Public Health England

Protecting and improving the nation's health

The National Cancer Registration and Analysis Service

A guide to cancer data and working with us

March 2020

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, research, 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.

Corporate member of
Plain English Campaign
Committed to clearer
communication
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SUSTAINABLE
DEVELOPMENT GOALS

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Background

This document has been produced by the National Cancer Registration and Analysis Service (NCRAS) in Public Health England (PHE), with the support of the PHE Cancer Stakeholder Coordination Group chaired by Professor Sir Mike Richards. The Group brings together relevant partners and stakeholders to facilitate shared thinking and evolvement across the cancer activities that NCRAS is involved in, and to ensure that the most important issues for the whole system are addressed.

The purpose of this document is to provide NCRAS stakeholders, which include patient representatives, charities, academic, NHS organisations and industry partners, with details of cancer data collated and quality assured by the NCRAS, the outputs NCRAS produces and the range of ways that others can access the data and work with us.

This document is intended as an overview to NCRAS and a signposting guide. Links have been included throughout so that readers can easily find more detailed information should they need it.

It should be noted that PHE also holds non-cancer data: Further information about PHE datasets including national cancer screening programme data is available through the Office for Data Release.

Updating the guide

This document will be updated every 6 months. If you wish to provide feedback or suggest an edit or update, please send details to: NDRSengagement@phe.gov.uk

Introduction

Disease registration is central to public health and healthcare. PHE's National Disease Registration Service (NDRS) includes the National Cancer Registration and Analysis Service (NCRAS), one of the largest, most advanced and complex cancer data curation service anywhere in the world and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

NCRAS provides near-real time, cost-effective, comprehensive, quality-assured data services covering the entire cancer pathway on all patients in England.

The service collects data about, and then follows-up, all 500,000 patients diagnosed with cancer in England each year, over 300,000 of which are new diagnoses of invasive cancer. NCRAS builds a longitudinal, health-care event-based linked dataset on every cancer patient. It creates a data curation and linkage service that can be used to identify patients with a diagnosis of cancer. We provide expert analysis and interpretation of the data and it is used as a source of intelligence for patients, clinicians, public health, health-care performance, basic and applied research, and commissioning and industrial partners.

NDRS employs over 360 staff and collects and quality-assures data on all cancers, congenital anomalies and rare diseases diagnosed in England.

Number of staff* working in NDRS
(*whole time equivalent)

- Cancer registration (153)
- Non-cancer (112)
- Cancer analysis (47)
- SACT paternership (17)
- Office for Data Release (8)
- Genomics (7)
- Management (5)
- Engagement (3)

153 | 112 | 47 | 17 | 8 | 7 | 5 | 3
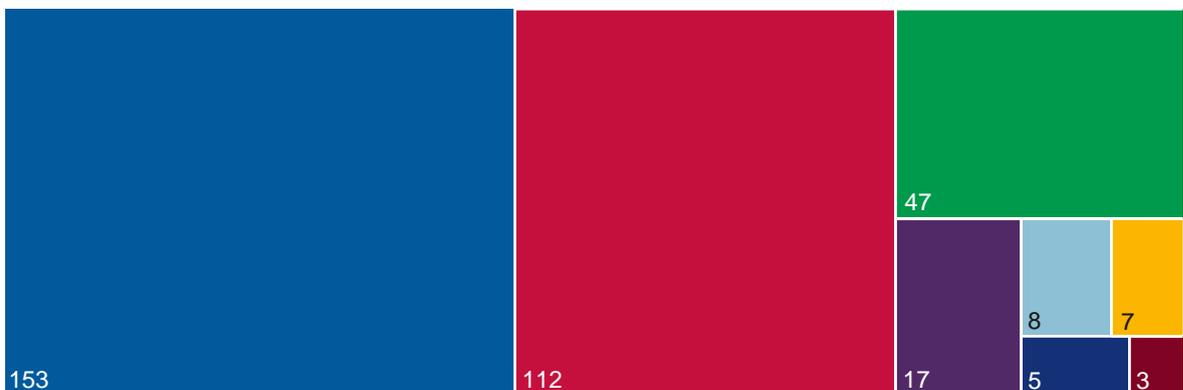
Cancer registration is a complex process. A wide range of information is received and used to develop a rich data resource over time. Data are submitted by NHS hospitals and reviewed by skilled Cancer Registration Officers with the assistance of automated tools for data linkage and de-duplication of identical data sources. Review of the data includes manual extraction and interpretation of data from text-based pathology reports. Cancer Registration Officers require detailed knowledge of cancer biology, coding and medical terminology.

In 2019 the International Journal of Epidemiology published 'Data Resource Profile: National Cancer Registration Dataset in England', which gives a useful overview of the overall process and data collected.

NCRAS has a team of analysts and epidemiologists who use the registration data to produce a range of outputs including official statistics and data tools. The team quality assures and links the data to other data sources such as Hospital Episodes Statistics (HES) data and prepares research datasets for release to external researchers via the Office for Data Release.

Putting security and confidentiality first

The information we hold is crucial to improving the way cancer patients are treated and services are provided, but we know it's also highly sensitive and very personal. For this reason, security and patient confidentiality are at the forefront of everything we do.

We have a special legal permission to collect patient information without needing a patient's consent. This is granted to us under Section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002. The NHS Act 2006 and the Regulations enable the common law duty of confidentiality to be lifted so that confidential patient information can be processed without there being a breach of the common law duty of confidentiality.

