What cancer statistics are available, and where can I find them?
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December 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
- England: 2011
- European and international comparators: 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 2010 for the UK, UK countries and primary care trusts (PCTs). Work is underway to update the e-Atlas to clinical commissioning group (CCG) geographies. Data for the old cancer networks are available for 2006 to 2008. 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](http://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/](http://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 2011 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: [http://ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/index.html](http://ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/index.html) [www.ons.gov.uk/ons/taxonomy/index.html?nscl=Cancer](http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Cancer)
What cancer statistics are available, and where can I find them?

- A range of statistics are provided by Public Health England\(^1\), 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 Wales, Scotland and Northern Ireland. Their website addresses are available from the UK & Ireland Association of Cancer Registries (UKIACR) website at: [www.ukacr.org/registries](http://www.ukacr.org/registries).

- The UK Cancer Information System (UKCIS) is an online analytical tool providing incidence, mortality and survival data for the cancer analytical community for which login access is needed: [www.ncin.org.uk/cancer_information_tools/ukcis](http://www.ncin.org.uk/cancer_information_tools/ukcis).

- The Cancer Commissioning Toolkit (CCT) is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are two levels of access – public open access (to comply with the government open data policy) and Professional NHS (login required to meet information governance requirements).
  - [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)


- 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](http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles)

- The National Cancer Intelligence Network (NCIN) website has a number of publications around incidence which can be found under the publication section of the website: [http://www.ncin.org.uk/publications/](http://www.ncin.org.uk/publications/). More recent publications include:
  - Uterine cancer in the UK: Overall trends and variation by age
  - Outline of uterine cancer in the UK: Incidence, mortality and survival
  - Data quality and completeness report: 2010 registrations for head and neck cancer
  - Blood cancers data quality report
  - A data briefing entitled ‘Recent trends in lung cancer incidence, mortality and survival’ will be published in December 2013

- Several of the most viewed include:
  - Trends in incidence of primary liver cancer subtypes
  - Lung cancer incidence & survival in England
  - Thyroid cancer - trends by sex, age and histological type
  - Differentiated teratoma of the testis

**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/](http://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 2012 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/](http://globocan.iarc.fr/)

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\(^1\) 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.
What cancer statistics are available, and where can I find them?


Incidence projections:
- These statistics will be presented on the Cancer Research UK website when available: www.cancerresearchuk.org/cancer-info/cancerstats/incidence/projections/
- 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: 2012
- European and international comparators: 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 2011 for the UK, UK countries and primary care trusts (PCTs). Work is underway to update the e-Atlas to clinical commissioning group (CCG) geographies. Old cancer network geographies have mortality data for 2007 to 2009. 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:
What cancer statistics are available, and where can I find them?

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 2012 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 & Ireland Association of Cancer Registries (UKIACR) website at: www.ukacr.org/registries

- The UK Cancer Information System (UKCIS) is an online analytical tool providing incidence, mortality and survival data for the cancer analytical community for which login access is needed: www.ncin.org.uk/cancer_information_tools/ukcis

- The Cancer Commissioning Toolkit (CCT) is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are two levels of access – public open access (to comply with the government open data policy) and Professional NHS (login required to meet information governance requirements). www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk

- The National Cancer Intelligence Network (NCIN) website has a number of publications around mortality which can be found under the publication section of the website: http://www.ncin.org.uk/publications/ , for example a data briefing on short term ovarian cancer mortality.

- 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

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 2012 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/

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

**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/](http://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](http://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 2011
- Five-year survival: Based on patients diagnosed up to 2007

**Useful data sources:**
**UK and regional statistics:**
- 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/](http://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 of School of Hygiene and Tropical Medicine (LSHTM). The latest available ONS statistics provide net survival for patients diagnosed up to 2011 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:
What cancer statistics are available, and where can I find them?


These data will be updated to reflect the new geographies of CCG and strategic clinical networks (SCN) in future publications.

