible to look at age at the time of diagnosis or age at the end of the period studied. Figure 4.2.1 shows the number of people alive following a diagnosis of cancer in the UK by their age in 2010, rather than age at diagnosis. There were just under 600,000 people aged 75 or over, and around 240,000 aged under 50 who had a diagnosis of cancer in the previous 20 years.

Figure 4.2.1. Persons living with cancer by time since diagnosis and age at end of 2010, UK, 1991 to 2010



Source: Macmillan-NCIN, Segmenting the cancer survivor population.

#### Where to go for further information

More information on the UK Cancer Prevalence Project can be found on the NCIN website. The Phase One Cancer Prevalence workbook shows the number of people living with and beyond a diagnosis of cancer for all cancers combined (excluding non-melanoma skin cancer) in the UK.

# 4.3. Cancer prevalence by sex

In the UK in 2010 there were more females alive with cancer than males (Figure 4.3.1). The difference in the number of people in each time since diagnosis group increased the longer ago the patients were diagnosed. Similar numbers of males and females were diagnosed within a year, but there were more than twice as many females who had been diagnosed between 15 and 20 years prior to 2010. This may partly be due to the differences in the type of cancer males and females are diagnosed with.

1,200,000 1,000,000 Time since first diagnosis Number of persons ■ 15-20 yrs 800.000 ■ 10-15 yrs ■5-10 yrs 600,000 ■2-5 yrs ■1-2 yrs 400,000 ■ 0-1 yrs 200,000 0 Males **Females** 

Figure 4.3.1. Persons living with cancer at end of 2010 by time since diagnosis and sex, England, 1991 to 2010

Source: Macmillan-NCIN, Segmenting the cancer survivor population.

#### Where to go for further information

More information on the UK Cancer Prevalence Project can be found on the NCIN website. The Phase One Cancer Prevalence workbook shows the number of people living with and beyond a diagnosis of cancer for all cancers combined (excluding non-melanoma skin cancer) in the UK.

## 4.4. Cancer prevalence by deprivation

Figure 4.4.1 shows the number of people alive in England by deprivation quintile at time of diagnosis. As many cancers are more commonly diagnosed in more deprived areas (see section 1.4), the lower numbers of people in the more deprived groups partially reflect the worse survival for these patients (see section 3.3).

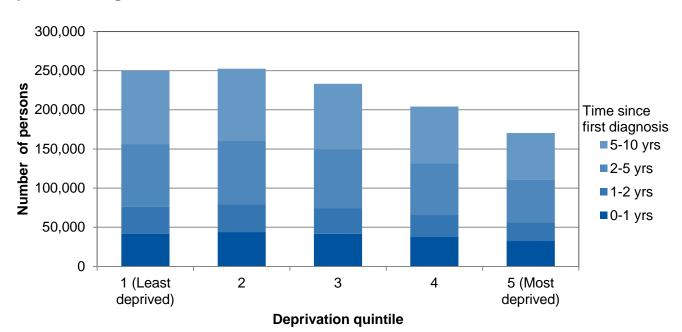


Figure 4.4.1. Persons living with cancer at end of 2010 by time since diagnosis and deprivation, England, 2001 to 2010

Source: Macmillan-NCIN, Segmenting the cancer survivor population.

#### Where to go for further information

More information on the UK Cancer Prevalence Project can be found on the NCIN website. The Phase One Cancer Prevalence workbook shows the number of people living with and beyond a diagnosis of cancer for all cancers combined (excluding non-melanoma skin cancer) in the UK.

#### 4.5. Cancer prevalence by ethnicity

As ethnicity has historically been poorly recorded for cancer registrations (see section 5), it is not possible to assign an ethnic group to all patients, particularly those diagnosed in an earlier period. This means it is not yet possible to assess 10- or 20-year cancer prevalence by ethnicity.

# 5. Ethnicity coding compliance

# 5.1. 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, while 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 to 2006, 76% had a self-reported ethnicity derived from Hospital Episode Statistics (HES). For tumours diagnosed in 2008 to 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 in 2008 to 2010 with an assigned ethnicity is now 95%. Ethnicity is assigned by linking cancer registrations with admitted care HES, outpatient HES, Accident and Emergency (A&E) HES, and also from information collected for cancer registration purposes. Of the proportion of records with no ethnic group assigned, the majority did not have ethnicity recorded in HES rather than there being no link to hospital episodes.

Table 5.1.1. Proportion of newly diagnosed cases by ethnicity and sex, selected cancer types England, 2008 to 2010

	White	Asian	Black	Chinese	Mixed	Other	Unknown
Breast (F)	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%

<sup>\*</sup> 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.

#### 5.2. Completeness of ethnicity in HES data linked to cancer registrations

In 2004/05, 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. Table 5.2.1 shows the distribution of ethnicity in admitted patient care records from 2012. Complete coding of ethnicity in HES enables us to produce national analyses by ethnic group. The lack of ethnicity information 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.

Table 5.2.1. Proportion of admitted patient care HES episodes by 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%

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

See also Figure 5.3.1 for completeness of ethnicity by trust for episodes in 2012.

Outpatient and A&E data were linked to cancer registrations for the first time in 2013. Table 5.2.2 shows the improvement of ethnicity coding in these datasets 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.

Table 5.2.2. Completeness of ethnicity recording in outpatient, and accident and emergency HES records linked to cancer registrations, England, 2010 to 2012

	2010	2011	2012
Outpatient HES records	38.3%	72.8%	93.7%
Accident and Emergency HES records	31.5%	64.8%	85.5%

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

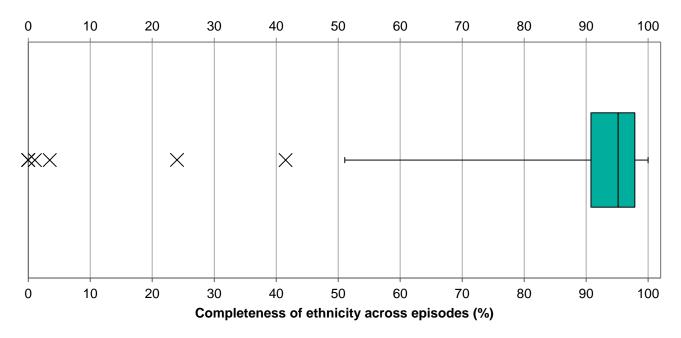
#### Where to go for further information

More information on HES, including descriptions and publications, can be found on the Health and Social Care Information Centre website.

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

For cancer registrations, HES are received for both people with a registered tumour and for people in HES with a diagnosis code of a neoplasm. 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 5.3.1). This excludes any trust with less than ten episodes submitted (six trusts). The median completeness is 95%.

