WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020 / 12
Date of Issue:	25th June 2020

Ministerial / Official Letter: N/A	**Subject:** National Cancer Data Standards for Wales – Site Specific - Haematology[1] [1](For the purposes of COSD v9 reference, includes Pathology v4)
Sponsor: Cancer Implementation Group (CIG) Welsh Government	
Implementation Date: The Cancer Informatics Solution (CIS) MUST comply with this Standard with immediate effect. Services/data providers, however, MUST operate to **'business as usual'** in terms of the data being collected and reported (see section Actions Required in this Notice)	

DATA STANDARDS CHANGE NOTICE

A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.

This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 18th June 2020

WISB Reference: ISRN 2020 / 008

Summary:

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

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 Haematology, i.e.:

- Lymphoma
- Leukaemia
- Myeloma

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 Haematology, 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 – Haematology 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
Core - Diagnosis. Record for All Haematopoietic and Lymphoid Malignancies						
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	M	N/A
Core - Patient. Record for All Haematopoietic and Lymphoid Malignancies						
Bone Marrow Transplant (BMT) Serology or Viral Screen	Has the patient undergone a BMT Serology or Viral Screen **Note:** 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 IgG	Code List	Y	Yes	M	N/A
			N	No		
			9	Not recorded		
Bone Marrow Transplant (BMT) Serology or Viral Screen Date	Date the patient underwent a BMT Serology or Viral Screen **Note:** This data item is only required where *Bone Marrow Transplant (BMT) Serology or Viral Screen* is recorded as *Yes*	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 **Note:** This data item is only required	Code List	1	Positive	R	N/A

	where *Bone Marrow Transplant (BMT) Serology or Viral Screen* is recorded as *Yes*		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 **Note:** This data item is only required where *Bone Marrow Transplant (BMT) Serology or Viral Screen Results* is recorded as *Positive*	max an50	N/A	N/A	R	N/A
Patient Eligibility Status for Stem Cell Transplantation	An indication of whether a patient is eligible for stem cell transplantation as part of the pathway **Note:** If *Eligible* is recorded for this data item, the section *Stem Cell Transplantation* should also be completed	Code List	1	Eligible	R	N/A
			2	Not Eligible		
Tissue Typing Sent for Analysis	Has tissue been sent for tissue typing	Code List	Y	Yes	R	N/A
			N	No		
Date Tissue Sent	Record the date the tissue was sent for tissue typing/analysis **Note:** Only required if *Tissue Typing Sent for Analysis* is recorded as *Yes*	ccyymmdd	N/A	N/A	R	N/A
Core. Record for all Haematopoietic and Lymphoid Malignancy Data Items						
Transfusion Dependent	Does the patient require regular blood transfusions **Note:** Required to derive the DIPSS Plus prognostic score	Code List	Y	Yes	M	N/A
			N	No		

Blood Haemoglobin Concentration (Grams per Litre) (at diagnosis)	Blood haemoglobin concentration g/l. **Note:** Required to derive the: DIPSS & DIPSS Plus prognostic score IPSS & IPSS-R Index prognostic score RAI stage Binet stage Hasenclever Index FLIPI-2 Index	max n3	N/A	N/A	M	N/A
White Blood Cell Count (Highest Pre Treatment)	Highest white blood cell count pre-treatment (x10^9 per litre). **Note:** Required to derive the: DIPSS & DIPSS Plus prognostic score RAI stage MIPI Score Hasenclever Index	max n3.max n1 Range 0.0 to 999.9	N/A	N/A	M	White Blood Cell Count (Highest Pre Treatment) (HA8150)
Platelet Count	Level of platelets in blood as n x10^9 per litre, to be collected at diagnosis. **Note:** Required to derive the: DIPSS Plus prognostic score IPSS & IPSS-R Index prognostic score RAI stage Binet stage Sokal Index	max n4 Range 0-5000	N/A	N/A	M	N/A
Neutrophil Count	Blood neutrophil count n/dl. **Note:** Required to derive the IPSS & IPSS-R Index prognostic score	max n3.max n1 Range 0.0 to 999.9	N/A	N/A	M	N/A
		Code List	Y	Yes	M	N/A

