



Protecting and improving the nation's health

## Cancer statistics: availability and location

September 2018 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-leading 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 Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

Public Health England Wellington House 133-155 Waterloo Road London SE1 8UG

Tel: 020 7654 8000

www.gov.uk/phe Twitter: @PHE\_uk

Facebook: www.facebook.com/PublicHealthEngland

Prepared by: CADEAS with quality assurance support from NCRAS.

#### Cancer Alliance Data Evidence and Analysis Service (CADEAS)

This document is produced by The Cancer Alliance Data, Evidence and Analysis Service (CADEAS), a partnership between NHS England and Public Health England. The Service supports Alliance delivery using a whole pathway and cross-organisational approach. It aims to influence, inform and share best practice ensuring evidence-based local decision making.



#### © Crown copyright 2018

You may re-use this information (excluding logos) free of charge in any format or medium, under the terms of the Open Government Licence v3.0. To view this licence, visit OGL. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This document is available in other formats on request. Please call 020 76548158 or email ncrasenquiries@phe.gov.uk

Published September 2018 PHE publications gateway number: 2018451

Corporate member of Plain English Campaign Committed to clearer communication

PHE supports the UN Sustainable Development Goals



## Contents

About Public Health England	2
Executive summary	4
Reducing growth in the number of cancer cases	5
Risk factors, prevention and cancer awareness	5
Cancer incidence	9
Improving survival	11
Cancer screening	11
Operational performance	14
Early diagnosis	15
Cancer mortality	18
Cancer survival	19
Improving experiences of care, treatment and support	22
Treatment	22
Quality of care	24
Cancer patient experience	25
Improving the quality of life of patients after treatment and at the end of life	26
Cancer prevalence	26
International comparisons:	27
Quality of life	27
Reducing inequalities	28
Whole pathway	29
Glossary of terms	31

## **Executive summary**

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

This is intended to be a useful reference guide for users of cancer statistics or audiences that may not be familiar with this information. This document is structured using key topics in the 'Achieving World Class Cancer Outcomes: Strategy for England 2015 - 2020' report (https://www.gov.uk/government/publications/cancer-taskforce-recommendations-progress-report), and with geographical breakdowns of data sources.

# Reducing growth in the number of cancer cases

#### Risk factors, prevention and cancer awareness

#### What is it?

#### Risk factors

As well as increasing age, genetics and exposure to environmental factors contribute to the risk of developing cancer. Lifestyle-related factors such as smoking, alcohol consumption, obesity and physical activity have been associated with increased risk of cancer. In 2015 almost 4 in 10 cancer cases in the UK were associated with known risk factors.<sup>1</sup>

Smoking remains the largest preventable cause of cancer in the UK. In 2017, 15.1% of people in the UK aged 18 years and above smoked cigarettes<sup>2</sup>. Obesity is estimated to affect 1 in 4 adults and 1 in 5 reception-aged children in the UK.<sup>3</sup>

#### Prevention

Cancer prevention involves taking measures to reduce risk factors. Being overweight or obese was the second largest cause of cancer which is preventable, accounting for 6.3% of all cases in the UK in 2015.<sup>1</sup>

#### Cancer awareness

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.

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, Cancer Research UK, University College London, King's College London and the University of Oxford, as part of the National Awareness and Early Diagnosis Initiative (NAEDI), 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

Cancer statistics: availability and location. September 2018 update

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.

#### Where to find the key statistics?

Location	Years covered	Geography
Risk factor - smoking  https://fingertips.phe.org.uk/search/smoking	2016 - 2017	England; Region; STP; CCG; County & UA; District & UA; GP practice
Risk factor - alcohol consumption: https://fingertips.phe.org.uk/profile/local-alcohol- profiles/data#page/0/gid/1938132984/pat/6/par/E1200 0004/ati/102/are/E06000015/iid/91414/age/1/sex/4	2014/15 - 2016/17	England; Region; County & UA; District & UA
Risk factor – physical activity: https://fingertips.phe.org.uk/profile/physical- activity/data#page/0/gid/1938132899/pat/15/par/E920 00001/ati/6/are/E12000007/iid/93014/age/298/sex/4	2014/15 - 2016/17	England; Region; County & UA; District & UA
Risk factor - report and data on obesity: https://digital.nhs.uk/data-and- information/publications/statistical/statistics-on- obesity-physical-activity-and-diet/statistics-on-obesity- physical-activity-and-diet-england-2018	2006/07 - 2016/17	England; Region; STP; CCG; Local Authority;
Cancer Research UK statistics on preventable cancers: www.cancerresearchuk.org/health- professional/cancer-statistics/risk/preventable- cancers	2015	UK; England; Scotland; Wales; Northern Ireland
Cancer Awareness Measure (CAM) report on 'Key Findings Report; 2014 & Trends Analysis (2008-2014)' which contains data tables: http://www.cancerresearchuk.org/sites/default/files/cam_key_findings_report2014_trends_analysis_v5.pdf	2008 - 2014	UK; England; Scotland; Wales

#### Other sources of statistics and information

- Be Clear on Cancer campaign reports: http://www.ncin.org.uk/cancer\_type\_and\_topic\_specific\_work/topic\_specific\_work/be\_clear on cancer/
- World Cancer Research Fund, Estimate of preventable cancers in the UK: https://www.wcrf-uk.org/uk/preventing-cancer/cancer-preventability-statistics/
- Results of Be Clear on Cancer campaigns 2011 2013 (Oesophagogastric, Bowel, Lung, Breast, bladder and kidney, Ovarian):
   http://www.cancerresearchuk.org/sites/default/files/evaluation\_results\_2014.pdf
- 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

