

Systemic Anti Cancer Therapy (SACT) data set

Requirements Specification DAPB1533

Data Alliance Partnership Board

The Data Alliance Partnership Board (DAPB), which holds delegated authority from the Secretary of State for Health and Social Care, has approved a change to an existing information standard for publication under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Governance, Assurance and Testing (DGAT) team and endorsed by the Data Assurance Board (DAB).

This information standard comprises the following documents:

- requirements specification
- change specification
- implementation guide
- information standard notice

An Information Standards Notice (DAPB1533 Amd 20/2025) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled copies of these documents can be found on the [Standards and collections - NHS England](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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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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Version(s)	Date	Amendment History
SACT v4.0	10 April 2025	Draft document sent to DGAT for review
SACT v4.0	16 April 2025	Updated NHSE URL's
SACT v4.0	13 May 2025	Final edited version for publication

Executive summary

The purpose of this document is to provide guidance intended to support providers of Cancer Services and developers (both in-house and commercial system suppliers), to prepare for the implementation of the Systemic Anti Cancer Therapy (SACT) data set, v4.0 from April 2026.

All documents (or links to them) can be found on either the [National Disease Registration Service \(NDRS\) SACT pages](#) or the [NHS England website](#) unless otherwise stated. These provide assurances that the proposed approach meets the business requirements identified in the requirements specification for DAPB1533 Amd 20/2025 and has been adequately researched and can be delivered.

This is an update to an existing information standard DCB1533 Amd 80/2018. This is required to ensure that the data set still meets the business objectives, scope, and content of the standard and continues to be clinically accurate and relevant.

To maintain the clinical accuracy, it is important to regularly review the SACT data set with clinical experts from across the NHS. Occasionally other information standards have specific data items which interact with SACT. Where this happens, the Head of Cancer Datasets has liaised with the developers of those standards, to ensure all data items remain accurate and are updated.

Introduction

Background

The SACT data set is the national standard for reporting systemic anti-cancer therapy treatments within the NHS in England. The National Disease Registration Service (NDRS) are responsible for ongoing maintenance, development, and implementation of the standard. The standard itself assists in achieving the business objectives of the data set, as well as specialist commissioning and related policies.

All patients receiving systemic anti-cancer therapies in or funded by the NHS in England are covered by the standard. This includes adult and paediatric cancer patients receiving systemic anti-cancer treatment, in acute inpatient, day-case and outpatient settings and delivery in the community for solid tumours and haematological malignancies, including patients in clinical trials.

In addition, SACT is a compiled data set, which provides the standard for secondary uses information required to support national cancer registration and associated analysis (at local, regional, national, and international level), as well as other national cancer audit programmes.

The standard consists of:

- a set of individual data items, with their definitions
- the assemblage of these data items into discrete sections
- the means of flowing the data items
- compilation of the data items into a single reconciled and verified data set

Providers of systemic anti-cancer therapy services are required to provide monthly returns on all activity using this data set. Details of these returns, including the format and structure of the double quote, comma separated values (csv) file, can be found in the technical and implementation guides.

The standard may also inform the design of electronic prescribing and other clinical systems, as it defines for consistent use, terms such as regimen, administration, cycle and dose that are used in systemic anti-cancer therapy treatments, prescribed and administered to individual patients.

Why is it needed?

Periodically we need to revise the SACT data set, to ensure that we meet the current information requirements for the NHS.

The ‘[NHS Long Term Plan](#)’ aims to save thousands of lives each year by dramatically improving how we diagnose and treat cancer. The ambition is that by 2028, an extra 55,000 people each year will survive for five years or more following their cancer diagnosis.

The need to have strong cancer data collection, empowers NHS England to enforce this through the mandate of data collections. These data will be the base for cancer analysis and research for the next 5 years.

Who does SACT apply to:

SACT applies to the following key groups and organisations:

- cancer centres and all other providers of NHS commissioned systemic anti-cancer therapy services
- developers and suppliers of electronic prescribing systems for use in NHS commissioned cancer centres and NHS provider services
- organisations purchasing electronic prescribing systems for use in NHS commissioned cancer centres and NHS provider services
- users of secondary data about systemic anti-cancer therapy at both national and local levels, including:
 - at a national level:
 - Department of Health and Social Care (DHSC)
 - National Disease Registration Service (NDRS)
 - other appropriate national information, research and service planning organisations, for example:
 - NHS England (NHSE)
 - Care Quality Commission (CQC)
 - at a local level:
 - cancer alliances
 - local cancer service provider networks
 - commissioners and providers

As SACT is for secondary care uses, there is no intention for this to be used by primary care or private hospitals.