Figure 5.3.1. Completeness of ethnicity recording by trust, admitted patient care HES data for cancer registrations or people with a diagnosis of a neoplasm within HES, England, 2012



× represents a trust with <50% of registrations with ethnicity recorded but more than 10 episodes

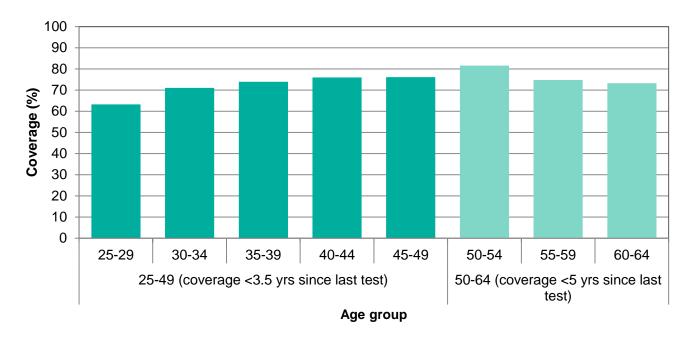
Source: NCIN, reproduced with permission from the Health and Social Care Information Centre.

# Cancer screening programmes

# 6.1. Cervical screening coverage by age

Cervical screening is an important way of preventing cancers as well as catching them at an early stage. Women aged 25 to 49 are invited every three years while those aged 50 to 64 are invited every five years. Coverage is defined as the percentage of women in a population eligible for screening at a given point in time who were screened adequately within a specified period. Figure 6.1.1 shows the coverage for different age groups within their appropriate invitation period. Coverage is lowest in the youngest age group and highest in the 50 to 54 group.

Figure 6.1.1. Cervical screening coverage by age and time since last screened, England, 31 March 2014



Source: Health and Social Care Information Centre KC53 (Parts A2 and A3)

#### Where to go for further information

Further information on cervical screening is also available from the NHS cervical screening programme and the Health and Social Care Information Centre websites.

# 6.2. Breast cancer screening uptake by age

Women aged 50 to 70 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. Uptake is defined as the percentage of women invited in the year who were screened adequately within six months of the invitation.

Figure 6.2.1 shows screening uptake for different age groups in England. Screening uptake generally increases with age until women aged between 60 and 70, and is lower in 71 to 74 year olds. Much of this will be due to the changing age range of women routinely invited for screening appointments. As women are invited every three years, a woman may not receive her first invitation until the age of 53, however, women aged 50 to 52 currently have a very similar level of uptake as those aged 53 to 54.

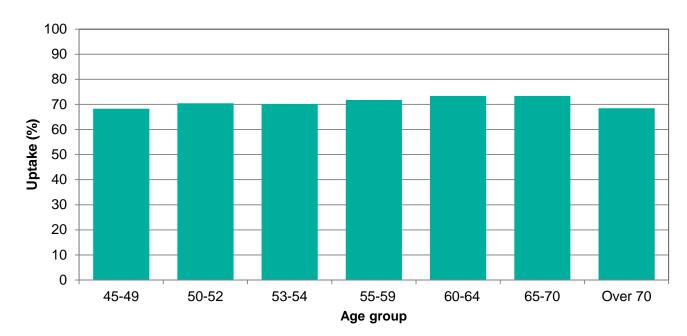


Figure 6.2.1. Breast screening uptake by age, England, 2013/14

Source: Health and Social Care Information Centre, KC62 (Part 1, Tables A to D).

#### Where to go for further information

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

## 6.3. Bowel screening uptake by age and sex

Bowel cancer screening was originally offered to people aged 60 to 69, although an extension to invite people up to their 75<sup>th</sup> birthday began in 2008. In 2013/14, screening uptake was slightly higher amongst females than males in the 60 to 69 age group (Figure 6.3.1). There was very little difference in uptake between males and females aged 70 to 74. The Routes to Diagnosis project (see section 7) showed that for patients diagnosed in 2006 to 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.<sup>2</sup>

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<sup>&</sup>lt;sup>2</sup> Routes to diagnosis http://www.ncin.org.uk/publications/routes\_to\_diagnosis

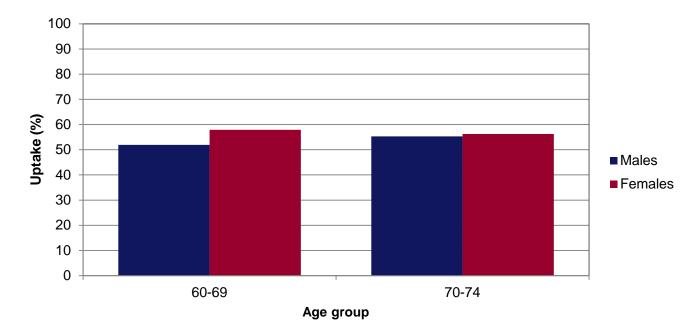


Figure 6.3.1. Bowel cancer screening uptake by age and sex, England, 2013/2014

Source: NHS Cancer Screening Programme, OBIEE reporting system 11g 08/05/2015.

### Where to go for further information

Further information on the bowel cancer screening programme is available from the NHS bowel cancer screening programme webiste. The Cancer Screening Programmes' national office can be contacted via info@cancerscreening.nhs.uk.

## 6.4. Screening uptake by deprivation and ethnicity

While assessing screening uptake by deprivation should be straightforward, as deprivation is measured based on postcode of residence, it is not routinely reported. Calculating uptake be ethnicity is more difficult, as knowing the ethnicity of people invited for screening, who then do not attend relies on ethnicity information recorded by GPs and linked to screening services data.

# 7. Routes to Diagnosis

The Routes to Diagnosis project determined how each patient presented to secondary care on their way to being diagnosed with cancer. Emergency presentations are defined as a combination of an emergency route via A&E, emergency GP referral, emergency transfer, emergency consultant outpatient referral, emergency admission or attendance. Other routes include the two week wait route, GP referral, inpatient elective and other outpatient. Relative survival estimates were also calculated, showing that patients diagnosed through the emergency presentation route have the poorest survival.

## 7.1. Proportion of emergency presentations by age

The proportions of patients who present through the emergency route in each age group for female breast, colorectal, lung and prostate cancer are shown in Figure 7.1.1. Very low proportions of breast and prostate cancers are diagnosed through the emergency route in patients aged under 80 years, with the proportion increasing with age, and being highest in the 85 and older group. The 60 to 69 age group have the lowest proportion of emergency presentations in the colorectal cancer group, which is likely to be influenced by the introduction of the bowel cancer screening programme in 2006. The highest proportions of emergency presentations are again seen in the oldest age groups. Of the cancer types examined here, lung cancer patients have the highest proportions of emergency presentations (38% overall). The proportion increases with age, and 57% of patients aged 85 or older were diagnosed through this route.