Bone Marrow Examination Performed	Has the patient had a bone marrow examination		N	No		
			9	Not Known		
Bone Marrow Involved	Is the patient's bone marrow involved **Note:** This data item is only required where *Bone Marrow Examination Performed* is recorded as *Yes*	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		
Date Bone Marrow Examination undertaken	To record the date the bone marrow examination was done **Note:** This data item is only required where *Bone Marrow Examination Performed* is recorded as *Yes*	ccyymmdd	N/A	N/A	R	N/A
Bone Marrow Examination Type	To record the type of Bone Marrow Examination undertaken **Note:** This data item is only required where *Bone Marrow Examination Performed* is recorded as *Yes*	Code List	1	Trephine	R	N/A
			2	Aspirate		
Result of Bone Marrow Examination	The result of the bone marrow examination done **Note:** This data item is only required where *Bone Marrow Examination Performed* is recorded as *Yes*	Code List	1	Positive	R	N/A
			2	Negative		
			3	Equivocal		
Transformation	Has the patient's disease transformed	Code List	Y	Yes	M	N/A
			N	No		
			9	Not recorded		
Date of Transformation	Date the patient's disease transformed	ccyymmdd	N/A	N/A	M	N/A
Lymphoma Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items						

Ann Arbor Stage	Staging based on location of detected disease **Note:** Required to derive the: Hasenclever Index R-IPI Index CNS-IPI Index FLIPI-2 Index	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		
Ann Arbor Symptoms	Additional stage designation based on presence or absence of specific symptoms	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:** (i) For Primary Nodal Lymphoma: Code E if there is involvement of a single extranodal site by contiguous spread (ie directly adjoining) from the known nodal group. (ii) For Primary Extranodal Lymphoma: 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) (iii) The designation of Stage 4 for nodal disease implies disseminated disease	Code List	E	E - Extranodal involvement	M	Ann Arbor Extranodality (HA8300)

	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 4 even if the disease is isolated to that organ.		0	No Extranodal involvement		
Ann Arbor Bulk	Additional staging designation based on presence of bulky disease. **Note:** Code *Bulky disease present* if there is presence of 'bulky' disease, that is, a nodal mass whose greatest dimension is more than 10 cm in size, and/or a widening of the mediastinum (middle chest) but more than one-third	Code List	X	Bulky disease present	M	Ann Arbor Bulk (HA8310)
			0	No bulky disease present		
Ann Arbor Splenic Involvement	Additional staging designation based on splenomegaly or normal spleen size with confirmed disease involvement. **Note:** Record *Spleen involvement or splenomegaly* if either is true	Code List	S	Spleen involvement or splenomegaly	M	Ann Arbor Splenic Involvement (HA8680)
			0	No spleen involvement or splenomegaly		
Number of Abnormal Nodal Areas	Number of abnormal nodal areas detected clinically and radiologically **Note:** Required to derive the FLIPI-2 Index	max n2	N/A	N/A	M	Number of Abnormal Nodal Areas (HA8320)
Number of Extranodal Sites Code	Number of sites with lymphoma outside lymph nodes (clinical assessment)	Code List	0	0	M	Number of Extranodal Sites Code (HA8420)

	Note: i. The Codes *3*, *4* and *5* are not present in COSD but have been added here as a site-specific requirement. Also note that COSD defines Code *2* as *More than 1*. ii. This data item is required to derive the: R-IPI Index CNS-IPI Index		1	1		
			2	2		
			3	3		
			4	4		
			5	5 and over		
Primary Extranodal Site	Site of origin of lymphoma if believed to be outside lymph nodes as agreed by MDT based on clinical and radiological findings	Code List	01	Blood	M	Primary Extranodal Site (HA8330)
			02	Bone		
			03	CNS		
			04	GIT		
			05	GU		
			06	Liver		
			07	Marrow		
			08	Muscle		
			09	Orbit		
			10	Pericardium		
			11	Pulmonary		
			12	Salivary gland		
			13	Skin		
			14	Thyroid		
			15	Other		
Lactate Dehydrogenase Level (LDH)	Lactate Dehydrogenase level in serum measured pre-treatment. Normally provided from Biochemistry laboratory before treatment.	Code List	1	Above normal	M	N/A

