WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020/26
Date of Issue:	5th November 2020

Ministerial / Official Letter:
N/A

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)

Subject: National Cancer Data Standards for Wales – Site Specific – Urology[1]

[1](For the purposes of COSD v9 reference, includes Pathology v4)

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 22nd October 2020

WISB Reference: ISRN 2020 / 030

Summary:

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

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 E-mail: data.standards@wales.nhs.uk / Tel: 02920502539
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 Urology i.e.:

- Prostate
- Bladder
- Testicular
- Renal (Kidney)
- Penile
- pTa and Carcinoma in Situ (CIS) – all bladder pTa and Carcinoma in Situ (CIS) tumours are required to be recorded. A reporting output is also required. Clinically G3pTa and CIS tumours are high risk tumours. These behave very differently from G2pTa and G1pTa tumours and all categories require different treatments. pTa bladder tumours cover a very broad spectrum of disease and, unlike other cancers, cannot be clubbed together and should be coded according to international coding principles. It is also important to note that where an invasive tumour is diagnosed in a patient previously diagnosed with a non-invasive tumour a new disease should be recorded which will be subject to CWT rules. By doing this transformation times can be accurately reported.

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 Urology, 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 – Urology 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 ccyymmdd.

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.

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Prostate - Diagnostic Procedures To carry cancer diagnostic details for Prostate (One occurrence per core diagnostic procedure group)						
Prostate Biopsy Technique	Record the type of prostate biopsy technique performed before treatment. **Note:** Of the adjacent codes, *Template Biopsy* is not present in COSD. This has been added here to provide greater granularity.	Code List	10	TRUS guided biopsy (standard)	M	Prostate Biopsy Technique (UR15410)
			11	TRUS guided biopsy (targeted)		
			12	TRUS guided biopsy (targeted & standard)		
			13	Transperineal biopsy (systematic)		
			14	Transperineal biopsy (targeted)		
			15	Transperineal biopsy (targeted & systematic)		
			16	Template Biopsy		
			99	Not known		
Biopsy Anaesthetic	Record the type of anaesthetic used during the biopsy	Code List	1	Local	M	Biopsy Anaesthetic (UR15440)
			2	Sedation		
			3	General		
			9	Not known		
Prostate - Diagnosis To carry specific diagnosis details for Prostate (One occurrence per core diagnosis group)						
mpMRI Pre-Biopsy	Was a multiparametric mpMRI performed on the patient before the biopsy	Code List	Y	Yes	R	mpMRI Pre-Biopsy (UR15500)
			N	No		
			9	Not Known		
MRI/Fusion Biopsy	Was a MRI/Fusion biopsy performed on the patient	Code List	Y	Yes	R	MRI/Fusion Biopsy (UR15510)
			N	No		
			9	Not Known		

PSA (Diagnosis)	Prostate Specific Antigen blood level in ng/ml measured at time of diagnosis	maxn5.n1	N/A	N/A	R	PSA (Diagnosis) (UR15070)
Treatment - Prostate To carry additional cancer treatment details for Prostate (One occurrence per Core Treatment)						
Type of First Cancer Treatment*	This denotes the first specific treatment modality administered to a patient (Multiple responses possible) **Note:** Of the adjacent codes, *Watchful Waiting, Radical Prostatectomy, Transurethral Resection of Prostate (TURP), Bilateral Orchidectomy, Focal Therapy (any modality), Low Dose Rate Brachytherapy, High Dose Rate Brachytherapy, Continuous Androgen Deprivation Therapy, Intermittent Androgen Deprivation Therapy, Neoadjuvant Hormone Therapy, Adjuvant Hormone Therapy* and *Palliative Radiotherapy* are not present in Core. These have been added here to provide greater granularity. Whilst the Core data item has additional codes, only the adjacent codes are applicable to the Urology - Prostate site-specific standard.	Code List	43	Watchful Waiting	R	Cancer Treatment Modality (Registration) (CR2040)
			08	Active Monitoring (excluding non-specialist Palliative Care)		
			32	Radical Prostatectomy		
			33	Transurethral Resection of Prostate (TURP)		
			34	Bilateral Orchidectomy		
			12	Cryotherapy		
			11	High Intensity Focused Ultrasound (HIFU)		
			35	Focal Therapy (any modality)		
			05	Teletherapy (Beam Radiation excluding Proton Therapy)		
			36	Low Dose Rate Brachytherapy		
			37	High Dose Rate Brachytherapy		
			38	Continuous Androgen Deprivation Therapy		
			39	Intermittent Androgen Deprivation Therapy		
			40	Neoadjuvant Hormone Therapy		

