Public Health England

Protecting and improving the nation's health

Systemic Anti-Cancer Therapy (SACT) Data Set

User Guide

Version 3.0.2 Final

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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Published December 2018
PHE publications
gateway number: 2018638

PHE supports the UN
Sustainable Development Goals

Version Control

Version	Date	Brief Summary of Change	Editors
3.0 Final	06-12-2018	Final version published	Andrew Murphy
3.0.1 Final	14-01-2018	Amendment to guidance for Height At Start Of Regimen, Weight At Start Of Regimen (Pg28) and Weight At Start Of Cycle (Pg30)	Andrew Murphy
3.0.2 Final	05-12-2019	Amendment to Drug Name description (pg32)	Andrew Murphy/Wayne Brown

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Status – User Guide

Systemic Anti-Cancer Therapy (SACT) Data set – Version 3.0 Release (September 2019)

This User Guide is one of a suite of documents to aid users in implementing the SACT Information Standard (DCB1533 Amd 80/2018)[1]. It includes all the data items in SACT together with definitions, formats, codes and values and additional guidance on collection and implementation.

This User Guide is aligned with and should be read in conjunction with version 3.0 of the data set which is available to download on the SACT website[2]. Other guidance and supporting documents are also available on the SACT website and we are continuing to explore an online version of the Guide.

This version of the User Guide incorporates some amendments to the data set, a change of scope and a revision of the current specification in order to continue to meet the business objectives of the standard. It accompanies a change notice for the standard (Amd 80/2018) which has been accepted by the Data Coordination Board (DCB), see the section 'What's changed' for a summary of changes.

Implementation of the Standard is carried out by the SACT central team within the National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England (PHE). Queries regarding the information standard itself or implementation should be addressed in the first instance to sact@phe.gov.uk or your local SACT Liaison Manager.

All Providers have access to their current monthly position via the CancerStats2 website[3] (NHS N3 connections only) which is now managed by NCRAS. This provides feedback on files as well as the completion/quality of data submitted.

We would like to take this opportunity to thank all those who have been involved in the development and implementation of the standard and encourage you to continue to send us your comments which help to identify necessary amendments and improvements.

[1] https://digital.nhs.uk/isce/publication/dcb1533
[2] www.chemodataset.nhs.uk/guides_and_support/
[3] https://cancerstats.ndrs.nhs.uk/

Introduction

What is the Systemic Anti-Cancer Therapy (SACT) data set?

The Systemic Anti-Cancer Therapy (SACT) Information Standard applies to all organisations providing systemic anti-cancer treatment therapies in, or funded by, the NHS in England. The SACT data set collects information reported routinely by NHS trusts on the treatment of malignant disease in secondary care in England.

This data set relates to all cancer patients, both adult and paediatric, in acute inpatient, day-case and outpatient settings and delivery in the community. It covers systemic anti-cancer treatment for all solid and haematological malignancies, including patients in clinical trials.

The impact of the standard will vary, depending on the configuration of hospitals and services and the existing and planned implementation of electronic prescribing and other clinical electronic systems.

The contents of this User Guidance document should be made available to all staff groups involved in responding to the standard, including:

- medical and nursing
- pharmacy
- information
- IT
- management staff

It is not intended that the standard should have any direct impact on the delivery of patient care. However, the above groups, which are involved in the local implementation of the information standard, need to take account of any new changes of the standard in their work area and develop a strategy to fully meet its requirements by the end of the implementation period.

If you are a new provider of systemic anti-cancer therapies, as well as reading the Implementation User Guide, please contact the SACT Helpdesk at sact@phe.gov.uk.

Other useful recourses to support the collection of the SACT data set, such as Frequently Asked Questions, can be found here: www.chemodataset.nhs.uk/frequently_asked_questions/.

Background

The national collection of all systemic anti-cancer therapy (SACT) information in the NHS in England commenced in April 2012. This was in line with the requirements of the Department of Health's policy document Improving Outcomes: A Strategy for Cancer January 2011.

SACT is a major part of cancer treatment, with new types of drugs being introduced capable of targeting individual cancers. Historically the recording of SACT activity was held within individual patients' notes. Systemic anti-cancer therapies are increasingly successful as a treatment but are ever more complex and expensive. Accurate, timely and complete data collection is a priority and supported through electronic clinical data collection.

SACT is a mainstay treatment for patients with cancer, with a cost estimated at approximately £1.5 billion[4] for the NHS in England annually. Since 2012, provider trusts have been submitting regular SACT activity for their patient's national collection and analysis of SACT provided within the NHS.

The SACT Information Standard addresses the requirement to standardise the recording of SACT treatment and outcomes through electronic systems. Version 3.0 is an extension to the standard, introducing new data, correcting existing data (for better analysis) and removing data to reduce the burden of data collection wherever possible.

Benefits

From April 2012, a staged monthly data collection commenced, initially from trusts with e-prescribing systems, though all organisations delivering any SACT for cancer were expected to provide some information. Since 2012, data collection and reporting processes have been established and SACT data has been used for a series of important analyses including on 30-day mortality post SACT[5]. The PHE team is working together with provider trusts to continually review and improve both submissions and reporting processes, ensuring the recording of high-quality data.

This is an important initiative with a wide range of benefits in terms of understanding patterns of clinical management in systemic anti-cancer treatment therapies. This is already recognised as being very valuable for those providing and commissioning services, ensuring that services are both of high quality and delivered efficiently.

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[4] Source: NICE Feb 2018

[5] www.chemodataset.nhs.uk/reports/

Equally importantly, it aims to support patients and their clinical teams in choosing appropriate care, based on accurate knowledge of current practice and the corresponding benefits and toxicities of treatment. The aim is for this information, therefore, to support patient choice and empowerment in a way that has not previously been possible.

The SACT data set is also integrated with the other clinical NHS data sets (through the National Cancer Registration and Analysis Service – NCRAS), ultimately enabling the outcome of the complete patient pathway to be understood.

For details of the implementation timetable refer to Appendix E.

SACT within PHE

The national collection of SACT data is held and analysed by the National Cancer Registration and Analysis Service (NCRAS). NCRAS is responsible to Public Health England and complies with Section 251 of the NHS Act 2006.

In order to provide an accurate and complete analysis of clinical practice, the data collected includes information on the patient and their condition, with details of every prescription for SACT treatments. It also records some information of the outcome of SACT regimens.

Information Governance

The SACT Providers do not need to get specific consent from patients in order to submit patient identifiable SACT data to the data set, as it is covered by the same governance rules as other data sets collected by the National Cancer Registration and Analysis Service.

The data set contains sensitive and patient-identifiable information items. The NHS Health Research Authority has confirmed that reporting of patient identifiable data to SACT is covered by the NCRAS existing support under the Health Service (Control of Patient Information) Regulations 2002.

Reported data will be managed by NCRAS, where there is expertise in managing large volumes of confidential data.

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.
Where patients have requested that their data is not shared, the provider organisation must ensure that their records are not included in the data

downloads submitted to SACT. It is suggested that a “no consent" or similar flag is provided in local systems so that the record can then be omitted from the monthly upload.

If a patient discovers that their information has been uploaded to the central repository and they wish for this to be deleted, the organisation must complete a Subject Deletion Request form (available on the SACT Upload Portal) and send this to NCRAS to action. The PHE team will then delete the record from the database along with any backup files.

An updated Patient Information Leaflet, which explains that individuals have the right to access and have their own data held by the NCRAS deleted, and the process by which to do this was circulated to all NHS trusts in February 2018[6]. The NCRAS consulted on the leaflet with patient groups and cancer charities on its content.

General Data Protection Regulations (GDPR)

The lawful basis upon which NCRAS as part of the cancer registry, will processes personal health data, including that collected by the SACT data set, 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 interests of improving patient care, or in the public interest, where seeking consent is not practical and there is no practical alternative.

[6] www.ndrs.nhs.uk/wp-content/uploads/2018/05/Cancer-Registration-Information-Leaflet.pdf

Clinical Governance

Analysis of the clinical content of the data collected has provided new 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 NCRAS team.

Mapping Local Data to the SACT Information Standard

There is no requirement to modify local clinical practices or data recording, however local system managers will be required to map local nomenclature and data formats to those defined in the SACT information standard before transmission.

Provider organisations are encouraged to review the content of the standard and consider whether making primary data recording consistent with the standard would benefit their services in terms of safety and efficiency.

Maintenance and Updating

Any changes required to improve the functionality and changes that are required from time to time to ensure that the data standard remains consistent with need, will be coordinated through the SACT Chemotherapy Clinical Information Groups (CCIG).

This group consists of senior clinician’s (including medical and clinical oncologists), pharmacists and representatives from charities, covering both adults and children, teenage and young adults (CTYA). This group will report to the SACT Programme Board, who have the final sign off the data set.

Provider organisations are encouraged to submit comments or requests concerning the data set, its collection and analysis to sact@phe.gov.uk for consideration.

Agreed changes or enhancements to the implementation of the data standard will be circulated to all contributors on a regular basis via the SACT national team.

Definitions for the National Systemic Anti-Cancer Therapy Data Set

Within the National Systemic Anti-Cancer Therapy Data Set, it is important that field naming is consistent within hospital systems and the definitions of the fields are unambiguous and applied by all providers.

Where possible, field naming and definitions should either be aligned with those agreed for the Radiotherapy Data set (ISB0111), Cancer Outcomes and Services Data set (DCB1521) or avoided.

Definitions

The term ‘Regimen’ is used to identify a standard combination of drugs.

The term ‘Cycle’ is used to identify treatment intervals within a regimen.

The term ‘Administration’ is used to identify the physical administration of drugs.

The relationships between programmes, regimens, cycles and administration dates are shown in the accompanying graphic and examples of data set structures (page 12)

Regimen: A SACT regimen identifies a standard for a combination of drugs (or single drug) given in a planned schedule.

A regimen can be standard, part of a trial or specifically designed for an individual treatment plan.

The SACT drug regimen title will be as agreed by the SACT team and an NHS support pharmacists’ group, as they maintain the regimen list, and this will inform the OPCS Guidance.

Cycle: Apart from continuous SACT, a regimen normally contains identifiable repeating elements and each repeat should be identified and numbered. Some regimens have alternating repeating elements, and some have consecutive sets of repeating elements. In all these cases the term “cycle” would be equally valid and help to identify the stage of progress of the patient through SACT.

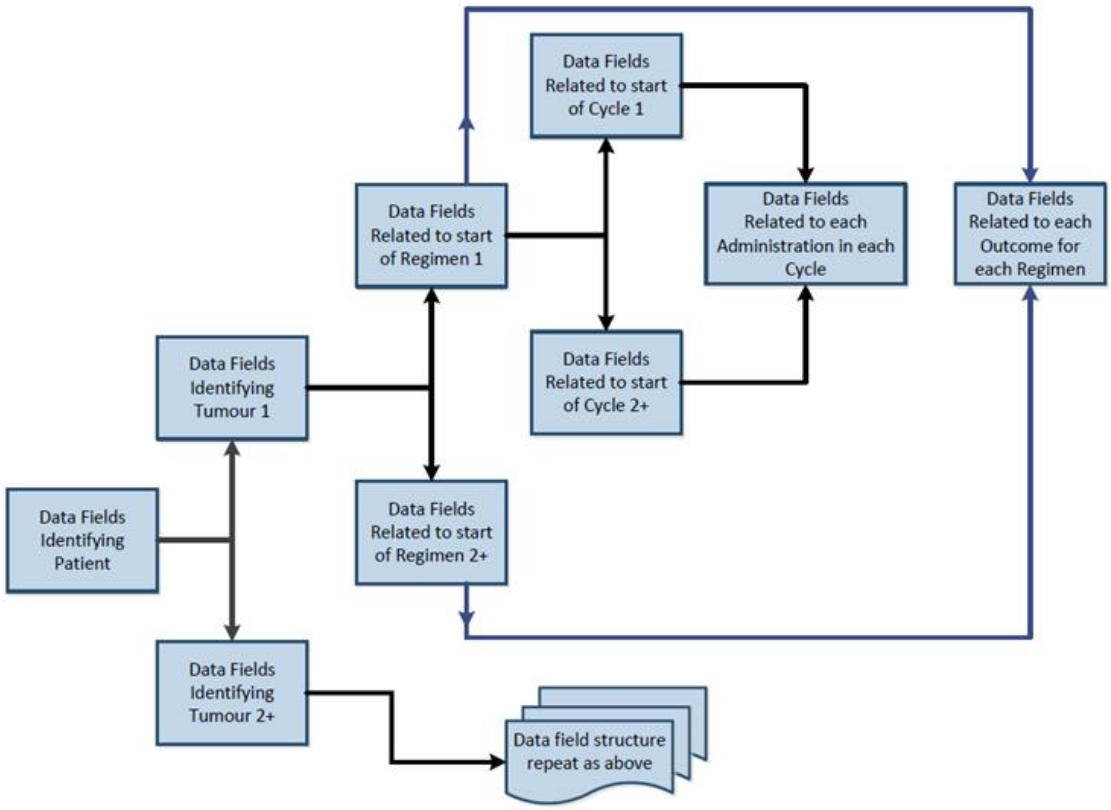
Cycle number: These will be numbered sequentially within a regimen and the option to start from any number must be available to allow for prior management not recorded on the current system.

Administration date: Consistent terminology is required to identify each contact between the patient and the clinical team when systemic anti-cancer therapies are administered. This will cover initial and subsequent contacts and needs to be recorded for inpatient treatment, clinic attendances, attendances in a primary care setting and domiciliary administration by a specialist service. In the case of infusions, the administration date will be the day the infusion was commenced.

For continuous oral chemotherapy, the administration date will be the first day of the nominal cycle.

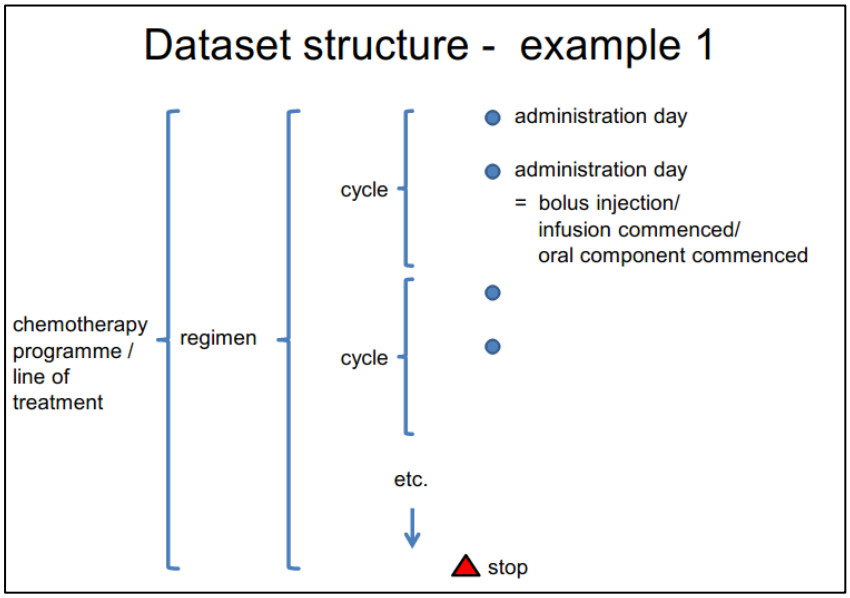
SACT Data Model

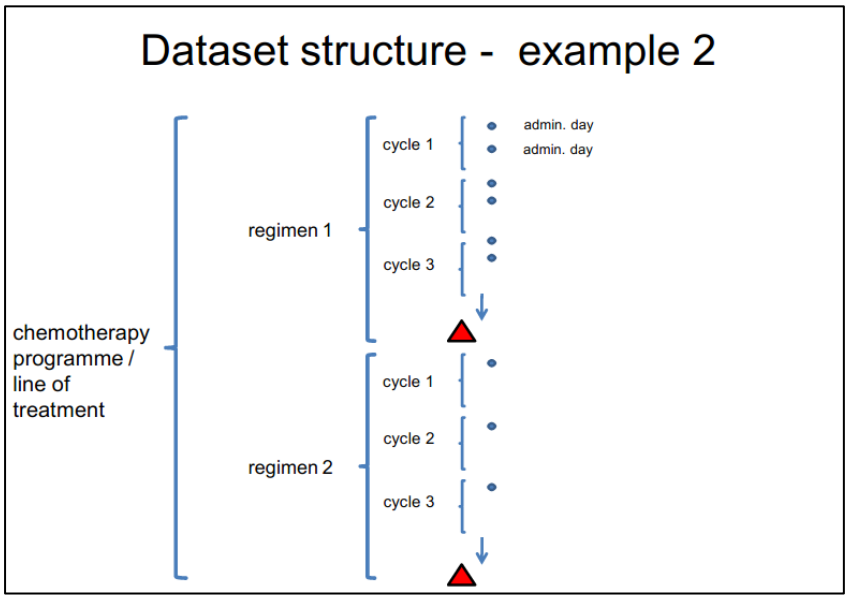
The following data model explains the relationship between the data and the treatment process (Regimen and Cycle), provided to a patient:

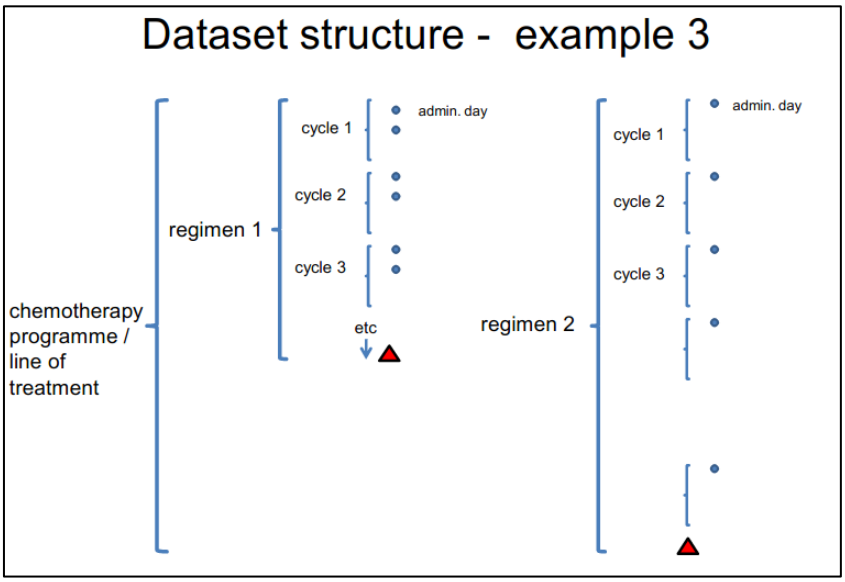


The Data Structures

The data structures are described below using 3 examples:







Other Guidance Documentation

Technical Guidance is provided separately and is available on the following web page www.chemodataset.nhs.uk/guides_and_support/.

Which Diagnoses Does SACT Apply To?

For the purposes of SACT the term ‘cancer’ relates to all conditions defined as registerable by the UK and Ireland Association of Cancer Registries (UKIACR) and these are listed in Appendix B.

These are in addition to Appendix A – Cancer Waiting Times ICD10 Codes and Tumour Groups for Primary Diagnoses. SACT requires that all treatments for new diagnoses and secondary/metastatic cancer are recorded.

All treatments for recurrences diagnosed at each trust must also be included.

Schema Specification

For the purpose of SACT v3.0, there will no longer be an expectation to convert local reporting to an XML schema. All trusts should therefore continue to report using the formatted .csv uploads as normal.

Mandatory
A section cannot be included in the record submitted unless it contains completed Mandatory items in that section. If there is other data in a section and the Mandatory items are not completed the record will not pass validation tests.

Required
Most other data-items are set as ‘Required’. This means that if they are applicable to the reported tumour or patient pathway, they must be completed and treated as a mandatory item. Not every data-item however will be applicable to every patient or tumour. By using ‘Required’, this allows for a more accurate and inclusive collection of data. Therefore, all applicable data in each section marked as ‘required’ must be submitted for each record as soon as available.

Pilot
In some cases, new data-items maybe piloted by a small group of trusts. These data do not have to be completed by any other trust unless you are part of the pilot. If you want to submit these data, please speak with your regional SACT liaison team(s). All pilot data-items are under review and may change in future version controls of SACT.

Optional
There are a few data-items that are optional, any trust can submit these data, but there is no requirement to enforce this data collection at this point. All optional data-items are under review and may change in future version controls of SACT.

Meaning of "NOT KNOWN" value
"Not known" includes both "not recorded" and for example "test not done". This is usually coded 9 or 99 (depending on the data item format).

List of Registerable Diseases
The ICD10 disease codes lists for all registerable conditions (C & D codes) are provided in Appendices A and B. The Haematological ICDO3 codes list can be found in Appendix C and D, these include ICD codes and WHO disease groups.

When Should the Data Be Submitted?

All SACT providers are required to upload their SACT activity regularly in the form of a 2-month schedule as follows:

Upload month	Activity month
June	April

Date	Process
1st – 30th June*	File containing April data must be uploaded to the portal and all errors on the file must be resolved
By 15th July	Regimen mapping must be completed (*this process can start at any point once the file has been uploaded*)
By 31st July	All regimen queries must be resolved and the file must be submitted

The portal imposes the following deadlines:

- upload and approval
  - all errors must be corrected prior to upload
  - all approvals must be completed, and all complete files uploaded by the last day of the reporting month
  - 100% of all data supplied must pass the SACT data validations[7], in order for the file to be uploaded to the portal
    - an updated set of validations and updated document will be created to support his version change of SACT
- map regimens
  - all local regimen names are required to be mapped to national values

[7] www.chemodataset.nhs.uk/view?rid=233

  - all regimen mapping will need to be completed prior to the file being submitted to the data set
  - regimens must be mapped by the 15th in the month following upload
- resolved queries on mapped regimens
  - all queries on mapped regimens must be resolved by the last day of the 3rd month

Date	Process
1st – 30th June	File containing April patient data must be uploaded to the portal
By 30th June	All errors on the file must be resolved
1st – 15th July	Regimen mapping must be completed
By 31st July	All regimen queries must be resolved and file must be submitted

Note: All provider trusts are advised to upload as early as possible in the month as this will allow more time to fix any errors. Uploading on the last day will mean that there may not be enough time to fix any errors and therefore trusts may become 'non-compliant' for various measures. Uploading earlier in the month will allow more time for regimen mapping if needed.

There is additional step-by-step documentation on the following web page, which will help new users understand how to upload all their data to SACT www.chemodataset.nhs.uk/guides_and_support/

Online Training

There is free online training available via the SACT website[8].

Feedback and Queries

This User Guide provides additional information to support the SACT Specification and should also be used in conjunction with the SACT Data set v3.0, Implementation and Technical Guidance documents.

Feedback and questions relating to the SACT are welcomed and should be emailed to sact@phe.gov.uk

[8] www.chemodataset.nhs.uk/training/

SACT Data Items

Key to Data Item Tables

All data items are listed as follows:

Data item No.	The reference number for the SACT data item
Data Item Section	The section in which the data item appears
Data Item Name	The name of the data item. This is followed by the *[DATA DICTIONARY ITEM NAME]* if different in purple
Format	Format required for submission of the data item
Schema specification (M/R/O/P)	The detailed schema for submission of the data is included in the Technical Guidance. XML has been dropped from the scope for the data set from v3.0, due to concerns with the burden of data collection and reporting. This column identifies whether items are required for the extract to pass validation rules when submitted. M = Mandatory: A section cannot be included in the record submitted unless it contains completed Mandatory items in that section. If there is other data in a section and the Mandatory items are not completed the record will not pass validation tests. R = Required: This data item (where applicable) should be submitted as soon as possible, but is not required to validate the submitted record. O = Optional: This item may be submitted at the discretion of the Provider. It is either not currently required nationally or it will be obtained/derived by SACT from other sources. P = For use in a pilot project only.

ICD-10 and ICD-O-3 CODES

The SACT data items should be collected for all cancers and other registerable conditions where applicable, where systemic anti-cancer therapies have been delivered as a primary or subsequent treatment. See Appendix A to C for the full lists of ICD10 and ICD-O-3 codes.

SACT Data Items in Detail

In order to ensure that records submitted can be linked appropriately some key data fields must be completed for each record submitted. These are set to Mandatory.

Demographics and Consultant

May be up to 1 occurrence per submission (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
1	DEMOGRAPHICS AND CONSULTANT	**NHS NUMBER**	n10	M[9]
44	DEMOGRAPHICS AND CONSULTANT	**LOCAL PATIENT IDENTIFIER** *[LOCAL PATIENT IDENTIFIER (EXTENDED)]*	min an1 max an20	M[10]
43	DEMOGRAPHICS AND CONSULTANT	**NHS NUMBER STATUS INDICATOR CODE**	an2	M
45	DEMOGRAPHICS AND CONSULTANT	**PERSON FAMILY NAME**	max an35	M
46	DEMOGRAPHICS AND CONSULTANT	**PERSON GIVEN NAME**	max an35	M
2	DEMOGRAPHICS AND CONSULTANT	**DATE OF BIRTH** *[PERSON BIRTH DATE]*	an10 ccyy-mm-dd	M
47	DEMOGRAPHICS AND CONSULTANT	**PERSON STATED GENDER CODE**	an1	R
5	DEMOGRAPHICS AND CONSULTANT	**PATIENT POSTCODE** *[POSTCODE OF USUAL ADDRESS]*	Max an8	M
7	DEMOGRAPHICS AND CONSULTANT	**CONSULTANT GMC CODE** *[CONSULTANT CODE (INITIATED SYSTEMIC ANTI-CANCER THERAPY)]*	an8	R
8	DEMOGRAPHICS AND CONSULTANT	**CONSULTANT SPECIALTY CODE** *[CARE PROFESSIONAL MAIN SPECIALTY CODE (START SYSTEMIC ANTI-CANCER THERAPY)]*	an3	R
9	DEMOGRAPHICS AND CONSULTANT	**ORGANISATION IDENTIFIER (CODE OF PROVIDER)**	min an3 max an5	M

Note: the following items have been retired from the data set in v3:

- gender current
- ethnicity
- registered GP practice code

[9] A combination of either **NHS NUMBER** and/or **LOCAL PATIENT IDENTIFIER** is Mandatory
[10] A combination of either **LOCAL PATIENT IDENTIFIER** and/or **NHS NUMBER** is Mandatory

NHS NUMBER: The NHS NUMBER is a unique identifier for a PATIENT within the NHS in England and Wales. This will not vary between any ORGANISATIONS of which a PERSON is a PATIENT.

- a valid NHS Number must be 10 digits long (numbers only) and must pass the MOD 11 check, an algorithm is incorporated into the validation engine of the portal which undertakes this check
  - the check is explained at the following url: www.datadictionary.nhs.uk/data_dictionary/messages/clinical_data_sets/data_sets/systemic_anti-cancer_therapy_data_set_fr.asp?shownav=1
- for Scottish patients treated in England the CHI patient identifier for Scotland is acceptable

LOCAL PATIENT IDENTIFIER: This is a new data item. For linkage purposes, NHS NUMBER and/or LOCAL PATIENT IDENTIFIER are required. This is a number used to identify a PATIENT uniquely within a Health Care Provider. It may be different from the PATIENT's case note number and may be assigned automatically by the computer system.

- to allow for cases to be reported, where a patient does not have an NHS Number
- must be the same as the organisation provider who is providing the treatment

NHS NUMBER STATUS INDICATOR CODE: The NHS NUMBER STATUS INDICATOR CODE indicates the verification status of the NHS number provided.

01	Number present and verified
02	Number present but not traced
03	Trace required
04	Trace attempted – No match or multiple match found
05	Trace needs to be resolved – (NHS Number or patient detail conflict)
06	Trace in progress
07	Number not present and trace not required
08	Trace postponed (baby under 6 weeks old)

PERSON FAMILY NAME: This is a new data item that records the part of a PERSON's name which is used to describe family, clan, tribal group, or marital association.

PERSON GIVEN NAME: This is a new data item that records the forename(s) or given name(s) of a PERSON.

PERSON BIRTH DATE: The date on which a PERSON was born or is officially deemed to have been born.

- all date formats should be ccyy-mm-dd
- SACT will not recognise or accept American formatted dates

PERSON STATED GENDER CODE: This is a new data item that records the person's gender as self-declared (or inferred by observation for those unable to declare their PERSON STATED GENDER).

1	Male
2	Female
9	Indeterminate (Unable to be classified as either male or female)
X	Not known (PERSON STATED GENDER CODE not recorded)

PATIENT POSTCODE: The code allocated by the Post Office to identify a group of postal delivery points. A code used primarily for the delivery of correspondence to ADDRESSES. POSTCODES may also be used to define a GEOGRAPHIC AREA.

CONSULTANT GMC CODE: Code of consultant who initiated SACT programme

- the GENERAL MEDICAL COUNCIL REFERENCE NUMBER should be used, prefixed with "C"

CONSULTANT SPECIALTY CODE: Specialty code of consultant who initiated SACT programme

- there is no current role for either obstetricians or gynaecologists in initiating chemotherapy (if they appear in returns it is probably an error), the only main specialities that are relevant to the SACT at present are Clinical Oncology, Medical Oncology, Haematology and Paediatrics
- urologists may be involved with bladder instillations and it is theoretically possible that gynaecologists may in the future have a similar role, in that case any of the 3 codes would suffice

ORGANISATION IDENTIFIER (CODE OF PROVIDER): The ORGANISATION IDENTIFIER of the Organisation acting as a Health Care Provider. This is the 3 or 5 digit code of the organisation submitting the demographic details. This will therefore normally be the treating organisation.

- **if you wish to be able to report at hospital level within a trust**: all sites reporting data within a given trust should submit data using the 5 digit hospital code, by submitting the 3 digit trust code for just 1 of several

hospitals reporting data, SACT is unable to discriminate between hospitals and consequently unable to generate hospital level reports

- **if you change your code:** SACT will be unable to report on the data submitted on the previous code the database cannot handle more than 1 code per trust or per individual hospital, these are primary keys on the trust and hospital tables respectively, and cannot therefore allow duplicates
  - in addition, your previous data submissions will not be visible on the portal for the purposes of approval or data quality reporting, this also means that you will be unable to see an aggregate of data for your trust for the period before the change in code
- **uploading and approving data:** if you submit data using a trust level code you will only be able to view it by selecting the trust
  - conversely if you submit data using the hospital code you will only be able to view the individual hospital's data on the upload and approval screens by selecting the hospital
- **non NHS providers:** at the moment we only expect NHS providers to be identified
  - private and other providers can be recorded using the new data item [Delivery Location]

Clinical Status

May be up to 1 occurrence per submission (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
10	CLINICAL STATUS	**PRIMARY DIAGNOSIS** *[PRIMARY DIAGNOSIS (ICD AT START SYSTEMIC ANTI-CANCER THERAPY)]*	min an4 max an6	M
11	CLINICAL STATUS	**MORPHOLOGY ICD-O** *[MORPHOLOGY (ICD-O AT START SYSTEMIC ANTI-CANCER THERAPY)]*	min an5 – max an7	M
48	CLINICAL STATUS	**DIAGNOSIS CODE (SNOMED CT)** *[DIAGNOSIS (SNOMED CT)]*	min n6 max n18	O

Note the following items have been retired from the data set in v3:

- TNM Stage Grouping (Final Pretreatment)

PRIMARY DIAGNOSIS (ICD): The primary diagnosis is normally agreed at the MDT Meeting where the patient is discussed.

ICD10 is the International Statistical Classification of Diseases and Related Health Problems (ICD) and is a comprehensive classification of causes of morbidity and mortality. The primary diagnosis is the main condition treated or investigated during the relevant episode of healthcare.

- all ICD codes must be provided using the full 4 digit code, to allow for accurate analysis and reporting
- all codes must be submitted without the full stop for example where the code is C34.8, the submitted code should be C348
- where the ICD10 code only has 3 characters, for example C01, please add “X” as a ‘packing digit’ to meet the validation rules (for example C01.X, C07.X, C73.X etc.)
- SACT accepts both C and D codes for Cancer, we also accept E85 – E859 for Amyloidosis
  - use Appendix A and B for more information

Note: trusts must provide either morphology or primary diagnosis for the data to be accepted, SACT aim to receive both in time

MORPHOLOGY ICD-O: The morphology code for the diagnosed cancer as defined by ICDO3.

- it is expected that for Haematology cases ICD-O should be used in preference to Primary Diagnosis ICD
- please refer to the tables in Appendix C and D for additional support and linkage

Note: Trusts must provide either morphology or primary diagnosis for the data to be accepted, SACT aim to receive both in time
DIAGNOSIS CODE (SNOMED CT):

This is a new data item. DIAGNOSIS CODE (SNOMED CT) is the SNOMED CT concept ID which is used to identify the clinical diagnosis given to the patient.

