Public Health
England

Protecting and improving the nation's health

Systemic Anti-Cancer Therapy (SACT) Data Set

Specification

Version 3.0

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Senior Responsible Officer	Professor John Newton	**Version**	3.0
Developer	Andrew Murphy		
Author(s)	Andrew Murphy	**Version Date**	06/12/2018

Amendment history:

Version	Date	Amendment history
1.2	24-09-2013	Updated following comments received following the ISB appraisal
3.0 Draft	31-08-2018	Draft version for internal review and comment
3.1 Draft	05-10-2018	Draft version for DSAS review
3.0 Final	28-10-2018	Final version for publication
3.0 Final	06-12-2018	Final version published

Approvals:

This data set has been approved by the following:

Name	Signature	Title / Responsibility	Date	Version
SACT Chemotherapy Clinical Information Group (CCIG)	SACT Chemotherapy Clinical Information Group (CCIG)	This group consists of senior clinicians including medical and clinical oncologists, pharmacists and charity representatives. The group reports to the Programme Board.	28-06-2018	3.0
SACT Programme Board	SACT Programme Board	This board will have the final sign off, of the data set.	31-07-2018	3.0

Data Coordination Board

This information standard (DCB1533) has been approved for publication by the Department of Health and Social Care 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 Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Implementation Guide
- Change Request

An Information Standards Notice (DCB1533 Amd 80/2018) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the NHS Digital website. Any copies held outside of that area, in whatever format (for example paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Date of publication: 6 December 2018

Glossary of Terms:

Term	Acronym	Definition
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[1].
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 Outcomes and Services Data set (DCB1521 Amd 74/2016 v8)	COSD	The COSD is the national standard for reporting cancer in the NHS in England. It replaced the previous National Cancer Data set and includes the former Cancer Registration data set and additional site specific data items relevant to the different tumour types.
Cancer Registries		Organisations which exist internationally to collect, process, analyse and disseminate data on cancer patients in their local regions.
Cancer Stats 2 Portal[2]		Online resource that allows trusts to review specific cancer data for 1 or more standards via this portal
Care Quality Commission	CQC	One of the independent regulators of health and social care in England[3].
Chemotherapy Intelligence Unit	CIU	Team responsible for initially supporting SACT. CIU is now fully embedded within NCRAS (and no longer exists as a standalone entity).

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[1] http://whobluebooks.iarc.fr/
[2] https://cancerstats.ndrs.nhs.uk/
[3] www.cqc.org.uk/

Comma Separated Values	CSV	CSV is a delimited text file that uses a comma to separate values. This is used in the export and for the submission of all data files required for SACT.
Commissioners		Organisations that plan, purchase and monitor services to meet the health needs of their local population.
Data Coordination Board	DCB	The Data Coordination Board (DCB) meets on a monthly basis to review and approve the assurance of information standards and data collections (including extractions), known collectively as ISCE.
Dictionary of Medicines and Devices[4]	DM+D	This information standard SCCI0052 is a dictionary for use in the National Health Service (NHS) of medicines licensed in the United Kingdom.
Extensible Markup Language	XML	Extensible Markup Language (XML) is a set of rules for encoding documents in machine-readable form.
Improving Outcomes: A Strategy for Cancer	IOSC	The overarching strategy for cancer services in England[5].
Information Standard	IS	A document containing standards that ensures information is managed in a consistent manner across health and social care, both by the computers and the staff.
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.

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[4] www.nhsbsa.nhs.uk/pharmacies-gp-practices-and-appliance-contractors/dictionary-medicines-and-devices-dmd

[5] www.gov.uk/government/uploads/system/uploads/attachment_data/file/388160/fourth_annual_report.pdf

International Classification of Diseases for Oncology	ICD-O	An extension of the ICD coding system used principally in tumour or cancer registries for coding the site (topography) and the histology (morphology) of neoplasms. The title is followed by the revision number, for example ICD-O-3 is the third revision.
Multi-Disciplinary Team	MDT	The Multi-Disciplinary Team (MDT) is a group of experts who collectively make decisions about diagnostic tests required and the treatment management of patients suspected of or diagnosed with cancer.
National Cancer Registration and Analysis Service	NCRAS	The NCRAS is the National Cancer Registration and Analysis Service for England, collecting cancer data from all NHS Providers of cancer care in England. The NCRAS is a function within the National Disease Registration Service within Public Health England.
NHS Digital	NHS Digital	NHS Digital (previously known as the Health and Social Care Information Centre), is England's central, authoritative source of health and social care information for frontline decision makers, which builds upon the Health and Social Care Act 2012.
Office of National Statistics	ONS	The UK's largest independent producer of official statistics and the recognised national statistical institute of the UK.
OPCS Classification of Interventions and Procedures	OPCS	The OPCS Classification of Interventions and Procedures is a Fundamental Information Standard which is revised periodically. The classification is used by Health Care Providers and national and regional organisations. OPCS-4 is the current version used to support operational and strategic planning, resource utilisation, performance management, reimbursement, research and epidemiology. It is used by NHS suppliers to build/update software to support NHS business functions and interoperability.
Providers		Organisations that provide health services.

Public Health England	PHE	Public Health England is an executive agency of the Department of Health in the United Kingdom, taking up its full powers from 1 April 2013. Its role is protecting and improving the nation's health and wellbeing and to reduce inequalities.
SACT Chemotherapy Clinical Information Group	CCIG	This group consists of senior clinicians including medical and clinical oncologists, pharmacists and representatives from charities. It covers both adults and children, teenage and young adults (CTYA). CCIG reports to the Programme Board.
SACT Programme Board		This board will have the final sign off of the data set, before submission to DCB for approval.
Systemic Anti-Cancer Therapy Data set	SACT	The national collection of all systemic anti-cancer therapies in or funded by the NHS in England is covered by the standard. This includes adult and paediatric cancer patients receiving systemic anti-cancer treatment for solid tumours and haematological malignancies, including patients in clinical trials, and covers acute inpatient, day case, outpatient and community settings[6].
United Kingdom and Ireland Association of Cancer Registries	UKIACR	The UKIACR brings together organisations with an interest in developing cancer registration as a resource for studying and controlling cancer in the UK and Ireland[7].
XML schema		The documentation, definitions and descriptions required to enable the production and transmission of data for a specific XML.

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[6] http://digital.nhs.uk/isce/publication/dcb1533
[7] www.ukiacr.org/

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Overview

Summary

The table below contains a summary of the information standard.

