



Public Health
England

Protecting and improving the nation's health

Systemic Anti-Cancer Therapy (SACT) Data Set

Change Request

Version 3.0

About Public Health England

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Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: [@PHE_uk](https://twitter.com/PHE_uk)
Facebook: www.facebook.com/PublicHealthEngland



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Published December 2018
PHE publications
gateway number: 2018638

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Title	Systemic Anti-Cancer Therapy Data Set (SACT) Change Request Version 3.0		
DCB reference	DCB1533 Amd 80/2018		
Sponsor	Dr Jem Rashbass	Status	Final
Senior responsible officer	Professor John Newton	Version	3.0
Author(s)	Andrew Murphy	Version Date	06/12/2018

Amendment history:

Version	Date	Amendment history
3.0 Draft	07-08-2018	Draft v3.0 sent to SACT management team for review
3.1 Draft	30-08-2018	Draft for DSAS assessment (SACT v3.0)
3.2 Draft	01-10-2018	Final draft for DSAS assessment
3.0 Final	26-10-2018	Final version for publication
3.0 Final	06-12-2018	Final version published

Approvals:

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

Data Coordination Board

This information standard (DCB1533) has been approved for publication by the Department of Health and Social Care under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the act and is appropriate for the use stated in the specification document has been provided by the Data Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Implementation guide
- Change request

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

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

Date of publication: 6 December 2018

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Overview

Summary:

Standard	
Standard number	DCB1533
Standard title	Systemic Anti-Cancer Therapy (SACT) data set
Release	
Release number	Amd 80/2018
Release version	Version 3.0
Description	<p>This is a change to the Systemic Anti-Cancer Therapy (SACT) data set standard which builds on the work that has continued over the past 4 years, since the last update. These changes were required in order to make the data set clinically accurate and also meet the business objectives of the data set.</p> <p>Extensive consultation was conducted over a 6 month period with 42 groups/organisations and 76 experts. These groups consist of clinical experts in their fields (this included clinicians, pharmacists, oncologists, pharma representatives, commissioners and lay members). For the first time, cancer charities and patient groups were also consulted with.</p> <p>This process allowed the data set to be clinically reviewed, validated and updated by experts in all fields of cancer and ensure the data set continues to remain a clinically sound set of data to be collected from 2019, and for the lifetime of the data set.</p> <p>The changes are:</p> <p>Change of scope: Extensible Markup Language (XML) will no longer be a requirement of this standard, and this has been reflected in a change to the scope of the standard.</p> <p>This decision was taken after review and due to the financial burden this would have cost Trusts and SACT in changing reporting structures, training of staff and the reporting of data files in this format.</p> <p>Changes to data set: In order to align with current business needs and clinical practice and to support data quality, various</p>

changes have been made to the data set.

In total, there are 44 data items (an increase from 43 in the previous version), however this includes 2 pilot items added to assess burden and 3 optional items to meet the demands of SNOMED CT by 2020. These 5, along with 3 additional identifiers for linkage/identification purposes (for those who do not have an NHS number), do not create any additional burden of data collection.

18 new data items have been added most of these data are either collected already in e-prescribing systems or within other local clinical systems and have been heavily consulted upon, of which:

2 data items have been added, to allow for accurate reporting of Performance Status in adults aged 19 years and above.

6 data items have been added, to improve the quality of data submitted (1 as a pilot).

2 data items have been added, to record the accurate measurement (per dose) administered.

3 data item have been added, which complies with the Information Standard SCCI0034 SNOMED CT.

1 data item has been added, as a required change to meet NHS Data Model and Dictionary consistency.

3 data items have been added, to allow for cases where a patient does not have an NHS number to be reported.

1 data item has been added, as a pilot, to help link SACT and dictionary of medicines and devices (dm+d) data to improve information about drugs administered.

17 data items have been deleted of which:

8 data items have been deleted, as they were no longer required for the accurate recording of treatment data.

5 data items have been deleted, to reduce burden, data can be linked with other PHE data sets.

2 data items have been deleted, to improve the accurate reporting of Performance Status.

2 data items have been deleted, but replaced with newer or more functional items.