- this is optional for v3.0 but expected to become a required data item in v4.0 onwards
- this optional item complies with information standard SCCI0034 and future proofs the data set

Programme and Regimen

May be up to 1 occurrence per submission (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
49	PROGRAMME AND REGIMEN	**ADJUNCTIVE THERAPY** *[ADJUNCTIVE THERAPY TYPE]*	an1	R
15	PROGRAMME AND REGIMEN	**INTENT OF TREATMENT** *[SYSTEMIC ANTI-CANCER THERAPY DRUG REGIMEN TREATMENT INTENT]*	an2	R
16	PROGRAMME AND REGIMEN	**REGIMEN** *[SYSTEMIC ANTI-CANCER THERAPY DRUG REGIMEN ACRONYM]*	max an150	M
17	PROGRAMME AND REGIMEN	**HEIGHT AT START OF REGIMEN** *[PERSON HEIGHT IN METRES (START OF SYSTEMIC ANTI-CANCER THERAPY DRUG REGIMEN)]*	n1.max n2	R
18	PROGRAMME AND REGIMEN	**WEIGHT AT START OF REGIMEN** *[PERSON WEIGHT (START OF SYSTEMIC ANTI-CANCER THERAPY DRUG REGIMEN)]*	max n3.max n3	R
50	PROGRAMME AND REGIMEN	**PERFORMANCE STATUS AT START OF REGIMEN – ADULT** *[PERFORMANCE STATUS (ADULT START OF SYSTEMIC ANTI-CANCER THERAPY DRUG REGIMEN)]*	an1	R
20	PROGRAMME AND REGIMEN	**CO-MORBIDITY ADJUSTMENT** *[CO-MORBIDITY ADJUSTMENT INDICATOR]*	an1	R
21	PROGRAMME AND REGIMEN	**DATE DECISION TO TREAT** *[DECISION TO TREAT DATE (SYSTEMIC ANTI CANCER THERAPY DRUG REGIMEN)]*	an10 ccyy-mm-dd	R
22	PROGRAMME AND REGIMEN	**START DATE OF REGIMEN** *[START DATE (SYSTEMIC ANTI CANCER THERAPY DRUG REGIMEN)]*	an10 ccyy-mm-dd	M
23	PROGRAMME AND REGIMEN	**CLINICAL TRIAL** *[CLINICAL TRAIL INDICATOR]*	an2	R

Note: the following items have been retired from the data set in v3:

- SACT Programme Number
- Regimen Number
- Performance Status at Start of Regimen
- Chemo Radiation
- Number of Cycles Planned

ADJUNCTIVE THERAPY: This is a new data item. Adjunctive therapy is therapy given in addition to the main therapy to maximize its effectiveness.

1	Adjuvant
2	Neoadjuvant
3	Not Applicable (Primary Treatment)
9	Not Known

- this field allows for the accurate recording of these to determine if:
  - adjunctive therapy was adjuvant (after the main therapy)

- neo-adjuvant (before the main therapy) or not applicable

INTENT OF TREATMENT: The intention of the SACT regimen provided during a treatment Spell. This has been completely reviewed, COSD and RTDS will also use a combination of these fields.

~~A~~	~~Adjuvant~~
~~N~~	~~Neo-Adjuvant~~
~~C~~	~~Curative~~
~~P~~	~~Palliative~~
~~D~~	~~Disease Modification~~
01	Curative Systemic Anti-Cancer Therapy – Aiming to permanently eradicate disease
02	Palliative – Aiming to extend life expectancy
03	Palliative – Aiming to relieve and/or control malignancy related symptoms
04	Palliative – Aiming to achieve remission
05	Palliative – Aiming to delay tumour progression
98	Other
99	Not Known

- this is a repeating data item, which allow for multiple attributes to be selected at the same time
- data should be returned (within the output .csv report), using the following sequence where more than 1 attribute is reported:
  - “,“02;04”,” *(using a semi-colon to separate each attribute within the double quote)*

REGIMEN: The component drug derived from the drugs used in the Anti-Cancer Drug Regimen used to identify the drugs used in the regimen.

- SACT does not require trusts to change existing practice or change local regimen names
  - regimen names must refer to a single identifiable regimen, that is ‘bucket codes’ must not be used
  - a bucket code is a code that refers to more than 1 regimen, for example ‘Chemotherapy’
- once uploaded, local regimen names need to be mapped to a national standard list
  - this is a quick and easy process and can be done via the SACT online mapping tool, pharmacists are usually the best people to do this
- the SACT portal data checker will accept any text that is used in the Regimen column, on upload, all regimen names are checked to the OPCS+ list included on the portal

  - this list is a version of the OPCS Chemotherapy Regimen List, as updated by SACT pharmacists to include new regimens, trials etc.
  - if your local name for a particular regimen exactly matches the OPCS+ list, it will be automatically mapped via the portal
- if the regimen name as it appears on the mapping tool is truncated or unclear, please contact SACT
- regimens are mapped by trust, so those uploaded by all the hospitals within your trust will appear together
  - it may require pharmacists from all hospitals within the trust to work together in order to complete all the mapping

HEIGHT AT START OF REGIMEN: Record the height in metres at start of SACT regimen.

- a value of 136 will need to be submitted as 1.36
- local QA should be implemented to ensure any value over 2 metres are reviewed prior to upload

WEIGHT AT START OF REGIMEN: Record the weight in kilogrammes at start of SACT regimen.

PERFORMANCE STATUS AT START OF REGIMEN – ADULT: This is a new data item. The World Health organization classification indicating a PERSON's status relating to activity / disability.

0	Able to carry out all normal activity without restriction
1	Restricted in physically strenuous activity, but able to walk and do light work
2	Able to walk and capable of all self care, but unable to carry out any work. Up and about more than 50% of waking hours
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair

Note: This is only to be used for patients aged 19yrs and above

CO-MORBIDITY ADJUSTMENT: Whether or not patient's overall physical state (other diseases and conditions) was a significant factor in deciding on regimen, or in varying the dose or treatment interval.

Y	Yes
N	No

DATE DECISION TO TREAT: This is the date that the consultation between the PATIENT and the clinician took place and a Planned Cancer Treatment was agreed.

- all date formats should be ccyy-mm-dd
- SACT ***Will Not*** recognise or accept American date formats

START DATE OF REGIMEN: This is the first administration date of the first cycle of a regimen. This is a Mandatory date for all submissions.

- all date formats should be ccyy-mm-dd
- SACT ***Will Not*** recognise or accept American date formats

CLINICAL TRIAL: For the SACT data set, this identifies if a PATIENT is currently taking part within a CLINICAL TRIAL.

01	PATIENT is taking part in a CLINICAL TRIAL
02	PATIENT is not taking part in a CLINICAL TRIAL
99	Not Known

- this relates to the regimen only

Cycle

May be multiple occurrences per submission (0..*)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
26	CYCLE	**CYCLE NUMBER** *[SYSTEMIC ANTI CANCER THERAPY DRUG CYCLE IDENTIFIER]*	max n3	R
27	CYCLE	**START DATE OF CYCLE** *[START DATE (SYSTEMIC ANTI-CANCER THERAPY DRUG CYCLE)]*	an10 ccyy-mm-dd	M
28	CYCLE	**WEIGHT AT START OF CYCLE** *[PERSON WEIGHT (START OF SYSTEMIC ANTI-CANCER THERAPY DRUG CYCLE)]*	max n3.max n3	R
51	CYCLE	**PERFORMANCE STATUS AT START OF CYCLE – ADULT** *[PERFORMANCE STATUS (ADULT START OF SYSTEMIC ANTI-CANCER THERAPY DRUG CYCLE)]*	an1	R

Note: the following items have been retired from the data set in v3:

- Performance Status at Start of Cycle
- OPCS Procurement Code

CYCLE NUMBER: Cycles numbered sequentially within each regimen.

- the cycle number and start date of cycle are the only mandatory fields within this group
  - for the remainder of the fields, with the exception of weight at start of cycle (obtaining the weight may not always be possible or appropriate), we would expect to receive the information as these provide valuable information on the patient's suitability for further treatment
- where patients are part way through their programme, regimen or even cycles, simply record the data for activity in the relevant month
- over time, we would expect to build a picture of full treatments for each patient, but initially we expect to receive partial data

START DATE OF CYCLE: Date of first drug administration in each cycle.

- all date formats should be ccyy-mm-dd
- SACT ***Will Not*** recognise or accept American date formats

WEIGHT AT START OF CYCLE: The Weight in kilogrammes at start of the cycle.

PERFORMANCE STATUS AT START OF CYCLE – ADULT: This is a new data item. The World Health Organization classification indicating a PERSON's status relating to activity / disability.

0	Able to carry out all normal activity without restriction
1	Restricted in physically strenuous activity, but able to walk and do light work
2	Able to walk and capable of all self care, but unable to carry out any work. Up and about more than 50% of waking hours
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair

Note: This is only to be used for patients aged 19yrs and above

Drug Details

May be multiple occurrences per submission (0..*)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
31	DRUG DETAILS	**DRUG NAME** *[SYSTEMIC ANTI-CANCER THERAPY DRUG NAME]*	max an55	M
52	DRUG DETAILS	**DM+D** *[SYSTEMIC ANTI-CANCER THERAPY DRUG (SNOMED CT DM+D)]*	max n18	P
32	DRUG DETAILS	**ACTUAL DOSE PER ADMINISTRATION** *[SYSTEMIC ANTI-CANCER THERAPY ACTUAL DOSE]*	max n8	R
53	DRUG DETAILS	**ADMINISTRATION MEASUREMENT PER ACTUAL DOSE** *[UNIT OF MEASUREMENT (SYSTEMIC ANTI-CANCER THERAPY)]*	an2	R
54	DRUG DETAILS	**OTHER - ADMINISTRATION MEASUREMENT PER ACTUAL DOSE** *[OTHER UNIT OF MEASUREMENT DESCRIPTION (SYSTEMIC ANTI-CANCER THERAPY)]*	an15	R
55	DRUG DETAILS	**UNIT OF MEASUREMENT (SNOMED CT DM+D)**	min n6 max n18	O
33	DRUG DETAILS	**SACT ADMINISTRATION ROUTE** *[SYSTEMIC ANTI-CANCER THERAPY DRUG ROUTE OF ADMINISTRATION]*	an2	R
56	DRUG DETAILS	**ROUTE OF ADMINISTRATION (SNOMED CT DM+D)**	min n6 max n18	O
34	DRUG DETAILS	**ADMINISTRATION DATE** *[SYSTEMIC ANTI-CANCER THERAPY ADMINISTRATION DATE]*	an10 ccyy-mm-dd	M
35	DRUG DETAILS	**ORGANISATION IDENTIFIER OF SACT ADMINISTRATION** *[ORGANISATION IDENTIFIER (OF SYSTEMIC ANTI-CANCER THERAPY ADMINISTRATION)]*	min an3 max an5	R

Note: the following items have been retired from the data set in v3:

- OPCS Delivery Code

DRUG NAME: The name of the SACT drug given to a PATIENT during an Anti-Cancer Drug Regimen. The name is taken from British National Formulary (BNF).

- SACT would wish to receive all anti-cancer drugs, but please note that anti-cancer drugs can include BCG, bisphosphonates, Biological Therapies and hormonal treatments
  - if you happen to include anti-sickness drugs and the like, SACT will accept them
- all anti-cancer drugs by any administration route are included in the SACT, but local arrangements may be necessary to add these to the download
- for drugs not yet in the BNF, use the approved name as this will usually be the drug name used by the pharmacy

DM+D: This is a new data item. This is the unique ID from the dm+d database, based around the drug name/manufacture.

Note: This is a pilot item for this version change, and only required to be collected by the official Pilot sites

ACTUAL DOSE PER ADMINISTRATION: Dose in mg or other applicable unit for each administration in a SACT cycle.

- We will accept the dose entered by the clinician, using the correct number of decimal places to represent the dosage in mg to a maximum of 8 digits.
  - Where drugs are in units other than milligrams, this will usually be specific to the drug and can now be specified in the following 2 new data items

ADMINISTRATION MEASUREMENT PER ACTUAL DOSE: This is a new data item, which records the actual units of measurements used for each administration in a SACT cycle.

01	mg
02	Mcg
03	g
04	Units
05	Cells
06	x10^6 PFU
07	x10^8 PFU
98	Other
99	Not Known

OTHER – ADMINISTRATION MEASUREMENT PER ACTUAL DOSE: This is a new data item. Record other 'actual dose measurements' not available within [Administration Measurement per Actual Dose] field, if option 98 is selected.

UNIT OF MEASUREMENT (SNOMED CT DM+D): This is a new data item. The SNOMED CT® concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the unit of measurement.

SACT ADMINISTRATION ROUTE: The prescribed method of delivery for each administration in a SACT cycle.

01	Intravenous
02	Oral
03	Intrathecal
04	Intramuscular
05	Subcutaneous

06	Intraarterial
07	Intraperitoneal
08	Other intracavity Intracavernous
09	Intravesical (Intra-Vesicular)
~~10~~	~~Intratumour / Intralesional~~
11	Cutaneous (Topical)
12	Intradermal
13	Intratumour
14	Intralesional
98	Other

Note: Separation of certain attributes have been made within this field and within NHS Data Dictionary, to make these compatible and map to SNOMED CT

ROUTE OF ADMINISTRATION (SNOMED CT DM+D): This is a new data item. The SNOMED CT® concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the route of administration.

ADMINISTRATION DATE: The date on which the anti-cancer drug was administered to a patient, an infusion commenced, or an oral drug initially dispensed to the patient.

- this is now a **mandatory** data item
- all date formats should be ccyy-mm-dd
- SACT ***Will Not*** recognise or accept American date formats

ORGANISATION IDENTIFIER OF SACT ADMINISTRATION: Organisation Identifier of the organisation for each administration in a SACT cycle.

- the provider code is also required at drug level, as part or whole of subsequent cycles may be given by different providers

Outcome

May be up to 1 occurrence per submission (0..1)

Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
38	OUTCOME	**REGIMEN MODIFICATION – DOSE REDUCTION** *[SYSTEMIC ANTI-CANCER THERAPY REGIMEN MODIFICATION INDICATOR (DOSE REDUCTION)]*	an1	R
57	OUTCOME	**REGIMEN OUTCOME SUMMARY – CURATIVE (COMPLETED AS PLANNED)** *[SYSTEMIC ANTI-CANCER THERAPY CURATIVE TREATMENT COMPLETED AS PLANNED INDICATOR]*	an1	R
58	OUTCOME	**REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON** *[SYSTEMIC ANTI-CANCER THERAPY CURATIVE TREATMENT NOT COMPLETED OUTCOME REASON]*	an1	R
59	OUTCOME	**OTHER – REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON** *[OTHER SYSTEMIC ANTI-CANCER THERAPY CURATIVE TREATMENT NOT COMPLETED OUTCOME REASON]*	an55	R
60	OUTCOME	**REGIMEN OUTCOME SUMMARY – NON CURATIVE** *[SYSTEMIC ANTI-CANCER THERAPY NON CURATIVE TREATMENT PATIENT BENEFIT INDICATOR]*	an1	R
61	OUTCOME	**REGIMEN OUTCOME SUMMARY – TOXICITY** *[SYSTEMIC ANTI-CANCER THERAPY TOXICITY MODIFICATION INDICATOR]*	an1	P

Note: the following items have been retired from the data set in v3:

- Date of Final Treatment
- Regimen Modification – Time Delay
- Regimen Modification – Stopped Early
- Regimen Outcome Summary
- Date Of Death

REGIMEN MODIFICATION – DOSE REDUCTION: Identifies if a regimen was modified by reducing the dose of any anti-cancer drug administered at any point in the regimen after commencement of the regimen.

Y	Yes
N	No

REGIMEN OUTCOME SUMMARY – CURATIVE (COMPLETED AS PLANNED): This is a new data item that Identifies whether the curative treatment was completed as planned.

Y	Yes

N	No

REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON: This is a new data item that records the reason why the curative treatment was not completed as planned (where No is selected in the [regimen outcome summary – curative (completed as planned)]) field.