NCRAS knows that many people are concerned about the security of data collection and therefore applies the strongest form of encryption to the data they hold. Data about an individual's health is highly sensitive, and so great care is taken over the way it is collected, stored, and analysed. There is also an obligation to the National Data Guardian to ensure all sensitive data is strongly encrypted and stored on NHS compliant secure servers. The data is only accessible by staff who have been vetted and operate under the strictest of controls. Security procedures are regularly reviewed to make sure that all systems use the most up to date and effective ways to protect patient data.

We are aware that some people do not want their information held by NCRAS and we uphold the individual's right to opt out of cancer registration. Information is provided to Trusts and other locations such as GP surgeries and radiotherapy centres, to help inform patients about cancer registration and their right to opt-out should they wish.

For more information about your right to opt-out and frequently asked questions about how we protect and share patient data please go to our public facing website www.ndrs.nhs.uk.

Cancer registration - the data journey

1 The patient

The patient's cancer journey is the source of the data

2 Patient's data is created and collected

... by their NHS healthcare team. NCRAS* supports hospitals to code and collate the data

3 Data sent to NCRAS Cancer Registration Teams

... who securely collate and quality assure the data

4 Data is put in to a secure central system

... where it can be linked with data sources from other organisations

5 The data is then used by†:

NCRAS analysts, researchers, charity organisations, NHS, policy makers and commissioners

To inform and improve a range of functions, including:

Future NHS services for cancer, NHS workforce for cancer, understand and address inequalities, environmental causes, better outcomes for patients

*National Cancer Registration and Analysis Service, run by PHE

†Patient data is only released under strict regulations and for medical purposes

What are our key achievements?

- The **quality, range and timeliness** of data we now collect: over the last 7 years through a combination of new technologies and the restructuring of the regional cancer registries we have created a single service that has increased the quality, timeliness and richness of data collected while cutting costs by 30%.

Improving data quality, completeness and consistency
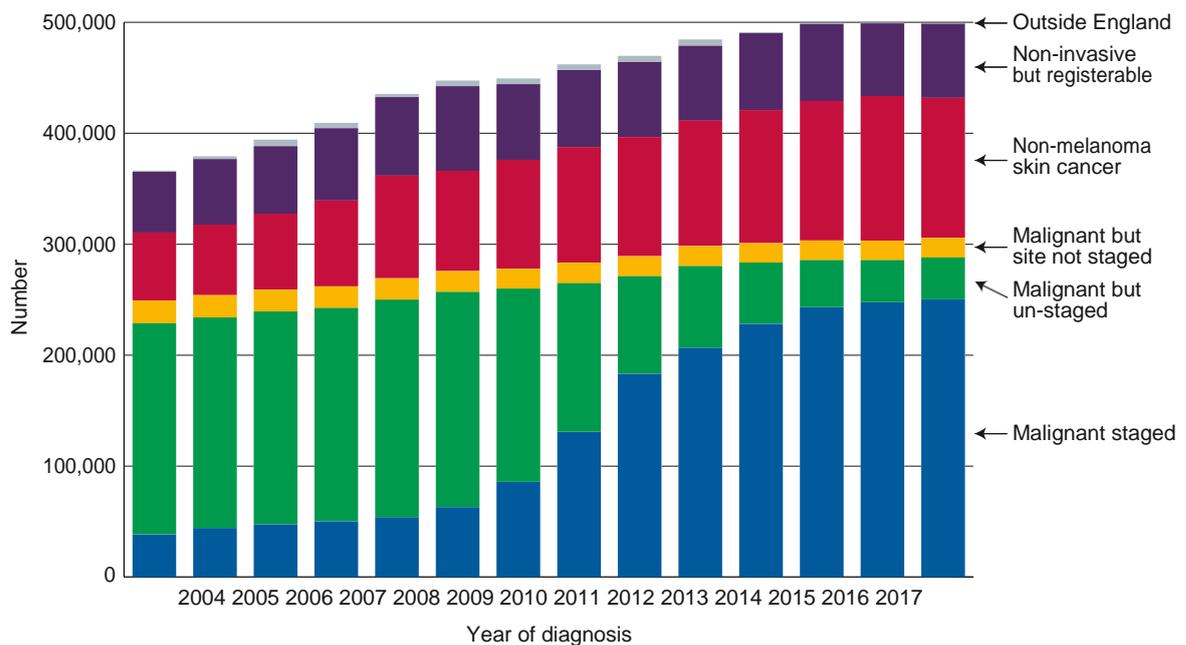
- We developed the award-winning Routes to Diagnosis which significantly changed healthcare policy and commissioning of cancer services by describing and quantifying the different patient routes or pathways to a cancer diagnosis. This has been expanded to now include breakdowns by Cancer Alliance as well as routes for children and teenagers. It is maintained annually.

- From 2020 NCRAS will produce the official and national statistics on cancer. This includes reports on cancer diagnoses and age-standardised incidence rates for all types of cancer by age, sex and region, and reports on cancer survival statistics, including 1-year, 5-year and 10-year net-survival estimates by cancer type, patient age, sex and stage at diagnosis.

- We improved the collection and recording of cancer stage at diagnosis so that this is now nationally reportable on a quarterly basis and can be used to better measure outcomes for cancer patients – including the NHS Long Term Plan ambition to diagnose 75% of patients at an early stage.

- With multiple data sources and dataset linkage we are able to demonstrate treatment variations across the patient pathway by geography, cancer type and measures of inequality.

