

# **CancerStats2**

## **An Introduction to the Reporting Platform**

June 2021

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# 1. Purpose of this Guide

Disease registration is central to public health and healthcare. Public Health England's (PHE) National Disease Registration Service (NDRS) includes the National Cancer Registration and Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

This user guide focuses on the content available via the CancerStats2 reporting platform and the work of the National Cancer Registration and Analysis Service (NCRAS).

NCRAS knows that many people are concerned about the security of data collection and therefore applies the strongest form of encryption to the data it holds. 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, and that we are transparent about exactly how, when and by whom patient data is collected and used.

It is important that users of the CancerStats2 reporting platform are aware that data is only accessible by staff who have specific permission to view, use and share data and that they operate within the strictest controls. Security procedures are regularly reviewed to make sure that all systems use the most up to date and effective methods for protecting patient data.

## 2. Introduction to Cancer Registration

NCRAS is one of the largest, most advanced and complex cancer data curation services anywhere in the world. Every year the service collects information on 500,000 patients diagnosed with cancer in England, as well as detailed data about the type of cancer, how advanced it is and the treatment the patient receives.

NCRAS provides expert analysis and interpretation of the data, which is used as a source of intelligence for patients, clinicians, public health, health-care performance, basic and applied research, commissioning and industrial partners.

NCRAS has been granted specific legal permission to collect information about patients with cancer for specific purposes, without the need to seek consent. These purposes include health improvement and service provision. This permission was granted through Section 251 of the NHS Act 2006. This support is reviewed annually by the Confidentiality Advisory Group of the Health Research Authority. NCRAS data releases are subject to strict confidentiality provisions in line with the requirements of the Common Law Duty of Confidentiality, the General Data Protection Regulation (EU) 2016/679 and the 7 Caldicott principles.

NCRAS has very strict policies that cover data collection, storage and release. These policies define how data is collected, the requirements for the storage environment, the contractual arrangements for employing staff and the approvals required for any release.

Cancer registration is a complex process. A wide range of rich data sources and information is submitted by NHS trusts 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 many data sources such as text-based pathology reports and national datasets.

NCRAS has a team of analysts and epidemiologists who use the data collected to produce a range of outputs including official statistics and publicly available data tools. NCRAS also works closely with NHS Trusts to ensure that clinical teams have oversight of their own data quality and completeness prior to submission.

### 3. Overview of CancerStats2

The primary purpose of the CancerStats2 platform is to provide operational feedback to key stakeholders of NCRAS such as medical professionals, hospital cancer teams and commissioners to drive the quality and completeness of cancer data and improve outcomes for cancer patients.

CancerStats2 is a secure platform, powered by a statistical software solution (SAS). It enables key stakeholders of NCRAS to generate reports using NCRAS data on a self-service basis.

The platform was originally created to provide rapid operational feedback to NHS Trusts, following their monthly data submissions to NCRAS.

Since it was first launched in 2018, the platform has grown rapidly, with the content and functionality expanding to include:

- new datasets
- audit programmes
- NHS partnership projects
- training and guidance documentation
- molecular somatic data reporting and
- most recently the Rapid Cancer Registration Dashboard.

Users can access the platform via: <https://cancerstats.ndrs.nhs.uk/>

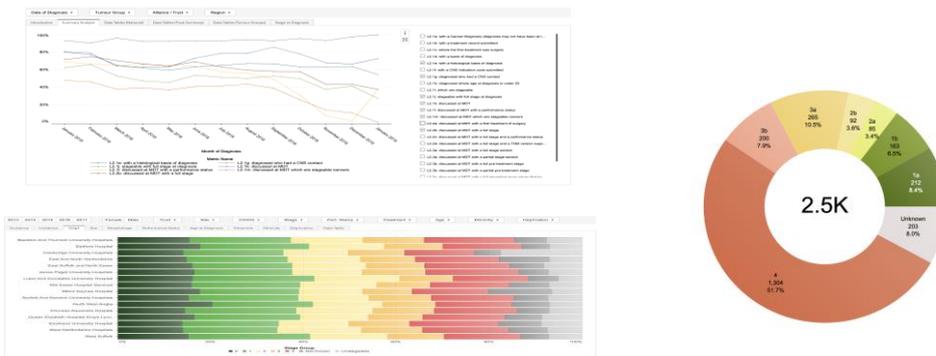
The platform requires an N3/HSCN secure network connection. To ensure the best user experience, we encourage the use of modern web browsers such as Google Chrome, Mozilla Firefox or Microsoft Edge to access the platform. A small number of platform users have reported issues when opening reports using Internet Explorer.

