

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020 / 13
Date of Issue:	25 th June 2020

Ministerial / Official Letter: N/A	Subject: National Cancer Data Standards for Wales – Site Specific - Lung 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)	

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 18th June 2020

WISB Reference: ISRN 2020 / 008

Summary:

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

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 Lung Cancer Minimum Reporting Requirements v4.0 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 Lung. 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 Lung, 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

Information Specification

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

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Identification of Patient						
Age at Date of Diagnosis	Record the patient age at diagnosis. Note: This is a derived data item from Date of Birth and Date of Diagnosis	an3	N/A	N/A	D	N/A
Diagnostic Procedures						
Transthoracic Echocardiogram Result	The Transthoracic Echocardiogram left ventricular ejection fraction result Note: This is required where <i>U20.1</i> is recorded for <i>Diagnostic Procedure (OPCS)</i> or <i>434158009</i> is recorded for <i>Diagnostic Procedure (SNOMED)</i>	max n3 % Range 0 - 100	N/A	N/A	M	Transthoracic Echocardiogram Result (LU10350)
Diffusion Capacity (DLCO or TLCO) Result	The diffusion capacity (DLCO) or transfer factor of the lungs for carbon monoxide (TLCO) result (% predicted) (0-200)	max n3 % predicted. Range 0 - 200	N/A	N/A	M	Diffusion Capacity (DLCO or TLCO) Result (LU10310)
FEV1 Absolute Value	The absolute value of the patients Forced Expiratory Volume in the first second in litres	max n1.max n2 Range 0.10 - 9.99	N/A	N/A	R	FEV1 Absolute Value (LU10050)
FEV1 Percentage	The Forced Expiratory Volume in the first second as a percentage of the predicted value	max n3 Integer. Range 1 to 200	N/A	N/A	R	FEV1 Percentage (LU10040)
Cardiopulmonary Test Type	Indicate which cardiopulmonary test was used	Code List	1	Incremental shuttle walk test (ISWT)	R	Cardiopulmonary Test Type (LU10420)
			2	Oxygen consumption (VO2)		

Cardiopulmonary Exercise Test Result (NLCA)	The Cardiopulmonary Exercise Test result	max n3 % predicted. Range 0 - 200	N/A	N/A	R	Cardiopulmonary Exercise Test Result (NLCA) (LU10370)
Bronchoscopy Performed Type	What type of Bronchoscopy was performed on the patient?	Code List	1	Flexible Bronchoscopy	M	Bronchoscopy Performed Type (LU10400)
			2	Rigid		
			3	Endobronchial Ultrasound (EBUS) - Diagnostic		
			4	Endobronchial Ultrasound (EBUS) - Staging		
			9	Not known		
Mediastinal Sampling Indicator	Record if the patient had a mediastinoscopy, mediastinotomy, open mediastinal sampling or other type of mediastinal biopsy (e.g., Endobronchial ultrasound or transbronchial needle aspiration biopsy).	Code List	Y	Yes	R	Mediastinal Sampling Indicator (LU10060)
			N	No		
			9	Not known		
Biomarkers (One occurrence of this group per Core)						
Epidermal Growth Factor Receptor Mutational Status	Select the recorded outcome for the Epidermal Growth Factor Receptor Mutational status.	Code List	07	Wild Type	R	Epidermal Growth Factor Receptor Mutational Status (LU10090)
			08	Sensitising/activating mutation(s) only		
			09	Resistance mutation (to 1st gen TKIs) - with or without other mutation		
			98	Not Applicable (Not Assessed)		
			99	Not Known (Failed Analysis)		
ALK Fusion Status	Select the recorded outcome for the Anaplastic Lymphoma Kinase (ALK) Gene Fusion Status	Code List	1	Positive	R	ALK Fusion Status (LU10500)
			2	Negative		
			3	Indeterminate/Test Failed		
			8	Not Applicable (Not Tested)		

			9	Not known		
ROS1 Fusion Status	Select the recorded outcome for the ROS 1 Gene Fusion Status	Code List	1	Positive	R	ROS1 Fusion Status (LU10510)
			2	Negative		
			3	Indeterminate/Test Failed		
			8	Not Applicable (Not Tested)		
			9	Not known		
PD-L1 Expression	Select the recorded outcome for the PD-L1 Expression percentage	Code List	1	Not Tested	R	PD-L1 Expression (LU10520)
			2	<1%		
			3	1%-50%		
			4	>50%		
			5	Indeterminate/Test Failed		
			9	Not Known		
PDL1 % Value	Specify the absolute % value of the PD-L1 expression	n3	N/A	N/A	R	N/A
Surgery (One occurrence per core surgery and other procedures)						
Regional Anaesthetic Technique	Record the regional anaesthetic technique used on the patient	Code List	1	Epidural	R	Regional Anaesthetic Technique (LU10390)
			2	Paravertebral Catheter		
			3	Other Technique		
			4	No regional anaesthesia		
			9	Not known		
Pathology (One occurrence per pathology report)						
Extent of Atelectasis	Extent of Atelectasis/obstructive pneumonitis	Code List	4	Extends to the hilar region, either involving part of the lung or the whole lung	R	Extent of Atelectasis (pLU10110)
			5	None/less than the other category		
Extent of Pleural Invasion	What is the extent of pleural invasion	Code List	1	No pleural invasion	R	

			2	Visceral pleural only		Extent of Pleural Invasion (pLU10120)
			3	Parietal pleura/chest wall		
Pericardial Invasion	Does the tumour invade the pericardium	Code List	Y	Yes	R	Pericardial Invasion (pLU10130)
			N	No		
			9	Not known (Cannot be assessed)		
Diaphragm Invasion	Does the tumour invade the diaphragm	Code List	Y	Yes	R	Diaphragm Invasion (pLU10140)
			N	No		
			9	Not known (Cannot be assessed)		
Invasion into Great Vessel	Does the tumour invade the great vessels (aorta, central pulmonary artery or vein)	Code List	Y	Yes	R	Invasion into Great Vessel (pLU10150)
			N	No		
			9	Not known (Cannot be assessed)		
Invasion into Heart	Does the tumour invade the Atrium or Heart	Code List	Y	Yes	R	Invasion into Heart (pLU10160)
			N	No		
			9	Not known (Cannot be assessed)		
Malignant Pleural Effusion	Is there evidence of malignant pleural effusion	Code List	Y	Yes	R	Malignant Pleural Effusion (pLU10170)
			N	No		
			9	Not known (Cannot be assessed)		
Invasion into Mediastinum	Does the tumour invade the mediastinum	Code List	Y	Yes	R	Invasion into Mediastinum (pLU10190)
			N	No		
			9	Not known (Cannot be assessed)		
Satellite Tumour Nodules Location	Record the most distant location of separate tumour nodules	Code List	1	Separate tumour nodules in same lobe	R	Satellite Tumour Nodules Location (pLU10180)

			2	Separate tumour nodules in a different ipsilateral lobe		
			3	Separate tumour nodules in a contralateral lobe		
			4	No separate tumour nodules		
			9	Not known		