



## WELSH INFORMATION STANDARDS BOARD

<b>DSC Notice:</b>	DSCN 2020/24
<b>Date of Issue:</b>	5 <sup>th</sup> November 2020

<p><b>Ministerial / Official Letter:</b> N/A</p>	<p><b>Subject:</b> National Cancer Data Standards for Wales – Site Specific - Sarcoma<sup>1</sup></p> <p><sup>1</sup>(For the purposes of COSD v9 reference, includes Pathology v4)</p>
<p><b>Sponsor:</b> Cancer Implementation Group (CIG) Welsh Government</p>	
<p><b>Implementation Date:</b></p> <p>The Cancer Informatics Solution (CIS) MUST comply with this Standard with immediate effect.</p> <p>Services/data providers, however, MUST operate to <b>'business as usual'</b> in terms of the data being collected and reported (see section <a href="#">Actions Required</a> in this Notice)</p>	

### DATA STANDARDS CHANGE NOTICE

A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.

This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 22<sup>nd</sup> October 2020

**WISB Reference:** ISRN 2020 / 030

**Summary:**

To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Sarcoma.

Whilst this introduces a change to an existing information standard, the immediate use of this mandate will be used as a framework for the development of the CIS, therefore services/data providers should continue with **'business as usual'** in terms of the data being collected and reported (see section [Actions Required](#) in this Notice).

**Data sets / returns affected:**

N/A

Please address enquiries about this Data Standards Change Notice to the Data Standards Team in NHS Wales Informatics Service

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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:

<http://howis.wales.nhs.uk/sites3/page.cfm?orgid=742&pid=24632>

## 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-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) (<http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20191210-DSCN%202019%2009-National%20Cancer%20Data%20Standards%20for%20Wales%20-%20Core-v1-0.pdf>). **Core data items should be collected for all cancers.**

This Notice encompasses the site-specific cancer minimum reporting requirements for Sarcoma. This should be used in conjunction with National Cancer Data Standards for Wales – Core (DSCN 2019/09).

### Description of Change

This Standard covers the data items for Sarcoma, listed in NHS England Cancer Outcome and Services Data set (COSD) V9.0 (which includes Pathology V4.0) for comparability, and additional items to reflect NHS Wales reporting.

Whilst this introduces a change to an existing information standard, the immediate use of this mandate will be used as a framework for the development of the CIS, therefore services/data providers should continue with **'business as usual'** in terms of the data being collected and reported (see section [Actions Required](#) in this Notice).

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.

Given that the immediate use of this mandate will be as a framework for the development of the CIS only, the changes introduced by this DSCN will not be published to the NHS Wales Data Dictionary until such time that it applies to a wider audience and fully replaces the existing Standard.

## Actions Required

Actions for the NHS Wales Informatics Service:

- To apply this Standard with immediate effect in the development of the CIS
- 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:

There are no actions for health boards/trusts with regards to the changes in this Standard presently. However, health boards are expected to continue with '**business as usual**' as it pertains to the existing Standard, namely to collect and report data using existing national systems, i.e. CaNISC, 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.

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 – Site Specific – Sarcoma and their equivalent labels in COSD V9.0, 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).

**Core data items should be collected for all cancers.** To reduce replication of information, Core data items have not been listed in this site-specific Standard and users should refer to National Cancer Data Standards for Wales – Core (DSCN 2019/09)(<http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20191210-DSCN%202019%2009-National%20Cancer%20Data%20Standards%20for%20Wales%20-%20Core-v1-0.pdf>) for a list of Core requirements. However, in some cases, the site-specific application of Core data items may differ e.g. a particular tumour site may require additional or fewer codes to those already published in Core, or perhaps have additional business rules as to how the Core data item should be coded. Where this occurs, the Core data item will be replicated in the site-specific Standard with the respective additional site-specific detail. These are flagged in the following table with an \* next to the data item name.

## National Cancer Data Standards – Sarcoma

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
<b>Diagnosis (One occurrence per core diagnosis)</b>						
Sarcoma Tumour Site (Bone)	<p>Location of the bone sarcoma within the body as defined by OPCS4 code. (This is more specific than ICD10/ICD03 Sites)</p> <p><b>Note:</b> Use Cranium (Z639) for instances of Sarcoma of the Skull</p> <p><b>Note:</b> The OPCS-4 site codes here are used in the context of providing a list of established reference codes already in use and not in the context in which they would typically occur i.e. in conjunction with OPCS-4 procedure codes.</p>	Code List	Z639	Cranium	R	Sarcoma Tumour Site (Bone) (SA11000)
			Z649	Face		
			Z659	Jaw		
			Z663	Cervical Spine		
			Z664	Thoracic Spine		
			Z665	Lumbar Spine		
			Z681	Clavicle		
			Z684	Glenoid		
			Z685	Scapula		
			Z699	Humerus		
			Z709	Radius		
			Z719	Ulna		
			Z724	Carpal		
			Z732	Metacarpal		
			Z733	Thumb		
			Z742	Finger		
			Z746	Sternum		
			Z751	Ileum		
			Z753	Ischium		
			Z754	Pubis		
Z755	Acetabulum					
Z756	Coccyx					
Z769	Femur					
Z779	Tibia					
Z786	Fibula					