It is important to note however, that if a patient is on an NHS pathway but the treatment is carried out in a private hospital (due to capacity issues or at the request of the NHS Trust), these data must be collected and reported (within SACT) by the NHS Trust, as if the treatment was carried out by themselves.

This does not apply to systemic anti-cancer therapies given to treat patients with a diagnosis other than cancer, for example dermatological or rheumatological conditions.

Key changes since v3.0

As part of the on-going implementation and maintenance of the SACT data set, several changes were identified as required. These included new data-items, re-alignment of data structure, amendments and contains corrections, for example where there were errors in previous versions and updates where clinical practice has changed from SACT data set v3.0 and should be used to help data collection.

Throughout the data set there are now a series of choices which will make collecting and reporting data easier to understand and will be supported by the new technical document.

In addition, there are some key new sections to link potentially orphaned data items throughout the data set.

The proposed changes can be divided into the five key areas:

- deleted data items
- new data items
- data items with amended attributes
- moved data items
- schema specification changes

Note:

- in some cases, the same data item is used in different sections of the data set, in these circumstances they are only counted once

The following are the major changes to SACT v4.0:

Key Change	Numbers
Deleted Data Items	11
New Data Items	27
Data Items with Amended Attributes	11
Moved Data Items	5
Schema Specification Change	7

In v4.0, there are an additional 16 data items overall, compared with v3.0 and of them, 4 are compulsory due to the change in the way date and consultant codes are now recorded. In addition, most of the other increases were to ensure that 'Regimen', 'Cycle' and 'Dose Modification' as well as 'Cycle Delay' were correctly structured and recordable.

A detailed list of these changes is available in both the data set document (change log) worksheet, as well as the Change Specification document.

Clinical review

SACT has already been through a rigorous clinical review/assessment and consultation, this has involved talking to and engaging with:

- SACT:
 - management board
 - clinical leads group
- National Disease Registration Service (NDRS):
 - Senior Leadership Team (SLT)
 - internal developers
 - specialist analysts
 - clinical leads
- NHS England (NHSE):
 - cancer programme
 - expert cancer groups
 - Cancer Drugs Fund (CDF) partnership group
 - Trusts that deliver SACT
 - specialist commissioning (Spec Comms) pharmacy team
- National Institute for Health and Care Excellence (NICE)
- electronic prescribing (ePrescribing) system suppliers
- Royal Colleges
- Association of the British Pharmaceutical Industry (ABPI)
- National Cancer Audit Collaborating Centre (NATCAN)
- patient groups
- cancer charities
- Acute Oncology Service (AOS)

In total over 155 individuals supported the change process and were involved within the clinical review and consultation.

Implementation start and full conformance timeline

The following timeframe will be used to support the implementation, data collection and outline the full conformance dates:

- implementation is between 29 July 2025 to 31 March 2026 (8 months)
- data collection will start from 01 April 2026 (with a three-month roll-out period between 01 April 2026 to 30 June 2026)
- full conformance from 01 July 2026 (reported in the July batch, within the September upload)

Supporting Documentation

The 'Requirement Specification' should be read in conjunction with the following documents (websites are imbedded within each bullet point header below):

[NHS England - DAPB1533 SACT:](#)

- requirements specification
- change specification
- implementation guide
- data set v4.0
- technical guidance
- information standard notice

[NDRS - SACT webpage:](#)

- SACT v4.0 user guide

These documents are intended to support providers and developers who wish to identify and plan changes to their systems.

Contacts

The following are a list of key contacts responsible for the development and management of the data set:

- sponsor - Deputy Director for National Disease Registration
- senior responsible officer - Head of Data Operations, NDRS
- developer - Head of Cancer Datasets, NDRS
- implementation manager - Senior Project Manager, NDRS

SACT uses a team of dedicated Data Liaison Managers across England to support Trusts with implementation and ongoing support.

Trusts should contact their local NDRS office or regional data liaison manager to discuss any issues regarding the standard itself. [If you are unsure who your local NDRS Liaison Manager, these can be found on the NDRS website using this link.](#)

Health and Care Organisations

Requirements

The following are a series of requirements which all health care organisations must comply with:

- NHS Providers of cancer services (hereinafter referred to as NHS Providers) MUST read the Requirements Specification and Change Specification in conjunction with the Implementation Guidance to identify how the standard is applicable to them
- NHS Providers MUST review their clinical services against this standard to identify any changes required to current practice to ensure that all data items in SACT v4.0 can be flowed electronically by the dates specified in this document
- an experienced head of cancer services in each provider organisation SHOULD guide the service and system review, based on a good understanding of the scope, definitions and rules behind the data items (from the implementation guide)
- all providers of oncology cancer services MUST submit data files to the SACT portal on a regular basis, according to the 2-monthly reporting schedule as outlined in the technical guidance
- where patients have requested that their data is not shared, the provider organisation MUST ensure that records of these patients are not included in the data downloads submitted to SACT
- data items MUST be submitted in the formats specified in the data set, technical and user guides
- downloads MUST be submitted only in comma separated values (csv) format, with a text delimiter set to the double-quote character, to allow the use of commas in data values
- validation checks will be carried out as data is submitted onto the API portal, any reports that are sent back to the data supplier SHOULD be used to resolve any data quality issues and a resubmission MAY be required as set out in the technical guide
- it must be possible for the SACT team to reconstitute details of each patient's sequential management from the data supplied
 - providers of cancer services therefore MUST include mandatory data items, and required data items (which are part of the NHS business rules where available and applicable), otherwise files will be rejected

Conformance Criteria

The following are a series of conformance requirements, which all health care organisations must read:

- SACT portal submission QA:
 - SACT submission files are tested against the agreed business rules
 - a 'file validation report' is issued to demonstrate provider compliance
 - 100% of mandatory fields MUST be completed to submit a file
- Clinical QA:
 - where required, feedback on compliance of 'OPCS Regimen List' is required to maintain accuracy
 - where anomalies exist in the regimen list, the data is reviewed by the clinical and Medical Oncologist and Oncology Pharmacist through an iterative process
- General:
 - notify the NDRS regional data liaison manager (as soon as possible after discovery) of any known reasons for significant variation in the numbers of new cases submitted monthly in comparison to previous months
 - monthly feedback is routinely provided from the SACT team for review, [using the CancerStats2 portal](#) (see below)
 - this would allow teams within each submitting organisation to assess if the data uploaded meets their expectation, and if not then they should be challenged with the cancer services manager
 - a minimum of 80% of all expected cases is to be reported by provider Trusts
 - all data extracted from Trust cancer information management systems, Electronic Patient Records (EPRs) or ePrescribing systems MUST be reported in double quote, comma separated values (csv) only, in line with the technical guidance

Since its conception in 2012, SACT data has been used for a series of important analyses, including 30-day mortality post SACT. In addition, [the CancerStats2 portal has now become the home of SACT analysis reporting](#) and contains many additional reports as follows:

- SACT activity
- data completeness and quality reports
- dose branding
- specific CTYA data analysis
- time to first treatment

In addition, there is also analysis and reports around the cancer drugs fund.

To access CancerStats2, you need to be on a Health and Social Care Network (HSCN) and have a valid user account. If you feel you need access to these reports, please speak to your regional data liaison manager and they will support you with this.

IT Systems

It would be expected that all Trusts have a service level agreement (SLA), with their system provider to ensure future development needs are sufficient to meet changes to the standard.

Requirements

Trusts **MUST** ensure that system providers of ePrescribing systems or cancer IT systems, in accordance with their contractual arrangements **MUST** implement changes to enable all specified data items in the SACT data set to be captured and extracted in compliance with the specification document, as well as the technical and implementation guides.

Conformance Criteria

The requirements above **MUST** be met.

NHS Providers **MUST** submit the agreed data items in monthly reports of current activity (as set out in the technical guide), including regimens started and completed or ceased in that period. The DAPB standard provides all the documentation to support this process, including:

- requirement specification
- change specification
- implementation guide
- technical guidance
- data set v4.0
- user guide v4.0

Each regional NDRS office has a data liaison manager who will help and support any Trust struggling to meet the standard.

SACT upload portal

This is used by Trusts to submit their monthly SACT data submissions. The portal has been designed to improve:

- the accuracy of data received, by providing validations at the point of upload
- the security of data transfer, by removing the need for Trusts to email submissions

Once the submission process is complete via the 'Submit to registry' function, all uploaded data is encrypted. The only data that can be seen is the error report and this can only be seen by other people with permission to access your Trust's data.

Support, training, and testing is available for new users via their regional NDRS data liaison manager, and they can provide you with an in-depth user guidance document for the SACT upload portal.

The SACT upload portal can be accessed online, however:

- the submission portal is only available via a HSCN connection
- a portal login is required using a username and password
- all accounts must be created for an individual user rather than any shared account usage

Scope

In scope

This standard specifies a data set for use at both national and local levels to generate secondary uses information about systemic anti-cancer therapy treatment. It assists in achieving the business objectives of the data set, as well as specialist commissioning and related policies.

All patients receiving systemic anti-cancer therapies in or funded by the NHS in England are covered by the standard. This includes adult and paediatric cancer patients in acute inpatient, day-case and outpatient settings and delivered in the community for solid tumours and haematological malignancies, including patients in clinical trials.

