

What cancer statistics are available,
and where can I find them?



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June 2013

This document aims to provide an overview about cancer statistics, including information on the latest statistics publicly available and where to find them.

This is intended to be a useful reference guide for infrequent users of cancer statistics or for audiences that may not be familiar with this information. This document is structured using key chapters in the Improving Outcomes: a Strategy for Cancer.

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MEASURING IMPROVEMENTS IN CANCER OUTCOMES

CANCER INCIDENCE

What is it?

The number of new cases of cancer diagnosed for a given period, usually a year. The statistics are provided as the total number of cases or as rates (number of cases per 100,000 population).

Incidence rates can be 'crude' or age-standardised. The crude rate is calculated by dividing the number of patients who live in a given area by the population of that area. However, the age-standardised rate (ASR) is more commonly used because the incidence of cancer rises sharply with age. The ASR calculation takes into account the variation in the age structures of populations to allow comparisons between different areas to be made. Cancer is much more common in the elderly, so a more elderly population will in general have a higher crude rate. Therefore age-standardised rates are the figures that should be used when making comparisons between different areas or different time periods, if one wishes to account for differences in the age distribution. ASRs are most commonly standardised using the European Standard Population or World Standard Population statistics.

What are the latest data available?

- UK and regional data: **2010**
- European and international comparators: **2008, estimates for 2012**
- Projections: Predictions for **2020** in England; Predictions up to **2030** for the UK

Useful data sources:

UK and Regional statistics:

- The National Cancer Intelligence Network (NCIN) Cancer e-Atlas is an interactive web-based cancer information tool, providing users easy visual access to cancer incidence, mortality and survival statistics for the UK. It includes cancer incidence up to 2008 for the UK, UK countries, cancer networks, primary care trusts (PCTs) and local authorities. The e-Atlas will be updated in June 2013. The e-Atlas produces a graphical presentation of the statistics with the option to download the data in an excel format. The Cancer e-Atlas is available on the NCIN website at: www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx
- Cancer Research UK (CRUK) provides detailed information about cancer incidence up to 2010, mortality and survival statistics. These data are available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/
- The Office for National Statistics (ONS) provides cancer incidence, mortality and survival statistics over time through the release of statistical bulletins. The ONS statistics on incidence up to 2010 are for England and its government office regions; these can be downloaded in an excel format. These data are available on the ONS website at: www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html
www.ons.gov.uk/ons/taxonomy/index.html?nscl=Cancer
- A range of statistics are provided by Public Health England¹, the Welsh Cancer Intelligence and Surveillance Unit, and the Scottish and Northern Irish Cancer Registries. These include statistics for the different regions in England and for Northern Ireland, Scotland and Wales. Their website

¹ PHE incorporates the cancer registration and analytical teams, with the latter now part of regional Knowledge and Intelligence Teams (KITs), of the former eight cancer registries in England.

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addresses are available from the UK Association of Cancer Registries (UKACR) website at: www.ukacr.org/registries

- Gynaecological cancer profiles is an online tool providing incidence and mortality rates for the main gynaecological cancers, survival, and influencing factors, such as deprivation, smoking prevalence and obesity. Cervical screening coverage indicators are also available. www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles
- The UK Cancer Information System (UKCIS) is an online analytical tool providing incidence, mortality and survival data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/ukcis
- The Cancer Commissioning Toolkit (CCT) is an online analytical tool providing incidence, mortality and survival data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct

International comparisons:

- There are a range of sources for European and international cancer incidence statistics. The CANCER Mondial website provides access to various databases containing information on the occurrence of cancer worldwide. It is held and managed by the Section of Cancer Information (CIN) of International Agency for Research on Cancer (IARC). The CANCER Mondial website is: www-dep.iarc.fr/
- As an example, GLOBOCAN provides worldwide country estimates for the incidence of and mortality from major cancer types. The most recent GLOBOCAN estimates are presented for 2008 and can be downloaded as fact sheets or tabulations, while charts and predictions can be generated in response to defined search criteria. These data are available on the GLOBOCAN website at: globocan.iarc.fr/
- And EUCAN presents estimates of incidence, mortality and prevalence for 24 major cancer types in 40 European countries for 2012. Available on the EUCAN website at: eco.iarc.fr/EUCAN/Default.aspx

Incidence projections:

- A paper published by H Møller *et al.* in 2007, examined 'The future burden of cancer in England: incidence and numbers of new patients in 2020'. British Journal of Cancer 2007; 96:1484-8. www.nature.com/bjc/journal/v96/n9/full/6603746a.html
- A paper published by P Sasieni *et al.* in 2011, examined 'Cancer incidence in the UK: Projections to the year 2030'. British Journal of Cancer 2011; 105:1795–1803. www.nature.com/bjc/journal/v105/n11/full/bjc2011430a.html
These statistics will be presented on the Cancer Research UK website when available: www.cancerresearchuk.org/cancer-info/cancerstats/incidence/projections/
- The Cancer Incidence Projections report gives projections for the number of cancer cases in Scotland up to 2020, with policy and methodology background, is available on the ISD Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Cancer-Incidence-Projections-Scotland-to-2020.pdf
- GLOBOCAN provides UK and worldwide incidence (and mortality) predictions for up to 2030 using data held in GLOBOCAN. Predictions can be generated on the future burden of a selected cancer or group of cancers, in a selected group of populations in a selected year. Available on the GLOBOCAN website at: globocan.iarc.fr/burden_sel.asp

CANCER MORTALITY

What is it?

Cancer mortality is the number of people who have died from cancer. The statistics show the number and the rate of cancer deaths per year. Cancer mortality is commonly expressed as crude and age-standardised rates in exactly the same way as cancer incidence (see above).

