WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020/29
Date of Issue:	10th December 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 – Patient Group Specific – Childhood[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 19th November 2020

WISB Reference: ISRN 2020 / 030

Summary:

To introduce a new standard for patient group specific cancer minimum reporting requirements for Childhood.

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/Patient Group 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 patient group specific cancer minimum reporting requirements for Childhood.

For adult patients, in addition to referencing Core information standards (National Cancer Data Standards for Wales – Core (DSCN 2019/09)) services are also required to consult all other associated site-specific standards as relevant to the diagnosed tumour site e.g. National Cancer Data Standards for Wales – Site Specific – Haematology (DSCN 2020/12).

For children, as care is delivered through dedicated paediatric services, site-specific information would be recorded by the paediatric service as opposed to multiple teams specialising in specific tumour sites. Consequently, all site-specific information required for childhood cancers is published in this Standard (i.e. National Cancer Data Standards for Wales – Patient Group Specific – Childhood), noting that this will still need to 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 Childhood, listed in NHS England Cancer Outcome and Services Data set (COSD) V9.0 (which includes Pathology V4.0) for comparability[2], 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.

[2] NHS England Cancer Outcome and Services Data set (COSD) V9.0 and Pathology V4.0 present Childhood and Teenage Young Adult (TYA) cancers as a combined category (CTYA).

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 – Patient Group Specific – Childhood 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 patient group 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/patient group specific application of Core data items may differ e.g. a particular site/patient group 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/patient group specific Standard with the respective additional site/patient group 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
Childhood - Core - To be completed for all cases						
Childhood - Referral. To be collected for all Childhood tumours. To carry additional referral details for Childhood						
Specialty (Referrer to Specialist)	The specialty of the person referring to the Principal Treatment Centre (PTC) **Note:** Refer to code list in NHS Wales Data Dictionary *Main Specialty (Consultant)*	Code List		Refer to code list in NHS Wales Data Dictionary *Main Specialty (Consultant)*	R	Specialty (Referrer to Specialist) (CT6050)
Childhood - Diagnosis. To be collected for all Childhood tumours. To carry additional diagnosis details for Childhood						
Consultant Specialty (At Diagnosis)	The specialty of the consultant responsible for the patient at the time of diagnosis **Note:** Refer to code list in NHS Wales Data Dictionary Main Specialty (Consultant)	Code List		Refer to code list in NHS Wales Data Dictionary *Main Specialty (Consultant)*	R	Consultant Specialty (At Diagnosis) (CT6030)
Consultant Age Specialty (At Diagnosis)	The age group specialty of the consultant responsible for the patient at the time of the diagnosis. This will be defined by the MDT	Code List	P	Paediatric	R	Consultant Age Specialty (At Diagnosis) (CT6040)
			T	Teenage and Young Adult		
			A	Adult		
Lansky Performance Scale (at Diagnosis)	Record the Lansky Performance Scale for the patient at the time of diagnosis **Note:** Not applicable to patients over 16 years of age	Code List	100	Fully active, normal	R	N/A
			90	Minor restrictions with strenuous physical activity		
			80	Active, but gets tired more quickly		

			70	Both greater restriction of, and less time spent in, active play		
			60	Up and around, but minimal active play; keeps busy with quieter activities		
			50	Lying around much of the day, but gets dressed; no active play; participates in all quiet play and activities		
			40	Mostly in bed; participates in quiet activities		
			30	Stuck in bed; needs help even for quiet play		
			20	Often sleeping; play is entirely limited to very passive activities		
			10	Does not play nor get out of bed		
			0	Unresponsive		
Childhood - Surgery Details. Additional data item to be collected for Surgery for all Childhood tumours. To carry additional diagnosis details for Childhood						
Time of Surgery	Record the start time that the surgery was performed. The start time is defined as the start of the procedure.	24 hr hh:mm	N/A	N/A	R	N/A
Childhood - Treatment - Chemotherapy. To carry chemotherapy treatment details for Childhood						
Specialty Sub Code (Chemotherapy Consultant)	The age group specialty of the Consultant responsible for prescription of chemotherapy	Code List	P	Paediatric	R	Specialty Sub Code (Chemotherapy Consultant) (CT6160)
			T	Teenage and Young Adult		

			A	Adult		
Childhood - Bone Marrow Transplant						
Bone Marrow Transplant (BMT) Serology or Viral Screen	Has the patient undergone a BMT Serology or Viral screen Serology or Viral Screen tests include - HepB surface antigen (HBsAg), Hep C antibody (anti-HCV), HIV AG/Ab, CMV IgG, Hep B total core antibody (Anti-HBc), Toxoplasma IgG, HTLV 1 and 2, Syphilis total antibody, EBV nuclear antigen, Measles IgG, Varicella IgG, HSV IgG	Code List	Y	Yes	M	N/A
			N	No		
			8	Not Applicable/Not Tested		
			9	Not Known		
Bone Marrow Transplant (BMT) Serology or Viral Screen Date	Date the patient underwent a BMT Serology or Viral Screen	ccyymmdd	N/A	N/A	R	N/A
Bone Marrow Transplant (BMT) Serology or Viral Screen Results	Record the results for the BMT Serology or Viral Screen performed	Code List	1	Positive	R	N/A
			2	Negative		
Clinical Comments on Positive BMT Serology or Viral Screen Results	Record in free text any clinical comments on positive results of the BMT Serology or Viral Screen if required	max an50	N/A	N/A	R	N/A
Childhood - Stem Cell Transplantation						
Core - Treatment - Stem Cell Transplantation. To be completed for all cases, where applicable (One occurrence of this group per core treatment)						
Organisation Site Code - Place where Stem Cell Transplantation was Performed	Record the Organisation Code of the Organisation where the stem cell transplantation was performed	See NHS Wales Data Dictionary - Terms (Organisation Code -	N/A	N/A	R	N/A