			41	Adjuvant Hormone Therapy		
			02	Anti-cancer Drug Regimen (Cytotoxic Chemotherapy)		
			42	Palliative Radiotherapy		
			07	Specialist Palliative Care		
			97	Other Treatment		
Treatment - Surgery - Prostate To carry additional surgical cancer treatment details for Prostate (One occurrence per Core Treatment)						
Procedure - Nerve Sparing	Extent of surgical nerve sparing.	Code List	1	Bilateral	R	Procedure - Nerve Sparing (UR15420)
			2	Unilateral		
			3	None		
			9	Not known		
Radical Prostatectomy Margin Status	The surgical margin status following radical prostatectomy	Code List	1	Negative margins	R	Radical Prostatectomy Margin Status (UR15430)
			2	Positive margins <3mm in length		
			3	Positive margins ≥3mm in length		
			4	Positive margins, length unknown		
			9	Not Known		
Pathology - Prostate To carry the cancer pathology details for Prostate (One occurrence per path report)						
Gleason Grade (Primary)	What is the most extensive Gleason grade?	an1		Range 2-5 (in categories)	R	Gleason Grade (Primary) (pUR15210)

Gleason Grade (Secondary)	If additional grades are present, what is the highest grade (biopsy) or the second most extensive grade (TURP and radicals). If no additional grades are present, primary and secondary are the same	an1		Range 2-5 (in categories)	R	Gleason Grade (Secondary) (pUR15220)
Gleason Grade (Tertiary)	Is there a different third grade in addition to the primary and secondary grades and what is the value? **Note:** The Tertiary Grade is not the added value of the Primary and Secondary Gleason grades	an1		Range 3-5 (in categories)	R	Gleason Grade (Tertiary) (pUR15230)
			8	Not applicable		
Perineural Invasion	Is there perineural invasion (invasion into perineurium of nerve bundles - PNI)	Code List	Y	Yes (Present)	R	Perineural Invasion (pUR15240)
			N	No (Not identified)		
			9	Not Known		
TURP Tumour Percentage	For TURP only, what percentage of tumour if clinically unsuspected tumour.	max n3 Range 0-100	N/A	N/A	R	TURP Tumour Percentage (pUR15270)
Other - Prostate						
Low Volume Metastases	Is there low volume metastases present (Low Volume = 5 or less)	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Imaging - Bladder - Urological To carry the additional imaging details for Bladder cancers						
Date of Image Request	The date on which imaging is requested that contributes to pre-treatment staging Multiples may be added for various imaging modalities. **Note:** This data item is required for CT Urogram/MRI/CT Abdo & Pelvis	ccyymmdd	N/A	N/A	R	N/A
FDG PET-CT Required Due to Indeterminate Findings on CT/MRI	Record if there are indeterminate findings identified on CT or MRI justifying a FDG PET CT. This is required for MIBC and High Risk NMIBC patients prior to radical treatment with indeterminate findings on MRI or CT. **Note:** i. High Risk Non Muscle Invasive Bladder Cancer (HR-NMIBC) = any grade with T1, Grade 3 pTa, CIS ii. Muscle Invasive Bladder Cancer (MIBC) = T2 and above	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		
Cancer Care Plan - Bladder - Urological To carry the cancer care plan details for Urological cancers (One occurrence per Core Cancer Care Plan)						
Hydronephrosis	Consequence of reduced outflow of urine from Kidney. May be present in one or both kidneys	Code List	0	None	R	Hydronephrosis (UR15010)
			L	Left		
			R	Right		

