

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020 / 11
Date of Issue:	25 th June 2020

Ministerial / Official Letter: N/A	Subject: National Cancer Data Standards for Wales – Site Specific - Colorectal 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 / 008</p>	
Summary: To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Colorectal. 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 Colorectal Cancer Minimum Reporting Requirements v9.0 including Core Reporting Items v5.0

Please address enquiries about this Data Standards Change Notice to the Data Standards Team in
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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 Colorectal. 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 Colorectal, 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 – Colorectal 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 – Colorectal

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Colorectal - Diagnosis. To carry diagnostic details for Colorectal cancer (One occurrence per core diagnosis group)						
Synchronous Tumour Indicator	<p>Record any synchronous tumours in the Colon as identified by the clinician at presentation.</p> <p>Synchronous tumours are defined as discrete tumours apparently not in continuity with other primary cancers originating in the same site or tissue.</p> <p>To establish the frequency of multiple cancers.</p> <p>More than one synchronous cancer may be recorded.</p>	Code List	01	Caecum	R	Synchronous Tumour Indicator (CO5400)
			02	Appendix		
			03	Ascending Colon		
			04	Hepatic Flexure		
			05	Transverse Colon		
			06	Splenic Flexure		
			07	Descending Colon		
			08	Sigmoid Colon		
			09	Rectosigmoid		
			10	Rectum		
Tumour Height Above Anal Verge	<p>Record the approximate height in centimetres of the lower limit of the tumour above anal verge as measured by rigid sigmoidoscopy only.</p> <p>Note: I. For rectal cancers only ii. Do not use 0 for Not Known, instead leave field blank</p>	max n2 Range 0-15	N/A	N/A	R	Tumour Height Above Anal Verge (CO5160)
Pre-habilitation Programme Status	Did the patient undergo a formal pre-habilitation programme	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		

Cardiopulmonary Test Type	Indicate which cardiopulmonary test was used Note: This is a COSD data item but in COSD relates to Lung only. It has been added here as it is a requirement in Wales for the Colorectal site-specific standard.	Code List	1	Incremental shuttle walk test (ISWT)	R	Cardiopulmonary Test Type (LU10420)
			2	Oxygen consumption (VO2)		
Cardiopulmonary Exercise Test Result	The Cardiopulmonary Exercise Test result Note: This is a COSD data item but in COSD relates to Lung only. It has been added here as it is a requirement in Wales for the Colorectal site-specific standard.	max n3 % predicted. Range 0 - 200	N/A	N/A	R	Cardiopulmonary Exercise Test Result (NLCA) (LU10370)
Cardiopulmonary Exercise Testing (CPEX) Anaerobic Threshold	Record the anaerobic threshold	max n2.max n1 Range 0-99	N/A	N/A	R	N/A
Mismatch Repair Proteins	An indication of the presence or absence of mismatch repair proteins in the cancer Note: Only required for completion if <i>Microsatellite Instability (MSI) / Mismatch Repair Analysis</i> is recorded for Core data item <i>Gene or Stratification Biomarker Analysed</i>	Code List	1	Deficient	R	N/A
			2	Proficient		
Colorectal - Clinical Nurse Specialist. To carry details of Clinical Nurse Specialist Type (Multiple occurrences as per Core - CNS & Risk Factor Group)						
Clinical Nurse Specialist Type	The type of clinical Nurse Specialist assigned to the patient during their treatment pathway	Code List	1	Clinical Nurse Specialist	R	Clinical Nurse Specialist Type (CO5180)
			2	Stoma Nurse Specialist		
			8	Other		
			9	Not Known		
Colorectal - Surgery. To carry additional surgery details for Colorectal cancer (One occurrence per core surgery group)						

Reason for No Surgical Treatment	The reason why surgical treatment was not carried out	Code List	1	Patient unfit due to a pre-diagnosed medical condition	R	N/A
			2	Patient refused treatment		
			3	Advanced disease		
			7	Other		
Reason for No Surgical Treatment - 'Other'	If <i>Other</i> is recorded for data item <i>Reason for No Surgical Treatment</i> , please specify the reason why surgical treatment was not carried out	max an100	N/A	N/A	R	N/A
Consultant Code - Surgical Treatment	The GMC code for the Consultant who was actually in overall charge of the patient's surgical treatment during the time the patient was in hospital undergoing surgery Note: Refer to NHS Wales Data Dictionary definition for <i>Consultant Code</i> for further information on the code's format	an8	N/A	N/A	R	N/A
Surgical Admission Type *	Record the mode of surgery performed Note: The codes <i>Scheduled/Expedited</i> and <i>Urgent</i> are not present in Core but have been added here as a site-specific requirement.	Code List	1	Elective	R	Surgical Admission Type (CR8500)
			2	Emergency		
			3	Scheduled/Expedited		
			4	Urgent		
			9	Not Known		
Surgical Access Type *	Approach to surgery (laparoscopic, thoracoscopic, open, robotic or converted). Record the access used to perform the main procedure. Recording the surgical access is standard clinical practice and should be obtained from the operational notes.	Code List	1	Open operation	R	Surgical Access Type (CR6310)
			3	Laparoscopic/Thoracoscopic with unplanned conversion to open surgery		

