

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020 / 08
Date of Issue:	25 th June 2020

Ministerial / Official Letter: n/a	Subject: National Cancer Data Standards for Wales – Site Specific - Gynaecology ¹ ¹ (For the purposes of COSD v9 reference, includes Pathology v4)
Sponsor: Cancer Implementation Group (CIG) Welsh Government	
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 / 006

Summary:

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

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 Gynaecological Cancer Minimum Reporting Requirements v1.0 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 Gynaecology. 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 Gynaecology, 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 – Gynaecology 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 – Gynaecology

Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Surgery. (One occurrence per Core Surgery)						
Early onset (\leq 30 days post surgery) complications	The complication(s) which arise less than or equal to 30 days post surgery. Multiple responses are possible.	Code List	1	Blood loss \Rightarrow 1000 ml	R	N/A
			2	Wound infection		
			3	Superficial wound breakdown		
			4	Wound dehiscence (full thickness)		
			5	Anastomotic leak		
			6	Paralytic ileus		
			7	Vault Haematoma		
			8	Pelvic abscess		
			9	Bladder injury		
			10	Ureteric injury		
			11	Bowel injury		
			12	Deep vein thrombosis/pulmonary embolism		
			13	Myocardial infarct		
			14	Other: infection requiring treatment		
			15	Other: resulting in return to theatre		
			16	Other: resulting in an unscheduled stay on intensive care unit/HDU		
			97	Other: specify		
Other Early onset (< 30 days post surgery) complications	If <i>Other: Specify</i> is recorded for <i>Early onset (< 30 days post surgery) complications</i> , specify the complications that arose	max an60	N/A	N/A	N/A	N/A

	(Free Text field)					
Grade of early onset (\leq 30 days post surgery) complication(s)	The worse case grade of each complication which arises less than or equal to 30 days post surgery - Refer to the Clavien Dindo classification of surgical complications	Code List	1	Grade I	R	N/A
			2	Grade II		
			3	Grade IIIa		
			4	Grade IIIb		
			5	Grade IVa		
			6	Grade IVb		
			7	Grade V		
			9	Not Known/Not Recorded		
Surgeon Grade	Grade of senior surgeon present at operation Note: 'Colposcopist NOS' - Where the procedure is a colposcopy this may be a qualified colposcopist who is not a surgeon	Code List	S	Subspecialist Gynaecological Oncologist	R	Surgeon Grade
			C	Consultant Gynaecologist (not subspecialist)		
			N	Non training sub consultant grade		
			T	Trainee including subspecialty fellow and ST Trainee		
			G	General Surgeon/other surgical specialty		
			Z	Colposcopist NOS		
Residual Disease	The estimated maximal tumour diameter of residual disease (tumour) left after the surgery, as documented by the surgeon at the completion of the procedure, and would be captured by/at the MDT. Note: This data item would apply to ovarian, fallopian tube and peritoneal cancers managed surgically	Code List	1	0 cm	R	Residual Disease
			2	>0 and <1 cm		
			3	>= 1 cm		
Pathology. To carry pathology details for Gynae. (One occurrence per Path Report)						
Fallopian Tube Involvement	For endometrial and epithelial/ovarian cancers, is there microscopic involvement of fallopian tubes	Code List	1	Not involved	R	Fallopian Tube Involvement
			2	Right involved		
			3	Left involved		
			4	Both involved		
			X	Not assessable		
Ovarian Involvement		Code List	1	Not involved	R	Ovarian Involvement

	For endometrial and fallopian cancers, is there microscopic involvement of ovaries		2	Right involved		
			3	Left involved		
			4	Both involved		
			X	Not assessable		
Serosal Involvement	For endometrial, epithelial/ovarian and fallopian cancers, is there microscopic involvement of uterine serosa	Code List	I	Invasive carcinoma	R	Serosal Involvement
			B	Borderline changes (non-invasive implants)		
			N	Not Involved		
			X	Not assessable		
Omental Involvement	For endometrium, ovary, fallopian tube and primary peritoneal cancers, is there involvement of the omentum	Code List	1	Involved - deposit size not specified	R	Omental Involvement
			2	Involved - deposit(s) 20 mm or less		
			3	Involved - deposit(s) greater than 20 mm		
			4	Not Involved		
			X	Not assessable/Not sent		
Pathology - For Fallopian Tube, Ovarian Epithelial & Primary Peritoneal. (One occurrence per Path Report)						
Capsule Status	Capsule status of ovaries (record the most severe)	Code List	1	Intact	R	Capsule Status
			2	Disrupted		
			3	Involved		
			X	Not assessable		
Ovarian Surface Involvement	Is there involvement of the surface of either ovary	Code List	Y	Yes	R	Ovarian Surface Involvement
			N	No		
			X	Not assessable		
Peritoneal Cytology	Result of peritoneal cytology	Code List	1	Involved	R	Peritoneal Cytology
			2	Not involved		
			3	Equivocal		
			X	Not sent		
Peritoneal Involvement	Is there peritoneal involvement	Code List	I	Invasive carcinoma/invasive implants	R	Peritoneal Involvement
			B	Non-invasive borderline implants		
			N	No (Not involved)		
			X	Not assessable/Not sent		