The standard covers neoplasms coded within ICD-10 diagnosis code range C00-C97, D00-D48, as well as E85.8 and E85.9.

Out of scope

It does not apply to systemic anti-cancer therapies given to treat patients with a diagnosis other than cancer, for example for dermatological or rheumatological conditions.

As a 'secondary users' data set, this standard does not define record level data to be used in the delivery of care. The data for SACT should be derived from patient identifiable data, which are already recorded for the purpose of care management.

Implementation and use

Submission of data

Details about the fields which comprise of the SACT data set, including their data dictionary definitions, permissible values and other qualifying descriptions, are contained in the accompanying implementation guide, technical guidance, change specification, data set v4.0 and user guide documents.

Systemic anti-cancer therapies are given over a prolonged period, often months or years, comprising of repeating and sequential elements. The patient may attend two or more providers during their treatment pathway. To track the patient during treatment, the data set must be capable of linking all elements of care in a consistent and ordered way.

To achieve this, the data set required a branching structure which links the initial data fields and will remain consistent during the treatment, with details of each regimen, cycle and drug administration.

At the completion or cessation of a treatment regimen, the outcome field must be submitted by the provider organisation. This links the treatment to the outcome.

Monthly submissions from the provider to the central repository will be in the form of monthly reports of current activity, including regimens started and completed or ceased in that reporting period.

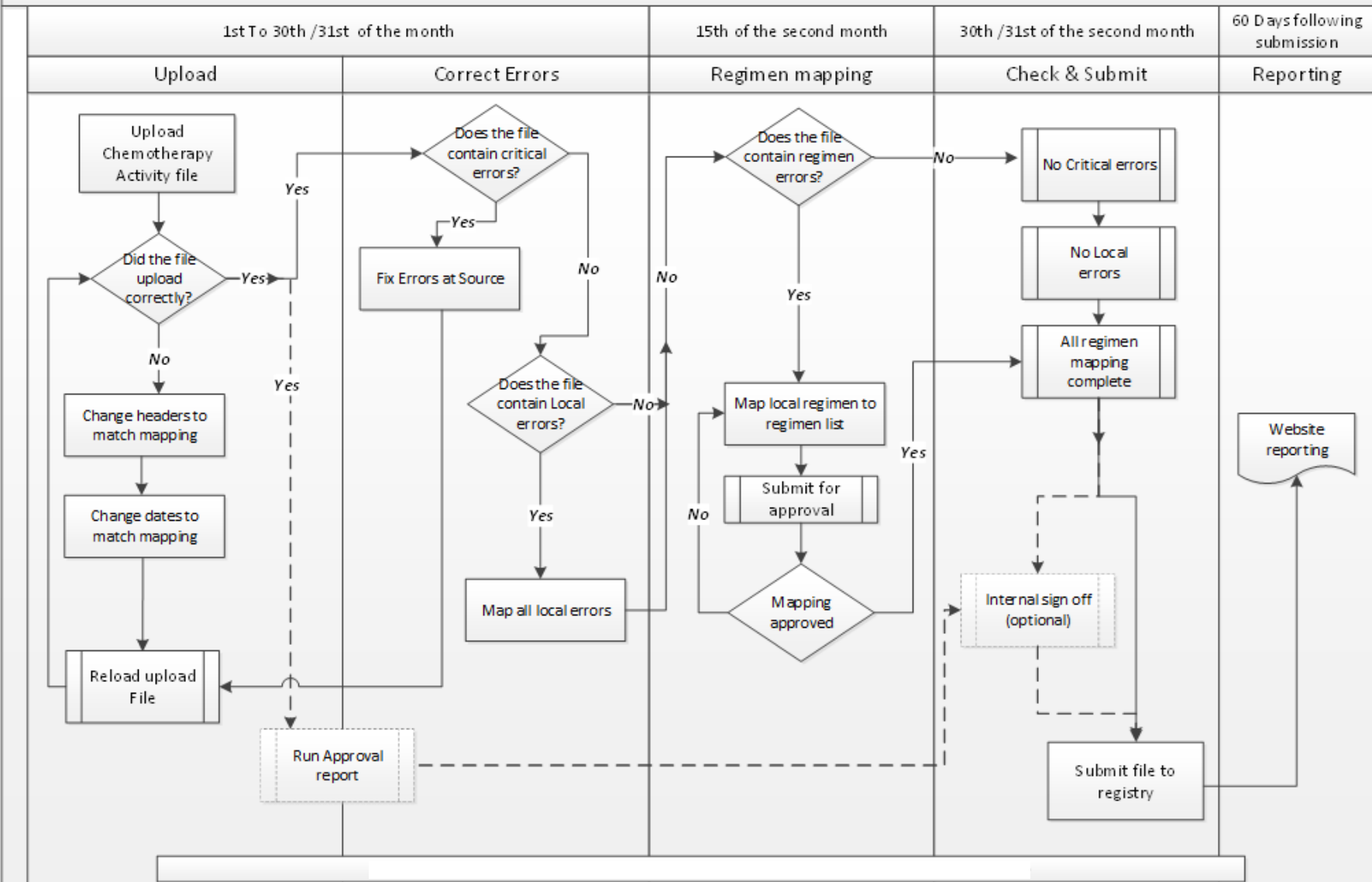
It must be possible for the SACT team to reconstitute details of each patient's sequential management from these data. Mandatory fields enable this process to be accurate, even when the data comes from different providers.