	Note: Required to derive the: MIPI Score IELSG Index R-IPI Index CNS-IPI Index FLIPI-2 Index		2	Not above normal		
			3	Test not done		
Kidney/Adrenal Involvement	Has the patient got kidney and/or adrenal involvement **Note:** Required to derive the CNS-IPI Index	Code List	Y	Yes	M	N/A
			N	No		
Biopsy	Has the patient had a biopsy performed	Code List	Y	Yes	R	N/A
			N	No		
			9	Not Known		
Date of Biopsy	To record the date the biopsy was taken **Note:** Only required where *Biopsy* is recorded as *Yes*	ccyymmdd	N/A	N/A	R	N/A
Site of Biopsy	To record the body site from where the biopsy was taken **Note:** Only required where *Biopsy* is recorded as *Yes*	Code List	01	Chest	R	N/A
			02	Abdomen		
			03	Bone		
			04	Brain		
			05	Lymph Nodes		
			06	Pleura		
			07	Mediastinum		
			08	Liver		
			09	Pancreas		
			10	Spleen		
			11	Skin		

			97	Other		
Result of Biopsy	The result of the biopsy that was taken **Note:** Only required where *Biopsy* is recorded as *Yes*	Code List	P	Positive	R	N/A
			N	Negative		
			E	Equivocal		
All Wales Lymphoma Panel Review	Has the patient's pathology been reviewed by the All Wales Lymphoma panel	Code List	Y	Yes	M	N/A
			N	No		
			9	Not recorded		
Date of Report Issued by Lymphoma Panel	Date the All Wales Lymphoma Panel issue the report following review of pathology **Note:** Only required where *All Wales Lymphoma Panel Review* is recorded as *Yes*	ccyymmdd	N/A	N/A	R	N/A
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			02	MRD+ - Minimal Residual Disease Positive		
			03	VGPR - Very Good Partial Response		
			04	GPR - Good Partial Response		
			05	SD - Stable Disease		
			06	PD - Progressive Disease		
			99	NE - Non Evaluable		
			00	Death		
Non Hodgkin Lymphoma Data Item. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
ALK Fusion Status for ALCL	The Anaplastic Lymphoma Kinase (ALK) protein is expressed in a subset of ALCL due to underlying gene fusion events. Its presence or absence distinguishes	an1	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		
Follicular Lymphoma Data Item. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
FLIPI 2 Index Score	Follicular Lymphoma International Prognostic Index Score 2 (FLIPI 2) **Note:** This is derived data item from age, Serum beta 2 microglobulin, bone marrow involvement, longest diameter of largest involved node and Haemoglobin. A score of 1 is given for each of the following scenarios: Age>60 years HB <120 g/l >4 nodal areas LDH above normal Ann Arbor Stage III or IV	n1 Range 0-5	N/A	N/A	D	FLIPI 2 Index Score (HA8360)
Diffuse Large B Cell Lymphoma (DLBCL) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
(R)IPI Index for DLBCL Score	Revised International Prognostic Index Score **Note:** This is derived data item from Age, performance status, LDH, extranodal sites, Ann Arbor Stage. A score of 1 is given for each of the following scenarios: Age >60 Performance Status >2 LDH above Normal >1 extranodal site Ann Arbor Stage III or IV	n1 Range 0-5	N/A	N/A	D	(R)IPI Index for DLBCL Score (HA8450)

