



Public Health
England

Protecting and improving the nation's health

National Cancer Registration and Analysis Service

Cancer statistics: availability and location

May 2017 update

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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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?

- England: 2015
- UK and regional statistics: 2014 (Ireland: 2015, Scotland: 2014, Wales: 2015)
- European and international comparators: 2012-2013
- Projections: predictions for 2020 in England; predictions up to 2035 for the UK, predictions up to 2035 globally

UK and regional statistics:

- the National Cancer Registration and Analysis Service's (NCRAS) CancerStats 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.nhs.uk

- CancerStats has England data for 2014 incidence, 2014 mortality and 2008 - 2013 survival. Data for Scotland, Wales and Northern Ireland covers 2013 incidence, with updated mortality and survival being added in the future. Data is available at CCG and local authority level
- A subset of this data is available to the public without the need for a login at: www.cancerdata.nhs.uk
- This data is also available on NHS England and PHE's cancer dashboard: <https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview&ccg=02N>
- Cancer Research UK (CRUK) provides detailed information about cancer incidence up to 2014. 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: <http://lci.cancertoolkit.co.uk>
- 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 2015 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: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/datasets/cancerregistrationstatisticsengland>
- Accompanying this is a statistical bulletin summarising the 2015 data: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/firstrelease2015>
- 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, 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 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 legacy 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:

- Childhood cancer registration in England: incidence and survival report
- Incidence and survival in neuroendocrine tumours and neuro-endocrine carcinomas

- Completeness of the national Systemic Anti-Cancer Therapy data set compared with the cancer waiting times data set
- Be Clear on Cancer: prostate cancer awareness local pilot campaign
- Trends in cancer waiting times metrics, England, 2009/10 to 2014/15
- Routes to diagnosis of cancer by stage, 2012-2013

International comparisons:

- There are a range of sources for European and international cancer incidence statistics. The Global Cancer Observatory 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 Global Cancer Observatory (GCO) website is: <http://gco.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 GCO website at: <http://gco.iarc.fr/today/home>
- 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: <http://eco.iarc.fr/EUCAN/Default.aspx>
- This tool and a range of others can be accessed at the European Cancer Observatory (ECO) site: <http://eco.iarc.fr/Default.aspx>
- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD) provides the topical cancer incidence statistics for Germany from 1995 - 2013. In an interactive database query, information on incidence, mortality rates, prevalence and survival rates for different types of cancer can be obtained. http://www.krebsdaten.de/Krebs/EN/Database/databasequery_step1_node.html
- The National Cancer Institute (NCI) provides access to reports and interactive tools containing cancer incidence information (1992 – 2013) across the USA. This data can be segmented by state and a range of demographic factors. Website: <https://surveillance.cancer.gov/statistics/types/incidence.html>

Incidence projections:

- A paper published by H Møller et al in 2007 examined 'The future burden of cancer in England: incidence and numbers of new patients in 2020'. British Journal of Cancer 2007; 96:1484-8: www.nature.com/bjc/journal/v96/n9/full/6603746a.html

- A paper 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 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
- A paper published by Smittenaar, Petersen, Stewart, and Moitt looked at 'Cancer Incidence and Mortality Projections in the UK Until 2035'. British Journal of Cancer 2016; 115(9), 1147-1155:
<http://www.nature.com/bjc/journal/v115/n9/abs/bjc2016304a.html>
- The above data is visualised by CRUK to display projection for incidence of all cancers combined: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined#heading-Three>
- 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, up to 2035, 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 2035 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: http://globocan.iarc.fr/Pages/burden_sel.aspx
- In the following article by Bray et al, the Human Development Index was used to highlight past and present cancer specific patterns and produce a future burden scenario for 2030: Bray, F., Jemal, A., Grey, N., Ferlay, J., & Forman, D. (2012). Global cancer transitions according to the Human Development Index (2008–2030): a population-based study. The lancet oncology, 13(8), 790-801.

