# CancerStats2: Introduction to the reporting platform

Updated October 2023

# About the NDRS

The National Disease Registration Service (NDRS) is part of NHS England. Its purpose is to collect, collate and analyse data on patients with cancer, congenital anomalies, and rare diseases. It provides robust surveillance to monitor and detect changes in health and disease in the population. NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases, and congenital anomalies
- improve diagnosis
- plan NHS services
- improve treatment
- evaluate policy
- improve genetic counselling

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# Contents

# 1. Purpose of this user guide

Disease registration is central to public health and healthcare. The 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.

The NDRS has legal permission to collect patient data to use it to protect the health of the population. Permission is provided to NHS England under legal instructions known as Directions, from the Secretary of State for Health and Social Care, under section 254 of the Health and Social Care Act 2012. The Directions are called the National Disease Registries Directions 2021. They instruct NHS England to collect and use confidential patient information to operate the NDRS.

The NDRS has powers to publish anonymous statistical data under section 260 of the 2012 Act and to share data under section 261 of the 2012 Act. It also has powers to share data, subject to security and privacy safeguards outlined above, under other laws, for example under Regulations 2, 3 and 5 of the Health Service (Control of Patient Information) regulations 2002 (COPI).

Find out more about how NDRS collects and records data of people with cancer, rare diseases, or congenital anomalies.

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. Registration of the data includes manual extraction and interpretation of many data sources such as text-based pathology reports and national data sets.

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. The CancerStats2 platform

## Overview

The primary purpose of the CancerStats2 (opens in a new window) 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 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 cover new data sets, NHS partnership projects and genomics data.

## Access requirements

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.

## Limitation of reuse

The content hosted on CancerStats2 is intended to be used for data improvement projects and for NHS teams to monitor their own data upon submission to NCRAS. For this reason, data presented may not be well suited for outcome analysis or epidemiological research due to limitations in the data quality and completeness.

Each report will clearly outline the intended audience, purpose, and limitations of the data used on its guidance page. If a report can be used for other types of analysis and is intended for sharing with a wider audience without the need for additional measures, it will be clearly stated.

For further information on how CancerStats2 data should be used, please refer to chapter 5 of this guide.

# 4. The suite of reporting tools

CancerStats2 is divided into sections, each providing a suite of tailored reports based on that area of expertise:

## a) Cancer Outcomes and Services Dataset (COSD)

This data set supports national cancer registration and associated analysis (at local, regional, national, and international level) in addition to other national cancer audit programmes. All NHS providers of cancer services in England have been required to provide a monthly return using this data set for all cancer diagnoses since January 2013.

These reports have been designed to support trust data collection teams, facilitate data improvement work and to enable clinicians and management boards to understand their COSD conformance and the quality of their submissions.

### Reporting data set, update frequency and retention

COSD reports hosted on CancerStats2 are typically derived from an aggregate data set of selected metrics in provider COSD submissions made to NDRS. This aggregate data does not include patient demographic items. Counts for each metric are aggregated by provider, month of diagnosis and broad cancer groups.

As this data set is focused on rapid feedback of the trust COSD submission to support the improvement of current and recent data, the update frequency is dependent on the month of diagnosis where:

Cancer diagnoses in previous 12 months: Updated daily
Cancer diagnoses more than 12 months ago: Updated monthly

However, certain specialist reports (with a unique collection of COSD data items) may have a different update schedule as described in those reports. Specific data items and the details of any calculated items, groupings, exemptions, and exclusions are also detailed in the methodology of individual reports.

### Usage and limitations

Unless otherwise specified in an individual report, any data visualisation, count, score or ranking shown is provided for monitoring and data improvement purposes only and is reflective only of data quality in the COSD submission. It is not indicative of the quality of clinical care, treatment, or the outcomes of those treatments for patients in any health geography or NHS Trust shown.

Counts in the COSD aggregate data set are assigned to the reporting trust. Unless otherwise specified, assignment to health geographies (such as NHS Region, Cancer Alliance or Integrated Care Board) in these reports is based on trust membership of that geography and not that of the patient. Additionally, individual patients with complex or extended pathways that cross trust boundaries may be counted against data items for multiple providers.

Consequently, and unless otherwise directly stated, these COSD reporting data set(s) and any dashboard exports are not suitable for use in any further analysis beyond their stated audience and purpose.