			B	Bilateral		
			8	Not Applicable (No kidneys)		
			9	Not known		
Treatment - Bladder To carry the cancer treatment details for Bladder (One occurrence per Core Treatment)						
Intravesical Chemotherapy Received Indicator	Only required for patients having chemotherapy. This distinguishes patients having intravesical chemotherapy from those receiving intravenous therapy. Record *Post Op Single Dose* if the patient received a single dose of chemotherapy post operatively within 24 hours and/or *6 Week Chemotherapy Course* if the patient was treated with a 6 week course of chemotherapy. **Note:** Of the adjacent codes *Post Op Single Dose* and *6 Week Chemotherapy Course* are not present in COSD. They have been added here to provide greater granularity.	Code List	P	Post Op Single Dose	M	Intravesical Chemotherapy Received Indicator (UR15100)
			S	6 Week Chemotherapy Course		
			N	No		
			9	Not Known		
Intravesical Chemotherapy - Date Course Completed	Record the date that the intravesical 6 week course of chemotherapy was completed. **Note:** Only required for completion if *6 Week Chemotherapy Course* is recorded for Data Item *Intravesical Chemotherapy Received Indicator*	ccyymmdd	N/A	N/A	R	N/A

Intravesical Immunotherapy Received Indicator	Only required for patients having immunotherapy. This distinguishes patients having intravesical immunotherapy from those receiving intravenous therapy. Record *Induction Course* if the patient is having intravesical immunotherapy as an induction treatment and/or *Maintenance Course* if the patient is having intravesical immunotherapy as a maintenance course of treatment **Note:** Of the adjacent codes *Induction Course* and *Maintenance Cours*e are not present in COSD. They have been added here to provide greater granularity.	Code List	I	Induction Course	M	Intravesical Immunotherapy Received Indicator (UR15110)
			M	Maintenance Course		
			N	No		
			9	Not Known		
Intravesical Immunotherapy - Maintenance course completed	Only required for patients having immunotherapy. Record *Yes* for patients who have completed a maintenance course of intravesical immunotherapy **for at least 1 year**	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		
Surgery - Bladder To carry additional surgical details for Bladder Cancer where TURBT is the procedure undertaken						
Documentation Recorded Describing Tumour details	Only required for patients having undergone a TURBT procedure. Indicate if there is a bladder diagram detailing the tumour	Code List	Y	Yes	R	N/A

	location, size, number and appearance at initial resection. If there is not a bladder diagram, detail can be provided using text only.		N	No		
Resection Complete at Time of Initial TURBT	For all TURBT procedures, record if the resection was complete at the time of the initial TURBT	Code List	Y	Yes	R	N/A
			N	No		
			9	Not known		
Tumour located in bladder diverticulum	Record if the tumour is located in a bladder diverticulum	Code List	Y	Yes	R	N/A
			N	No		
			9	Not known		
Surgery - Bladder To carry additional surgical details for High Risk Non Muscle Invasive Bladder Cancer						
Second TURBT or early Cystoscopy (with or without biopsy) performed	Record if a second resection of TURBT or early cystoscopy (with or without biopsy) was done. For a definition of early cystoscopy refer to QPI guidelines	Code List	Y	Yes	R	N/A
			N	No		
Date second TURBT or Early Cystoscopy was performed	Record the date the second resection of TURBT or early cystoscopy was performed	ccyymmdd			R	N/A
Was this within 6 weeks (42 days) of the initial resection	Record if the second resection of TURBT or early cystoscopy was done within 6 weeks (42 days) of the initial resection	Code List	Y	Yes	R	N/A
			N	No		
Surgery - Bladder To carry additional surgical details for Bladder Cancer						
Surgical Pathway Type	Record the type of surgical pathway that the patient followed	Code List	1	A protocol enhanced recovery (ERAS) without daily documentation in medical notes	R	N/A
			2	A protocol enhanced recovery (ERAS) with daily documentation in medical notes		

			3	A standard surgical pathway		
			9	Not Known		
ERAS Pathway Completed	Did the patient complete the ERAS pathway **Note:** This data item is only required where *Surgical Pathway Type* is recorded as *A protocol enhanced recovery (ERAS) without daily documentation in medical notes* or *A protocol enhanced recovery (ERAS) with daily documentation in medical notes*	Code List	1	Yes	R	N/A
			2	No, but partial completion		
			3	No, non-completion		
			9	Unknown/Not documented		
Hospital Admission Details - Bladder To carry hospital admission details for Bladder Cancer						
Date of Re-admission to Hospital follow Cystectomy	Only required for patients who have received a cystectomy. Record the date of re-admission following cystectomy where this was within 90 days following cystectomy. Any subsequent admission to hospital required within 90 days is assumed related to cystectomy surgery	ccyymmdd	N/A	N/A	R	N/A