- Paper on 'The impact of national cancer awareness campaigns for bowel and lung cancer symptoms on sociodemographic inequalities in immediate key symptom awareness and GP attendances' report: <a href="https://www.nature.com/articles/bjc201531">https://www.nature.com/articles/bjc201531</a>
- 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: https://www.ncbi.nlm.nih.gov/pubmed/21933805
- 2016 England survey findings on public knowledge of link between alcohol and cancer: http://www.cancerresearchuk.org/sites/default/files/buykxetal\_executive\_summary.compressed.pdf.
- Paper on cancer attributable risk factors for England, Scotland, Wales, Northern Ireland and the UK: https://www.nature.com/articles/s41416-018-0029-6
- CAM National Baseline Report published in 2009. This report, titled 'Public awareness of cancer in Britain':
  - 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: http://www.nature.com/bjc/journal/v101/n2s/full/6605386a.html; S. Stubbings et al. details the 'Development of a measurement tool to assess public awareness of cancer'. British Journal of Cancer 2009; 101:S13–S17: http://www.nature.com/articles/6605385
- 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':
  - www.cancerresearchuk.org/prod\_consump/groups/cr\_common/%40abt/%40gen/documents/generalcontent/cr\_085096.pdf
- Cervical cancer 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: https://www.ncbi.nlm.nih.gov/pubmed/22683170
- Colorectal cancer 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: https://www.ncbi.nlm.nih.gov/pubmed/21859500
- Lung cancer 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 populationbased survey'. Thorax. 2012 May; 67(5):426-32.
   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:
  - www.nature.com/bjc/journal/v108/n2/full/bjc2012542a.html

#### 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 overall incidence of cancer increases 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.

#### Where to find the key statistics?

Location	Years covered	Geography
Cancer registration statistics - age-standardised incidence rates for all cancers types: https://www.ons.gov.uk/peoplepopulationandcom munity/healthandsocialcare/conditionsanddiseases /datasets/cancerregistrationstatisticscancerregistra tionstatisticsengland Data workbook: https://www.ons.gov.uk/file?uri=/peoplepopulation andcommunity/healthandsocialcare/conditionsand diseases/datasets/cancerregistrationstatisticscancerregistrationstatisticsengland/2016/2016cancerregistrationsreferencetablesfinal.xls	2016	England
The National Cancer Registration and Analysis Service's (NCRAS) CancerStats portal is an online analytical tool providing incidence (in addition to mortality and survival data) for which login access is required:  https://cancerstats.ndrs.nhs.uk/user/login The NCRAS CancerData system provides cancer data and analysis that is safe to release in the public domain, including cancer incidence data: https://www.cancerdata.nhs.uk/incidence	2016	England; Cancer Alliance; STP; CCG; Local Authority

#### Other sources of statistics and information

 Northern Ireland cancer registrations: http://www.qub.ac.uk/researchcentres/nicr/CancerInformation/official-statistics/

- Scotland cancer registrations: http://www.isdscotland.org/Health-Topics/Cancer/Publications/2018-04-24/visualisation.asp
- Wales cancer registrations: http://www.wcisu.wales.nhs.uk/cancer-incidence-in-wales 1
- The latest performance indicators for the cancer registries of the United Kingdom and Ireland International Association of Cancer Registries (UKIACR) are available on: www.ukiacr.org/kpis
- 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: https://www.nature.com/articles/6603746
- A paper by Macmillan cancer support, based on the above data focusing on the cancer burden by 2020 can be found at: https://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013executive-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: https://www.nature.com/articles/bjc2011430
- 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
- CRUK data visualisation displays projection for incidence of all cancers combined: http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined
- The cancer incidence projections report gives projections for the number of cancer cases in Scotland up to 2027 with policy and methodology background. It is available on the ISD Scotland website at: http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Incidence-Projections/
- Cancer incidence projections for Ireland, up to 2040, are available from National Cancer Registry Ireland: https://www.ncri.ie/news/article/cancer-projections-ireland-2015-%E2%80%93-2040

#### 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 the International Agency for Research on Cancer (IARC). The Global Cancer Observatory (GCO) website is: http://gco.iarc.fr
- 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
- GLOBOCAN also 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

- This tool and a range of others can be accessed at the European Cancer Observatory (ECO) site: <a href="https://ecis.jrc.ec.europa.eu/">https://ecis.jrc.ec.europa.eu/</a>
- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD) provides the topical cancer incidence statistics for Germany from 1999 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 (1999 – 2015) 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
- 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), 790-80: https://www.ncbi.nlm.nih.gov/pubmed/22658655

## Improving survival

#### **Cancer screening**

#### What is it?

The UK National Screening Committee makes UK-wide policies. It recommends systematic population screening programmes for breast, cervical and bowel cancers. 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. The key measures used are screening 'coverage' and 'uptake'.

Definitions of coverage and uptake 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.

Uptake: the percentage of women who, having been sent an invitation for screening, attend a screening unit and undergo mammography in response to that invitation.

#### Cervical screening

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

Invited population: The cervical screening programmes for England, Scotland, Wales and Northern Ireland invite women for screening every three years for those aged 25 to 49 and every five years for those aged 50 to 64.

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.