			Z787	Patella		
			Z799	Tarsus		
			Z802	Metatarsus		
			Z803	Great Toe		
			Z804	Toe		
			Z928	Other Specified Region of Body		
			Z929	Unknown		
Sarcoma Tumour Subsite (Bone)	Sub-location of the bone sarcoma within the tumour site. This gives a more detailed location of the tumour and should be recorded by speciality centres treating the patient.	Code List	PR	Proximal	R	Sarcoma Tumour Subsite (Bone) (SA11010)
			DS	Distal		
			DP	Diaphyseal (Middle)		
			TO	Total		
			OO	Other		
			NK	Not Known		
Sarcoma Tumour Site (Soft Tissue)	Location of the soft tissue sarcoma within the body as defined by OPCS4 code. (This is more specific than ICD10/ICD03 sites)  <b>Note:</b> The OPCS-4 site codes here are used in the context of providing a list of established reference codes already in use and not in the context in which they would typically occur i.e. in conjunction with OPCS-4 procedure codes.	Code List	Z272	Stomach	R	Sarcoma Tumour Site (Soft Tissue) (SA11080)
			Z301	Liver		
			Z459	Uterus		
			Z533	Peritoneum		
			Z891	Shoulder		
			Z892	Upper Arm		
			Z893	Forearm		
			Z894	Hand		
			Z898	Specified Arm Region (to include wrist and elbow)		
			Z901	Buttock		
			Z903	Upper Leg (to include thigh)		
			Z904	Lower Leg (to include calf)		
			Z905	Foot		
			Z908	Specified leg region (to include groin, knee, ankle)		
			Z921	Head		

			Z923	Neck		
			Z924	Chest (to include Intrathoracic)		
			Z927	Trunk (to include upper and lower)		
			Z928	Other Specified Region of Body		
			Z929	Unknown		
Sarcoma Tumour Subsite (Soft Tissue)	Sub-location of the soft tissue sarcoma within the tumour site. This gives a more detailed location of the tumour and should be recorded by the specialist centre treating the patient	Code List	RP	Retroperitoneal (Subsite of Z53.3)	R	Sarcoma Tumour Subsite (Soft Tissue) (SA11090)
			IP	Intraperitoneal (subsite of Z53.3)		
			WR	Wrist (Subsite of Z89.8)		
			EB	Elbow (Subsite of Z89.8)		
			UT	Upper Trunk (Subsite of Z92.7)		
			LT	Lower Trunk (Subsite of Z92.7)		
			AD	Adductors (Subsite of Z90.3 & Z90.4)		
			AN	Anterior (subsite of Z90.3 & Z90.4)		
			PO	Posterior (Subsite of Z90.3 & Z90.4)		
			LA	Lateral (Subsite of Z90.3 & Z90.4)		
			NK	Not Known (No record or Test not carried out)		
			NA	Not Applicable		
Multifocal or Synchronous Tumour Indicator	An indicator of the presence of tumours at multiple sites arising synchronously/concurrently	Code List	Y	Yes	R	Multifocal or Synchronous Tumour Indicator (SA11025)
			N	No		



			9	Not known		
<b>Diagnosis - Rhabdomyosarcoma and Other Soft Tissue Sarcomas (One occurrence per core diagnosis)</b>						
IRS Post Surgical Group	IRS group defines the post-surgical disease status at diagnosis. This information should be available for the MDT discussion following treatment but will only apply to a small number of cases.  <b>Note:</b> Please refer to user guide for Code List (Text) definitions	Code List	1	Group 1	R	IRS Post Surgical Group (CT6350)
			2	Group 2		
			3	Group 3		
			4	Group 4		
IRS Post Surgical Group Date	The date on which the IRS Post Surgical Group was recorded	ccyymmdd	N/A	N/A	R	IRS Post Surgical Group Date (CT6750)
Rhabdomyosarcoma Site Prognosis Code	Grouping of anatomical sites which imply prognostic significance. This information should be available for the MDT discussion but will only apply to a small number of cases.  <b>Note:</b> Please refer to user guide for Code List (Text) definitions	Code List	F	Favourable Sites	R	Rhabdomyosarcoma Site Prognosis Code (CT6370)
			U	Unfavourable Sites		
<b>Diagnosis - Ewings (One occurrence per core diagnosis)</b>						
Tumour Volume at Diagnosis	Radiologically calculated estimate of tumour volume at diagnosis which has value in determining treatment.	Code List	L	Less than 200ml	M	Tumour Volume at Diagnosis (CT6450)
			M	200ml or greater		
<b>Treatment - Radiotherapy - Sarcoma. To carry additional radiotherapy cancer treatment details for Sarcoma (One occurrence per Core Treatment)</b>						
Proton Beam Therapy Referral Eligibility	Does the patient fulfil nationally set referral criteria for proton beam therapy?	Code List	Y	Yes, referral criteria fulfilled	R	N/A