Pathology - Bladder To carry the cancer pathology details for Bladder (One occurrence per path report)						
Date of Pathology Report	The date the pathology report was authorised Required for clinical indicator reporting - To determine the time interval between date sample taken and pathology being reported	ccyymmdd	N/A	N/A	R	N/A
Detrusor Muscle Presence Indicator	Presence or absence of detrusor muscle in the specimen	Code List	1	Present (Yes)	R	Detrusor Muscle Presence Indicator (pUR15120)
			2	Absent (No)		
			3	Indeterminate		
			X	Not applicable		
Tumour Grade (Urology)	Specify whether Low, High Grade or PUNLMP (Papillary Urothelial Neoplasm of Low Malignant Potential)	Code List	L	Low	R	Tumour Grade (Urology) (pUR15290)
			H	High		
			P	PUNLMP		
			X	Not applicable		
Associated Carcinoma in situ (CIS)	Presence or absence of associated carcinoma in situ in the specimen **Note**: only for completion when recorded morphology (Core data item Histological Diagnosis (Morphology) (ICD)) is 8120/3 or 8130/3	Code List	Y	Present (Yes)	R	N/A
			N	Absent (No)		
			9	Not Known		
Necrosis	Presence or absence of necrosis in the specimen	Code List	Y	Present (Yes)	R	N/A
			N	Absent (No)		
			8	Not Applicable		
Lymphovascular Invasion*	An indication of the presence of absence of unequivocal tumour in lymphatic and/or vascular spaces.	Code List	NU	No, vascular/lymphatic invasion not present	R	Cancer vascular or lymphatic invasion pCR0870

	Note: i. Data item not applicable to Haematological diagnoses ii. Of the adjacent codes *Not Applicable* is not present in Core. This has been added here to provide greater granularity.		YU	Yes, vascular/lymphatic invasion present		
			YV	Vascular invasion only present		
			YL	Lymphatic invasion only present		
			YB	Both lymphatic and vascular invasion present		
			UU	Uncertain whether vascular/lymphatic invasion is present or not		
			XX	Cannot be assessed		
			99	Not known		
			98	Not Applicable		
Biomarkers (One occurrence of this group per Core)						
PD-L1 Expression	Select the recorded outcome for the PD-L1	Code List	1	Present (Yes)	R	N/A
			2	Absent (No)		
			5	Indeterminate/Test Failed		
			9	Not Known		
PDL1 % Value	Specify the absolute % value of the PD-L1 expression	an3	N/A	N/A	R	N/A

National Cancer Data Standards – Urology: Testicular

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Cancer Care Plan - Urological - Testicular To carry the cancer care plan details for Urological cancers						
S-Category	Based on serum tumour markers AFP, HCG and LDH. For Testicular Cancer S-Category is an additional prognostic factor	Code List	SX	Tumour marker studies not available or not performed	R	S-Category (UR15030)
			S0	Tumour marker levels within normal limits		
			S1	LDH <1.5 X Normal and HCG (mIU/ml) <5000 and AFP (ug/ml) < 1000		
			S2	LDH 1.5-10 X Normal or HCG (mIU/ml) 5000-50,000 or AFP (ug/ml) 1000-10,000		
			S3	LDH >10 X Normal or HCG (mIU/ml) >50,000 or AFP (ug/ml) >10,000		
Laboratory Results - Urological - Testicular To carry Urological Laboratory result details (One occurrence per Core - Lab results)						
S-Category AFP	AFP (Alpha Feto-Protein) is a serum tumour marker. To be collected once at diagnosis by specialist MDT	max n6 Range (0-999999)	N/A	N/A	R	S-Category AFP (UR15040)
S-Category HCG	HCG (Human Chorionic Gonadotropin) is a serum tumour marker. To be collected once at diagnosis by specialist MDT	max n7 Range (0-9999999)	N/A	N/A	R	S-Category HCG (UR15050)