1	Progressive/recurrent cancer
2	Toxicity
3	Death
4	Patient choice
5	Other

- this is a repeating data item, which allow for multiple attributes to be selected at the same time
- data should be returned (within the output .csv report), using the following sequence where more than 1 attribute is reported
  - “,“02;04”,” (using a semi-colon to separate each attribute within the double quote)

OTHER – REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON: This is a new data item that records other reasons not available within [regimen outcome summary – curative (not completed as planned) reason] field, if option 5 is selected.

REGIMEN OUTCOME SUMMARY – NON CURATIVE: This is a new data item to record whether the patient benefited from the non-curative treatment.

Y	Yes
N	No

REGIMEN OUTCOME SUMMARY – TOXICITY: This is a new data item to record whether Toxicity was a deciding factor in modifying the treatment regimen.

Y	Yes
N	No

Note: This is a pilot item for this version change, and only required to be collected by the official Pilot sites

What's Changed Since v2.0

This User Guide includes 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 coding or staging values changed from SACT data set v2.0, and should be used to help data collection.

Overall the data set has remained similar in size with 17 data items deleted and 16 new ones added to the data set as follows:

Deleted items:

- **GENDER – CURRENT** – to reduce burden, data can be linked with other PHE data sets
- **ETHNICITY** – To reduce burden, data can be linked with other PHE data sets
- **REGISTERED GP PRACTICE CODE** – to reduce burden, data can be linked with other PHE data sets
- **TNM STAGE GROUPING (FINAL PRETREATMENT)** – to reduce burden, data can be linked with other PHE data sets
- **SACT PROGRAMME NUMBER** – no longer required for the accurate recording of treatment data
- **REGIMEN NUMBER** – no longer required for the accurate recording of treatment data
- **PERFORMANCE STATUS AT START OF REGIMEN** – replaced with data items 49 + 50, to improve the accurate reporting of Performance Status at the start of regimen
- **CHEMO-RADIATION** – to reduce burden, data can be linked with other PHE data sets
- **NUMBER OF CYCLES PLANNED** – no longer required for the accurate recording of treatment data
- **PERFORMANCE STATUS AT START OF CYCLE** – replaced with data items 51 + 52, to improve the accurate reporting of Performance Status at the start of cycle
- **OPCS PROCUREMENT CODE** – no longer required for the accurate recording of treatment data
- **OPCS DELIVERY CODE** – no longer required for the accurate recording of treatment data
- **DATE OF FINAL TREATMENT** – no longer required for the accurate recording of treatment data
- **REGIMEN MODIFICATION – TIME DELAY** – no longer required for the accurate recording of treatment data
- **REGIMEN MODIFICATION – STOPPED EARLY** – no longer required for the accurate recording of treatment data

- **REGIMEN OUTCOME SUMMARY** – Replaced with 3 new data items to improve the outcome reporting of curative treatments
- **DATE OF DEATH** – to reduce burden, data can be linked with other data sets collated by PHE

New items:

- **LOCAL PATIENT IDENTIFIER** – to allow for cases where a patient does not have an NHS Number to be reported
- **PERSON FAMILY NAME** – This has been added to allow for cases (where a patient does not have an NHS Number) to be traced
- **PERSON GIVEN NAME** – This has been added to allow for cases (where a patient does not have an NHS Number) to be traced
- **PERSON STATED GENDER CODE** – required to update standard to current data collection for gender
- **DIAGNOSIS CODE (SNOMED CT)** – optional item to comply with information standard SCCI0034
- **ADJUNCTIVE THERAPY** – to improve the accurate recording of adjunctive therapy
- **PERFORMANCE STATUS AT START OF REGIMEN – ADULT** – to allow for accurate reporting of Performance Status (in adults aged 19yrs and above) at start of regimen
- **PERFORMANCE STATUS AT START OF CYCLE – ADULT** – to allow for accurate reporting of Performance Status (in adults aged 19yrs and above) at start of cycle
- **ADMINISTRATION MEASUREMENT PER ACTUAL DOSE** – to record the accurate measurement (per dose) administered
- **OTHER – ADMINISTRATION MEASUREMENT PER ACTUAL DOSE** – This has been added to record other 'unit of measurements' not available within the [administration measurement per actual dose] field, if option 98 is selected
- **UNIT OF MEASUREMENT (SNOMED CT DM+D)** – The SNOMED CT® concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the unit of measurement
- **ROUTE OF ADMINISTRATION (SNOMED CT DM+D)** – The SNOMED CT® concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the route of administration
- **REGIMEN OUTCOME SUMMARY – CURATIVE (COMPLETED AS PLANNED) –** This has been added to record if the curative treatment was completed as planned
- **REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON –** This has been added to record the reason why the curative treatment was not completed as planned
- **OTHER – REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON –** This has been added to record

other reasons not available within the [regimen outcome summary – curative (not completed as planned) reason] field, if option 5 is selected
- **REGIMEN OUTCOME SUMMARY – NON CURATIVE** – This has been added to record if the patient benefitted from the treatment, where the intent was non-curative

There have also been 2 data items added as a 'Pilot', for the lifetime of the data set. This will allow the PHE team assess availability of these data and the accessibility for data collection, without creating too much burden on the trusts as follows:

- **DM+D** – To help link SACT and dm+d data to improve drug details information
- **REGIMEN OUTCOME SUMMARY – TOXICITY** – To record if the Toxicity was a deciding factor in modifying the treatment regimen (where applicable)

These data are only required to be collected by the agreed 'Pilot' sites, and not all providers of SACT services.

There have been other changes to data items as well to improve the data requested, all of which are clearly explained in the data set itself, the main area of changes are as follows:

- amended attributes
- amended format
- description changes
- element name changes
- name changes
- schema specification

These changes also help to reduce the burden of data collected wherever possible and improve the quality of the data being requested. New analysis and reports will be created to monitor and improve the data ascertainment and address issues where there are local difficulties in collecting any of the new or changed data items.

Appendix A: Cancer Waiting Times ICD10 Codes and Tumour Groups for Primary Diagnoses

(Applicable from April 2012) These are registerable conditions for the purposes of Cancer Waiting Times and used within Cancer Registration that is NCRAS mandatory fields

Notes:

- **The following table lists all the registerable diseases by ICD10 code, together with the expected data set to be completed and the potential stage.**
- **This table provides general guidelines only as not all permutations can be covered and there will always be exceptions. Local clinical input is essential to identify and complete the appropriate stage.**
- **Further guidance is available from your local cancer registration service office.**

Key:
() = if applicable
* = different data set from CWT group specified

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Comment
C00.0	External upper lip	Head and Neck	
C00.1	External lower lip	Head and Neck	
C00.2	External lip, unspecified	Head and Neck	
C00.3	Upper lip, inner aspect	Head and Neck	
C00.4	Lower lip, inner aspect	Head and Neck	
C00.5	Lip, unspecified, inner aspect	Head and Neck	
C00.6	Commissure of lip	Head and Neck	
C00.8	Overlapping lesion of lip	Head and Neck	
C00.9	Lip, unspecified	Head and Neck	
C01	Malignant neoplasm of base of tongue	Head and Neck	
C02.0	Dorsal surface of tongue	Head and Neck	
C02.1	Border of tongue	Head and Neck	
C02.2	Ventral surface of tongue	Head and Neck	
C02.3	Anterior two-thirds of tongue, part unspecified	Head and Neck	
C02.4	Lingual tonsil	Head and Neck	
C02.8	Overlapping lesion of tongue	Head and Neck	
C02.9	Tongue, unspecified	Head and Neck	
C03.0	Upper gum	Head and Neck	
C03.1	Lower gum	Head and Neck	
C03.9	Gum, unspecified	Head and Neck	
C04.0	Anterior floor of mouth	Head and Neck	

C04.1	Lateral floor of mouth	Head and Neck	
C04.8	Overlapping lesion of floor of mouth	Head and Neck	
C04.9	Floor of mouth, unspecified	Head and Neck	
C05.0	Hard palate	Head and Neck	
C05.1	Soft palate	Head and Neck	
C05.2	Uvula	Head and Neck	
C05.8	Overlapping lesion of palate	Head and Neck	
C05.9	Palate, unspecified	Head and Neck	
C06.0	Cheek mucosa	Head and Neck	
C06.1	Vestibule of mouth	Head and Neck	
C06.2	Retromolar area	Head and Neck	
C06.8	Overlapping lesion of other and unspecified parts of mouth	Head and Neck	
C06.9	Mouth, unspecified	Head and Neck	
C07	Malignant neoplasm of parotid gland	Head and Neck	
C08.0	Submandibular gland	Head and Neck	
C08.1	Sublingual gland	Head and Neck	
C08.8	Overlapping lesion of major salivary glands	Head and Neck	
C08.9	Major salivary gland, unspecified	Head and Neck	
C09.0	Tonsillar fossa	Head and Neck	
C09.1	Tonsillar pillar (anterior) (posterior)	Head and Neck	
C09.8	Overlapping lesion of tonsil	Head and Neck	
C09.9	Tonsil, unspecified	Head and Neck	
C10.0	Vallecula	Head and Neck	
C10.1	Anterior surface of epiglottis	Head and Neck	
C10.2	Lateral wall of oropharynx	Head and Neck	
C10.3	Posterior wall of oropharynx	Head and Neck	
C10.4	Branchial cleft	Head and Neck	
C10.8	Overlapping lesion of oropharynx	Head and Neck	
C10.9	Oropharynx, unspecified	Head and Neck	
C11.0	Superior wall of nasopharynx	Head and Neck	
C11.1	Posterior wall of nasopharynx	Head and Neck	
C11.2	Lateral wall of nasopharynx	Head and Neck	
C11.3	Anterior wall of nasopharynx	Head and Neck	
C11.8	Overlapping lesion of nasopharynx	Head and Neck	
C11.9	Nasopharynx, unspecified	Head and Neck	
C12	Malignant neoplasm of pyriform sinus	Head and Neck	
C13.0	Postcricoid region	Head and Neck	
C13.1	Aryepiglottic fold, hypopharyngeal aspect	Head and Neck	
C13.2	Posterior wall of hypopharynx	Head and Neck	
C13.8	Overlapping lesion of hypopharynx	Head and Neck	
C13.9	Hypopharynx, unspecified	Head and Neck	
C14.0	Pharynx, unspecified	Head and Neck	
C14.2	Waldeyer's ring	Head and Neck	
C14.8	Overlapping lesion of lip, oral cavity and pharynx	Head and Neck	
C15.0	*Cervical part of oesophagus*	*Upper Gastrointestinal*	*Usually treated by Head & Neck MDT.*
C15.1	Thoracic part of oesophagus	Upper Gastrointestinal	
C15.2	Abdominal part of oesophagus	Upper Gastrointestinal	
C15.3	Upper third of oesophagus	Upper Gastrointestinal	
C15.4	Middle third of oesophagus	Upper Gastrointestinal	
C15.5	Lower third of oesophagus	Upper Gastrointestinal	
C15.8	Overlapping lesion of oesophagus	Upper Gastrointestinal	
C15.9	Oesophagus, unspecified	Upper Gastrointestinal	
C16.0	Cardia	Upper Gastrointestinal	
C16.1	Fundus of stomach	Upper Gastrointestinal	
C16.2	Body of stomach	Upper Gastrointestinal	
C16.3	Pyloric antrum	Upper Gastrointestinal	
C16.4	Pylorus	Upper Gastrointestinal	
C16.5	Lesser curvature of stomach, unspecified	Upper Gastrointestinal	
C16.6	Greater curvature of stomach, unspecified	Upper Gastrointestinal	
C16.8	Overlapping lesion of stomach	Upper Gastrointestinal	

C16.9	Stomach, unspecified	Upper Gastrointestinal	
C17.0	*Duodenum*	*Colorectal*	*Usually treated by Upper GI MDT*
C17.1	*Jejunum*	*Colorectal*	*Usually treated by Upper GI MDT*
C17.2	*Ileum*	*Colorectal*	*Usually treated by Upper GI MDT*
C17.3	*Meckel's diverticulum*	*Colorectal*	*Usually treated by Upper GI MDT*
C17.8	*Overlapping lesion of small intestine*	*Colorectal*	*Usually treated by Upper GI MDT*
C17.9	*Small intestine, unspecified*	*Colorectal*	*Usually treated by Upper GI MDT*
C18.0	Caecum	Colorectal	
C18.1	Appendix	Colorectal	
C18.2	Ascending colon	Colorectal	
C18.3	Hepatic flexure	Colorectal	
C18.4	Transverse colon	Colorectal	
C18.5	Splenic flexure	Colorectal	
C18.6	Descending colon	Colorectal	
C18.7	Sigmoid colon	Colorectal	
C18.8	Overlapping lesion of colon	Colorectal	
C18.9	Colon, unspecified	Colorectal	
C19	Malignant neoplasm of rectosigmoid junction	Colorectal	
C20	Malignant neoplasm of rectum	Colorectal	
C21.0	Anus, unspecified	Colorectal	
C21.1	Anal canal	Colorectal	
C21.2	Cloacogenic zone	Colorectal	
C21.8	Overlapping lesion of rectum, anus and anal canal	Colorectal	
C22.0	Liver cell carcinoma	Upper Gastrointestinal	Liver cell carcinoma is also known as HCC.
C22.1	Intrahepatic bile duct carcinoma	Upper Gastrointestinal	
C22.2	Hepatoblastoma	Upper Gastrointestinal	
C22.3	Angiosarcoma of liver	Upper Gastrointestinal	
C22.4	Other sarcomas of liver	Upper Gastrointestinal	
C22.7	Other specified carcinomas of liver	Upper Gastrointestinal	
C22.9	Liver, unspecified	Upper Gastrointestinal	
C23	Malignant neoplasm of gallbladder	Upper Gastrointestinal	
C24.0	Extrahepatic bile duct	Upper Gastrointestinal	
C24.1	Ampulla of Vater	Upper Gastrointestinal	
C24.8	Overlapping lesion of biliary tract	Upper Gastrointestinal	
C24.9	Biliary tract, unspecified	Upper Gastrointestinal	
C25.0	Head of pancreas	Upper Gastrointestinal	
C25.1	Body of pancreas	Upper Gastrointestinal	
C25.2	Tail of pancreas	Upper Gastrointestinal	
C25.3	Pancreatic duct	Upper Gastrointestinal	
C25.4	Endocrine pancreas	Upper Gastrointestinal	
C25.7	Other parts of pancreas	Upper Gastrointestinal	
C25.8	Overlapping lesion of pancreas	Upper Gastrointestinal	
C25.9	Pancreas, unspecified	Upper Gastrointestinal	
C26.0	Intestinal tract, part unspecified	Colorectal	
C26.1	Spleen	Colorectal	
C26.8	Overlapping lesion of digestive system	Colorectal	
C26.9	Ill-defined sites within the digestive system	Colorectal	
C30.0	Nasal cavity	Head and Neck	
C30.1	Middle ear	Head and Neck	
C31.0	Maxillary sinus	Head and Neck	
C31.1	Ethmoidal sinus	Head and Neck	
C31.2	Frontal sinus	Head and Neck	
C31.3	Sphenoidal sinus	Head and Neck	
C31.8	Overlapping lesion of accessory sinuses	Head and Neck	
C31.9	Accessory sinus, unspecified	Head and Neck	
C32.0	Glottis	Head and Neck	