		LHB/Trust Site Code)				
Childhood - Principal Treatment Centre. To carry treatment details for the patients Principal Treatment Centre						
Childhood Principal Treatment Centre	Record the patients nominated Childrens Principal Treatment Centre (PTC), whether they have chosen to have treatment at the PTC. If the service is integrated between two PTC's, record both PTC's Repeating data item as multiples can be recorded	Code List	7A4H1	Noah's Ark Children's Hospital	M	Childhood Principal Treatment Centre (CT7600)
			RBS01	Alder Hey Children's NHS Foundation Trust		
			RQ301	Birmingham Children's Hospital NHS Foundation Trust		
Shared Care Centre Site Code	Record the organisation where shared care treatment was provided by a local organisation	Code List	7A35L	Morriston Hospital	R	N/A
			7A2AG	Glangwili General Hospital		
			7A1A1	Ysbyty Glan Clwyd		
			7A1A4	Wrexham Maelor Hospital		
			7A1AU	Ysbyty Gwynedd		
			EN	Shared Care Provider in England		
			NA	Not Applicable		
Childhood - Neuroblastoma						
Childhood - Diagnosis - Neuroblastoma. To carry additional diagnostic details for Neuroblastoma for Childhood						
Life Threatening Symptoms at Presentation	Record if there were any life threatening symptoms at presentation	Code List	Y	Yes	R	Life Threatening Symptoms at Presentation (CT7070)
			N	No		
Childhood - Site Specific Staging - Neuroblastoma. To carry site specific staging details for Neuroblastoma for Childhood						

International Neuroblastoma Risk Group (INRG) Staging System	The International Neuroblastoma Risk Group Staging System (INRGSS) was designed for the International Neuroblastoma Risk Group (INRG) pre-treatment classification system. Unlike the INSS, the INRGSS uses the results from imaging tests taken before surgery. It does not include surgical results or spread to lymph nodes to determine the stage. Knowledge regarding the presence or absence of image defined risk factors (IDRF) are required for this staging system. **Note:** Please refer to user guide for Code List (Text) definitions	Code List	L1	Stage L1	M	International Neuroblastoma Risk Group (INRG) Staging System (CT7050)
			L2	Stage L2		
			M	Stage M		
			MS	Stage MS		
Childhood - Laboratory Results - Neuroblastoma. To carry laboratory details for Neuroblastoma for Childhood						
Urine VMA/Creatinine Ratio	Urinary vanillylmandelic acid (VMA) used to evaluate catecholamine production, useful in the diagnosis of pheochromocytoma and neuroblastoma and in confirmation of elevated catecholamine levels	max n2 n1 Range 0.0-10.0	N/A	N/A	R	Urine VMA/Creatinine Ratio (CT7090)
Childhood - Pathology - Neuroblastoma. To carry additional pathology details for Childhood						
Molecular Diagnostics Code	Chromosomal or genetic markers associated with the brain tumour **Note:** This data item is part of the site-specific standard for Central Nervous System. Whilst that Standard has additional codes, only the adjacent codes are applicable to the Childhood patient group specific standard	Code List	53	Evidence of MYC/MYCN amplification	R	Molecular Diagnostics Code (pBA3070)
			54	Evidence of MYC/MYCN normal copy number		

Childhood - Medulloblastoma						
Childhood - Site Specific Staging - Medulloblastoma. To carry site specific staging details for Medulloblastoma for Childhood						
Chang Staging System Stage	Chang staging is now a standard staging procedure for Medulloblastoma, CNS PNET, ATRT, ependymoma and CNS germ cell tumours	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		
Childhood - Germ Cell CNS Tumours						
Childhood - Laboratory Results - Germ Cell CNS Tumours. To carry laboratory details for Germ Cell CNS Tumours for Childhood						
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. (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. (Measured only for CNS germ cell tumours)	max n8 (0-99999999)	N/A	N/A	R	Beta Human Chorionic Gonadotropin (Cerebrospinal Fluid) (CT6550)
Childhood - Renal Tumours						
Childhood - Site Specific Staging - Wilms Tumour. To carry site specific staging details for Wilms Tumour for Childhood						

Wilms Tumour Stage	Stage is determined by the results of the imaging studies and both the surgical and pathologic findings at nephrectomy	Code List	1	Stage 1	M	Wilms Tumour Stage (CT6330)
			2	Stage 2		
			3	Stage 3		
			4	Stage 4		
			5	Stage 5		
Childhood - Tumour Details - Renal Tumours. To carry additional tumour details for Renal Tumours for Childhood						
Risk Classification (Pathological) After Immediate Nephrectomy	Classification and timing of surgery determine histological risk **Note:** Please refer to user guide for Code List (Text) definitions	Code List	F	Favourable	R	Risk Classification (Pathological) After Immediate Nephrectomy (CT6680)
			U	Unfavourable		
Risk Classification (Pathological) After Pre-Operative Chemotherapy	Classification after pre-operative chemotherapy determines histological risk **Note:** Please refer to user guide for Code List (Text) definitions	Code List	L	Low	R	Risk Classification (Pathological) After Pre-Operative Chemotherapy (CT6340)
			I	Intermediate		
			H	High		
Childhood - Pathology - Renal Tumours (Paediatric Kidney). To carry additional pathology details for Childhood						
Tumour Rupture	Integrity of tumour margins based on pathologist's assessment	Code List	Y	Yes	R	Tumour Rupture (pCT6610)
			N	No		
			X	Not stated		
Anaplastic Nephroblastoma	Is there evidence of anaplasia, focal or diffused, based on established pathological classification	Code List	F	Focal	R	Anaplastic Nephroblastoma (pCT6620)
			D	Diffused		
			U	Uncertain		
Perirenal Fat Invasion	Are there areas of perineal fat suspected for tumour infiltration	Code List	Y	Yes	R	Perirenal Fat Invasion (pCT6630)
			N	No		
			U	Uncertain		
Renal Sinus Invasion	Is there evidence of invasion of renal sinus by tumour	Code List	Y	Yes	R	Renal Sinus Invasion (pCT6640)
			N	No		
			U	Uncertain		
Renal Vein Tumour		Code List	Y	Yes	R	