## 4. The Suite of Reporting Tools

CancerStats2 has a number of modules, each providing a suite of tailored reports based on that area of expertise:

### Cancer Outcomes and Services Dataset (COSD)

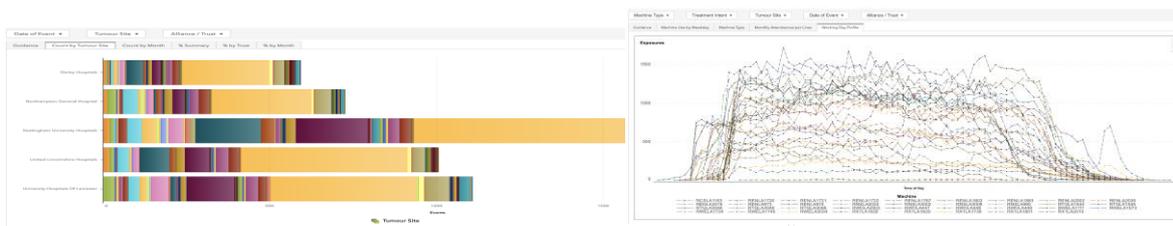
These reports have been designed to give providers of COSD and cancer data rapid, meaningful feedback on the quality of their submissions. It allows users to look at the completeness of key data items and to conduct comparisons with local, regional and national averages to calculate relative performance. All patients (adult and paediatric) diagnosed with cancer or receiving cancer treatment in or funded by the NHS in England are covered by the standard.



### Radiotherapy Dataset (RTDS)

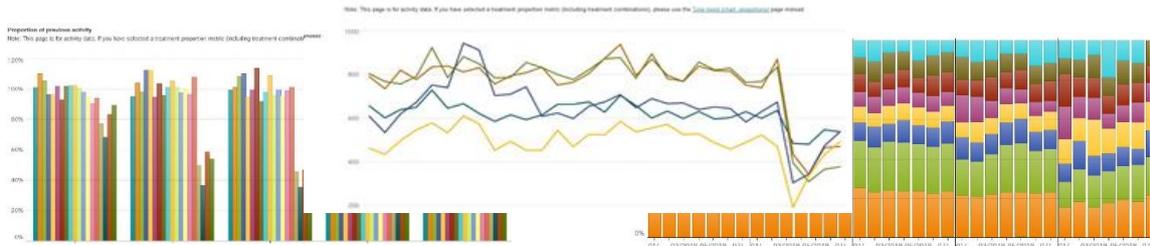
The Radiotherapy Data Set (RTDS) standard collects consistent and comparable data across all NHS Acute Trust providers of radiotherapy services in England. This data can then be used to provide intelligence for service planning, commissioning, clinical practice and research and operational provision of radiotherapy services across England.

All NHS radiotherapy activity data is collected including external beam radiotherapy



## Rapid Cancer Registration Dataset

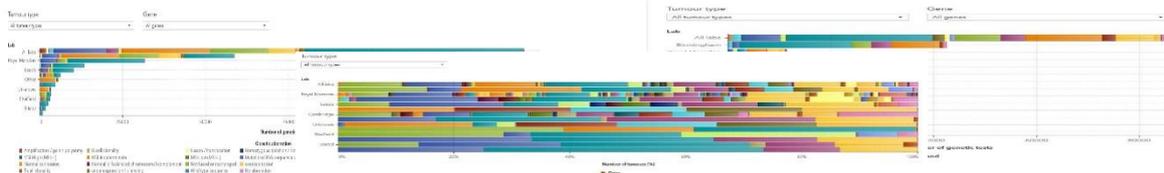
This report is designed to support cancer services in responding to the impact of the Covid-19 pandemic. It reports monthly data on the numbers of new diagnoses and surgical tumour resection procedures, along with treatment proportions (surgical tumour resection, chemotherapy, radiotherapy and combinations), from January 2018 up to recent months. It includes comparisons to the same data in the previous year. Data can be selected for England, cancer alliances or trusts. There are breakdowns by cancer groups, patient and tumour factors (e.g. age, route to diagnosis) and time to treatment.