C32.1	Supraglottis	Head and Neck	
C32.2	Subglottis	Head and Neck	
C32.3	Laryngeal cartilage	Head and Neck	
C32.8	Overlapping lesion of larynx	Head and Neck	
C32.9	Larynx, unspecified	Head and Neck	
C33	Malignant neoplasm of trachea	Lung	
C34.0	Main bronchus	Lung	
C34.1	Upper lobe, bronchus or lung	Lung	
C34.2	Middle lobe, bronchus or lung	Lung	
C34.3	Lower lobe, bronchus or lung	Lung	
C34.8	Overlapping lesion of bronchus and lung	Lung	
C34.9	Bronchus or lung, unspecified	Lung	
C37	Malignant neoplasm of thymus	Lung	
C38.0	Heart	Lung	
C38.1	Anterior mediastinum	Lung	
C38.2	Posterior mediastinum	Lung	
C38.3	Mediastinum, part unspecified	Lung	
C38.4	Pleura	Lung	
C38.8	Overlapping lesion of heart, mediastinum and pleura	Lung	
C39.0	Upper respiratory tract, part unspecified	Lung	
C39.8	Overlapping lesion of respiratory and intrathoracic organs	Lung	
C39.9	Ill-defined sites within the respiratory system	Lung	
C40.0	Scapula and long bones of upper limb	Sarcoma	
C40.1	Short bones of upper limb	Sarcoma	
C40.2	Long bones of lower limb	Sarcoma	
C40.3	Short bones of lower limb	Sarcoma	
C40.8	Overlapping lesion of bone and articular cartilage of limbs	Sarcoma	
C40.9	Bone and articular cartilage of limb, unspecified	Sarcoma	
C41.0	Bones of skull and face	Sarcoma	
C41.1	Mandible	Sarcoma	
C41.2	Vertebral column	Sarcoma	
C41.3	Ribs, sternum and clavicle	Sarcoma	
C41.4	Pelvic bones, sacrum and coccyx	Sarcoma	
C41.8	Overlapping lesion of bone and articular cartilage	Sarcoma	
C41.9	Bone and articular cartilage, unspecified	Sarcoma	
C43.0	Malignant melanoma of lip	Skin	
C43.1	Malignant melanoma of eyelid, including canthus	Skin	
C43.2	Malignant melanoma of ear and external auricular canal	Skin	
C43.3	Malignant melanoma of other and unspecified parts of face	Skin	
C43.4	Malignant melanoma of scalp and neck	Skin	
C43.5	Malignant melanoma of trunk	Skin	
C43.6	Malignant melanoma of upper limb, including shoulder	Skin	
C43.7	Malignant melanoma of lower limb, including hip	Skin	
C43.8	Overlapping malignant melanoma of skin	Skin	
C43.9	Malignant melanoma of skin, unspecified	Skin	
C44.0	Skin of lip	Skin	
C44.1	Skin of eyelid, including canthus	Skin	
C44.2	Skin of ear and external auricular canal	Skin	

C44.3	Skin of other and unspecified parts of face	Skin	
C44.4	Skin of scalp and neck	Skin	
C44.5	Skin of trunk	Skin	
C44.6	Skin of upper limb, including shoulder	Skin	
C44.7	Skin of lower limb, including hip	Skin	
C44.8	Overlapping lesion of skin	Skin	
C44.9	Malignant neoplasm of skin, unspecified	Skin	
C45.0	Mesothelioma of pleura	Lung	
C45.1	Mesothelioma of peritoneum	Lung	
C45.2	Mesothelioma of pericardium	Lung	
C45.7	Mesothelioma of other sites	Lung	
C45.9	Mesothelioma, unspecified	Lung	
C46.0	Kaposi sarcoma of skin	Sarcoma	
C46.1	Kaposi sarcoma of soft tissue	Sarcoma	
C46.2	Kaposi sarcoma of palate	Sarcoma	
C46.3	Kaposi sarcoma of lymph nodes	Sarcoma	
C46.7	Kaposi sarcoma of other sites	Sarcoma	
C46.8	Kaposi sarcoma of multiple organs	Sarcoma	
C46.9	Kaposi sarcoma, unspecified	Sarcoma	
C47.0	*Peripheral nerves of head, face and neck*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.1	*Peripheral nerves of upper limb, including shoulder*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.2	*Peripheral nerves of lower limb, including hip*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.3	*Peripheral nerves of thorax*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.4	*Peripheral nerves of abdomen*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.5	*Peripheral nerves of pelvis*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.6	*Peripheral nerves of trunk, unspecified*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.8	*Overlapping lesion of peripheral nerves and autonomic nervous system*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C47.9	*Peripheral nerves and autonomic nervous system, unspecified*	*Brain/Central Nervous System*	*Usually treated by Sarcoma MDT.*
C48.0	*Retroperitoneum*	*Sarcoma*	*Usually treated by Sarcoma MDT.*
C48.1	*Specified parts of peritoneum*	*Sarcoma*	
C48.2	*Peritoneum, unspecified*	*Sarcoma*	
C48.8	Overlapping lesion of retroperitoneum and peritoneum	Sarcoma	
C49.0	Connective and soft tissue of head, face and neck	Sarcoma	
C49.1	Connective and soft tissue of upper limb, including shoulder	Sarcoma	
C49.2	Connective and soft tissue of lower limb, including hip	Sarcoma	
C49.3	Connective and soft tissue of thorax	Sarcoma	
C49.4	Connective and soft tissue of abdomen	Sarcoma	
C49.5	Connective and soft tissue of pelvis	Sarcoma	
C49.6	Connective and soft tissue of trunk, unspecified	Sarcoma	
C49.8	Overlapping lesion of connective and soft tissue	Sarcoma	
C49.9	Connective and soft tissue, unspecified	Sarcoma	
C50.0	Nipple and areola	Breast	
C50.1	Central portion of breast	Breast	
C50.2	Upper-inner quadrant of breast	Breast	
C50.3	Lower-inner quadrant of breast	Breast	
C50.4	Upper-outer quadrant of breast	Breast	

C50.5	Lower-outer quadrant of breast	Breast	
C50.6	Axillary tail of breast	Breast	
C50.8	Overlapping lesion of breast	Breast	
C50.9	Breast, unspecified	Breast	
C51.0	*Labium majus*	*Gynaecological*	
C51.1	*Labium minus*	*Gynaecological*	
C51.2	*Clitoris*	*Gynaecological*	
C51.8	*Overlapping lesion of vulva*	*Gynaecological*	
C51.9	*Vulva, unspecified*	*Gynaecological*	
C52	Malignant neoplasm of vagina	Gynaecological	
C53.0	Endocervix	Gynaecological	
C53.1	Exocervix	Gynaecological	
C53.8	Overlapping lesion of cervix uteri	Gynaecological	
C53.9	Cervix uteri, unspecified	Gynaecological	
C54.0	Isthmus uteri	Gynaecological	
C54.1	Endometrium	Gynaecological	
C54.2	Myometrium	Gynaecological	
C54.3	Fundus uteri	Gynaecological	
C54.8	Overlapping lesion of corpus uteri	Gynaecological	
C54.9	Corpus uteri, unspecified	Gynaecological	
C55	Malignant neoplasm of uterus, part unspecified	Gynaecological	
C56	Malignant neoplasm of ovary	Gynaecological	
C57.0	Fallopian tube	Gynaecological	
C57.1	Broad ligament	Gynaecological	
C57.2	Round ligament	Gynaecological	
C57.3	Parametrium	Gynaecological	
C57.4	Uterine adnexa, unspecified	Gynaecological	
C57.7	Other specified female genital organs	Gynaecological	
C57.8	Overlapping lesion of female genital organs	Gynaecological	
C57.9	Female genital organ, unspecified	Gynaecological	
C58	Malignant neoplasm of placenta	Gynaecological	
C60.0	*Prepuce*	*Urological*	
C60.1	*Glans penis*	*Urological*	
C60.2	*Body of penis*	*Urological*	
C60.8	*Overlapping lesion of penis*	*Urological*	
C60.9	*Penis, unspecified*	*Urological*	
C61	Malignant neoplasm of prostate	Urological	
C62.0	Undescended testis	Urological	
C62.1	Descended testis	Urological	
C62.9	Testis, unspecified	Urological	
C63.0	Epididymis	Urological	
C63.1	Spermatic cord	Urological	
C63.2	Scrotum	Urological	
C63.7	Other specified male genital organs	Urological	
C63.8	Overlapping lesion of male genital organs	Urological	
C63.9	Male genital organ, unspecified	Urological	
C64	Malignant neoplasm of kidney, except renal pelvis	Urological	
C65	Malignant neoplasm of renal pelvis	Urological	
C66	Malignant neoplasm of ureter	Urological	
C67.0	Trigone of bladder	Urological	
C67.1	Dome of bladder	Urological	
C67.2	Lateral wall of bladder	Urological	
C67.3	Anterior wall of bladder	Urological	
C67.4	Posterior wall of bladder	Urological	
C67.5	Bladder neck	Urological	
C67.6	Ureteric orifice	Urological	
C67.7	Urachus	Urological	
C67.8	Overlapping lesion of bladder	Urological	
C67.9	Bladder, unspecified	Urological	
C68.0	Urethra	Urological	
C68.1	Paraurethral glands	Urological	
C68.8	Overlapping lesion of urinary organs	Urological	

C68.9	Urinary organ, unspecified	Urological	
C69.0	*Conjunctiva*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.1	*Cornea*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.2	*Retina*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.3	*Choroid*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.4	*Ciliary body*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.5	*Lachrymal gland and duct*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.6	*Orbit*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT. Maybe treated by Sarcoma MDT.*
C69.8	*Overlapping lesion of eye and adnexa*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C69.9	*Eye, unspecified*	*Brain/Central Nervous System*	*Not normally treated by CNS MDT.*
C70.0	Cerebral meninges	Brain/Central Nervous System	
C70.1	Spinal meninges	Brain/Central Nervous System	
C70.9	Meninges, unspecified	Brain/Central Nervous System	
C71.0	Cerebrum, except lobes and ventricles	Brain/Central Nervous System	
C71.1	Frontal lobe	Brain/Central Nervous System	
C71.2	Temporal lobe	Brain/Central Nervous System	
C71.3	Parietal lobe	Brain/Central Nervous System	
C71.4	Occipital lobe	Brain/Central Nervous System	
C71.5	Cerebral ventricle	Brain/Central Nervous System	
C71.6	Cerebellum	Brain/Central Nervous System	
C71.7	Brain stem	Brain/Central Nervous System	
C71.8	Overlapping lesion of brain	Brain/Central Nervous System	
C71.9	Brain, unspecified	Brain/Central Nervous System	
C72.0	Spinal cord	Brain/Central Nervous System	
C72.1	Cauda equina	Brain/Central Nervous System	
C72.2	Olfactory nerve	Brain/Central Nervous System	
C72.3	Optic nerve	Brain/Central Nervous System	
C72.4	Acoustic nerve	Brain/Central Nervous System	
C72.5	Other and unspecified cranial nerves	Brain/Central Nervous System	
C72.8	Overlapping lesion of brain and other parts of central nervous system	Brain/Central Nervous System	
C72.9	Central nervous system, unspecified	Brain/Central Nervous System	
C73	Malignant neoplasm of thyroid gland	Head and Neck	
C74.0	Cortex of adrenal gland	Other	
C74.1	Medulla of adrenal gland	Other	
C74.9	Adrenal gland, unspecified	Other	
C75.0	Parathyroid gland	Other	
C75.1	*Pituitary gland*	*Other*	*Usually treated by CNS MDT.*

C75.2	*Craniopharyngeal duct*	*Other*	*Usually treated by CNS MDT.*
C75.3	*Pineal gland*	*Other*	*Usually treated by CNS MDT.*
C75.4	Carotid body	Other	
C75.5	Aortic body and other paraganglia	Other	
C75.8	Pluriglandular involvement, unspecified	Other	
C75.9	Endocrine gland, unspecified	Other	
C76.0	Head, face and neck	Other	Other and ill defined - use only if unable to code to specific primary site
C76.1	Thorax	Other	Other and ill defined - use only if unable to code to specific primary site
C76.2	Abdomen	Other	Other and ill defined - use only if unable to code to specific primary site
C76.3	Pelvis	Other	Other and ill defined - use only if unable to code to specific primary site
C76.4	Upper limb	Other	Other and ill defined - use only if unable to code to specific primary site
C76.5	Lower limb	Other	Other and ill defined - use only if unable to code to specific primary site
C76.7	Other ill-defined sites	Other	Other and ill defined - use only if unable to code to specific primary site
C76.8	Overlapping lesion of other and ill-defined sites	Other	Other and ill defined - use only if unable to code to specific primary site
C77.0	Lymph nodes of head, face and neck	Head and Neck	Secondary - only use if unable to code to specific primary site
C77.1	Intrathoracic lymph nodes	Other	Secondary - only use if unable to code to specific primary site
C77.2	Intra-abdominal lymph nodes	Other	Secondary - only use if unable to code to specific primary site
C77.3	Axillary and upper limb lymph nodes	Other	Secondary - only use if unable to code to specific primary site
C77.4	Inguinal and lower limb lymph nodes	Other	Secondary - only use if unable to code to specific primary site
C77.5	Intrapelvic lymph nodes	Other	Secondary - only use if unable to code to specific primary site
C77.8	Lymph nodes of multiple regions	Other	Secondary - only use if unable to code to specific primary site
C77.9	Lymph node, unspecified	Other	Secondary - only use if unable to code to specific primary site
C78.0	Secondary malignant neoplasm of lung	Lung	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.1	Secondary malignant neoplasm of mediastinum	Lung	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.2	Secondary malignant neoplasm of pleura	Lung	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.3	Secondary malignant neoplasm of other and unspecified respiratory organs	Lung	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.4	Secondary malignant neoplasm of small intestine	Colorectal	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.5	Secondary malignant neoplasm of large intestine and rectum	Colorectal	Normally treated by MDT of site of primary tumour. Only

			use if unable to code to specific primary site.
C78.6	Secondary malignant neoplasm of retroperitoneum and peritoneum	Sarcoma	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.7	Secondary malignant neoplasm of liver and intrahepatic bile duct	Upper Gastrointestinal	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C78.8	Secondary malignant neoplasm of other and unspecified digestive organs	Colorectal	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.0	Secondary malignant neoplasm of kidney and renal pelvis	Urological	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.1	Secondary malignant neoplasm of bladder and other and unspecified urinary organs	Urological	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.2	Secondary malignant neoplasm of skin	Skin	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.3	Secondary malignant neoplasm of brain and cerebral meninges	Brain/Central Nervous System	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.4	Secondary malignant neoplasm of other and unspecified parts of nervous system	Brain/Central Nervous System	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.5	Secondary malignant neoplasm of bone and bone marrow	Sarcoma	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.6	Secondary malignant neoplasm of ovary	Gynaecological	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.7	Secondary malignant neoplasm of adrenal gland	Other	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.8	Secondary malignant neoplasm of other specified sites	Other	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C79.9	Secondary malignant neoplasm, unspecified site	Other	Normally treated by MDT of site of primary tumour. Only use if unable to code to specific primary site.
C80.0	Malignant neoplasm, primary site unknown, so stated	Other	Only use if unable to code to specific primary site.
C80.9	Malignant neoplasm, unspecified	Other	Only use if unable to code to specific primary site.
C81.0	Nodular lymphocyte predominant Hodgkin lymphoma	Haematological	See the Haematological ICD-O of User Guide (Appendix C) for information regarding what is required to be submitted for these Haematological diseases.
C81.1	Nodular sclerosis classical Hodgkin lymphoma	Haematological	
C81.2	Mixed cellularity classical Hodgkin lymphoma	Haematological	
C81.3	Lymphocytic depleted classical Hodgkin lymphoma	Haematological	
C81.4	Lymphocyte-rich classical Hodgkin lymphoma	Haematological	
C81.7	Other classical Hodgkin lymphoma	Haematological	

C81.9	Hodgkin lymphoma, unspecified	Haematological	
C82.0	Follicular lymphoma grade i	Haematological	
C82.1	Follicular lymphoma grade ii	Haematological	
C82.2	Follicular lymphoma grade iii, unspecified	Haematological	
C82.3	Follicular lymphoma grade iiia	Haematological	
C82.4	Follicular lymphoma grade iiib	Haematological	
C82.5	Diffuse follicle centre lymphoma	Haematological	
C82.6	Cutaneous follicle centre lymphoma	Haematological	
C82.7	Other types of follicular lymphoma	Haematological	
C82.9	Follicular lymphoma, unspecified	Haematological	
C83.0	Small cell B-cell lymphoma	Haematological	
C83.1	Mantle cell lymphoma	Haematological	
C83.3	Diffuse large B-cell lymphoma	Haematological	
C83.5	Lymphoblastic (diffuse) lymphoma	Haematological	
C83.7	Burkitt lymphoma	Haematological	
C83.8	Other non-follicular lymphoma	Haematological	
C83.9	Non-follicular (diffuse) lymphoma, unspecified	Haematological	
C84.0	Mycosis fungoides	Haematological	
C84.1	Sézery disease	Haematological	
C84.4	Peripheral T-cell lymphoma, not elsewhere classified	Haematological	
C84.5	Other mature T/NK-cell lymphomas	Haematological	
C84.6	Anaplastic large cell lymphoma, ALK-positive	Haematological	
C84.7	Anaplastic large cell lymphoma, ALK-negative	Haematological	
C84.8	Cutaneous T-cell lymphoma, unspecified	Haematological	
C84.9	Mature T/NK-cell lymphoma, unspecified	Haematological	
C85.1	B-cell lymphoma, unspecified	Haematological	
C85.2	Mediastinal (thymic) large B-cell lymphoma	Haematological	
C85.7	Other specified types of non-Hodgkin lymphoma	Haematological	
C85.9	Non-Hodgkin lymphoma, unspecified	Haematological	
C86.0	Extranodal NK/T-cell lymphoma, nasal type	Haematological	
C86.1	Hepatosplenic T-cell lymphoma	Haematological	
C86.2	Enteropathy-type (intestinal) T-cell lymphoma	Haematological	
C86.3	Subcutaneous panniculitis-like T-cell lymphoma	Haematological	
C86.4	Blastic N/K-cell lymphoma	Haematological	
C86.5	Angioimmunoblastic T-cell lymphoma	Haematological	
C86.6	Primary cutaneous CD30-positive T-cell proliferations	Haematological	
C88.0	Waldenström macroglobulinaemia	Haematological	
C88.2	Other heavy chain disease	Haematological	
C88.3	Immunoproliferative small intestinal disease	Haematological	
C88.4	Extranodal marginal zone B-cell lymphoma of mucosa associated lymphoid tissue (MALT-lymphoma)	Haematological	
C88.7	Other malignant immunoproliferative diseases	Haematological	
C88.9	Malignant immunoproliferative disease, unspecified	Haematological	
C90.0	Multiple myeloma	Haematological	
C90.1	Plasma cell leukaemia	Haematological	
C90.2	Extramedullary plasmacytoma	Haematological	
C90.3	Solitary plasmacytoma	Haematological	
C91.0	Acute lymphoblastic leukaemia [ALL]	Haematological	