S-Category LDH	LDH (Serum Lactate Dehydrogenase) is a serum tumour marker. To be collected once at diagnosis by specialist MDT	max n6 Range (0-999999)	N/A	N/A	R	S-Category LDH (UR15060)
Normal LDH	This is the upper limit of normal for the LDH (Lactate Dehydrogenase Level) assay which is used to calculate the S Category To be collected once at diagnosis by specialist MDT	max n6 Range (0-999999)	N/A	N/A	R	Normal LDH (UR15020)
Site Specific Staging - Testicular To carry staging details for Testicular Cancer (One occurrence per Core site specific staging group)						
Stage Grouping (Testicular)	Nationally agreed anatomical stage groupings as defined by The Royal Marsden Hospital (RMH)	Code List	1	Stage 1 - Confined to testis	R	Stage Grouping (Testicular) (UR15300)
			1S	Stage 1S		
			1M	Stage 1M - Rising post orchidectomy markers only		
			2A	Stage 2A - Abdominal lymphadenopathy <2cm		
			2B	Stage 2B - Abdominal lymphadenopathy 2cm-5cm		
			2C	Stage 2C - Abdominal lymphadenopathy >5 cm		
			3A	Stage 3A - Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy <2cm		

			3B	Stage 3B - Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy 2cm-5cm		
			3C	Stage 3C - Supradiaphragmatic lymphadenopathy with abdominal lymphadenopathy >5cm		
			4A	Stage 4A - Extralymphatic metastases with abdominal lymphadenopathy <2cm		
			4B	Stage 4B - Extralymphatic metastases with abdominal lymphadenopathy 2cm-5cm		
			4C	Stage 4C - Extralymphatic metastases with abdominal lymphadenopathy >5cm		
Extranodal Metastases	For Testicular Cancer Stage 4 only. Indicate the extent of metastatic spread. This is a repeating data item.	Code List	H	Liver involvement	R	Extranodal Metastases (UR15320)
			B	Brain involvement		
			M	Mediastinal involvement		
			N	Neck nodes		
			L	Lung involvement		
Lung Metastases Sub Stage Grouping		Code List	L1	Less than or equal to 3 metastases	R	

	Where lung metastases are identified, specify the RMH grouping.		L2	Greater than 3 metastases		Lung Metastases Sub Stage Grouping (UR15330)
			L3	Greater than 3 metastases, one or more greater than or equal to 2 cm diameter		
Pathology - Testicular To carry the cancer pathology details for Testicular (One occurrence per path report)						
Rete Testes Invasion	For Seminoma only Does the tumour invade the rete testis	Code List	Y	Yes (Present)	M	Rete Testes Invasion (pUR15310)
			N	No (Not identified)		
			X	Not applicable (cannot be assessed)		
Size of Tumour	For Seminoma only Outline the description the size of the tumour	Code List	1	>=4 cm	M	N/A
			2	<4 cm		

National Cancer Data Standards – Urology: Renal (Kidney)

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Cancer Care Plan - Urological - Renal To carry the cancer care plan details for Urological cancers						
Estimated Glomerular Filtration Rate	This is the estimated Glomerular Filtration Rate. It is a measurement of kidney function in mls/min/1.73m2. This is to be collected once at diagnosis.	max n2 Positive numerical values (categories can be derived from this at a later stage) Range (0-99)	N/A	N/A	R	Estimated Glomerular Filtration Rate (UR15000)
Pathology - Renal/Kidney To carry the cancer pathology details for Kidney (One occurrence per path report)						
Tumour Necrosis Indicator	Is there evidence of coagulative tumour necrosis	Code List	1	Macroscopic (confluent)	R	Tumour Necrosis Indicator (pUR15130)
			2	Microscopic (coagulative)		
			3	Not identified		
			8	Cannot be assessed (eg, post embolisation)		
Perinephric Fat Invasion	Is there evidence of perinephric fat invasion	Code List	Y	Yes (Present)	R	Perinephric Fat Invasion (pUR15140)
			N	No (Not identified)		
			9	Cannot be assessed/Not applicable		
Adrenal Invasion	Is there evidence of direct adrenal invasion	Code List	1	Present, direct extension	R	Adrenal Invasion (pUR15150)
			2	Present, metastasis		
			3	Not identified		