Standard	
Standard Number	DCB1533
Standard Title	Systemic Anti-Cancer Therapy (SACT) Data set
Description	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 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. The standard covers neoplasms coded within ICD-10 diagnosis codes range C00 - C97, D00 - D48 and E85.9[8]. This standard consists of: • a set of individual data items, with their definitions • the assemblage of these data items into discrete data groups • the means of flowing the data items • compilation of the data items into a single reconciled and verified data set

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[8] Although Primary amyloidosis (E85.9) is listed as an E ICD code in the World Health Organization (WHO) disease classification, amongst clinicians it is widely acknowledged and subsequently treated as a cancer, receiving Chemotherapy in cases. Whilst we await the WHO disease classification being updated to reflect this fact, we have extended the scope of the COSD to include this. The United Kingdom and Ireland Association of Cancer Registries (UKIACR) is currently considering its inclusion in the UKIACR Library of Recommendations, which we have referenced in Appendix A.

	Providers of systemic anti-cancer therapy services are required to provide a monthly return on all activity using this data set. The standard may also inform design of electronic prescribing and other clinical systems as it defines, for consistent use, terms such as regimen and cycle that are used in systemic anti-cancer therapy treatments prescribed and administered to individual patients. This specification and the accompanying guidance documents together comprise the Information Standard and are subject to DCB Information Standards change control processes.

Applies to	The information standard applies to the following:
	• 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 Cancer Registration and Analysis Service
	• other appropriate national information, research and service planning organisations, for example
	• NHS Digital
	  • Care Quality Commission (CQC)
	  • NHS Improvement[9]
	  • Public Health England (PHE)
	  • NHS England

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[9] https://improvement.nhs.uk/

	At a local level: • strategic clinical networks (SCNs) • cancer alliances/vanguards • local cancer service provider networks • local NCRAS offices • 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. However: • it is important to note 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 (who commissioned the private provider), 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
Release	
Release Number	Amd 80/2018
Release Title	Version 3.0
Description	As part of the SACT data set on-going implementation and maintenance, a number of changes have been identified and these introduce: new data items • amendments to existing data items • deletions of data items where required • clearer definitions and expanded formats to improve the quality of data submitted within the current data set • the removal of the intention to change to xml submission These changes will allow the SACT data set to continue to meet the business objectives of the standard.

The new data items will help identify and analyse:

- local patient identifier, patient family and given names
    - to allow for cases where a patient does not have an NHS Number to be reported
- person stated gender code
    - required change to meet NHS Data Model and Dictionary consistency
- diagnoses using SNOMED CT
    - optional item to comply with information standard SCCI0034
- adjunctive therapy
    - to improve the accurate recording of adjunctive therapy type
- performance status (adult aged 19 years and older)
    - improved to allow for accurate recording of data
- administration measurement per actual dose
    - to record the accurate measurement (per dose) administered
- a series of new outcome summaries, measuring
    - curative (completed)
    - curative (not completed)
    - non curative

There will be 2 new pilots conducted for the life-time of the data set, checking the ability to collect:

- dm+d
    - to help link SACT and dm+d data to improve drug details information
- regimen outcome summary - toxicity
    - record if the toxicity was a deciding factor in modifying the treatment regimen

Other data items have improved descriptions, amended formats or updated attributes to help improve both the data quality and ascertainment of data through the data set.

The full list of new data items, those deleted and those that have changed are reported within the Change Request document.

Implementation start and completion date	Implementation will be between 06-12-2018 and 31-08-2019 (8½ months) data collection will start from 01-09-2019 (with a 3 month roll-out period between 01-09-2019 and 30-11-2019) full conformance by 01-12-2019

Supporting Documents

This specification should be read in conjunction with the following documents:

Product	Document Reference	Title
Information Standards Notice	http://digital.nhs.uk/isce/publication/dcb1533	DCB1533 SACT Information Standards Notice
Change Request	http://digital.nhs.uk/isce/publication/dcb1533	DCB1533 SACT Change Request
Data set v3.0	www.chemodataset.nhs.uk/guides_and_support/	SACT Data set 3.0
User Guide	www.chemodataset.nhs.uk/guides_and_support/	SACT v3.0 User Guide
Implementation Guide	http://digital.nhs.uk/isce/publication/dcb1533	DCB1533 SACT Implementation Guide
Technical Guide	www.chemodataset.nhs.uk/guides_and_support/	DCB1533 SACT Technical Guide

Related Standards

This Specification should be read in conjunction with the following standards:

Ref #	Reference	Title
ISB 0149-02	https://digital.nhs.uk/isce/publication/isb0149	NHS Number
SCCI0021	https://digital.nhs.uk/isce/publication/scci0021	International Statistical Classification of Diseases and Health Related Problems (ICD-10)
SCCI0034	https://digital.nhs.uk/isce/publication/scci0034	SNOMED CT
DCB0090	https://digital.nhs.uk/isce/publication/dcb0090	Health and Social Care Organisation Reference Data
DCB1521	https://digital.nhs.uk/isce/publication/dcb1521	Cancer Outcomes and Services Data set

Contacts

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Email Address	sact@phe.gov.uk

Health and Care Organisations

Requirements

#	Requirement
1	NHS Providers of cancer services (hereinafter referred to as NHS Providers) **MUST** read the Specification and Change Request in conjunction with the Implementation Guidance, to identify how the standard is applicable to them.
2	Providers of cancer services **SHOULD** review their clinical services and confirm which areas of the standard apply to their clinical practice. They **SHOULD** also carry out a data mapping exercise to assess how well their existing systems align to the SACT data set specification, and develop a plan for alignment if required.
3	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).
4	All providers of cancer services **MUST** submit data files to the SACT portal on a regular basis according to the approved staged programme. This is available along with a schedule for monthly submissions in section 6 of the Technical Guide.
5	Where patients have requested that their data is not shared, the provider organisation **MUST** ensure the records of these patients are not included in the data downloads submitted to SACT.
6	Clinical and operational staff predominantly record data for primary purposes, including data held in electronic prescribing systems, to record clinical events and facilitate medical intervention. Provider organisations **MUST NOT** utilise this data set for record keeping or to support their clinical and operational data capture. This standard must only be used for secondary uses.
7	Data items **MUST** be submitted in the formats specified in the data set, technical and user guides.
8	Downloads **MUST** be submitted only in Comma Separated Values (CSV) format.
9	Data quality 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.
10	It must be possible for the SACT team to reconstitute details of each patient's sequential management from data supplied. Providers of cancer services therefore **MUST** include mandatory data items, and required data items (which are part of NHS business rules where available or applicable), otherwise files will be rejected.

Conformance Criteria

Organisational Type	#	Criteria
Providers	***SACT Portal Submission QA***	
	1	SACT submission files are tested against the agreed business rules.
	2	A ‘file validation report[10]' is issued to demonstrate provider compliance.
	3	100% of the mandatory fields **MUST** be compliant in order to submit a file.
	Clinical QA	
	1	Where required, feedback on compliance of OPCS Regimen List is required to maintain accuracy.
	2	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	
	1	Notify the SACT help desk (as soon as possible after discovery) of any known reasons for significant variation[11] in the number of new cases submitted monthly in comparison to previous months.
	2	Monthly feedback is routinely provided from the SACT team for review, using the CancerStats2 portal[12]. This will allow cancer 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.
	3	A minimum of 80% of all expected cases is to be reported by provider trusts.
	4	All data extracted from trust cancer information management systems MUST be reported in CSV only.

