

WELSH INFORMATION STANDARDS BOARD

	DSC Notice:	DSCN 2021 / 03
	Date of Issue:	8 th February 2021
Ministerial / Official Letter: N/A	Subject: National Cancer Data Standards for Wales – Site Specific – Brain & Central Nervous System (CNS) 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 21 st January 2021		
WISB Reference: ISRN 2021 / 001		
Summary: To introduce a new standard for site-specific cancer minimum reporting requirements for tumour site - Brain & Central Nervous System (CNS). 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 Brain & Central Nervous System (CNS). 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 Brain & Central Nervous System (CNS), 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.

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 – Brain & Central Nervous System (CNS) 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 – Brain & Central Nervous System (CNS)

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Additional Imaging Details (One occurrence per Core Imaging group)						
Principal Diagnostic Imaging Type	Indicate the principal imaging procedure undertaken to diagnose the tumour. Note: <i>PET Scan</i> includes PET-CT Scan	Code List	01	CT scan	R	Principal Diagnostic Imaging Type (BA3050)
			02	MRI scan		
			03	PET scan		
Lesion Location (Radiological)	Radiologically determined anatomical location of lesion (largest lesion if more than one) or where centred. This is recorded prior to treatment.	Code List	01	Frontal lobe	R	Lesion Location (Radiological) (BA3000)
			02	Temporal lobe		
			03	Parietal lobe		
			04	Occipital lobe		
			05	Pineal region		
			06	Hypothalamic		
			07	Basal ganglia/thalamic		
			08	Cerebellar		
			09	Midbrain		
			10	Pons		
			11	Medulla		
			12	Fourth Ventricle		
			13	Third Ventricle		
			14	Lateral Ventricle		
			15	Parasagittal/parafalcine dura		
			16	Posterior fossa convexity dura		
			17	Convexity dura		
18	Petrous temporal bone					
19	Orbital roof					
20	Skull vault					

			21	Scalp		
			22	Anterior cranial fossa		
			23	Middle cranial fossa		
			25	Infratemporal fossa		
			26	Pterygopalatine fossa		
			27	Anterior clinoid dura		
			28	Sphenoid wing dura		
			29	Subfrontal dura		
			30	Suprasellar dura		
			31	Clival dura		
			32	Cavernous sinus		
			33	Cerebellopontine angle		
			34	Jugular bulb		
			35	Venous angle dura		
			36	Foramen magnum		
			37	Cervical Intramedullary		
			38	Cervical intradural		
			39	Cervical extradural		
			40	Cervical bony		
			41	Thoracic intramedullary		
			42	Thoracic intradural		
			43	Thoracic extradural		
			44	Thoracic bony		
			45	Lumbar intramedullary		
			46	Lumbar intradural		
			47	Lumbar extradural		
			48	Lumbar bony		
			98	Other		
Number of lesions (Radiological)	Radiologically determined number of lesions	max n2	N/A	N/A	R	Number of lesions (Radiological) (BA3020)

Lesion Size (Radiological)	Radiological estimate in millimetres (mm) of the maximum diameter of the tumour measured prior to treatment (largest lesion if more than one). Record as "0" to indicate not assessable for diffuse tumours (e.g. gliomatosis cerebri)	max n3.max n2 mm	N/A	N/A	R	Lesion Size (Radiological) (BA3030)
Radiological Tumour Grade	Record the Radiological Tumour grade, as reported by the Radiologist, as this will determine specific diagnosis and treatment	Code List	1	Low Grade	R	N/A
			2	High Grade		
			8	Not Applicable		
			9	Not Recorded		
Additional Imaging Details - Relating to all treatment lines (all 3 data items are applicable each time patient has surgery) (Multiple occurrences could occur as patient progress through pathways)						
MRI Scan (Pre Treatment)	Record if a contrast enhanced MRI was carried out prior to surgical treatment	Code List	1	Yes	R	N/A
			2	No - Patient refused investigation		
			3	No - Contraindication to intravenous contrast medium		
			4	No - Clinically Inappropriate		
			5	No - Not Applicable		
			9	Not Recorded		
Date of MRI Scan (Pre Treatment)	Record the date the contrast enhanced MRI scan investigation was carried out prior to surgical treatment	ccyyymmdd	N/A	N/A	R	N/A