			8	Cannot be assessed/Not applicable		
Renal Vein Tumour	Is there evidence of tumour thrombus in the renal vein	Code List	1	Microscopic involvement only	R	Renal Vein Tumour (pUR15160)
			2	Gross involvement confirmed microscopically		
			3	Not identified		
			8	Cannot be assessed/Not applicable		
Gerota's Fascia Invasion	Is there evidence of invasion into Gerota's fascia	Code List	Y	Yes (Present)	R	Gerota's Fascia Invasion (pUR15170)
			N	No (Not identified)		
			9	Cannot be assessed/Not applicable		
Prognostic Score - For Metastatic Renal Cell Carcinoma To carry prognostic score details for patients who present with metastatic renal cell ca or develop metastatic disease as part of primary/non primary cancer pathway						
IMDC/HENG Absolute Value (International Metastatic RCC Database Consortium) Risk Score (formerly known as Heng score)	Record the absolute value for IMDC/HENG	an1 Range (0-6)	N/A	N/A	R	N/A
IMDC/HENG Risk Score (International Metastatic RCC Database Consortium) Risk Score (formerly	Record the associated risk factor for the patient. The prognostic score predicts survival in patients with metastatic renal cell carcinoma treated with systemic therapy	Code List	0	0 - Favourable Risk	D	N/A
			1	1-2 - Intermediate Risk		

known as Heng score)	**Note:** This data item is derived from the absolute value recorded in *IMDC/HENG Absolute Value*		2	3-6 - Poor Risk		

National Cancer Data Standards – Urology: Penile

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Diagnostic Procedures - Staging - Sentinel Node Details - Penile To carry specific staging details for Penile (One occurrence per core diagnosis group)						
Nodes Examined Number (Sentinel) Right Laterality	The number of Sentinel nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A
Nodes Positive Number (Sentinel) Right Laterality	The number of sentinel nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
Extra Capsular Extension (Sentinel) Right Laterality	Is there evidence of extra capsular spread/extension?	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Nodes Examined Number (Sentinel) Left Laterality	The number of Sentinel nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A

Nodes Positive Number (Sentinel) Left Laterality	The number of sentinel nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
Extra Capsular Extension (Sentinel) Left Laterality	Is there evidence of extra capsular spread/extension?	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Pathology - Penile To carry the cancer pathology details for Penis (One occurrence per path report)						
Sub-Type of Tumour	Further details to record the sub-type of tumour (Multiple response can be chosen if tumour is a mixed tumour)	Code List	1	Squamous Carcinoma (usual type)	R	N/A
			2	Basaloid Squamous Carcinoma		
			3	Warty/Condylomatous Carcinoma		
			4	Verrucous Carcinoma		
			5	Papillary Squamous Carcinoma		
			6	Sarcomatoid/Spindle Cell Carcinoma		
			7	Other		
Other - Sub Type of Tumour	If Other is chosen in Sub-type of tumour, specify the other type	an50	N/A	N/A	R	N/A
Grade of Differentiation (Pathological)*	Grade of Differentiation is the definitive grade of the tumour based on the evidence from a pathological examination **Note:** i. In Core there are codes of G4 (Undifferentiated/anaplastic) and	Code List	G1	Well differentiated	R	Grade of Differentiation (Pathological) (pCR0860)
			G2	Moderately differentiated		

	GX (Grade of differentiation is not appropriate or cannot be assessed). Those codes are not applicable within the Urology - Penile site-specific standard. ii. Of the adjacent codes Sarcomatoid Areas Present is not present in Core. This has been added here to provide greater granularity.		G3	Poorly differentiated		
			G5	Sarcomatoid Areas Present		
Maximum Tumour Width	Record the size in mm of the maximum tumour width Record 0 if Not Assessable	max n2	N/A	N/A	R	N/A
Depth of Tumour Invasion	Record the depth of invasion of the tumour in mm Record 0 if Not Assessable	max n2	N/A	N/A	R	N/A
Perineural Invasion	Presence or absence of perineural invasion (PNI) invasion in the specimen **Note:** Of the adjacent codes Cannot be Assessed is not present in COSD. This has been added here to provide greater granularity.	Code List	Y	Yes (Present)	R	Perineural Invasion (pUR15240)
			N	No (Not identified)		
			X	Cannot be assessed		
Excision Margin*	An indication as to whether the excision margin was clear of the tumour and, if so, by how much. Where the measurement is more than one measurement, record the closest or closest relevant margin. Where measurements are not taken use 01, 05, 06 **Note:** Of the adjacent codes,	Code List	01	Excision margins are clear (distance from margin not stated)	R	Excision Margin (pCR0880)
			02	Excision margins are clear (tumour >5 mm from the margin)		
			05	Tumour reaches excision margin		
			06	Uncertain		