## Somatic Molecular Dataset

The NCRAS somatic molecular dataset is a collection of data from NHS laboratories across England performing molecular diagnostics directly on tumours / cancer-derived material. These data cover genetic mutations occurring only in the tumour (i.e. somatic / acquired mutation). The dataset is not yet mandated, however many laboratories across the country have supported our efforts and submitted their data.

This report contains data for somatic molecular testing reported by regional genetics / molecular pathology laboratories.



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

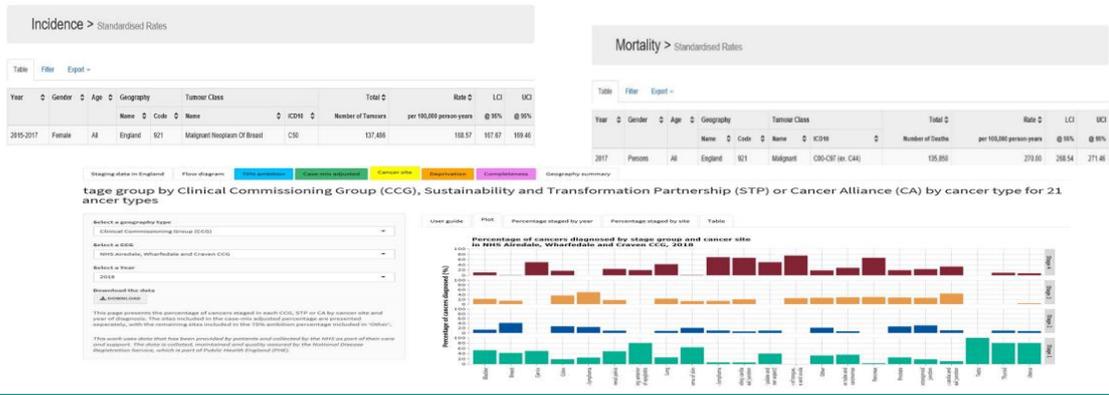
CADEAS is a partnership between NHS England and NHS Improvement and PHE, supporting the Cancer Alliances' analytical needs enabling them to lead transformation using a whole pathway and cross-organisational approach.

CADEAS has produced a range of cancer-related metrics to help drive the Alliances' evidence-based local decision making. These indicators use the latest data from a variety of sources across the cancer pathway, from operational performance and prevention through to outcomes and patient experience. There has been a pause on updating the reports during the COVID disruption due to reallocated resources.



## Cancer Incidence and Mortality

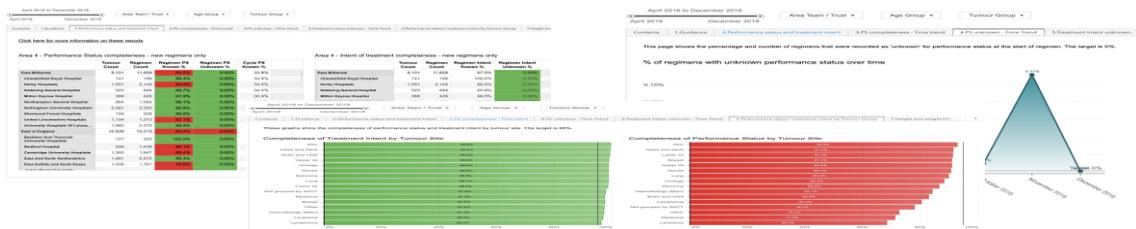
The reports show numbers, crude rates and age-and-sex standardised rates for cancer incidence and cancer mortality. Rates can be presented for different cancer sites, different time periods, and different geographies.