- 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 & Ireland Association of Cancer Registries (UKIACR) website at: [www.ukacr.org/registries](http://www.ukacr.org/registries)
- 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. The Cancer e-Atlas is available on the NCIN website at: [www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx](http://www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx)
- The UK Cancer Information System (UKCIS) is an online analytical tool providing survival, incidence and mortality data for the cancer analytical community for which login access is needed: [www.ncin.org.uk/cancer_information_tools/ukcis](http://www.ncin.org.uk/cancer_information_tools/ukcis)
- The Cancer Commissioning Toolkit (CCT) is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are two levels of access – public open access (to comply with the government open data policy) and Professional NHS (login required to meet information governance requirements). [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)
- 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](http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles)
- The National Cancer Intelligence Network (NCIN) website has a number of publications around survival which can be found under the publication section of the website: [http://www.ncin.org.uk/publications/](http://www.ncin.org.uk/publications/). The most viewed publication on survival is “Survival of CTYA with cancer in England”.

More recent publications include:
- Astrocytic brain tumours: survival rates in England
- Ependymal tumours of the brain and spinal cord: survival rates in England
- A data briefing entitled One-year relative survival rates for pancreatic cancer in Great Britain, 1995-2009 will be published in December 2013
What cancer statistics are available, and where can I find them?

International comparisons:


- 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/](http://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 2012 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/](http://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/](http://www.eurocare.it/)
What cancer statistics are available, and where can I find them?

**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/](http://www.cancerresearchuk.org/cancer-info/spotcancerearly/naedi/AboutNAEDI/Researchevaluationandmonitoring/naedi_cam/)
- Two papers published in 2009 provide further information about the Cancer Awareness Measure:
- 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:
What cancer statistics are available, and where can I find them?

Further site-specific CAMs have been used in national surveys and key results have been published in the following peer-reviewed papers:


**International comparisons:**

- A comparison between six countries including the UK was published in January 2013 looking at differences in awareness and belief about cancer as part of the International Cancer Benchmarking Partnership: [http://www.nature.com/bjc/journal/v108/n2/full/bjc2012542a.html](http://www.nature.com/bjc/journal/v108/n2/full/bjc2012542a.html)

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


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.
- 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

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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]. A second annual report is available here: https://www.gov.uk/government/publications/the-national-cancer-strategy-second-annual-report
- Screening data for England are available from the Cancer Commissioning Toolkit (CCT) which is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are two levels of access – public open access (to comply with the government open data policy) and Professional NHS (login required to meet information governance requirements).
  www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk

Breast Screening statistics for:

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

Cervical Screening statistics for:

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

- 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:
- England: R Logan et al. in 2011 examined the ‘Outcomes of the Bowel Cancer Screening Programme (BCSP) in England after the first 1 million tests’. GUT. 2011 December. Published online at: http://gut.bmj.com/content/early/2011/11/22/gutjnl-2011-300843.full

**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.


**What are the latest data available?**
- For England: Patients diagnosed from 2006 to 2010 [to be updated in December 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
  - An updated workbook, ‘Routes to Diagnosis 2006-2010’ will be published in December 2013: This shows the percentage of total cancers that are diagnosed by each route, and the relative survival for 1, 3, 6, 9, 12, 24 and 36 month intervals for each Route. This new workbook includes a number of extra cancer sites and data at Strategic clinical Network (SCN) level. Further updates will add ethnicity data and Clinical Commissioning Group (CCG) data to the workbook.
  - 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.
What cancer statistics are available, and where can I find them?

- Routes to Diagnosis 2006-2008 Technical Document: Summarises the data sources and methodology used for this Routes to Diagnosis project. This will be updated with the release of the 2006-2010 workbook.
  - An NCIN data briefing “Routes to diagnosis for cancer of unknown primary” will be published in December 2013, and will be available from the NCIN website [http://www.ncin.org.uk/publications/](http://www.ncin.org.uk/publications/)
  - Routes to Diagnosis data are available from the Cancer Commissioning Toolkit (CCT) which is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are two levels of access – public open access (to comply with the government open data policy) and Professional NHS (login required to meet information governance requirements). [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk)
What cancer statistics are available, and where can I find them?

**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 2010
- Regional: Strategic Clinical Networks 2010, Cancer network 2006 and primary care trust (PCT) 2004
- European estimates for 2012

**Useful data sources:**
- Cancer Prevalence e-Atlas available on the NCIN website at: [www.ncin.org.uk/Prevalence/1_5_10_Year/atlas.html](http://www.ncin.org.uk/Prevalence/1_5_10_Year/atlas.html).
- 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](http://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](http://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
What cancer statistics are available, and where can I find them?