- The Radiotherapy (RTDS) and Systemic Anti-Cancer Therapy (SACT) Datasets have been instrumental in informing decisions on the Cancer Drugs Fund and the roll out of Linear Accelerators as part of the national cancer plan.

Cancer Drugs Fund

Since July 2016, the National Institute for Health and Care Excellence (NICE) has been appraising all new cancer drugs, including those made available through the new Cancer Drugs Fund (CDF). The CDF aims to make promising treatments available to patients while NICE decides whether treatments should be approved routinely on the NHS.

A fundamental element, integral to the success of the CDF, is the cancer data partnership between NHS England and PHE. The partnership provides insights into patient outcomes, including duration of treatment and survival, based on routinely reported data, including data from the Systemic Anti-Cancer Therapy dataset. Our CDF reports together with clinical trials data inform NICE committee decision making on whether a drug should be made available to patients routinely on the NHS.

Since the introduction of the reformed CDF in July 2016, over 21,600 patients have been approved for treatment with a drug undergoing live data collection to address the uncertainty identified by NICE committees. The number of positive recommendations from NICE has risen from 64% pre-June 2016 to 89% July 2016 onwards. This increase is also seen across rare cancers (increase 63% to 91%). Real-world data reported by PHE is the primary information used to answer NICE uncertainty for 25% of CDF treatments.

- A wide range of **analytical partnerships** have successfully demonstrated that working collaboratively across the health sector increases the breadth and depth of the work that NCRAS data underpins.

- Working with partners at the Clinical Practice Research Datalink (CPRD) we provide cancer registration data that can be **linked with CPRD data** (this is data from primary care) and then disseminated in a depersonalised format by CPRD (via NHS Digital) to external researchers to access and analyse, subject to prior approval by the CPRD Independent Scientific Advisory Committee.

- Working with other UK cancer registries we have published an improved methodology for calculating a more representative incidence of non-melanoma skin cancers: the new method identifies the first basal and cutaneous squamous cell carcinoma (BCC and cSCC) per patient per year, picking up an additional 51% tumours compared to previous counts.

How patient data supports treatment decision making

Patient data was analysed to understand how well different treatments have worked in the past for breast cancer patients after they had surgery. The results were gathered together to create an online tool called Predict which helps new breast cancer patients and their doctors choose a treatment plan together. The tool uses data about the survival of women with similar characteristics and medical history to show patients and doctors the likely benefit of different types of treatment. Then doctors and patients can decide if the benefits of a treatment outweigh the side effects of that treatment and choose the best plan together. Predict is now used as a clinical consultation tool in the NHS and has also been expanded to cover prostate cancer.

What data are collected?

We collect data on all tumours[1] diagnosed each year in England. NCRAS receives about 25 million records annually in order to register these cancers.

Data items are aligned where possible to follow international standards such as:

- topography and morphology (World Health Organization ICD-O classification)
- stage (Union for International Cancer Control TNM)
- basis of diagnosis (European Network of Cancer Registries)

Where international standards do not exist, data items have been defined in the Cancer Outcomes and Service Dataset following consultation with relevant clinical services.

In 2018 there were 501,399 registrations in total of which 435,445 were malignant, including 118,765 non-melanoma skin cancers (NMSC). Cancer incidence figures are usually quoted without NMSC included, because the policies and practices for the recording of NMSC have varied among the cancer registries and the numbers are known to be an underestimate. Therefore in 2018 there were 316,680 new cancer diagnoses excluding NMSC.

Data on cancer registrations are published as National Statistics: 2018 data was published in January 2020.

These records are submitted by 162 health care providers, which incorporate around 2,000 multidisciplinary teams (MDTs). As cancer care is often delivered at different hospitals, information may relate to patient episodes at many organisations, which can introduce inconsistencies in the incoming data. The Cancer Registration Officers will examine all data sources and, if necessary, seek additional source information from primary or secondary care via correspondence or direct interrogation of hospital radiology or electronic health records via remote secure access.

We collect data from multiple sources on people diagnosed with or a condition that could lead to cancer including:

- pathology laboratory reports
- oncology records
- diagnostic imaging reports
- treatment records
- molecular laboratory reports
- hospital activity records

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1 With the exception of benign tumours outside the central nervous system.

- Multi-Disciplinary Team (MDT) meeting records
- cancer management systems
- patient administration systems
- clinical cancer audits
- screening services
- death certificates (from the Office for National Statistics)
- hospices
- GPs
- community prescribing services

1700
Multidisciplinary
Team meetings

162
providers

142
Chemotherapy
centres

56
Radiotherapy
centres

82
Breast screening
centres

22
Molecular
testing labs

26+
other sources

The specific datasets collected are described in the next section.

NCRAS provides rapid feedback to the hospitals and MDTs about the quality and completeness of the data that have been submitted. Interactive online reports are provided on the secure CancerStats2 portal which is available to users within the NHS.

Following initial registration by a Cancer Registration Officer, a 6-month period is allowed for treatment to occur, the health care provider to submit data and the data to be processed. The registration is then reviewed and finalised. This time lag results in improved data completeness and quality, but it prevents the publication of more timely data. When each year of data is assessed as being complete, it is released to produce national statistics, approximately one year following the end of a diagnosis year.

NCRAS will continue to process any data received about new tumours, and thus the number of cancer registrations for previous years may increase slightly, for example because of late submission of data from health care providers, or due to seeking further data after initial notification via death certificate.