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 was available to those aged 60 to 74. In August 2018 the UK National Screening Committee recommended the bowel cancer screening in England should be offered from age 50 to 74 using the new faecal immunochemical home test kit. A further one-off diagnostic test using flexible sigmoidoscopy is being piloted in England, aimed at men and women aged 55.

Coverage: The proportion of eligible men and women of a specified age invited for screening who have had an adequate screening result in the previous 30 months.

Uptake: The proportion of eligible men and women of a specified age invited to participate in bowel cancer screening who adequately participate.

#### Where to find the key statistics?

Location	Years covered	Geography
PHE publishes three indicators related to screening in the Public Health Outcomes Framework, Health Improvement Metrics 2.20i-iii by a variety of geographies: https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/1/gid/1000042/pat/6/par/E120 00004/ati/102/are/E06000015 The Cancer Services section also include indicators on screening: https://fingertips.phe.org.uk/profile/cancerservices/data#page/0	2017	England; Region; County & UA; District & UA; GP practice
Breast Screening Programme, including an interactive dashboard: https://digital.nhs.uk/data-and-information/publications/statistical/breast-screening-programme/breast-screening-programme-england2016-17	2016 - 2017	England; Region
NHS breast screening programme and Association of Breast Surgery audit of screen cancers detected breast. Appendix 2 data tables: https://associationofbreastsurgery.org.uk/media/63741/nhs-bsp-abs-audit-2015-16.pdf	2015 - 2016	England; Region. Scotland; Wales; Northern Ireland
NHS cervical cancer screening programme 2015-2016 in England statistics available at:  https://digital.nhs.uk/data-and- information/publications/statistical/cervical- screening-programme/cervical-screening- programme-england-2016-17	2016 - 2017	England; CCG; GP practice

#### Other sources of statistics and information

- Information on the UK screening programmes is available on the UK screening portal at: www.gov.uk/topic/population-screening-programmes
- NCRAS data briefing 'Improved Survival for Screen-Detected Breast Cancer' based on data from the ABS Audit.
  - http://www.ncin.org.uk/publications/data\_briefings/improved\_survival\_for\_screen\_dete cted\_breast\_cancer
- Outcomes from the first UK bowel cancer screening programme (BCSP) site:

- screening and surveillance experience since 2006, August 2006 to December 2013: http://gut.bmj.com/content/64/Suppl\_1/A211.2
- Palmer et al.in 2014 published a study examining factors affecting uptake in the BCSP for England: 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\_sigmoisoscopy.pdf
- Nationwide bowel cancer screening programme in England: cohort study of lifestyle factors affecting participation and outcomes in women (published 2015): https://www.nature.com/articles/bjc201569
- Outcomes of the Bowel Cancer Screening Programme (BCSP) in England after the first one million tests: England published 2012: http://gut.bmj.com/content/61/10/1439
- Scotland breast screening statistics: Annual statistics: http://www.isdscotland.org/Health-Topics/Cancer/Breast-Screening/
- Scotland bowel screening statistics: Key performance indicators (KPIs): http://www.isdscotland.org/Health-Topics/Cancer/Bowel-Screening/
- Scotland cervical screening statistics: Scottish Cervical Screening Programme: http://www.isdscotland.org/Health-Topics/Cancer/Cervical-Screening/
- Wales breast screening statistics: Annual statistical report: http://www.breasttestwales.wales.nhs.uk/reports-1
- Wales cervical screening statistics: Cervical Screening Wales Programme: http://www.cervicalscreeningwales.wales.nhs.uk/statistical-reports
- Wales bowel screening statistics: The first annual report from Bowel Screening Wales: http://www.wales.nhs.uk/sitesplus/888/news/47573/
- Northern Ireland bowel screening statistics: Bowel screening programme: http://www.cancerscreening.hscni.net/Bowel\_Screening\_Health\_Professionals.htm
- Northern Ireland cervical screening statistics: Northern Ireland cancer screening programme: http://www.cancerscreening.hscni.net/2162.htm
- Northern Ireland breast screening statistics: Annual report and statistical bulletin: <a href="http://www.cancerscreening.hscni.net/Breast\_Professional\_Pubs.htm">http://www.cancerscreening.hscni.net/Breast\_Professional\_Pubs.htm</a>

#### **Operational performance**

#### What is it?

It is important that cancer services are delivered to patients in a timely manner. To achieve this, the UK government has set a number of national operational standards in England. In order to monitor cancer waiting times and plan service improvements, the National Cancer Waiting Times system was set up for NHS providers to record data derived from patient care activity.

In 2015, the Cancer Taskforce recommended the introduction of a new 28 day Faster Diagnosis Standard. Changes to the CWT system and dataset that were introduced from April 2018 mark the start of the implementation of this new standard, which will be fully implemented by 2020.

#### Where to find the key statistics?

Location	Years covered	Geography
Cancer Waiting Times (CWT) validated data with monthly and quarterly statistics published by NHS England: https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/	2009 - 2018	England; CCG; Trust
PHE Fingertips provides further CWT two-week waiting times data including referral rates per 100,000 population, indirectly age-sex standardised referral ratio, and conversion and detection rates: https://fingertips.phe.org.uk/profile/cancerservices/da ta#page/0/gid/1938133085/pat/152/par/E38000001/ati/7/are/B83620/iid/91882/age/1/sex/4	2016/17	England; CCG; GP practice

#### Other sources of statistics and information

 Cancer Waiting Times Annual Report shows a summary of the statistics on Waiting Times for Suspected and Diagnosed Cancer Patients within the English NHS for the period 2017-18. The data presented is an aggregate version of the provider-based quarterly statistics:

https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/06/Cancer-Waiting-Times-Annual-Report-201718.pdf

#### **Early diagnosis**

#### What is it?

Cancers detected at an early stage are often easier to treat, and show better survival than late 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. 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.