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[10] This is a QA report created by the SACT portal for use by provider organisations to monitor compliance

[11] This would be any file where there is a 30% difference month on month

[12] https://cancerstats.ndrs.nhs.uk/

IT Systems

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

Requirements

#	Requirement
1	Suppliers of e-prescribing 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 and Implementation Guide.

Conformance Criteria

Criteria
The requirement 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 time period, The DCB standard provides all the documentation to support this process, including: • Implementation Guide • Change Request • Specification Document • SACT Data set v3.0 • Data Set User Guide Each regional NCRAS office has a nominated Cancer Improvement Lead who will help and support any trust struggling to meet the standard. They are supported by the very experienced SACT Liaison Officers. Software suppliers are invited to use the SACT supplier test portal to validate their new CSV report extracts, which comply with the changes as specified in the change request, data set, implementation and technical guides. The portal will validate against the file, then against each of the data items to establish compliance. A test report will be produced to confirm compliance.

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 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.

The standard covers neoplasms coded within ICD-10 diagnosis codes range C00 - C97, D00 - D48 and E85.913. See Appendix A for list of Mandatory Registerable Conditions.

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.

Submission of data in xml format is now out of scope of this information standard, due to the additional financial cost and burden of implementation.

As a ‘Secondary Uses’ 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.

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[13] Although Primary amyloidosis (E85.9) 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. Whilst we await the WHO disease classification being updated to reflect this fact, we have extended the scope of the COSD to include this. The United Kingdom and Ireland Association of Cancer Registries (UKIACR) is currently considering its inclusion in the UKIACR Library of Recommendations, which we have referenced in Appendix A.

Data Definitions

Details of the fields which comprise the SACT data set, including their Data Dictionary definitions, permissible values and other qualifying descriptions, are contained in the accompanying Implementation Guide, Change Request, Data Set v3.0 and new User Guide documents.

SACT has been carefully reviewed to support other major data sets and wherever possible, data items have been removed to reduce the burden of data collection.

In addition discussions have taken place with other data set owners to refine data items where cross-over is possible, to maximise the clinical relevance and prevent multiple (similar) data being created with different meanings. This work is supported by the NHS Digital, Data Dictionary and Terminology teams.

The Cancer Outcomes and Services Data set (COSD) has some overlapping content with the SACT data standard. Where this occurs, field definitions are consistent to allow data to be interoperable.

Data Set Structure

Systemic anti-cancer therapies are given over a prolonged period of time, often months or years, comprising repeating and sequential elements. The patient may attend 2 or more providers during the course of treatment. In order to track the patient during treatment the data set must be capable of linking all the elements of care in a consistent and ordered way.

In order to achieve this, the data set requires a branching structure which links the initial data fields, which will remain constant during the treatment, with detail of each regimen, cycle and drug administration. Examples of this are shown diagrammatically in the new SACT User Guide[14].

At the completion or cessation of a treatment regimen, the outcome section must link back to all previous fields, which have been submitted by the provider organisation (linking treatment with outcome).

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[14] www.chemodataset.nhs.uk/guides_and_support/

Monthly submissions from providers to the central repository will be in the form of monthly reports of current activity, including regimens started and completed or ceased in that time 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 where data comes from different providers.

Implementation and Use

Submission of Data

When a CSV file is ready for submission to SACT, staff at the reporting organisation can connect using the National Cancer Registration and Analysis Service (NCRAS) secure file upload system, which sits behind the English National Cancer Online Registration Environment (EnCORE) application programming interface (API) web portal[15].

Data Sources

The data will be provided by all hospitals and providers treating cancer patients with systemic anti-cancer therapies. Collation 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 and should be linked electronically to the e-prescribing systems, where these are in use
- details of the patient's clinical picture may also be derived from a variety of hospital systems or may need direct entry into an e-prescribing system
- details of specific systemic anti-cancer therapy (regimens, cycles and administration), will be recorded in the course of clinical practice and will be derived either from an e-prescribing system or other clinical databases
- details of the outcome of systemic anti-cancer therapies will also be recorded as part of patient management and will form part of the standard output from an e-prescribing system

Approach and Timelines

The SACT Information Standard was first implemented in England from April 2012, with a staged implementation of national collection of the SACT data set between April 2012 and April 2014.

This version change is important in order to continue to meet the business objectives of the standard, and to ensure that all data requested are clinically accurate and relevant for the lifetime of the standard.

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[15] https://nww.api.encore.nhs.uk/users/sign_in

The SACT data set has been designed to mirror the clinical decision making in prescribing systemic anti-cancer therapies, and is divided into 6 sections:

- demographics and consultant
- clinical status
- programme and regimen
- cycle
- drug details
- outcome

A list of SACT definitions (regimen, cycle and administration), can be found in the Implementation Guide, section 3.

Working Practices

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 staff group need to be aware of the existence of the data set collection process and may be responsible for 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 with the operation of this information standard
- 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 information standard, and should be disseminated as necessary through the relevant professional bodies

Nursing staff:
- this staff group have the major role in the administration of systemic anti-cancer therapies to the patient and in the recording of detailed information of the patient's progression through treatment

- new staff need to be briefed initially, as a normal part of their induction process, but ‘hands on’ training on e-prescribing systems is necessary to ensure efficient and accurate recording of data
- this training is required wherever an e-prescribing system is in operation

Medical staff:

- this staff group is primarily responsible for initiating the:
    - prescription
    - monitoring the patient's clinical progress
    - making adjustments to the prescription as required
    - summarising the treatment episode
- familiarisation with electronic prescribing 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 treatment summary in the e-prescribing system

IT staff:

- this staff group are required to have the necessary skills and training to maintain the functionality of e-prescribing systems
- this now includes the creation of extracts for submission to the SACT data repository
- details of this are covered in the SACT Implementation, Technical and new User Guide documents

All groups require access to appropriate user guidance in electronic and paper form. There are supplier specific ‘user forum’ arrangements already in existence and these provide a route to offering additional support on incorporating updates, and any practical issues arising from the introduction or implementation of a revision of the SACT information standard.

User Guidance

Please refer to the SACT Implementation, Technical and the new User Guides created for v3.0.[16][17]

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[16] http://digital.nhs.uk/isce/publication/dcb1533
[17] www.chemodataset.nhs.uk/guides_and_support/

It is preferable for local guidance to be grafted seamlessly into that already provided for users of electronic prescribing systems, either by system suppliers or local teams (using the above documents). This must be consistent with the SACT Information Standard, but also system specific and tailored to the architecture and graphic interface of individual suppliers' systems.

Governance

Information Governance

Data collection from all the new sources required to support cancer registration are covered by existing permissions granted by the Confidentiality Advisory Group (CAG) of the Health Research Authority (HRA).