## Systemic Anti-Cancer Therapy Dataset (SACT)

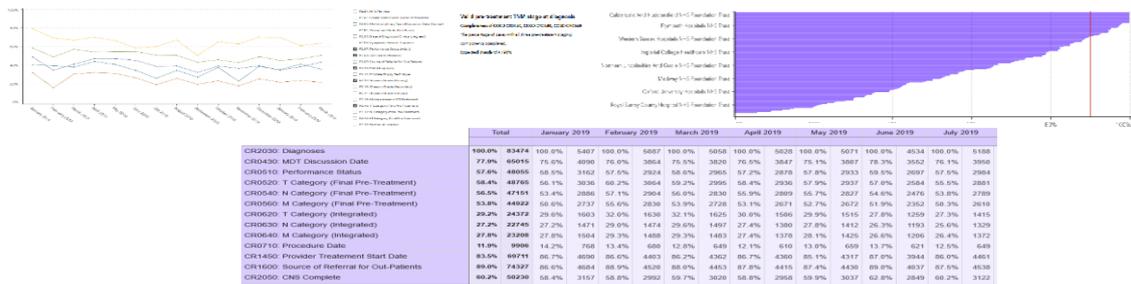
The SACT dataset collects systemic anti-cancer therapy activity from all NHS providers in England. It is a mandatory collection and the world's first comprehensive database, allowing us to understand treatment patterns and outcomes on a national scale. These detailed reports allow users to review SACT activity, data completeness and compliance for key areas.

Systemic anti-cancer therapies are increasingly successful as a treatment but are ever more complex and expensive. Accurate, timely and complete data collection is a priority and supported through electronic clinical data collection.



The national audit report modules have Level 2 data completeness reports for the key data items which the audit teams encourage Trusts to collect. There are also Level 3 data analysis reports that allow users to interrogate the data that has been published in the annual reports.

## The National Prostate Cancer Audit (NPCA)

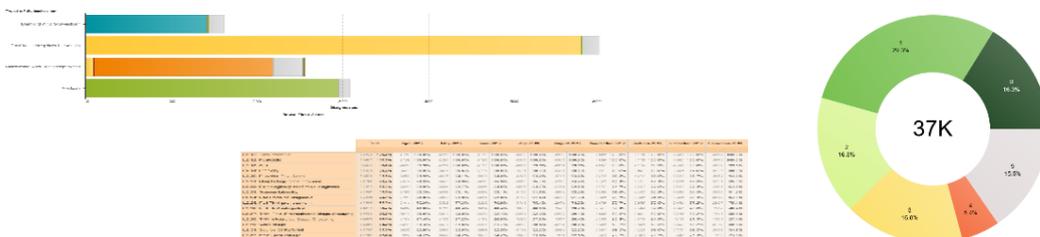


The aim the NPCA is to evaluate the process of care and its outcomes in men diagnosed with prostate cancer in England and Wales, and to promote quality improvement.

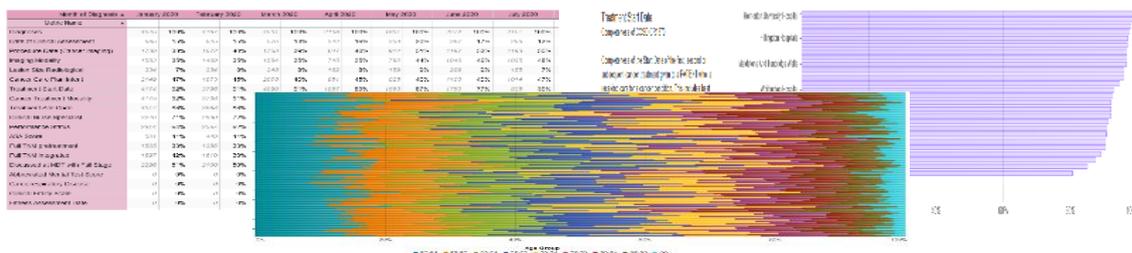
The NPCA determines whether the care that men receive following a diagnosis of prostate cancer is consistent with current recommended practice and provides information to support healthcare providers, commissioners, regulators, patient groups and patients in helping improve care.

## The National Lung Cancer Audit (NLCA)

The Royal College of Physicians (RCP) was awarded the contract to deliver the National Lung Cancer Audit in April 2015. The RCP is working in partnership with NCRAS to collect hospital and healthcare information and report on how well people with lung cancer are being diagnosed and treated in hospitals across England, Wales, (and more recently) Jersey and Guernsey. The RCP are responsible for the delivery and project management of the NLCA.