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: 2014
- England: 2015
- European and international comparators: 2012 - 2014
- Projections: estimates up to 2035 for the UK and worldwide

UK and regional statistics:

- the National Cancer Registration and Analysis Service's (NCRAS) CancerStats 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.nhs.uk
- CancerStats has England data for 2014 incidence, 2014 mortality and 2008 - 2013 survival. Data for Scotland, Wales and Northern Ireland covers 2013 incidence, with updated mortality and survival being added in the future. Data is available at CCG and local authority level
- A subset of this data is available to the public without the need for a login at: www.cancerdata.nhs.uk
- CRUK provides detailed information about cancer mortality in the UK up to 2014. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/mortality
- Macmillan cancer support 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 a .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 2015 are for England and Wales; these can be downloaded in an Excel format. This data is available on the ONS website at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths#datasets>
- Further sources of mortality data for Scotland and Wales (up to 2014) can be found here: www.ncin.org.uk/cancer_information_tools/eatlas/links_to_useful_data_sources
- Queen's University Belfast use data from The Northern Ireland Cancer Registry to publish incidence, prevalence, survival and mortality statistics up to 2015. These can be downloaded as excel files: <https://www.qub.ac.uk/research-centres/nicr/CancerInformation/official-statistics/BySite/all-cancers/>
- The legacy 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 report on mortality in the first year after ovarian cancer diagnosis.

- 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, Northern Ireland, Scotland and Wales. Their website addresses are available from the UKIACR website at: www.ukiacr.org

International comparisons:

- There are a range of sources for European and international cancer mortality statistics. The Global Cancer Observatory (GCO) 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 GCO website is:

<http://gco.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:

<http://gco.iarc.fr/today/home>

- 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: <http://eco.iarc.fr/EUCAN/Default.aspx>

- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD) provides topical cancer mortality statistics for Germany from 1995 - 2014. In an interactive database query, information on incidence, mortality rates, prevalence and survival rates for different types of cancer can be obtained.

http://www.krebsdaten.de/Krebs/EN/Database/databasequery_step1_node.html

- The National Cancer Institute (NCI) provides access to reports and interactive tools containing cancer incidence information (1992 – 2013) across the USA. This data can be segmented by state and a range of demographic factors. Website:

<https://surveillance.cancer.gov/statistics/types/incidence.html>

Mortality projections:

- CRUK provides cancer mortality projections up to 2035 for all cancers combined. This data is available on the CRUK website at:

<http://www.cancerresearchuk.org/health-professional/cancer-statistics/mortality/all-cancers-combined#heading-Three>

- The following paper by Smittenar et al in 2016 made cancer incidence and mortality projections in the UK until 2035:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5117795/>

- GLOBOCAN provides UK and worldwide mortality (and incidence) predictions for up to 2035 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:

http://globocan.iarc.fr/Pages/burden_sel.aspx

- Macmillan Cancer Support produced the following report in 2013, assimilating data focusing on the cancer burden by 2020 and associated mortality:

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 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 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 2014
- five-year survival: based on patients diagnosed up to 2014

UK and regional statistics:

- The National Cancer Registration and Analysis Service's (NCRAS) CancerStats 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.nhs.uk
- CancerStats has England data for 2014 incidence, 2014 mortality and 2008 - 2013 survival. Data for Scotland, Wales and Northern Ireland covers 2013 incidence, with updated mortality and survival being added in the future. Data is

available at CCG and local authority level. This data is also available on NHS England and PHE's cancer dashboard:

<https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview&ccg=02N>

- CRUK provides detailed information about relative cancer survival on patients diagnosed in England and Wales up to 2010 - 2011. This data is available on the CRUK website at: www.cancerresearchuk.org/cancer-info/cancerstats/survival

- Macmillan Cancer Support provide one-year and five-year survival data at CCG level for patients diagnosed between 1997-2012 in the local cancer intelligence tool. Data is taken from ONS survival statistics in collaboration with the London School of Hygiene and tropical Medicine: lci.cancertoolkit.co.uk