18 data items have been amended (some have multiple changes) to allow for changes in their attributes, format, descriptions, field names or csv schema specifications and

	<p>should improve the collection of the standard. Of which:</p> <p>4 data items have been updated, to change the format size to improve data submissions.</p> <p>5 data items have been updated, to improve the data-item name or description.</p> <p>2 data items have been updated, to update the data-item attributes.</p> <p>2 data items have been updated, to meet the new requirement due to the new Health and Social Care Organisation Reference Data standard (ANANA) - DCB0090.</p> <p>17 data items have been updated, to include a change to the csv schema specification or element name.</p>
Implementation start and completion date	<p>Implementation will be between 06-12-2018 and 31-08-2019 (8½ months).</p> <p>Data collection will start from 01-09-2019 (with a 3 month roll-out period between 01-09-2019 and 30-11-2019).</p> <p>Full conformance by 01-12-2019.</p>

Supporting products:

Product	Document Reference	Title
Specification	http://digital.nhs.uk/isce/publication/dcb1533	DCB1533 SACT Specification
Implementation Guide	http://digital.nhs.uk/isce/publication/dcb1533	DCB1533 SACT Implementation Guide
Data set v3.0	www.chemodataset.nhs.uk/guides_and_support/	SACT Data set v3.0
User Guide	www.chemodataset.nhs.uk/guides_and_support/	SACT v3.0 User Guide
Technical Guide	www.chemodataset.nhs.uk/guides_and_support/	DCB1533 SACT Technical Guide

Related Standards:

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

Change Specification

This is a complex data set covering 200 diseases and requiring alignment with changing clinical practice. It is therefore expected that regular changes will be required. The new items reflect this and are introduced to align with current business needs and clinical practice and to support data quality.

New data items have been added after extensive consultation was conducted with all the Public Health England Expert Advisory Groups (EAG), experts from within the National Cancer Registration and Analysis Service (NCRAS), as well as clinical support and advice from senior clinicians, medical oncologists, pharmacists, commissioners and charities. Details of the consultation process were provided as supporting evidence to the Data Coordination Board (DCB) in the consultation plan document.

This process allowed the data set to be clinically reviewed, validated and updated by experts in all fields of cancer and ensured that it continued to remain a clinically sound set of data to be collected from 2019 and for the lifetime of this version of the data set.

In addition there is new data to help:

- identify patients that do not have an NHS number
- improve the quality of the data submitted
- link SACT and the dictionary of medicines and devices (dm+d), data to improve information about drugs administered – this will be in the form of a pilot for the lifetime of this version of the data set
- record the accurate measurement (per dose) administered
- record improved outcome measurements – toxicity will be in the form of a pilot for the lifetime of this version of the data set

The data set should be easily maintained within each trust and has a small increase in size from 43 data items to 44. Although the total number has increased, there is a reduction in the burden of data collection, along with better alignment of the data requested. This will help ease the burden of data collection, whilst improving the ascertainment and data quality.

Not all data is required, and the new sequencing of data requested means that several data items are reliant on specific answers to others.

For example if 'Yes' is selected in the 'Regimen Outcome Summary – Curative (Completed As Planned)' field, then neither of the following items are required to be completed:

- 'Regimen Outcome Summary – Curative (Not Completed As Planned) Reason'
- 'Other – Regimen Outcome Summary – Curative (Not Completed As Planned) Reason'

Two new items have also been added as a pilot and will be monitored, tested and analysed throughout the lifetime of this version of the data set, with a view to adding these as permanent data items in the next version.

In addition, 3 data items have been added as optional items to meet the demands of SNOMED CT by 2020.

A full breakdown of the reduction in the burden of data collection and the reduction in the overall financial burden can be found in the Business Justification document (section 1.3 Burden vs Benefit).

Note:

- it is recommended that the SACT data set v3.0 is used in conjunction with the User Guide when reviewing this document; this will help give context to and an understanding of all the changes, attribute lists and field formats
- both the 'Demographics and Consultant' and 'Clinical Status' sections are mandatory for every submission of patient data – it is important that this is adopted and enforced within all reporting systems
- some data items have multiple changes – these are listed below and also in the SACT data set v3.0 workbook, within the additional worksheets

New Items

Details of all the new items are listed below; italics indicate the section of the data set where the items are located.

- **LOCAL PATIENT IDENTIFIER**

- *DEMOGRAPHICS AND CONSULTANT*

This has been added to allow for cases (where a patient does not have an NHS number) to be reported.

- **PERSON FAMILY NAME**

- *DEMOGRAPHICS AND CONSULTANT*

This has been added to allow for cases (where a patient does not have an NHS number) to be traced through the NHS Digital demographics batch service bureau¹.

- **PERSON GIVEN NAME**

- *DEMOGRAPHICS AND CONSULTANT*

This has been added to allow for cases (where a patient does not have an NHS number) to be traced through the NHS Digital demographics batch service bureau.

- **PERSON STATED GENDER CODE**

- *DEMOGRAPHICS AND CONSULTANT*

This has been added to replace the older (now removed) field of [Gender - Current] and to meet NHS Data Model and Dictionary consistency.