70 Emergency presentations (%) 60 50 40 30 20 10 0 69-09 70-79 80-84 85+ 69-09 70-79 80-84 69-09 70-79 <50 69-09 70-79 80-84 85+ <50 80-84 85+ **Breast (females)** Colorectal **Prostate** Lung

Figure 7.1.1. Proportion of emergency presentations by age, England, 2006 to 2010

Source: NCIN, Routes to Diagnosis.

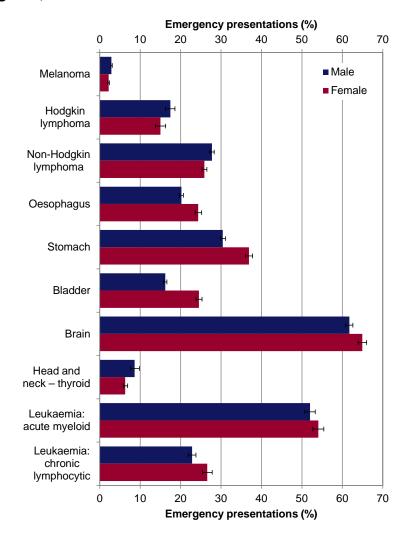
#### Where to go for further information

The NCIN report and workbooks on Routes to Diagnosis are available from the NCIN website.

## 7.2. Proportion of emergency presentations by sex

The Routes to Diagnosis project presents results by sex for each cancer type. For the majority, there were only small differences observed in the proportion of emergency presentations between sexes for all ages, however, there were some differences, described below. Figure 7.2.1 shows the proportion of emergencies by sex for a selection of non-sex specific cancer types. Some of the differences between males and females will be due to the different age distributions of the sexes, as older patients are more likely to be diagnosed as emergency presentations. Of the cancer types shown, males had a higher proportion of emergency presentations for melanoma, non-Hodgkin lymphoma and thyroid cancer. Females had a higher proportion for chronic lymphocytic leukaemia, oesophagus, stomach, bladder, and brain cancer.

Figure 7.2.1. Proportion of emergency presentations by sex, selected non-sex specific cancer types, England, 2006 to 2010



Source: NCIN, Routes to Diagnosis.

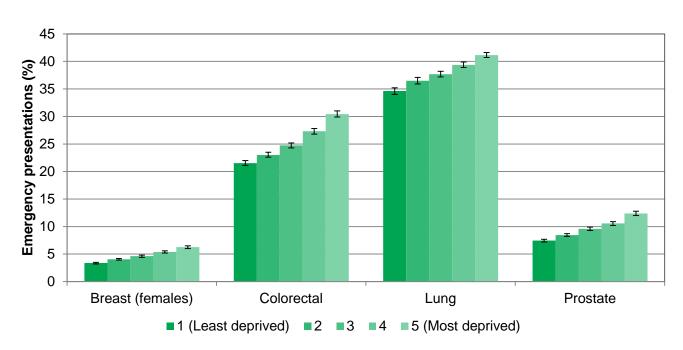
#### Where to go for further information

The NCIN report and workbooks on Routes to Diagnosis are available from the NCIN website.

#### 7.3. Proportion of emergency presentations by deprivation

For many cancer types, differences were also observed by deprivation with a higher proportion of emergencies in the most deprived group. A clear gradient can be seen in Figure 7.3.1 for female breast, colorectal, lung and prostate cancer, however, these percentages do not take into account the varying age structures and other factors between the populations, and further work is required to understand the underlying cause behind these differences.

Figure 7.3.1. Proportion of emergency presentations by deprivation, England, 2006 to 2010



Source: NCIN, Routes to Diagnosis.

#### Where to go for further information

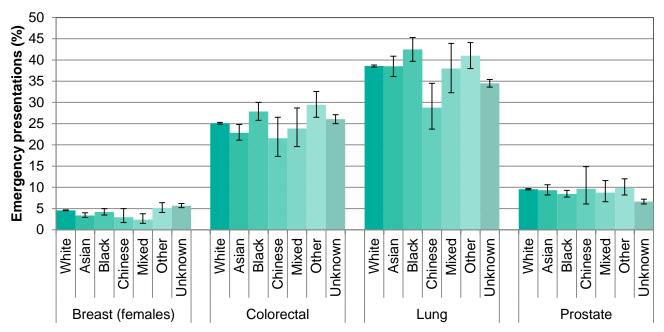
The NCIN report and workbooks on Routes to Diagnosis are available from the NCIN website.

## 7.4. Proportion of emergency presentations by ethnicity

The proportions of patients diagnosed following an emergency presentation for each ethnic group are shown in Figure 7.4.1 for the most common cancer types. There are small numbers of patients in some ethnic groups for some of the cancer types, leading

to large confidence intervals. Age structures are very different for the different age groups which will have a large impact on the proportion of emergency presentations. Further work is required to understand fully the differences in presentation routes by ethnic group.

Figure 7.4.1. Proportion of emergency presentations by ethnicity, England, 2006 to 2010



Source: NCIN, Routes to Diagnosis.

#### Where to go for further information

The NCIN report and workbooks on Routes to Diagnosis are available from the NCIN website.

# 8. 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 is analysed by a range of equality groups. The survey comprises of 78 questions, including 63 where the patient scored their care on a wide range of issues including information provision, communication 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 Quality Health's national report, Cancer Patient Experience Survey 2014.

It is important to note throughout this section that many of the CPES findings by equality groups are similar to those of 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 2014. It covered inpatient and day case cancer patients treated between 1 September and 30 November 2013. 153 NHS Trusts providing cancer services identified patients and over 70,000 patients chose to respond. This was very similar to the previous surveys undertaken.

#### Where to go for further information

Quality Health provide publications and breakdowns by the patients' Clinical Commissioning Group of residence. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

## 8.1. Patient experience by age

The Cancer Patient Experience Survey 2014 National Report 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, 41 in 2013 and 41 in 2014. Examples of the responses by different age groups are shown in Figure 8.1.1.

Across all surveys, the youngest age band generally was the least positive about their patient experience. For example, in 2014, 51% of the youngest age group said they completely understood the explanation as to what was wrong with them, compared with over 75% of the oldest age group. Responses to this question indicate a need for easier to understand information for patients across all age groups, and especially amongst younger cancer patients.

Conversely, the opposite picture is seen for some questions, including whether the taking part in cancer research was discussed with the patient. Just over half of the youngest age group answered positively to this compared with 21% of the oldest age group. There was a large drop between respondents from the 16 to 25 age group and the age groups between 26 and 75 years (all around 30% to 35%).

Not all questions produced large differences in responses between age groups. Around 50% of patients in all age groups reported they had been given information on financial help or benefits they might be entitled to by hospital staff.

100 90 80 70 Agree (%) 60 50 40 30 20 10 0 36-50 36-75 16-2536-50 36-50 51-65 **76**+ 76+ <u>6</u> Completely understood Given information on Taking part in cancer explanation of what was financial help/benefits by research discussed

hospital staff

Figure 8.1.1. Cancer Patient Experience Survey 2014 responses by age, selected questions, England

Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

#### Where to go for further information

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Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

## 8.2. Patient experience by sex

Differences in the views of patients related to their sex tended to be of smaller scale than for some of the other demographic factors, however, due the large number of respondents in the survey, many of these small differences were statistically significant, and should still be considered to see why such differences exist.

