



Llywodraeth Cymru  
Welsh Government

## WELSH INFORMATION STANDARDS BOARD

	<b>DSC Notice:</b>	DSCN 2020/31
	<b>Date of Issue:</b>	10 <sup>th</sup> December 2020
<b>Ministerial / Official Letter:</b> N/A	<b>Subject:</b> National Cancer Data Standards for Wales – Systemic Anti-Cancer Therapy (SACT)	
<b>Sponsor:</b> Cancer Implementation Group (CIG) Welsh Government		
<b>Implementation Date:</b> With immediate effect (or as soon as practicable following necessary updates to ChemoCare). <sup>1</sup>		
<b>DATA STANDARDS CHANGE NOTICE</b>		
<p>A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.</p> <p>This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 19<sup>th</sup> November 2020</p> <p><b>WISB Reference:</b> ISRN 2020 / 033</p>		
<b>Summary:</b> To introduce a new standard for cancer minimum reporting requirements for Systemic Anti-Cancer Therapy (SACT).		
<b>Data sets / returns affected:</b> N/A		
<p>Please address enquiries about this Data Standards Change Notice to the Data Standards Team in NHS Wales Informatics Service</p> <p>E-mail: <a href="mailto:data.standards@wales.nhs.uk">data.standards@wales.nhs.uk</a> / Tel: 02920502539</p>		
<p>The Welsh Information Standards Board is responsible for appraising information standards. Submission documents and WISB Outcomes relating to the approval of this standard can be found at:</p> <p><a href="http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&amp;pid=24632">http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&amp;pid=24632</a></p>		

<sup>1</sup> Timelines and processes for implementation will be progressed through the All Wales SACT Group.

## DATA STANDARDS CHANGE NOTICE

### Introduction

The original All Wales Cancer Minimum Reporting Requirements were mandated via Data Standards Change Notices (DSCNs) in 2011 for Core and Site Specific (<http://nww.nwisinformationstandards.wales.nhs.uk/empty-5>)

A revision of the existing all Wales Core Cancer Minimum Reporting Requirements together with the development of new Site/Patient Group Specific Cancer Minimum Reporting Requirements is necessary to ensure Wales has effective, efficient and timely world-class healthcare information to provide intelligence and the insight to drive healthcare service improvements.

A revised standard for Core was mandated through National Cancer Data Standards for Wales – Core (DSCN 2019/09) and a number of site and patient group specific standards have also been published (see <http://nww.nwisinformationstandards.wales.nhs.uk/dscns-2020>).

This Notice encompasses the cancer minimum reporting requirements for Systemic Anti-Cancer Therapy (SACT). As this is an independent data set which is based on NHS England Systemic Anti-Cancer Therapy (SACT) Data Set V 3.0.2, unlike other National Cancer Data Standards for Wales there is no dependency with National Cancer Data Standards for Wales – Core (DSCN 2019/09).

### Description of Change

This Standard covers the data items for Systemic Anti-Cancer Therapy (SACT), listed in NHS England Systemic Anti-Cancer Therapy (SACT) Data Set V 3.0.2, and additional items to reflect NHS Wales reporting.

Typically, within the DSCN we use a combination of 'strike through' and highlighted text to denote changes to the existing standard, however given that there have been a number of iterations of the COSD in England since the publication of the All Wales Cancer Minimum Reporting Requirements in Wales, for usability this practice has not been followed in this document.

## Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.10 of the NHS Wales Data Dictionary.

## Actions Required

Actions for the NHS Wales Informatics Service:

- To apply this Standard with immediate effect (or as soon as practicable following necessary updates to ChemoCare).
- Continue to make routine extracts available to the Welsh Cancer Intelligence and Surveillance Unit (WCISU) for the purpose of cancer registration via existing means.

Actions for Health Boards/Trusts:

Health boards are expected to continue with '**business as usual**' namely, to collect and report data using existing national systems, i.e. CaNISC, ChemoCare, PMS, WPAS, Cancer Tracking Module (Tracker 7) for the following:

- National Cancer Audits for Wales - a Tier 1 Welsh Government requirement
- Collection and reporting to the existing standards for cancer, the All Wales Core and Site-specific minimum reporting requirements (see <http://howis.wales.nhs.uk/sites3/page.cfm?orgid=769&pid=19419>)
- Collection and reporting of data required for Cancer Waiting Times and Single Cancer Pathway as per DSCNs issued.