The data will be provided by all hospitals and providers treating cancer patients with systemic anti-cancer therapies. Collection of data will depend on local system implementation and configuration, for example:

- patient identifiers, demographics and details of the provider, will be derived from existing patient administration systems
- details of the patient's clinical picture may be derived from a variety of hospital systems or may need direct entry into an ePrescribing system
- details of specific SACT regimens, cycles and administration, will be recorded during clinical practice and will be derived either from an ePrescribing system or other clinical databases
- the outcome will be recorded as part of the ePrescribing system output

Below is a diagram of the SACT monthly activity, outlining each step and timeline.

SACT Monthly Activity Diagram



The SACT data set has been designed to mirror the clinical decision making in prescribing systemic anti-cancer therapies, and is divided into 7 distinct sections as follows:

- linkage – patient identity details
- demographic and care professional details
- clinical status
- regimen
- cycle
- drug details
- outcome

Staff Working Groups

Implementation of the SACT data set has implications for the skills and training of several staff groups as follows:

Clerical staff:

- this group needs to be aware of the existence of the data set collection process and maybe responsible for the inclusion of demographic data from hospital systems
- they are not expected to enter clinical data
- briefing on the SACT data standard should be incorporated into their induction training

Pharmacy staff:

- pharmacy processes are integral within the operation of this information standard notice (ISN)
- implementation of the standard does not require any change in their work practices but nomenclature in documentation should be checked to ensure it is consistent with the ISN, and should be disseminated as necessary through the relevant professional bodies

Nursing staff:

- this group have a major role in the administration of systemic anti-cancer therapies to the patient and in recording the detailed information of the patient's progression through treatment
- new staff need to be briefed initially as part of their induction process, but 'hands on' training on ePrescribing systems is necessary to ensure efficient and accurate recording of data

Medical staff:

- this group is primarily responsible for initiating the:
 - prescription
 - monitoring the patient's clinical progress
 - making any adjustments to the prescription as required

- summarising the treatment episode
- familiarisation with ePrescribing will be incorporated into post graduate training with the co-operation of the Royal Colleges
- junior doctors will also need ‘hands on’ experience in using the local system
- consultants are expected to personally prescribe systemic anti-cancer therapy treatments as agreed by the MDT, and to be responsible for completing the end of the treatment summary in the ePrescribing system

IT staff:

- this group are required to have the necessary skills and training to maintain the functionality of ePrescribing systems
- this includes the creation of extracts for submission to the SACT data repository, via the NDRS API portal
- details of this are covered in the SACT implementation, technical and user guides

All groups must have access to the appropriate user guidance in electronic or paper format, and these can be found on either the [National Disease Registration Service \(NDRS\) SACT pages](#) or the [NHS England website](#) unless otherwise stated.

It is preferable for local guidance to be grafted seamlessly into that already provided for users of ePrescribing systems, either by system suppliers or local teams (using the above documentation). This must be consistent with the SACT ISN, but also system specific and tailored to the architecture and graphical interface of individual suppliers’ systems.

Governance

Information Governance, Clinical Safety and Data Protection

The primary purpose of the standard is for secondary uses only and will therefore have no direct impact on Clinical Safety and [as such is not in scope of DCB0129](#). Consequently, a Clinical Safety Case Report is not required to support the standard.

NDRS is part of NHS England, which is an executive agency of the Department of Health and Social Care. The function of NDRS is to fulfil the Secretary of State for Health's statutory responsibilities to protect and improve public health and reduce health inequalities. Running national data collections on a range of diseases, including cancer, is a vital part of this work.

National Disease Registries Directions 2021

The 'National Disease Registries Directions 2021' was issued on the 30 September 2021.