What are the latest data available?

- UK and regional data: **2011**
- European and international comparators: **2008**, estimates for **2012**
- Projections: Estimates up to **2030** for the UK

Useful data sources:

UK and Regional statistics:

- The National Cancer Intelligence Network (NCIN) Cancer e-Atlas is an interactive web-based cancer information tool, providing users easy visual access to timely cancer incidence, mortality and survival statistics for the UK. It includes cancer mortality up to 2009 for the UK, UK countries, cancer networks, primary care trusts (PCTs) and local authorities. The e-Atlas will be updated in June 2013. The e-Atlas produces a graphical presentation of the statistics with the option to download the data in an excel format. The Cancer e-Atlas is available on the NCIN website at: www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx
- Cancer Research UK (CRUK) provides detailed information about cancer mortality up to 2010, incidence and survival statistics. These data are available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/
- Cancer Mortality Profiles are interactive spreadsheets showing trends in cancer mortality rates in England for under 75 year olds by different levels of geography. This tool has been developed to support the monitoring, commissioning and planning of local cancer services. www.swpho.nhs.uk/resource/browse.aspx?RID=76240
- The Office for National Statistics (ONS) provides cancer mortality, incidence and survival statistics over time through the release of statistical bulletins. The ONS statistics on mortality up to 2011 are for England and Wales; these can be downloaded in an Excel format. These data are available on the ONS website at: www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/index.html
- A range of statistics are provided by Public Health England, the Welsh Cancer Intelligence and Surveillance Unit, and the Scottish and Northern Irish Cancer Registries. These include statistics for the different regions in England and for Northern Ireland, Scotland and Wales. Their website addresses are available from the UK Association of Cancer Registries (UKACR) website at: www.ukacr.org/registries
- Gynaecological cancer profiles is an online tool providing incidence and mortality rates for the main gynaecological cancers, survival, and influencing factors, such as deprivation, smoking prevalence and obesity. Cervical screening coverage indicators are also available. www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles
- The UK Cancer Information System (UKCIS) is an online analytical tool providing incidence, mortality and survival data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/ukcis
- The Cancer Commissioning Toolkit (CCT) is an online analytical tool providing incidence, mortality and survival data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct

International comparisons:

- There are a range of sources for European and international cancer mortality statistics. The CANCER Mondial website provides access to various databases containing information on the occurrence of cancer worldwide. It is held and managed by the Section of Cancer Information (CIN) of International Agency for Research on Cancer (IARC). The CANCER Mondial website is: www-dep.iarc.fr/
- As an example, GLOBOCAN provides worldwide country estimates for the incidence of and mortality from major cancer types. The most recent GLOBOCAN estimates are presented for 2008 and can be downloaded as fact sheets or tabulations, while charts and predictions can be generated in response to defined search criteria. These data are available on the GLOBOCAN website at: globocan.iarc.fr/
- And EUCAN presents estimates of incidence, mortality and prevalence for 24 major cancer types in 40 European countries for 2012. Available on the EUCAN website at: eco.iarc.fr/EUCAN/Default.aspx

Mortality projections:

- Cancer Research UK provides cancer mortality projections up to 2030 for all cancers combined. These data are available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/mortality/mortality-projections/
- GLOBOCAN provides UK and worldwide mortality (and incidence) predictions for up to 2030 using data held in GLOBOCAN. Predictions can be generated on the future burden of a selected cancer or group of cancers, in a selected group of populations in a selected year. Available on the GLOBOCAN website at: globocan.iarc.fr/burden_sel.asp

CANCER SURVIVAL

What is it?

Survival estimates are the percentage of patients who are still alive a specified time after their diagnosis of cancer. The most common estimates are one-year and five-year survival. There are a number of methods used to calculate cancer survival. The most commonly used method is called relative survival.

Relative survival: provides an estimate of the percentage of patients still alive a specified number of days/months/years from their diagnosis, whilst taking into account the background mortality in the general population (e.g. the percentage of patients that would be expected to have died from other causes during that period if they did not have cancer). It is therefore an estimate of the proportion of patients who survive their cancer for the specified time period.

Net survival: accounts for the so-called "informative censoring" bias, i.e. the fact that some groups of patients are less likely than others to be observed until death, independently of their cancer prognosis. It is the advised method to be used where the cause of death is not known. Net survival probability enables the desired comparability between countries, because it is independent of general population mortality.

What are the latest data available?

- One-year survival: Based on patients diagnosed up to **2010**
- Five-year survival: Based on patients diagnosed up to **2006**

Useful data sources:

UK and regional statistics:

- The National Cancer Intelligence Network (NCIN) Cancer e-Atlas is an interactive web-based cancer information tool, providing users easy visual access to cancer incidence, mortality and relative survival statistics for the UK. It includes cancer survival on patients diagnosed up to 2008 for the UK and cancer networks. This will be updated in 2013. The e-Atlas produces a graphical presentation of the statistics with the option to download the data in an excel format. The Cancer e-Atlas is available on the NCIN website at:
www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx
- Cancer Research UK (CRUK) provides detailed information about cancer (relative) survival on patients diagnosed up to 2009, incidence and mortality statistics. These data are available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/
- The Office for National Statistics (ONS) provides cancer survival, incidence and mortality statistics over time through the release of statistical bulletins. The ONS survival statistics are produced in collaboration with the London School of Hygiene and Tropical Medicine (LSHTM). The latest available ONS statistics provide net survival for patients diagnosed up to 2010 in England; also published are survival statistics for UK, cancer network and primary care trust areas. These data are available on the ONS website at:
 - For England: www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/index.html
 - For UK: A paper published by M Coleman *et al.* in 2010. Survival from twenty adult cancers in the UK and Republic of Ireland in the late twentieth century. *Health Statistics Quarterly (2010) 46*, 7-26. www.palgrave-journals.com/hsq/journal/v46/n1/abs/hsq20109a.html
 - For cancer networks: www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-by-cancer-network/index.html
 - For primary care trusts: <http://www.ons.gov.uk/ons/rel/cancer-unit/combined-cancer-survival-by-primary-care-trusts/index.html>
 - Geographic patterns of cancer survival in England: <http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-by-gor--sha-and-cancer-network/index.html>
- A range of statistics are provided by Public Health England, the Welsh Cancer Intelligence and Surveillance Unit, and the Scottish and Northern Irish Cancer Registries. These include statistics for the different regions in England and for Northern Ireland, Scotland and Wales. Their website addresses are available from the UK Association of Cancer Registries (UKACR) website at: www.ukacr.org/registries
- Gynaecological cancer profiles is an online tool providing incidence and mortality rates for the main gynaecological cancers, survival, and influencing factors, such as deprivation, smoking prevalence and obesity. Cervical screening coverage indicators are also available. www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles
- The UK Cancer Information System (UKCIS) is an online analytical tool providing survival, incidence and mortality data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/ukcis
- The Cancer Commissioning Toolkit (CCT) is an online analytical tool providing incidence, mortality and survival data for commissioners and providers for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct
- Net survival methodology is examined in a paper published by M Perme *et al.* in 2012 'On estimation in relative survival'. *Biometrics* 2012; 68(1): 113-120. www.ncbi.nlm.nih.gov/pubmed/21689081

International comparisons:

- A paper published by M Coleman *et al.* in 2011, examined ‘Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Project) an analysis of population-based cancer registry data’. *Lancet* 2011; 377: 127-138. [www.thelancet.com/journals/lancet/article/PIIS0140-6736\(10\)62231-3/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(10)62231-3/fulltext)
- There are a range of sources for European and international cancer survival statistics. The CANCER Mondial website provides access to various databases containing information on the occurrence of cancer worldwide. It is held and managed by the Section of Cancer Information (CIN) of International Agency for Research on Cancer (IARC). The CANCER Mondial website is: www-dep.iarc.fr/
- As an example, GLOBOCAN provides worldwide country estimates for the incidence of and mortality from major cancer types. The most recent GLOBOCAN estimates are presented for 2008 and can be downloaded as fact sheets or tabulations, while charts and predictions can be generated in response to defined search criteria. These data are available on the GLOBOCAN website at: globocan.iarc.fr/
- EUROCARE (EUROpean CANcer REgistry-based study on survival and care of cancer patients) is a cancer epidemiology research project on the survival of European cancer patients. A range of data and publications are available on the EUROCARE website at: www.eurocare.it/

IMPROVING OUTCOMES FOR CANCER PATIENTS: PREVENTION AND EARLY DIAGNOSIS

CANCER AWARENESS

What is it?

Public awareness of the potential signs and symptoms of cancer, as well as an understanding of when and how to seek help, can play an important part in ensuring that cancer is diagnosed at an early stage.

What are the latest data available?

A range of surveys and research have been carried out looking at cancer awareness over the years. In order to assess levels of public awareness and to track changes over time, and as part of the National Awareness and Early Diagnosis Initiative (NAEDI), Cancer Research UK, University College London, King's College London and the University of Oxford have developed a Cancer Awareness Measure (CAM) to measure public awareness. The CAM is a validated set of questions designed to reliably assess public awareness of cancer warning signs, anticipated delay and perceived barriers to seeking medical advice. The data come from two surveys: i) an Office for National Statistics (ONS) Opinions Survey which is sampled to be representative of the UK population; and ii) an Ethnibus survey of the main ethnic minority groups in England. The survey was last carried out in 2010. The data collection for the 2012 survey is currently underway.

Site specific Cancer Awareness Measures have also been completed for breast, colorectal/bowel, cervical, lung and ovarian cancer. These measures were developed with the support of Breakthrough

Breast Cancer, Breast Cancer Care, Cancer Research UK, Ovarian Cancer Action, The Eve Appeal, Ovacome, Target Ovarian Cancer and the Department of Health.

Useful data sources:

- Further information on how to access detailed statistics on the CAM (including downloads of the data in excel/database format) is available on the Cancer Research UK website at: www.cancerresearchuk.org/cancer-info/spotcancerearly/naedi/AboutNAEDI/Researchevaluationandmonitoring/naedi_cam/
A Cancer Research UK and Tesco report was published in 2012. It details key results from the CAM 2010 survey, and the problems of diagnosing cancer early and why we need to solve them. This report 'Delay Kills' is available on the Cancer Research UK website at: www.cancerresearchuk.org/prod_consump/groups/cr_common/@abt/@gen/documents/generalcontent/cr_085096.pdf
- CAM National Baseline Report was published in 2009. This report 'Public awareness of cancer in Britain' is available on the UK Government Web Archive at: webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108749
- Two papers published in 2009 provide further information about the Cancer Awareness Measure:
 - K Robb *et al.* details the process of data collection and analysis in 'Public awareness of cancer in Britain: a population-based survey of adults'. British Journal of Cancer 2009; 101:S18–S23. www.nature.com/bjc/journal/v101/n2s/full/6605386a.html
 - S Stubbings *et al.* details the 'Development of a measurement tool to assess public awareness of cancer'. British Journal of Cancer 2009; 101:S13–S17. www.nature.com/bjc/journal/v101/n2s/full/6605385a.html
- The Ovarian CAM has been implemented in the Target Ovarian Cancer pathfinder study. The 2012 Target Ovarian Cancer Pathfinder Study report is available on the Target Ovarian Cancer website at: www.targetovariancancer.org.uk/page.asp?section=538§ionTitle=The+2012+Target+Ovarian+Cancer+Pathfinder+Study
- Further site-specific CAMs have been used in national surveys and key results have been published in the following peer-reviewed papers:
 - Breast - L Linsell *et al.* in 2010 examined 'Validation of a measurement tool to assess awareness of breast cancer'. European Journal of Cancer. 2010 May; 46(8):1374-81. www.ncbi.nlm.nih.gov/pubmed/20335018
 - Cervical and Ovarian - A Simon *et al.* in 2012 examined 'Ovarian and cervical cancer awareness: development of two validated measurement tools'. Journal of Family Planning and Reproductive Health Care. 2012 Jul; 38(3):167-74. www.ncbi.nlm.nih.gov/pubmed/21933805
 - Cervical - E Low *et al.* asked 'What do British women know about cervical cancer symptoms and risk factors?' European Journal of Cancer. 2012 Nov; 48(16):3001-8. www.ncbi.nlm.nih.gov/pubmed/22683170
 - Colorectal/Bowel - E Power *et al.* in 2011 examined 'Assessing awareness of colorectal cancer symptoms: measure development and results from a population survey in the UK' BMC Cancer. 2011 Aug 23; 11:366. www.ncbi.nlm.nih.gov/pubmed/21859500
 - Lung - A Simon *et al.* in 2012 examined 'Knowledge of lung cancer symptoms and risk factors in the UK: development of a measure and results from a population-based survey'. Thorax. 2012 May; 67(5):426-32. www.ncbi.nlm.nih.gov/pubmed/22426791

PARTICIPATION IN SCREENING

What is it?

The UK National Screening Committee makes UK-wide policies. It recommends systematic population screening programmes for breast cancer, cervical cancer and bowel cancer. It is up to each part of the UK to determine when, and how, to put those policies into practice. This means that there will be some differences in the screening services available in England, Northern Ireland, Scotland or Wales. A wide range of statistics are published on screening. A key measure used is screening 'coverage'. Definitions of coverage are given below.

Breast Screening:

Purpose: Breast screening is intended to detect breast cancer at an early stage, enabling more effective treatment.

Invited population: In the UK, women aged 50-70 are routinely invited for breast screening every three years under a national programme. Women over the age of 70 can request screening every three years by making an appointment at their local screening unit, but they do not receive invitations. The NHS Screening Programme in England has, since 2010, been phasing in an extension of the age range of women eligible for breast screening to those aged 47 to 73. In Wales, younger women at increased risk of breast cancer can be referred by the All Wales Cancer Genetics service for screening.

Coverage: Defined as the percentage of women resident and eligible for screening at a particular point in time who had a test with a recorded result within the last 3 years.

Latest review: Concluded that the NHS Breast Screening Programmes "confer significant benefit and should continue". Their best estimate is that the Programme prevents 1,300 deaths a year. This report published in October 2012 is available on the Cancer Research website at:

www.cancerresearchuk.org/cancer-info/publicpolicy/ourpolicypositions/symptom_Awareness/cancer_screening/breast-screening-review/breast-screening-review?utm_source=Lancet&utm_medium=report&utm_campaign=breast_screen_review

Cervical screening:

Purpose: Cervical screening is intended to detect abnormalities within the cervix that could, if untreated, develop into cancer.

Invited population: UK policy on age of commencement and frequency for cervical screening is varied. The cervical screening policy for England and Northern Ireland invites women for screening every three years for those aged 25-49 and every five years for those aged 50-64. The policy in Wales is to invite women aged 20-64 years every three years; and in Scotland to invite women aged 20-60 years every three years. From 2013 in Wales, and from 2015 in Scotland, the age of commencement and frequency for cervical screening will align with existing practice in England and Northern Ireland.

Coverage: 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. As the frequency with which women are invited for screening is dependent on age and country, coverage is calculated differently for different age groups, for example in England and Northern Ireland:

- For women aged 25-49, coverage is calculated as the number of women in this age group who have had an adequate screening test within the last 3.5 years as a percentage of the eligible population aged 25-49.

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- For women aged 50-64, coverage is calculated as the number of women in this age group who have had an adequate screening test within the last 5 years as a percentage of the eligible population aged 50-64.

Bowel Screening:

Purpose: Bowel cancer screening aims to detect bowel cancer at an early stage, when treatment is more likely to be effective or to help prevent cancer from developing in the first place by allowing the treatment of pre-cancerous conditions.

Invited population: All UK programmes invite men and women for bowel screening every two years. However, the age group offered bowel screening varies by country. In Scotland, bowel cancer screening is offered to people aged 50-74, in Wales to those aged 60-74, and in Northern Ireland to those aged 60-71. In England, bowel cancer screening is available to those aged 60-69, with this age range currently being extended to 60-74. A further one off diagnostic test using Flexible Sigmoidoscopy is being piloted in England, aimed at men and women aged 55.

Uptake: Not currently available as national statistics are not yet routinely published (as for the Breast and Cervical screening programmes). However, statistics can be found in the reports that evaluate the pilots.

What are the latest data available?