Enhancing Component Present on Pre-Treatment MRI Imaging	A record to determine if enhancement is displayed on pre-treatment MRI Note: Only applicable for MRI If the status of enhancement is unknown, record as 9 - <i>Not Recorded</i> If no imaging is performed, record as 8 - <i>Not Applicable</i>	Code List	Y	Yes	R	N/A
			N	No		
			8	Not applicable		
			9	Not recorded		
Care Plan (One occurrence per Core Cancer Care Plan group)						
MDT Provisional Diagnosis (ICD)	Working diagnosis as defined at MDT where the first definitive treatment is agreed. This is the clinical opinion which may also be informed by biopsy, radiological and/or other investigations	min an4 max an6	N/A	N/A	R	MDT Provisional Diagnosis (ICD) (BA3080)
Intent of Surgery (MDT)	Final assessment of intent of surgery as <u>defined by MDT</u>	Code List	1	Maximal surgical resection (>90% reduction in tumour volume is intended)	R	N/A
			2	Partial resection/biopsy or debulking surgery (\leq 90% reduction in tumour volume is intended)		
			8	Not applicable		
			9	Not recorded		
MDT Details - Additional MDT Details (Multiple occurrences of MDT)						
Date of Referral to NeuroSurgery MDT	Record the date the referral was made to the NeuroSurgery MDT	ccyymmdd	N/A	N/A	R	N/A
Additional Diagnosis Details - General (One occurrence per Core Diagnosis group)						
		Code List	Y	Yes	R	N/A

Seizure Presentation (at diagnosis)	Record if the patient has presented with seizures at the time of diagnosis		N 9	No Not recorded		
Seen by Neurologist and/or Named Epilepsy Specialist Nurse (ESN)	<p>Record if the patient was seen by a Neurologist and/or named Epilepsy Specialist Nurse (ESN)</p> <p>Note:</p> <p>i. A named ESN is a named nurse with expertise in epilepsy management</p> <p>ii. The patient should be seen by the Neurologist and/or named Epilepsy Specialist Nurse (ESN) within 2 weeks of date of diagnosis. Record whether the patient was seen regardless of the timeframe.</p>	Code List	1	Named Epilepsy Specialist Nurse (ESN)	R	N/A
			2	Neurologist		
			3	Seen by Both (Neurologist and named ESN)		
			4	Not Seen		
			9	Not recorded		
Date Seen by Neurologist and/or Named Epilepsy Specialist Nurse (ESN)	<p>Record the date the patient was seen by a Neurologist and/or named Epilepsy Specialist Nurse (ESN)</p> <p>Note:</p> <p>i. A named ESN is a named nurse with expertise in epilepsy management</p> <p>ii. The date should relate to when the patient was first seen by a Neurologist and/or named ESN following diagnosis. Where the patient was seen on more than one occasion the first date of contact should be recorded.</p>	ccyymmdd	N/A	N/A	R	N/A
Diagnosis - Low Grade Glioma (One occurrence per Core Diagnosis group)						
		Code List	1	Left - Normal	R	

Visual Acuity at Presentation	Record the visual acuity at presentation on the patient, this can be a repeating data item		2	Right - Normal		Visual Acuity at Presentation (CT7030)
			3	Left - Abnormal		
			4	Right -Abnormal		
			9	Not Known		
Visual Fields at Presentation	Record the visual fields at presentation on the patient, this can be a repeating data item.	Code List	1	Left - Normal	R	Visual Fields at Presentation (CT7400)
			2	Right - Normal		
			3	Left - Abnormal		
			4	Right -Abnormal		
			9	Not Known		
Brain/CNS - Treatment Details. Additional Treatment Summary Details						
Type of First Cancer Treatment*	This denotes the first specific treatment modality administered to a patient Note: (i) This is required where data item Cancer Treatment Event Type is recorded as <i>First Definitive Treatment for a New Primary Cancer</i> (ii) Where the therapy is part of a combined treatment please record each part of the treatment using the adjacent codes. This, along with Core data items <i>Cancer Treatment Event Type</i> and <i>Treatment Start Date (Cancer)</i> will then denote that it is a combined treatment (see National Cancer Data Standards for Wales – User Guide for further information). (iii) Of the adjacent codes, <i>Supportive Care Only, Watchful Waiting, Patient Died Before</i>	Code List	01	Surgery	R	Cancer Treatment Modality (Registration) (CR2040)
			02	Anti-Cancer Drug Regimen (Cytotoxic Chemotherapy)		
			05	Teletherapy (Beam Radiation excluding Proton Therapy)		
			27	Supportive Care Only		
			97	Other Treatment (not listed)		
			43	Watchful Waiting		
			21	Biological Therapies (excluding Immunotherapy)		
			04	Chemoradiotherapy		
			96	Patient died before treatment		
98	All treatment declined					