This was written on behalf of the Secretary of State for Health and Social Care (the Secretary of State) to provide Directions to the Health and Social Care Information Centre, known as and hereafter referred to in these Directions as NHS Digital, now NHS England.

These Directions are given in exercise of the powers conferred by sections 254(1) and (6), section 260(2)(d), section 261(2)(e) and section 304(9), (10) and (12) of the Health and Social Care Act 2012 (the 2012 Act) and Regulation 32 of the National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013 (the Regulations).

[Full details of the Direction can be found on the NHS England's 'directions and data provision notices/secretary of state directions' webpage](#)

Data Provision Notice (DPN)

In addition, the NDRS have a published Data Provision Notice, which covers the following key areas:

- purpose of collection
- benefits of collection
- legal basis for the collection, analysis, publication, and dissemination
- persons consulted
- scope of the collection
- form, manner, and timing
- burden of the collection

This data provision notice covers all the work NDRS does, not just SACT, however provides in-depth advice and information around the legal framework to which the organisation works.

Full details of the DPN can be found on the NHS England's 'data provision notices' webpage.

General Data Protection Regulation (GDPR)

Under General Data Protection Regulation (GDPR) the lawful basis upon which the NDRS will process personal data is

- UK GDPR Article 6(1)(c) - processing is necessary for compliance with a legal obligation to which the controller is subject (the Directions)

The lawful basis for processing (disseminating) personal data is:

- UK GDPR Article 6(1)(e) - processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller

The conditions which apply to processing (collecting, analysing or disseminating) of special categories of personal data are:

- UK GDPR Article 9(2)(g) - processing is necessary for reasons of substantial public interest, on the basis of domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject, supplemented by:
 - Data Protection Act 2018 Schedule 1, Part 2, paragraph 6: Statutory etc and government purposes
- UK GDPR Article 9(2)(h) - processing is necessary for the... management of health or social care systems and services, supplemented by:
 - Data Protection Act 2018 Schedule 1, Part 1, paragraph 2: Health or social care purposes
- UK GDPR Article 9(2)(i) - processing is necessary for reasons of public interest in the area of public health, supplemented by:
 - Data Protection Act 2018 Schedule 1, Part 1, paragraph 3: Public interest purposes
- UK GDPR Article 9(2)(j) - processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1), supplemented by:
 - Data Protection Act 2018 Schedule 1, Part 1, paragraph 4: *Research etc purposes*

Full details of NHS England's GDPR guidance, can be found on the 'NHS England as a data controller page'.

Consent process

Where patients have requested their data are not shared, the provider organisation must ensure that their records are not included in the data downloads submitted through the SACT data set.

It is suggested that a dissent; for example, the proactive expression of dissent by an individual from whom consent had been obtained (or similar flag), should be created in the provider organisation systems, so that the record can then be omitted from the monthly upload.

NDRS has published a patient information leaflet, which explains that individuals have the right to access and have their own data held in the NDRS removed and explains the process. This includes a digitally accessible version of the leaflet.

Opt-out

The NHS National Opt-Out does not apply to the NDRS in England. [The registry operates a separate opt-out mechanism](#). Please contact the opt out team at NDRSoptout@nhs.net to discuss your request and commence the process.

Data retention

The NDRS holds data indefinitely, as without this facility, accurate mortality and survival data cannot be calculated. If a patient wants their data removed at any point, this facility is available as explained above.

Data disclosure

The data collected is used by a team of experienced analysts and the outcomes help monitor existing treatments and improve future drug regimens. In accordance with the Data Protection Act, EU GDPR and Caldicott principles, NDRS takes steps to limit its processing of confidential patient information.

SACT is fully incorporated within the NDRS which uses the English National Cancer Online Registration Environment (EnCORE) and the tied, but functionally discrete, Cancer Analysis System (CAS).

EnCORE and CAS provide a secure, role-based separation between the essential requirement to process the confidential patient information needed to register a cancer case, and the pseudonymised data that is needed to analyse cancer incidence, prevalence, treatment and outcomes.

Role-based access controls are in place for CAS to ensure that authorised users can only see the data they need to do their job. There are 3 levels of access, with increasingly rigorous approval processes. These are:

- level one users of the system, can only see record-level diagnosis and treatment data and partial dates (such as month and year but not day) but are not able to access names, addresses, NHS numbers or postcodes
- level two users, are provided with access to the minimum numbers of patient identifiers needed for linkage purposes – such as NHS number, date of birth and postcode – but cannot view other direct identifiers such as names and street addresses
- level three users, who are provided with full access to all the patient identifiers recorded in the cancer registration data set, are reviewed by NDRS senior managers and only granted for analyses that depend on the complex matching of patient records

In summary, cancer registration in England fundamentally depends on the ability of the NDRS to process confidential patient information. But while it is not practicable or proportionate to obtain consent or to work with anonymised data only, the NDRS does take steps to limit the processing of confidential data to ensure compliance with data protection legislation and the Caldicott principles.