	Is there evidence of tumour thrombus in the renal vein		N	No		Renal Vein Tumour (pCT6650)
			U	Uncertain		
Viable Tumour at Resection Margin	If the resection margins are involved, is there evidence of viable tumour at the resection margin	Code List	V	Viable	R	Viable Tumour at Resection Margin (pCT6680)
			N	Non-viable		
			X	Not applicable		
Tumour Local Stage (Pathological)	Local stage of the tumour as assessed by Pathologist. Classification system used is International Society of Paediatric Oncology (SIOP)	Code List	1	Stage I	R	Tumour Local Stage (Pathological) (pCT6670)
			2	Stage II		
			3	Stage III		
Childhood - Hepatoblastoma						
Childhood - Site Specific Staging - Hepatoblastoma. To carry site specific staging details for Hepatoblastoma for Childhood						
Pretext Staging System Stage	Pretext 1-4 refers to sectors of liver involved	Code List	1	Stage 1: Tumour involves only 1 quadrant	M	Pretext Staging System Stage (CT6500)
			2	Stage 2: Tumour involves 2 adjoining quadrants; 2 adjoining sections free		
			3	Stage 3: Tumour involves 3 adjoining quadrants; only 1 quadrant free or 2 non-adjoining quadrants free		
			4	Stage 4: Tumour involves all 4 quadrants		
			9	Not Known		
Pretext Annotation Factors	Additional Pretext staging used to describe the annotation factors relating to the liver	Code List	V	Extension' into the vena cava and/or all three hepatic veins	M	Pretext Annotation Factors (CT7500)

			P	Extension' into the main and/or both left and right branches of the portal vein		
			E	Extra-hepatic disease		
			M	Presence of distant metastases		
			C	Caudate lode		
			F	Multiple tumour nodules		
			N	Lymph node involvement		
			R	Rupture		
			Z	None		
Childhood - Retinoblastoma						
Childhood - Site Specific Staging - Retinoblastoma. To carry site specific staging details for Retinoblastoma for Childhood						
International Staging System for Retinoblastoma	The international staging system for intraocular and extraocular retinoblastoma	Code List	0	Stage 0: Patients treated conservatively, grouped according to intraocular classification	M	International Staging System for Retinoblastoma (CT6800)
			1	Stage 1: Eye enucleated, completely resected histologically		
			2	Stage 2: Eye enucleated, microscopic residual tumour		
			3	Stage 3: Regional extension (a) Overt orbital disease (b) Pre-auricular or		

				cervical lymph node extension		
			4	Stage 4: Metastatic disease (a) Haematogenous metastasis, 1 Single lesion, 2 Multiple lesions (b) CNS extension, 1 Prechiasmatic lesion, 2 CNS mass, 3 Leptomeningeal disease		
Childhood - Tumour Details - Retinoblastoma. To carry additional tumour details for Retinoblastoma for Childhood (Multiple occurrences can be added for left and right)						
Retinoblastoma Assessment Laterality	The laterality for which the retinoblastoma details were recorded	Code List	L	Left eye	R	Retinoblastoma Assessment Laterality (CT6780)
			R	Right eye		
International Classification for Intraocular Retinoblastoma	The intraocular classification for retinoblastoma as approved by the international community	Code List	A	Group A Small tumour away from the foveola and disc: -Tumours less than 3 mm in greatest dimension confined to the retina, and - Located at least 3mm from the foveola and 1.5 mm from the optic disc	R	International Classification for Intraocular Retinoblastoma (CT6790)

			B	Group B All remaining tumours confined to the retina: - All tumours confined to the retina not in group A - Subretinal fluid (without subretinal seeding) less than 3 mm from the base of the tumour		
			C	Group C Local subretinal fluid or seeding: - Subretinal fluid alone greater than 3mm to less than 6 mm from the tumour - Vitreous seeding or subretinal seeding less than 3 mm from tumour		
			D	Group D Diffuse subretinal fluid or seeding: - Subretinal fluid alone greater than 6 mm from the tumour - Vitreous seeding or subretinal seeding greater than 3 mm from tumour		

			E	Group E Presence of one or more of these poor prognosis features: - Greater than 2/3 globe filled with tumour - Tumour in anterior segment - Tumour in or on the ciliary body - Iris neovascularisation - Neovascular glaucoma - Opaque media from haemorrhage - Tumour necrosis with septic orbital cellulitis - Phthisis bulbi		
Childhood - Paediatric Haematology						
Childhood - Diagnosis - Paediatric Haematology. Record for Paediatric Haematology						
Morphology - WHO Classification of Tumours of Haematopoietic and Lymphoid tissues 2017	To use the gold standard classification to record the morphological type of haematopoietic/lymphoid tissue - this is the most reliable method of recording the type of tumour which integrates the diagnosis - to be used as the lead code and translate to other coding systems as required	an6	N/A	N/A	R	N/A
Childhood - Paediatric Myelodysplasia						
Childhood - Laboratory Results - Paediatric Myelodysplasia. To carry additional tumour details for Paediatric Myelodysplasia for Childhood						