- One year survival is available broken down by TNM stage for patients diagnosed between 2012-2014 in England:

www.ncin.org.uk/publications/survival_by_stage

- McPhail et al. produced the following paper in 2015: Stage at diagnosis and early mortality from cancer in England. British Journal of Cancer 2015; 112:S108-S115. See: www.nature.com/bjc/journal/v112/n1s/full/bjc201549a.html

- PHE and the ONS have published figures on survival by stage for England covering patients diagnosed between 2012, - 2014 and followed up in 2015:

<https://www.ons.gov.uk/releases/cancersurvivalbystageatdiagnosisexperimentalstatistics2012to2014>

- 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 2014 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 patients diagnosed between 2010-2014 (followed up to 2015) in England: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinenglandadultsdiagnosed/2010and2014andfollowedupto2015>

- Survival data by CCG for patients diagnosed between 1998-2013 (followed up to 2014) in England: <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/indexofcancersurvivalforclinicalcommissioninggroupsinengland/adultsdiagnosed19982013andfollowedupto2014>

- Geographic patterns of cancer survival in patients diagnosed between 2005-2009 (followed up to 2014) in England:

<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/geographicpatternsofcancersurvivalinengland/adultsdiagnosed2005to2009andfollowedupto2014>

- Childhood cancer survival for children diagnosed between 1990 - 2009 (followed up to 2014) in England:
<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/childhoodcancersurvivalinengland/childrendiagnosedfrom1990to2009andfollowedupto2014experimentalstatistics>
- The ONS have published a number of visualisations looking at survival trends over a 40 year period: <http://visual.ons.gov.uk/40-years-of-cancer/>
- A range of statistics is 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
- Coleman et al. produced the following paper 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
- 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
- The legacy 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:
 - Routes to Diagnosis 2006-2013 workbook A, incidence and survival
 - Relative survival in Upper Gastrointestinal (UGI) cancer patients in England, by socioeconomic deprivation
 - Older people and cancer
 - the NCIN website contains survival data in interactive maps of data for urological, gynaecological, skin and head & neck cancer

International comparisons:

- A paper was published by Alemani et al. in 2015 investigating 'Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2)'. Lancet 2015;385(9972):977–1010. See: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)62038-9/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)62038-9/fulltext)
- A summary of the research above is hosted on the Centre for Disease Control and Prevention website:
<https://www.cdc.gov/cancer/dcpc/research/articles/concord-2.htm>

- 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 Global Cancer Observatory (GCO) 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 GCO website is: <http://gco.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
- EUROCORE (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 EUROCORE website at: www.eurocare.it
- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD) provides cancer survival rates for patients diagnosed between 2007-2012 in Germany. In an interactive database query, 1-10 year survival crude/age standardised survival rates can be obtained for different types of cancer. Website: http://www.krebsdaten.de/Krebs/EN/Database/databasequery_step1_node.html
- The National Cancer Institute (NCI) provides a Cancer Statistics Review (1975-2013, USA) for which data tables and reports can be accessed via interactive database query. Relative survival rates by year of diagnosis (1975-2012) and 5 year survival (2006-2012) for all cancer sites are also available. Website: https://seer.cancer.gov/csr/1975_2013/

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). 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:

- An ONS opinions survey that is sampled to be representative of the UK population
- An Ethnibus survey of the main ethnic minority groups in England. Surveys were carried out in 2008, 2010, 2012 and 2014.

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, 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: <http://www.cancerresearchuk.org/health-professional/prevention-and-awareness/the-cancer-awareness-measures-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/%40abt/%40gen/documents/generalcontent/cr_085096.pdf
- CAM National Baseline Report was published in 2009. This report, titled 'Public awareness of cancer in Britain', is available at: www.cancerresearchuk.org/sites/default/files/public_awareness_of_cancer_in_britain_dh_report.pdf
- Two papers published in 2009 provide further information about the CAM: K Robbet 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 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: See: www.nature.com/bjc/journal/v108/n2/full/bjc2012542a.html
- The following paper examined breast cancer awareness among Saudi women in Jeddah through a modified Arabic version of the Breast Cancer Awareness Measure: http://www.koreascience.or.kr/article/ArticleFullRecord.jsp?cn=POCPA9_2013_v14n7_4307

Early diagnosis

What is it?