- **DIAGNOSIS CODE (SNOMED CT)**

- *CLINICAL STATUS*

This has been added as an optional item to comply with the information standard SCCI0034 SNOMED CT2.

- **ADJUNCTIVE THERAPY**

- *PROGRAMME AND REGIMEN*

This has been added to improve the accurate recording of adjunctive therapy, and to align with other major cancer data sets.

¹ <https://digital.nhs.uk/services/national-back-office-for-the-personal-demographics-service/demographics-batch-service-bureau>

² <https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/scci0034-snomed-ct>

- **PERFORMANCE STATUS AT START OF REGIMEN – ADULT**

- *PROGRAMME AND REGIMEN*

This has been added to allow for accurate reporting of Performance Status (in adults aged 19 years and above) at the start of the regimen.

- **PERFORMANCE STATUS AT START OF CYCLE – ADULT**

- *CYCLE*

This has been added to allow for accurate reporting of Performance Status (in adults aged 19 years and above) at the start of the cycle.

- **ADMINISTRATION MEASUREMENT PER ACTUAL DOSE**

- *DRUG DETAILS*

This has been added to record the accurate measurement (per dose) administered.

- **OTHER - ADMINISTRATION MEASUREMENT PER ACTUAL DOSE**

- *DRUG DETAILS*

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)**

- *DRUG DETAILS*

This has been added to record 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)**

- *DRUG DETAILS*

This has been added to record 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)**

- *OUTCOME*

This has been added to record if the curative treatment was completed as planned.

- **REGIMEN OUTCOME SUMMARY – CURATIVE (NOT COMPLETED AS PLANNED) REASON**

- *OUTCOME*

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**

- *OUTCOME*

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**

- *OUTCOME*

This has been added to record if the patient benefitted from the treatment, where the intent was non-curative.

New Pilot Items

Two new data items below are being added in a pilot format for the lifetime of this version of the data set, to assess burden and availability of data collection.

- **DM+D**

- *DRUG DETAILS*

This has been added to help link SACT and dm+d data to improve drug detail information.

- **REGIMEN OUTCOME SUMMARY – TOXICITY**

- *OUTCOME*

This has been added to record if the toxicity was a deciding factor in modifying the treatment regimen.

Amendments

The amendments below are in 3 sections, substantial, cosmetic and csv schema amendment changes as follows:

Substantial Amendment Changes

- **NHS NUMBER**

- *DEMOGRAPHICS AND CONSULTANT*

This item is now a mandatory item but is an either/or with [Local Patient Identifier], allowing for cases where a patient does not have an NHS number to be reported.

- **PRIMARY DIAGNOSIS**

- *CLINICAL STATUS*

This data item has had the description updated and is now mandatory (and is an either/or item with Morphology ICD-O), to support accurate recording of the diagnosis using the current coding version of ICD.

- **MORPHOLOGY ICD-O**

- *CLINICAL STATUS*

This item has had a name change to improve an understanding as to what is being requested, a description change to support accurate recording of the diagnosis using ICD-O-3 coding, and made mandatory (adding the ability to be an either/or submission with field [10 - PRIMARY DIAGNOSIS]).

- **INTENT OF TREATMENT**

- *PROGRAMME AND REGIMEN*

This item has updated attributes to improve [Treatment Intent] specifically for Systemic Anti-Cancer Therapy treatments and is a multiple repeating item from v3 onwards.

- **REGIMEN**

- *PROGRAMME AND REGIMEN*

This item has had the format increased to allow for ever more complex regimens to be submitted, and an updated element name for consistency.

- **CYCLE NUMBER**

- *CYCLE*

The format of this item has been increased to futureproof the data set, if more than 99 cycles are ever required to be reported, and an updated element name for consistency.

- **START DATE OF CYCLE**

- *CYCLE*

This item is now mandatory to enforce the completion of the data item for every record submitted, and an updated element name for consistency.

- **DRUG NAME**

- *DRUG DETAILS*

This item is now mandatory to enforce completion of the data item for every record submitted, and the format has been increased to allow trusts to submit longer drug names.

- **ACTUAL DOSE PER ADMINISTRATION**

- *DRUG DETAILS*

The format for this item has been increased to future proof the data set.

- **SACT ADMINISTRATION ROUTE**

- *DRUG DETAILS*

This data item has had updates to the attribute field to comply with all NHS Data Model and Dictionary attributes.

- **ADMINISTRATION DATE**

- *DRUG DETAILS*

This item is now mandatory to enforce completion of the data item for every record submitted.

Cosmetic Amendment Changes

- **CONSULTANT SPECIALTY CODE**

- *DEMOGRAPHICS AND CONSULTANT*

This data item has had updates to the attribute field to comply with all NHS Data Model and Dictionary attributes.

