

## WELSH INFORMATION STANDARDS BOARD

<b>DSC Notice:</b>	DSCN 2020 / 09
<b>Date of Issue:</b>	25 <sup>th</sup> June 2020

<p><b>Ministerial / Official Letter:</b> n/a</p>	<p><b>Subject:</b> National Cancer Data Standards for Wales – Site Specific - Head and Neck<sup>1</sup></p>
<p><b>Sponsor:</b> Cancer Implementation Group (CIG) Welsh Government</p>	<p><sup>1</sup>(For the purposes of COSD v9 reference, includes Pathology v4)</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 18<sup>th</sup> June 2020

**WISB Reference:** ISRN 2020 / 006

**Summary:**

To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Head and Neck.

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:**

- All Wales Head & Neck Cancer Minimum Reporting Requirements v6.0 including Core Reporting Items v5.0

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 Head and Neck. 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 Head and Neck, 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 the 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 - Head and Neck 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 – Head and Neck

Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
<b>Key Investigations. (Multiples can be added)</b>						
Date of Image Request	The date on which imaging is requested that contributes to pre-treatment staging	ccyymmdd	N/A	N/A	R	N/A
<b>Diagnosis. (One occurrence of this group)</b>						
Date Patient Informed of Diagnosis	The date the patient was informed whether malignant or downgrade.	ccyymmdd	N/A	N/A	R	N/A
Date GP Informed of Diagnosis	NHS Wales Data Dictionary	ccyymmdd	N/A	N/A	R	N/A
Date Referral Made to Smoking Cessation Service	The date the referral was made to the smoking cessation service	ccyymmdd	N/A	N/A	R	N/A
<b>Pre-Treatment Assessment. To carry pre-treatment assessment details for Head and Neck cancer. (May be up to one occurrence for this group)</b>						
Cancer Dental Assessment Date	The date of the first dental assessment by a dentally qualified practitioner which contributes to preparation for treatment.	ccyymmdd	N/A	N/A	R	Cancer Dental Assessment Date
Cancer Dental Extraction Required	Specify if the patient required pre-treatment dental extraction/s	Code List	Y	Yes	R	N/A
			N	No		
Date Cancer Dental Extraction Performed	The date that the pre-treatment dental extraction/s was performed (Only required if Yes recorded for data item 'Cancer Dental Extraction Required')	ccyymmdd	N/A	N/A	R	N/A
Care Contact Date (Dietitian Initial)	The date that the patient was first assessed by a Dietitian	ccyymmdd	N/A	N/A	R	Care Contact Date (Dietitian Initial)
Care Contact Date (Speech and Language Therapist (SLT) Initial)	The date that the patient was first assessed by a speech and language therapist	ccyymmdd	N/A	N/A	R	Care Contact Date (SLT Initial)

<b>Surgery. To carry Surgery details for Head and Neck cancer. (May be up to one occurrence of this group per Core - Surgery)</b>						
Surgical Access Type	Select the appropriate surgical access type used for the patients operation from the following types	Code List	1	Mandibulotomy	R	Surgical Access Type
			2	Lip split and Mandibulotomy		
			3	Weber Ferguson Approach		
			4	Drop through the Neck		
			8	Other (Specify)		
			9	Not Known/Not Recorded		
Other Surgical Access Type	If Other (Specify) is recorded for <i>Surgical Access Type</i> , specify what surgical access type was used	max an60	N/A	N/A	R	Other Surgical Access Type
<b>Pathology - General - Various sites. To carry pathology details for various head and neck cancer. (One occurrence per Path Report)</b>						
Date of Pathology Report	The date the pathology report was reported	ccyymmdd	N/A	N/A	R	N/A
Maximum Depth of Invasion	The maximum depth of invasion in mm. Record as 00 to indicate 'not applicable'. (NOTE: This is not applicable for nasopharynx, hypopharynx, nasal cavity or sinuses)	max n3	N/A	N/A	R	Maximum Depth of Invasion
Bone Invasion	Is there evidence of invasion into bone	Code List	1	Present	R	Bone Invasion
			2	Absent		
			3	Not assessed		
			4	Not applicable		
Cartilage Invasion	Is there evidence of invasion into cartilage	Code List	1	Present	R	Cartilage Invasion
			2	Absent		
			3	Not assessed		
			4	Not applicable		
Neck Dissection Laterality	Identify laterality of neck dissection, if performed	Code List	1	Left	R	Neck Dissection Laterality
			2	Right		
			3	Bilateral		
			4	Not performed		
			8	Not applicable		
Perineural Invasion	Is there evidence of perineural invasion	Code List	1	Present (Yes)	R	N/A
			2	Absent (No)		