Datasets curated by NCRAS

A comprehensive list and description of the PHE datasets, linkage and availability can be found here. In the table below, we provide an overview of the key datasets and those that we link to.

Dataset	Description
Cancer Outcomes and Service Dataset (COSD)	The Cancer Outcomes and Services Dataset (COSD) is the national data standard for reporting cancer in the NHS in England and is collected and managed by NCRAS; it has been mandated/collected since 2013. It is the overarching framework that describes the cancer datasets collected in England. The COSD data structure is extensive, containing 489 items in version 8 and covers clinical and pathological items. The data structure specifies the information to be sourced from a number of datasets, such as operational data on patient waiting times, treatment data including surgery, chemotherapy and radiotherapy, and mortality data.
National Cancer Registration Dataset	NCRAS merges data from multiple datasets to create the National Cancer Registration Dataset. This dataset contains 3 types of tables for patient information, tumour information and treatment information, which are linked by NHS number. The national cancer registration dataset includes a subset of COSD, as well as the Route to Diagnosis for each tumour, Charlson co-mobidity, and information from the Index of Multiple Deprivation (IMD).
Systemic Anti-Cancer Therapy (SACT) dataset	Since April 2012 NCRAS has collected data on systemic anti-cancer therapy (SACT) activities, which includes chemotherapy, from all NHS England chemotherapy providers to create the SACT dataset. The SACT dataset collects clinical information about treatments given to patients.
Radiotherapy dataset (RTDS)	Introduced in 2009, the Radiotherapy Dataset (RTDS) is the national data standard for collecting information about radiotherapy treatment. The RTDS collects data from all NHS Acute Trust providers of radiotherapy services in England, who submit data to NCRAS monthly.

Dataset	Description
Somatic molecular dataset	NCRAS has been collecting somatic molecular data from 2016 onwards. Somatic tests are performed directly on tumour tissue to identify molecular abnormalities that are specific to the tumour and not present elsewhere in the body. We record all aberration types, from very small variants at the DNA level up to large chromosomal abnormalities. The results of somatic testing are used for cancer diagnosis, prognosis and increasingly for precision medicine to identify the most appropriate treatment for a tumour based on its molecular profile (targeted therapies).
Germline molecular dataset	NCRAS collects germline molecular data performed in individuals with a strong familial predisposition to cancer. Germline testing differs from somatic testing in that the molecular abnormalities detected are not restricted to the tumour but instead are present in every cell in the body, causing a high lifetime risk of developing cancer. Pilot data collection work has focused on the BRCA1 and BRCA2 genes, with NCRAS leading and coordinating the contribution of England and Wales to the BRCA Challenge, an international collaboration to aggregate anonymised data on variants within the BRCA1 and BRCA2 genes on a global scale. The germline work is also being extended to include hereditary colorectal cancer predisposition syndromes and others.
National Cancer Diagnosis Audit (NCDA)	NCRAS collects and manages data for the National Cancer Diagnosis Audit, which contains information about the diagnosis of cancer patients in primary and secondary care. Participating GPs securely submit information about the primary care part of the pathway for their patients who were diagnosed with cancer during the timeframe selected for the audit.
National Clinical Audits for Lung, Breast and Prostate Cancer	NCRAS manages the data collection for the National Lung Cancer Audit, the National Prostate Cancer Audit and the National Audit for Breast Cancer in Older Patients.

Datasets linked by NCRAS to the Cancer Register

NCRAS link registration data to additional datasets collected through other organisations such as NHS Digital. This data linkage enables more comprehensive analysis of cancer data for public benefit.

Dataset	Description
Hospital Episodes Statistics (HES)	The Hospital Episode Statistics (HES) dataset is collected and managed by NHS Digital and contains administrative data on hospital admissions within the NHS. This includes inpatient, outpatient and A&E attendances and appointments. It is used by the NHS to allow hospitals to be paid for the care they deliver.
Diagnostic Imaging Dataset (DID)	The Diagnostic Imaging Dataset (DID) collected by NHS Digital contains information on diagnostic imaging tests carried out by the NHS. It includes details about the type of test used, where on the body it was conducted, the source of referral as well as patient demographic information
Prescription data	The prescriptions data collected and managed by the NHS Business Service Authority (NHSBSA) contains details of the treatments dispensed in primary care from GPs, pharmacists, dentists and opticians. The prescriptions records for cancer patients only can be linked to cancer registration data by NHS numbers to understand more about treatments and investigate patterns in prescriptions before, during and after a diagnosis.
National Cancer Waiting Times (CWT) Monitoring data	The National Cancer Waiting Times (CWT) Monitoring dataset from NHS England includes data on the time between referral, diagnosis and treatment for cancer patients in the NHS. It is used to support the cancer waiting times standards between different points of the cancer pathway.
National Cancer Patient Experience Survey (CPES)	Commissioned by NHS England, the National Cancer Patient Experience Survey (CPES) dataset is based on surveys sent to patients asking about their cancer journey from symptoms, diagnosis and treatment to aftercare.
National Head and Neck Cancer Audit	Managed by NHS Digital, the National Head and Neck Cancer Audit collected data from hospitals in England and Wales on the diagnosis and treatment of patients with cancer of the head and neck, covering patients diagnosed up to 2014.