Bone Marrow Blasts	Percentage value of Bone Marrow Blasts	max n3 Range (%) 0-100	N/A	N/A	R	Bone Marrow Blasts (Bone Marrow Blast Cells Percentage)
Cellularity	Percentage value of cellularity	max n3 Range (%) 0-100	N/A	N/A	R	Cellularity (CT7340)
DEB Test	Record the outcome of DEB (Diepoxybutane) Test	Code List	P	Positive	R	DEB Test (CT7350)
			N	Negative		
			9	Not Known		
Dysplastic Haemopoiesis	Record if the bone marrow produced (Haemopoiesis) is Unilineage, Bilineage or Trilineages dysplastic	Code List	1	Unilineage	R	Dysplastic Haemopoiesis (CT7360)
			2	Bilineage		
			3	Trilineage		
Childhood - Diagnosis - Paediatric Myelodysplasia. To carry diagnostic details for Paediatric Myelodysplasia for Childhood						
Paediatric Myelodysplasia	Record the Paediatric Myelodysplasia clinical findings at diagnosis (Repeating data item - more than one finding may be chosen)	Code List	1	De Novo MDS	R	Paediatric Myelodysplasia (CT7260)
			2	Refractory Cytopenia		
			3	Refractory Cytopenia with Ringed Sideroblasts		
			4	Refractory Cytopenia with Excess Blasts		
			5	RAEB in Transformation		
Underlying Disease associated with MDS	Record any underlying disease associated with MDS at diagnosis (Repeating data item - more than one finding may be chosen)	Code List	1	IBFMS	R	Underlying Disease associated with MDS (CT7270)
			2	Previous Malignancy		
			3	Radiation		
			4	Toxic Insult		

			5	Mitochondrial Disorder		
			6	Other Systematic Disorder		
			7	Congenital Anomalies		
			9	No underlying disease		
Congenital Anomalies	Record any congenital anomalies associated with MDS at diagnosis	Max an300	N/A	N/A	R	Congenital Anomalies (CT7380)
Myelodysplasia Symptoms at Diagnosis	Record any other Myelodysplasia symptoms present at diagnosis (Repeating data item - more than one finding may be chosen)	Code List	1	Consanguinity	R	Myelodysplasia Symptoms at Diagnosis (CT7310)
			2	Organomegaly at Diagnosis		
			3	Lymphadenopathy at Diagnosis		
			4	Severe Infections prior to Diagnosis		
			5	Immunodeficiency at Diagnosis		
IPSS-R (Myelodysplasia)	The Revised International Prognostic Scoring System (IPSS-R) for Myelodysplastic Syndromes Risk Assessment Calculator is derived from Haemoglobin, Absolute Neutrophil Count, Platelets and Bone Marrow Blasts. Refer to User Guide for more information	mx n1.n1	N/A	N/A	R	IPSS-R (Myelodysplasia) (HA9000)
Childhood - Acute Lymphoblastic Leukaemia (ALL)						
Childhood - Laboratory Results - Acute Lymphoblastic Leukaemia (ALL). To carry additional tumour details for Acute Lymphoblastic Leukaemia (ALL) for Childhood						
White Blood Cell Count (Highest Pre Treatment)	Highest white blood cell count pre-treatment (x10^9 per litre).	max n3.n1 Range 0.0 to 999.9	N/A	N/A	R	White Blood Cell Count (Highest Pre Treatment) (HA8150)
Cytogenetic Risk Code		Code List	F	Favourable	R	N/A
			A	Adverse		

	Cytogenetic analysis of bone marrow (preferably) or blood sample		I	Intermediate		
			N	No Result		
			O	Other		
Cytogenetics Subsidiary Comment	Description of cytogenetic findings	max an50	N/A	N/A	R	Cytogenetics Subsidiary Comment (CT6240)
Post Induction MRD (ALL Response)	Percentage of leukaemic cells present at the end of Induction (Day 28 Bone Marrow), Minimal Residual Disease (MRD)	Code List	1	0%	M	Post Induction MRD (CT7700)
			2	<0.01%		
			3	<0.1%		
			4	<1%		
			5	<5%		
			6	>=5%		
			9	Unknown		
Childhood - Diagnosis - Acute Lymphoblastic Leukaemia (ALL). To carry additional Diagnosis details for Acute Lymphoblastic Leukaemia (ALL) for Childhood						
Extramedullary Disease	Site/s of disease identified outside bone marrow, including presence of blasts within CSF (more than one option can be recorded)	Code List	1	CNS1 (without blasts)	M	Extramedullary Disease (HA8270)
			2	CNS2 (<5WBC in the CSF with blasts)		
			3	CNS3 (≥WBC in the CSF with blasts		
			4	Testes		
			9	Other		
Childhood - Acute Lymphoblastic Leukaemia (ALL). To carry additional tumour details for Acute Lymphoblastic Leukaemia (ALL) for Childhood						
Mixed Lineage Leukaemia Gene (MLL) Status	Record the gene status for the patient	Code List	1	Rearranged	R	N/A
			2	Normal		
			X	Not stated		

