



Public Health
England

Protecting and improving the nation's health

National Cancer Intelligence Network

Cancer statistics: availability and location

December 2014 update

About Public Health England

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

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The intelligence networks

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

National Cancer Intelligence Network

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

National Cardiovascular Intelligence Network

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

National Child and Maternal Health Intelligence Network

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

National Mental Health Intelligence Network

The National Mental Health Intelligence Network (NMHIN) is a single shared network in partnership with key stakeholder organisations. The network will seek to put information and intelligence into the hands of decision makers to improve mental health and wellbeing.

National End of Life Care Intelligence Network

The National End of Life Care Intelligence Network (NEoLCIN) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

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Executive summary

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' report.

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 is the latest data available?

- UK and regional data: 2012
- England: 2012
- 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 former primary care trusts (PCTs). Work is under way to update the e-Atlas to clinical commissioning group (CCG) geographies. Data for the old cancer networks is 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

- Cancer Research UK (CRUK) provides detailed information about cancer incidence up to 2011. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/incidence/
- Macmillan cancer support also provide information at CCG level on incidence, mortality, survival and prevalence in the Local Cancer Intelligence tool: lci.cancertoolkit.co.uk/ This data can be downloaded in an .csv format that can be opened in Excel.
- 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 2012 are for England and its government office regions. These can be downloaded in an Excel format. This data is available on the ONS website at: www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/index.html
- accompanying this is an 'infographic' on the 10 most common cancers diagnosed in 2012: www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--43--2012/info-most-common-cancers.html
- the ONS has also provided an animated map of cancer incidence in England, 1995-1997 to 2009-2011 by local authority: www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/dynamic-cancer-maps.html
- the ONS has produced a video with an overview of cancer statistics: www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/vid-cancer-statistics.html
- a range of statistics are provided by PHE¹, 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 and Ireland Association of Cancer Registries (UKIACR) website at: [/www.ukiacr.org/](http://www.ukiacr.org/) and cancer related indicators are available on www.ukiacr.org/kpis
- Further links to incidence, mortality and survival data for Scotland, Wales, Northern Ireland and Ireland can be found here: www.ncin.org.uk/cancer_information_tools/eatlas/links_to_useful_data_sources
- the National Cancer Registration Service's (NCRS) cascade system is an online analytical tool providing incidence, mortality and survival data for the cancer analytical community for which login access is needed: nww.cancerstats.encore.nhs.uk/users/sign_in. The UK Cancer Information System (UKCIS) remains temporarily available for reference, but is no longer supported.

¹ PHE incorporates the cancer registration and analytical teams of the former eight cancer registries in England, with the latter team now within the regional knowledge and intelligence teams (KITs).

Cascade has initial England data for 2012 incidence, 2011 mortality and 2007 to 2011 survival. Celtic country data covers 2011 incidence, with updated mortality and survival being added in the future

- 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). For more information on the CCT see www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- Gynaecological Cancer Profiles is an online tool providing incidence and mortality rates, survival, and influencing factors, such as deprivation, smoking prevalence and obesity for the main gynaecological cancers. Cervical screening coverage indicators are also available. For further information, see www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles
- the NCIN website has a number of publications around incidence that can be found under the publication section of the website: www.ncin.org.uk/publications. More recent publications include:
 - Vulval cancer – trends and variations by age
 - Penile cancer – incidence by age
 - 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

Several of the most viewed include:

- Trends in incidence of primary liver cancer subtypes
- Lung cancer incidence and 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/
- as an example, GLOBOCAN provides worldwide nation 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 factsheets or tabulations, while charts and predictions can be generated in response to defined search criteria. This data is available on the GLOBOCAN website at: globocan.iarc.fr/Default.aspx

- 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
- this tool and a range of others can be accessed at the European Cancer Observatory (ECO) site: eco.iarc.fr/Default.aspx

Incidence projections:

- projections for CCGs in England are included in Macmillans Local Cancer Intelligence tool: lci.cancertoolkit.co.uk/
- 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 by Macmillan Cancer Support, based on the above data focusing on the cancer burden by 2020 can be found at: www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf
- 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 to 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. It is available on the ISD Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Cancer-Incidence-Projections-Scotland-to-2020.pdf
- cancer incidence projections for Ireland are available from National Cancer Registry Ireland: www.ncri.ie/publications/cancer-trends-and-projections/cancer-projections-2005-2035
- 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/Pages/burden_sel.aspx

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 is the latest data available?