Patient Reported Outcome Measures (PROMs) datasets	Data from Patient Reported Outcome Measures (PROMs) data collections are held by NCRAS. PROMs surveys collect data from patients about their experience of their journey from diagnosis to aftercare. The data provides a snapshot of patient reported outcomes at specific points in time when the surveys were conducted and are not measured and collected routinely by NCRAS. Datasets held by NCRAS include bladder, breast, colorectal, gynaecological, Non-Hodgkin Lymphoma and prostate cancer snapshots.

Regular outputs

As a core part of its remit NCRAS produces a variety of reports and publications using cancer registration data, including national statistics, peer-reviewed articles in scientific journals, data reports, data tables, and cancer information tools. Since 2013 the NCRAS team has authored over 200 peer reviewed articles using cancer registration data.

In a typical year NCRAS releases outputs and data in a range of different formats. For example, in 2019, 463 major outputs and publications were released as well as numerous responses to parliamentary questions, Freedom of Information requests and ad hoc enquiries. A list of recent publications can be found in our Publications Library here.

Breakdown of release outputs by type:

- 38 Scientific papers (25 with first/last authorship)
- 168 Reports/spreadsheets/data-packs/blogs
- 45 Be Clear on Cancer metric summaries
- 37 Cancer Drugs Fund reports
- 20 External tools/updates to tools
- 50 Internal tools/signigicant updates i.e. CancerStats2
- 11 Official statistics
- 94 Cancer data releases through the Office for Data Release

How patient data can help identify other support needs of people affected by cancer

NCRAS analysed patient data to understand the risk of suicide among cancer patients in England. NCRAS found that suicide was highest within the first 6 months after a cancer diagnosis and was more common among patients with certain types of cancers (mesothelioma, pancreatic, oesophageal and lung cancer). The study has brought attention to the psychological and physical effects of cancer and the need to address the underdiagnosis and undertreatment of depression and anxiety in cancer patients. This knowledge will help to fuel further research and improvements in care to provide cancer patients with better psychological support. The published article, Risk of Suicide After Cancer Diagnosis in England, can be found here.

A range of NCRAS outputs are published and updated on a regular basis:

Output	Description	Frequency/ type	Latest data available
Cancer incidence	The numbers and rates of newly-diagnosed malignant primary neoplasms (cancer tumours) registered each year (previous bulletins produced in partnership with the Office for National Statistics).	Annual/ National Statistic	2018
Cancer mortality	The numbers and rates of people dying from cancer each year (bulletin produced in partnership with the Office for National Statistics).	Annual/ National Statistic	2017
Cancer prevalence	The number of people who are alive on a specified date and have previously been diagnosed with cancer.	Annual from 2020	2017

Output	Description	Frequency/type	Latest data available
Cancer Survival Statistics – England; Adults and Childhood	The percentage of patients who are still alive a specified time after their diagnosis of cancer (bulletins produced in partnership with the Office for National Statistics).	Annual/ National Statistic	2017
Geographic Patterns of cancer survival		Annual/ National Statistic	2016
Survival by stage - England, adults		Annual/ National Statistic	2017
Cancer survival: index for Clinical Commissioning Groups	One-year cancer survival by Clinical Commissioning Group (CCG) for all-cancers combined, 3 cancers combined, breast, colorectal and lung.	Annual/ National Statistic	2017
Stage at Diagnosis (early stage metric)	The proportion of 10 cancers diagnosed in each quarter that are recorded as presenting as an early stage case (NB this will be replaced in 2020 by the 75% stage monitoring metric).	Quarterly	2018/19 Q1 (April-June 2018)
Stage by CCG	Detailed stage breakdown by cancer site and CCG for all cancers (13 cancers and other).	Annual	2017
75% stage monitoring	Measuring progress against the Long Term Plan ambition to diagnose 75% of all cancers at an early stage – indicator currently under development.	Quarterly – to be published in spring 2020	n/a

Output	Description	Frequency/ type	Latest data available
Routes to Diagnosis	Cancer incidence breakdowns categorised by the different diagnostic routes to a cancer diagnosis.	Annual	2016
Treatment	Population-based statistics on the patients recorded to have received chemotherapy, radiotherapy and surgical tumour resections for their tumour.	Will be annual	2015
Emergency Presentations	Estimated proportion of all malignant cancers where patients first presented as an emergency.	Quarterly/ Official statistic	2018/19 Q4 (Jan-March 2019)
Radiotherapy activity	Radiotherapy activity (episodes and attendances) in hospitals for different cancers and the proportion of treatments using intensity modulated radiotherapy.	Will be annual	2017/18
30-day mortality after Systemic Anti-Cancer Therapy	30-day post-chemotherapy mortality for patients with certain cancers treated with curative or palliative intent.	TBC	2016
Chemotherapy activity	Chemotherapy activity (detail TBC) in hospitals for different cancers.	TBC	Not yet published
Recurrence	Recurrence data reported to NCRAS by hospital Trust (note this does not capture all cancer recurrences).	Annual	2017

Output	Description	Frequency/ type	Latest data available
Cancer Services Profiles	31 indicators on demographics; cancer screening; TWW referrals; diagnostic services; emergency presentations and admissions by GP practices, CCG and at National level.	Annual/ Official statistic	2018/19
Childhood cancer statistics	Incidence, survival, prevalence and mortality for cancer diagnosed among children under the age of 15 resident in England (to be expanded to UK).	Annual	2015
Practice Profiles Plus	Summary of key cancer diagnosis and referral indicators for each practice or CCG.	Annual	2017/18
Cancer Alliance reporting	Summary indicator grids containing a range of cancer metrics by Cancer Alliance, Sustainability and Transformation Partnership (STP) and Clinical Commissioning Group (CCG), compared with the national benchmark, expected values or operational standards.	Monthly	January 2020

More granular outputs are made available to authorised users via the CancerStats portal. For further information on eligibility to access Cancerstats please go to cancerstats.ndrs.nhs.uk.