	Note: i. The code <i>Trans Anal (for TME excisions)</i> is not present in Core but has been added here as a site-specific requirement. Whilst the Core data item has additional codes, only the adjacent codes are applicable to the Colorectal site-specific standard. ii. Code 5 is applicable to rectal tumours only		4 5 Z	Laparoscopic/Thoracoscopic completed Trans Anal (For TME excisions) Not applicable		
Stoma	Specify the type of stoma created	Code List	1 2 3 4	Ileostomy temporary Ileostomy permanent Colostomy temporary Colostomy permanent	R	N/A
Surgical Complications	Any complications relevant to the surgical treatments that the patient has received (during primary treatment period) (Multiples can be chosen)	Code List	1 2 3 4 5 6 7	Leak Abscess Bleed Obstruction Stoma malfunction Readmission (within 14 days of surgical procedure) Other	R	N/A
Surgical Complications - 'Other'	If <i>Other</i> is recorded for data item <i>Surgical Complications</i> , please specify the surgical complications relevant to the surgical treatments that the patient has received (during primary treatment period)	max an100	N/A	N/A	R	N/A
Cancer Treatment Curability	The Surgeons opinion of the completeness of the excision based on clinical findings at the time of the operation which should not be revised in the light of subsequent histopathology reporting.	Code List	1 2	Curative Palliative	R	N/A

	Curative means no local tumour was visibly present after the surgical procedure. Palliative means that visible tumour was left behind after the surgical resection		3	Uncertain		
Immediate Post Operative Care	To determine immediate post operative care requirements for the patient	Code List	1	Standard Ward Care	R	N/A
			2	High Care Area		
			3	Level 2 HDU care		
			4	Level 3 ICU care		
Colorectal - Pathology. To carry details of pathology for colorectal cancer (May be up to one occurrence of this group per pathology report)						
Local Invasion Polypoid Tumours (Haggitt level)	The level of invasion into the stalk of the polyp For pT1 or ypT1 stage only	Code List	1	Haggitt Level 1 - carcinoma invading through muscularis mucosa into submucosa but limited to the head of the polyp	R	N/A
			2	Haggitt Level 2 - Carcinoma invading the level of the neck of the adenoma		
			3	Haggitt Level 3 - Carcinoma invading any part of the stalk		
			4	Haggitt Level 4 - Carcinoma invading into the submucosa of the bowel wall below the stalk of the polyp but above the muscularis propria		
			8	Haggitt Level - Not applicable/Not assessable		
Local Invasion Sessile Tumours (Kikuchi level)	The level of sub mucosal infiltration of the pathological T1 tumour Note: For pT1 or ypT1 Stage only	Code List	1	Kikuchi Level Sm1 - Invasion of the superficial one-third of the submucosa	R	N/A

			2	Kikuchi Level Sm2 - Invasion of the middle one-third of the submucosa		
			3	Kikuchi Level Sm3 - Invasion of the deep one-third of the submucosa		
			8	Kikuchi Level - Not applicable/Not assessable		
Status of Circumferential Excision Margin	Record if the edge of the tumour is 1 mm or less from the circumferential resection margin (ie, margin involved). Circumferential margin refers to the completeness of the surgeon's resection margin in the opinion of the histopathologist. In parts of the colon where it is completely surrounded by peritoneum, recording of the circumferential resection margin (CRM) is not appropriate	Code List	0	Margin Not Involved	R	Status of Circumferential Excision Margin (pCO5300)
			1	Margin Involved		
			9	Not Known		
Distance to Circumferential Margin	Record the distance from the outer margin of the tumour to the closest non peritonealised circumferential resection margin in mm. Note: For rectal cancer only	max n2.max n2	N/A	N/A	R	Distance to Circumferential Margin (pCO5210)
Plane of Surgical Excision	This is the quality of the surgical excision as seen by the pathologist. This grades the resection on its worst plane. Note: For rectal cancer only	Code List	1	Mesorectal fascia plane	R	Plane of Surgical Excision (pCO5260)
			2	Intramesorectal plane		
			3	Muscularis propria plane		
Response to Pre-Operative Therapy	If preoperative therapy was given what was the response. Note: A four tier system, similar to that described by Ryan et al. (Pathological	Code List	08	No viable cancer cells (TRS 0)	R	Response to Pre-Operative Therapy (pCO5290)
			09	Single cells or rare small groups of cancer cells (TRS 1)		