From 2021 treatment providers will aim to supply treatment details, where possible, of the SACT data items held within their Chemocare system, until such time that a new e-prescribing solution for Wales is in use and will be able to collect and report the SACT data standard in full. Minimal setting changes with the current ChemoCare systems may be required to collect and report data as set out in this Standard. Timelines and processes for implementation of this data standard will be progressed through the All Wales SACT Group.

In conjunction with the above points for Health Boards/Trusts, it is also important to note that:

Interim changes are currently in development for WPAS and Cancer Tracking Module (Tracker 7) to support the single cancer pathway data collection.

That data continues to be entered into the CWT fields within CaNISC, as many standard reports rely on the completion of those data items in report logic. Such reports continue to be used for many reporting purposes including national audit submissions.

# SPECIFICATION

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## Information Specification

The data items required for National Cancer Data Standards for Wales – Systemic Anti-Cancer Therapy (SACT) and their equivalent labels in SACT V3.0.2, where there is an equivalent, are listed below.

Where the specification cites **NHS Wales Data Dictionary**, please refer to the Dictionary for the relevant guidance i.e. definition, format or code list.

For consistency, all dates listed in the Specification are standardised as ccyyymmdd.

Where *D* is denoted in Status, this indicates that the information should be derived from another data item. This typically occurs with data items that are simply text representations of their code counterparts. Other Status codes are *M* (Mandatory), *R* (Required) – the data item should be recorded where applicable and *O* (Optional).

## National Cancer Data Standards – Systemic Anti-Cancer Therapy (SACT)

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	SACT
<b>DEMOGRAPHICS AND CONSULTANT. To carry details for the Demographics and Consultant. May be up to one occurrence per submission</b>						
NHS Number	NHS Wales Data Dictionary (NHS Number)	NHS Wales Data Dictionary	N/A	N/A	M	NHS Number (1)
Local Patient Identifier	NHS Wales Data Dictionary (Local Patient Identifier)	NHS Wales Data Dictionary	N/A	N/A	M	Local Patient Identifier (44)
NHS Number Status Indicator	NHS Wales Data Dictionary (NHS Number Status Indicator)	Code List	NHS Wales Data Dictionary	NHS Wales Data Dictionary	M	NHS Number Status Indicator Code (43)
Person Family Name - Surname	The patients surname used to describe family, clan or marital association	max an35	N/A	N/A	R	Person Family Name (45)
Person Given Name - Forename	The persons forename(s) or given name(s)	max an35	N/A	N/A	R	Person Given Name (46)
Date Of Birth/Birth Date	NHS Wales Data Dictionary (Birth Date)	ccyymmdd	N/A	N/A	M	Date of Birth (2)
Sex (At Birth)	NHS Wales Data Dictionary (Sex)	Code List	F	Female	R	N/A
			I	Indeterminate		
			M	Male		
			Z	Not disclosed or Unknown (e.g. for unborn baby)		
Person Stated Gender Code (Gender Identity)	NHS Wales Data Dictionary (Gender)	Code List	F	Female	R	Person Stated Gender Code (47)
			M	Male		
			N	Non-Binary		
			Z	Not disclosed or Unknown (e.g. for unborn baby)		

Patient Postcode	NHS Wales Data Dictionary (Postcode of Usual Address)  At admission, attendance or diagnosis	NHS Wales Data Dictionary	N/A	N/A	M	Patient Postcode (5)
Consultant GMC Code	NHS Wales Data Dictionary (Consultant Code)  Code of consultant who initiated SACT programme	NHS Wales Data Dictionary	N/A	N/A	R	Consultant GMC Code (7)
Consultant Specialty Code	NHS Wales Data Dictionary (Main Specialty (Consultant))  Specialty code of consultant who initiated SACT programme  Main specialities relevant to SACT are 370 Medical Oncology, 800 Clinical Oncology, 823 Haematology and 420 Paediatrics	NHS Wales Data Dictionary	N/A	N/A	R	Consultant Specialty Code (8)
Organisation Identifier (Code Of Provider)	The organisation identifier of the Organisation acting as a Health Care Provider.	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	M	Organisation Identifier (Code Of Provider) (9)
<b>CLINICAL STATUS. To carry details for Clinical Status. May be up to one occurrence per submission.</b>						
Primary Diagnosis	Primary diagnosis at time of decision to treat. The primary diagnosis is normally agreed at the MDT meeting where the patient is discussed  For the Systemic Anti-Cancer Therapy Data Set, this is the Primary Diagnosis at the start of	min an4 max an6	N/A	N/A	M	Primary Diagnosis (10)