- Breast screening: **2011/2012** (financial year)
- Cervical screening: **2011/2012** (financial year)
- Bowel screening: Routine national statistics not yet available

Useful data sources:

- Information on the UK Screening programmes is available on the UK Screening Portal at: www.screening.nhs.uk/
- Information on the NHS Cancer Screening Programmes in England is available at: www.cancerscreening.nhs.uk/
- 'Over 5% of all cancers are currently diagnosed via screening' is a statistic quoted from the Department of Health publication 'Improving outcomes: A Strategy for Cancer', available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371 This figure comes from the Routes to Diagnosis analyses [see Routes to Diagnosis section]
- Screening data for England are available from the Cancer Commissioning Toolkit (CCT), for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct

Breast Screening statistics for:

- UK: Published in
 - NHS Breast Cancer Screening Programme: Annual Review 2012, available at: www.cancerscreening.nhs.uk/breastscreen/publications/2012review.html
 - Association of Breast Surgery (ABS) Breast Screening Audit 2010 – 2011, available at: www.cancerscreening.nhs.uk/breastscreen/publications/ba10-11.html.
 - The Second All Breast Cancer Report. Breast cancers diagnosed in the UK in 2007, available at: www.ncin.org.uk/view.aspx?rid=612
 - NCIN data briefing 'Improved Survival for Screen-Detected Breast Cancer' based on data from the ABS Audit is available at: www.ncin.org.uk/publications/data_briefings/improved_survival_for_screen_detected_breast_cancer.aspx
- England: Published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/searchcatalogue?productid=11172&q=breast+screening&sort=Relevance&size=10&page=1#top

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- Scotland: Published on the Information Services Division (ISD) Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Breast-Screening/
- Wales: Published on the Screening Services Wales website at: www.screeningservices.org.uk/btw/reports/reports.asp
- Northern Ireland: Published on the Northern Ireland Cancer Screening Programmes website at: www.cancerscreening.hscni.net/2051.htm

Cervical Screening statistics for:

- NHS Cervical Cancer Screening Programme 2012 Annual Review (England) available at: www.cancerscreening.nhs.uk/cervical/publications/2012review.html
- England: Published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/catalogue/PUB07990
- Scotland: Published on the Information Services Division (ISD) Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Cervical-Screening/
- Wales: Published on the Screening Services Wales website at: www.screeningservices.org.uk/csw/prof/reports/
- Northern Ireland: Published on the Northern Ireland Cancer Screening Programmes website at: www.cancerscreening.hscni.net/pdf/ANNUAL_REPORT_2010-11.pdf

Bowel Screening statistics for:

- Scotland: 'Scottish Bowel Screening Programme - Key Performance Indicators Report: May 2012 data submission, Invitations between 1st November 2009 and 31st October 2011' published on the Information Services Division (ISD) Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/

ROUTES TO DIAGNOSIS

What is it?

Routes to Diagnosis defines a methodology by which the route the patient follows to the point of diagnosis can be categorised, in order to examine demographic, organisational, service and personal reasons for delayed diagnosis. Administrative Hospital Episode Statistics (HES) data are combined with Cancer Waiting Times (CWT) data, data from the cancer screening programmes and cancer registration data from the National Cancer Data Repository (NCDR). Using these datasets every case of cancer registered is categorised into one of eight 'Routes to Diagnosis'.

Different cancers show substantial differences in the proportion of cases that present by each route, in reasonable agreement with previous clinical studies. Patients presenting via emergency routes have substantially lower one-year relative survival. This methodology can be used to explore possible reasons for delayed diagnosis, direct the focus of early diagnosis initiatives and identify areas for further research.

The methodology is described in a paper published by L Ellis-Brookes *et al.* in 2012. 'Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets'. British Journal of Cancer 2012; 107:1220-1226.

www.nature.com/bjc/journal/v107/n8/abs/bjc2012408a.html

What are the latest data available?

- For England: Patients diagnosed from **2006 to 2008** [to be updated in 2013]

Useful data sources:

- A range of information detailed below is provided on the NCIN website www.ncin.org.uk/publications/routes_to_diagnosis.aspx
 - Routes to diagnosis 2006-2008 NCIN Information Supplement: The report summarises the routes by cancer type, age group and deprivation quintile. Associated relative survival estimates are shown for 1, 3, 6, 9 and 12 month survival intervals with 12 month survival also broken down by age group.
 - Routes to Diagnosis 2006-2008 Workbook: Shows the percentage of total cancers that are diagnosed by each route, and the relative survival for each Route.
 - Routes to Diagnosis 2006-2008 Technical Document: Summarises the data sources and methodology used for this Routes to Diagnosis project.
- Initial NCIN data briefing 'Routes to Diagnosis' published in 2010, for patients diagnosed in 2007. www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis.aspx
- NCIN data briefing 'Routes to Diagnosis: Exploring Emergency Presentations'. www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis_exploring_emergency_presentations

IMPROVING OUTCOMES FOR CANCER PATIENTS: QUALITY OF LIFE AND PATIENT EXPERIENCE

CANCER PREVALENCE

What is it?

Cancer prevalence is the number of people, or the proportion of the population, who are alive on a specified date and have previously been diagnosed with cancer. As such it is an indicator of the burden of cancer and can help to inform health care service planning. The number of people alive with a diagnosis of cancer is increasing as incidence rises and survival improves.

What are the latest data available?

- UK estimates for **2008**
- Regional: Cancer network, **2006** and primary care trust (PCT) **2004**
- European estimates for **2012**

Useful data sources:

- 'There were 2 million cancer survivors in the United Kingdom at the end of 2008, or around 3% of the overall population' is a statistic quoted from a paper published by J Maddams *et al.* in 2009. 'Cancer Prevalence in the United Kingdom: estimates for 2008'. British Journal of Cancer 2009; 101:541-547. www.nature.com/bjc/journal/v101/n3/pdf/6605148a.pdf
- 'One, Five and Ten Year Cancer Prevalence by Cancer Network and the UK, as of December 31st 2006' - NCIN Report, available at: www.ncin.org.uk/view?rid=76
- Cancer Prevalence e-Atlas available on the NCIN website at: www.ncin.org.uk/Prevalence/1_5_10_Year/atlas.html.
- One-year and five-year cancer prevalence estimates by primary care trust as of 31st December 2004, are available on the the Association of Public Health Observatories website at: www.apho.org.uk/resource/item.aspx?RID=63803

What cancer statistics are available, and where can I find them?