Find out more about COSD and view all the guidance documents and downloads.

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

CADEAS is a partnership between NHS England and NDRS supporting 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 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.

The intended uses and audience and the limitations of the data will vary according to each report. For more details, see the guidance page of each report.

Find out more about this NDRS analytical partnership programme.

## c) Cancer prevalence (CASCADE)

The reports show numbers, crude rates and age and gender standardised rates for cancer prevalence. Rates can be presented for different cancer sites, different time periods, and different geographies.

### Reporting dataset and update frequency

Cancer prevalence is useful to understand how many people in the population are living with a cancer diagnosis. Cancer prevalence is a product of both cancer incidence and survival and should be interpreted with these factors in mind, especially if making comparisons across different cancer types or populations.

There are two cancer prevalence reports:

1. Patient-level observed cancer prevalence
2. Tumour-level observed cancer prevalence

These reports are updated annually, and the specific methodologies and definitions applied have been outlined in each report guidance page.

Find out more about the NDRS work programmes focused on cancer data.

## d) Genomics

The Genomics team, work with NHS laboratories to bring molecular diagnostic data into the National Disease Registration Service (NDRS). All cancer cells contain errors in their DNA. These DNA errors drive the abnormal behaviour of the cancer cell. Genomic testing enables us to understand which genes are damaged, and how. It gives us useful information about the biology of the tumour, how it is likely to behave, and what its weak spots are. If we carry out a genetic test directly on a tumour, this is called a somatic test.

### Reporting data set

Currently data presented is taken from the NCRAS somatic and germline molecular datasets. The somatic molecular dataset is a collection of data from NHS laboratories across England that perform molecular diagnostics directly on tumours and cancer-derived material. It covers genetic mutations that occur only in the tumour and are known as somatic mutations or acquired mutations.

### Usage and limitations

The intended uses and audience and the limitations of the data will vary according to each report. For more details, see the guidance page of each report.

Find out more about the work of the NDRS genomics team.

## e) Living with and Beyond Cancer (LWBC)

The LWBC suite of reports have been designed to support trust data collection teams, facilitate data improvement work and to enable clinicians and management boards to understand the quality of their submissions.

### Reporting data set, update frequency and retention

The reports are derived from an aggregate data set of selected metrics in provider COSD submissions made to NDRS. This aggregate data does not include patient demographic items. Counts for each metric are aggregated by provider, Date (of offer or provision of Holistic Needs Assessment, Personalised Care and Support Plan or End of Treatment Summary) and broad cancer groups.

All reports are focused on rapid feedback of the trust COSD submission to support the improvement of current and recent data. Data is available from October 2020 up to recent months and are updated monthly.

Specific data items and the details of any calculated items, groupings, exemptions, and exclusions are also detailed in the methodology of individual reports.

### Usage and limitations

Unless otherwise specified on an individual report guidance page, any content including data visualisation, counts, score or ranking shown, is provided for monitoring and data improvement purposes only and is reflective only of data quality in the COSD submission. It is not indicative of the quality of clinical care, treatment, or the outcomes of those treatments for patients in any health geography or NHS Trust shown.

Aggregate counts are assigned to the reporting trust. Unless otherwise specified, assignment to health geographies (such as NHS Region, Cancer Alliance or Integrated Care Board) in these reports is based on trust membership of that geography and not that of the patient. Additionally, individual patients with complex or extended pathways that cross trust boundaries may be counted against data items for multiple providers.

Consequently, and unless otherwise directly stated, these LWBC reports, and any dashboard exports are not suitable for use in any further analysis beyond their stated audience and purpose.

Find out more about the work of the LWBC team.

## f) Radiotherapy Dataset (RTDS)

The RTDS standard collects consistent and comparable data across all NHS Acute Trust providers of radiotherapy services in England, and additional NHS centres delivering radiotherapy services in Scotland and Wales. This data can be used to provide intelligence for services planning, commissioning, clinical practice and research and operational provision of radiotherapy services across the UK. All NHS radiotherapy activity data is collected including external beam radiotherapy and brachytherapy.

### Reporting data set, update frequency and retention

Aggregated summaries of received RTDS data are provided on the CancerStats2 portal. These reports are updated to varying schedules, with the most frequent being weekly. The reporting schedules for the various reports and further details on how to interpret them can be found on the guidance page of each individual report.