			N	No, referral criteria not fulfilled		
Proton Beam Therapy Referral	<p>Has the patient fulfilling nationally set referral criteria for proton beam therapy been referred for PBT?</p> <p><b>Note:</b> This data item is only required where <i>Proton Beam Therapy Referral Eligibility</i> is recorded as <i>Yes, referral criteria fulfilled</i></p>	Code List	R	Referred for PBT	R	N/A
			NR	Not Referred for PBT		
			NK	Not Known/Not Recorded		
<b>Pathology (One occurrence per Pathology Report)</b>						
Grade of Differentiation (Pathological)*	<p>The definitive grade of the tumour based on the evidence from the pathological examination.</p> <p><b>Note:</b> In Core there are codes of G4 (Undifferentiated/anaplastic) and GX (Grade of differentiation is not appropriate or cannot be assessed). Those codes are not applicable within the Sarcoma site-specific standard.</p>	Code List	G1	Well differentiated (Low Grade)	R	Grade of Differentiation (Pathological) (pCR0860)
			G2	Moderately differentiated (Intermediate Grade)		
			G3	Poorly differentiated (High Grade)		
Residual Tumour Classification	<p>The absence or presence of residual tumour after treatment is reported by the symbol R (Residual). The R classification deals with tumour status after treatment - refer to UICC (International Union Against Cancer) TNM (Tumour, Node and Metastasis) Classifications of Malignant Tumours. It reflects the effects of therapy, influences further therapeutic procedures and is a strong predictor of prognosis.</p>	Code List	RX	Presence of residual tumour cannot be assessed	R	N/A
			R0	No residual tumour		
			R1	Microscopic residual tumour		

			R2	Macroscopic residual tumour		
<b>Pathology - Bone and Soft Tissue (One occurrence per Pathology Report)</b>						
Genetic Confirmation Indicator	Are there any cytogenetic or molecular genetic data confirming the histological diagnosis?	Code List	Y	Yes, confirmed	R	Genetic Confirmation Indicator (pSA11170)
			N	No, not confirmed		
			X	Test not done		
<b>Pathology - Bone (One occurrence per Pathology Report)</b>						
Extent of Local Spread (Bone)	FOR MEDULLARY TUMOURS ONLY Does the tumour breach the cortex? The extent of local spread will determine whether the tumour is intracompartmental or extracompartmental.	Code List	I	Intracompartmental	R	Extent of Local Spread (Bone) (pSA11130)
			E	Extracompartmental		
Tumour Necrosis	Approximate percentage of tumour necrosis in response to pre-operative therapy.	max n3 Range 0-100	N/A	N/A	R	Tumour Necrosis (pSA11140)
<b>Pathology - Soft Tissue (One occurrence per Pathology Report)</b>						
Tumour Depth	Record the deepest tissue compartment where the tumour is located	Code List	1	Intradermal/cutaneous	R	Tumour Depth (pSA11100)
			2	Subcutaneous		
			3	Fascial/subfascial		
			9	Not Known		
Mitotic Rate (Sarcoma)	Mitotic rate per 5mm squared. Also known as mitotic index and mitotic count. <b>Only applicable to GISTS.</b>	max n3	N/A	N/A	R	Mitotic Rate (Sarcoma) (pSA11220)
<b>Laboratory Results - Rhabdomyosarcoma and Other soft tissue sarcomas (One occurrence per submission)</b>						
Cytogenetics for Alveolar Rhabdomyosarcoma	Presence of a specific cytogenetic abnormality. This information should be available for	Code List	P	Fusion positive	M	Cytogenetics for Alveolar Rhabdomyosarcoma (CT6360)
			N	Fusion negative		

	the MDT discussion but will only apply to a small number of cases.		X	Non informative		
			9	Not known (Not available)		
<b>Laboratory Results - Ewings (One occurrence per submission)</b>						
Cytogenetics for Ewings Sarcoma	Cytogenetic analysis	Code List	11	t(11;22)	M	Cytogenetics for Ewings Sarcoma (CT6460)
			VT	Variant Translocation		
			NG	Negative		
			NA	Not Available		