Cancers detected at an early stage are often easier to treat, and show better survival than later stage cancers. Several measures for early diagnosis exist, some of which include the route a patient was diagnosed by (see the Routes to diagnosis section) and the stage at diagnosis.

What is the latest data available?

Staging data for England has been improving in quality and completeness for a number of years, and was made publicly available for the first time in 2012. As data quality continues to improve more cancer sites will be published and a greater range of analytical work carried out. Data is available from 2012 to the end of 2015.

Useful data sources:

- PHE and the ONS produced statistics on survival by stage of diagnosis for adults diagnosed in England up to 2014 and followed up to 2015: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalbystageatdiagnosisforenglandexperimentalstatistics/adultsdiagnosed20122013and2014andfollowedupto2015>
- A variety of publications are available on staging data from 2014, including geographic and site breakdowns. These are available here: www.ncin.org.uk/publications/survival_by_stage
- An indicator for stage at diagnosis was created in 2013 to be updated routinely. The data for this can be found here, with data up to 2015: www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/cancer_outcome_metrics

- The following paper used population-based patient level data (including stage of diagnosis and resource use) to provide evidence on the cost of cancer. The effects of early diagnosis and alternate routes to diagnosis are modelled:
<http://www.nature.com/bjc/journal/v114/n11/full/bjc201677a.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 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 three years.

2012 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 is available on the Cancer Research website at: www.cancerresearchuk.org/about-cancer/type/breast-cancer/about/screening/breast-screening-review-2012

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 to 49 and every five years for those aged 50 to 64. The policy in Wales is to invite women aged 20 to 64 years every three years; and in Scotland to invite women aged 20 to 60 years every three years. From 2013 in Wales, and from 2016 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 five 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 two 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 74. 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 one-off diagnostic test using flexible sigmoidoscopy is being piloted in England, aimed at men and women aged 55. By 2016, everyone in England will be invited to have this test at the appropriate age.

Uptake: Uptake is available for regions in England.

What is the latest data available?

- Breast screening: UK: 2015, England: 2015, Scotland: 2015, Wales: 2016, NI: 2013
- Cervical screening: England: 2016, Scotland: 2016, Wales: 2016, NI: 2015
- Bowel screening: England: 2011, Scotland: 2016, Wales: 2014, NI: 2013

Useful data sources:

- PHE publishes three indicators related to screening in the Public Health Outcomes Framework, Health Improvement Metrics 2.20i-iii by a variety of geographies: www.phoutcomes.info/public-health-outcomes-framework#page/1/gid/1000042/pat/6/par/E12000004/ati/102/are/E06000015
- Information on the UK screening programmes is available on the UK screening portal at: www.gov.uk/topic/population-screening-programmes
- '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: <https://www.gov.uk/government/publications/the-national-cancer-strategy>. This figure comes from the Routes to Diagnosis analyses [see Routes to Diagnosis section]. A fourth annual report is available here: www.gov.uk/government/publications/the-national-cancer-strategy-4th-annual-report

Breast screening statistics for:

UK

- Published in NHS breast cancer screening programme: Annual Review 2012, available at: webarchive.nationalarchives.gov.uk/20150506150512/http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-annualreview2012.pdf
- NHS breast screening programme and Association of Breast Surgery audit of screen detected breast cancers 2014 - 2015, available at: http://www.associationofbreastsurgery.org.uk/media/63035/nhsbsp_abs_breast_screening_audit_201415_full_audit_v3.pdf
- The Third All Breast Cancer Report. Breast cancers diagnosed in the UK in 2008, available at: www.ncin.org.uk/view?rid=2935
- NCRAS 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

- Breast Screening Programme statistics 2014-2015 published on the Health and Social Care Information Centre website at:
<http://content.digital.nhs.uk/catalogue/PUB20018/bres-scre-prog-eng-2014-15-rep.pdf>