## The National Audit of Breast Cancer in Older Patients (NABCOP)



The aim of the NABCOP is to support clinicians, healthcare providers and commissioners to improve the quality of hospital care for older woman (aged 70+years) diagnosed with breast cancer in NHS hospitals within England and Wales.

All data used by the NABCOP are routinely collected data used in clinical practice. NCRAS provide the data for patients diagnosed in England, collected from a variety of sources.

## 5. How Should I Use the Data?

There are the 4 main categories of reports available on CancerStats2:

- **Level 1 is operational feedback** based on receipt and format of incoming data submissions. These are RAG rated tables by NHS Trust and used to report whether NCRAS have received the correct data feed, within the stated timescales and in the correct format. They do not include record counts or expected volumes of data. These tables are regularly updated as and when we receive new submissions.
- **Level 2 is raw data feedback.** Data is analysed prior to curation by the NCRAS Registration Teams. These reports contain basic record counts at Trust level and are regularly updated as and when we receive new submissions. Please check each report cover/landing page for the most recent update date
- **Rapid Cancer Registration Dataset (RCRD)** reporting. This data is primarily based on COSD feeds but may incorporate other datasets such as Cancer Waiting Times. This is intended to be a more timely proxy for Level 3 fully registered data. RCRD data is created using an algorithm to replicate the 'Gold Standard' cancer registration data as much as possible. However, some newly diagnosed cancers may be missed or falsely reported due to the limitations of the incoming data quality and completeness at this stage in the process. The quality of the RCRD is closely monitored and a [monthly report](#) is available online.
- **Level 3 is a more comprehensive/curated and time-lagged version of RCRD.** The data will contain multiple feeds of information from different NHS Trusts and will include different datasets that have been curated by the NCRAS Registration Teams and linked together at patient pathway and tumour level (please note that patients can have more than one cancer diagnosis within the same period and therefore may be counted more than once at tumour level). Assignment of patients may differ depending on the purpose of the report. Level 3 reports can be filtered according to core registration variables.

Most level 3 reports are produced once the data has been quality assured and signed off by the NCRAS registration team. This is usually twice a year. However for some reports, such as the national audits, these updates may only be annually. This is because these audits require additional input from external analytical teams.

It is important that platform users understand the varying levels of data used in the different reports. They should not try to replicate patient pathway numbers (RCRD and Level 3)

using the raw data (Level 2), as this was not its intended purpose and the overall results will be different.

Level 2 data should be used to understand the data submitted by a provider and can be used to understand overall volume of activity, for example counts of treatments per month by trust or Cancer Alliance.

The RCRD should be used in preference to Level 2 data where the intent is:

- a) to understand multi-provider patient pathways;
- b) to understand clinical activity in relation to the date of first diagnosis; or
- c) to use data which integrates all of a patient's COSD records plus other derived features such as comorbidity or route to diagnosis.

However, users should be mindful that the RCRD represents an early proxy for finalised cancer registrations, and there are data quality caveats such as the inclusion of some falsely reported cancers or incomplete or inaccurate stage recording which may affect the robustness of the results.

Users can filter reports according to their areas of interest or expertise and drill down to focus on specific 'groups' of patients, for example:

- by a geographical area;
- by type of cancer;
- by stage of disease progression.
- by different types of treatment; and/or
- by patient specific demographics (such as age or socioeconomic deprivation).

With such rich insight, NCRAS can help clinical teams to paint a detailed picture of their practice, as well as deepen their understanding of the diagnosis, treatment and outcomes of cancer patients.

Most information held on CancerStats2 is [de-personalised data](#). It is information at population level, so that it would not be possible to identify an individual from the data. However, information about small groups or people with rare conditions could potentially allow someone to be identified and so would not be considered anonymous.

NCRAS publishes data on the provision of health care services in England and is duty bound to follow the [Anonymisation Standard for Publishing Health and Social Care Data](#). This standard provides guidance on what is and isn't identifiable information and provides the tools to anonymise data and protect personal privacy.