The data set contains sensitive and patient-identifiable information items. The Confidentiality Advisory Group (CAG) of the Health Research Authority (HRA) has confirmed that reporting of patient identifiable data is covered by the NCRAS existing support under the Health Service (Control of Patient Information) Regulations 2002. Reported data will be managed by the NCRAS where there is long standing expertise in managing large volumes of confidential data.

Although the data items which are flowed to the NCRAS have changed, the data flows (i.e. which organisations will be receiving the data in identifiable form) remain unchanged. In compliance with the fair processing requirement within the Data Protection Act, provider organisations are expected to inform patients of this purpose for reporting their information and of the potential use of the information for service development, analysis and statistical research[18.]

To help and support trusts with this, the NCRAS have developed a patient information leaflet[19] (see Appendix B) that is a useful resource for organisations wanting to develop or revise local information materials. This has been written with the patient in mind and consulted upon to ensure it is easy to understand, and an updated version was issued in January 2018, taking into consideration the new General Data Protection Regulation (GDPR).

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[18] www.ndrs.nhs.uk/national-disease-registration-service/patients/

[19] www.gov.uk/government/publications/cancer-registration-patient-information-leaflet

These leaflets are provided without cost to all NHS trusts in England. More information about the review of informed choice for cancer registration can be found on the cancer research website[20].

NCRAS, as part of PHE, comes under the Department of Health and Social Care, Data Protection Act registration with the Information Commissioner's Office (ICO). The NCRAS has reviewed its information governance policies to correlate them with those of PHE and maintain compliance with all national information governance guidelines.
These policies inform for example:

- access controls of data, including data security awareness
- server security and encryption, including threats to data security and how to avoid them
- data transfer procedures, including breaches and incidents
- general data protection regulation (GDPR), and other legal requirement

General Data Protection Regulation (GDPR)

The lawful basis upon which the SACT as part of the cancer registry processes personal health data, is under 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 registry receives health data in accordance with conditions for “special category” data, set out in GDPR article 9(2)(h) “processing is necessary for the… provision of health care treatment or the management of health… care systems and services.”

And GDPR article 9(2)(i) “processing is necessary for reasons of public interest in the area of public health such as… ensuring high standards or quality and safety of health care… on the basis of (UK) law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.”

The Registry’s function is legal under the Health Service (Control of Patient Information) Regulation 2002, which sets aside the Common Law duty of Confidence for the processing of health data for medical purposes in the

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[20] www.cancerresearchuk.org/health-professional/review-of-informed-choice-for-cancer-registration

interests of improving patient care, or in the public interest, where seeking consent is not practical and there is no practical alternative.

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 (i.e. the proactive expression of dissent by an individual from whom consent has not been obtained) or a similar flag should be provided in the provider organisation systems so that the record can then be omitted from the monthly upload.

The NCRAS has published a Patient Information Leaflet (Appendix B) which explains that individuals have the right to access and have their own data held in the NCRAS removed, and explains the process. If patients use assistive technology (such as a screen reader) and need a version of this document in a more accessible format, they can email publications@phe.gov.uk

If a patient discovers that their information has been uploaded to the NCRAS (via SACT) and they wish for this to be deleted, the requester can email their request to optout@phe.gov.uk or write to the Director of NDR[21] using the address in the patient leaflet. The NCRAS will then remove the patient from the NCRAS database.

The NCRAS information for patients wishing to have their information removed as far as possible from the database is available on the following website (https://www.ndrs.nhs.uk/national-disease-registration-service/patients/opting-out/). See Appendix C for further information.

Opt-Out

The NHS National Data Opt-Out does not apply to the National Cancer Registry in England. The Registry operates a separate opt-out mechanism, as described above, therefore all providers should include all cancer patients data in submissions to the registry.

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[21] National Disease Registration

Data Retention

The NCRAS 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, then this facility is available as explained in 5.5.3 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 General Data Protection Regulation and Caldicott principles, the PHE cancer registration service does take steps to limit its processing of confidential patient information.

Although SACT has only been fully incorporated into the NCRAS data registration process since 2017, all the PHE cancer registration offices have been using the single English National Cancer Online Registration Environment (EnCORE) and the tied, but functionally discrete, Cancer Analysis System (CAS) since 2013.

EnCORE and CAS provide a secure, role-based separation between the essential requirement to process the confidential patient information needed to register cancer cases, 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:

- first level users of the system who can 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 and postcodes.
- second level users who are provided with access to the minimum number 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.
- third level users who are provided with full access to all the patient identifiers recorded in the cancer registration data set but these requests are reviewed by NCRAS 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 PHE to process confidential patient information. But while it is not practicable or proportionate to obtain consent or to work with anonymised data only, the National Cancer Registration and Analysis Service does take steps to limit the processing of confidential data to ensure compliance with data protection legislation and the Caldicott principles.

As the NCRAS is part of PHE, all such requests must be approved by the Office of Data Release (ODR).

Subject Access Requests

Subject Access Requests (SARs) are managed through PHE's Public Accountability Unit, in line with PHE's Data Protection Policy[22] and the Data Protection Act[23].

For SARs, relating to cancer registration, there is a 2 stage information release process. This is designed to balance the needs of the individual with our statutory requirement to protect patient confidentiality.

At the first stage, we provide the subject with a summary report known as an 'exemplar report'. This report contains information about data sources attached to the subject's cancer registration, the data we received from them and the originating organisation. The report gives examples of the type of information these sources might contain and a glossary of terms.

Following this, if the subject requires more information, PHE also offer to send a copy of the actual records attached to the subject's cancer registration to the primary care physician (the General Practitioner) or another clinician who knows the patient. This allows the GP to verify that the data has been sent to the correct person and, because some of the information is quite technical, the recipient also has the opportunity to ask the practice staff to explain anything they may not understand.

All the information is reviewed by the NCRAS' own Caldicott Guardian before being released. Requests are fulfilled within the time periods required by the Data Protection Act. There is a sample process map attached in Appendix D.