C91.1	Chronic lymphocytic leukaemia of B-cell type	Haematological	
C91.3	Prolymphocytic leukaemia of B-cell type	Haematological	
C91.4	Hairy-cell leukaemia	Haematological	
C91.5	Adult T-cell lymphoma/leukaemia (HTLV-1-associated)	Haematological	
C91.6	Prolymphocytic leukaemia of T-cell type	Haematological	
C91.7	Other lymphoid leukaemia	Haematological	
C91.8	Mature B-cell leukaemia Burkitt-type	Haematological	
C91.9	Lymphoid leukaemia, unspecified	Haematological	
C92.0	Acute myeloid leukaemia [AML]	Haematological	
C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	Haematological	
C92.2	Atypical chronic myeloid leukaemia, BCR/ABL-negative	Haematological	
C92.3	Myeloid sarcoma	Haematological	
C92.4	Acute promyelocytic leukaemia [PML]	Haematological	
C92.5	Acute myelomonocytic leukaemia	Haematological	
C92.6	Acute myeloid leukaemia with 11q23-abnormality	Haematological	
C92.7	Other myeloid leukaemia	Haematological	
C92.8	Acute myeloid leukaemia with multilineage dysplasia	Haematological	
C92.9	Myeloid leukaemia, unspecified	Haematological	
C93.0	Acute monoblastic/monocytic leukaemia	Haematological	
C93.1	Chronic myelomonocytic leukaemia	Haematological	
C93.3	Juvenile myelomonocytic leukaemia	Haematological	
C93.7	Other monocytic leukaemia	Haematological	
C93.9	Monocytic leukaemia, unspecified	Haematological	
C94.0	Acute erythroid leukaemia	Haematological	
C94.2	Acute megakaryoblastic leukaemia	Haematological	
C94.3	Mast cell leukaemia	Haematological	
C94.4	Acute panmyelosis with myelofibrosis	Haematological	
C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	Haematological	
C94.7	Other specified leukaemias	Haematological	
C95.0	Acute leukaemia of unspecified cell type	Haematological	
C95.1	Chronic leukaemia of unspecified cell type	Haematological	
C95.7	Other leukaemia of unspecified cell type	Haematological	
C95.9	Leukaemia, unspecified	Haematological	
C96.0	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	Haematological	
C96.2	Malignant mast cell tumour	Haematological	
C96.4	Sarcoma of dendritic cells (accessory cells)	Haematological	
C96.5	Multifocal and unisystemic (disseminated) Langerhans-cell histiocytosis	Haematological	
C96.6	Unifocal Langerhans-cell histiocytosis	Haematological	
C96.7	Other specified malignant neoplasms of lymphoid, haematopoietic and related tissue	Haematological	
C96.8	Histiocytic sarcoma	Haematological	
C97	Malignant neoplasms of independent (primary) multiple sites	Other	
D05.0	Lobular carcinoma in situ	Breast	
D05.1	Intraductal carcinoma in situ	Breast	

D05.7	Other carcinoma in situ of breast	Breast	
D05.9	Carcinoma in situ of breast, unspecified	Breast	
C97	Malignant neoplasms of independent (primary) multiple sites	Other	

Appendix B: Mandatory Registerable Conditions

MANDATORY REGISTERABLE CONDITIONS

Further details to be provided regarding applicable data fields for each disease. These are additional Cancer Registration that is NCRAS mandatory registerable conditions

Notes:

- **The following table lists all the registerable diseases by ICD10 code, together with the expected data set to be completed and the potential stage.**
- **This table provides general guidelines only as not all permutations can be covered and there will always be exceptions. Local clinical input is essential to identify and complete the appropriate stage.**
- **Further guidance is available from your local cancer registration service office.**

ICD-10 4th Edition All C Codes are Malignant Neoplasms	Description	Cancer Waiting Times Site specific group	Comment
C00.0 – C97			
D00.0	Carcinoma in situ of Lip, oral cavity and pharynx	Head and Neck	
D00.1	Carcinoma in situ of Oesophagus	Upper Gastrointestinal	
D00.2	Carcinoma in situ of Stomach	Upper Gastrointestinal	
D01.0	Carcinoma in situ of Colon	Colorectal	
D01.1	Carcinoma in situ of Rectosigmoid junction	Colorectal	
D01.2	Carcinoma in situ of Rectum	Colorectal	
D01.3	Carcinoma in situ of Anus and anal canal	Colorectal	
D01.4	Carcinoma in situ of Anus and anal canal	Colorectal	
D01.5	Carcinoma in situ of Liver, gallbladder and bile ducts	Upper Gastrointestinal	
D01.7	Other specified digestive organs	Colorectal	
D01.9	Carcinoma in situ of Digestive organ, unspecified	Colorectal	
D02.0	Carcinoma in situ of Larynx	Head and Neck	
D02.1	Carcinoma in situ of Trachea	Lung	
D02.2	Carcinoma in situ of Bronchus and lung	Lung	
D02.3	Carcinoma in situ of Other parts of respiratory system	Lung	
D02.4	Carcinoma in situ of Respiratory system, unspecified	Lung	
D03.0	Melanoma in situ of lip	Skin	
D03.1	Melanoma in situ of eyelid, including canthus	Skin	

D03.2	Melanoma in situ, of ear and external auricular canal	Skin	
D03.3	Melanoma in situ of other and unspecified parts of face	Skin	
D03.4	Melanoma in situ of scalp and neck	Skin	
D03.5	Melanoma in situ of trunk	Skin	
D03.6	Melanoma in situ of upper limb, including shoulder	Skin	
D03.7	Melanoma in situ of lower limb, including hip	Skin	
D03.8	Melanoma in situ of other sites	Other	
D03.9	Melanoma in situ, unspecified	Skin	
D05.0	Lobular carcinoma in situ	Breast	
D05.1	Intraductal carcinoma in situ	Breast	
D05.7	Other carcinoma in situ of breast	Breast	
D05.9	Carcinoma in situ of breast, unspecified	Breast	
D06.0	carcinoma in situ of endocervix	Gynaecological	
D06.1	carcinoma in situ of exocervix	Gynaecological	
D06.7	carcinoma in situ of other parts of cervix	Gynaecological	
D06.9	carcinoma in situ of cervix, unspecified	Gynaecological	
D07.0	carcinoma in situ of endometrium	Gynaecological	
D07.1	carcinoma in situ of vulva	Gynaecological	
D07.2	carcinoma in situ of vagina	Gynaecological	
D07.3	carcinoma in situ of other and unspecified female genital organs	Gynaecological	
D07.4	carcinoma in situ of penis	Urological	
D07.5	carcinoma in situ of prostate	Urological	
D07.6	carcinoma in situ of other and unspecified male genital organs	Urological	
D09.0	Carcinoma in situ of Bladder	Urological	
D09.1	carcinoma in situ of other and unspecified urinary organs	Urological	
D09.2	carcinoma in situ of eye	Other	
D09.3	carcinoma in situ of thyroid and other endocrine glands	Head and Neck	
D09.7	carcinoma in situ of other specified sites	Other	
D09.9	carcinoma in situ, unspecified	Other	
D32.0	benign neoplasm of cerebral meninges	Brain/Central Nervous System	
D32.1	benign neoplasm of spinal meninges	Brain/Central Nervous System	
D32.9	benign neoplasm of meninges, unspecified	Brain/Central Nervous System	
D33.0	Benign neoplasm of brain, supratentorial	Brain/Central Nervous System	
D33.1	Benign neoplasm of brain, infratentorial	Brain/Central Nervous System	
D33.2	Benign neoplasm of brain, unspecified	Brain/Central Nervous System	
D33.3	Benign neoplasm of cranial nerves	Brain/Central Nervous System	
D33.4	Benign neoplasm of spinal cord	Brain/Central Nervous System	
D33.7	Benign neoplasm of other specified parts of central nervous system	Brain/Central Nervous System	
D33.9	Benign neoplasm of central nervous system, unspecified	Brain/Central Nervous System	
D35.2	Benign neoplasm of Pituitary gland	Brain/Central Nervous System	
D35.3	*Benign neoplasm of Craniopharyngeal duct*	*Other*	*Usually classified as CNS*
D35.4	Benign neoplasm of Pineal gland	Brain/Central Nervous System	
D37.0	Neoplasm of uncertain or unknown behaviour of lip, oral cavity and pharynx	Head and Neck	
D37.1	Neoplasm of uncertain or unknown behaviour of Stomach	Upper Gastrointestinal	

D37.2	Neoplasm of uncertain or unknown behaviour of Small intestine	Upper Gastrointestinal	
D37.3	Neoplasm of uncertain or unknown behaviour of Appendix	Colorectal	
D37.4	Neoplasm of uncertain or unknown behaviour of Colon	Colorectal	
D37.5	Neoplasm of uncertain or unknown behaviour of Rectum	Colorectal	
D37.6	Liver, gallbladder and bile ducts	Upper Gastrointestinal	
D37.7	Other digestive organs	Colorectal/Upper Gastrointestinal	
D37.9	Digestive organ, unspecified	Colorectal/Upper Gastrointestinal	
D38.0	Neoplasm of uncertain or unknown behaviour of Larynx	Head and Neck	
D38.1	Neoplasm of uncertain or unknown behaviour of Trachea, bronchus and lung	Lung	
D38.2	Neoplasm of uncertain or unknown behaviour of Pleura	Lung	
D38.3	Neoplasm of uncertain or unknown behaviour of Mediastinum	Lung	
D38.4	Neoplasm of uncertain or unknown behaviour of Thymus	Lung	
D38.5	Neoplasm of uncertain or unknown behaviour of Other respiratory organs	Lung	
D38.6	Neoplasm of uncertain or unknown behaviour of Respiratory organ, unspecified	Lung	
D39.0	Neoplasm of uncertain or unknown behaviour of Uterus	Gynaecological	
D39.1	Neoplasm of uncertain or unknown behaviour of Ovary	Gynaecological	
D39.2	Neoplasm of uncertain or unknown behaviour of Placenta	Gynaecological	
D39.7	Neoplasm of uncertain or unknown behaviour of Other female genital organs	Gynaecological	
D39.9	Neoplasm of uncertain or unknown behaviour of Female genital organ, unspecified	Gynaecological	
D40.0	Neoplasm of uncertain or unknown behaviour of prostate	Urological	
D40.1	Neoplasm of uncertain or unknown behaviour of testis	Urological	
D40.7	Neoplasm of uncertain or unknown behaviour of other male genital organs	Urological	
D40.9	Neoplasm of uncertain or unknown behaviour of male genital organs, unspecified	Urological	
D41.0	Neoplasm of uncertain or unknown behaviour of kidney	Urological	
D41.1	Neoplasm of uncertain or unknown behaviour of renal pelvis	Urological	
D41.2	Neoplasm of uncertain or unknown behaviour of ureter	Urological	
D41.3	Neoplasm of uncertain or unknown behaviour of urethra	Urological	
D41.4	Neoplasm of uncertain or unknown behaviour of bladder	Urological	
D41.7	Neoplasm of uncertain or unknown behaviour of other urinary organs	Urological	
D41.9	Neoplasm of uncertain or unknown behaviour of urinary organs, unspecified	Urological	
D42.0	Neoplasm of uncertain or unknown behaviour of cerebral meninges	Brain/Central Nervous System	

D42.1	Neoplasm of uncertain or unknown behaviour of spinal meninges	Brain/Central Nervous System	
D42.9	Neoplasm of uncertain or unknown behaviour of meninges, unspecified	Brain/Central Nervous System	
D43.0	Neoplasm of uncertain or unknown behaviour of brain, supratentorial	Brain/Central Nervous System	
D43.1	Neoplasm of uncertain or unknown behaviour of brain, infratentorial	Brain/Central Nervous System	
D43.2	Neoplasm of uncertain or unknown behaviour of brain, unspecified	Brain/Central Nervous System	
D43.3	Neoplasm of uncertain or unknown behaviour of cranial nerves	Brain/Central Nervous System	
D43.4	Neoplasm of uncertain or unknown behaviour of spinal cord	Brain/Central Nervous System	
D43.7	Neoplasm of uncertain or unknown behaviour of other parts of central nervous system	Brain/Central Nervous System	
D43.9	Neoplasm of uncertain or unknown behaviour of central nervous system, unspecified	Brain/Central Nervous System	
D44.0	Neoplasm of uncertain or unknown behaviour of thyroid gland	Head and Neck	
D44.1	Neoplasm of uncertain or unknown behaviour of adrenal gland	Other	
D44.2	Neoplasm of uncertain or unknown behaviour of parathyroid gland	Other	
D44.3	Neoplasm of uncertain or unknown behaviour of pituitary gland	Brain/Central Nervous System	
D44.4	Neoplasm of uncertain or unknown behaviour of Craniopharyngeal duct	Brain/Central Nervous System	
D44 .5	Neoplasm of uncertain or unknown behaviour of pineal gland	Brain/Central Nervous System	
D44 .6	Neoplasm of uncertain or unknown behaviour of carotid body	Other	
D44 .7	Neoplasm of uncertain or unknown behaviour of aortic body and other paraganglia body	Other	
D44 .8	Neoplasm of uncertain or unknown behaviour of pluriglandular involvement	Other	
D44 .9	Neoplasm of uncertain or unknown behaviour of endocrine gland, unspecified	Other	
D45	Polycythaemia vera	Haematological	See the Haematological ICD-O of User Guide (Appendix C) for information regarding what is required to be submitted for these Haematological diseases.
D46.0	Refractory anaemia without ringed sideroblasts, so stated	Haematological	
D46.1	Refractory anaemia with ringed sideroblasts	Haematological	
D46.2	Refractory anaemia with excess of blasts	Haematological	
D46.4	Refractory anaemia, unspecified	Haematological	
D46.5	Refractory anaemia with multi-lineage dysplasia	Haematological	
D46.6	Myelodysplastic syndrome with isolated del(5q) chromosomal abnormality	Haematological	
D46.7	Other myelodysplastic syndromes	Haematological	
D46.9	Myelodysplastic syndrome, unspecified	Haematological	
D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	Haematological	
D47.1	Chronic myeloproliferative disease	Haematological	
D47.3	Essential (haemorrhagic) thrombocythaemia	Haematological	
D47.4	Osteomyelofibrosis	Haematological	
D47.5	Chronic eosinophilic leukaemia (hypereosinophilic syndrome)	Haematological	
D47.7	Other specified neoplasms of uncertain or unknown behaviour of	Haematological	

	lymphoid, haematopoietic and related tissue		
D47.9	Neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue, unspecified	Haematological	
D48.0	Neoplasm of uncertain or unknown behaviour of Bone and articular cartilage	Sarcoma	
D48.1	Neoplasm of uncertain or unknown behaviour of Connective and other soft tissue	Sarcoma	Only applicable for GISTs
D48.2	Neoplasm of uncertain or unknown behaviour of Peripheral nerves and autonomic nervous system	Other	
D48.3	Neoplasm of uncertain or unknown behaviour of Retroperitoneum	Other	
D48.4	Neoplasm of uncertain or unknown behaviour of Peritoneum	Other	
D48.5	Neoplasm of uncertain or unknown behaviour of Skin	Skin	
D48.6	Neoplasm of uncertain or unknown behaviour of Breast	Breast	
D48.7	Neoplasm of uncertain or unknown behaviour of Other specified sites	Other	
D48.9	Neoplasm of uncertain or unknown behaviour unspecified	Other	
E85.9[11]	Amyloidosis, unspecified	Haematology	See the Haematological ICD-O of User Guide (Appendix C) for information regarding what is required to be submitted for these Haematological diseases.