Scotland

- Annual statistics (2015) published on the Information Services Division (ISD) Scotland website at: www.isdscotland.org/Health-Topics/Cancer/Breast-Screening
- Most recent publications can be found here:
<http://www.isdscotland.org/Health-Topics/Cancer/Publications/>

Wales:

- Annual statistical report (2015 – 2016) published on the Screening Services Wales website at: <http://www.breasttestwales.wales.nhs.uk/reports-1>

Northern Ireland:

- Annual report and statistical bulletin (2012 – 2013) published on the Northern Ireland cancer screening programmes website at:
http://www.cancerscreening.hscni.net/Breast_Professional_Pubs.htm

Cervical screening statistics for:

England

- NHS cervical cancer screening programme 2015-2016 statistics available at:
<http://www.content.digital.nhs.uk/catalogue/PUB22414>

Scotland

- Scottish Cervical Screening Programme 2015-2016 statistics published on the Information Services Division (ISD) Scotland website at:
www.isdscotland.org/Health-Topics/Cancer/Cervical-Screening

Wales

- Cervical Screening Wales Programme 2015 – 2016 statistics published on the Screening Services Wales website at:
www.screeningservices.org.uk/csw/prof/reports

Northern Ireland

- Statistical publications available up to 2015 on the Northern Ireland cancer screening programmes website at:
<http://www.cancerscreening.hscni.net/2162.htm>

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 one million tests'. GUT. 2011 December. Published online at:

<http://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.bowelcanceruk.org.uk/media/195036/03_prof_wendy_atkin_-_flexible_sigmoidoscopy.pdf

Scotland

- Scottish bowel screening programme key performance indicators (KPIs) published on the ISD Scotland website up to 2016 at: www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening

Wales

- The first annual report from Bowels Screening Wales 2014 can be found here:
<http://www.wales.nhs.uk/sitesplus/888/news/36504>

Northern Ireland

- Bowel screening programme reports up to 2013 can be found here:
http://www.cancerscreening.hscni.net/Bowel_Screening_Health_Professionals.htm

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 is combined with cancer waiting times (CWT) data, data from the cancer screening programmes and cancer registration data. Using these datasets, every case of cancer registered is categorised into one of eight routes to diagnosis.

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

The methodology is described in a paper published by L 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?

- England: patients diagnosed from 2006 to 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
- Workbooks for routes to diagnosis 2006 - 2013 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 one, three, six, nine, 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=3053 and here: www.ncin.org.uk/view?rid=2644

- A workbook with data for proxy emergency presentations up to quarter three 2015 is available at:
www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/cancer_outcome_metrics
- A 2015 update report on routes to diagnosis for colorectal cancer:
<http://www.ncin.org.uk/view?rid=3147>
- A 2015 update on routes to diagnosis for lung cancer:
<http://www.ncin.org.uk/view?rid=3120>
- A 2015 update report on routes to diagnosis for stomach cancer:
<http://www.ncin.org.uk/view?rid=3137>
- A 2015 update report on routes to diagnosis for leukaemia:
<http://www.ncin.org.uk/view?rid=3117>
- A report on major resections by route: www.ncin.org.uk/view?rid=2972 along with a workbook: www.ncin.org.uk/view?rid=3073
- Routes to diagnosis 2006 to 2013 technical document: summarises the data sources and methodology used for this routes to diagnosis project
- Initial NCRAS 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
- NCRAS data briefing 'Routes to Diagnosis: Exploring Emergency Presentations'.
www.ncin.org.uk/publications/data_briefings/routes_to_diagnosis_exploring_emergency_presentations
- NCRAS and CRUK short report 'Routes to Diagnosis: Comparing multiple studies'. See: www.ncin.org.uk/view?rid=2240
- Y Zhou et al. in 2016. 'Diagnosis of cancer as an emergency: a critical review of current evidence' nature reviews 2016. 14, 45–56. See:
<http://www.nature.com/nrclinonc/journal/v14/n1/full/nrclinonc.2016.155.html>
- G Abel et al. in 2015. 'Cancer-specific variation in emergency presentation by sex, age and deprivation across 27 common and rarer cancers' British Journal of Cancer 2015; 112:S129-S136. See:
www.nature.com/bjc/journal/v112/n1s/full/bjc201552a.html
- 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 NCRAS data briefing 'Routes to diagnosis for cancer of unknown primary'. See: www.ncin.org.uk/view?rid=2597