- Cancer Research UK (CRUK) provides detailed information about cancer prevalence up to 2006. These data are available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/incidence/prevalence/prevalence-uk

International comparisons:

- One, three and five-year cancer prevalence estimates for 40 European countries for 2012 are available on the EUCAN website at: eco.iarc.fr/EUCAN/Default.aspx

Prevalence projections:

- ‘The number of older people (aged 65 and over) living with cancer in the UK was set to more than treble by 2040, i.e. from 1.3 million in 2010 to 4.1 million by 2040’ is a statistic quoted from a paper published by J Maddams *et al.* in 2012 ‘Projections of cancer prevalence in the United Kingdom, 2010–2040’. *British Journal of Cancer* 2012; 107:1195–1202. www.nature.com/bjc/journal/v107/n7/abs/bjc2012366a.html

PATIENT EXPERIENCE

What is it?

The National Cancer Patient Experience Survey is undertaken by the Department of Health and provides an insight into the level of care experienced by cancer patients across England who were treated as day cases or inpatients. NHS Trusts providing cancer services identify cancer patients of which a proportion chose to take part. Each of the NHS Trusts taking part in the survey is provided with a bespoke report which enables them to compare their provision of cancer patient experience with other Trusts, and to drive quality improvements and better outcomes locally.

What are the latest data available?

- For England: Cancer Patient Experience Survey **2011/2012**
 - Nearly 72,000 cancer patients participated in the survey, a 1% increase on the 2010 survey.
 - Cancer patients were treated between 1 September and 30 November 2011.
 - 36% were inpatients and 64% were day case patients.
 - This survey questionnaire largely replicated the 2010 survey with nine new questions.

Useful data sources:

- ‘Cancer Patient Experience Survey 2011/2012 National Report’ is published on the Inside Government website at: www.gov.uk/government/publications/second-national-cancer-patient-experience-survey
- National Cancer Patient Experience Survey 2011-12 – Trust Level Reports, are published on the Quality Health website at: www.quality-health.co.uk/2012cancerreports
- ‘2011-2012 National Cancer Patient Experience Survey Trust Results’ dataset is available on the NCIN website at: www.ncin.org.uk/cancer_information_tools/cancer_patient_experience.aspx.

QUALITY OF LIFE

What is it?

The Patient Reported Outcome Measures (PROMs) pilot survey was carried out by the Department of Health to demonstrate the feasibility of collecting information on the quality of life of cancer survivors. The survey was conducted to understand the quality of life health outcomes of a sample of adult cancer patients at various time points since diagnosis. This is the largest survey of cancer

survivors covering multiple cancer types, to have been conducted in Europe. The quality of life for survivors of breast, colorectal, prostate cancer and non-Hodgkin's lymphoma (NHL) at one, two, three and five years after diagnosis, were assessed using a standard health questionnaire (EQ-5D). This questionnaire has five items covering problems with walking about, washing or dressing, doing usual activities, pain or discomfort and anxiety or depression. Tumour-specific questions were drawn from the relevant Functional Assessment of Cancer Therapy (FACT) questionnaires. A total of 43 questions were common to all tumour groups, with around 20-30 additional questions depending on tumour type. Future PROMs surveys will include additional cancer sites.

What are the latest data available?

- Pilot Patient Reported Outcome Measures Survey conducted in **July 2011**.
- Patients resident in the areas covered by the three former cancer registries of Eastern Cancer Registration and Information Centre (ECRIC), Thames Cancer Registry (TCR) and West Midlands Cancer Intelligence Unit (WMCIU).
- Nearly 3,300 cancer patients participated in the survey, a response rate of 66%.

Useful data sources:

- The report on the pilot survey using Patient Reported Outcome Measures (PROMS) was published in 2012. This report 'Quality of Life of Cancer Survivors in England' is available on the Inside Government website at:
www.gov.uk/government/uploads/system/uploads/attachment_data/file/127273/9284-TSO-2900701-PROMS.pdf

QUALITY OF CARE

What is it?

National Cancer Peer Review (NCPR) is a national quality assurance programme for NHS cancer services. A first round of peer review commenced at a regional level in 2001 and the national programme was established in 2004. The programme involves both self-assessment by Multi-Disciplinary Teams (MDTs) and external reviews of MDTs conducted by professional peers, against nationally agreed "quality measures". The National Cancer Peer Review Programme aims to improve the care of people with cancer and their families.

Following a national consultation in 2008, the number of measures were reduced by approximately 40% and greater emphasis placed on outputs and outcomes with the introduction of clinical lines of enquiry (CLE). The use of CLE has now been extended to six tumour types; breast, lung, colorectal, upper GI, gynaecology and head and neck services. This has been received well by clinical teams and has moved the focus of peer review towards clinical outcomes.

What are the latest data available?

- The National Cancer Peer Review Programme Report **2011/2012** (An overview of the findings from the 2011/2012 National Cancer Peer Review of Cancer Services in England) was published in **October 2012**.
- Individual reports for the 28 cancer networks were published in **June 2012** for the **2011/2012** cycle of the National Cancer Peer Review Programme.