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[22] http://phenet.phe.gov.uk/Policies-and-Procedures/Pages/Data-protection-policy.aspx

[23] www.gov.uk/data-protection

Clinical Governance

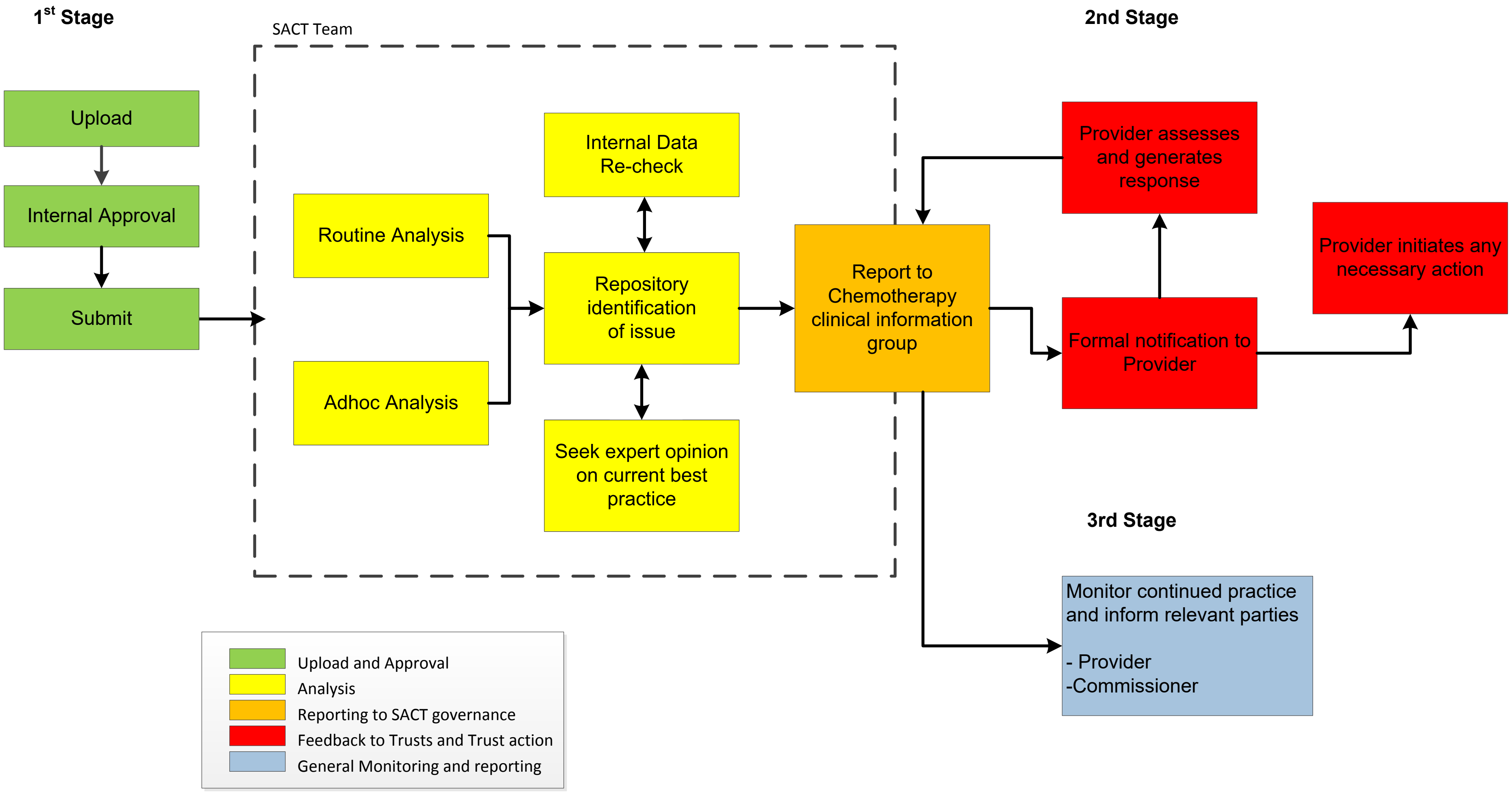
This is a secondary uses standard - no direct patient safety hazards were identified for the data set itself. Analysis of the clinical content of the data collected will provide previously impossible insights into the patterns of systemic anti-cancer therapies, being delivered by individual providers and to individual patient groups and communities.

The format and content of reporting will be matched to the reasonable requirements of the various recipients of the data and reports, and the confidence intervals applying to each analysis made clear. When an apparently unacceptable variation in clinical practice is revealed by analysis, a formal staged process of investigation must be undertaken by SACT. This process will determine whether:

- this is an issue of variation within acceptable range but with limited patient choice
- this is an acceptable practice but worrying trend
- this is an issue which requires action within an agreed timescale
- this is an issue of immediate clinical concern

This will decide the urgency of appropriate action which will be managed by the SACT senior leadership team.

The process to be undertaken is presented in the following diagram:



Data Quality

The SACT data set has complex and interrelated content, so it is essential that data errors are eliminated to prevent corruption of sometimes complex analyses dependent on many disparate data elements. Conformance criteria are listed in sections 2 and 3 above and further detail are provided in the section 4 of the SACT Implementation Guide.

Initial quality assurance reports will be issued to providers of data immediately following submission. Once initial data quality standards have been achieved, a suite of standard clinical activity reports will be generated. These will cover defined time periods sufficient to be assessed meaningfully, and circulated to providers, with the request that they are reviewed by clinically competent staff in each provider organisation, to eliminate possible errors in clinical content.

When technical, coding and clinical errors have been corrected, the data will be released for the generation of a full range of analysis and reporting. This process runs in parallel with the clinical governance process in section 5.5.8 above.

Demographic Data

Cancer registration is dynamic and individual tumour records are updated from numerous disparate data sources including SACT. Linkage from some of these sources across the NHS is not sufficiently good to allow accurate mapping of new data to existing items without patient-identifiable data.

An example could be when using only NHS Number. There is a risk that a typo could cause the wrong data to be inadvertently added to the wrong patient or a new record created to a patient who does not have cancer, or a new record created for an existing patient, so not linking up pathways.

Having additional patient identifiers (introduced in this release) helps to reduce that possibility and provides an invaluable quality assurance process between the trusts and SACT.

Even once linked, retaining addresses and names remains important; the address stored by the registries is that at the time of diagnosis of the tumour and is essential for cancer cluster analyses, possibly many years later when the patient may have moved address.

Nevertheless it is registry practice to use pseudonymised or even anonymous (possibly still disclosive) data sets for analysis where patient identity is not needed. Access to identifiable and potentially disclosive data requires appropriate permissions from the Office of Data Release (ODR). This is a function of the National Disease Registry (NDR) within Public Health England.

For details on how the cancer registry processes deal with linkage and data discrepancies please see Appendix E.

Maintenance Arrangements

The Chemotherapy Intelligence Unit (CIU) was established on 1 April 2011. The term ‘CIU - Chemotherapy Intelligence Unit’ was the SACT team name prior to SACT’s integration with the wider NCRAS team. Although this was a name change, the core team remained who were present at the time of the name change.

The SACT team is the conduit for all routine communications relating to the establishment and maintenance of the national systemic anti-cancer therapy data set and data collection.

Any changes required to improve the data collection process and changes required from time to time to ensure that the Information Standard remains consistent with need, will be coordinated through the Chemotherapy Clinical Information Group (CCIG).

This group consists of senior clinicians including medical and clinical oncologists, pharmacists and charity representatives, covering both adults and children, teenage and young adults (CTYA).

CCIG report to the SACT Programme Board, which consists of 3 senior members of the SACT team including the Director for National Disease Registration. The programme board formally signs off any changes proposed by CCIG.

Organisations and suppliers are encouraged to submit comments or requests concerning the data set, its collection and analysis to SACT via email to sact@phe.gov.uk to initiate this process.