There were 47 questions with significant differences between males and females, with males giving more positive responses for 34 questions, and females for 13. This generally poorer experience of cancer care in females is similar to previous years.

A selection of responses are shown in Figure 8.2.1. Males reported a better experience compared with females regarding being given enough emotional support while being treated as an outpatient or day case and having confidence and trust in the doctors treating them. A higher proportion of males felt that their health got worse while waiting for their first appointment with a hospital doctor compared with females. Females were more likely to report being given the name of a clinical nurse specialist who would be in charge of their care. Some differences may be due to the cancer type that the patients had, the age distributions of males and females, or other unmeasured factors.

100 90 80 70 Agree (%) 60 50 40 30 20 10 0 Had confidence and Health got worse while Given the name of a Given enough emotional support from trust in doctors waiting for first Clinical Nurse hospital staff while appointment Specialist being treated as ■ Male ■ Female outpatient or day case

Figure 8.2.1. Cancer Patient Experience Survey 2014 responses by sex, selected questions, England

Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

## Where to go for further information

Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

## 8.3. Patient experience by deprivation

Questions in the survey have been analysed by deprivation. There were 37 questions where there was a statistically significant difference between the least and most deprived groups. For 25 of these, patients living in the less deprived groups reported a

better experience. For example, 19% of patients in the least deprived group said their health got worse while they waited for their first appointment with a hospital doctor, compared with 23% of those in the most deprived group; and 89% in the least deprived group were given written information about tests compared with 84% in the most deprived group (Figure 8.3.1). For a smaller number of questions (12) a significantly better experience was reported by those in the most deprived groups. This is illustrated by 19% of the least deprived group being offered a written assessment and care plan, compared with 29% of the most deprived group.

100 90 80 70 Agree (%) 60 50 40 30 20 10 0 Health got worse whilst Given written Offered written waiting for first appointment information about tests assessment / care plan ■1 (Least deprived) ■2 ■3 ■4 ■5 (Most deprived)

Figure 8.3.1. Cancer Patient Experience Survey 2014 responses by deprivation, selected questions, England

Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

#### Where to go for further information

Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

## 8.4. Patient experience by ethnicity

The majority of respondents to the Cancer Patient Experience Survey described their ethnicity as white. Broad ethnic groups (white, mixed, Asian, black and other) were therefore used to examine patient experience by ethnicity.

In 2014, there were 21 questions where patients from different ethnic groups had significantly different responses. White patients were least likely to agree that they had been asked to take part in cancer research (Figure 8.4.1) and been given a written

assessment and care plan, consistent with previous surveys. Lower proportions of patients from the Asian (Indian, Pakistani, Bangladeshi, Chinese and other Asian) and Other ethnic groups (Arab and any other ethnic group) reported that they did not feel treated like a set of cancer symptoms (Figure 8.4.1).

100 90 80 70 60 Agree (%) 50 40 30 20 10 0 White Mixed Asian Black Asian Black Other Other White Mixed Did not feel treated like a set of symptoms Taking part in cancer research discussed

Figure 8.4.1. Cancer Patient Experience Survey 2014 responses by ethnicity, selected questions, England

Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

### Where to go for further information

Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

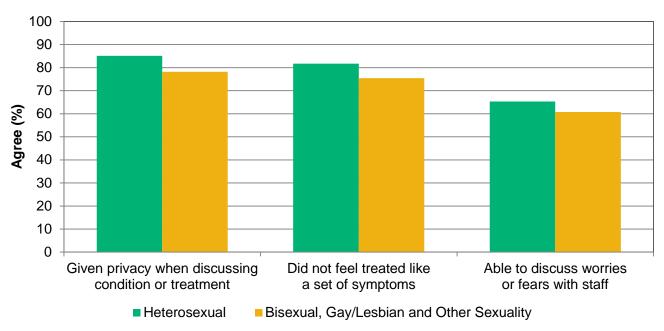
## 8.5. Patient experience by sexual orientation

CPES respondents were asked describe their sexual orientation, using the categories of heterosexual, gay or lesbian, bisexual, other, or 'prefer not to answer'. Small numbers of respondents chose any of the non-heterosexual groups and have therefore been grouped together and compared with the heterosexual group. Patients who did not answer have been excluded from the analyses.

There were 24 questions where there was a difference in the responses by sexual orientation. For all of these, the heterosexual group reported a more positive experience. A selection of these are shown in Figure 8.5.1, where heterosexual patients were more likely to agree that they were given privacy when discussing their condition

or treatment, did not feel like they were treated like a set of symptoms, and were able to discuss worries or fears with staff during their hospital visit.

Figure 8.5.1. Cancer Patient Experience Survey 2014 responses by sexual orientation, selected questions, England



Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

## Where to go for further information

Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

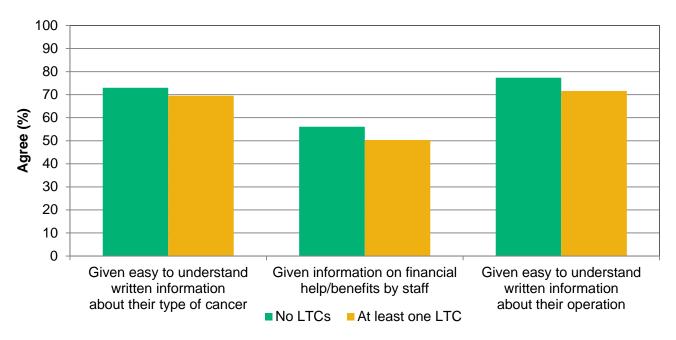
## 8.6. Patient experience by comorbidity

The CPES asked patients to state whether they had any long-term conditions (LTCs), other than cancer. Patients were able to select multiple items from: deafness or severe hearing impairment; blindness or partially sighted; a long standing physical condition; a learning disability; a mental health condition; or a long standing illness such as HIV, diabetes, chronic heart disease, or epilepsy.

Responses are shown for patients who had no long-term conditions and those who selected at least one. Patients with long-term conditions were less positive about their cancer care than patients without such conditions across a wide range of issues measured in the survey. Figure 8.6.1 shows three of these questions, where those with at least one long-term condition were less likely to say they were given easy to understand written information about their type of cancer or their operation, or given information on financial help or benefits by hospital staff. Examining the patterns for the

specific long-term conditions may help to identify where action is needed to improve patients' experiences.

Figure 8.6.1. Cancer Patient Experience Survey 2014 responses for patients with no long-term conditions (LTCs) and with at least one LTC, selected questions, England



Source: Quality Health, Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement.