Useful data sources:

- The National and Cancer Network Reports can be found on the resource section of the Cancer Quality Information Network System (CQuINS) website at: www.cquins.nhs.uk/?menu=resources
- Clinical Lines of Enquiry briefing papers and Peer Review Reports can be found on the public view of the Cancer Commissioning Toolkit (CCT) at: www.ncin.org.uk/cancer_information_tools/cct

IMPROVING OUTCOMES FOR CANCER PATIENTS: BETTER TREATMENT

TREATMENT AND QUALITY OF CARE

What is it?

The quality of treatment available to cancer patients is also an important determinant of outcomes. Information about the treatments available and the outcomes of care delivered is necessary for patients to make informed choices, for commissioners to effectively performance manage services and for healthcare professionals to identify the need for, and to introduce, improvements. There is a wide range of data and research available about cancer treatment and hospital activity.

Most national statistics are based on the Hospital Episodes Statistics (HES), the national statistical data warehouse for England of the care provided by NHS hospitals and for NHS hospital patients treated elsewhere. HES is the data source for a wide range of healthcare analysis by the NHS, Government and many other organisations and individuals. In 2008, a National Cancer Data repository was set up. This links a range of patient data related to cancer, including cancer registry records and HES. This new source of linked data is invaluable for improving our understanding of cancer and the patient journey. Useful research and analysis is already emerging out of this. The examples given below include cancer patients receiving major surgical resections and thirty-day postoperative mortality after colorectal cancer surgery.

What are the latest data available?

- NCDR: Admitted care Hospital Episodes Statistics **2011/2012** (financial year) linked to cancer registrations to 2010
- Some data are available for **2012/13** including provisional HES data reports from the Health and Social Care Information Centre and Cancer Waiting Times data in the PCT profiles.

Useful data sources:

- Tabulations of HES data relating to admitted patient care in NHS hospitals in England, for a range of topics, including operations and diagnoses are available on Health and Social Care Information Centre website at: www.hscic.gov.uk/hes
- Provisional monthly HES data for England (admitted patient care, outpatients and, accident and emergency data from April 2012 to January 2013) are available on the Health and Social Care Information Centre website at: www.hscic.gov.uk/searchcatalogue?productid=11643&returnid=1684
- Radiotherapy Services in England 2012 report is published on the National Cancer Services Analysis Team (NATCANSAT) website at: www.canceruk.net/rtservices/rtlds/
- Radiotherapy profiles provide information about key indicators relating to radiotherapy services in England. These are available from the NCIN Cancer Commissioning Toolkit (CCT), for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct
- National collection of all cancer chemotherapy in the NHS in England commenced in April 2012, for more information see:

- The SACT Systemic Anti-Cancer Therapy Chemotherapy Dataset website at: www.chemodataset.nhs.uk/about_sact/default.aspx
- National collection and analysis of cancer chemotherapy - NCIN data briefing, available on the NCIN website at: www.ncin.org.uk/publications/data_briefings/national_collection_and_analysis_of_cancer_chemotherapy
- Cancer Outcomes and Services Dataset (COSD) replaces the previous National Cancer Dataset as the new national standard for reporting cancer in the NHS in England from January 2013. For more information see: www.ncin.org.uk/collecting_and_using_data/data_collection/cosd.aspx
- The following are published in the Improving Cancer Outcomes Strategy: information supplement available on the NCIN website at: www.ncin.org.uk/view.aspx?rid=663
 - Major urological operations: for England (table 4) and by hospital trust (appendix 5);
 - Major Oesophago-gastric operations: England (table 5) and by hospital trust (appendix 5), Percentage of laparoscopic colorectal resections, England (table 6);
 - Average length of ordinary episode (days) (table 8).
- General Practice (GP) Profiles for Cancer provide information about key indicators relating to cancer services for most GP practices in England. These are available on the NCIN website at: www.ncin.org.uk/cancer_information_tools/profiles/gp_profiles.aspx

Some information has been removed to protect patient confidentiality. Unsuppressed versions of the profiles remain available to NHS users and GPs from the Cancer Commissioning Toolkit (CCT), for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct
- Primary Care Trust (PCT) Profiles for Cancer provide information about 26 key indicators relating to cancer services for every PCT in England. They are intended to help primary care trusts think about clinical practice and service delivery in cancer. These are available on the NCIN website at: www.ncin.org.uk/cancer_information_tools/profiles/pctprofiles.aspx ; and available on the public view of the Cancer Commissioning Toolkit (CCT) at: www.ncin.org.uk/cancer_information_tools/cct
- Service Profiles for Cancer provide information about key indicators relating to cancer services for breast and colorectal cancer by NHS Trust in England; a further profile for lung cancer will be available from the end of June 2013. These can be accessed on the Cancer Commissioning Toolkit (CCT), for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct
- Cancer Nurse Specialist reports are available on the public view of the Cancer Commissioning Toolkit (CCT) at: www.ncin.org.uk/cancer_information_tools/cct
- Chemotherapy Nursing workforce reports are available on the public view of the Cancer Commissioning Toolkit (CCT) at: www.ncin.org.uk/cancer_information_tools/cct
- Cancer Waiting Times data is available from the Cancer Commissioning Toolkit (CCT), for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct
- The following National Cancer Intelligence Network (NCIN) data briefings are available on the NCIN website at: www.ncin.org.uk/publications/data_briefings/default.aspx
 - Urgent GP referral rates for suspected cancer;
 - NHS treated cancer patients receiving major surgical resections;
 - Variation in surgical resection for lung cancer in relation to survival: population based study in England 2004-2006;
 - Time from final surgery to radiotherapy for screen-detected breast cancer;
 - Thirty-day postoperative mortality after colorectal cancer surgery in England;
 - Characteristics of individuals with colorectal cancer who die rapidly after their diagnosis;
 - Recurrent and metastatic breast cancer;
 - Co-morbidities of bone sarcoma patients.
- Peer reviewed publications making use of the National Cancer Data Repository are listed on the National Cancer Intelligence Network website at: www.ncin.org.uk/publications/peer_reviewed.aspx

- NHS comparators is an analytical service for commissioners and providers for which login access is needed: www.hscic.gov.uk/nhscomparators
- RTDS (National Radiotherapy Dataset) Microsite is an online analytical tools providing data for commissioners and providers for which login access is needed: www.canceruk.net/s2rt/rtdsmicrosite.aspx

TREATMENT OUTCOMES DATA

What is it?