A need for changes to the Standard and the User Guidance may be identified through this route or during planned evaluation of the implementation of the Standard. Such changes will be subject to consultation, testing, formal approval and notification according to the change process requirements of the Data Coordination Board (DCB).

Agreed changes or enhancements to the implementation approach will be circulated to all contributors on a regular basis via the SACT. The SACT Programme Board will continue to be responsible for overall strategy.

Technical Architecture

Implementation Overview

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

Submission of Data

Providers will submit the data to the SACT regularly in CSV format only, using the current NHS approved standards of submission (see Implementation and Technical Guidance for further details).

XML Format for Submissions

XML submissions will no longer be a requirement of this standard, and this has been reflected in a change to the scope of the standard. This decision was taken after review and due to the financial burden this would have cost trusts and SACT in changing reporting structures, training of staff and the reporting of data files in this format.

Phased Approach to Implementation for Data Set v3.0

The revised data set v3.0 will have a 6 month implementation period for trusts and suppliers to make and test the changes required throughout the new standard.

A phased roll-out from 1 September 2019 (for start of data collection).has been agreed, full conformance of the standard must be achieved by 1 December 2019 at the latest.

This is to make allowance for the varied timescales of different software suppliers and in-house developers. During this 3 month period, data can be submitted in accordance with either data set v2.0 or v3.0.

By Date	All Providers
October - November 2018	Supplier system testing
6 December 2018	DCB1533 Amd 80/2018 ISN Publication
7 December 2018	Implementation period starts (8½ months)
May - June 2019	Trust system testing
31 August 2019	Implementation period ends (8½ months)
1 September 2019	Start of data collection of the revised SACT data set (v3.0)
1 September - 30 November 2019	Three month roll-out period, to support system developers
1 December 2019	Full Conformance of the SACT data set (v3.0 Revision)

The time extension will allow all partners to develop and update protocols and guidelines and for software vendors to develop, test, and deploy their products in time for the data collection and implementation of SACT v3.0.

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 electronic prescribing or reporting systems
- 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

- these organisations may need to amend their transmission methods to enable the new and changed data items to flow and be centrally collated by the SACT
- there may be training implications for staff given changes to data item definitions or the implementation of new data items
- provider organisations may need to adjust their previous processes for capturing data in order to include all the data items in the monthly extracts and ensure accuracy of clinical items

Implementation Guidance

Implementation guidance has been developed to support users, organisations and systems suppliers to implement the standard. Versions of the documentation are available on the NHS Digital standard website[24].

A new SACT Technical and User Guide for v3.0 have also been developed to support the publication of the latest version change and are available on the 'Guides and Support' page of the SACT website[25].

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[24] http://digital.nhs.uk/isce/publication/dcb1533
[25] www.chemodataset.nhs.uk/guides_and_support/

Contact Details

- information, including the SACT data set and SACT User Guide is available on the SACT website at:
  - www.chemodataset.nhs.uk/guides_and_support/
- queries regarding these documents (including suggested amendments for future revisions) should be addressed to:
  - sact@phe.gov.uk
- queries regarding submissions should be discussed with the SACT helpdesk
  - contact emails and telephone numbers are available on the following website: www.chemodataset.nhs.uk/home

Appendix A: 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))
E85.9	Primary Amyloidosis[26]

Please see SACT User Guide for full list of Mandatory Registerable Conditions.

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[26] Although Primary amyloidosis (E85.9) 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 systemic anti-cancer therapy in cases.

Appendix B: NCRAS/CRUK Patient Information Leaflet

Where can I get more information?

- Online at **www.ndrs.nhs.uk**
- Talk to a member of your healthcare team.
- If there is a local support centre in your area, you will find their details in the box below.

Your Local Contact:

The National Cancer Registration and Analysis Service is part of Public Health England and collects information about all cancers in England.

Public Health England

Protecting and improving the nation's health

NHS

PHE Publications gateway number: 2017764. Version 4 updated January 2018

Can I ask for my information not to be included in cancer registration?

Yes, you have the right to opt out of cancer registration and this will not affect the immediate care you receive.

If you would like to find out why cancer registration is so important or have any questions about the work we do, visit us online at **www.ndrs.nhs.uk**.

If you do not want your information included in the register, you can contact us at optout@phe.gov.uk or write to us at:

Director
National Cancer Registration and Analysis Service
Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG.

We are supported by all the main UK cancer charities and cancer patient groups.

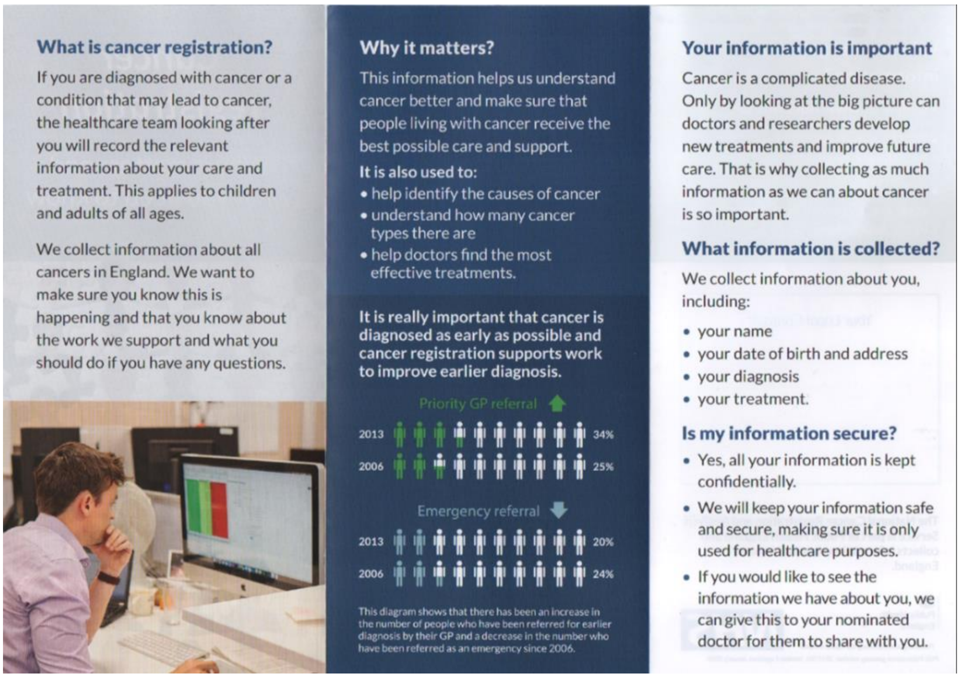
This leaflet is reviewed regularly.
If you have any comments please email NCRASfeedback@phe.gov.uk

For GDPR compliance information, visit www.ndrs.nhs.uk/GDPR

Crystal Mark 22491 Clarity approved by Plain English Campaign

Cancer registration

Why it matters and what you need to know



What is cancer registration?