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 estimates: strategic clinical networks 2010, Cancer Network 2006
- European estimates for 2012
- Worldwide estimates: 2012 - 2013

Useful data sources:

- 'There were two 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-NCRAS 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=2954. This prevalence data is provided by other geographies: www.ncin.org.uk/about_ncin/segmentation
- 'One, Five and Ten Year Cancer Prevalence by Cancer Network and the UK, as of 31 December 2006'. NCRAS 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

- Macmillan produced the following infographic detailing current and future cancer prevalence in the UK:
<http://www.macmillan.org.uk/images/getinvolved/campaigns/generalelection2015/25-million-infographic-full-jan2015.jpg?origin=GE2015-RHS>

International comparisons:

- One, three and five-year cancer prevalence estimates for 40 European countries for 2012 are available on the EUCAN website at:
<http://eco.iarc.fr/EUCAN/Default.aspx>
- Age-standardised rate for all cancers ordered by the countries with the 50 highest rates in the world (2012) : <http://www.wcrf.org/int/cancer-facts-figures/data-cancer-frequency-country>
- Estimated cancer prevalence worldwide for all cancers in 2012 (excluding non-melanoma skin cancer):
http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx
- The National Cancer Institute hosts cancer prevalence reports and interactive tools for the USA up to 2013:
<https://surveillance.cancer.gov/statistics/types/prevalence.html>
- The Australian institute of health and welfare published cancer survival and prevalence statistics for the period from 1982-2010. Report and summary tables are available here: <http://www.aihw.gov.au/publication-detail/?id=10737422720>

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
- Macmillan published the following factsheet which includes prevalence projections:
<http://www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf>

Patient experience

What is it?

The National Cancer Patient Experience Survey (CPES) 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?

- England: Cancer Patient Experience Survey 2015
- Wales: Cancer Patient Experience Survey 213
- Northern Ireland: Cancer Patient Experience Survey 2015
- Scotland: Cancer Patient Experience Survey 2015

Useful data sources:

England

- A range of summary and trust level reports on CPES 2015 are available at www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey
- A report detailing the linkage of CPES data to cancer registration data: www.ncin.org.uk/view?rid=3064

Wales

- A report on CPES 2013: wales.gov.uk/topics/health/publications/health/reports/report13/?lang=en

Northern Ireland

- Results of CPES 2015 for all trusts is reported here: <https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancer-patient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-ireland-cancer-patient-experience-survey-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file>
- Methodology and data tables supplement for results of CPES 2015: <https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancer-patient-experience-survey-1/2015-northern-ireland-cancer-patient-experience-survey/northern-ireland->

[cancer-patient-experience-survey-reports/696-2015-ni-cancer-patient-experience-survey-methodology-data-tables/file](#)

Scotland

- The first CPES survey was run in Scotland for years 2015-6. The full report can be viewed here: <http://www.gov.scot/Resource/0050/00501127.pdf>

Quality of life

What is it?

The patient reported outcome measures (PROMs) pilot survey was carried out by the Department of Health in 2011 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 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 to 30 additional questions depending on tumour type. Future PROMs surveys will include additional cancer sites.

What is the latest data available?

- National PROMs survey of colorectal cancer patients diagnosed in 2010 and 2011
- 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 GOV.UK website at: www.gov.uk/government/publications/cancer-survivors-give-their-views-in-pilot-survey

- A paper assessing the integration of PROMS into routine cancer using patient and clinicians perspectives of acceptability and value:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4636110/>
- A paper assessing the feasibility of collecting PROMS, published in 2013:
bmjopen.bmj.com/content/3/4/e002317.short
- Reports on the pilot studies for gynaecological and bladder cancers, and the national colorectal cancer survey, are all available from NHS England:
<https://www.england.nhs.uk/cancer/resources/>

International comparison:

- A paper assessing best practice of the use of PROMs in oncology (USA) 2014: <http://ascopubs.org/doi/full/10.1200/JOP.2014.001423>

Quality of care

What is it?