#### Where to find the key statistics?

Location	Years covered	Geography
The proportion of cancers diagnosed at early stage (10 cancers diagnosed in each quarter that are recorded as presenting as an early stage case, i.e., stage 1 or 2 as opposed to stage 3, 4, or unknown):  http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/cancer_outcome_metrics	2012 - 2017	England; CCG
National Cancer Diagnosis Audit (NCDA) in 2014		England;
Supplementary Data:	2014	Scotland;
http://www.ncin.org.uk/collecting_and_using_data/ncda		North Wales;

Diagnostic waiting times and activity data is available via three outputs, monthly, quarterly, and annual imaging and radiodiagnostics data:  https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostics-waiting-times-and-activity/	2008/09 - 2018/19	England
Diagnostic Imaging Dataset (DID) is imaging test data on NHS patients that is collected via Radiology Information System (RIS) and by monthly submissions:  https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostic-imaging-dataset/	2012/13 - 2018	England; Region; CCG; Trust

#### Other sources of statistics and information

- Rapid cancer diagnostic and assessment pathways: https://www.england.nhs.uk/publication/rapid-cancer-diagnostic-and-assessment-pathways/
- Identifying anticipated barriers to help-seeking to promote earlier diagnosis of cancer in Great Britain. Data available in UK Data Archive, 2014 UK wide: http://europepmc.org/articles/PMC5157686;jsessionid=DDB3EB5872EC7D938C4F21 DC1BE26244
- 2016 cancer breakdown by stage, at CCG level: http://www.ncin.org.uk/publications/survival\_by\_stage
- 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

#### Routes to Diagnosis

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 net 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.

#### Where to find the key statistics?

Location	Years covered	Geography
A workbook with data for Routes to Diagnosis and treatment split by treatment modality, age, stage, and comorbidity: <a href="http://www.ncin.org.uk/view?rid=3745">http://www.ncin.org.uk/view?rid=3745</a>	2013-2015	England
A workbook with data for Routes to Diagnosis and stage split by sex, age, ethnicity, and deprivation: http://www.ncin.org.uk/view?rid=3071	2012-2013	England
Route to Diagnosis data in Excel workbooks (which include breakdowns for CCG and Cancer Alliance for some outputs) http://www.ncin.org.uk/publications/routes_to_diagnosis	2006-2015	England; Cancer Alliance; CCG
The estimated proportion of all malignant cancers which present as an emergency: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/cancer_outcome_metrics	2012 -2017	England; Cancer Alliance; CCG
A report on major resections by route: http://www.ncin.org.uk/publications/reports/ along with a workbook: www.ncin.org.uk/view?rid=3073	2006-2010	England

#### Other sources of statistics and information

- The Routes to diagnosis methodology is described in a paper published by 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
- Routes to Diagnosis Interactive tools (Routes; Emergency, Survival by site and route, Route and treatment):
  - https://www.cancerdata.nhs.uk/routestodiagnosis
- Y Zhou et al. in 2016, 'Diagnosis of cancer as an emergency: a critical review of current evidence, 2016. 14,' nature reviews 45–56. See: https://www.nature.com/articles/nrclinonc.2016.155
- 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: 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:
   www.nature.com/bjc/journal/v109/n8/full/bjc2013569a.html
- A range of information is provided on the NCRAS website: www.ncin.org.uk/publications/routes\_to\_diagnosis.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 (number of cases per 100,000 population) of cancer deaths per year. Cancer mortality is commonly expressed as crude and agestandardised rates in exactly the same way as cancer incidence.

#### Where to find the key statistics?

Location	Years covered	Geography
The ONS provides cancer mortality statistics through the release of statistical bulletins: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathregistrationssummarytablesenglandandwalesreferencetables	2017	England; Wales
The National Cancer Registration and Analysis Service's (NCRAS) CancerStats system is an online analytical tool providing mortality (in addition to national cancer audits, COSD conformance framework, incidence and survival) data for the health care and cancer analytical community, for which login access is needed: <a href="https://nww.cancerstats.nhs.uk/users/sign_in">https://nww.cancerstats.nhs.uk/users/sign_in</a> The NCRAS CancerData system provides cancer data and analysis that is safe to release in the public domain including cancer mortality data: <a href="https://www.cancerdata.nhs.uk/mortality">https://www.cancerdata.nhs.uk/mortality</a> and www.cancerdata.nhs.uk/dashboard	2001-2016	England; Cancer Alliance; CCG
Portal with statistics on all cancer mortality, including premature mortality, by various geographies compared with England: http://www.localhealth.org.uk/#l=en;v=map13	2011-2015	England; NHS sub-region; CCG; Ward
Longer Lives highlights premature mortality across every local authority in England: https://healthierlives.phe.org.uk/topic/mortality	2014-2016	England District & UA; County & UA

#### Other sources of statistics and information

- The legacy NCIN website has a number of publications around mortality that can be found under the publication section of the website: <a href="http://www.ncin.org.uk/publications/">http://www.ncin.org.uk/publications/</a> for example a report on mortality in the first year after ovarian cancer diagnosis.
- 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/healthprofessional/cancer-statistics/mortality#heading-Zero
- 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/

