

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020 / 10
Date of Issue:	25 th June 2020

Ministerial / Official Letter: n/a	Subject: National Cancer Data Standards for Wales – Site Specific - Thyroid ¹
Sponsor: Cancer Implementation Group (CIG) Welsh Government	¹ (For the purposes of COSD v9 reference, includes Pathology v4)
Implementation Date: The Cancer Informatics Solution (CIS) MUST comply with this Standard with immediate effect. Services/data providers, however, MUST operate to ' business as usual ' in terms of the data being collected and reported (see section Actions Required in this Notice)	
<div style="text-align: center;"> DATA STANDARDS CHANGE NOTICE </div> <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 18th June 2020</p> <p>WISB Reference: ISRN 2020 / 006</p>	
Summary: To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Thyroid. 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 Thyroid. 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 Thyroid, 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

Information Specification

The data items required for National Cancer Data Standards for Wales – Site Specific – Thyroid 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 – Thyroid

Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
For Differentiated & Medullary Thyroid Cancers (DTC & MTC). Key Investigations - Imaging. To carry additional imaging details for Thyroid patients						
Pre-Operative Ultrasound - U Score	Record the pre-operative U Score of the primary thyroid tumour before treatment	Code List	1	Normal - no nodules	R	N/A
			2	Benign - hyperechoic or isoechoic with a halo/cystic change with ring down artefact (colloid)/microcystic or spongiform appearance/peripheral egg-shell calcification/peripheral vascularity		
			3	Indeterminate - solid homogenous markedly hyperechoic nodule with halo (follicular lesions)/hypoechoic with equivocal echogenic foci or cystic change/mixed or central vascularity		
			4	Suspicious - solid hypoechoic (compared with thyroid)/solid very hypoechoic (compared with strap muscles)/hypoechoic with disrupted peripheral calcification/lobulated outline		
			5	Malignant - solid hypoechoic with a lobulated or irregular outline and microcalcification (papillary carcinoma)/solid hypoechoic with lobulated or irregular outline and globular calcification (medullary carcinoma)/intranodular vascularity/taller than wide axilly (AP>ML)/characteristic associated lymphadenopathy		
Pre-Operative Ultrasound Key Staging Reported	Record if the pre-operative staging ultrasound scan reports on key staging items:	Code List	Y	Yes	R	N/A

	(a) the size of the tumour (b) the lymph node status		N	No		
For Differentiated Thyroid Cancers (DTC). Pre- Operative Staging						
Diagnosed at Pre Op	Patients staged at pre-operative diagnosis	Code List	Y	Yes	R	N/A
			N	No		
Pre-operative Diagnostic Category - Cytology (FNA)	Select the appropriate pre-operative diagnostic category from FNA cytology	Code List	1	Thy1	R	N/A
			2	Thy2		
			3	Thy3a		
			4	Thy3f		
			5	Thy4		
			6	Thy5		
For Differentiated & Medullary Thyroid Cancers (DTC & MTC). Surgery. (One occurrence of this group per Core - Surgery)						
Calcium Supplements	For patients who have undergone total thyroidectomy, was calcium supplements prescribed	Code List	Y	Yes	R	N/A
			N	No		
For Differentiated & Medullary Thyroid Cancers (DTC & MTC). Post Surgical Complications						
Post Surgical Complications	Record if there were any associated post surgical complications. Possible multiple entries	Code List	0	No Post Surgical Complication	R	N/A
			2	Hypoparathyroidism		
			3	Recurrent Vocal Cord Palsy		
			7	Other Post Surgical Complication		
Other Post Surgical Complication	Record any other associated post surgical complication/s Note: Only provide this information if Code 7 - Other Post Surgical Complication was recorded for Data Item <i>Post Surgical Complications</i>	an100	N/A	N/A	R	N/A
For Differentiated & Medullary Thyroid Cancer (DTC & MTC). Post Surgical Assessment						

Post Operative Vocal Cord Functional Assessment Performed	Record if the patient had a post operative vocal cord functional assessment after receiving thyroid surgery	Code List	Y	Yes	R	N/A
			N	No		
Date Vocal Cord Functional Assessment Performed	Specify the date the functional vocal cord assessment was performed	ccyymmdd	N/A	N/A	R	N/A
Calcium/Vitamin D Supplementation Requirement (3 months Post Surgery)	Did the patient require Calcium/Vitamin D Supplements 3 months post surgery in order to maintain a normal serum calcium level	Code List	Y	Yes	R	N/A
			N	No		
For Differentiated Thyroid Cancers (DTC). Prognostic Score						
MACIS Prognostic Score	<p>3.1 (if aged less than or equal to 39 years) or $0.08 \times \text{age}$ (if aged greater than or equal to 40 years), + 0.3 x tumour size (in centimetres), +1 (if incompletely resected), +1 (if locally invasive), +3 (if distant metastases present). Twenty-year cause-specific survival rates for patients with:</p> <p>MACIS < 6: 99% MACIS 6-6.99: 89% MACIS 7-7.99: 56% MACIS 8+: 24%</p>	Code List	1	Low Risk (<6)	R	N/A
			2	Median Risk (6–7.99)		
			3	High Risk (8+)		
For Differentiated Thyroid Cancer (DTC). Subsequent Treatment						
Radioactive Iodine Therapy Given Following Surgery	For DTC, record if radioactive iodine therapy was given following surgery	Code List	Y	Yes	R	N/A
			N	No		
For Medullary Thyroid Cancer (MTC). Post Treatment assessment						
Tumour Marker Post operative Calcitonin Value	Record the post operative Calcitonin Absolute Value (ng/l)	max n2.max n1	N/A	N/A	R	N/A