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 2013

Useful data sources:

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


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?
- Individual reports for the 27 Area Teams for the 2012/2013 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 and NHS view of the Cancer Commissioning Toolkit (CCT) at: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
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.

In England for example, 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?
- Varies by source

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 2013 to July 2013) are available on the Health and Social Care Information Centre website at: http://www.hscic.gov.uk/searchcatalogue?productid=12612&q=title%3a%22Provisional+Monthly+Hospital+Episode+Statistics%22&sort=Relevance&size=10&page=1#top
- Radiotherapy Services in England 2012 report is published on the National Cancer Services Analysis Team (NATCANSAT) website at: www.canceruk.net/rtservices/rtds/
- 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 or www.cancertoolkit.co.uk
- Radiotherapy data / charts are also available via the Cancer Commissioning Toolkit
- 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
- 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
What cancer statistics are available, and where can I find them?

  - 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 via the Cancer Commissioning Toolkit (both public and professional view) [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk).

- Some information has been removed to protect patient confidentiality. Unsuppressed versions of the profiles remain available to NHS users and GPs.

- 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](http://www.ncin.org.uk/cancer_information_tools/profiles/pctprofiles.aspx); and available on both the public and professional view of the Cancer Commissioning Toolkit (CCT) at: [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk). These are being updated to reflect the new CCG geographies and data will flow into the CCG profile from December 2013 – all data sources within the profile will be updated once all data are available in 2014.

- Service Profiles for Cancer provide information about key indicators relating to cancer services for breast, colorectal, lung, gynaecological, head & neck, oesophago-gastric cancer and sarcoma by NHS Trust in England. These can be accessed via the Cancer Commissioning Toolkit (CCT), NHS professional view (access required): [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk). As part of the government transparency open data policy - Lung profiles will be available in the CCT public view following governance approval to share data publicly...

- Cancer Nurse Specialist reports are available on the public and professional view of the Cancer Commissioning Toolkit (CCT): [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) and [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk).

- Chemotherapy Nursing workforce reports are available on the public and professional view of the Cancer Commissioning Toolkit (CCT): [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk).

- Cancer Waiting Times data is available from the Cancer Commissioning Toolkit (CCT), professional view for which login access is needed: [www.ncin.org.uk/cancer_information_tools/cct](http://www.ncin.org.uk/cancer_information_tools/cct) or [www.cancertoolkit.co.uk](http://www.cancertoolkit.co.uk).

- 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](http://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](http://www.ncin.org.uk/publications/peer_reviewed.aspx)
What cancer statistics are available, and where can I find them?

- 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 Head and Neck Cancer Audit (DAHNO) Report 2012 - audit period Nov 2011 to Oct 2012

Useful data sources:
- Audit reports are published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/Article/1806
What cancer statistics are available, and where can I find them?

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.
- An overview of key equality metrics including age, sex, deprivation and ethnicity covering the most recent data available was published on the NCIN website in July 2013.

Useful data sources:
- The NCIN report on equality metrics can be found at: [www.ncin.org.uk/view?rid=2243](http://www.ncin.org.uk/view?rid=2243)
- The National Cancer Intelligence Network publishes reports on the NCIN website at: [www.ncin.org.uk/publications/reports/](http://www.ncin.org.uk/publications/reports/). Examples include:
  - Estimated completeness of ascertainment for childhood cancer in the UK, 2005-2010
  - Frequency of non-specific morphology codes (ICD-O M) within the National Cancer Data Repository (2007-09) for cancer in Teenagers and Young Adults (TYA)
  - Routes to diagnosis: investigating the different pathways for cancer referrals in England for Teenagers and Young Adults
  - Diverging trends in lung cancer survival between males and females 1999-2008
- The following National Cancer Intelligence Network data briefings are published on the NCIN website at: [www.ncin.org.uk/publications/data_briefings/default.aspx](http://www.ncin.org.uk/publications/data_briefings/default.aspx). Examples include:
  - Short-term survival of children with cancer
  - Thyroid cancer – trends by sex, age and histological type
  - Variation in incidence of primary liver cancer between ethnic groups, 2001-2007
- Awareness Measure Tool (see section on Cancer Awareness above) provides a range of statistics by socio-economic group.
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