	<i>Treatment and Not Recorded</i> 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 Brain and CNS site-specific standard.		99	Not Recorded		
Date of First Cancer Treatment	This denotes the date the Type of First Cancer Treatment was given to the patient. Note: This is a derived data item from data item <i>Treatment Start Date (Cancer)</i> where data item <i>Cancer Treatment Event Type</i> is recorded as <i>First Definitive Treatment for a New Primary Cancer</i>	ccyymmdd	N/A	N/A	D	N/A
Brain/CNS - Surgery - General (One occurrence per Core Surgery)						
Tumour Location (Surgical)	Surgically determined anatomical location of lesion(s) or where centred	Code List	01	Frontal Lobe	R	Tumour Location (Surgical) (BA3100)
			02	Temporal lobe		
			03	Parietal lobe		
			04	Occipital lobe		
			05	Pineal region		
			06	Hypothalamic		
			07	Basal ganglia/thalamic		
			08	Cerebellar		
			09	Midbrain		
			10	Pons		
			11	Medulla		
			12	Fourth Ventricle		
			13	Third Ventricle		
			14	Lateral Ventricle		

15	Parasagittal/parafalcine dura
16	Posterior fossa convexity dura
17	Convexity dura
18	Petrous temporal bone
19	Orbital roof
20	Skull Vault
21	Scalp
22	Anterior cranial fossa
23	Middle cranial fossa
25	Infratemporal fossa
26	Pterygopalatine fosse
27	Anterior clinoid dura
28	Sphenoid wing dura
29	Subfrontal dura
30	Suprasellar dura
31	Clival dura
32	Cavernous sinus
33	Cerebellopontine angle
34	Jugular bulb
35	Venous angle dura
36	Foramen magnum
37	Cervical Intramedullary
38	Cervical Intradural
39	Cervical Extradural
40	Cervical bony
41	Thoracic intramedullary
42	Thoracic intradural
43	Thoracic extradural
44	Thoracic bony
45	Lumbar intramedullary
46	Lumbar intradural

			47	Lumbar extradural		
			48	Lumbar bony		
			98	Other		
Biopsy Type	Identify type of biopsy (where performed)	Code List	1	Frame-based stereotactic biopsy	R	Biopsy Type (BA3200)
			2	Frameless stereotactic biopsy		
			3	Open biopsy		
			4	Percutaneous biopsy		
			5	Endoscopic biopsy		
			6	Other biopsy		
			9	Not Known		
Excision or Procedure Type	Identify type of excision or procedure (where performed)	Code List	1	Limited (<50%)	R	Excision or Procedure Type (BA3210)
			2	Partial (50%-69%)		
			3	Subtotal (70-95%)		
			4	Total Macroscopic		
			5	Extent Uncertain		
			6	CSF Division Procedure		
			9	Not Known		
Brain/CNS - Surgery - For Definitive Surgery Only (One occurrence for Definitive Surgery)						
Date of Main (Definitive) Surgery	Record the date of the main (definitive) surgery performed on the patients <u>for treatment</u> of Brain/CNS cancer	ccyymmdd	N/A	N/A	R	N/A
Location Site Code for Organisation for Main (Definitive) Cancer Surgery	Record the hospital where the main (definitive) surgery took place.	See NHS Wales Data Dictionary - Terms <i>Organisation Code - LHB/Trust Site Code</i>	N/A	N/A	R	N/A
Brain/CNS - Surgery - Additional Surgical Data Items (Multiple occurrences for Surgery throughout pathway)						