BCR-ABL Gene Rearrangement	Record the BCR-ABL gene rearrangement status. This is recorded at the time of bone marrow, at diagnosis	Code List	P	Present	R	N/A
			N	Not present		
			9	Not Known		
Childhood - Acute Myeloid Leukaemia (AML)						
Childhood - Laboratory Results - Acute Myeloid Leukaemia (AML). To carry additional tumour details for Acute Myeloid Leukaemia (AML) for Childhood						
White Blood Cell Count (Highest Pre Treatment)	Highest white blood cell count pre-treatment (x10^9 per litre).	max n3.n1 Range 0.0 to 999.9			R	White Blood Cell Count (Highest Pre Treatment) (HA8150)
Cytogenetic Risk Code	Cytogenetic analysis of bone marrow (preferably) or blood sample	Code List	F	Favourable	R	N/A
			A	Adverse		
			I	Intermediate		
			N	No Result		
			O	Other		
Cytogenetics Subsidiary Comment	Description of cytogenetic findings	max an50			R	Cytogenetics Subsidiary Comment (CT6240)
Post Induction MRD (AML Response)	Percentage of leukaemic cells present at the end of Minimal Residual Disease (MRD) Induction following 2 cycles of chemotherapy	Code List	1	0%	M	Post Induction MRD (CT7700)
			2	<0.01%		
			3	<0.1%		
			4	<1%		
			5	<5%		
			6	>=5%		
			9	Unknown		
Childhood - Diagnosis - Acute Myeloid Leukaemia (AML). To carry additional Diagnosis details for Acute Myeloid Leukaemia (AML) for Childhood						
European Leukaemia NET (ELN) Genetic Risk (Acute Myeloid Leukaemia)	Cytogenetic and molecular analysis of bone marrow (preferably) or blood	Code List	F	Favourable	R	European Leukaemia NET (ELN) Genetic Risk (Acute Myeloid Leukaemia) (HA9200)
			I	Intermediate		
			A	Adverse		
			N	No results		

FAB Classification	FAB Classification of AML used during diagnosis of acute myeloid leukaemia (AML)	Code List	M0	Undifferentiated acute myeloblastic leukaemia	R	FAB Classification (CT7160)
			M1	Acute myeloblastic leukaemia with minimal maturation		
			M2	Acute myeloblastic leukaemia with maturation		
			M3	Acute promyelocytic leukaemia		
			M4	Acute myelomonocytic leukaemia		
			M4EOS	Acute myelomonocytic leukaemia with eosinophilia		
			M5	Acute monocytic leukaemia		
			M6	Acute erythroid leukaemia		
			M7	Acute megakaryocytic leukaemia		
Paediatric Cytogenetic/ Molecular Genetic Risk Group	Risk groups for ages 0-18 - cytogenetic and molecular genetic abnormalities	Code List	1	Good Risk	R	Paediatric Cytogenetic/ Molecular Genetic Risk Group (CT7170)
			2	Intermediate Risk		
			3	Poor Risk		
			9	Not Known		
AML Risk Factors	Record if any of these risk factors are present in a patient at diagnosis	Code List	1	De Novo	R	AML Risk Factors (CT7180)
			2	High Risk MDS		
			3	Secondary AML		
Extramedullary Disease	Site/s of disease identified outside bone marrow, including presence	Code List	1	CNS1 (without blasts)	M	Extramedullary Disease (HA8270)
			2	CNS2 (<5WBC in the CSF with blasts)		

	of blasts within CSF (more than one option can be recorded)		3	CNS3 (≥WBC in the CSF with blasts		
			4	Testes		
			9	Other		
Cytogenetic Marker	Specify relevant cytogenetic marker (this is related to morphology from WHO classification)	Code List	01	t(8:21)(q22;q22.1); RUNX1-RUNX1T1 (9896/3)	R	N/A
			02	inv(16)(p13.1q22) or t(16;16)(p13, 1;q22); CBFB-MYH11(9871/3)		
			03	PML-RARA (9866/3)		
			04	t(9;11)(p21 .3;q23.3); KMT2A-MLLT3 (9897/3)		
			05	t(6;9)(p23;q34.1); DEK-NUP214 (9865/3)		
			06	inv(3)(q21.3q26.2) or (t3;3)(q21.3;q26.2); GATA2, MECOM (9869/3)		
			07	t(1;22)(p13.3;q13.1) ; RBM15-MKL1 (9911/3)		
			08	AML with BCR-ABL1 (9912/3)		
			09	AML with mutated NPM1 (9877/3)		
			10	AML with biallelic mutation of CEBPA (9878/3)		
			11	AML with mutated RUNX1 (9879/3)		

Cytogenetic Marker - Other	Specify the Other Cytogenetic Marker **Note:** This is only required if the marker is not one of those listed in data item Cytogenetic Marker	max an50	N/A	N/A	R	N/A
Molecular Genetic Results - FLT-3 and ITD	Specify the molecular genetic results for FLT-3 and ITD	Code List	1	Positive	R	N/A
			2	Negative		
Molecular Genetic Results - NPM1	Specify the molecular genetic results for NPM1	Code List	1	Positive	R	N/A
			2	Negative		
Childhood - Mixed Phenotype Acute Leukaemia						
Childhood - Diagnosis - Mixed Phenotype Acute Leukaemia. To carry diagnostic details for Mixed Phenotype Acute Leukaemia for Childhood						
Mixed Phenotype Symptoms (At Diagnosis)	Record if any of the associated symptoms were present at diagnosis (Repeating data item - more than one finding may be chosen)	Code List	1	Hepatomegaly	R	Mixed Phenotype Symptoms (At Diagnosis) (CT7200)
			2	Splenomegaly		
			3	Lymphadenopathy		
			4	Mediastinal Mass		
EGIL Score	The EGIL Score (European Group for the Immunological Classification of Leukaemia) assigns score points to major antigens to determine if certain lineage is present	Code List	1	2 - Points	R	EGIL Score (CT7240)
			2	1 - Point		
			3	0.5 - Point		
CD19 Status	Record the CD19 status. Morphology combined with CD19 status is used to inform decision on type of chemotherapy treatment	Code List	P	Present	R	N/A
			N	Not present		
			9	Not Known		
Childhood - Chronic Myeloid Leukaemia (CML)						
Childhood - Chronic Myeloid Leukaemia (CML). To carry additional details for CML for Childhood						
		Code List	Y	Yes	R	

Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy		N 9	No Not known		Primary Induction Failure (CT7110)
Sokal Index (Chronic Myeloid Leukaemia)	Index derived from age at diagnosis, spleen size, platelet count, myeloblasts %	max n1.n1	N/A	N/A	D	Sokal Index (Chronic Myeloid Leukaemia) (HA8010)
Blood Myeloblasts Percentage	Myeloblasts as percentage of total white cells. **Note:** This is a derived data item where the absolute value of myeloblasts /white cell count x 100 = % blood myeloblasts	max n3 %. Range 0-100	N/A	N/A	D	N/A
Blood Basophils Percentage	Basophils as percentage of total white cells. **Note:** This is a derived data item where the absolute value of basophils /white cell count x 100 = % blood basophils	max n3 %. Range 0-100	N/A	N/A	D	N/A
Blood Eosinophils Percentage	Eosinophils as percentage of total white cells. **Note:** This is a derived data item where the absolute value of eosinophils /white cell count x 100 = % blood eosinophils	max n3 %. Range 0-100	N/A	N/A	D	N/A
BCR Level ABL Ratio at 12 months	Record the BCR Level ABL Ratio at 12 months **Note:** Undetectable must be recorded as text as clinically it is not the same as 0%	Record % with 4 decimal places e.g., 0.0032 or Undetectable	N/A	N/A	R	N/A
Molecular Response at 12 months	Record the result of the molecular response at 12 months	max n3 %. Range 0-100	N/A	N/A	R	N/A
Treatment Response		Code List	99	NE - Non Evaluable	R	N/A

	To indicate the patient's response to treatment		07	BC - Blast Crisis		
			08	AD - Accelerated Disease		
			09	CP - Chronic Phase bcr/abl PCR > 0.1%		
			10	LMR - Loss of MR3		
			11	MR3 - Molecular Response 3 - bcr/abl PCR <0.1%		
			12	MR4 - Molecular Response 4 - bcr/abl PCR <0.01%		
			13	MR5 - Molecular Response 5 - bcr/abl PCR <0.001%		
Childhood - Non Hodgkins Lymphoma (NHL)						
Childhood - Site Specific Staging - Non Hodgkins Lymphoma (NHL). To carry site specific staging details for Non-Hodgkins Lymphoma (NHL) for Childhood						
Murphy (ST JUDE) Stage	The St Jude Children's Research Hospital model (Murphy Staging), which separates patients on the basis of limited versus extensive disease. (http://www.cancer.gov/cancertopics/pdq/treatment) **Note:** Associated information is recorded in Core – Site Specific Staging Section	Code List	1	Stage 1	M	Murphy (ST JUDE) Stage (CT6250)
			2	Stage 2		
			3	Stage 3		
			4	Stage 4		
Childhood - Molecular and Biomarkers - Somatic Testing for Targeted Therapy and Personalised Therapy - Non Hodgkins Lymphoma (NHL). To carry molecular and biomarker result details for Non-Hodgkins Lymphoma (NHL) for Childhood						
ALK Fusion Status for ALCL (Non Hodgkins Lymphoma)	The Anaplastic Lymphoma Kinase (ALK) protein is expressed in a subset of ALCL due to underlying gene fusion events. Its presence or absence distinguishes	Code List	1	Positive	M	ALK Fusion Status for ALCL (CT6260)
			2	Negative		
			3	Indeterminate/Test Failed		

	prognostically important subsets of this diagnosis		8	Not Applicable (Not Tested)		
			9	Not Known		
Childhood - Hodgkins Lymphoma						
Childhood - Site Specific Staging - Hodgkins Lymphoma. To carry site specific staging details for Hodgkins Lymphoma for Childhood						
Ann Arbor Stage	Staging based on location of detected disease	Code List	1	I = One region of lymph nodes, or spleen or thymus or Waldeyer's ring enlarged	M	Ann Arbor Stage (HA8280)
			2	II = 2 regions of lymph nodes enlarged on same side of diaphragm		
			3	III = lymph nodes enlarged on both sides of diaphragm		
			4	IV = disease outside lymph nodes e.g., liver, bone marrow		
Childhood - Diagnosis - Hodgkins Lymphoma. To carry additional diagnosis details for Hodgkins Lymphoma for Childhood						
Ann Arbor Symptoms	Additional stage designation based on presence or absence of specific symptoms One occurrence per core staging - collected at Diagnosis	Code List	A	No symptoms	M	Ann Arbor Symptoms (HA8290)
			B	Presence of any of the following: unexplained persistent or recurrent fever (greater than 38°C/101.5°F), drenching night sweats, unexplained weight loss of 10% or more within the last 6 months		

Ann Arbor Extranodality	Additional staging designation based on extranodal involvement **Note:** <u>For Primary Nodal Lymphoma</u>: Code E if there is involvement of a single extranodal site by contiguous spread (i.e. directly adjoining) from the known nodal group. <u>For Primary Extranodal Lymphoma</u>: Code E if there is a single extranodal lesion with or without lymphatic involvement in the draining area (e.g., a thyroid lymphoma with draining cervical lymph node involvement = IIE) The designation of Stage IV for nodal disease implies disseminated disease involving (distant) extranodal sites. Multiple extranodal deposits should be considered Stage IV and E should not be used. However by convention, involvement of the bone marrow, liver, lung, pleura and CSF are always considered Stage IV even if the disease is isolated to that organ.	Code List	E	E - Extranodal involvement	M	Ann Arbor Extranodality (HA8300)
			0	No Extranodal involvement		
Erythrocyte Sedimentation Rate (ESR)	Record the ESR at time of diagnosis	n3 mm/hr	N/A	N/A	R	N/A
Childhood - Sarcoma - Osteosarcoma						
Childhood - Diagnosis - Sarcoma - Osteosarcoma. To carry diagnosis details for Osteosarcoma for Childhood						
Sarcoma Tumour Site (Bone)	Location of the bone sarcoma within the body as defined by OPCS4 code. This is (more specific	Code List	Z639	Cranium	R	Sarcoma Tumour Site (Bone) (SA11000)
			Z649	Face		
			Z659	Jaw		