In order to provide accurate operational data back to NHS Trusts, CancerStats2 may produce reports with small numbers of patients. This could lead to inadvertently identifying patients through their unique or rare cases. Platform users must therefore be aware of their responsibilities to protect patient confidentiality and must assess (in consultation with

their local IG teams and Caldicott Guardian) the risk of re-identification when onwards sharing of any data derived from CancerStats2.

The risks of sharing data should be balanced against the perceived benefits associated with doing so, and only ever with organisations or individuals who have a legitimate need to see it. Platform users must only publish and share data that is about their own organisation or when compared to an England benchmark. They must ensure that published data passes the anonymisation standard and should seek advice from their local IG lead and/or Caldicott Guardian if they have any queries or concerns.

If a report on CancerStats2 is intended for sharing with a wider audience without the need for additional measures, it will be clearly stated on the report guidance/landing page.

Permission from the following must be sought in advance of any publications that contain Welsh and/or Scottish data:

- Public Health Wales - [WCISU.enquires@Wales.nhs.uk](mailto:WCISU.enquires@Wales.nhs.uk)
- Public Health Scotland - [nicola.redgwell@nhs.scot](mailto:nicola.redgwell@nhs.scot)

When publishing data please refer to the [Acknowledging use of cancer registry data - Standard Operating Procedure](#) which provides guidance for staff and stakeholders about how and when to acknowledge use of cancer registry patient-level data.

Here are examples of the usage of CancerStats2 reports, dashboards or data tables for internal operational reasons that fall within the intended purpose of the platform (this list is not exhaustive):

- A Trust Data Manager taking a screenshot of a COSD or Audit Level 2 Completeness Report to share at the next Cancer Team meeting
- A Trust Performance Manager downloads a regional COSD completeness report to share at the Trust Board meeting
- A clinician reviews the SACT Treatment Activity Report to compare their Trust activity against similar Trusts in the region
- A lead analyst at a CCG reviews the RTDS Events Report to monitor treatment pathways across their region
- An MDT Co-ordinator downloads the COSD Training guide

All CancerStats2 platform users must have a legitimate need to access the data and should not access data that is beyond their remit or responsibility. CancerStats2 platform users must not access the platform if their role no longer requires it and must notify NCRAS immediately so that their account can be closed. User accounts are regularly reviewed and accounts that remain 'inactive' and are not accessed for a period of more than 12 months, are automatically deleted. Users can always re-apply for an account if access is required again at a later stage – see Section 6 below.

## 6. Requesting an Account and the User Declaration

When a user requests access to the CancerStats2 platform they are required to complete a registration form and agree to the following 'User Declaration':

1. *I understand the sensitive nature of the data on CancerStats2 and accept my responsibilities to protect these data from inappropriate disclosure or use.*
2. *I will act in accordance with the [Caldicott principles](#), [General Data Protection Regulations \(GDPR\)](#) and the [Data Protection Act 2018](#) and understand that that unauthorised disclosure of identifiable or potentially identifiable data will result in personal liability.*
3. *I am aware of my organisation's data protection and confidentiality policies and will act in accordance with them.*
4. *I have read and understood the 'NCRAS CancerStats2 – An Introduction to the Reporting Platform' guidance document.*

This declaration ensures that platform users fully understand their data protection and data security responsibilities and that they have fully read and understood this document.

To request a CancerStats2 account please follow the link below, click on 'Create new account' tab and complete the registration form: <https://cancerstats.ndrs.nhs.uk/>

The platform requires an N3/HSCN secure network connection.

## 7. Feedback & Support

This guide will be reviewed annually and we welcome all feedback. If you have any comments or questions about any of the information covered in this document, please get in touch by emailing the team at [PHE.cancerstats@nhs.net](mailto:PHE.cancerstats@nhs.net).

The Data Liaison team within the National Cancer Registration and Analysis Service (NCRAS) and Welsh Cancer Intelligence and Surveillance Unit (WCISU) have a wealth of knowledge on cancer pathways and processes within NHS Trusts.

NHS teams submitting data to NCRAS can seek advice, support and find out more about the data improvement initiatives available to them directly from the NCRAS [Data Liaison team](#).