[11] 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 Systemic anti-cancer therapy in cases. Whilst we await the WHO disease classification being updated to reflect this fact, it's inclusion as a registerable condition requiring collection has been agreed with the National Cancer Registration and Analysis Service of Public Health England.

Appendix C: ICD Codes and WHO Disease Groups

The following table shows the full list of ICD10 codes which are applicable for Haematological diagnoses mapped against the relevant ICDO3 codes as well as the data set which should be completed for each disease and the WHO Disease Group. (Please see Appendix D for Description of Disease Groups).

IMPORTANT NOTE: Where a suffix has been added this should be used consistently as shown to ensure that diseases with the same ICDO3 code can be correctly distinguished. To ensure that consistent coding continues to be applied nationally, please advise the SACT team if you identify potential changes or additional coding requirements. (For visual clarity the ICDO3 codes in the table are formatted differently from the specification. Records should be submitted according to the format in the specification, either “MXXXXX”, or “MXXXXXX” with suffix).

LYMPHOBLASTIC LEUKAEMIA/LYMPHOBLASTIC LYMPHOMA CODING
Lymphoblastic lymphoma and lymphoblastic leukaemia are now known to be the same entity. This is reflected in the latest ICDO3 coding update which assigns the same morphology code to both and uses the combined term 'lymphoblastic leukaemia/lymphoma'. Historically different codes were assigned to lymphoblastic lymphoma and leukaemia and ICD10 coding still distinguishes between these 2 groups. The coding list below therefore retains the separate ICD10 codes (C83.5 and C91.0) but assigns the same ICDO3 codes to each pair of diseases. (Further detail can be provided if required).

RECORDING AMYLOIDOSIS WITHIN SACT
The aim is to register patients presenting with symptoms referable to an underlying diagnosis of amyloidosis in the absence of a known, registerable plasma cell or lymphoid neoplasm.

Amyloidosis may be associated with plasma cell neoplasms such as multiple myeloma, other B cell neoplasms (such as lymphoplasmacytic lymphoma), or with paraproteinaemias (which are not associated with identified myeloma or lymphoma (that is MGUS).

If amyloidosis is identified in association with a registerable condition (such as multiple myeloma, plasmacytoma, lymphoplasmacytic lymphoma, Waldenstroms macroglobulinaemia etc.), only the data for the associated registerable condition and treatments should be submitted through SACT, and these will be recorded as new treatments by the cancer registries. Amyloidosis should not be submitted for SACT in these circumstances.

Amyloid deposition associated with chronic infection, medullary carcinoma of the thyroid, insulinoma, prolactinoma, Alzheimer disease, prion diseases and other non-AL types of amyloid, is considered to be secondary amyloidosis and should not be submitted for SACT.

If amyloidosis is identified in the absence of a registerable condition or before the identification of a registerable condition, then data for Primary Amyloidosis* should be submitted for SACT and these will be registered as new treatments by the cancer registries.

Please note that for the purpose of SACT, MGUS (monoclonal gammopathy of unknown significance) is not a registerable disease and therefore amyloidosis associated with a paraprotein/MGUS should be submitted for SACT.

Amyloidosis as identified above should be recorded for SACT and coded as follows:

- ICD10 code: E85.9 (Amyloidosis unspecified)
- ICDO3 morphology code: M9769/1

Primary Amyloidosis is composed of abnormal immunoglobulin light chains (or rarely heavy chains) which deposit (either intact or in fragments) in various tissues. These form B-pleated sheets (AL amyloid) that bind Congo Red dye with characteristic birefringence.

Note: ICD-O-3 codes 9678/3 and 9712/3 have been realigned to ICD10 code C83.8 since the previous version of this table

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9740/1 A	Cutaneous mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9740/1 B	Extracutaneous mastocytoma	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9740/3	Mast Cell Sarcoma	C96.2	Malignant mast cell tumour	CORE ONLY	1
9741/1	Indolent systemic mastocytosis	D47.0	Histiocytic and mast cell tumours of uncertain and unknown behaviour	CORE ONLY	1
9741/3	Systemic mastocytosis (including systemic mastocytosis with AHNMD or aggressive systemic mastocytosis)	C96.2	Malignant mast cell tumour	CORE ONLY	1
9742/3	Mast Cell Leukaemia	C94.3	Mast cell leukaemia	CORE ONLY	1
9875/3	Chronic Myelogenous Leukaemia, BCR-ABL1 positive	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/3 A	Chronic Myelogenous Leukaemia, Accelerated Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9875/3 B	Chronic Myelogenous Leukaemia, Blastic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9875/3 C	Chronic Myelogenous Leukaemia, Chronic Phase	C92.1	Chronic myeloid leukaemia [CML], BCR/ABL-positive	CML	1
9876/3	Atypical chronic myeloid leukaemia, BCR-ABL1 negative	C92.2	Atypical chronic myeloid leukaemia, BCR/ABL-negative	MDS	1
9950/3	Polycythaemia vera*	D45	Polycythaemia vera	CORE ONLY	1
9961/3	Primary myelofibrosis*	D47.4	Osteomyelofibrosis	CORE ONLY	1
9962/3	Essential Thrombocythaemia*	D47.3	Essential (haemorrhagic) thrombocythaemia	CORE ONLY	1
9963/3	Chronic neutrophilic leukaemia	D47.1	Chronic myeloproliferative disease	CORE ONLY	1
9964/3	Chronic eosinophilic leukaemia, NOS*	D47.5	Chronic eosinophilic leukaemia [hypereosinophilic syndrome]	CORE ONLY	1
9975/3	Myeloproliferative neoplasm, unclassifiable*	D47.1	Chronic myeloproliferative disease	CORE ONLY	1
9965/3	Myeloid and lymphoid neoplasms with PDGFRA re-arrangement	C92.7	Other myeloid leukaemia	CORE ONLY	2
9966/3	Myeloid neoplasms with PDGFRB	C92.7	Other myeloid leukaemia	CORE ONLY	2
9967/3	Myeloid and lymphoid neoplasms with FGFR1 abnormalities	C92.7	Other myeloid leukaemia	CORE ONLY	2
9945/3	Chronic myelomonocytic leukaemia	C93.1	Chronic myelomonocytic leukaemia	MDS	3
9946/3	Juvenile myelomonocytic leukaemia	C93.3	Juvenile myelomonocytic leukaemia	MDS	3
9975/3 A	Myelodysplastic/Myeloproliferative neoplasm, unclassifiable	C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	CORE ONLY	3
9980/3	Refractory anaemia*	D46.4	Refractory anaemia, unspecified	MDS	4
9982/3 A	Refractory anaemia with ring sideroblasts*	D46.1	Refractory anaemia with ringed sideroblasts	MDS	4
9982/3 B	Refractory anaemia with ring sideroblasts associated with marked thrombocytosis*	D46.1	Refractory anaemia with ringed sideroblasts	MDS	4
9983/3	Refractory anaemia with excess blasts*	D46.2	Refractory anaemia with excess of blasts	MDS	4
9985/3	Refractory cytopenia with multilineage dysplasia*	D46.5	Refractory anaemia with multi-lineage dysplasia	MDS	4
9985/3 A	Refractory cytopenia of childhood*	D46.5	Refractory anaemia with multi-lineage dysplasia	MDS	4
9986/3	Myelodysplastic syndrome associated with isolated del(5q)*	D46.6	Myelodysplastic syndrome with isolated del(5q) chromosomal abnormality	MDS	4
9989/3	Myelodysplastic syndrome, unclassifiable*	D46.9	Myelodysplastic syndrome, unspecified	MDS	4
9991/3	Refractory neutropenia*	D46.7	Other Myelodysplastic syndromes	MDS	4
9992/3	Refractory thrombocytopenia*	D46.7	Other Myelodysplastic syndromes	MDS	4
9727/3	Blastic plasmacytoid dendritic cell neoplasm	C86.4	Blastic NK-cell lymphoma	AML	5
9840/3	Acute erythroid leukaemia	C94.0	Acute erythroid leukaemia	AML	5
9861/3 A	AML with mutated CEBPA	C92.0	Acute myeloblastic leukaemia [AML]	AML	5

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9861/3 B	AML with mutated NPM1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9861/3 C	Acute myeloid leukaemia, NOS	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9865/3	AML with t(6;9)(p23;q34) DEK-NUP214	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9866/3	Acute promyelocytic leukaemia with t(15;17)(q22;q12) PML-RARA	C92.4	Acute promyelocytic leukaemia [PML]	AML	5
9867/3	Acute myelomonocytic leukaemia	C92.5	Acute myelomonocytic leukaemia	AML	5
9869/3	AML with inv(3)(q21q26.2) or t(3;3)(q21;q26.2) RPRN1-EVI1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9870/3	Acute basophilic leukaemia	C94.7	Other specified leukaemia	AML	5
9871/3	AML with inv(16)(p13.1;q22) or t(16;16)(p13.1;q22) CBFB-MYH11	C92.5	Acute myelomonocytic leukaemia	AML	5
9872/3	AML with minimal differentiation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9873/3	AML without maturation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9874/3	AML with maturation	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9891/3	Acute monoblastic and monocytic leukaemia	C93.0	Acute monoblastic/monocytic leukaemia	AML	5
9895/3	AML with myelodysplasia-related changes	C92.8	Acute myeloid leukaemia with multilineage dysplasia	AML	5
9896/3	AML with t(8;21)(q22;q22) RUNX1-RUNX1T1	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9897/3	AML with t(9;11)(p22;q23) MLLT3-MLL	C92.6	Acute myeloid leukaemia with 11q23-abnormality	AML	5
9898/1	Transient abnormal myelopoiesis	D47.1	Chronic myeloproliferative disease	CORE ONLY	5
9898/3	Myeloid leukaemia associated with Down syndrome	C92.7	Other myeloid leukaemia	AML	5
9910/3	Acute megakaryoblastic leukaemia	C94.2	Acute megakaryoblastic leukaemia	AML	5
9911/3	AML (megakaryoblastic) with t(1;22)(p13;q13) RBM15-MKL1	C94.2	Acute megakaryoblastic leukaemia	AML	5
9920/3	t-AML	C92.0	Acute myeloblastic leukaemia [AML]	AML	5
9920/3 A	t-MDS/MPN	C94.6	Myelodysplastic and myeloproliferative disease, not elsewhere classified	MDS	5
9920/3 B	t-MDS	D46.7	Other myelodysplastic syndromes	MDS	5
9930/3	Myeloid sarcoma	C92.3	Myeloid sarcoma	CORE ONLY	5
9931/3	Acute panmyelosis with myelofibrosis	C94.4	Acute panmyelosis with myelofibrosis	CORE ONLY	5
9801/3	Acute undifferentiated leukaemia	C95.0	Acute leukaemia of unspecified cell type	AML	6

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9805/3	Mixed phenotype acute leukaemia NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9806/3	Mixed phenotype acute leukaemia with t(9;22)(q34;q11.2) BCR-ABL1	C95.0	Acute leukaemia of unspecified cell type	AML	6
9807/3	Mixed phenotype acute leukaemia with t(v;11q23) MLL re-arranged	C95.0	Acute leukaemia of unspecified cell type	AML	6
9808/3	Mixed phenotype acute leukaemia, B/myeloid, NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9809/3	Mixed phenotype acute leukaemia, T/myeloid, NOS	C95.0	Acute leukaemia of unspecified cell type	AML	6
9811/3 A	B lymphoblastic lymphoma, NOS	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9811/3 B	B lymphoblastic leukaemia, NOS	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9812/3 A	B lymphoblastic lymphoma with t(9;22)(q34;q11.2);BCR-ABL1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9812/3 B	B lymphoblastic leukaemia with t(9;22)(q34;q11.2);BCR-ABL1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9813/3 A	B lymphoblastic lymphoma with t(v;11q23);MLL re-arranged	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9813/3 B	B lymphoblastic leukaemia with t(v;11q23);MLL re-arranged	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9814/3 A	B lymphoblastic lymphoma with t(12;21)p13;q22);ETV6-RUNX1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9814/3 B	B lymphoblastic leukaemia with t(12;21)p13;q22);ETV6-RUNX1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9815/3 A	B lymphoblastic lymphoma with hyperdiploidy	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9815/3 B	B lymphoblastic leukaemia with hyperdiploidy	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9816/3 A	B lymphoblastic lymphoma with hypodiploidy (hypodiploid ALL)	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9816/3 B	B lymphoblastic leukaemia with hypodiploidy (hypodiploid ALL)	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9817/3 A	B lymphoblastic lymphoma with t(5;14)(q31;q32);IL3-IGH	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9817/3 B	B lymphoblastic leukaemia with t(5;14)(q31;q32);IL3-IGH	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9818/3 A	B lymphoblastic lymphoma with t(1;19)(q23;p13.3);TCF3-PBX1	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	7
9818/3 B	B lymphoblastic leukaemia with t(1;19)(q23;p13.3);TCF3-PBX1	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	7
9729/3	T lymphoblastic lymphoma	C83.5	Lymphoblastic (diffuse) lymphoma	ALL	8
9837/3	T lymphoblastic leukaemia	C91.0	Acute lymphoblastic leukaemia [ALL]	ALL	8
9591/3 A	Hairy cell leukaemia variant	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 B	Splenic diffuse red pulp small B-cell lymphoma	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 C	Splenic B-cell lymphoma/leukaemia, unclassifiable	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9591/3 D	B cell lymphoma, NOS	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9596/3	B-cell lymphoma, intermediate between DLBCL/Classical Hodgkins	C85.1	B-cell lymphoma, unspecified	Other Lymphomas	9
9597/3	Primary cutaneous follicle centre lymphoma	C82.6	Cutaneous follicle centre lymphoma	Follicular	9
9671/3	Lymphoplasmacytic lymphoma	C83.0	Diffuse large B-cell lymphoma	Other Lymphomas	9
9673/3	Mantle cell lymphoma	C83.1	Mantle cell lymphoma	Other Lymphomas	9
9678/3	Primary effusion lymphoma	C83.8	Diffuse large B-cell lymphoma	Other Lymphomas	9
9679/3	Primary mediastinal (thymic) large B-cell lymphoma	C85.2	Mediastinal (thymic)large B-cell lymphoma	Other Lymphomas	9
9680/3	Diffuse large B-cell lymphoma (DLBCL), NOS	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 A	Primary DLBCL of the CNS	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 B	EBV positive DLBCL of the elderly	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 C	B-cell lymphoma, intermediate between DLBCL /Burkitt lymphoma	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 D	Primary cutaneous DLBCL, leg type	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9680/3 E	DLBCL associated with chronic inflammation	C83.3	Diffuse large B-cell lymphoma	DLBCL	9
9687/3	Burkitt lymphoma	C83.7	Burkitt lymphoma	Other Lymphomas	9
9688/3	T-cell/histiocyte rich large B-cell lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9689/3	Splenic marginal zone lymphoma	C83.0	Small cell B-cell lymphoma	Other Lymphomas	9
9690/3	Follicular lymphoma	C82.9	Follicular lymphoma, unspecified	Follicular	9
9691/3	Follicular lymphoma Grade 2	C82.1	Follicular lymphoma grade II	Follicular	9
9695/3	Follicular lymphoma Grade 1	C82.0	Follicular lymphoma grade I	Follicular	9
9698/3	Follicular lymphoma Grade 3	C82.2	Follicular lymphoma grade III, unspecified	Follicular	9
9698/3 A	Follicular lymphoma Grade 3A	C82.3	Follicular lymphoma grade IIIa	Follicular	9
9698/3 B	Follicular lymphoma Grade 3B	C82.4	Follicular lymphoma grade IIIb	Follicular	9
9699/3 A	Extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue (MALT)	C88.4	Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue [MALT-lymphoma]	Other Lymphomas	9
9699/3 B	Nodal marginal zone lymphoma	C83.0	Small cell B-cell lymphoma	Other Lymphomas	9
9712/3	Intravascular large B-cell lymphoma	C83.8	Other non-follicular lymphoma	Other Lymphomas	9
9731/3	Solitary plasmacytoma of bone	C90.3	Solitary plasmacytoma	CORE ONLY	9