	than ICD10/ICD03 Sites) **Note:** i. The OPCS-4 site codes here are used in the context of providing a list of established reference codes already in use and not in the context in which they would typically occur i.e. in conjunction with OPCS-4 procedure codes. ii. Use Cranium (Z639) for instances of Sarcoma of the Skull		Z663	Cervical Spine		
			Z664	Thoracic Spine		
			Z665	Lumbar Spine		
			Z681	Clavicle		
			Z684	Glenoid		
			Z685	Scapula		
			Z699	Humerus		
			Z709	Radius		
			Z719	Ulna		
			Z724	Carpal		
			Z732	Metacarpal		
			Z733	Thumb		
			Z742	Finger		
			Z746	Sternum		
			Z751	Ileum		
			Z753	Ischium		
			Z754	Pubis		
			Z755	Acetabulum		
			Z756	Coccyx		
			Z769	Femur		
			Z779	Tibia		
			Z786	Fibula		
			Z787	Patella		
			Z799	Tarsus		
			Z802	Metatarsus		
			Z803	Great Toe		
			Z804	Toe		
			Z928	Other Specified Region of Body		
			Z929	Unknown		
		Code List	PR	Proximal	R	

Sarcoma Tumour Subsite (Bone)	Sub-location of the bone sarcoma within the tumour site. This gives a more details location of the tumour and should be recorded by speciality centres treating the patient.		DS	Distal		Sarcoma Tumour Subsite (Bone) (SA11010)
			DP	Diaphyseal (Middle)		
			TO	Total		
			OO	Other		
			NK	Not Known		
Childhood - Sarcoma - Ewings						
Childhood - Diagnosis - Sarcoma - Ewings. To carry diagnosis details for Ewings for Childhood						
Sarcoma Tumour Site (Bone)	Location of the bone sarcoma within the body as defined by OPCS4 code. This is (more specific than ICD10/ICD03 Sites) **Note:** i. The OPCS-4 site codes here are used in the context of providing a list of established reference codes already in use and not in the context in which they would typically occur i.e. in conjunction with OPCS-4 procedure codes. ii. Use Cranium (Z639) for instances of Sarcoma of the Skull	Code List	Z639	Cranium	R	Sarcoma Tumour Site (Bone) (SA11000)
			Z649	Face		
			Z659	Jaw		
			Z663	Cervical Spine		
			Z664	Thoracic Spine		
			Z665	Lumbar Spine		
			Z681	Clavicle		
			Z684	Glenoid		
			Z685	Scapula		
			Z699	Humerus		
			Z709	Radius		
			Z719	Ulna		
			Z724	Carpal		
			Z732	Metacarpal		
			Z733	Thumb		
			Z742	Finger		
			Z746	Sternum		
			Z751	Ileum		
			Z753	Ischium		
			Z754	Pubis		
			Z755	Acetabulum		
			Z756	Coccyx		
			Z769	Femur		

			Z779	Tibia		
			Z786	Fibula		
			Z787	Patella		
			Z799	Tarsus		
			Z802	Metatarsus		
			Z803	Great Toe		
			Z804	Toe		
			Z928	Other Specified Region of Body		
			Z929	Unknown		
Sarcoma Tumour Subsite (Bone)	Sub-location of the bone sarcoma within the tumour site. This gives a more details location of the tumour and should be recorded by speciality centres treating the patient.	Code List	PR	Proximal	R	Sarcoma Tumour Subsite (Bone) (SA11010)
			DS	Distal		
			DP	Diaphyseal (Middle)		
			TO	Total		
			OO	Other		
			NK	Not Known		
Tumour Volume at Diagnosis	Radiologically calculated estimate of tumour volume at diagnosis which has value in determining treatment.	Code List	L	Less than 200ml	M	Tumour Volume at Diagnosis (CT6450)
			M	200ml or greater		
Childhood - Laboratory Results - Ewings. To carry additional Laboratory details for Ewings for Childhood						
Cytogenetics for Ewings Sarcoma	Cytogenetic analysis	Code List	11	t(11;22)	M	Cytogenetics for Ewings Sarcoma (CT6460)
			VT	Variant Translocation		
			NG	Negative		
			NA	Not Available		
Childhood - Sarcoma - Other Soft Tissue Site (excluding Rhabdomyosarcoma)						
Childhood - Diagnosis - Sarcoma - Other Soft Tissue Site (excluding Rhabdomyosarcoma). To carry diagnosis details for Other Soft Tissue Sites for Childhood						
Sarcoma Tumour Site (Soft Tissue)	Location of the soft tissue sarcoma within the body as defined by OPCS4 code. This is (more specific	Code List	Z272	Stomach	R	Sarcoma Tumour Site (Soft Tissue) (SA11080)
			Z301	Liver		
			Z459	Uterus		

	than ICD10/ICD02 sites) **Note:** The OPCS-4 site codes here are used in the context of providing a list of established reference codes already in use and not in the context in which they would typically occur i.e. in conjunction with OPCS-4 procedure codes.		Z533	Peritoneum		
			Z891	Shoulder		
			Z892	Upper Arm		
			Z893	Forearm		
			Z894	Hand		
			Z898	Specified Arm Region (to include wrist and elbow)		
			Z901	Buttock		
			Z903	Upper Leg (to include thigh)		
			Z904	Lower Leg (to include calf)		
			Z905	Foot		
			Z908	Specified leg region (to include groin, knee, ankle)		
			Z921	Head		
			Z923	Neck		
			Z924	Chest (to include Intrathoracic)		
			Z927	Trunk (to include upper and lower)		
			Z928	Other Specified Region of Body		
			Z929	Unknown		
Sarcoma Tumour Subsite (Soft Tissue)	Sub-location of the soft tissue sarcoma within the tumour site. This gives a more details location of the tumour and should be recorded by specialist centre treating the patient	Code List	RP	Retroperitoneal (subsite of Z53.3)	R	Sarcoma Tumour Subsite (Soft Tissue) (SA11090)
			IP	Intraperitoneal (subsite of Z53.3)		
			WR	Wrist (Subsite of Z89.8)		
			EB	Elbow (Subsite of Z89.8)		