Working with National and International partners

United Kingdom and Ireland Association of Cancer Registries (UKIACR)

The NCRAS is a Full Member of the UKIACR along with the:
- National Cancer Registry Ireland
- Northern Ireland Cancer Registry
- Office for National Statisics (UK)
- Scottish Cancer Registry
- Welsh Cancer Intelligence and Surveillance Unit

The UKIACR aims to promote and develop cancer registration across the UK and Ireland and provides opportunity to continually improve standards, data accuracy and providing a national picture of registration and cancer.

All 5 UK and Ireland cancer registries extract data relating to a number of performance indicators to allow comparisons of the timeliness, quality and completeness of their data. More information about the UKIACR and the performance indicators can be found here.

Internationally, we work to support the development of cancer registration in other countries including through representation at the European Network of Cancer Registries (ENCR) where we are helping develop training materials for European Cancer Registries. We are also represented on the editorial board of the WHO classification of tumours and the ICD-O (International Classification of Diseases, Oncology) which determine the international classification of tumours.

We are a member of the International Cancer BenchMarking Partnership which provides international comparisons of incidence and survival statistics and looks into possible reasons for differences.

Supporting others to access cancer data

The data that NCRAS collects and analyses can only be used for health care purposes that will benefit individuals and society; our absolute responsibility is to make sure that every individual patient's confidentiality is protected.
Access to the health records of people who have cancer is a great privilege, and everyone who works in the NDRS takes great care when handling this data. Personal data that can identify someone is only used when absolutely necessary – such as when the NHS wants to send a questionnaire to patients to get a better understanding of the effects of treatment. For almost all the research work conducted by the registration service and for the work organisations like cancer charities or academics carry out, the data we provide is anonymised or de-personalised before it is released. More information is available on the NDRS website.

How to access the data

We make cancer data available for health research purposes so that improvements in treatment and outcomes can be realised faster. We provide support for those wanting to access and work with the data. This document describes the recommended ways to access the data, for more information please contact NCRASenquiries@phe.gov.uk or ODR@phe.gov.uk in the first instance.

Accessing personally identifiable data

The PHE Office for Data Release (ODR) is responsible for managing the release of personally identifiable or de-personalised data from PHE. The ODR facilitates access to cancer registration data to applicants who demonstrate that there is a justified purpose for the data release and that there is an appropriate legal basis with safeguards in place to protect the data. Dependent on the request, ethical approval may be required. A cost may be associated with the data release, and this is agreed before work commences. Full details, including data dictionaries, are available here. Pre-application advice can be sought by contacting odr@phe.gov.uk.

The ODR maintains a data release register with details of the type of data released, to whom, for what purpose, as well as the legal basis for the release.

How NCRAS supports genetic requests

NCRAS supports NHS Clinical Genetics services by offering a family history diagnosis checking service. Individuals with a strong family history of particular types of cancer, often at an unusually young age, attend cancer genetic counselling clinics in order that a genetic cause for their cancer predisposition can be investigated, and appropriate testing or screening can be offered. Clinical Geneticists and Genetic Counsellors working in registered NHS genetics or family

cancer services can access the NCRAS secure online portal on the NHS network, into which they can input details of their patient's relative(s), along with signed consent in the case of living family members. NCRAS matches each person's details to their record in the cancer registration dataset, and returns information on the correct diagnosis to the clinical genetics service, via a secure NHS email account. This service enables the clinical geneticist or genetic counsellor to

have complete confidence of the diagnoses within the family, and thus to be able to give personalised genetic counselling and to offer the most appropriate management to their patient. In some cases, obtaining the correct diagnoses from NCRAS can completely alter the clinical management of the family.

In January 2019, the old paper-based genetic enquiries service was moved to the online portal; over the course of that year, 19,506 enquiries from clinical genetics services across the country were answered, with an average response rate of

just 3 working days. Feedback from genetics services has been overwhelmingly positive; example comments include, "It is a fantastic, easy to use service", "Find the new system user friendly and requests are returned promptly; has made requesting information much easier. Thank you!", and "It has changed my life!"

Subject Access Requests

Some people want to see the data that the NCRAS holds about them. Patients can make a request to PHE to see their data – this is called a Subject Access Request. PHE will first check the identity of the person making the request by asking for some forms of ID. As a further layer of security, PHE will only send the information to their GP or health specialist who can then verify the individual is the person making the request. The GP or health specialist will then handover the data to the individual.

Guidance on how to request this information is available via the PHE Freedom of Information (FOI) service here.

Open access data tools

Aggregated and anonymous data is released by NCRAS in publications, reports and intelligence tools. All anonymous data shared by NCRAS conforms to the Anonymisation Standard for Publishing Health and Social Care Data (ISB1523).

CancerData is the main portal to all open access sources of NCRAS cancer data. It includes publications of routine incidence, mortality, survival, pathway, stage and treatment data, along with detailed statistics released by the Get Data Out programme (see below). It also hosts the National Cancer Taskforce Dashboard, which is maintained by NHS England.