The quality surveillance team (QST) 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 was 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 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?

- An overview of the findings from the 2013 to 2014 NPRP of Cancer Services in England was published in March 2015
- The National Peer Review Programme report 2013 to 2014
- Individual reports for the 27 area teams for the 2012 to 2013 cycle

Useful data sources:

- The NHS quality surveillance team replaces the NPRP. The latest peer review visit reports can be found under the relevant service profile on the Quality Surveillance Information System (QSI): <https://www.qst.england.nhs.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, most national statistics are based on the Hospital Episode Statistics (HES), the national statistical data warehouse for England, recording data on 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?

- HES (2016)
- Radiotherapy (2016)
- Chemotherapy (2014)
- Cancer outcomes and services
- Diagnostic imaging data (2014)
- Major operations (see tables)
- Cancer services at GP and CCG level (2016)
- NCRAS (see sources)

Useful data sources:

HES

- 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 the NHS Digital website at: <http://digital.nhs.uk/hes>
- Provisional monthly HES data for England (admitted patient care, outpatients, accident and emergency data up to January 2017) are available on the NHS Digital website at

<http://content.digital.nhs.uk/searchcatalogue?q=title%3A%22Provisional+Monthly+Hospital+Episode+Statistics%22&area=&size=10&sort=Relevance>

Radiotherapy

- A report on the radiotherapy services in England 2012 is published on: 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 HES/radiotherapy related publications (2016). <http://www.natcansat.nhs.uk/>
- A national radiotherapy dataset (RTDS) microsite is an online analytical tool providing data for commissioners and providers for which login access is needed: www.rtds.nhs.uk/microsite/rtds

Chemotherapy

- The National collection of all cancer chemotherapy in the NHS in England commenced in April 2012. The Systemic Anti-Cancer Therapy (SACT) chemotherapy dataset website contains all of the latest information available up to 2014 : www.chemodataset.nhs.uk/home
- The national collection and analysis of cancer chemotherapy (NCRAS) data briefing is available on the NCIN website at: www.ncin.org.uk/publications/data_briefings/national_collection_and_analysis_of_cancer_chemotherapy
- A short report on the completeness of chemotherapy data compared to cancer waiting times can be found here: www.ncin.org.uk/publications/data_briefings/sact_cwt
- A study on 30-day mortality after chemotherapy for breast and lung cancers was published in the Lancet Oncology: [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(16\)30383-7/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(16)30383-7/fulltext)

Cancer outcomes and services

- Cancer Outcomes and Services Dataset (COSD) replaced the previous national cancer dataset as the new national standard for reporting cancer in the NHS in England as of January 2013. For more information see: www.ncin.org.uk/collecting_and_using_data/data_collection/cosd.aspx

- The following are published in the Improving Cancer Outcomes Strategy: information supplement available on the NCIN website at: www.ncin.org.uk/view.aspx?rid=663

Diagnostic Imaging Dataset

- 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/2/2014/06/Technical-Report-2013-14-DID-pdf-842-KB.pdf
- The latest DID (2016-2017) can be found here: <https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/diagnostic-imaging-dataset-2016-17-data/>

Major Operations

- 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)

Cancer services at GP and CCG level

- GP profiles for cancer provide information about key indicators relating to cancer services for most GP practices in England up to 2016. These are available through the Public Health profiles tool at: fingertips.phe.org.uk/profile/cancerservices Some information has been removed to protect patient confidentiality
- CCG profiles for cancer will provide information about 26 key indicators relating to cancer services for every CCG in England up to 2016. They are intended to help CCGs think about clinical practice and service delivery in cancer. These are available through the Public Health profiles tool at fingertips.phe.org.uk/profile/cancerservices
- Clinical headline indicators up to 2014 are available on NCRAS's CancerStats website: www.cancerstats.nhs.uk