## Where to go for further information

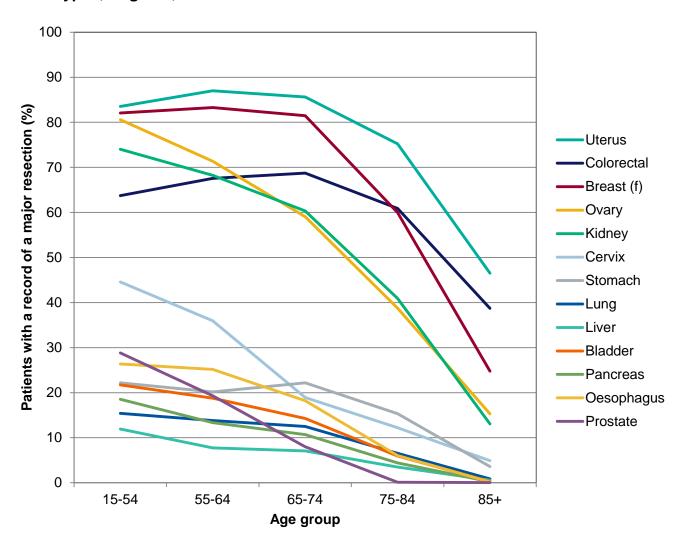
Publications and data tables are available on the Quality Health website. A range of information on the Cancer Patient Experience Surveys can also be found on the patient experience section of the NCIN website.

## 9. Treatment

## 9.1. Major resections by age

Surgery information contained within Hospital Episode Statistics has been linked to cancer registration information to assess whether patients underwent major resections as part of their cancer treatment. Figure 9.1.1 shows the proportion of patients diagnosed in England between 2006 and 2010 with a record of a major resection, for 13 different types of cancer. For all of these cancer types older patients were less likely to have had surgery, and this decline often started from the youngest age group.

Figure 9.1.1. Percentage of patients with a record of a major resection by age, selected cancer types, England, 2006 to 2010



Source: NCIN, Major Surgical Resections.

## Where to go for further information

The most recent work on major resections can be found on the NCIN website.

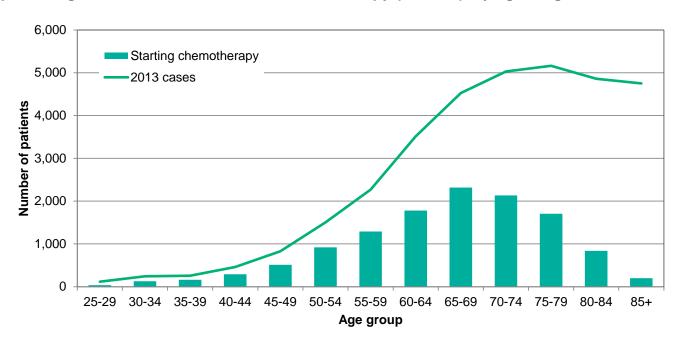
## 9.2. Chemotherapy by age

The Systemic Anti-Cancer Therapy (SACT) Dataset contains information on all patients receiving chemotherapy for cancer in, or funded by, the NHS in England. The NCIN Older People and Cancer report examined the number of patients in different age groups who were diagnosed with colorectal cancer, lung cancer and breast cancer in 2012 alongside the number of patients with these cancers who were given at least one course of chemotherapy between April 2013 and March 2014. These are updated in the figures below to show diagnoses from 2013, compared with the same chemotherapy data. This is not as exact as being able to tabulate which patients had chemotherapy, as was possible for major resections (see section 9.1) and radiotherapy (see section 9.3), but is a useful indication to see where chemotherapy has a different age distribution compared with newly diagnosed patients.

#### 9.2.1. Colorectal cancer

Figure 9.2.1 shows the age distributions of cases diagnosed and those undergoing chemotherapy for colorectal cancer patients. The numbers of both increase with age, until a peak of chemotherapy in the 65 to 69 age group, and a peak of cases in the 75 to 79 age group. While cases then decline slightly, the number of patients receiving chemotherapy rapidly drop to much lower numbers in the 85 and older age group.

Figure 9.2.1. Diagnoses of colorectal cancer (2013) and the number of colorectal cancer patients given at least one course of chemotherapy (2013/14), by age, England



Sources: Chemotherapy Intelligence Unit (chemotherapy data); CASCADE, based on CAS February 2015 snapshot (number of cases).

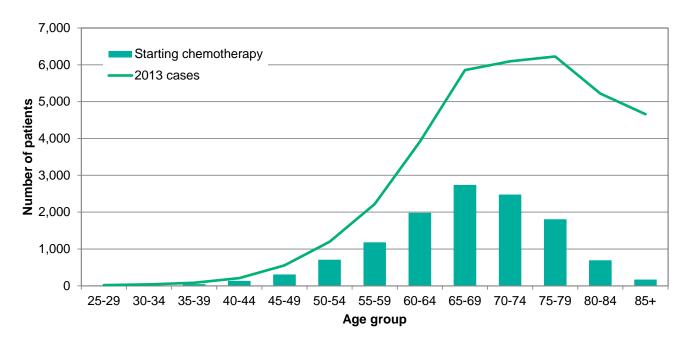
### Where to go for further information

A previous version of this figure was in the NCIN Older People and Cancer report. More information is available on the Systemic Anti-Cancer Therapy Dataset website.

## 9.2.2. Lung cancer

The number of lung cancer patients starting chemotherapy in different age groups follows a pattern similar to the number of lung cancer cases diagnosed (Figure 9.2.2). There is a drop in the number of cases diagnosed in the over 80s which is mirrored by the decrease in the number of patients starting chemotherapy, although this decrease starts following the peak in 65 to 69 year olds.

Figure 9.2.2. Diagnoses of lung cancer (2013) and the number of lung cancer patients given at least one course of chemotherapy (2013/14), by age, England



Sources: Chemotherapy Intelligence Unit (chemotherapy data); CASCADE, based on CAS February 2015 snapshot (number of cases).

#### Where to go for further information

A previous version of this figure was in the NCIN Older People and Cancer report. More information is available on the Systemic Anti-Cancer Therapy Dataset website.

#### 9.2.3. Breast cancer

The number of breast cancer patients starting chemotherapy is between 2,000 and 3,000 in each of the age groups between 45 and 69. This number then decreases for older patients. The number of patients diagnosed generally increases with age, until a peak in 65 to 69 year olds, and then decreases in older patients.