- Macmillan Cancer Support produced the following report in 2013, assimilating data focusing on the cancer burden by 2020 and associated mortality: https://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013executive-summary-FINAL.pdf
- Mortality statistics in Scotland: https://www.gov.scot/Topics/Statistics/Browse/Health/TrendMortalityRates
- Mortality statistics in Wales: http://www.wcisu.wales.nhs.uk/cancer-mortality-in-wales
- Mortality statistics in Northern Ireland: http://www.qub.ac.uk/researchcentres/nicr/CancerInformation/official-statistics/

#### 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: <a href="http://gco.iarc.fr/">http://gco.iarc.fr/</a>
- 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
- GLOBOCAN also provides UK and worldwide mortality (and incidence) predictions for up to 2035. 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: http://globocan.iarc.fr/Pages/burden\_sel.aspx
- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD)
  provides topical cancer mortality statistics for Germany from 1999 2015. In an
  interactive database query, information on incidence, mortality rates, prevalence and
  survival rates for different types of cancer can be obtained:
  <a href="http://www.krebsdaten.de/Krebs/EN/Database/databasequery\_step1\_node.html">http://www.krebsdaten.de/Krebs/EN/Database/databasequery\_step1\_node.html</a>
- The National Cancer Institute (NCI) provides access to reports and interactive tools containing cancer incidence information (1999 – 2015) across the USA. This data can be segmented by state and a range of demographic factors: https://surveillance.cancer.gov/statistics/types/incidence.html

#### 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 net survival.

Net survival can be defined as the survival of cancer patients where competing causes of death, approximately equal to population mortality rates, are removed, leaving cancer as the only possible cause of death. Net survival is a more

appropriate estimate for international comparisons because it is independence of general population mortality.

### Where to find the key statistics?

Location	Years covered	Geography
Adult cancer survival. 1-year, 5-year and 10-year age-standardised net cancer survival for tumours diagnosed in England during 2011 to 2015 and followed up for at least one whole calendar year (to 31 December 2016), for the 25 most common cancers.  https://www.ons.gov.uk/peoplepopulationa ndcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivaline ngland/adultstageatdiagnosisandchildhood patientsfollowedupto2016	2011-2015	England
Adult cancer survival by stage at diagnosis. 1-year age-standardised net cancer survival for tumours diagnosed in England in 2015 and followed up for at least one whole calendar year (to 31 December 2016), with an estimate of survival from nine common cancers separately. https://www.ons.gov.uk/peoplepopulationa ndcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivaline ngland/adultstageatdiagnosisandchildhood patientsfollowedupto2016	2012-2015	England
Childhood cancer survival in England: patients followed up to 2017. Long-term survival trends for children (aged 0 to 14 years) diagnosed with cancer in England. https://www.ons.gov.uk/peoplepopulationa ndcommunity/healthandsocialcare/conditionsanddiseases/datasets/childhoodcancers urvivalinengland	2001-2017	England
Geographic patterns of cancer survival in England: Adults diagnosed 2011 to 2015 and followed up to 2016: https://www.ons.gov.uk/peoplepopulationa ndcommunity/healthandsocialcare/conditio nsanddiseases/bulletins/geographicpattern sofcancersurvivalinengland/adultsdiagnose d2011to2015andfollowedupto2016	2011 - 2015	England; NHS Region; Cancer Alliance; STP
Index of cancer survival for Clinical Commissioning Groups in England: adults	2000 - 2015	England; STP; CCG

diagnosed 2000 to 2015 and followed up to	
2016. One-year cancer survival for all-	
cancers combined; for breast, colorectal	
and lung cancer separately; and for these	
three cancers combined	
https://www.ons.gov.uk/peoplepopulationa	
ndcommunity/healthandsocialcare/conditio	
nsanddiseases/bulletins/indexofcancersurv	
ivalforclinicalcommissioninggroupsinenglan	
d/adultsdiagnosed2000to2015andfollowed	
upto2016	

#### Other sources of statistics and information

- Cancer survival statistical bulletin methodology: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/methodologies/cancersurvivalstatisticalbulletinsgmi
- 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:S108S115. See: https://www.nature.com/articles/bjc201549
- A number of publications on survival by stage are available on the NCRAS website: www.ncin.org.uk/publications/survival\_by\_stage
- 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/
- One-year and five-year cancer survival in England and Wales (2015): https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/condition sanddiseases/datasets/cancersurvivalratescancersurvivalenglandandwalesoneandfive yearsurvivalofpatientsmajorcancerssexandage
- Northern Ireland cancer registry data: http://www.qub.ac.uk/researchcentres/nicr/CancerInformation/official-statistics/
- Scotland cancer registry data: http://www.isdscotland.org
- Wales cancer registry data: http://www.wcisu.wales.nhs.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
- 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

#### 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)620389/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:

#### https://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/
- 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: <a href="http://www.eurocare.it/">http://www.eurocare.it/</a>
- The Centre for Cancer registration Data (Zentrum für Krebsregisterdaten, ZfKD)
  provides cancer survival rates for patients diagnosed between 2007-2014 in Germany.
  In an interactive database query, 1-10 year survival crude/age standardised survival
  rates can be obtained for different types of cancer:
  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 (1975-2013) and 5 year survival (2006-2012) for all cancer sites are also available: <a href="https://seer.cancer.gov/csr/1975\_2013/">https://seer.cancer.gov/csr/1975\_2013/</a>
- Paper published by A.J. Breugom et al. in 2018 examined 'Oncologic treatment strategies and relative survival of patients with stage I–III rectal cancer A EURECCA international comparison between the Netherlands, Belgium, Denmark, Sweden, England, Ireland, Spain, and Lithuania' European Journal of Surgical Oncology, Volume 44, Issue 9, September 2018, Pages 1338-1343, see: <a href="https://www.sciencedirect.com/science/article/pii/S0748798318310795">https://www.sciencedirect.com/science/article/pii/S0748798318310795</a>