If you are diagnosed with cancer or a condition that may lead to cancer, the healthcare team looking after you will record the relevant information about your care and treatment. This applies to children and adults of all ages.

We collect information about all cancers in England. We want to make sure you know this is happening and that you know about the work we support and what you should do if you have any questions.

Why it matters?

This information helps us understand cancer better and make sure that people living with cancer receive the best possible care and support.

It is also used to:

- help identify the causes of cancer
- understand how many cancer types there are
- help doctors find the most effective treatments.

It is really important that cancer is diagnosed as early as possible and cancer registration supports work to improve earlier diagnosis.

This diagram shows that there has been an increase in the number of people who have been referred for earlier diagnosis by their GP and a decrease in the number who have been referred as an emergency since 2006.

Your information is important

Cancer is a complicated disease. Only by looking at the big picture can doctors and researchers develop new treatments and improve future care. That is why collecting as much information as we can about cancer is so important.

What information is collected?

We collect information about you, including:

- your name
- your date of birth and address
- your diagnosis
- your treatment.

Is my information secure?

- Yes, all your information is kept confidentially.
- We will keep your information safe and secure, making sure it is only used for healthcare purposes.
- If you would like to see the information we have about you, we can give this to your nominated doctor for them to share with you.

This leaflet (v4 − updated Jan 2018) can be downloaded from the ndrs website[27].All NHS provider trusts are supplied with these leaflets and re-supply is monitored and recorded within the NCRAS.

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[27] www.ndrs.nhs.uk/wp-content/uploads/2017/10/NDRS-Leaflet-2017.pdf

Appendix C: Patient Opt Out Request Form

Patient Opt-Out Request Form

This form is for use by patients to request that their personal information be excluded from processing onto the National Cancer Registration Service's cancer registration database.

The personal information collected on this form is needed so that we can process your request correctly. It will only be used in connection with carrying out this request.

To be completed by the patient. Please complete as fully as possible.

My details	
My name	
My address	NHS Number
	Date of birth
	Sex
	Telephone number
	Place last treated
Post code	Date last treated

My request

I wish the cancer registration system in England to stop adding information about me to the cancer registration database and either

☐ Delete everything except for 'My Details'

Remove, as far as possible all clinical information relating to me but **retain** my NHS Number and the information I have provided in the 'My Details' section above in the 'watch list', so that any further information received about me will not be processed by the national cancer registration system.

Or:

☐ Delete everything
Remove, as far as possible all clinical and personal information relating to me including my NHS Number and the information I have provided in the 'My Details' section above. I understand the registry will not keep any record of my details, so, will not know that any information received about me in the future should not be processed.

We will send you a copy of the leaflet, '*Cancer Registration – what it is, the benefits of being on the register, and your options*'', in the hope that you may change your mind about opting out. If you do change your mind then please contact us as soon as you can.

Signed______________________ Date_______________________

Please return to:
Dr Jem Rashbass
Director,
National Cancer Registration Service
Public Health England
Wellington House
London
SE1 8UG

Patient advice

The Health Service (Control of Patient Information) Regulations 2002[28] permits the National Cancer Registration and Analysis Service (NCRAS) to collect information on all cancer patients in England.

All patient have the right to opt out of cancer registration. The first stage of opt out is usually a discussion with a clinician. The clinician will ensure that you are fully aware of the value of your information to research and for improving cancer treatments.

If you still want to opt out and have your details removed from the cancer registration data, you must apply in writing preferably by using the 'Patient Opt-Out Request' form above.

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[28] www.legislation.gov.uk/uksi/2002/1438/made

The NCRAS will then add your NHS number to an ‘exemption list’. By adding your details to this list, the NCRAS can ensure that it will not collect any incoming information about you.

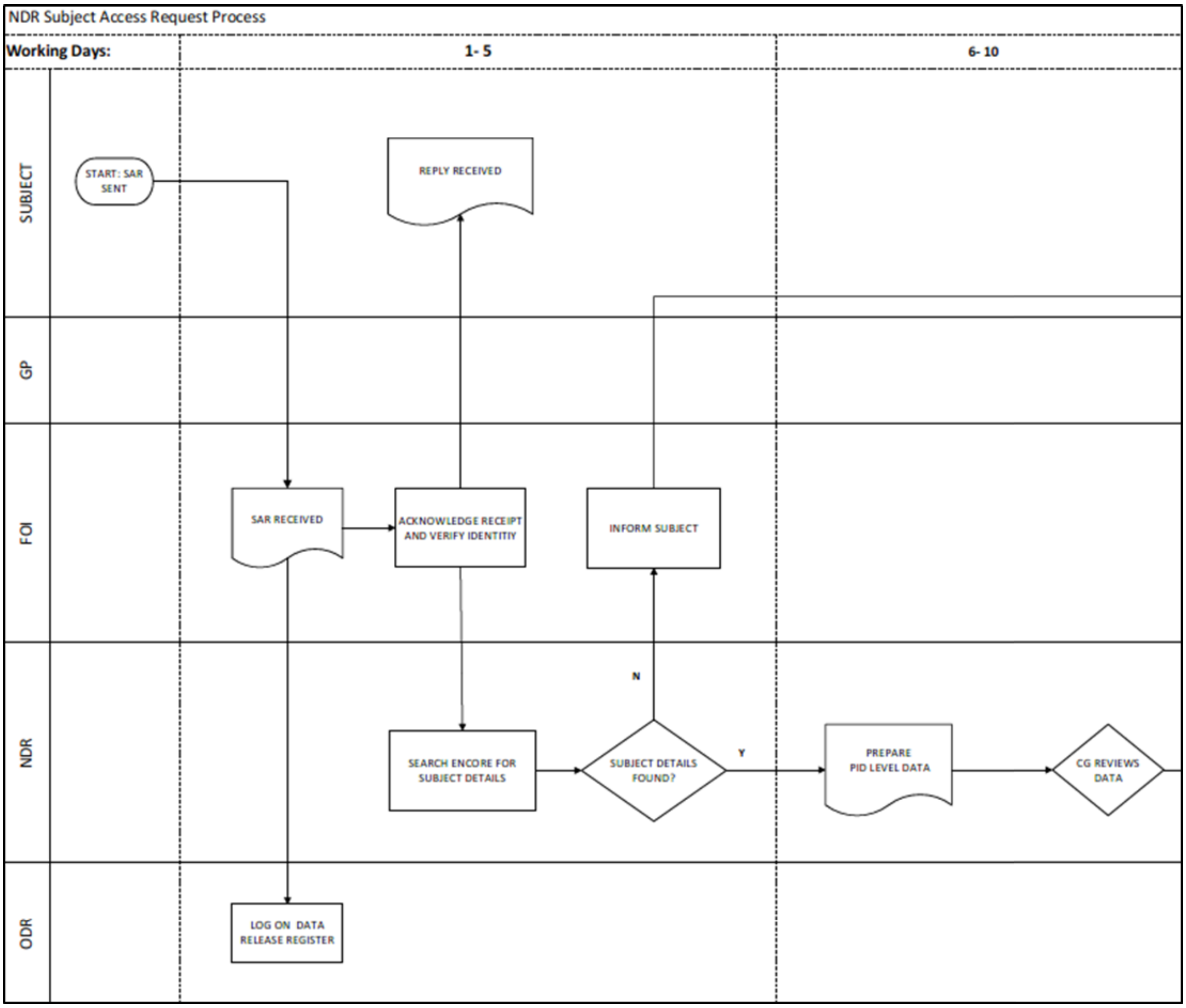
The NCRAS will search all cancer registration files and records and as far as is practicable delete any existing information relating to you that it may already have.