	the Systemic Anti-Cancer Therapy.					
Morphology ICD-O	<p>Morphology ICD-O at time of decision to treat.</p> <p>For the Systemic Anti-Cancer Therapy Data set this is the Morphology ICD-O at the start of the Systematic Anti-Cancer Therapy, this is a requirement for Haematology</p> <p>For linkage purposes Primary Diagnosis and/or Morphology ICD-O are required.</p>	min an5 max an7	N/A	N/A	M	Morphology ICD-O (11)
Diagnosis Code (SNOMED CT)	<p>DIAGNOSIS CODE (SNOMED) is the SNOMED concept ID which is used to identify the clinical diagnosis given to the patient.</p>	min n6 max n18	N/A	N/A	O	Diagnosis Code (SNOMED CT) (48)
Organisation Site Identifier (Of Diagnosis)	<p>NHS Wales Data Dictionary</p> <p>The organisation site where the patient diagnosis took place</p>	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	M	N/A
<b>PROGRAMME AND REGIMEN. To carry details for the Programme and Regimen. May be up to one occurrence per submission</b>						
<b>Start of repeating item - INTENT OF TREATMENT. Multiple occurrences of this item are permitted</b>						

Intent Of Treatment	The intention of the SACT regimen provided during a treatment Spell.  <b>Note:</b> The adjacent codes differ to those in SACT V3.0.2 in order to provide the specific reporting requirements within Wales	Code List	01	Curative - to give the best possible chance of being cured	R	Intent Of Treatment (15)
			02	Palliative/Disease Control - the aim is not to cure but to control or shrink the disease. The aim is to improve both quality of life and survival		
			03	Adjuvant - therapy given after surgery to reduce the risk of the cancer coming back		
			04	Neo-Adjuvant - therapy given before surgery/radiotherapy to shrink the cancer, allow radical treatment and reduce the risk of the cancer coming back		
			05	To obtain or maintain remission (for Haematology Only)		
			99	Not Known		
<b>End of repeating item - INTENT OF TREATMENT</b>						
Priority	Record the priority of the treatment in order to measure treatment targets as part of optimal pathways	Code List	1	Emergency/Priority 1 - emergency (within 48 hours)	R	N/A
			2	Urgent/Priority 2 - within 14 days (for Curative, Palliative/Disease Control, Haematology)		



				remission and Neoadjuvant intent)		
			3	Routine/Priority 3 - within 21 days (for adjuvant intent)		
Regimen	The acronym derived from the drugs used in the Anti-Cancer Drug Regimen used to identify the drugs used in the regimen	max an150	N/A	N/A	M	Regimen (16)
Height At Start Of Regimen	Height in metres at start of SACT regimen	max n1. max n2	N/A	N/A	R	Height At Start Of Regimen (17)
Weight At Start Of Regimen	Weight in kilogrammes at start of SACT regimen	max n3.max n3	N/A	N/A	R	Weight At Start Of Regimen (18)
Performance Status At Start Of Regimen - Adult	A World Health Organisation classification indicating a person's status relating to activity / disability  This is to be used for all patients aged 19yrs and above	Code List	0	Able to carry out all normal activity without restriction	R	Performance Status At Start Of Regimen - Adult (50)
			1	Restricted in strenuous activity but ambulatory and able to carry out light work		
			2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours		
			3	Symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden		