# Improving experiences of care, treatment and support

#### **Treatment**

#### 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. The national cancer audits currently undertaken include Lung; Bowel; Head and Neck; Oesophago-Gastric; Prostate; National Cancer Diagnosis Audit (NCDA); and National Audit of Breast Cancer in Older Patients (NABCOP). The intention is that all acute NHS trusts that provide any type of service for relevant groups of cancer patients should participate in these audits, collecting and reporting a complete dataset on each of their patients. This will allow valid comparisons to be made between trusts, taking account of case-mix variations (e.g. stage of disease, age and co-morbidity). These comparisons should in turn help to drive up quality.

#### Where to find the key statistics?

Location	Years covered	Geography
Statistics on patients receiving chemotherapy, radiotherapy and surgical tumour resections, for all cancer types: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/main_cancer_treatment s	2013 - 2015	England; Cancer Alliance
Statistics on Radiotherapy Data Set (RTDS) can be found on the CancerStats portal requiring an account and secure N3 internet connection (see Glossary):  https://nww.cancerstats.nhs.uk/rtds	2009/10 - 2018/19	England; Cancer Alliance; Trust
Statistics on Systemic Anti-Cancer Therapy (SACT) can be found on the CancerStats portal requiring an account and secure N3 internet connection: https://cancerstats.ndrs.nhs.uk/sact	2017-2018	England; Trust
Chemotherapy: SACT workbook 30-day post-chemotherapy mortality for patients with breast cancer or non-small cell lung cancer (NSCLC) treated with curative or palliative intent in 2014, by NHS hospital trust: http://www.chemodataset.nhs.uk/view?rid=219	2014	England; Trust
Statistics on Cancer Outcomes and Services Dataset (COSD) can be found on the CancerStats portal requiring an account and N3 internet connection: https://cancerstats.ndrs.nhs.uk/cosd	2013-2016	England; Cancer Alliance; STP; CCG; Trust
National cancer audits for bowel, head and neck, Oesophago-gastric cancers: https://digital.nhs.uk/search?query=cancer+audits&r 21_r2:page=2&r21_r2:pageSize=10	2015 - 2016	England; Wales
Lung and Prostate National Cancer Audit reports 2017. Lung: https://www.rcplondon.ac.uk/projects/outputs/nlca-annual-report-2017 Prostate: https://www.npca.org.uk/content/uploads/2018/02/N PCA-2017-Annual-Report_final_211117.pdf	2015 - 2016	England; Trust. Wales
NABCOP is a national clinical audit run by the Association of Breast Surgery (ABS) and the Clinical Effectiveness Unit (CEU) of the Royal College of Surgeons of England (RCS): https://www.nabcop.org.uk/	2014 - 2016	England; Wales

#### Other sources of statistics and information

 Latest HES provisional monthly data containing inpatient care, outpatient appointments and A&E attendance records for England is from April 2017 – March

- 2018, under the publication section of NHS digital website. Annual statistics can also be found at: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics
- The national collection of all cancer chemotherapy in the NHS in England commenced in April 2012. The Systemic Anti-Cancer Therapy (SACT) dataset website contains all of the latest information available <a href="http://www.chemodataset.nhs.uk/home">http://www.chemodataset.nhs.uk/home</a>
- The 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: http://www.ncin.org.uk/collecting\_and\_using\_data/data\_collection/cosd
- Radiotherapy: A report introduces new data on the percentage of tumours diagnosed in England in 2013 – 2014, recorded as receiving radiotherapy, chemotherapy or tumour resection. It looks at the differences by cancer site and stage at diagnosis. http://www.ncin.org.uk/view?rid=3459
- Radiotherapy: A report on the radiotherapy services in England 2012 is published on: https://www.gov.uk/government/publications/radiotherapy-services-in-england-2012
- Radiotherapy: A radiotherapy dashboard is to be developed under the Specialised Services Quality Dashboard (SSQD) which is a tool for examining the quality of service and will allow services to be compared between Trusts: https://www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/
- Information on the scope and data collection for the Systemic Anti-Cancer Therapy Dataset (Chemotherapy) in England :http://www.ncin.org.uk/collecting\_and\_using\_data/data\_collection/chemotherapy
- The national collection and analysis of cancer chemotherapy data briefing is available on the NCRAS website at: http://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: http://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
- Cancer outcomes and services: 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
- National bowel cancer audit report (2016): England and Wales:https://www.nboca.org.uk/content/uploads/2017/12/NBOCA-annual-report-2017-v2.pdf
- The Head and Neck Audit (HANA) is available at: http://headandneckaudit.com/
- 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

#### **Quality of care**

#### What is it?

The quality surveillance team (QST) formerly National Peer Review Programme (NPRP) aims to improve the care of people with cancer. As part of the National Specialised Commissioning Directorates' Quality Assurance and Improvement

Framework (QAIF), it is responsible for improving quality and outcomes of clinical services by delivering a sustainable and embedded quality assurance framework for all cancer services and specialised commissioned services within NHS England.