### Usage and Limitations

Please note there may be a small amount of private patient data included in any figures. Please also note that many reports show new data with events occurring in the last three months. Where this is the case, take caution in interpreting the data. Data submissions often need review and resubmission beyond the initial upload. Please refer to section 5 of this document to read more about how data can be used.

Find out more about RTDS and their latest publications and data outputs.

## g) Rapid Cancer Registration Dataset (RCRD)

RCRD aims to support cancer services by providing near-real-time analysis of cancer data. It is based on a rapid processing of cancer registration data sources. Compared to the National Cancer Registration Data (which relies on additional data sources, enhanced follow-up with trusts and expert processing by cancer registration officers), RCRD provides a quicker, indicative source of cancer data. The RCRD data may be useful for healthcare planning, prioritisation, and service improvement, but it is poorly suited for epidemiological research due to limitations in the data quality and completeness.

The RCRD report hosted on CancerStats2 provides a suite of metrics relating to cancer incidence and treatment data, with breakdowns by cancer groups; cancer alliance or provider; and/or patient or tumour factors (e.g. age, route to diagnosis).

### Reporting data set, update frequency and retention

The RCRD data is derived by NDRS using an algorithm which aims to replicate the National Cancer Registration Data as much as possible. RCRD is primarily based on submissions of the Cancer Outcomes and Services Dataset (COSD), but it also incorporates other data sets, particularly Cancer Waiting Times and Hospital Episode Statistics.

The RCRD report provides monthly RCRD data on the numbers of new diagnoses and surgical tumour resection procedures, along with treatment proportions (surgical tumour resection, chemotherapy, radiotherapy, and combinations). It includes comparisons to the same data in a previous year. Data can be selected for England, cancer alliances or providers. There are breakdowns by cancer groups; patient or tumour factors (e.g. age, route to diagnosis); and time to treatment.

Data is available from January 2018 up to recent months (with data usually first published around 4 months after the diagnoses). The report is updated on a monthly basis, with the next intended release date stated in the ‘Data timeliness’ section of the report’s guidance page.

All data in the report is refreshed with each release, as more data becomes available and sometimes reflecting updates to the underlying algorithm. Later months in each release are those most likely to change when the data is refreshed, but older months can also change, particularly if any algorithm changes were implemented.

### Usage and limitations

The RCRD data, including summary data available here, may be useful for service improvement projects including healthcare planning and prioritisation. The data could be used to aid the planning of cancer services; to understand and monitor national or local changes to healthcare demand or practice; or, to highlight areas where it would be helpful to direct future service improvement or research activities.

However, it is poorly suited for epidemiological research due to limitations in the data quality and completeness. The RCRD data is affected by limitations in quality and completeness of data submitted within a few months of diagnosis and by limitations of the algorithm used to derive the data. For example, some newly diagnosed cancers may be missed, some falsely reported cancers may be included or there may be inaccurate and incomplete stage recording. These limitations may affect the robustness of the data and any results based on the data. The quality of the RCRD is closely monitored and a monthly quality report is produced.

This data is not suitable for making straightforward 'like-for-like' comparisons between cancer alliances or providers, and it should not be used as a performance metric to compare activity between areas. In addition to the numerous clinical factors which typically inform a treatment decision, data for individual cancer alliances or providers will be affected by a range of other factors, including the way the local healthcare system is organised and differences between alliances or providers in the socio-demographic characteristics of their patients.
The data is subject to change, as more data becomes available or if changes are made to the underlying algorithm.

Find out more about RCRD and the latest quality report.

## h) Systemic Anti-Cancer Therapy Dataset (SACT)

The SACT data set 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.

### Reporting data set, update frequency and retention

The majority of the SACT reports on CancerStats2 are derived from SACT submissions made by Trusts.  Where there is another source or an additional data source is used, details are included on the guidance page.

Most reports are updated monthly, with a few updated annually.  Details of the update frequency are included on the guidance page of each report.

The date period covered varies according to the report.  Details are included on the guidance page.

### Usage and limitations

The intended uses and audience and the limitations of the data will vary according to each report.  For more details, see the guidance page of each report.

Find out more about SACT and their latest publications and data outputs.

## i) Bespoke reports

This section hosts a collection of bespoke reports specifically designed for NDRS stakeholders to support cancer data collection and data quality reporting. Currently the following reports are available but this content changes periodically according to user need.