The NCRAS will also check whether it has sent any identifiable information to other permitted organisations such as the Office for National Statistics, and if so as far as is practicable contact that organisation and instruct them to delete the information.

The NCRAS will complete its actions within 20 days of receiving the written request and will confirm this in writing to you.

You may also request removal from the exemption list and the NCRAS will act on this request. However if your details are removed from the exemption list, the NCRAS will not be able to guarantee that your data are not added in future.

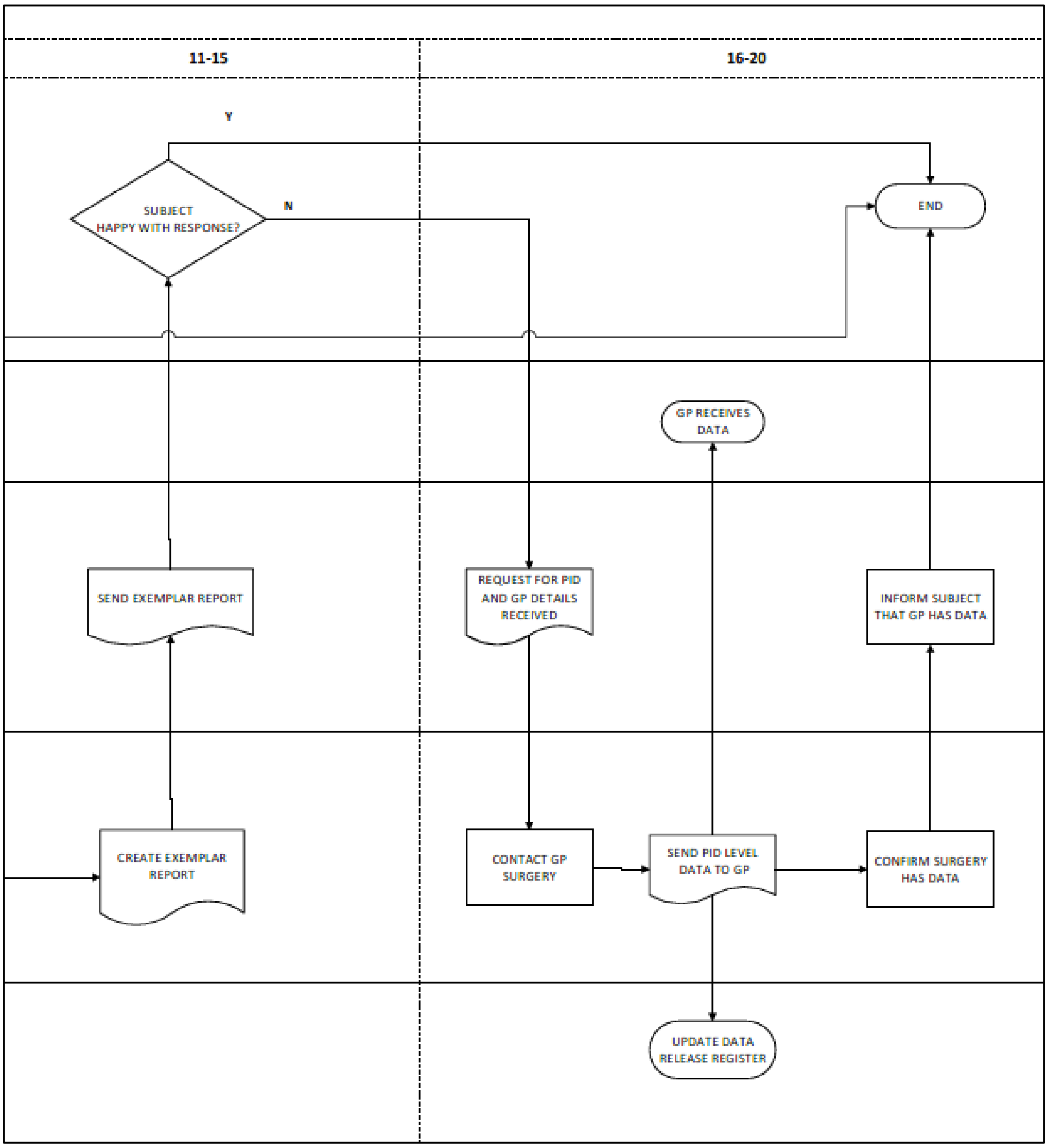
Appendix D: Subject Access Request Process Map



FOI days 1-5 and 6-10

Note: Process Map document is available upon request

Subject Access Request Process (continued)



(FOI days 11-15 and 16-20)

Note: Process Map document is available upon request

Appendix E: Data Linkage and Data Discrepancies

Linkage

Linkage is a complex issue, which has become far simpler in recent years with the rollout in use of the NHS Number. Registries use different linkage methods according to the type of data which is available. In essence, the more good quality linkage data that is available, the more confident the linkage is correct.

In fact linkage comprises 2 parts; blocking and weighting. Blocking takes an incoming record and uses a range of search criteria, determined by the incoming records content, to identify a series of possible matches in the database. Where the NHS Number is available, that is used, but other blocking is usually also applied. In a manual context, these blocks tend to be sequential, but in an automated setting they tend to run consecutively, with all potential matches passing to the second stage, weighting.

Weighting can be simple. Deterministic weighting is used for NHS Number matching, but this is always augmented with at least 1 other identifier. Probabilistic techniques use a wider set of data matches, and are usually used when the NHS Number is not available on either the source record or the blocked record. It looks for the 'commonness' of the data value in the overall database, and then uses that to weight up or down based on a series of random control matches. Probabilistic weighting is a well-defined science, with robust methodologies, however it is used far less than in past years.

Data Discrepancies

The fundamental principle of cancer registration is that it relies on multiple sources of data. When dealing with multiple sources, many of which may contain a common item, there is likelihood that 2 sources will give different values for a particular item of data.

The technical design of the registration schema is such that multiple sources and multiple data values are held against the summarised registration record. Registration clerks are trained to identify and deal with data discrepancy. This usually starts with some basic data checking with the source data supplier, but where conflicting data exists there are clear rules by which registry staff undertake this. At no stage is any source data overwritten or lost, and regular checks are included in the registration practice to examine random sets of records as part of the standard QA built into registration practice over many years.