Pathology - Salivary. To carry salivary pathology details for head and neck cancer. (One occurrence per Path Report)						
Macroscopic Extraglandular Extension	Macroscopic extension of tumour outside the capsule of the salivary gland	Code List	1	Present (Yes)	M	Macroscopic Extraglandular Extension
			2	Absent (No)		
Grade of Differentiation (Pathological) *	Grade of Differentiation (Pathological) is the definitive grade of the tumour based on the evidence from a pathological examination  <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 to Salivary tumours.	Code List	G1	Well differentiated	R	Grade of Differentiation (Pathological)
			G2	Moderately differentiated		
			G3	Poorly differentiated		
Pathology - General & Salivary. (One occurrence per Path Report)						
Positive Nodes Laterality	If nodes positive, specify laterality	Code List	1	Left	R	Positive Nodes Laterality
			2	Right		
			3	Bilateral		
			8	Not applicable		
Largest Metastasis Left Neck	If Neck dissected on Left side, the size in mm of the largest metastasis	max n3	N/A	N/A	R	Largest Metastasis Left Neck
Largest Metastasis Right Neck	If Neck dissected on Right side, the size in mm of the largest metastasis	max n3	N/A	N/A	R	Largest Metastasis Right Neck
Extracapsular Spread	Invasion of metastatic tumour outside the capsule of a lymph node	Code List	1	Present	R	Extracapsular Spread
			2	Absent		
			3	Not assessable		
Pathology - Human Papilloma Virus (HPV). (One occurrence per Path Report)						
p16 Testing Indicator	Indicate the result of p16 Immunohistochemistry	Code List	P	Positive	R	p16 Testing Indicator
			N	Negative		
			X	Not Performed/Not Known		
HPV-ISH Testing	Indicate the result of HPV-ISH testing (Human Papilloma Virus - In Situ Hybridisation)	Code List	P	Positive	R	HPV-ISH Testing
			N	Negative		
			X	Not Performed/Not Known		

<b>Post-Treatment Assessment. To carry post treatment assessment details for Head and Neck cancer. (Multiple occurrences for this group). COSD recommend information should be recorded 12 months post diagnosis as a minimum and annually thereafter, if possible</b>						
Clinical Status Assessment Date (Cancer)	The date on which a clinical assessment was performed	ccyymmdd	N/A	N/A	R	Clinical Status Assessment Date (Cancer)
Primary Tumour Status	The status of the primary tumour at this follow up contact	Code List	1	Residual primary tumour	R	Primary Tumour Status
			2	No evidence of primary tumour		
			3	Recurrent primary tumour		
			4	Not assessed		
			5	Uncertain		
Nodal Status	The status of the regional nodal metastases at this follow up contact	Code List	1	Residual regional nodal metastases	R	Nodal Status
			2	No evidence of regional nodal metastases		
			3	New regional nodal metastases		
			4	Not assessed		
			5	Uncertain		
Metastatic Status	The status of the distant metastases at this follow up contact	Code List	1	Residual distant metastases	R	Metastatic Status
			2	No evidence of metastases		
			3	New distant metastases		
			4	Not assessed		
			5	Uncertain		
Speech and Language Assessment Date	Record the date of contact where assessment swallowing occurs following completion of treatment. Whilst ideally data is entered at each contact after completion of treatment, key point of recording is at 6 months post cancer care plan agreed date	ccyymmdd	N/A	N/A	R	Speech and Language Assessment Date