Grade of Differentiation (Pathological) *	Grade of Differentiation (Pathological) is the definitive grade of the tumour based on the evidence from a pathological examination Note: In Core there is a code of GX (Grade of differentiation is not appropriate or cannot be assessed). That code is not applicable within the Gynaecology site-specific standard.	Code List	G1	Well differentiated	R	Grade of Differentiation (Pathological)
			G2	Moderately differentiated		
			G3	Poorly differentiated		
			G4	Undifferentiated/anaplastic		
Pathology - For Endometrial. (One occurrence per Path Report)						
Involvement of Cervical Stoma	Is there microscopic involvement of cervical stroma	Code List	Y	Yes (involved)	R	Involvement of Cervical Stoma
			N	No (Not involved)		
			X	Not Assessable		
Myometrial Invasion	Is there microscopic evidence of myometrial invasion	Code List	3	Greater than or equal to 50%	R	Myometrial Invasion
			4	None or less than 50%		
Parametrium Involvement	Is there microscopic involvement of parametrium	Code List	Y	Yes (Involved)	R	Parametrium Involvement
			N	No (Not involved)		
			X	Not assessable		
Peritoneal Washings	Were peritoneal washings submitted and if so were malignant cells seen	Code List	P	Positive	R	Peritoneal Washings
			N	Negative		
			X	Not sent/Not assessable		
Peritoneal Involvement	Is there peritoneal involvement for endometrial cancer	Code List	Y	Involved	R	Peritoneal Involvement (Endometrial)
			N	Not involved		
			X	Not assessable		
Site of Peritoneal Involvement	If there is peritoneal involvement, which site is involved	Code List	P	Pelvic	R	Site of Peritoneal Involvement
			A	Abdominal		
			X	Not assessable		
Pathology - For Cervical. (One occurrence per Path Report)						
CGIN Grade	Specify presence and grade of CGIN (cervical glandular intra-epithelial neoplasia)	Code List	1	Low	R	CGIN Grade
			2	High		
			3	Not present		
			X	Not assessable		
CIN Grade	Specify presence of grade of CIN (cervical intra-epithelial neoplasia)	Code List	1	Grade 1	R	CIN Grade
			2	Grade 2		

			3	Grade 3		
			4	Not present		
			X	Not assessable		
SMILE	Specify presence of SMILE (Stratified Mucin-Producing Intra-epithelial lesion)	Code List	1	Present	R	SMILE
			2	Absent		
			X	Not assessable		
Excision Margin (Pre Invasive)	Is there evidence of resection margin involvement by in/situ/pre-invasive disease (CIN/CGIN and SMILE)	Code List	Y	Yes	R	Excision Margin (Pre Invasive)
			N	No		
			X	Not assessable		
Paracervical or Parametrial Involvement	Is there evidence of paracervical and/or parametrial involvement	Code List	Y	Yes	R	Paracervical or Parametrial Involvement
			N	No		
			X	Not assessable		
Thickness Uninvolved Stroma	Minimum thickness of uninvolved cervical stroma in mm (minimum tumour free rim)	max n2. max n2	N/A	N/A	R	Thickness Uninvolved Stroma
Vaginal Involvement	Is there evidence of microscopic vaginal involvement	Code List	Y	Yes	R	Vaginal Involvement
			N	No		
			X	Not assessable		
Invasive Thickness	The thickness or depth of the invasive lesion in mm	max n2.max n2	N/A	N/A	R	Invasive Thickness
Pathology - For Nodes. (One occurrence per Path Report)						
Nodes Examined Number (Para-aortic)	The number of para-aortic nodes examined. Note: Not applicable for vulval cancers. Use 0 if nodes not sent	max n2	N/A	N/A	R	Nodes Examined Number (Para-aortic)
Nodes Positive Number (Para-aortic)	The number of para-aortic nodes reported as being positive for the presence of tumour metastases. Note: Not applicable for vulval cancers	max n2	N/A	N/A	R	Nodes Positive Number (Para-aortic)

Nodes Examined Number (Pelvic)	The number of pelvic nodes examined Note: Not applicable for vulval cancers. Use 0 if nodes not sent	max n2	N/A	N/A	R	Nodes Examined Number (Pelvic)
Nodes Positive Number (Pelvic)	The number of pelvic nodes reported as being positive for the presence of tumour metastases. Note: Not applicable for vulval cancers	max n2	N/A	N/A	R	Nodes Positive Number (Pelvic)
Nodes Examined Number (Inguino-Femoral)	The number of inguino-femoral nodes examined. Note: Only applicable to vulval cancers. Use 0 if nodes not sent	max n2	N/A	N/A	R	Nodes Examined Number (Inguino-Femoral)
Nodes Positive Number (Inguino-Femoral)	The number of inguino-femoral nodes reported as being positive for the presence of tumour metastases. Note: Only applicable to vulval cancers	max n2	N/A	N/A	R	Nodes Positive Number (Inguino-Femoral)
Extranodal Spread	Is there evidence of extranodal spread/extension	Code List	Y	Yes	R	Extranodal Spread
			N	No		
			X	Not assessable		
Staging						

Final FIGO Stage	The FIGO stage is generally confirmed at pathology review in MDT meetings following surgery for uterine and vulval malignancies and for ovarian malignancies undergoing primary surgery. For ovarian malignancies planned to undergo neo-adjuvant chemotherapy and for cases of cervical cancer (which is staged clinically), the final FIGO stage is determined at the time of review of clinical findings, imaging, cytology, and biopsy histology at the MDT meeting	max an7	N/A	N/A	M	Final FIGO Stage
Patient						
Oestrogen Receptor Status	The oestrogen receptor status of the patient at diagnosis (from specimen)	Code List	1	Positive	O	N/A
			2	Negative		
			9	Not Recorded		
Progesterone Receptor Status	The progesterone receptor status of the patient at diagnosis (from specimen)	Code List	1	Positive	O	N/A
			2	Negative		
			9	Not Recorded		