Post Surgical MRI Scan	Specify if a contrast enhanced MRI scan was carried out after surgery	Code List	1	Yes	R	N/A
			2	No - Patient refused investigation		
			3	No - Contraindication to intravenous contrast medium		
			4	No - Clinically Inappropriate		
			5	No - Not Applicable		
			9	Not Recorded		
Date of Post Surgical MRI Scan	Record the date the contrast enhanced MRI scan investigation was carried out following surgery	ccyymmdd	N/A	N/A	R	N/A
Reduction in Tumour Volume	Record the estimated percentage reduction volume achieved during surgical resection of a tumour as determined by radiology Note: This should be determined by comparing pre and post operation MRI scans and documented by radiologist. Reduction volume percentage should be clearly documented on the post operative MDT notes as defined by the radiologist and not deduced by audit/clerical staff. If it is not documented then this should be discussed with Clinician/Radiologist. Patients not undergoing both pre and post operation MRI scans should be recorded as <i>Not Applicable</i>	Code List	1	<50%	R	N/A
			2	50-89%		
			3	90-100%		
			8	Not applicable		
			9	Not recorded		
Resection Status		Code List	1	Complete resection	R	

	The Resection Status of the tumour. This is determined at MDT by a combination of surgical history and postop imaging		2	Incomplete resection (<1.5 cm2 remaining)		Resection Status (CT7390)	
			3	Incomplete resection (> 1.5cm2 remaining)			
			9	Not applicable, biopsy only			
Additional Surgery Details - Glioblastoma							
Administration of Gliolan (5-ALA)	Record if the patient was given Gliolan (5-ALA) 4-5 hours prior to surgical resection. This is applicable to cases of glioblastoma only	Code List	1	Yes	R	N/A	
			2	No			
			8	Not applicable			
			3	Contraindication			
			4	Clinically inappropriate			
			9	Not recorded			
Additional Pathology Details - General (One occurrence per Pathology Report)							
WHO CNS Grade	Record the WHO CNS Grade - this is a malignancy scale to determine the aggressiveness of tumours and to estimate the prognosis	Code List	1	Grade 1	R	N/A	
			2	Grade 2			
			3	Grade 3			
			4	Grade 4			
			8	Not applicable (No sample for pathology)			
			9	Not Recorded			
Histopathology Report Complete	Record if all information required in the pathology report is complete.	Code List	1	Complete	R	N/A	
			2	Not Complete			
			8	Not Applicable			
			9	Not Recorded			
Additional Pathology Details - Molecular analysis. Further information regarding molecular analysis (One occurrence per Pathology Report)							
Molecular Diagnostics Code	Chromosomal or genetic markers associated with the brain tumour.	Code List	06	Evidence of ALK rearrangement	R	Molecular Diagnostics Code (pBA3070)	
			07	Evidence of native ALK			

This may involve section of more than one value for each tumour.

Note: The code list is based on the 2016 WHO categories for Molecular Diagnostic Markers.

08	Evidence of ATRX mutation
09	Evidence of wt ATRX
10	Evidence of BRAF V600E mutation
11	Evidence of wt BRAF
12	Evidence of KIAA1549-BRAF fusion
13	Evidence of BRAF/RAF1 mutations, or fusions involving genes other than KIAA1549
14	Evidence of C11orf95-RELA fusion
15	Evidence of native CC11orf95 and RELA
16	Evidence of amplification or fusion of C19MC locus (chr.19q13.42)
17	Evidence of unaltered C19MC locus (chr.19q13.42)
18	Evidence of CDK4/6 amplification
19	Evidence of CDK4/6 normal copy number
20	Evidence of CDKN2A locus homozygous deletion
21	Evidence of CDKN2A locus normal copy number
22	Evidence of CCND1/2/3 amplification

23	Evidence of CCND1/2/3 normal copy number
24	Evidence of CTNNB1 Mutation
25	Evidence of wt CTNNB1
26	Evidence of amplification of EGFR
27	Evidence of mutation/rearrangement of EGFR
28	Evidence of unaltered EGFR
29	Evidence of EWSR1-FLI1 fusion
30	Evidence of native EWSR1 and FLI1
31	Evidence of FGFR1 mutation/rearrangement/ fusion
32	Evidence of unaltered FGFR1
33	Evidence of H3F3A/H3F3B (H3.3) K27M mutation
34	Evidence of H3F3A/H3F3B (H3.3) wt K27
35	Evidence of H3F3A/H3F3B (H3.3)G34R/V mutation
36	Evidence of H3F3A/H3F3B (H3.3) wt G34
37	Evidence of HIST1H3B K27M mutation
38	Evidence of HIST1H3B wt K27