Detailed Statistics are produced as part of the NCRAS 'Get Data Out' programme of work, which safely produces public statistics about small groups of patients without compromising patient confidentiality. Patients diagnosed with a certain type of tumour are split into many smaller groups, each of which contains approximately 100 patients with the same characteristics. For each group of patients, we routinely publish statistics about incidence, routes to diagnosis, treatments and survival. To date we have published data on brain, head and neck, ovarian, pancreatic, prostate and testicular cancer.

The Simulacrum imitates some of the data held securely by NCRAS. The data is entirely artificial, so users can never identify a real person. It allows anyone to use record-level cancer data safely with no danger of breaching patient confidentiality. The data model mirrors the real one so that it can be used to write and test queries that would run on the real data. Users can run simple queries on the Simulacrum and/or use it to refine queries before submitting them to PHE's Office for Data Release to run on real data. The Simulacrum is now being used by researchers to safely test out complex queries on large datasets that they would otherwise not have access to.

PHE is committed to optimising the use of public data. Many PHE data collections and data tools adopt Open Government Licences, so they can be publicly accessed, used or shared, without any financial, legal or technical barrier. The PHE Office for Data Release facilitates Open Data releases including cancer data; these resources are published and searchable through data.gov.uk.

Fingertips provides the cancer services profiles (replacing the GP profiles) and contains data at GP and CCG level. The profiles are for commissioners and health professionals to use when assessing the impact of cancer on the local population and to inform decision making about cancer services. They include data on the Two- Week Wait referral, emergency presentations, incidence and screening.

De-identified data

CancerStats2 is NCRAS's information and reporting portal for users within the NHS. It is only accessible to authorised users on the Health and Social Care Network. It is a repository of information from datasets managed or supported by NCRAS and currently includes detailed anonymous data:

- COSD reporting portal
- Detailed Radiotherapy (RTDS) and Systemic Anti-Cancer Therapy (SACT) reporting
- Detailed Incidence, Mortality and Prevalence
- National Audits
- Life After Prostate Cancer Diagnosis Survey
- Cancer Alliance reporting suite as part of our Cancer Alliance Data, Evidence and Analysis Service (CADEAS) partnership with NHS England & Improvement:
  – Prevention (obesity and smoking prevalence)
  – Faster diagnosis (cancer waiting times, diagnostic and treatment pathways)
  – Early diagnosis (screening, emergency presentations and admissions, early stage)
  – Treatment
  – Outcomes (mortality, survival and patient experience)
  – Living with and beyond cancer

A slide-deck is available that explains the statistics and metrics available on CancerStats2.

Ad-hoc analytical queries

The NCRAS enquiries email is the central point for receiving, managing, and tracking enquiries for the NCRAS team. The enquiries email address is NCRASenquiries@ phe.gov.uk. This is managed by the analysis team on a rota system. We aim to deal with new enquiries as soon as possible, within a day or two of receiving them, and definitely within 18 working days.

Many of the enquiries we receive can be answered using the wealth of information that has already been published or released. If some specific analysis (which is not readily available) needs to be produced, it needs to be assessed if the analysis can be released, for example in case the data are potentially identifiable. If the data being requested are not readily available and significant analytical resource would be required to produce bespoke analysis, other ways of meeting the request will be suggested; if it is possible to undertake the request within existing capacity the work will be prioritised in line with existing NCRAS commitments.

All data releases are sent with a completed cover sheet to provide an overview of what, when and who produced the analysis; this may also include the SQL code used to extract the cohort and any other code used to analyse the data.

FOIs/Parliamentary Questions

NCRAS also deals with Parliamentary Questions and Freedom of Information requests relating to cancer data and analysis and prioritises resource to respond to these as appropriate.

> ### Detecting late diagnosis in women with ovarian cancer
>
> Target Ovarian Cancer used anonymous patient data collected, analysed and published by NCRAS to highlight the challenge posed by late diagnosis. In the data they saw that 20% of women with ovarian cancer have neither surgery, chemotherapy or radiotherapy and suggested that this could be because by the time they are diagnosed women are too unwell to start treatment. The charity also found that over a quarter of women with ovarian cancer are diagnosed as an emergency (for example in A&E) which can mean the cancer is diagnosed at a late stage. The charity published a data briefing and an article sharing the data from NCRAS to improve awareness of ovarian cancer with the public.

Support to access and work with the data

NCRAS enquiries can provide initial advice and signposting for someone looking for cancer data, information and tools NCRASenquiries@phe.gov.uk.

CAS explorer shows the completeness of the cancer registration data held by the National Cancer Registration and Analysis Service (NCRAS) in Public Health England (PHE). It is designed to be used by researchers and analysts to gain a better understanding of the data quality and completeness of the fields in the 3 main tables, before submitting requests to NCRAS or the Office for Data Release (ODR).

ODR including cancer registration data dictionary https://www.gov.uk/government/publications/accessing-public-health-england-data.

For support using the Simulacrum enquiries can be made to simulacrumdata@healthdatainsight.co.uk.

Models of working with us

NCRAS works with a wide range of partners including other departments in PHE, patients, healthcare staff, NHS England and NHS Improvement, NHS Digital as well as the voluntary sector, patient and campaign groups, academia and researchers. We work with others in a range of different ways including:

- collation of different cancer datasets
- advising and collaborating on grants and academic papers
- engaging with stakeholders on programmes of work
- shaping and responding to policy
- hosting and/or supporting PhD students

NCRAS operate analytical and data partnerships with other organisations to conduct specific projects using registry data within secure PHE spaces. Partnership projects must align with Public Health England's objectives to improve and protect that nation's health. Organisations can propose partnerships to work within NCRAS.