	response following long-course neoadjuvant chemoradiotherapy for locally advanced rectal cancer)		10	Residual cancer with evident tumour regression (TRS 2)		
			11	No evident tumour regression (TRS 3)		
			97	Not Applicable		
Positive Proximal or Distal Resection Margin	Record whether the proximal or distal resection margins were involved. If the minimal distance from the cut margin is less than or equal to 1 mm the margin is considered involved	Code List	0	Margins not involved	R	Positive Proximal or Distal Resection Margin (pCO5190)
			1	Margin involved		
			8	Not submitted by pathologist		
			9	Not Known		
Distance from Dentate Line	Record the distance of the tumour from the dentate line in mm measured on the gross specimen Note: For abdominoperineal excision specimens only.	mm (max n3.max n2)	N/A	N/A	R	Distance from Dentate Line (pCO5270)
Distance Beyond Muscularis Propria	Maximum distance of spread beyond muscularis propria in mm. If there is doubt about the sites of the muscularis propria estimate the distance as accurately as possible	mm (max n3.max n2)	N/A	N/A	R	Distance Beyond Muscularis Propria (pCO5280)
Tumour Regression Grade	Record the tumour regression grade. This is applicable to Rectal cancers only treated with pre-operative Radiotherapy Note: For rectal cancer only	Code List	1	Grade 1 - Complete regression, no viable tumour cells, fibrosis extending through bowel wall	R	N/A
			2	Grade 2 - Isolated single cell or small clusters of tumour cells scattered through fibrosis		
			3	Grade 3 - Fibrosis predominates, outgrowing residual tumour		

			4	Grade 4 - Residual tumour outgrows fibrosis		
			5	Grade 5 - Extensive residual tumour without fibrosis		
Grade of Differentiation (Pathological) *	Grade of Differentiation (Pathological) is the definitive grade of the tumour based on the evidence from a pathological examination Note: The Core data item has additional codes, however only the adjacent codes are applicable to the Colorectal site-specific standard	Code List	G1	Well differentiated	R	Grade of Differentiation (Pathological) (pCR0860)
			G3	Poorly differentiated		
Colorectal - Treatment. To carry details of certain treatments for colorectal cancer (May be up to one occurrence of this group per treatments given)						
Biological/Immunological Treatment Given	Record the specific Biological/Immunological treatment given	Code List	1	Cetuximab	R	N/A
			2	Bevacizumab		
			3	Pantimumab		
			7	Other		
Other Biological/Immunological Treatment given	If <i>Other</i> is recorded for data item <i>Biological/Immunological Treatment Given</i> , please specify the biological/immunological treatment given	max an50	N/A	N/A	R	N/A
Biomarkers (One occurrence of this group per Core)						
Dihydropyrimidine Dehydrogenase (DPD) Performed	Record if DPD test was performed	Code List	Y	Yes	R	N/A
			N	No		
Dihydropyrimidine Dehydrogenase (DPD) Status	To record the DPD Status for the patient, if performed	Code List	1	DPYP variant homozygous	R	N/A
			2	DPYP variant heterozygous		
			3	No variant detected		
			9	Not known		

Vascular Endothelial Growth Factor (VEGF) Status	Select the recorded outcome for the VEGF Mutational status.	Code List	07	Wild Type	R	N/A
			08	Sensitising/activating mutation(s) only		
			09	Resistance mutation - with or without other mutation		
			98	Not Applicable (Not Assessed)		
			99	Not Known (Failed Analysis)		
KRAS Status	Select the recorded outcome for the KRAS Mutational status.	Code List	07	Wild Type	R	N/A
			08	Sensitising/activating mutation(s) only		
			09	Resistance mutation - with or without other mutation		
			98	Not Applicable (Not Assessed)		
			99	Not Known (Failed Analysis)		
NRAS Status	Select the recorded outcome for the NRAS Mutational status.	Code List	07	Wild Type	R	N/A
			08	Sensitising/activating mutation(s) only		
			09	Resistance mutation - with or without other mutation		
			98	Not Applicable (Not Assessed)		
			99	Not Known (Failed Analysis)		
BRAF Status	Select the recorded outcome for the BRAF Mutational status.	Code List	07	Wild Type	R	N/A
			08	Sensitising/activating mutation(s) only		
			09	Resistance mutation - with or without other mutation		
			98	Not Applicable (Not Assessed)		
			99	Not Known (Failed Analysis)		