CNS-IPI	CNS International Prognostic index. This estimates the risk of CNS relapse/progression **Note:** This is a derived data item from age at diagnosis, performance status, LDH, Extranodal sites, Stage, Ann Arbor Stage, Kidney and/or Adrenal involvement. The methodology for how the values are derived is located at https://qxmd.com/calculate/calculator_428/cns-international-prognostic-index-in-diffuse-large-b-cell-lymphoma-cns-ipi	Code List	1	Low Risk (0 or 1)	D	N/A
			2	Intermediate Risk (2 or 3)		
			3	High Risk (4 or 5)		
Germinal Centre	Is the gene present	Code List	Y	Yes	R	N/A
			N	No		
MYC Expressed	Is this gene present	Code List	Y	Yes	R	N/A
			N	No		
MYC Gene Mutated	Has this gene mutated	Code List	Y	Yes	R	N/A
			N	No		
BCL-2 Expressed	Is this gene present	Code List	Y	Yes	R	N/A
			N	No		
BCL-2 Mutated	Has this gene mutated	Code List	Y	Yes	R	N/A
			N	No		
Primary CNS Lymphoma Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
IELSG Index	IELSG prognostic index score **Note:** This is a derived data item from age at diagnosis, ECOG performance status, LDH, elevated cerebrospinal fluid protein, deep structures involved. The methodology for how the values are derived is located at https://oncologypro.esmo.org/Oncology-in-Practice/Practice-Tools/International-Prognostic-Index-Tools-for-Lymphoma/Index-for-CNS-Lymphoma	Code List	1	Low Risk (0-1)	D	N/A
			2	Intermediate Risk (2-3)		

			3	High Risk (4-5)		
Hodgkin Lymphoma Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Hasenclever Index	Hasenclever Index **Note:** This is a derived data item from age, gender, Hb, Albumin, white blood count, Lymphocyte count, Ann Arbor stage and is only required for lymphomas with Ann Arbor Stage III or IV. A score of 1 is given for each of the following scenarios: Age >44 Male gender Hb <105 Albumin <40 White blood count >14.9 Lymphocyte count <0.6 (or Lymphocyte percentage of WBC <8%) Ann Arbor Stage IV)). The methodology for how the values are derived is located at https://oncologypro.esmo.org/Oncology-in-Practice/Practice-Tools/Hasenclever-Index-for-Hodgkin-s-Disease	n1 Range 0-7	N/A	N/A	D	Hasenclever Index (HA8670)
Mantle Cell Lymphoma. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
MIPI Score	Mantle Cell Lymphoma International Prognostic Index (MIPI). **Note:** This is a derived data item from age (years), performance status, LDH, WCC,	Code List	1	Low Risk	D	N/A