			4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair		
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	Code List	Y1	Yes - Alternate Regimen Chosen	R	Co-Morbidity Adjustment (20)
			Y2	Yes - Dose Adjustment to First Choice Regimen		
			Y3	Yes - Alternate Regimen Chosen and Dose Adjustment Made		
			N	No		
Date Decision To Treat	This is the date the patient agrees with the clinician to have treatment	ccymmdd	N/A	N/A	M	Date Decision To Treat (21)
Start Date Of Regimen	This is the first administration date of the first cycle of a regimen	ccymmdd	N/A	N/A	M	Start Date Of Regimen (22)
Clinical Trial	To enable the recording of when a patient is currently in an active Systemic Anti Cancer Therapy trial	Code List	01	Patient is taking part in a SACT clinical trial	R	Clinical Trial (23)
			02	Patient is not taking part in a SACT clinical trial		
			99	Not Known		
<b>CYCLE. To carry details for the drug Cycle. May be multiple occurrences per submission.</b>						
Cycle Number	Cycles numbered sequentially within each regimen  Refer to the user guide for additional cycle information	max n3	N/A	N/A	R	Cycle Number (26)
Start Date Of Cycle	Date of first drug administration in each cycle	ccymmdd	N/A	N/A	M	Start Date Of Cycle (27)

Weight At Start Of Cycle	Weight in kilogrammes at start of the cycle	max n3.max n3	N/A	N/A	R	Weight At Start Of Cycle (28)
Performance Status At Start Of Cycle - Adult	A World Health Organisation classification indicating a person's status relating to activity / disability  This is to be used for all patients aged 19yrs and above	Code List	0	Able to carry out all normal activity without restriction	R	Performance Status At Start Of Cycle - Adult (51)
			1	Restricted in strenuous activity but ambulatory and able to carry out light work		
			2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours		
			3	Symptomatic and in a chair or in bed for greater than 50% of the day but not bedridden		
			4	Completely disabled. Cannot carry on any self care. Totally confined to bed or chair		
<b>DRUG DETAILS. To carry the drug Details for the patients treatment. May be multiple occurrences per submission</b>						
Drug Name	The name is taken from the British National Formulary  Refer to the user guide for additional drug detail information	max an55			M	Drug Name (31)

DM+D	This is the unique ID from the dm+d database, based around the drug name/manufacture.	min n6 max n18			O	DM+D (52)
Actual Dose Per Administration	Dose in mg or other applicable unit for each administration in a SACT cycle.	max n8			R	Actual Dose Per Administration (32)
Administration Measurement Per Actual Dose	Units of measurements used for each administration in a SACT cycle.	an2	01	mg (Milligram)	R	Administration Measurement Per Actual Dose (53)
			02	mcg (Microgram)		
			03	g (Gram)		
			04	Units		
			05	Cells		
			06	x10 <sup>6</sup> PFU		
			07	x10 <sup>8</sup> PFU		
			99	Not Known		
Other - Administration Measurement Per Actual Dose	Record other 'unit of measurement' not available within [administration measurement per actual dose] field, if option 98 is selected	Max an15			R	Other - Administration Measurement Per Actual Dose (54)
Unit Of Measurement (SNOMED CT DM+D)	The SNOMED concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the unit of measurement	min n6 max n18			O	Unit Of Measurement (SNOMED CT DM+D) (55)

SACT Administration Route	The prescribed method of delivery for each administration in a SACT cycle	an2	01 02 03 04 05 06 07 08 09 11 12 13 14 98	Intravenous Oral Intrathecal Intramuscular Subcutaneous Intraarterial Intraperitoneal Other intracavity Intracavernous Intravesical (Intra-Vesicular) Cutaneous (Topical) Intradermal Intratour Intralesional Other	R	SACT Administration Route (33)
Route Of Administration (SNOMED CT DM+D)	The SNOMED concept ID from the NHS Dictionary of Medicines and Devices which is used to identify the route of administration	min n6 max n18	N/A	N/A	O	Route Of Administration (SNOMED CT DM+D) (56)
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	ccyymmdd	N/A	N/A	M	Administration Date (34)
Organisation Identifier Of SACT Administration	Organisation Identifier of the organisation for each administration in a SACT cycle	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	R	Organisation Identifier Of SACT Administration (35)
<b>OUTCOME. To carry the Outcome Details applicable to the patients treatment. May be up to one occurrence per submission.</b>						