39	Evidence of HIST1H3C K27M mutation
40	Evidence of HIST1H3C wt K27
41	Evidence of ID2 amplification
42	Evidence of ID2 normal copy number
43	IDH1 (codon 132) or IDH2 (codon172) mutation identified
44	IDH1 (codon 132)and IDH2 (codon 172) wt confirmed
45	Evidence of KLF4 K409Q and TRAF7 mutations
46	Evidence of wt KLF4 and TRAF7
47	Evidence of MAP2K1 mutation
48	Evidence of wt MAP2K1
49	Evidence of MET amplification
50	Evidence of MET normal copy number
51	Evidence of significant MGMT promoter methylation
52	Evidence of unmethylated MGMT promoter
53	Evidence of MYC/MYCN amplification
54	Evidence of MYC/MYCN normal copy number

55	Evidence of NF1 biallelic loss/mutation
56	Evidence of unaltered NF1
57	Evidence of NF2 biallelic loss/mutation
58	Evidence of unaltered NF2
59	Evidence of NTRK Fusions
60	Evidence of native NTRK
61	Evidence of PTEN Biallelic loss/mutation
62	Evidence of Unaltered PTEN
63	Evidence of SDHB or SDHD mutation
64	Evidence of wt SDHB and SDHD
65	Evidence of SHH pathway activation
66	Evidence of normal SHH pathway
67	Evidence of inactivation of SMARCB1 (INI1)
68	Evidence of wt SMARCB1 (INI1)
69	Evidence of inactivation of SMARCA4
70	Evidence of wt SMARCA4
71	Evidence of TERT promoter mutation

72	Evidence of wt TERT promoter
73	Evidence of TP53 mutation
74	Evidence of wt TP53
75	Evidence of TSC1 or TSC2 mutation
76	Evidence of wt TSC1 and TSC2
77	Evidence of VHL mutation
78	Evidence of wt VHL gene
79	Evidence of WNT pathway activation
80	Evidence of normal WNT pathway
81	Evidence of WWTR1-CAMTA1 fusion
82	Evidence of native WWTR1-CAMTA1
83	Evidence of codeletion of chr.1p and chr.19q
84	Evidence of total chr 1p loss but normal copy number of chr.19q
85	Evidence of normal copy number of both chr.1p and chr 19q
86	Evidence of monosomy chr.6
87	Evidence of chr.6 normal copy number
88	Evidence of polysomy chr.7

			89	Evidence of chr.7 normal copy number		
			90	Evidence of loss of chr.10 or chr. 10q		
			91	Evidence of chr.10 normal copy number		
			92	Evidence of loss of chr.22 or chr.22q		
			93	Evidence of chr.22 or chr. 22q normal copy number		
			98	Other		
			99	Not known (Not Recorded)		
Immunohistochemistry Hormone Expression Type	Hormone expression by immunohistochemistry. For Pituitary Adenomas only (Multiple values may be recorded)	Code List	0	Non Functioning	R	Immunohistochemistry Hormone Expression Type (pBA3150)
			1	ACTH		
			2	LH		
			3	FSH		
			4	Alpha-subunit		
			5	TSH		
			6	Prolactin		
			7	Growth Hormone		
Additional Pathology Details - Glioma (One occurrence per Pathology Report)						
Molecular Diagnostics Tissue Analysis	Record if molecular diagnostics analysis has been performed on resected or biopsied tissue of patients with a Glioma This includes analysis for: combined loss of 1p/19q IDH mutation TERT promoter mutation	Code List	1	Performed	R	N/A
			2	Not done/Not Performed		
			3	Insufficient Sample		