- UK and regional data: 2013
- European and international comparators: 2012
- Projections: Estimates up to 2030 for the UK

Useful data sources:

UK and regional statistics:

- the 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 former PCTs. Work is under way to update the e-Atlas to 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
- CRUK provides detailed information about cancer mortality up to 2012. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/mortality/
- Macmillan cancer support also provide information at CCG level on incidence, mortality, survival and prevalence in the Local Cancer Intelligence tool: lci.cancertoolkit.co.uk/. This data can be downloaded in an .csv format that can be opened in Excel
- the ONS provides cancer mortality, incidence and survival statistics over time through the release of statistical bulletins. The ONS statistics on mortality up to 2013 are for England and Wales; these can be downloaded in an Excel format. This data is 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 PHE, 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 and Ireland Association of Cancer Registries (UKIACR) website at: www.ukiacr.org/ and cancer related indicators are available on www.ukiacr.org/kpis
- Further links to mortality data for Scotland, Wales, Northern Ireland and Ireland can be found here: www.ncin.org.uk/cancer_information_tools/eatlas/links_to_useful_data_sources

- the NCRS cascade system is an online analytical tool providing incidence, mortality and survival data for the cancer analytical community for which login access is needed: www.cancerstats.encore.nhs.uk/users/sign_in. The UKCIS remains temporarily available for reference, but is no longer supported. Cascade has initial England data for 2012 incidence, 2012 mortality and 2007-2011 survival. Celtic country data covers 2011 incidence with updated mortality and survival being added in the future
- the CCT is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are 2 levels of access – public open access (to comply with the government open data policy) and professional NHS (login required to meet information governance requirements). See www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- Cancer Mortality Profiles are interactive spreadsheets showing trends in cancer mortality rates in England for people aged under 75 by different levels of geography. This tool has been developed to support the monitoring, commissioning and planning of local cancer services. See www.swpho.nhs.uk/resource/browse.aspx?RID=76240
- the NCIN website has a number of publications around mortality that can be found under the publication section of the website: 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. See 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 CIN of IARC. The CANCER Mondial website is: www-dep.iarc.fr/
- as an example, GLOBOCAN provides worldwide nation 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 factsheets or tabulations, while charts and predictions can be generated in response to defined search criteria. This data is available on the GLOBOCAN website at: globocan.iarc.fr/Default.aspx
- EUCAN presents estimates of incidence, mortality and prevalence for 24 major cancer types in 40 European countries for 2012. Available on the ECO site at: eco.iarc.fr/EUCAN/Default.aspx

Mortality projections:

- CRUK provides cancer mortality projections up to 2030 for all cancers combined. This data is 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/Pages/burden_sel.aspx
- a paper by Macmillan Cancer Support based on various data focusing on the cancer burden by 2020 and associated mortality: See
www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf

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 1-year and 5-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, while taking into account the background mortality in the general population (eg 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, ie 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 is the latest data available?

- one-year survival: based on patients diagnosed up to 2012
- five-year survival: based on patients diagnosed up to 2007

Useful data sources:

UK and regional statistics:

- CRUK provides detailed information about relative cancer survival on patients diagnosed up to 2010 to 2011. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/survival/
- Macmillan cancer support also provide information at CCG level on incidence, mortality, survival and prevalence in the Local Cancer Intelligence tool: lci.cancertoolkit.co.uk/
- one year survival is available broken down by TNM stage for England, 2012: www.ncin.org.uk/publications/survival_by_stage
- the 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 2011 in England; also published are survival statistics for UK, CCGs, cancer network and former PCT areas. This data is available on the ONS website:
 - for the UK: A paper published by M Coleman et al. in 2010. Survival from 20 adult cancers in the UK and Republic of Ireland in the late 20th century. Health Statistics Quarterly (2010) 46, 7 to 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
 - survival for CCGs in England: www.ons.gov.uk/ons/rel/cancer-unit/a-cancer-survival-index-for-clinical-commissioning-groups/adults-diagnosed-1996-2011-and-followed-up-to-2012/stb---patients-diagnosed-1996-2011.html
 - for PCTs: www.ons.gov.uk/ons/rel/cancer-unit/combined-cancer-survival-by-primary-care-trusts/index.html
 - geographic patterns of cancer survival in England: 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 PHE, 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 UKIACR website at: www.ukiacr.org/ and cancer related indicators are available on www.ukiacr.org/kpis
- the 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. Survival data are available for the old Cancer Network

geographies. The Cancer e-Atlas is available on the NCIN website at:

www.ncin.org.uk/cancer_information_tools/eatlas/default.aspx

- the NCRS cascade system is an online analytical tool providing incidence, mortality and survival data for the cancer analytical community for which login access is needed: www.cancerstats.encore.nhs.uk/users/sign_in. The UKCIS remains temporarily available for reference, but is no longer supported. Cascade has initial England data for 2012 incidence, 2012 mortality and 2007 to 2011 survival. Celtic country data covers 2011 incidence with updated mortality and survival being added in the future
- the CCT is a web based database of multiple data sources and also includes incidence, mortality and survival data for commissioners and providers. There are 2 levels of access – public open access (to comply with the government open data policy) and professional NHS (login required to meet information governance requirements). See www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- 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 to 120. See www.ncbi.nlm.nih.gov/pubmed/21689081
- 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. See www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/gynaecological_cancer/gynaecological_cancer_hub/profiles
- the NCIN website has a number of publications around survival which can be found under the publication section of the website: www.ncin.org.uk/publications/. The most viewed publication on survival is 'Kidney cancer: survival report'.
- more recent publications include:
 - cancer survival in England by stage 2012
 - survival of small cell lung cancer patients undergoing surgery in England 1998 to 2009
 - one-year relative survival rates for pancreatic cancer in Great Britain, 1995 to 2009
 - high procedure volume is associated with improved survival after lung cancer surgery

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. See [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 CIN of IARC. The CANCER Mondial website is: www-dep.iarc.fr/
- as an example, GLOBOCAN provides worldwide nation 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. This data is available on the GLOBOCAN website at: globocan.iarc.fr/Default.aspx
- 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 is 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 2 surveys: 1) an ONS opinions survey that is sampled to be representative of the UK population; and 2) 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 CAMs 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, Ovacom, 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 CRUK and Tesco report was published in 2012. It details key results from the CAM 2010 survey, the problems of diagnosing cancer early and why we need to solve them. The report 'Delay Kills' is available on the CRUK 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. The report 'Public awareness of cancer in Britain' is available on the UK Government Web Archive at: webarchive.nationalarchives.gov.uk/20130107105354/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108777.pdf (copy link in to web browser)
- two papers published in 2009 provide further information about the CAM: 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. See www.nature.com/bjc/journal/v101/n2s/full/6605386a.html; and 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. See 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. See 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. See 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. See 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. See 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. See www.ncbi.nlm.nih.gov/pubmed/22426791

International comparisons:

- a comparison between 6 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: See 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 to 70 are routinely invited for breast screening every 3 years under a national programme. Women over the age of 70 can request screening every 3 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_revie
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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 3 years for those aged 25 to 49 and every 5 years for those aged 50 to 64. The policy in Wales is to invite women aged 20 to 64 years every 3 years; and in Scotland to invite women aged 20 to 60 years every 3 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 to 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 to 49.

For women aged 50 to 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 to 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 2 years, however, the age group offered bowel screening varies by country. In Scotland, bowel cancer screening is offered to people aged 50 to 74, in Wales to those aged 60 to 74, and in Northern Ireland to those aged 60 to 71. In England, bowel cancer screening is available to those aged 60 to 69, with this age range currently being extended to 60 to 74. A further 1-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 is the latest data available?

Breast screening: 2012 to 2013 (financial year)

Cervical screening: 2012 to 2013 (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]. A second annual report is available here: www.gov.uk/government/publications/the-national-cancer-strategy-second-annual-report
- screening data for England is available from the 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 2 levels of access – public open access (to comply with the government open data policy) and professional NHS (login required to meet information governance requirements). See www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk

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 2011 to 2012, available at: www.cancerscreening.nhs.uk/breastscreen/publications/ba11-12.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/catalogue/PUB13567

- 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.breasttestwales.wales.nhs.uk/sitesplus/documents/1025/programme_report_11-12.pdf
- 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/PUB11889
- 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:

- 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: gut.bmj.com/content/early/2011/11/22/gutjnl-2011-300843.full
- Palmer et al. in 2014 published a study examining factors affecting uptake in the BCSP: www.nature.com/bjc/journal/vaop/ncurrent/full/bjc2014125a.html
- Results for the flexible-sigmoidoscopy trial can be found at: www.cancerscreening.nhs.uk/bowel/uk-flexible-sigmoidoscopy-screening-trial-slides.pdf
- 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 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 8 '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 1-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 Elliss-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 is the latest data available?