Technical Architecture

Implementation overview

The SACT standard was reviewed and modified the requirements on NHS Providers to submit monthly cancer data returns to the NDRS by approved NHS secure methods. Providers should therefore have reviewed and revised their previous arrangements to submit monthly returns to their local NDRS office in relation to the timeframe, content, and format of those returns to conform to this Requirement Specification.

It is recognised that the data items may be recorded in different electronic systems, however it is recommended to send an integrated record of all data items in one file using the double quote, comma separated values (csv) format only. Details of the reporting process, format and structure of all files can be found in the implementation, technical and user guides.

Phased approach to implementation

The revised data set v4.0 will have a 6-month implementation period for Trusts and system suppliers to make and test the changes required throughout the new standard. In addition, there will be a phased roll-out from 01 April 2026 (for the start of collection), therefore full conformance of the standard will be 01 July 2026 at the latest.

This will allow system providers who have multiple clients to roll-out the new versions successfully and during this period either SACT v3.0 or SACT v4.0 can be uploaded via the NDRS API portal.

Details of this phased approach are available in the implementation guide.

Working practices

The implications of the data standard to data providers are as follows:

- all NHS providers and system suppliers need to include the new and changed data items in their ePrescribing or reporting system
- redundant (removed) data items should not be reported to SACT, as per the implementation and technical guides, however they may be maintained within existing local systems for future audit
- organisations MUST update their monthly reports to enable the new and changed data items to flow to SACT, as per the implementation and technical guides
- there may be training implications for staff who collect and report SACT

Appendix A - Glossary of Terms

The following is a glossary of terms which relate to and are referenced within this specification document. The term is followed (in brackets) by the acronym, then below is the definition, in some cases there are hyperlinks to websites for additional information:

Acute Oncology Service (AOS)

The Acute Oncology Service provides first-line care for people who are experiencing cancer-related emergencies. These could relate to a new diagnosis of cancer or include complications from cancer or its treatment.

Association of the British Pharmaceutical Industry (ABPI)

The Association of the British Pharmaceutical Industry (ABPI) is the trade association for over 120 companies in the UK, producing prescription medicines for humans, founded in 1891.

Cancer

For the purposes of this standard the term 'cancer' is used throughout the standard and related documents to cover all conditions defined by the [World Health Organization \(WHO\)](#) and [International Agency for Research on Cancer \(IARC\) Classification of Tumours](#).

Cancer Centres

Organisations which help people to live with, through and beyond cancer by bringing together specialist clinical and professional staff and communities of support.

Cancer Registries

Organisations which exist internationally to collect, process, analyse and disseminate data on cancer patients in their local regions.

CancerStats2 Portal

Online resource that allows Trusts to review specific cancer data.

Care Quality Commission (CQC)

[One of the independent regulators of health and social care in England.](#)

Comma Separated Values (CSV)

CSV is a delimited text file that uses a comma to separate values. For SACT, CSV files MUST be saved with a text delimiter set to the double-quote character, to allow the use of commas in data values. This is used in the export and submission of all data files.

Commissioners

Organisations that plan, purchase, and monitor services to meet the health needs of their local population.

Data Alliance Partnership Board (DAPB)

The DAPB is authorised by the Secretary of State for Health and Social Care to oversee the assurance of information standards and data collections. The DAPB delegates the review and approval to the DAB.

Data Assurance Board (DAB)

The DAB is responsible for scrutinising and approving the publication of new, updated, or retired information standards and data collections under the authority delegated by the DAPB.

Data Governance and Assurance Team (DGAT)

DGAT provide the assurance function on behalf of the DAB.

Department of Health and Social Care (DHSC)

The Department of Health and Social Care (DHSC) is a ministerial department of the Government of the United Kingdom. It is responsible for government policy on health and adult social care matters in England.

Information Standard Notice (ISN)

A document containing standards that relate to the processing of information.

International Statistical Classification of Diseases and Related Health Problems (ICD)

A medical classification list for the coding of diseases, signs and symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as maintained by the World Health Organization (WHO). The title is followed by the revision number. For example, ICD10 is the tenth revision.

Multi-Disciplinary Team (MDT)

The Multi-Disciplinary Team (MDT) is responsible for managing a patients care and making decisions about treatment options following diagnosis or recurrence of a cancer.