	Excision margins are clear (tumour 1mm from the margin), Excision margins are clear (tumour 2mm from margin), Excision margins are clear (tumour 3mm from margin), Excision margins are clear (tumour 4mm from margin) and *Excision margins are clear (tumour 5mm from margin)* are not present in Core. These have been added here to provide greater granularity. Whilst the Core data item has additional codes, only the adjacent codes are applicable to the Urology - Penile site-specific standard.		10	Excision margins are clear (tumour 1mm from the margin)		
			11	Excision margins are clear (tumour 2mm from margin)		
			12	Excision margins are clear (tumour 3mm from margin)		
			13	Excision margins are clear (tumour 4mm from margin)		
			14	Excision margins are clear (tumour 5mm from margin)		
			98	Not applicable		
			99	Not Known		
Associated PeIN	Presence or absence of PeIN in the specimen	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Sub-Type of PeIN	Record the subtype of PeIN	Code List	1	Undifferentiated	R	N/A
			2	Differentiated		
Corpus Spongiosum Invasion	Is there evidence of invasion into corpus spongiosum	Code List	Y	Yes	R	Corpus Spongiosum Invasion (pUR15180)
			N	No		
Corpus Cavernosum Invasion	Is there evidence of invasion into corpus cavenosum	Code List	Y	Yes	R	Corpus Cavernosum Invasion (pUR15190)
			N	No		
Urethra or Prostate Invasion	Is there evidence of invasion into the urethra or prostate	Code List	Y	Yes	R	Urethra or Prostate Invasion (pUR15200)
			N	No		
p16 Testing Indicator	Indicate the result of p16 Immunohistochemistry (Applicable for invasive and PeIN) Note: This is applicable to PeIN and Invasive tumours	Code List	P	Positive	R	p16 Testing Indicator (pHN9500)
			N	Negative		
			X	Not Performed/Not Known		
Frozen Section Pathology - Penile To carry the details of the frozen section pathology for Penile (One occurrence per path report)						

Tumour Present	Is there tumour present in the frozen section specimen	Code List	Y	Yes	R	N/A
			N	No		
Presence of PeIN	Presence or absence of PeIN in the frozen section specimen	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Pathology - For Nodes To carry the details of pathology for Nodes (One occurrence per path report)						
Nodes Examined Number (Inguinal) Right Laterality	The number of inguinal nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A
Nodes Positive Number (Inguinal) Right Laterality	The number of inguinal nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
Extracapsular Extension (Inguinal) Right Laterality	Is there evidence of extra capsular spread/extension?	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Nodes Examined Number (Inguinal) Left Laterality	The number of inguinal nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A
Nodes Positive Number (Inguinal) Left Laterality	The number of inguinal nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
Extracapsular Extension (Inguinal) Left Laterality	Is there evidence of extra capsular spread/extension?	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		
Nodes Examined Number (Pelvic) Right Laterality	The number of pelvic nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A
Nodes Positive Number (Pelvic) Right Laterality	The number of pelvic nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
		Code List	Y	Yes (Present)	R	N/A

Extracapsular Extension (Pelvic) Right Laterality	Is there evidence of extra capsular spread/extension?		N	No (Not identified)		
			X	Cannot be assessed		
Nodes Examined Number (Pelvic) Left Laterality	The number of pelvic nodes examined Record 0 if nodes not sent	max n2	N/A	N/A	R	N/A
Nodes Positive Number (Pelvic) Left Laterality	The number of pelvic nodes reported as being positive for the presence of tumour metastases.	max n2	N/A	N/A	R	N/A
Extracapsular Extension (Pelvic) Left Laterality	Is there evidence of extra capsular spread/extension?	Code List	Y	Yes (Present)	R	N/A
			N	No (Not identified)		
			X	Cannot be assessed		