Analytical and data partnerships

The focus of the partnerships between NCRAS and external organisations, including academic research groups and cancer charities, is to improve outcomes through cancer intelligence; to deliver insightful analysis through the use of high quality routinely collected data for England and the development and application of conventional and innovative approaches and statistical techniques to cancer data.

Partnerships are created in recognition of the significant amount of additional analyses that both parties are interested in taking forward but that neither organisation would otherwise be able to progress for various reasons including analytical capacity and access to data.

There are a number of different models of partnership working.

Collaborations
These involve defined pieces of analytical work that NCRAS wishes to be directly involved in. Examples would include researchers or interns accessing NCRAS data (usually a prepared anonymous) dataset, within a secure environment, on a short-term occasional basis, with little need for supervision or involvement. This could include PhD students. Some of the pieces of work include funding from bids or grants.

Hosted analysts

These involve a defined programme of analytical work that NCRAS wishes to undertake but does not have the capacity to deliver within core resources. Analysts are employed by the partner organisation and hosted full-time within the NCRAS analytical team. A hosting cost covers NCRAS management and supervision, training, equipment and accommodation charges. Each partnership is overseen by a steering group which agrees and monitors a defined work programme for delivery during the course of the agreement, which usually lasts around 2 years.

Full PHE partnerships

These involve a significant programme of work, usually over a number of years, and potentially expanding beyond the analytical team. A full business case is negotiated via usual PHE processes and a formal SLA agreed between the partner organisations. All funding is provided by the partner and analysts are then employed as PHE posts.

An NCRAS project proposal will usually need to be drawn up prior to the agreement of any new partnership, describing the proposed piece(s) of work, including the logistics of delivery, and explaining the operational and strategic benefit to PHE.

Any analyst accessing NCRAS data in PHE space requires a PHE Honorary Contract or Visiting Worker Agreement which requires pre-employment checks. They must be working as part of a formally agreed partnership which describes the remit of the analytical work, and a specific project proposal approved by the NCRAS project panel should describe the analysis and datasets that access is required for.

Informal discussions about potential partnership opportunities should be directed to NCRASenquiries@phe.gov.uk.

Events and Communications

Cancer Data Conference and One Day Events

NCRAS organises the Cancer Data Conference each year, the UK's foremost cancer data event which brings together to share best practice and innovation to drive improvements in patient care and outcomes. Each year the conference hosts around 400 attendees from the cancer data community both in the UK and internationally over 2 days to raise awareness of the breadth of data available, showcase new methodologies and support conversations and new collaborations.

Each year we also work with partners and patients and the public to host one-day events designed to inform audiences about the data we collect, how it can be accessed and support to undertake research to support the needs of charities, policy makers, patients, carers, industry and local service providers. We aim to host at least 2 events each year.

Across NCRAS the teams also organise specific events including the Cancer Outcomes and Services Dataset Roadshow and dataset specific workshops.

If you would like further information about any of our events please contact NDRSengagement@phe.gov.uk.

Newsletter

We produce a monthly newsletter covering all activities across the National Disease Registration Service, including recent data releases, publications, events and cancer stories. To subscribe please contact NDRSengagement@phe.gov.uk.

Further Information

Please see the details below to help you find out more about PHE's National Cancer Registration and Analysis Service.

For more information on working with us please contact NCRASenquiries@phe.gov.uk.

For more information about accessing cancer registration or other data that PHE holds, please contact odr@phe.gov.uk.

To make a subject access request to access a copy of the data we hold about you please send an email to FOI@phe.gov.uk.

If you are a patient or member of the public and would like to request further information about why we collect patient data and how we use it, or to understand more about your right to opt out please see www.ndrs.nhs.uk or contact us at NDRSengagement@phe.gov.uk.

For all other enquiries please contact NDRSengagement@phe.gov.uk.

Glossary

Acronym	Meaning
BCC	Basal Cell Carcinoma
CADEAS	Cancer Alliance Data, Evidence and Analysis Service
CAS	Cancer Analysis System
CCG	Clinical Commissioning Group
CDF	Cancer Drugs Fund
COSD	Cancer Outcomes and Services Dataset
CPES	Cancer Patient Experience Survey
CPRD	Clinical Practice Research Datalink
cSCC	cutaneous Squamous Cell Carcinoma
CWT	Cancer Waiting Times
DID	Diagnostic Imaging Dataset
FOI	Freedom Of Information
HES	Hospital Episodes Statistics
MDT	Multi-Disciplinary Team
NCARDRS	National Congenital Anomaly and Rare Disease Registration Service
NCRAS	National Cancer Registration and Analysis Service
NCDA	National Cancer Diagnosis Audit
NDRS	National Disease Registration Service
NHS	National Health Service
NHSD	National Health Service Digital
NMSC	Non-Melanoma Skin Cancers
ODR	Office for Data Release
PHE	Public Health England

Acronym	Meaning
PQs	Parliamentary Questions
PROMs	Patient Recorded Outcome Measures
RTDS	Radiotherapy Dataset
SACT	Systemic Anti-Cancer Therapy (Chemotherapy)
STP	Sustainability and Transformation Partnership
TWW	Two-Week Wait
UKIACR	United Kingdom and Ireland Association of Cancer Registries
WTE	Whole Time Equivalent (relating to posts and staff)