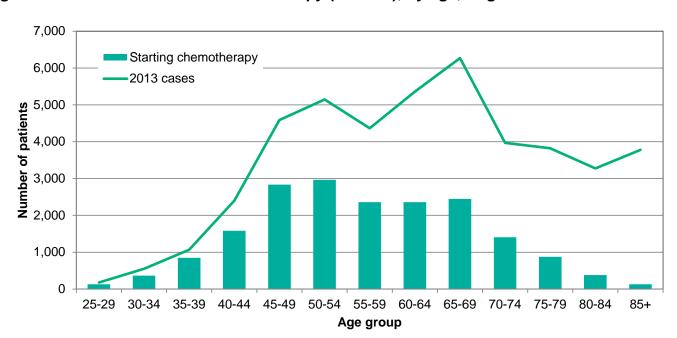


Figure 9.2.3. Diagnoses of breast cancer (2013) and the number of breast cancer patients given at least one course of chemotherapy (2013/14), by age, England

Sources: Chemotherapy Intelligence Unit (chemotherapy data); CASCADE, based on CAS February 2015 snapshot (number of cases).

## Where to go for further information

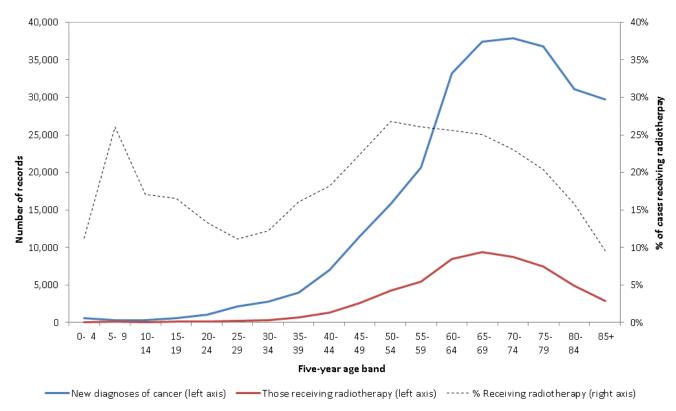
A previous version of this figure was in the NCIN Older People and Cancer report. More information is available on the Systemic Anti-Cancer Therapy Dataset website.

## 9.3. Radiotherapy by age

Radiotherapy treatment data have been linked to cancer registration data for patients diagnosed in England in 2011. Patients were recorded as having radiotherapy if there was a record of radiotherapy between one month before and six months after the patient's date of diagnosis. This is an exploratory analysis, and future work will be able to take important factors, such as cancer type, sex, and the radiotherapy intent (whether palliative or curative) into account.

Figure 9.3.1 shows the number of patients diagnosed with all cancers (excluding non-melanoma skin cancer), the number of patients with a record of radiotherapy, and the proportion of these patients receiving radiotherapy. There is an early peak in the proportion of patients having radiotherapy in the 5 to 9 age group, reflecting childhood cancer treatment. After decreasing in teenager and young adults, the proportion increases again, reaching another peak in patients aged 50 to 69 year olds, and decreases again for older patients.

Figure 9.3.1. New diagnoses of cancer and those receiving radiotherapy one month before to six months after diagnosis, all cancers (excluding non-melanoma skin cancer), England, 2011



Reproduced directly from the NCIN Older People and Cancer report

## Where to go for further information

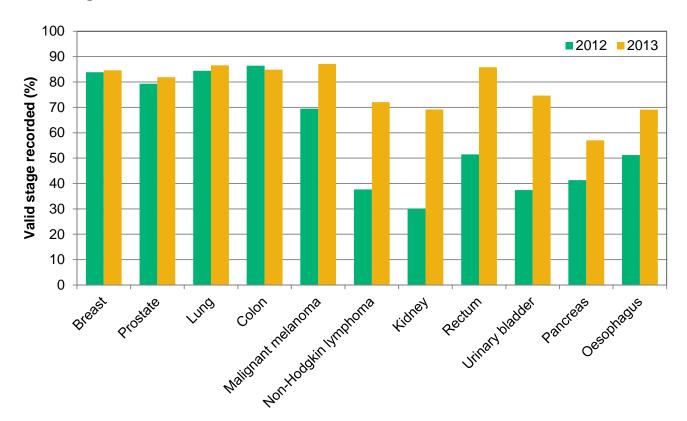
This figure is from the NCIN Older People and Cancer report. More information on the National Radiotherapy Dataset is available on the National Clinical Analysis and Specialised Applications Team (NATCANSAT) website.

# 10. Stage at diagnosis

## 10.1. The percentage of staging data recorded at diagnosis

The proportion of cancer patients with recorded stage is increasing. Previous data quality reports produced by the National Cancer Registration Service show that for 2010 cancer registrations, 40% of all cancers (excluding non-melanoma skin cancer) diagnosed in England had a recorded stage. This improved with 51% of registrations in 2011 and 62% of 2012 registrations having a stage recorded. This has increased again in 2013. For all invasive tumours (excluding non-melanoma skin cancer) diagnosed in England in 2013, 71% had a valid stage recorded. There have been particular improvements since 2012 for non-Hodgkin lymphoma, kidney, rectum, and urinary bladder cancers.

Figure 10.1.1. Proportion of cancers staged for most common cancer types, England, cancers registered in 2012 and 2013



Source: UKIACR, Performance indicators.

#### Where to go for further information

Data on various performance indicators, including completeness of stage, and commentary are available from the UKIACR website.

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

The different equality groups are not routinely reported as part of the performance indicator report. Now that staging completeness is high, and improving, as shown in section 10.1, breakdowns by different equality groups can be undertaken and reported on in the future.

# 11. Patient reported outcome measures

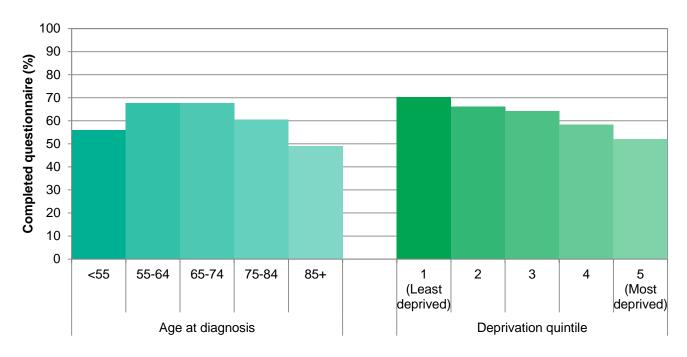
Patient Reported Outcomes Measures (PROMs) is a national programme organised by NHS England. The first cancer-specific pilot data collections surveyed people with non-Hodgkin lymphoma, breast, colorectal and prostate cancers. Response rates and measures of 'perfect' health and 'social distress' for colorectal cancer patients are described in section 11.1. Following this, a pilot for patients with gynaecological cancers (cervical, womb and ovarian cancers) was conducted in 2014. The response rates for these cancers are described in sections 11.2 to 11.4.

## 11.1. Colorectal cancer patient reported outcome measures (PROMs)

For the national survey of colorectal cancer survivors using Patient Reported Outcome Measures (PROMs), individuals alive 12 to 36 months after a diagnosis of colorectal cancer were identified via the National Cancer Registration Service and were sent a questionnaire in January 2013. Overall, of the 34,467 individuals approached, 21,802 returned a fully or partially completed questionnaire, giving a response rate of 63%.