The intended uses and audience and the limitations of the data will vary according to each report.  For more details, see the guidance page of each report.

### Acute Oncology

This dashboard was co-developed alongside the Acute Oncology society to support NHS teams to monitor the data quality and completeness of incoming data for unplanned care cancer patients received in an acute care environment.

(Link coming soon)

### Audits – National Prostate Cancer Audit (NPCA)

The aim the NPCA audit 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. A data completeness dashboard was created to support the audit team with the collection and monitoring key NPCA data quality.

Find out more about the work of the NPCA team.

### Audits – Ovarian Cancer Audit Feasibility Pilot (OCAFP)

The OCAFP was established with the aim of exploring a new approach to clinical audits. Rather than collecting new data, the pilot makes use of information that is routinely submitted by gynae-oncology teams across the country, and which form the monthly flow of data into the Cancer Outcomes and Services Dataset (COSD).

The completeness, short term mortality and variability in cancer treatment reports form part of the outputs produced by NDRS and the Ovarian Cancer Audit Feasibility Pilot (OCAFP), established with the aim of improving clinical practice through the analysis of data routinely collected from gynae-oncology teams.

Find out more about the work of the OCAFP team.

### Life After Prostate Cancer Diagnosis (LAPCD)

Prostate cancer is the most common lethal cancer in men in the United Kingdom (UK) and the number of men living with this disease is increasing. The treatments used can have physical, psychological, and social impacts, affecting the health-related quality of life (HRQL) of men and their partners/spouses. In addition to improving the effectiveness of treatment, increasing attention is now being given to understanding the patient's perspective of how prostate cancer affects their everyday lives.

Presented here are the results of the first and second Life After Prostate Cancer Diagnosis (LAPCD) surveys. The Life After Prostate Cancer Diagnosis study was funded by the Movember Foundation, in partnership with Prostate Cancer UK, as part of the Prostate Cancer Outcomes programme, grant number BO26/MO. The programme was delivered in partnership between University of Leeds, Queen's University Belfast, University of Southampton, Oxford Brookes University and Public Health England.

Find out more about the LAPCD study.

### Site specific – Kidney QPI

The Quality Performance Indicators (QPIs) were developed by the Kidney Cancer UK Accord and is aimed to measure the quality of kidney cancer services in England and identify if there is a need for a NICE guideline and quality standard for kidney cancer.

Find out more about the work of the Kidney Cancer UK team.

### Site specific – Sarcoma curated data

The sarcoma curated data dashboard has been created by the NDRS team in collaboration with the Sarcoma partnership. The dashboard mainly focusses on data quality for each analysis group as well as the impact of place of surgery on survival outcomes for Sarcoma patients.

Find out more about the sarcoma bespoke reports.

# 5. How to use the data

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 publicly 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 Information Governance teams and Caldicott Guardian) the risk of re-identification when onwards sharing 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.

Each report will clearly outline the intended audience, purpose, and limitations of the data used on its guidance page. If a report can be used for analysis and is intended for sharing with a wider audience without the need for additional measures, it will be clearly stated.

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

- Public Health Wales
- Public Health Scotland

When publishing data please ensure to follow the 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):

1. A trust Data Manager taking a screenshot of a COSD registration feedback report to share at the next cancer team meeting.

2. A trust Performance Manager downloads a copy of regional registration report to share staging completeness at the next trust board meeting.
3. A clinician reviews the SACT treatment activity report to compare their trust activity against similar trusts in the region.
4. A lead analyst at a cancer alliance reviews the RTDS events report to monitor treatment pathways across their region.

# 6. Requesting an account

To request a CancerStats2 account, click on the 'Create new account' (opens in a new window) tab on the CancerStats2 guidance page and complete the registration form.

Please note this platform requires an N3/HSCN secure network connection and all applications will be reviewed and approved before access is granted.

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.

# 7. User declaration

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

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 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 'NDRS 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.

# 8. Feedback and support

## Feedback

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 nhsdigital.ndrsdatahub@nhs.net

## Support for NHS teams

The NDRS data liaison team has 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 NDRS data liaison team.

## Training materials

The NDRS data liaison team have also produced a suite of training materials to assist NHS teams with understanding, collecting and recording cancer data and more specifically cancer staging guidance sheets.