National Cancer Registration and Analysis Service (NCRAS)

The NCRAS is responsible for collecting cancer data from all NHS Providers of cancer care in England. The NCRAS is a function within the NDRS within NHS England.

National Disease Registration Service (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.

NHS England (NHSE)

NHS England is an executive non-departmental public body (NDPB) of the department of Health and Social Care. NHS England provides national leadership for the NHS. They promote high quality health and care for all, and support NHS organisations to work in partnership to deliver better outcomes for patients and communities, at the best possible value for taxpayers and to continuously improve the NHS.

NHS Providers

Organisations that provide health services.

Systemic Anti-Cancer Therapy Data Set (SACT)

The national collection of all cancer systemic anti-cancer therapy data in the NHS in England, which covers all solid tumour and haematological malignancies.

Appendix B - Mandatory Registerable Conditions

ICD 10	Description of neoplasm
C00 - C97	All malignant neoplasms
D00 - D09 (excluding D04)	All carcinoma in-situ (excluding all D04 in-situ skin cancers)
D32 - D33 D35.2 & D35.3 D35.4	Benign neoplasms of brain & other parts of nervous system Benign neoplasms of pituitary gland & craniopharyngeal duct Benign neoplasms of pineal gland
D37 - D48 (excluding D47.2)	All neoplasms of uncertain behaviour Neoplasms of unspecified nature of bladder Neoplasm of unspecified nature of brain Neoplasm of unspecified nature of other parts of nervous system & pituitary gland only (Excluding D47.2 Monoclonal gammopathy of undetermined significance (MGUS))
E85.8 E85.9	Other Amyloidosis Amyloidosis, unspecified

Notes:

- although Amyloidosis (E85) is listed as an E ICD code in the World Health Organisation (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer, receiving Chemotherapy in cases
- NDRS publishes a full list of Mandatory Registerable Conditions, [this can be accessed via the NDRS website](#)

Appendix C - Uniform Resource Locator (URL) Glossary

This section provides the full URL address, to help and support sight impaired users access all links throughout the document.

Page 1:

- Section 251 website - <http://www.legislation.gov.uk/ukpga/2012/7/section/250>
- NHSE standards and collections website - <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections>
- National archives - <http://www.nationalarchives.gov.uk/doc/open-government-licence/>

Page 5:

- NDRS, SACT webpage - <https://digital.nhs.uk/ndrs/data/data-sets/sact>
- ISN publications - <https://digital.nhs.uk/data-and-information/information-standards/governance/latest-activity/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set/>

Page 7:

- Long Term Plan - <https://www.longtermplan.nhs.uk/>

Page 10:

- ISN publications - <https://digital.nhs.uk/data-and-information/information-standards/governance/latest-activity/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set/>
- NDRS, SACT webpage - <https://digital.nhs.uk/ndrs/data/data-sets/sact>
- NDRS data liaison contacts - <https://digital.nhs.uk/ndrs/data/data-sets/cosd#help-and-feedback>

Page 12:

- CancerStats2 portal - <https://cancerstats.ndrs.nhs.uk/>

Page 15:

- SACT upload portal - <http://nww.api.enclave.nhs.uk/>

Page 20:

- SACT documentation: - <https://digital.nhs.uk/ndrs/data/data-sets/sact#downloads-and-guides>

- ISN publications - <https://digital.nhs.uk/data-and-information/information-standards/governance/latest-activity/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set/>

Page 21:

- DCB0129: <https://digital.nhs.uk/data-and-information/information-standards/governance/latest-activity/standards-and-collections/dcb0129-clinical-risk-management-its-application-in-the-manufacture-of-health-it-systems/>
- NDRS Directions - <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/secretary-of-state-directions/national-disease-register-service-directions>

Page 22:

- DPN - <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notices/data-provision-notices-dpns/national-disease-registration-service>

Page 23:

- GDPR guidance - <https://www.england.nhs.uk/contact-us/privacy-notice/nhs-england-as-a-data-controller/>
- NDRS patient leaflet - <https://digital.nhs.uk/ndrs/patients/patient-leaflets>
- NDRS opt-out - <https://digital.nhs.uk/ndrs/patients/opting-out>

Page 26:

- WHO - <https://whobluebooks.iarc.fr/>
- CQC - <https://www.qcs.co.uk/>

Page 28:

- NHS England - <https://www.england.nhs.uk/>
- SACT - <https://digital.nhs.uk/data-and-information/information-standards/governance/latest-activity/standards-and-collections/dcb1533-systemic-anti-cancer-therapy-data-set/>

Page 29:

- Mandatory Conditions - <https://digital.nhs.uk/ndrs/data/data-sets/cosd/Error! Bookmark not defined.-user-guide-v10/appendix>