- for England: patients diagnosed from 2006 to 2010

Useful data sources:

- a range of information detailed below is provided on the NCIN website www.ncin.org.uk/publications/routes_to_diagnosis.aspx.
- updated workbooks for routes to diagnosis 2006 to 2010 cohort data. These show the percentage of total cancers that are diagnosed by each route by site, sex, age, deprivation quintile and ethnicity, and the relative survival for 1, 3, 6, 9, 12, 24 and 36 month intervals for each route. These new workbooks include a number of extra cancer sites and data at strategic clinical network (SCN) level and CCG level. They can be found at: www.ncin.org.uk/view?rid=2645 and here www.ncin.org.uk/view?rid=2644
- routes to diagnosis 2006 to 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 to 2010 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. See

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
- NCIN and CRUK short report 'Routes to Diagnosis: Comparing multiple studies'. See www.ncin.org.uk/view?rid=2240
- S McPhail et al. in 2013. 'Emergency presentation of cancer and short-term mortality'. British Journal of Cancer 2013; 109:2027-2034. See www.nature.com/bjc/journal/v109/n8/full/bjc2013569a.html
- the NCIN data briefing 'Routes to diagnosis for cancer of unknown primary'. See www.ncin.org.uk/view?rid=2597
- Routes to Diagnosis data are available from the 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 2 levels of access – public open access (to comply with the government open data policy) and professional NHS (login required to meet information governance requirements). See www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk

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 is the latest data available?

- UK estimates for 2010
- regional: strategic clinical networks 2010, Cancer Network 2006 and PCT 2004
- European estimates for 2012

Useful data sources:

- 'There were 2 million cancer survivors in the UK 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. See www.nature.com/bjc/journal/v101/n3/pdf/6605148a.pdf
- the Macmillan-NCIN partnership has produced an interactive Excel spreadsheet for 20-year cancer prevalence based on people diagnosed with cancer in the period 1991 to 2010 and alive at the end of December 2010, for all malignant cancers combined (excluding non-melanoma skin cancer). The spreadsheet provides cancer prevalence data by time since diagnosis, age at diagnosis, age at end of 2010, sex, UK constituent countries, Strategic Clinical Network for England, and deprivation quintile for England: www.ncin.org.uk/view?rid=2493. This prevalence data will be provided by other geographies in the future
- this data will be available from the CCT, in 2014. There are 2 levels of access – public open access (to comply with the government open data policy) and professional NHS (login required to meet information governance requirements). See www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- '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 5-year cancer prevalence estimates by PCT as of 31 December 2004 are available on the the Association of Public Health Observatories website at: www.apho.org.uk/resource/item.aspx?RID=63803
- CRUK provides detailed information about cancer prevalence up to 2006. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/incidence/prevalence/prevalence-uk

International comparisons:

- One, 3 and 5-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, ie 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 to 1202. See 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 is the latest data available?

- For England: Cancer Patient Experience Survey 2014

Useful data sources:

- for England: a range of summary and trust level reports on the Cancer Patient Experience Survey 2014 are available at www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey
- for Wales: a report on the survey for 2013: <http://wales.gov.uk/topics/health/publications/health/reports/report13/?lang=en>
- for Northern Ireland: results of a 2013 survey are expected in 2014: www.quality-health.co.uk/surveys/northern-ireland-cancer-patient-experience-survey
- for England: '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, ever conducted in Europe.

The quality of life for survivors of breast, colorectal, prostate cancer and non-Hodgkin's lymphoma (NHL) at 1, 2, 3 and 5 years after diagnosis, were assessed using a standard health questionnaire (EQ-5D). This questionnaire has 5 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 to 30 additional questions depending on tumour type. Future PROMs surveys will include additional cancer sites.

What is 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 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/publications/cancer-survivors-give-their-views-in-pilot-survey
- a paper assessing the feasibility of collecting PROMS, published in 2013: bmjopen.bmj.com/content/3/4/e002317.short

Quality of care

What is it?

The National Peer Review Programme (NPRP) 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 multidisciplinary teams (MDTs) and external reviews of MDTs conducted by professional peers, against nationally agreed 'quality measures'. The NPRP 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 6 tumour types; breast, lung, colorectal, upper gastrointestinal, 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 is the latest data available?