National Cancer Data Standards – Urology: pTa and Carcinoma in Situ (CIS) Tumours

Carcinoma in situ is an important prognostic indicator. It is **essential** that that pTa/CIS tumours are recorded in the correct way; this is as follows:

Stage pTa/Ta Tumours Graded 1/2/3 – (ICD10 codes D41.* & D09.*)

There are TWO different grading systems which are to be used to record information on these tumours:
1. WHO 1973: Non-invasive Papillary urothelial (transitional cell) carcinoma – Grade 1, Grade 2 or Grade 3
2. WHO 2004: Non-invasive Papillary Urothelial Neoplasm of Low Malignant Potential (PUNLMP); Papillary Urothelial carcinoma - Low Grade or High Grade

Neoplasm of Uncertain Behaviour of -
Diagnosis: D41* - Neoplasm of Uncertain Behaviour of …….
(4th digit: D410 Kidney, D411 Renal Pelvis, D412 Ureter, D413 Urethra, D414 Bladder, D419 Unspecified Urinary organ)

Morphology:
M8130/1 – Grade 1 (stage pTa) papillary urothelial (transitional cell) neoplasm of low malignant potential (PUNLMP)

M8130/1 - Grade 1 (pTa) papillary urothelial (transitional cell) neoplasm/carcinoma
M8130/1 - Papillary (stage pTa) urothelial (transitional cell) neoplasm of low malignant potential (PUNLMP)

pTa Tumours
Diagnosis: D09* - Carcinoma in-situ of ……
(4th digit: D090 Bladder, D091 Other and unspecified urinary sites)

Morphology:
M8130/2 – Papillary urothelial (transitional cell) neoplasm/carcinoma NOS
M8130/2 – Grade 1 (stage pTa) papillary low grade urothelial (transitional cell) neoplasm/carcinoma
M8130/2 – Grade 2 (stage pTa) papillary low grade urothelial (transitional cell) neoplasm/carcinoma
M8130/2 – Papillary low grade urothelial (transitional cell) neoplasm/carcinoma NOS (stage pTa)
M8130/2 – Grade 2 (stage pTa) papillary high grade urothelial (transitional cell) neoplasm/carcinoma
M8130/2 - Grade 2 (stage pTa) papillary urothelial (transitional cell) neoplasm/carcinoma
M8130/2 – Papillary high grade urothelial (transitional cell) neoplasm/carcinoma NOS (stage pTa)
M8130/2 – Grade 3 (stage pTa) papillary high grade urothelial (transitional cell) neoplasm/carcinoma
M8130/2 – Papillary high grade urothelial (transitional cell) neoplasm/carcinoma NOS (stage pTa)

Carcinoma in-situ of -
Diagnosis: D09* - Carcinoma in-situ of ……
(4th digit: D090 Bladder, D091 Other and unspecified urinary sites)

Morphology:
M8120/2 - Any TCC/papillary TCC with CIS is coded to 8120/2
M8130/1 or M8130/2 - Any TCC/papillary TCC without CIS is coded to 8130/1 or 8130/2

Examples:
Papillary G1 pTa and CIS would be registered as M8120/2
Papillary G3 pTa and CIS would be registered as M8120/2

Malignant Tumours should to be recorded as follows:
Malignant Neoplasm of -
Diagnosis: C67* - Malignant Neoplasm of Urinary Bladder

Morphology:
M8120/3 - Transitional cell carcinoma

As with all other site specific categories, Core data items should also be collected for Urology: pTa and Carcinoma in Situ (CIS) Tumours 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. In addition to the Core requirements, Urology: pTa and In Situ Tumours should also record the following information:

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Tumour Grade (Urology)	Specify whether Low, High Grade or PUNLMP (Papillary Urothelial Neoplasm of Low Malignant Potential)	Code List	L	Low	R	Tumour Grade (Urology) (pUR15290)
			H	High		
			P	PUNLMP		
			X	Not applicable		