#### Sources of statistics and information

- The latest peer review visit reports can be found under the relevant service profile on the Quality Surveillance Information System (QSIS): <a href="https://www.qst.england.nhs.uk/">https://www.qst.england.nhs.uk/</a>
- Kidney Cancer Patient Journey report presents patient views on care provided through the patient pathways from diagnosis to treatment in Scotland. https://www.kcuk.org.uk/wp-content/uploads/2012/09/kidney-Cancer-Patient-Journey-results.pdf

#### **Cancer patient experience**

#### What is it?

The National Cancer Patient Experience Survey (CPES) is undertaken by Quality Health on behalf of NHS England 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 who are invited 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.

#### Where to find the key statistics?

Location	Years covered	Geography
CPES in England: http://www.ncpes.co.uk/reports/2017-reports/local-reports-2	2017	England; Trust; CCG

#### Other sources of statistics and information

- England: A report on CPES, 2016: www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey
- English National Cancer Patient Experience Surveys linked to cancer registration data: www.ncin.org.uk/view?rid=3064
- CPES in Northern Ireland: 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-reports/702-2015-ni-cancer-patient-experience-survey-all-trusts-report/file
- CPES in Scotland: http://www.gov.scot/Resource/0050/00501127.pdf
- CPES in Wales: https://gov.wales/topics/health/publications/health/reports/report13/?lang=en

# Improving the quality of life of patients after treatment and at the end of life

#### **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.

#### Where to find the key statistics?

Location	Years covered	Geography
Prevalence data is presented by sex and cancer type and by either time since diagnosis, age at diagnosis, age in 2015, deprivation, ethnicity (10 year), or stage at diagnosis (4 year). http://www.ncin.org.uk/local_cancer_intelligence/tcst Workbooks: http://www.ncin.org.uk/view?rid=3635 and http://www.ncin.org.uk/view?rid=3579	1995 -2015	England; Region; Cancer Alliance; CCG
Macmillan-PHE Local Cancer Intelligence portal including prevalence projections: https://lci.macmillan.org.uk/England/all/prevalence	1995-2015	England

#### Other sources of statistics and information

- Macmillan produced the following infographic detailing current and future cancer prevalence in the UK: http://www.macmillan.org.uk/images/getinvolved/campaigns/generalelection2015/25million-infographic-full-jan2015.jpg?origin=GE2015-RHS
- 'The number of older people (aged 65 and over) living with cancer in the UK was set to more than treble by 2040, i.e. from 1.3 million in 2010 to 4.1 million by 2040' is a statistic quoted from a paper published by J Maddams et al. in 2012 'Projections of cancer prevalence in the United Kingdom, 2010–2040'. British Journal of Cancer 2012; 107:1195 to 1202: http://www.nature.com/articles/bjc2012366
- Macmillan published the following factsheet which includes prevalence projections: http://www.macmillan.org.uk/documents/aboutus/research/keystats/statisticsfactsheet.pdf
- Prevalence and comorbidity in London 1995 to 2014 by STP and CCG: http://www.ncin.org.uk/view?rid=3310

#### International comparisons:

- 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): <a href="http://globocan.iarc.fr/Pages/fact\_sheets\_cancer.aspx">http://globocan.iarc.fr/Pages/fact\_sheets\_cancer.aspx</a>
- The National Cancer Institute hosts cancer prevalence reports and interactive tools for the USA up to 2014: 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

#### **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 bladder; gynaecological; breast; colorectal; prostate; 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.

In 2015, the Cancer Taskforce recommended developing a national metric on quality of life which would enable better evaluation of long-term quality of life after treatment. The metric is currently being piloted by NHS England.

#### Where to find the key statistics?

Location	Years covered	Geography
PROMs report on colorectal cancer: https://www.england.nhs.uk/wp- content/uploads/2015/03/colorectal-cancer-proms- report-140314.pdf	2013	England
Living with and beyond cancer - pilot PROMs on bladder cancer: https://www.england.nhs.uk/wp-content/uploads/2015/10/proms-bladder-cancer.pdf	2013	England
Quality of Life for Gynaecological Cancers: Patient	2014	England

Report Outcome Measures (PROMs) Report Living with and beyond cervical cancer: http://www.ncin.org.uk/view?rid=2922 Living with and beyond ovarian cancer: http://www.ncin.org.uk/view?rid=2920 Living with and beyond womb cancer: http://www.ncin.org.uk/view?rid=2921		
This report sets out baseline activity data from January to March 2017 for Stratified Follow Up and Recovery Package interventions. https://www.england.nhs.uk/wp-content/uploads/2018/07/national-living-with-and-beyond-cancer-baseline-activity.pdf	2017	England
PROMs analysis on colorectal cancer: https://www.england.nhs.uk/wp- content/uploads/2015/03/national-level-tool- 080114.xlsx	2013	England
The PROMS pilot survey PROMS on Quality of life of cancer Survivors in England with a primary diagnosis of breast, prostate, colorectal cancer and non-Hodgkin's lymphoma:  www.gov.uk/government/publications/cancer-survivors-give-their-views-in-pilot-survey	2011	England

#### Other sources of statistics and information

- 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: https://bmjopen.bmj.com/content/3/4/e002317.short
- Quality of Life of Cancer Survivors in England: Analysis of Patients' Free Text Comments:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/213317/NCSS\_PROMs\_text\_analysis\_report\_Final\_Report\_040213.pdf

#### International comparisons:

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

### 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 the are to be reduced. Many of the sources included in this report have analysis broken down by age, sex, ethnicity and deprivation.