- the NPRP Report 2012 to 2013 (An overview of the findings from the 2012 to 2013 NPRP of Cancer Services in England) was published in October 2013
- individual reports for the 27 area teams for the 2012 to 2013 cycle of the NPRP

Useful data sources:

- The National and Cancer Network level reports can be found on the resource section of the Cancer Quality Information Network System (CQuINS) website at: www.cquins.nhs.uk/?menu=resources
- CLE briefing papers and peer review reports can be found on the public and NHS view of the CCT at: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk/

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.

In England for example, most national statistics are based on the 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 source of linked data is invaluable for improving our understanding of cancer and the patient journey. In 2012 this system was incorporated in to the Cancer Analysis System to analyse data from the NCRS. Examples of analysis given below include cancer patients receiving major surgical resections and 30-day postoperative mortality after colorectal cancer surgery.

What is 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, accident and emergency data from April 2013 to July 2013) are available on the Health and Social Care Information Centre website at: www.hscic.gov.uk/catalogue/PUB11901

- radiotherapy services in England 2012 report is published on <https://www.gov.uk/government/publications/radiotherapy-services-in-england-2012>
- the National Clinical Analysis and Specialised Applications Team (NATCANSAT) website hosts a number of national and academic publications: www.canceruk.net/rt/rtds.aspx
- radiotherapy profiles provide information about key indicators relating to radiotherapy services in England. These are available from the NCIN CCT, for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- radiotherapy data and charts are also available via the CCT
- national collection of all cancer chemotherapy in the NHS in England commenced in April 2012, for more information see: The Systemic Anti-Cancer Therapy (SACT) chemotherapy dataset website at: www.chemodataset.nhs.uk/home
- 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
- imaging is a central tool in detecting and diagnosing cancer. The Diagnostic Imaging Dataset (DID) is a central collection of detailed information about diagnostic imaging tests, such as ultrasound and MRI carried out on NHS patients: www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/. Imaging is used in the diagnosis of cancer, with commentary on early diagnosis and imaging relating to cancer here: www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2014/08/Provisional-Monthly-Diagnostic-Imaging-Dataset-Statistics1.pdf
- 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).
- GP profiles for cancer provide information about key indicators relating to cancer services for most GP practices in England. These are available via the CCT (both public and professional view) 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
- CCG profiles for Cancer will provide information about 26 key indicators relating to cancer services for every CCG in England. They are intended to help CCGs think about clinical practice and service delivery in cancer. These are available through

the NCIN website at:

www.ncin.org.uk/cancer_information_tools/profiles/pctprofiles.aspx, on both the public and professional view of the CCT at:

www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk. These will replace the PCT profiles and will be updated throughout 2014 to include all previous data sources

- service profiles for cancer provide information about key indicators relating to cancer services for breast, colorectal, lung, gynaecological, head and neck, oesophageo-gastric cancer and sarcoma by NHS trust in England. These can be accessed via the CCT, NHS professional view (access required) :
www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk. As part of the government transparency open data policy - lung profiles are available in the CCT public view following governance approval to share data publically
- cancer nurse specialist reports are available on the public and professional view of the CCT at: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- chemotherapy nursing workforce reports are available on the public and professional view of the CCT at: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- CWT data is available from the CCT, professional view for which login access is needed: www.ncin.org.uk/cancer_information_tools/cct or www.cancertoolkit.co.uk
- The following NCIN data briefings are available on the NCIN website at: www.ncin.org.uk/publications/data_briefings/default.aspx
 - high procedure volume is associated with improved survival after lung cancer surgery
 - 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 to 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
- peer-reviewed publications making use of the NCDR are listed on the NCIN 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
- national radiotherapy dataset (RTDS) microsite is an online analytical tools providing data for commissioners and providers for which login access is needed: www.rtds.nhs.uk/microsite/rtds/

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 5 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 (eg stage of disease, age and co-morbidity). These comparisons should in turn help to drive up quality.

What is the latest data available?

- The National Bowel Cancer Audit (NBCA) Report 2013 – audit period April 2011 to March 2012
- The National Head and Neck Cancer Audit (DAHNO) Report 2013 – audit period November 2012 to October 2013
- The National Lung Cancer Data Audit (LUCADA) Report 2013 – audit period 2012
- National Lung Cancer Audit Report 2014 Mesothelioma – audit period 2008 to 2012
- The National Oesophago-gastric Cancer Audit (NOGCA) Report 2013 – audit period April 2011 to March 2012

Useful data sources:

- audit reports are published on the Health and Social Care Information Centre website at: www.hscic.gov.uk/Article/1806

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 is 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 June 2014

Useful data sources:

- the NCIN report on equality metrics can be found at:
www.ncin.org.uk/view?rid=2697
- 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
- the NCIN publishes reports on the NCIN website at:
www.ncin.org.uk/publications/reports/. Examples include:
 - Cancer by deprivation in England - Incidence, 1996 to 2010, Mortality, 1997 to 2011
 - Deprivation and blood cancer survival in England: analysis of cancer registration data 2000 to 2007
 - Estimated completeness of ascertainment for childhood cancer in the UK, 2005 to 2010
 - Frequency of non-specific morphology codes (ICD-O M) within the NCDR (2007 to 2009) for cancer in Teenagers and Young Adults (TYA)
 - Routes to diagnosis: investigating the different pathways for cancer referrals in England for TYA

- Diverging trends in lung cancer survival between males and females 1999 to 2008
- the following NCIN data briefings are published on the NCIN website at: www.ncin.org.uk/publications/data_briefings/default.aspx. Examples include:
 - Interpreting geographic variation in cancer stage
 - Penile Cancer – Incidence by Age
 - Vulval Cancer – Trends and Variations by Age
 - Short-term survival of children with cancer
- a report looking at variation in incidence and mortality between males and females for the Republic of Ireland can be found here: www.ncri.ie/publications/research-reports/report-excess-burden-cancer-among-men-republic-ireland
- awareness measure tool (see section on cancer awareness above) provides a range of statistics by socio-economic group.
- ONS provides a report on mortality by deprivation for England and Wales: www.ons.gov.uk/ons/rel/hsq/health-statistics-quarterly/no--32--winter-2006/mortality-by-deprivation-and-cause-of-death-in-england-and-wales--1999-2003.pdf
- the NEOLCIN published a report on 'Deprivation and death: Variation in place and cause of death': www.endoflifecare-intelligence.org.uk/view?rid=254
- a report published by King's College London and Marie Curie examines end of life palliative care for Black, Asian and Minority Ethnic groups in the UK: www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf
- an article examining the cancer patient experience survey (see previous section) by sex, age and ethnicity: bmjopen.bmj.com/content/4/2/e004567.full.pdf+html
- geographic inequalities are accessible via the public health outcomes framework for measure on early staged cancers and screening: www.phoutcomes.info/ (under health improvement starting at indicator 2.19)

Glossary of Terms

ABS	Association of Breast Surgery
ASR	age-standardised rate
BCSP	Bowel Cancer Screening Programme
CAM	Cancer Awareness Measure
CCG	clinical commissioning group
CCT	Cancer Commissioning Toolkit
CIN	Section of Cancer Information
CLE	clinical lines of enquiry
COSD	Cancer Outcomes and Services Dataset
CQuINS	Cancer Quality Information Network System
CRUK	Cancer Research UK
CWT	Cancer Waiting Times
DAHNO	The National Head and Neck Cancer Audit
DID	Diagnostic Imaging Dataset
ECO	European Cancer Observatory
ECRIC	Eastern Cancer Registration and Information Centre
EUROCARE	EUROpean CANcer REgistry
FACT	Functional Assessment of Cancer Therapy
HES	Hospital Episode Statistics
IARC	International Agency for Research on Cancer
ISD	Information Services Division
LSHTM	London School of Hygiene and Tropical Medicine
LUCADA	The National Lung Cancer Data Audit
MDT	multidisciplinary team
MRI	magnetic resonance imaging
NAEDI	National Awareness and Early Diagnosis Initiative
NATCANSAT	National Clinical Analysis and Specialised Applications Team
NBCA	National Bowel Cancer Audit
NCDR	National Cancer Data Repository
NCEI	National Cancer Equalities Initiative
NCIN	National Cancer Intelligence Network
NCRS	National Cancer Registration Service
NCVIN	National Cardiovascular Intelligence Network
NEoLCIN	National End of Life Care Intelligence Network
NHL	non-Hodgkin's lymphoma
NMHIN	National Mental Health Intelligence Network
NOGCA	The National Oesophago-gastric Cancer Audit
NPRP	National Peer Review Programme
ONS	Office for National Statistics
PCT	primary care trust
PROMs	Patient Reported Outcome Measures
RTDS	national radiotherapy dataset
SACT	Systemic Anti-Cancer Therapy
SCN	strategic clinical network
TCR	Thames Cancer Registry

TYA	Teenagers and Young Adults
UKCIS	UK Cancer Information System
UKIACR	UK and Ireland Association of Cancer Registries
WMCIU	West Midlands Cancer Intelligence Unit