			UT	Upper Trunk (Subsite of Z92.7)		
			LT	Lower Trunk (Subsite of Z92.7)		
			AD	Adductors (subsite of Z90.3 & Z90.4)		
			AN	Anterior (subsite of Z90.3 & Z90.4)		
			PO	Posterior (subsite of Z90.3 & Z90.4)		
			LA	Lateral (Subsite of Z90.3 & Z90.4)		
			NK	Not Known (No record or Test not carried out)		
			NA	Not Applicable		
Childhood - Sarcoma - Rhabdomyosarcoma and Other Soft Tissue Sarcomas						
Childhood - Diagnosis - Rhabdomyosarcoma and Other Soft Tissue Sarcomas. To carry diagnosis details for Rhabdomyosarcoma and Other Soft Tissue Sarcomas for Childhood						
IRS Post Surgical Group	IRS group defines the post-surgical disease status at diagnosis. This information should be available for the MDT discussion following treatment but will only apply to a small number of cases. **Note:** Please refer to user guide for Code List (Text) definitions	Code List	1	Group 1 - Primary Complete Resection	R	IRS Post Surgical Group (CT6350)
			2	Group 2 - Microscopic residual disease or primary complete resection with (completely resected) lymph node involvement		
			3	Group 3 - Macroscopic residual disease		
			4	Group 4 - Distant Metastases		

IRS Post Surgical Group Date	The date on which the IRS Post Surgical Group was recorded	ccyymmdd			R	IRS Post Surgical Group Date (CT6750)
Rhabdomyosarcoma Site Prognosis Code	Grouping of anatomical sites which imply prognostic significance. This information should be available for the MDT discussion but will only apply to a small number of cases.	Code List	F	Favourable Sites - Orbit, Genitourinary non bladder prostate, Non-parameningeal Head and Neck	R	Rhabdomyosarcoma Site Prognosis Code (CT6370)
			U	Unfavourable Sites - all other sites of disease		
Childhood - Laboratory Results - Rhabdomyosarcoma and Other Soft Tissue Sarcomas. To carry additional Laboratory details for Rhabdomyosarcoma and Other Soft Tissue Sarcomas for Childhood						
Cytogenetics for Alveolar Rhabdomyosarcoma	Presence of a specific cytogenetic abnormality. This information should be available for the MDT discussion but will only apply to a small number of cases.	Code List	P	Fusion positive	M	Cytogenetics for Alveolar Rhabdomyosarcoma (CT6360)
			N	Fusion negative		
			X	Non informative		
			9	Not known (Not available)		
Childhood - Treatment – Children's Cancer and Leukaemia Group (CCLG) Guidelines. To carry treatment details for the Children's Cancer and Leukaemia Group (CCLG)						
Treated According to CCLG Guidelines	Record whether a patient was treated according to the Children's Cancer and Leukaemia Group Guidelines. Choose "Not Applicable" where there is a Clinical Trial open or no guideline is available. **Note:** Of the adjacent codes *Not Applicable* is not present in COSD. This has been added here to provide greater granularity.	Code List	Y	Yes	R	Treated According to CCLG Guidelines (CT7000)
			N	No		
			9	Not Known		
			8	Not Applicable		

CCLG Guideline Name	Record the name of the Children's Cancer and Leukaemia Group Guideline used	Max an100	N/A	N/A	R	CCLG Guideline Name (CT7010)
Patient - Fertility Information (Multiples can be added through pathway)						
Fertility Preservation Assessment Undertaken	Record if the patient underwent a fertility preservation assessment	Code List	01	Yes	R	N/A
			02	No		
Reason No Assessment Undertaken	Record the reason why No fertility assessment was undertaken **Note:** This data item is only required where *Fertility Preservation Assessment Undertaken* is recorded as *No*.	Code List	01	Not required/not appropriate	R	N/A
			02	Unable to assess due to clinical urgency to commence treatment		
			03	Offered but declined - patient preference		
			04	Not offered		
			09	Not known		
Fertility - Point in Pathway	The point in the pathway when fertility services was allocated	Code List	91	Point of Suspicion	R	N/A
			01	Initial cancer diagnosis		
			02	Start of treatment		
			03	During treatment		
			04	End of treatment		
			05	Diagnosis of recurrence		
			06	Transition to palliative care		
			07	Prehabilitation		
			08	Late onset - consequence of cancer		
			98	Other		

Date referred to Wales Fertility Institute	Record the date that the patient was referred to the Wales Fertility Institute	ccyymmdd	N/A	N/A	O	N/A
Type of Fertility Preservation Procedure Performed	Record the type of fertility preservation procedure that was performed	Code List	01	Sperm Collection	R	N/A
			02	Egg Collection		
			03	Testicular Biopsy		
			04	Ovarian Biopsy		
			05	Not Done		
Patient - Clinical Trials (Multiples can be added through pathway)						
Patient Trial Status*	An indication of whether a patient is taking part in a clinical trial **Note:** Of the adjacent codes *Patient not approached/Did not meet trial criteria* and *No trial available* are not present in Core. They have been added here to provide greater granularity.	Code List	01	Patient approached, consented to and entered clinical trial	R	Patient Trial Status (Cancer) (CR1290)
			02	Patient approached, but declined clinical trial		
			03	Patient approached and consented, but failed screening		
			04	Patient not approached/Did not meet trial criteria		
			09	Not Known (Not Recorded)		
			99	No Trial available		