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9732/3	Plasma cell myeloma	C90.0	Multiple myeloma	Myeloma	9
9733/3	Plasma cell leukaemia	C90.1	Plasma cell leukaemia	Myeloma	9
9734/3	Extraosseous plasmacytoma	C90.2	Extramedullary plasmacytoma	CORE ONLY	9
9735/3	Plasmablastic lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9737/3	ALK positive large B-cell lymphoma	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9738/3	Large B-cell lymphoma arising in HHV8-associated multicentric Castleman disease	C83.3	Diffuse large B-cell lymphoma	Other Lymphomas	9
9760/3	Immunoproliferative disease, NOS	C88.9	Malignant immunoproliferative disease, unspecified	CORE ONLY	9
9761/3	Waldenström macroglobulinaemia	C88.0	Waldenström macroglobulinaemia	Other Lymphomas	9
9762/3	Heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9762/3 A	Alpha heavy chain disease	C88.3	Immunoproliferative small intestinal disease	CORE ONLY	9
9762/3 B	Gamma heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9762/3 C	Mu heavy chain disease	C88.2	Other heavy chain disease	CORE ONLY	9
9764/3	Immunoproliferative small intestinal disease	C88.3	Immunoproliferative small intestinal disease	Other Lymphomas	9
9766/1	Lymphomatoid granulomatosis	C83.8	Other non-follicular lymphoma	CORE ONLY	9
9769/1	Primary Amyloidosis	E85.9	Amyloidosis, unspecified	CORE ONLY	9
9823/3	Chronic lymphocytic leukaemia/small lymphocytic lymphoma	C91.1	Chronic lymphocytic leukaemia of B-cell type	CLL	9
9826/3	Burkitt cell leukaemia	C91.8	Mature B-cell leukaemia Burkitt-type	Other Lymphomas	9
9833/3	B-cell prolymphocytic leukaemia	C91.3	Prolymphocytic leukaemia of B-cell type	CORE ONLY	9
9940/3	Hairy cell leukaemia	C91.4	Hairy-cell leukaemia	CORE ONLY	9
9700/3	Mycosis fungoides	C84.0	Mycosis fungoides	Other Lymphomas	10
9701/3	Sézary syndrome	C84.1	Sézary disease	Other Lymphomas	10
9702/3 A	Peripheral T-cell lymphoma, NOS	C84.4	Peripheral T-cell lymphoma, not elsewhere classified	Other Lymphomas	10
9702/3 B	Anaplastic large cell lymphoma, ALK negative	C84.7	Anaplastic large cell lymphoma, ALK-negative	Other Lymphomas	10
9705/3	Angioimmunoblastic T-cell lymphoma	C86.5	Angioimmunoblastic T-cell lymphoma	Other Lymphomas	10
9708/3	Subcutaneous panniculitis-like T-cell lymphoma	C86.3	Subcutaneous panniculitis-like T-cell lymphoma	Other Lymphomas	10
9709/3 A	Primary cutaneous CD8+ aggressive epidermotropic cytotoxic T-cell lymphoma	C84.8	Cutaneous T-cell lymphoma, unspecified	Other Lymphomas	10
9709/3 B	Primary cutaneous CD4 positive small/medium T-cell lymphoma	C84.8	Cutaneous T-cell lymphoma, unspecified	Other Lymphomas	10
9714/3	Anaplastic large cell lymphoma, ALK positive	C84.6	Anaplastic large cell lymphoma, ALK-positive	Other Lymphomas	10
9716/3	Hepatosplenic T-cell lymphoma	C86.1	Hepatosplenic T-cell lymphoma	Other Lymphomas	10
9717/3	Enteropathy-associated T-cell lymphoma	C86.2	Enteropathy-type (intestinal) T-cell lymphoma	Other Lymphomas	10

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9718/3	Primary cutaneous anaplastic large cell lymphoma	C86.6	Primary cutaneous CD30-positive T-cell proliferations	Other Lymphomas	10
9719/3	Extranodal NK/T cell lymphoma, nasal type	C86.0	Extranodal NK/T-cell lymphoma, nasal type	Other Lymphomas	10
9719/3 A	T/NK-cell lymphoma	C84.9	Mature T/NK-cell lymphoma, unspecified	CORE ONLY	10
9724/3	Systemic EBV positive T-cell lymphoproliferative disease of childhood	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10
9725/3	Hydroa vacciniforme-like lymphoma	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10
9726/3	Primary cutaneous gamma-delta T-cell lymphoma	C84.5	Other mature T/NK-cell lymphomas	Other Lymphomas	10
9827/3	Adult T-cell leukaemia/lymphoma	C91.5	Adult T-cell lymphoma/leukaemia (HTLV-1-associated)	Other Lymphomas	10
9831/3	T-cell large granular lymphocytic leukaemia	C91.7	Other lymphoid leukaemia	CORE ONLY	10
9831/3 A	Chronic lymphoproliferative disorder of NK-cells	C91.7	Other lymphoid leukaemia	CORE ONLY	10
9834/3	T-cell prolymphocytic leukaemia	C91.6	Prolymphocytic leukaemia of T-cell type	CORE ONLY	10
9948/3	Aggressive NK cell leukaemia	C95.0	Acute leukaemia of unspecified cell type	CORE ONLY	10
9650/3	Classical Hodgkin lymphoma	C81.9	Hodgkin lymphoma, unspecified	Hodgkin	11
9651/3	Lymphocyte-rich classical Hodgkin lymphoma	C81.4	Lymphocyte-rich classical Hodgkin lymphoma	Hodgkin	11
9652/3	Mixed cellularity classical Hodgkin lymphoma	C81.2	Mixed cellularity classical Hodgkin lymphoma	Hodgkin	11
9653/3	Lymphocyte-depleted classical Hodgkin lymphoma	C81.3	Lymphocytic depleted classical Hodgkin lymphoma	Hodgkin	11
9659/3	Nodular lymphocyte predominant Hodgkin lymphoma	C81.0	Nodular lymphocyte predominant Hodgkin lymphoma	Hodgkin	11
9663/3	Nodular sclerosis classical Hodgkin lymphoma	C81.1	Nodular sclerosis classical Hodgkin lymphoma	Hodgkin	11
9751/3 A	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	C96.0	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis [Letterer-Siwe disease]	CORE ONLY	12
9751/3 B	Multifocal and unisystemic (disseminated) Langerhans-cell histiocytosis	C96.5	Multifocal and unisystemic Langerhans-cell histiocytosis	CORE ONLY	12
9751/3 C	Unifocal Langerhans-cell histiocytosis	C96.6	Unifocal Langerhans-cell histiocytosis	CORE ONLY	12
9755/3	Histiocytic sarcoma	C96.8	Histiocytic sarcoma	CORE ONLY	12
9756/3	Langerhans cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9757/3	Interdigitating dendritic cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9757/3 A	Dendritic cell tumour, NOS	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9758/3	Follicular dendritic cell sarcoma	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9759/3	Fibroblastic reticular cell tumour	C96.4	Sarcoma of dendritic cells (accessory cells)	CORE ONLY	12
9971/1 A	Early lesions plasmacytic hyperplasia	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13

ICD-O-3	ICD-O-3 WHO Description	ICD-10 (4th Edition)	ICD10 Description	Clinical data set	WHO DISEASE GROUP
9971/1 B	Early lesions infectious mononucleosis-like PTLD	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 A	Polymorphic PTLD*	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 B	Monomorphic PTLD (B- and T/NK-cell types)*	D47.7	Other specified neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue	CORE ONLY	13
9971/3 C	Classical Hodgkin lymphoma type PTLD*	C81.9	Hodgkin lymphoma, unspecified	CORE ONLY	13
9591/3	Malignant lymphoma, non-Hodgkin, NOS	C85.9	Non-Hodgkin lymphoma, unspecified	Other Lymphomas	(No applicable group)
9800/3	Leukaemia, NOS	C95.9	Leukaemia, unspecified	CORE ONLY	
9860/3	Myeloid leukaemia, NOS	C92.9	Myeloid leukaemia, unspecified	CORE ONLY	
		C81.7	Other classical Hodgkin lymphoma	Redundant (reclassified)**	
		C82.5	Diffuse follicle centre lymphoma	Redundant (reclassified)**	
		C82.7	Other types of follicular lymphoma	Redundant (reclassified)**	
		C83.9	Non-follicular (diffuse) lymphoma, unspecified	Redundant (reclassified)**	
		C88.7	Other malignant immunoproliferative diseases	Redundant (reclassified)**	
		C93.7	Other monocytic leukaemia	Redundant (reclassified)**	
		C93.9	Monocytic leukaemia, unspecified	Redundant (reclassified)**	
		C94.7	Other specified leukaemias	Redundant (reclassified)**	
		C95.1	Chronic leukaemia of unspecified cell type	Redundant (reclassified)**	
		C95.7	Other leukaemia of unspecified cell type	Redundant (reclassified)**	
		C96.7	Other specified malignant neoplasms of lymphoid, haematopoietic and related tissue	Redundant (reclassified)**	
		C96.9	Malignant neoplasms of lymphoid, haematopoietic and related tissue, unspecified	Redundant (reclassified)**	
	not used in ICD-O-3 (D46.4 used instead)	D46.0	Refractory anaemia without ringed sideroblasts, so stated	Redundant (reclassified)**	
		D47.9	Neoplasm of uncertain or unknown behaviour of lymphoid, haematopoietic and related tissue, unspecified	Redundant (reclassified)**	

*** There is a behaviour discrepancy between the ICD10 site code and the new ICD-O-3 morphology code − although these diseases are now coded with a behaviour code of 3 they are still recorded with a D code in ICD10.**

**** Redundant − disease has been reclassified under other codes.**

Appendix D: WHO Classification of Tumours (Haematopoietic and Lymphoid Tissue)

Group numbers have been assigned for ease of reference as used in Section 7.2 ICD Codes and WHO Disease Groups in the Haematological section of the User Guide. (WHO Classification does not distinguish Groups 7 & 8 as separate disease groups).

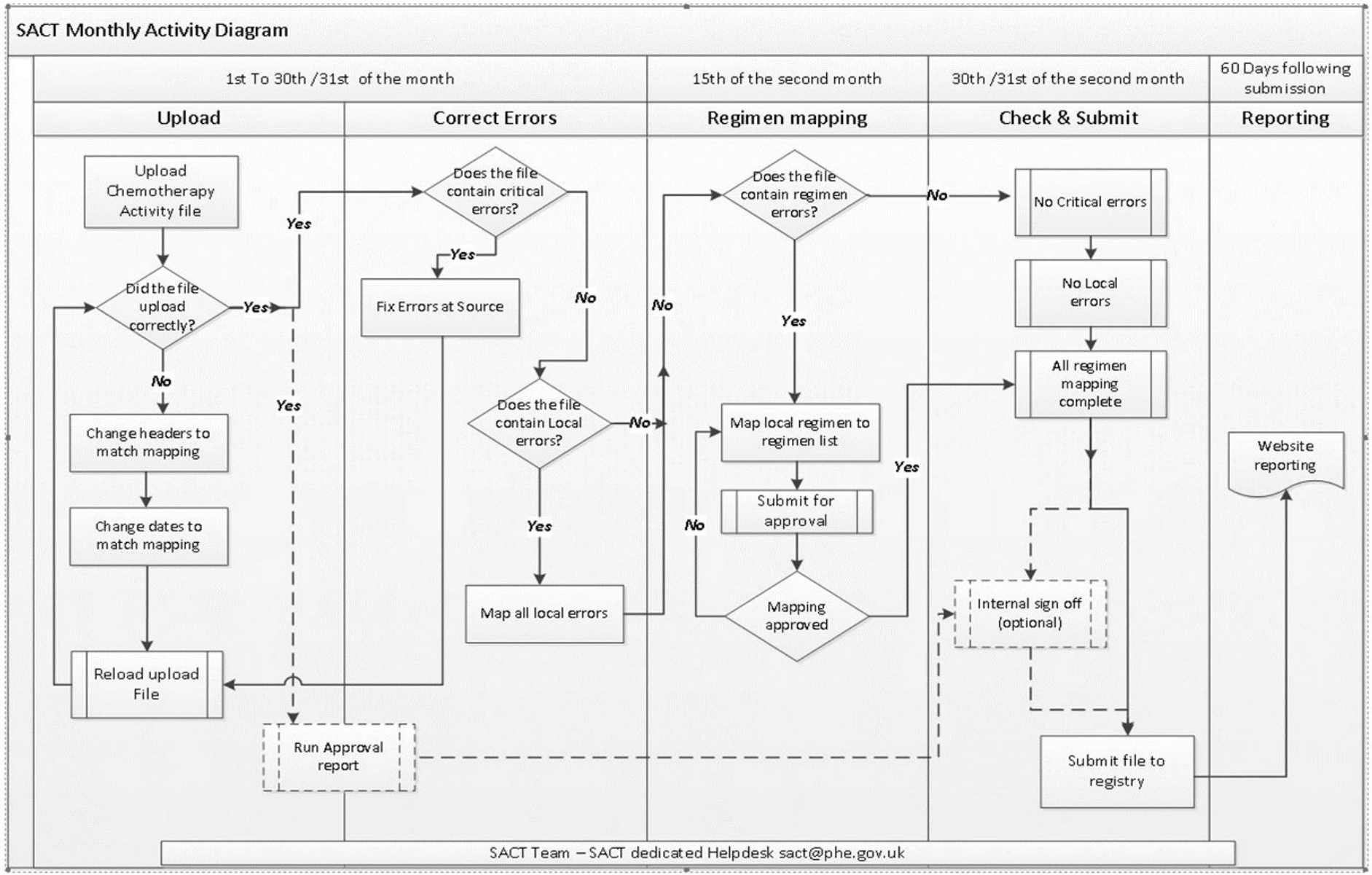
GROUP #	Description
GROUP 1	*Myeloproliferative neoplasms*
GROUP 2	*Myeloid and lymphoid neoplasms with eosinophilia and abnormalities of PDGFRA, PDGFRB or FGFR1*
GROUP 3	*Myelodysplastic/myeloproliferative neoplasms*
GROUP 4	*Myelodysplastic syndromes*
GROUP 5	*Acute myeloid leukaemia (AML) and related Precursor neoplasms*
GROUP 6	*Acute leukaemias of ambiguous lineage*
GROUP 7	*Precursor B lymphoid neoplasms*
GROUP 8	*Precursor T lymphoid neoplasms*
GROUP 9	*Mature B cell neoplasms*
GROUP 10	*Mature T-cell and NK-cell neoplasms*
GROUP 11	*Hodgkin lymphoma*
GROUP 12	*Histiocytic and dendritic cell neoplasm*
GROUP 13	*Post-transplant lymphoproliferative disorders (PTLD)*

Appendix E: Timetable for Implementation of Version 3.0

Submissions are accepted as follows for Version 3.0

Diagnosis month	Reporting Date	data set	Accepted MDT system submission format
June 2019		V2.0	csv only
July		V2.0	csv only
August		V2.0	csv only
September		V2.0 or v3.0	csv only
October		V2.0 or v3.0	csv only
November		V2.0 or v3.0	csv only
December		V3.0	csv only
January 2020		V3.0	csv only
February		V3.0	csv only

Please refer to the ‘SACT Portal Monthly Activity’ graph on page 61, for more detail on monthly submissions and reporting


SACT Monthly Activity Diagram
1st To 30th /31st of the month
15th of the second month
30th /31st of the second month
60 Days following submission
Upload
Correct Errors
Regimen mapping
Check & Submit
Reporting
Upload Chemotherapy Activity file
Did the file upload correctly?
Yes
No
Change headers to match mapping
Change dates to match mapping
Reload upload File
Does the file contain critical errors?
Yes
No
Fix Errors at Source
Does the file contain Local errors?
Yes
No
Map all local errors
Does the file contain regimen errors?
Yes
No
Map local regimen to regimen list
Submit for approval
Mapping approved
No
Yes
No Critical errors
No Local errors
All regimen mapping complete
Internal sign off (optional)
Submit file to registry
Website reporting
Run Approval report
SACT Team – SACT dedicated Helpdesk sact@phe.gov.uk