- **ORGANISATION IDENTIFIER (CODE OF PROVIDER)**

- *DEMOGRAPHICS AND CONSULTANT*

This item has had the name, description and element name updated to comply with ANANA standard DCB0090.

- **DATE DECISION TO TREAT**

- *PROGRAMME AND REGIMEN*

This change was required to standardise the data element name with the NHS Data Model and Dictionary.

- **START DATE OF REGIMEN**

- *PROGRAMME AND REGIMEN*

This change was required to standardise the data element name with the NHS Data Model and Dictionary.

- **CLINICAL TRIAL**

- *PROGRAMME AND REGIMEN*

The description has been rewritten to improve the understanding of the data item and improve ascertainment/quality of reported data.

- **ORGANISATION IDENTIFIER OF SACT ADMINISTRATION**

- *DRUG DETAILS*

This item has had the name, description and element name updated to comply with ANANA standard DCB0090.

CSV Schema Mandation Amendment Changes

- **WEIGHT AT START OF CYCLE**

- *CYCLE*

This item has changed from an optional to a required item to improve completion of data item for every record submitted.

Deletions

The following data items are deleted for the reasons stated against each item.

- **GENDER – CURRENT**

- *DEMOGRAPHICS AND CONSULTANT*

Replaced with [Person Stated Gender Code], as a required change to meet NHS Data Model and Dictionary consistency.

- **ETHNICITY**

- *DEMOGRAPHICS AND CONSULTANT*

Removed to reduce burden, data can be derived by linking with other PHE data sets.

- **REGISTERED GP PRACTICE CODE**

- *DEMOGRAPHICS AND CONSULTANT*

Removed to reduce burden, data can be derived by linking with other PHE data sets.

- **TNM STAGE GROUPING (FINAL PRETREATMENT)**

- *CLINICAL STATUS*

Removed to reduce burden, data can be derived by linking with other PHE data sets.

- **SACT PROGRAMME NUMBER**

- *PROGRAMME AND REGIMEN*

Removed as no longer required for the accurate recording of treatment data.

- **REGIMEN NUMBER**

- *PROGRAMME AND REGIMEN*

Removed as no longer required for the accurate recording of treatment data.

- **PERFORMANCE STATUS AT START OF REGIMEN**

- *PROGRAMME AND REGIMEN*

Replaced with data item 50, to improve the accurate reporting of Performance Status (in adults aged 19 years and above) at the start of regimen.

- **CHEMO-RADIATION**

- *PROGRAMME AND REGIMEN*

Removed to reduce burden; data can be derived by linking with other PHE data sets.

- **NUMBER OF CYCLES PLANNED**

- *PROGRAMME AND REGIMEN*

Removed as no longer required for the accurate recording of treatment data.

- **PERFORMANCE STATUS AT START OF CYCLE**

- *CYCLE*

Replaced with data item 51, to improve the accurate reporting of Performance Status (in adults aged 19 years and above) at the start of cycle.

- **OPCS PROCUREMENT CODE**

- *CYCLE*

Removed as no longer required for the accurate recording of treatment data.

- **OPCS DELIVERY CODE**

- *DRUG DETAILS*

Removed as no longer required for the accurate recording of treatment data.

- **DATE OF FINAL TREATMENT**

- *OUTCOME*

Removed as no longer required for the accurate recording of treatment data.

- **REGIMEN MODIFICATION – TIME DELAY**

- *OUTCOME*

Removed as no longer required for the accurate recording of treatment data.

- **REGIMEN MODIFICATION - STOPPED EARLY**

- *OUTCOME*

Removed as no longer required for the accurate recording of treatment data.

- **REGIMEN OUTCOME SUMMARY**

- *OUTCOME*

Replaced with 3 new data items to improve the outcome reporting of curative treatments:

- *REGIMEN OUTCOME SUMMARY - CURATIVE (COMPLETED AS PLANNED)*
- *REGIMEN OUTCOME SUMMARY - CURATIVE (NOT COMPLETED AS PLANNED) REASON*
- *OTHER - REGIMEN OUTCOME SUMMARY - CURATIVE (NOT COMPLETED AS PLANNED) REASON*

- **DATE OF DEATH**

- *OUTCOME*

Removed to reduce burden, data can be derived by linking with other PHE data sets.

Change of Scope

Submission of data in 'Extensible Markup Language' (XML) format is now out of scope of this information standard, due to the additional financial cost and burden of implementation. Please refer to the technical guide document for more information about the permitted values and formats for SACT v3.0, including the upload procedure.