#### Where to find the key statistics?

Location	Years covered	Geography
Cancer deaths by place and deprivation: http://www.ncin.org.uk/view?rid=3532	2011-2015	England
NCRAS report on equality metrics: www.ncin.org.uk/view?rid=2991	2013	England
Survival rates of cancer patients were investigated by travel time to their nearest hospital with a relevant multidisciplinary team (MDT) for breast, prostate, lung and colorectal cancer: <a href="http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/travel_times">http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/travel_times</a>	2004-2015	England
Report on the impact of travel time on rates of treatment with radiotherapy: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/travel_times	2013-2015	England

#### Other sources of statistics and information

- 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 focusing on variation by age, especially older people (2015): www.ncin.org.uk/view?rid=2950
- A report (2016) looking at variation by urban/rural status, social/socioeconomic deprivation, and age in incidence, survival, stage, treatment and comorbidity for cancer patients in Republic of Ireland: https://www.ncri.ie/publications/statisticalreports/cancer-inequalities-ireland
- Awareness measure tool (see section on cancer awareness above) provides a range of statistics by socio-economic group https://www.cancerresearchuk.org/healthprofessional/awareness-and-prevention/the-cancer-awareness-measures-cam
- 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 NEoLCIN published a report on 'Deprivation and death: Variation in place and cause of death' (2012): http://www.endoflifecare-intelligence.org.uk/home
- An article examining the cancer https://bmjopen.bmj.com/content/4/2/e004567
   Geographic inequalities are accessible via the public health outcomes framework for measure on early staged cancers and screening: https://fingertips.phe.org.uk/profile/public-health-outcomes-framework/data#page/0

## Whole pathway

This section presents sources of information that contain key statistics on a number of elements of the cancer patient pathway.

#### Where to find the key statistics?

Location	Years covered	Geography
'Cancer and tumours focus pack tool': http://tools.england.nhs.uk/cfv2016/cancer/atlas.html 'Data and Metadata': Workbook containing data used in the focus packs and tools: https://www.england.nhs.uk/rightcare/products/nhs- rightcare-intelligence-tools-and-support/	2006- 2015	England; CCG
'Where to look pack' contains data on variation and performance for each CCG: https://www.england.nhs.uk/rightcare/products/ccg-data-packs/where-to-look-packs/	2015/16	England; CCG
An overview of spend and outcomes for local authorities and CCG: https://www.gov.uk/government/publications/spend-and-outcome-tool-spot	2015- 2017; 2014- 2015	England; Local Authority; CCG
Demographics, screening, diagnosis, and 2-week waiting times data: https://fingertips.phe.org.uk/profile/cancerservices/data	2012- 2017	England; NHS Sub- region; STP; CCG; GP practice
Integrated cancer dashboard comparing performance against other similar organisations or the England average and tracking progress over time where data are available: <a href="https://www.cancerdata.nhs.uk/dashboard">www.cancerdata.nhs.uk/dashboard</a>	2013- 2015	England; CCG; Trust
Cancerstats portals, requiring N3 connection, contains various sources of data across the patient pathway including incidence, mortality and treatment: https://nww.cancerstats.nhs.uk and https://cancerstats.ndrs.nhs.uk/	Various	England; Cancer Alliance; CCG; Trust
Cancer Research UK Statistics on diagnosis and treatment: http://www.cancerresearchuk.org/health-professional/cancer-statistics/diagnosis-and-treatment	2013- 2014	UK
Macmillan cancer statistics tool on prevalence, incidence, mortality, patient experience: https://lci.macmillan.org.uk/England/	2015	England; CCG
Local Health presents data on incidence and mortality: http://www.localhealth.org.uk	2011- 2015	England; NHS Sub-region; CCG

#### Other sources of statistics and information

 The Pathfinder report is UK wide, published 2016 and uses data from CRUK's Cancer Awareness Measure survey, 2010, linked with cancer survival data from NCRAS:

https://www.targetovariancancer.org.uk/sites/default/files/Pathfinder-2016.pdf

## **Glossary of terms**

ABS	Association of Breast Surgery
ASR	age-standardised rate
BCSP	Bowel Cancer Screening Programme
BCOC	Be Clear on Cancer awareness campaign
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
HANA	Head And Neck Audit
HES	Hospital Episode Statistics
IARC	International Agency for Research on Cancer
ISD	Information Services Division
LSHTM	London of School of Hygiene and Tropical Medicine
LUCADA	The National Lung Cancer Data Audit
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
N3	The N3 Network is a secure IP network that facilitates the legal sharing of potentially identifiable information
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 (NCRAS from 2016 onwards)

NCRS	National Cancer Registration Service (NCRAS from 2016 onwards)
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
UA	Unitary Authorities (county or district)
UKCIS	UK Cancer Information System
UKIACR	UK and Ireland Association of Cancer Registries
WMCIU	West Midlands Cancer Intelligence Unit (incorporated into NCRAS)

#### References:

- 1- https://www.nature.com/articles/s41416-018-0029-6
- 2- https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/adultsmokinghabitsingreatbritain/2017
- 3- https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/condition sanddiseases/methodologies/agovernmentstatisticalserviceperspectiveonofficialestima tesofcalorieconsumption