	ATRX loss CDKN2A/B deletion Additional genetic and molecular markers as required		9	Not Recorded		
Date of Molecular Diagnostics Tissue Analysis	Record the date that the molecular diagnostics tissue analysis was carried out in patients with a Glioma	ccyymmdd	N/A	N/A	R	N/A
Staging - Site Specific Staging - CSF (Cerebrospinal Fluid) (One occurrence per Core Site Specific Staging group)						
Chang Staging System Stage	Chang staging is now a standard staging procedure for Medulloblastoma, CNS PNET, ATRT, ependymoma and CNS germ cell tumours Note: This should be used in conjunction with information in the Site Specific Staging section in Core. Consequently, Core data items <i>Organisation Site Identifier (Site Specific Stage)</i> and <i>Stage Date (Site Specific Stage)</i> should also be recorded if <i>Chang Staging System Stage</i> is collected	Code List	M0	No evidence of metastatic disease	M	Chang Staging System Stage (CT6560)
			M1	Microscopic tumour cells found in CSF		
			M2	Gross nodular seeding in cerebellum, cerebral subarachnoid space, or in the third or fourth ventricles		
			M3	Gross nodular seeding in spinal subarachnoid space		
			M4	Metastasis outside cerebrospinal axis		
Laboratory Results - Germ Cell CNS tumours (One occurrence per Core - Laboratory Results group)						
Alpha Fetoprotein (Cerebrospinal Fluid)	Maximum level of alpha feto protein in the cerebro spinal fluid at diagnosis. AFP units recorded in kU/l (values > 100,000 are recorded. Note: Measured only for CNS germ cell tumours	max n8 (0-99999999)	N/A	N/A	R	Alpha Fetoprotein (Cerebrospinal Fluid) (CT6530)

Beta Human Chorionic Gonadotropin (Cerebrospinal Fluid)	Maximum CSF level of HCG at diagnosis in IU/l. Note: Measured only for CNS germ cell tumours	max n8 (0-99999999)	N/A	N/A	R	Beta Human Chorionic Gonadotropin (Cerebrospinal Fluid) (CT6550)
Brain/CNS - Oncological Treatment - General (May be multiple occurrences)						
Professional Registration Issuer Code - Consultant (Specialist Neuro-Oncologist)	A code which identifies the professional registration body for the Consultant or Health Care Professional who is responsible for the oncological treatment of the patient	Code List	2	General Dental Council	M	N/A
			3	General Medical Council		
			4	General Optical Council		
			8	Health and Care Professions Council		
			9	Nursing and Midwifery Council		
Specialist Neuro-Oncologist	Record the Specialist Neuro-Oncologist managing the patient undergoing oncological treatment Note: A specialist neuro-oncologist can be defined as: - Having an interest in Brain/CNS cancer - Attends at least 50% of weekly neuro-oncology MDT meetings - Attends at least one national or international neuro-oncology conference every 2 years	See NHS Wales Data Dictionary - Data Item <i>Consultant Code</i>	N/A	N/A	M	N/A
Seen by Specialist Neuro-Oncologist	Record if the patient was seen by a Specialist Neuro-Oncologist	Code List	Y	Yes	R	N/A
			N	No		
			8	Not Applicable		
			9	Not Recorded		
Radiotherapy Course Type	Record the type of course of external beam radiotherapy	Code List	1	Radical - RT courses where ≥ 15 fractions are delivered	R	N/A

	administered for the treatment of cancer		2	Palliative - the aim is solely to relieve symptoms		
			3	Chemoradiotherapy - Radical radiotherapy given in combination with chemotherapy either concurrently or sequentially		
			4	Patient died before radiotherapy treatment		
			5	Patient refused radiotherapy treatment		
			8	Not Applicable - no radiotherapy given		
			9	Not Recorded		
Type of SACT	Record the type of course of cytotoxic or biological drugs administered for the treatment of cancer.	Code List	01	Adjuvant - Chemotherapy given after surgery	R	N/A
			02	Neoadjuvant - Therapy given prior to radiotherapy or first definitive surgery to reduce tumour size		
			04	Palliative - Systemic therapy given for symptom control without curative intent e.g., for patients with metastatic disease at time of diagnosis		
			05	Chemo-radiotherapy - For curative/radical treatment. Can be sequential or concurrent with radiotherapy		
			07	Biological Therapy		

			94	Patient died before SACT treatment		
			95	Patient refused SACT treatment		
			96	Not Applicable - Systemic therapy not given as primary part of therapy		
			99	Not Recorded		
Date Treatment Completed (SACT)	The date cancer treatment course ended	ccyymmdd	N/A	N/A	R	N/A