NCRAS

The following NCRAS 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
- 30-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 cancer registration data are listed on the NCIN website at: www.ncin.org.uk/publications/peer_reviewed.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 (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 2016 – audit period March 2014 to March 2015
- The National Head and Neck Cancer Audit (DAHNO) Report 2014 – audit period November 2013 to October 2014
- The National Lung Cancer Audit (NLCA) Report 2016 – audit period 2015
- The National Lung Cancer Audit Report 2016 Mesothelioma – audit period 2014
- The National Oesophago-gastric Cancer Audit (NOGCA) report 2016 – audit period April 2015 to March 2016

Useful data sources:

- National bowel cancer audit report (2016):
<http://content.digital.nhs.uk/searchcatalogue?productid=23896&q=title%3a%22bowel+cancer%22&sort=Relevance&size=10&page=1#top>
- The Head and Neck Audit (HANA) is available at:
<http://headandneckaudit.com/>
- The National Lung Cancer Audit (NLCA) audit is available from the Royal College of Physicians: <https://www.rcplondon.ac.uk/projects/outputs/nlca-annual-report-2016>
- The National Lung Cancer Audit Report 2016 Mesothelioma is available from the Royal College of Physicians:
<https://www.rcplondon.ac.uk/projects/outputs/national-lung-cancer-audit-pleural-mesothelioma-report-2016-audit-period-2014>
- The National Oesophago-gastric Cancer Audit (NOGCA) report 2016:
<http://content.digital.nhs.uk/og>

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, NCRAS analyses consider the different equality 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 is available on the NCIN website

Useful data sources:

- The latest NCRAS report (2015) on equality metrics can be found at: www.ncin.org.uk/view?rid=2991
- A report examining whether there is a common metric within the deprivation measures that can be applied across England, Wales, Scotland, Northern Ireland and Ireland (2016): <http://www.ncin.org.uk/view?rid=3278>
- A report at England level examining deprivation (2014): www.ncin.org.uk/view?rid=2691
- A report focusing on variation by age, especially older people (2015): www.ncin.org.uk/view?rid=2950
- The following NCRAS report provides evidence to March 2010 on cancer inequalities in England. It was originally published as an annex to the National Cancer Equalities Initiative (NCEI) report 'Reducing cancer inequality: evidence, progress and making it happen'. www.ncin.org.uk/view.aspx?rid=169
- NCRAS publishes reports on the NCIN website: www.ncin.org.uk/publications/reports.

Examples include:

- Older people and cancer
- 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 National Cancer Data Repository (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
- NCRAS published data briefings on the NCIN website:
www.ncin.org.uk/publications/data_briefings/default.aspx. Examples include:
 - Interpreting geographic variation in cancer stage
 - Comparison of teenage and young adult (TYA) cancer mortality rates in Great Britain with other countries
 - NCRAS Data Briefing Emergency presentations lung
 - Penile cancer – incidence by age
 - Vulval cancer – trends and variations by age
- A report (2013) 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
- The BJC published the following article which examines the association between cancer survival and inequalities in symptom awareness and help-seeking barriers: <http://www.nature.com/bjc/journal/v115/n7/full/bjc2016246a.html>
- The NCoLCIN published a report on 'Deprivation and death: Variation in place and cause of death' (2012): 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 (2013): https://www.mariecurie.org.uk/globalassets/media/documents/who-we-are/diversity-and-inclusion-research/palliative-care-bame_full-report.pdf
- An article examining the cancer patient experience survey of 2011-2012 (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
EUROCA	EUROpean CAncer REgistry
FACT	Functional Assessment of Cancer Therapy
HANA	Head And Neck Audit
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
NATCAN	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 (NCRAS from 2016)
NCRS	National Cancer Registration Service (NCRAS from 2016)
NCRAS	National Cancer Registration and analysis 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