Figure 11.1.1 shows the response rates by age and deprivation. The highest response rates were in patients aged 55 to 74, and patients aged 85 and over had the lowest response rate. Response rates were lower for patients living in more deprived areas.

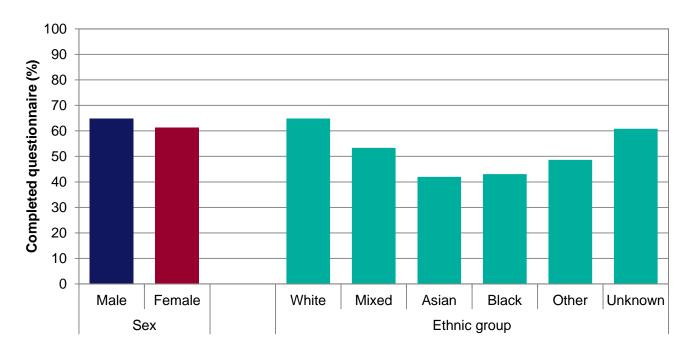
Figure 11.1.1. Response rate for colorectal cancer PROMs by age and deprivation, England, 2013



Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

Figure 11.1.2 shows the response rates by sex and ethnicity. Males had a slightly higher response rate than females. The highest response rate was in white patients, with Asian and black patients having the lowest response rates.

Figure 11.1.2. Response rate for colorectal cancer PROMs by sex and ethnicity, England, 2013

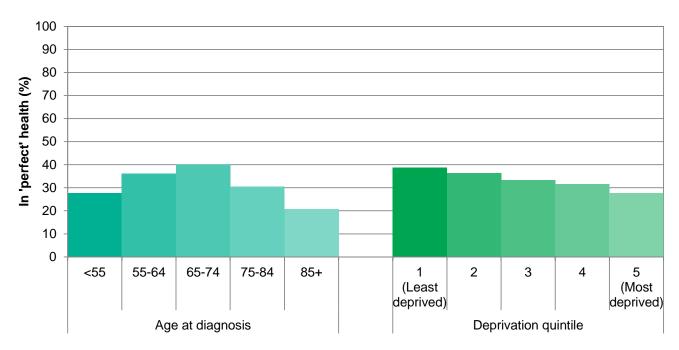


Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

Patients who reported no issues on any of the pain/discomfort, self-care, usual activities, mobility, and anxiety/depression domains were described as having 'perfect' health. Figure 11.1.3 shows the proportions of patients in 'perfect' health by age and deprivation. Patients aged 65 to 74 had the highest proportion in 'perfect' health (40%), and the lowest proportion was in patients aged 85 and over (21%). The proportion of patients in 'perfect' health decreased with increasing deprivation, from 39% in the least deprived group to 28% in the most deprived group.

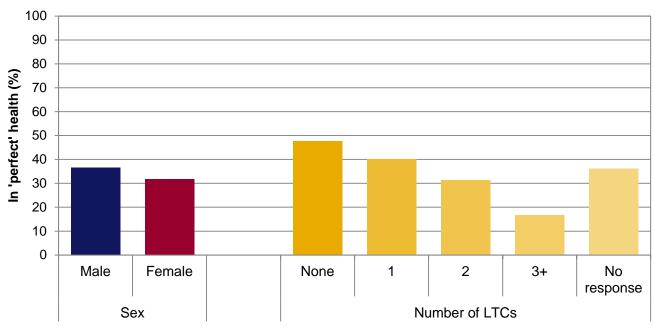
The proportions of patients with 'perfect' health by sex and number of long-term conditions (LTCs) are shown in Figure 11.1.4. Males (37%) were more likely to report 'perfect' health than females (32%). Unsurprisingly, the proportion of patients in 'perfect' health increased with decreasing numbers of long-term conditions. This ranged from 17% of those with three or more long-term conditions to 48% of those with none.

Figure 11.1.3. Proportion in 'perfect' health from colorectal cancer PROMs by age and deprivation, England, 2013



Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

Figure 11.1.4. Proportion in 'perfect' health from colorectal cancer PROMs by sex and number of long-term conditions (LTCs), England, 2013

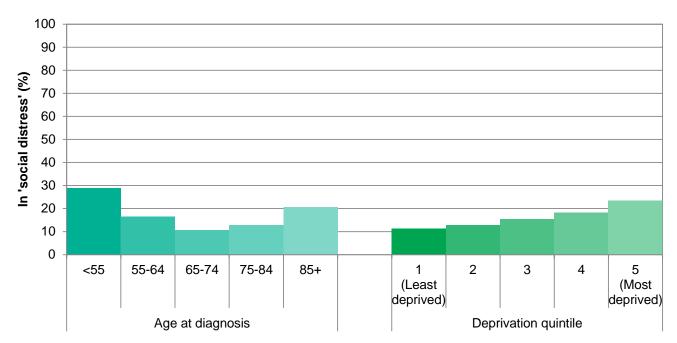


Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

The survey assessed 'social distress' using the Social Difficulties Inventory. Any problems experienced in the previous month around family, social activities, finances and work were identified.

The proportions of patients in 'social distress' by age and deprivation are shown in Figure 11.1.5. The highest proportion in 'social distress' (29%) was in the youngest age group (younger than 55). This decreased to 11% in the 65 to 74 age group, and then increased again, to 21% in the 85 and older group. Those living in the least deprived areas were least likely to report 'social distress' (11%), and this increased with deprivation to 23% of the most deprived group.

Figure 11.1.5. Proportion in 'social distress' from colorectal cancer PROMs by age and deprivation, England, 2013



Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

Figure 11.1.6 shows the proportion of patients in 'social distress' by sex and number of LTCs. There was no difference in the proportion of males and females (both 15%), while those with more LTCs reported higher proportions of 'social distress'. Of patients with no LTCs, 9% reported 'social distress' which increased to 27% of those with three or more LTCs.

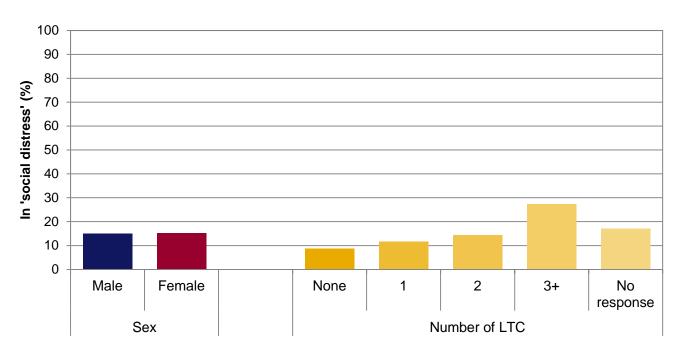


Figure 11.1.6. Proportion in 'social distress' from colorectal cancer PROMs by sex and number of long-term conditions (LTCs), England, 2013

Source: Quality of Life of Colorectal Cancer Survivors in England, Report on a national survey of colorectal cancer survivors using patient reported outcome measures (PROMs).