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	Code List	Y	Yes	R	Regimen Modification - Dose Reduction (38)
			N	No		
Regimen Outcome Summary - Curative (Completed As Planned)	An indicator of whether the curative treatment was completed as planned  <i>Note: Only for completion where Intent of Treatment is recorded as Curative</i>	Code List	Y	Yes	R	Regimen Outcome Summary - Curative (Completed As Planned) (57)
			N	No		
Regimen Outcome Summary - Curative (Completed As Planned - Deviation In Timescale)	Did the completed plan deviate from original treatment timescales?	Code List	Y	Yes	R	N/A
			N	No		
Regimen Outcome Summary - Curative (Completed As Planned - Reasons For Delay)	Specify the reason for the deviation to the treatment timescales  <b>Note:</b> Only for completion when <i>Regimen Outcome Summary - Curative (Completed As Planned - Deviation In Timescale)</i> is recorded as Yes	Code List	01	Patient Related Reasons/Factors	R	N/A
			02	Service Related Reasons/Factors		
<b>Start of repeating item - REGIMEN OUTCOME SUMMARY - CURATIVE (NOT COMPLETED AS PLANNED). Multiple occurrences of this item are permitted</b>						
Regimen Outcome Summary - Curative (Not Completed As Planned) Reason	To record the reason why the curative treatment was not completed as planned  <b>Note:</b> Only for completion when <i>Regimen Outcome Summary -</i>	Code List	1	Progressive/recurrent cancer	R	Regimen Outcome Summary - Curative (Not Completed As Planned) Reason (58)
			2	Toxicity		
			3	Death		
			4	Patient choice		

	<i>Curative (Completed As Planned)</i> is recorded as <i>No</i>		5	Other		
<b>End of repeating item - REGIMEN OUTCOME SUMMARY - CURATIVE (NOT COMPLETED AS PLANNED)</b>						
Other - Regimen Outcome Summary - Curative (Not Completed As Planned) Reason	Record other reasons why the curative treatment was not completed as planned  <b>Note:</b> Only for completion when <i>Regimen Outcome Summary - Curative (Not Completed As Planned) Reason</i> is recorded as <i>Other</i>	max an55	N/A	N/A	R	Other - Regimen Outcome Summary - Curative (Not Completed As Planned) Reason (59)
Regimen Outcome Summary - Non Curative	An indicator of whether the patient benefited from the non-curative treatment  <b>Note:</b> Only for completion where <i>Intent of Treatment</i> is recorded as <i>Palliative/Disease Control</i>	Code List	Y	Yes	R	Regimen Outcome Summary - Non Curative (60)
			N	No		
Regimen Outcome Summary - Toxicity	An indicator of whether Toxicity was a deciding factor in modifying the treatment regimen	Code List	Y	Yes	R	Regimen Outcome Summary - Toxicity (61)
			N	No		
<b>Start of repeating item - REGIMEN OUTCOME SUMMARY - TOXICITIES. Multiple occurrences of this item are permitted</b>						
Regimen Outcome Summary - Toxicities	Specify the toxicities that led to the modification in the treatment regimen	Code List	01	Allergic Reaction	R	N/A
			02	Autoimmunity		
			03	Bone Marrow Suppression		
			04	Cardiotoxicity		
			05	Death		
			06	Diarrhoea		
			07	Endocrinopathy		
			08	Extravasation		

			09	Fatigue and/or Performance Status		
			10	Haemorrhagic Cystitis		
			11	Hepatotoxicity		
			12	Infection		
			13	Infusion Related Reactions		
			14	Mucositis		
			15	Myalgia		
			16	Nausea & Vomiting		
			17	Neurotoxicity		
			18	Ototoxicity		
			19	Pulmonary		
			20	Nephrotoxicity		
			21	Sepsis		
			22	Skin Reactions		
			23	Vascular		
			98	Other		

**End of repeating item - REGIMEN OUTCOME SUMMARY - TOXICITIES**

Regimen Outcome Summary - Other Toxicities	Record other toxicities that led to the modification in the treatment regimen  <b>Note:</b> Only for completion when <i>Regimen Outcome Summary - Toxicities</i> is recorded as <i>Other</i>	max an55	N/A	N/A	R	N/A
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