Patients, commissioners and healthcare professionals all have an interest in understanding variations in the quality of treatment and the outcomes achieved. Clinical audit provides a valuable mechanism for assessing variations in treatment. There are currently five nationally designated clinical audits relating to different cancers. The intention is that all acute NHS Trusts that provide any type of service for relevant groups of cancer patients should participate in these audits, collecting and reporting a complete dataset on each of their patients. This will allow valid comparisons to be made between Trusts, taking account of case-mix variations (e.g. stage of disease, age and co-morbidity). These comparisons should in turn help to drive up quality.

What are the latest data available?

- The National Bowel Cancer Audit (NBCA) Report 2012 - audit period **Aug 2010 to Jul 2011**
- The National Head and Neck Cancer Audit (DAHNO) Report 2011 - audit period **Nov 2010 to Oct 2011**
- The National Lung Cancer Data Audit (LUCADA) Report 2012 - audit period **2011**
- The National Mastectomy and Breast Reconstruction Audit (NMBRA) Report 2011 - audit period **Jan 2008 to Mar 2009**
- The National Oesophago-gastric Cancer Audit (NOGCA) Report 2012- audit period **Oct 2007 to Jun 2009**

Useful data sources:

- Audit reports are published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/Article/1806
- The National Mastectomy and Breast Reconstruction Audit (NMBRA) Report is published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/article/2021/Website-Search?productid=67&q=Mastectomy+and+Breast+Reconstruction+Audit+&sort=Relevance&size=10&page=1&area=both#top

IMPROVING OUTCOMES FOR CANCER PATIENTS: REDUCING INEQUALITIES

What is it?

Reducing cancer inequality is of critical importance. Considerable inequalities in cancer incidence and outcomes still exist between different groups in the UK. Accurate information on the extent, nature and causes of cancer inequalities is important, if these are to be reduced in future.

What are the latest data available?

- Wherever possible NCIN analyses consider the different equalities domains, meaning that a wide range of publications are relevant to this topic.

Useful data sources:

- Evidence to March 2010 on cancer inequalities in England - NCIN report. This report was originally published as an annex to the National Cancer Equalities Initiative (NCEI) report 'Reducing cancer inequality: evidence, progress and making it happen'. The NCIN report is available on the NCIN website at: www.ncin.org.uk/view.aspx?rid=169. Equality data will be updated mid 2013 as a high level equality metrics report.
- The following National Cancer Intelligence Network reports are published on the NCIN website at: www.ncin.org.uk/publications/reports/
 - Cancer incidence and survival by major ethnic group;
 - Cancer incidence by deprivation;
 - The excess burden of cancer in men in the UK;
 - Patterns of deaths in the year following diagnosis in cancer patients aged 15-24 years in England.
- The following National Cancer Intelligence Network data briefings are published on the NCIN website at: www.ncin.org.uk/publications/data_briefings/default.aspx
 - Breast cancer: deprivation;
 - Breast cancer in the elderly;
 - Breast cancer: ethnicity;
 - Major resection rates for a range of socio-demographic groups;
 - The effect of rurality on cancer incidence and mortality;
 - Gender differences in survival among teenagers and young adults (TYA) with cancer in England;
 - Oral cavity cancer – this examines survival rates across areas with varied deprivation levels;
 - Ethnicity and lung cancer;
 - Lung cancer incidence and survival in England : An analysis by socioeconomic deprivation and urbanisation;
 - Cancer of unknown primary;
 - Morality, incidence and gender – malignant melanoma;
 - Variation in incidence of primary liver cancer between ethnic groups, 2001-2007;
 - Variation in incidence of oesophageal cancer subgroup between ethnic groups in England;
 - Variation in incidence of oesophageal and gastric cancer between ethnic groups;
 - Short-term survival for children with cancer;
 - Short-term survival for teenagers and young adults: 2005 to 2009;
 - The characteristics of individuals with colorectal cancer who die rapidly after their diagnosis;
 - Thyroid cancer – trends by sex, age and histological type;
 - Outcomes in leukaemia: Trends in five year survival between 1995 and 2003;
 - Short term ovarian cancer mortality;
 - Routes to Diagnosis: Exploring emergency presentations;
 - Non-melanoma skin cancer in England, Scotland, Northern Ireland and Ireland.
- Awareness Measure Tool (see section on Cancer Awareness above) provides a range of statistics by socio-economic group.
- ONS provide a report on mortality by deprivation for England and Wales: www.ons.gov.uk/ons/rel/hsg/health-statistics-quarterly/no--32--winter-2006/mortality-by-deprivation-and-cause-of-death-in-england-and-wales--1999-2003.pdf
- National End of Life Care Intelligence Network published a report on 'Deprivation and death: Variation in place and cause of death': www.endoflifecare-intelligence.org.uk/view?rid=254

What cancer statistics are available, and where can I find them?

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