## Where to go for further information

A report and the National Reporting Tool are available from the NHS England website, along with a tool showing the results from each Strategic Clinical Network (SCN), Clinical Commissioning Group (CCG) and Hospital NHS Trust.

## 11.2. Cervical cancer patient reported outcome measures (PROMs)

In the pilot of the patient reported outcome measures survey for gynaecological cancers, women aged 16 and over who had a diagnosis of cervical cancer between one and five years earlier were included. Of the 1,252 women sent the survey in 2013, 493 completed the questionnaire, giving a response rate of 39%. Figure 11.2.1 shows the response rate by age and deprivation. Older patients were more likely to respond (ranging from 32% of 16 to 29 year olds, to 44% of the 50 to 99 age group). The response rate decreased with deprivation, from 48% in the least deprived to 34% in the most deprived group.

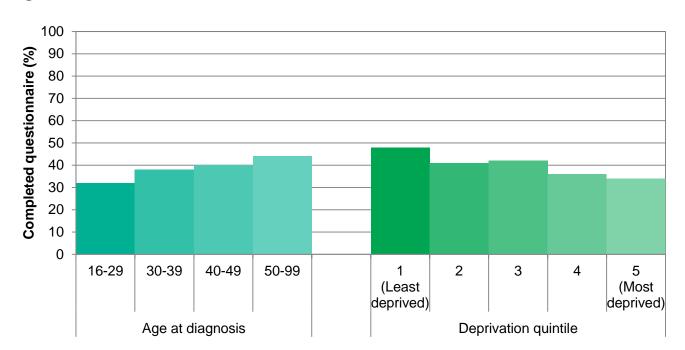


Figure 11.2.1. Response rate for cervical cancer PROMs by age and deprivation, England, 2013

Source: NHS England and PHE, Living with and beyond cervical cancer.

#### Where to go for further information

The joint NHS England and PHE living with and beyond cervical cancer report is available from the NCIN website.

## 11.3. Womb cancer patient reported outcome measures (PROMs)

In the pilot of the patient reported outcome measures survey for gynaecological cancers, women aged 16 and over who had a diagnosis of womb cancer between one and five years earlier were included. Of the 1,252 women sent the survey in 2013, 654 completed the questionnaire, giving a response rate of 52%. Figure 11.3.1 shows the response rate by age and deprivation. The response rate increased from 51% in the 16 to 29 age group to 57% in the 40 to 49 age group. The oldest age group (50 to 99) were least likely to respond (46%). There was little difference in the response rate in the three least deprived groups (56% to 57%), but a much smaller proportion responded in the most deprived group (35%).

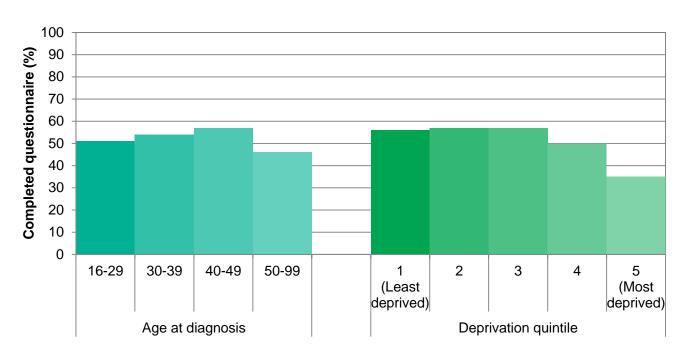


Figure 11.3.1. Response rate for womb cancer PROMs by age and deprivation, England, 2013

Source: NHS England and PHE, Living with and beyond womb cancer.

## Where to go for further information

The joint NHS England and PHE living with and beyond womb cancer report is available from the NCIN website.

## 11.4. Ovarian cancer patient reported outcome measures (PROMs)

In the pilot of the patient reported outcome measures survey for gynaecological cancers, women aged 16 and over who had a diagnosis of ovarian cancer between one and five years earlier were included. Of the 1,252 women sent the survey in 2013, 685 completed the questionnaire, giving a response rate of 55%. Figure 11.4.1 shows the response rate by age and deprivation. The highest response rate was in the 30 to 39 age group (65%), with other age groups having response rates of 50% to 54%. There was no clear evidence of a difference in the response rate by deprivation.

100 90 Completed questionnaire (%) 80 70 60 50 40 30 20 10 0 16-29 30-39 40-49 1 2 50-99 3 4 5 (Least (Most deprived) deprived) Age at diagnosis Deprivation quintile

Figure 11.4.1. Response rate for ovarian cancer PROMs by age and deprivation, England, 2013

Source: NHS England and PHE, Living with and beyond ovarian cancer.

## Where to go for further information

The NHS England and PHE living with and beyond ovarian cancer report is available from the NCIN website.

# Glossary

ASR Age standardised rate. Differences in the age structure of the populations

are taken into account when calculating incidence or mortality rates

CASCADE An online analytical tool providing incidence, mortality and survival data

from NCRS and NCIN

CAS Cancer Analysis System. The bridge between the National Cancer

Registration Service and users of cancer data, allowing analysts to log into

a database to run queries and access data on cancer

CCG Clinical commissioning group

CNS Central nervous system

CPES Cancer Patient Experience Survey

CRUK Cancer Research UK

Deprivation Deprivation in this report is measured using the income domain of the

Indices of Deprivation. These are split into five equal groups (quintiles) across England. People are assigned to a group ranging from 1 (least deprived) to 5 (most deprived) based on their postcode of residence when

they were diagnosed with cancer

HES Hospital Episode Statistics

HSCIC Health and Social Care Information Centre

Incidence The number of new cases diagnosed in a specified period. Presented either

as total numbers or as rates (the number of cases per 100,000 population),

usually age standardised to give age standardised rates

Mortality The number of deaths in a specified period. Presented either as total

numbers or as rates (the number of cases per 100,000 population), usually

age standardised to give age standardised rates

NATCANSAT National Clinical Analysis and Specialised Applications Team

NCEI National Cancer Equality Initiative

NCIN National Cancer Intelligence Network

NCDR National Cancer Data Repository

NCRS National Cancer Registration Service

Cancer and equality groups: key metrics – 2015 report

NHL Non-Hodgkin lymphoma

NMSC Non-melanoma skin cancer

ONS Office for National Statistics

Prevalence The number of people who have previously been diagnosed with cancer in

the period specified and were alive at the end of the period

PROMs Patient reported outcome measures

Relative An estimate of the percentage of patients still alive a specified period after

survival their diagnosis, while taking into account the background mortality in the

general population

SCN Strategic Clinical Network