	Ki-67(expressed as percentage). The methodology for the MIPI is (0.03535 x Age) + (0.6978 x (ECOG >1)) + (1.367 x log10 (LDH/ULN)) + (0.9393 x Log10 (white cell count))		2	Intermediate Risk		
			3	High Risk		
Acute Myeloid Leukaemia (AML) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy	Code List	Y	Yes	R	Primary Induction Failure (CT7110)
			N	No		
			9	Not known		
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	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		
AML Risk Factors	Record if any of these risk factors are present in a patient at diagnosis	Code List	1	Denovo	R	AML Risk Factors (CT7180)
			2	High Risk MDS		
			3	Secondary AML		
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		
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			02	MRD+ - Minimal Residual Disease Positive		
			03	VGPR - Very Good Partial Response		
			04	GPR - Good Partial Response		
			05	SD - Stable Disease		
			06	PD - Progressive Disease		
			99	NE - Non Evaluable		
			00	Death		
Acute Lymphoblastic Leukaemia (ALL) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy	Code List	Y	Yes	R	Primary Induction Failure (CT7110)
			N	No		
			9	Not known		
Extramedullary Disease	Site/s of disease identified outside bone marrow, including presence of blasts within CFS (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		
Post Induction MRD	Percentage of leukaemic cells present at the end of induction	Code List	1	0%	R	Post Induction MRD (CT7700)
			2	<0.01%		
			3	<0.1%		
			4	<1%		
			5	<5%		
			6	>=5%		
			9	Unknown		
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			02	MRD+ - Minimal Residual Disease Positive		
			03	VGPR - Very Good Partial Response		
			04	GPR - Good Partial Response		
			05	SD - Stable Disease		
			06	PD - Progressive Disease		
			99	NE - Non Evaluable		
			00	Death		
Chronic Myeloid Leukaemia (CML) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy	Code List	Y	Yes	R	Primary Induction Failure (CT7110)
			N	No		
			9	Not known		
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	Eosionophils 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	To indicate the patient's response to treatment	Code List	99	NE - Non Evaluable	R	N/A
			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%		
Chronic Lymphocytic Leukaemia (CLL) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy	Code List	Y	Yes	R	Primary Induction Failure (CT7110)
			N	No		
			9	Not known		
CD38 Status	To indicate the CD38 status	Code List	Y	Yes	M	N/A
			N	No		
CD38 % cell population	Record the CD38 % cell population	max n2.max n2	N/A	N/A	M	N/A
p53 Deletion Status	To indicate the p53 status **Note:** *No* = No abnormality = 0 points, *Yes* = deletion 17p by FISH or TP53 mutation or sequencing = 4 points	Code List	Y	Yes	M	N/A
			N	No		
Splenomegaly Indicator	Spleen enlargement identified from clinical examination	Code List	Y	Yes	M	Splenomegaly Indicator (HA8210)
			N	No		
Immunoglobulin Heavy Gene Rearrangement (IGHV) Status	Record the IGHV Status	Code List	1	Mutated	M	N/A
			2	Unmutated		
Binet Stage	Prognostic index derived from platelet count, Hb, lymphadenopathy, hepatomegaly and splenomegaly. **Note:** Immune cytopenias are not calculated when calculating the Stage (ie if Platelet count is below 100 and/or Haemoglobin levels are below 110 as a result of immune cytopenia).	Code List	A	Stage A: if platelet count >99 and Hb >99 and 0, 1 or 2 areas of organ enlargement (number of lymph node groups plus score 1 for hepatomegaly, 1 for splenomegaly)	D	Binet Stage (HA8240)

			B	Stage B: if platelet count >99 and Hb >99 and 3, 4 or 5 areas of organ enlargement		
			C	Stage C: if Hb <100 or platelet count <100		
RAI Stage	Record the RAI Stage for the patient **Note:** This is a derived data item as follows: Stage 0 - Lymphocytosis only (>4x10^9/L) Stage 1 - Lymphocytosis + lymph node enlargement Stage 2 - Lymphocytosis + spleen or liver (+/- lymph nodes) Stage 3 - Lymphocytosis + anaemia (Hb<110g/L) (+/- spleen or liver, nodes) Stage 4 - Lymphocytosis + thrombocytopenia (Platelets <100x10^9/L) (+/- spleen or liver, nodes)	Code List	0	Stage 0	D	N/A
			1	Stage 1		
			2	Stage 2		
			3	Stage 3		
			4	Stage 4		
CLL-IPI	Record the prognostic index **Note:** This is a derived data item as follows: Age: 65 years or under = 0 points Age: >65 years = 1 point Clinical Stage: Binet A or RAI 0 = 0 points; any other stages = 1 point Serum Beta-2 microglobulin: 3.5 or less = 0 points; anything >3.5 = 2 points Immunoglobulin heavy gene rearrangement (IGHV mutational status): Mutated = 0 points; Unmutated = 2 points P53: No abnormality = 0 points; deletion 17p by FISH or TP53 mutation or sequencing = 4 points	max n2 Range 0-10	N/A	N/A	D	N/A

Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			02	MRD+ - Minimal Residual Disease Positive		
			03	VGPR - Very Good Partial Response		
			04	GPR - Good Partial Response		
			05	SD - Stable Disease		
			06	PD - Progressive Disease		
			99	NE - Non Evaluable		
			00	Death		
Myelodysplasia (MDS) Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Bone Marrow Blasts	Blast cells in bone marrow aspirate as percentage of all nucleated cells. Normally taken from laboratory report on diagnostic bone marrow.	max n3 %. Range 0-100	N/A	N/A	M	Bone Marrow Blasts (CT7330)

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 as: Haemoglobin (g/dL) [4-20] – A possible conversion for Hb values: 10 g/dL= 6.2 mmol/L, 8 g/dL= 5.0 mmol/L Absolute Neutrophil Count (x109/L) [0-15] Platelets (x109/L) [0-2000] Bone Marrow Blasts (percent) [0-30] Cytogenetic Category The following website: https://www.mds-foundation.org/ipss-r-calculator/ is an online calculator for the IPSS- R scoring system.	max n1.n1	N/A	N/A	D	IPSS-R (Myelodysplasia) (HA9000)
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			14	HI - Hematologic Improvement		
			91	NR - No Response		
			05	SD - Stable Disease		
			15	Prog from Hi - Progression from Hematologic Improvement		
			16	Rel from CR - Relapse from Complete Response		
			17	Prog to AML - Progression to AML		
Myeloma Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Plasma Cell Count in Peripheral Blood	Highest plasma cell count in peripheral blood pre treatment.	max n3.max n1	N/A	N/A	R	N/A

Creatinine Level	Level of creatinine measured in umol/L at diagnosis/pre-treatment	max n4	N/A	N/A	R	N/A
eGFR (Estimation of Glomerular Function)	Level of Estimated GFR measured at diagnosis/pre-treatment	max n3. Units ML/min/1.73m^2) where m^2 is meters squared: m to the power of 2	N/A	N/A	R	N/A
Calcium	Level of calcium measured in mmol/L at diagnosis/pre-treatment	max n2.max n2	N/A	N/A	R	N/A
Lactate Dehydrogenase Level (LDH)	Lactate Dehydrogenase level in serum measured pre-treatment. Normally provided from Biochemistry laboratory before treatment.	Code List	A	Above normal	R	N/A
			B	Not above normal		
			9	Test not done		
Cytogenetic Group Risk Code	Cytogenetic Group risk factor based on cytogenetic analysis	Code List	1	Standard risk	R	N/A
			2	High risk		
			3	Failed		
			9	Not done		
FISH	Cytogenetic analysis of bone marrow for prognostic purposes	Code List	01	Normal	R	N/A
			02	t (4, 14)		
			03	t (14, 16)		
			04	t (14, 20)		
			05	p53-		
			06	1q+		
			07	1p-		
			08	Failed		
			99	Not done		
Paraprotein Level	Paraprotein level at diagnosis/pre-treatment g/dl	maxn2.max n1			R	N/A

Paraprotein Subtype	Paraprotein sub type at diagnosis/pre-treatment	Code List	1	IgA	R	N/A
			2	IgD		
			3	IgE		
			4	IgG		
			5	IgM		
			6	Non-secretory		
Serum Free Light Chains	Type of serum free light chain produced at diagnosis/pre-treatment	Code List	1	Kappa	R	N/A
			2	Lambda		
			3	K:L Ratio		
			4	K:L Ratio Normal		
ISS Stage	International Staging System for Myeloma derived from Beta2 microglobulin and Albumin lab results	Code List	1	Stage 1: Beta 2 M < 3.5 and Albumin greater than 34	R	N/A
			2	Stage 2: Beta 2 M less than 3.5 and Albumin less than 35 or Beta 2 M 3.5-5.5		
			3	Stage 3: Beta 2 M greater than 5.5		
R-ISS Stage for Myeloma	The Revised International Staging System (R-ISS) includes variables included in the original ISS (serum beta-2 microglobulin and serum albumin), while also including the additional prognostic information obtained from serum LDH and high-risk chromosomal abnormalities detected by interphase fluorescent in situ hybridization (iFISH) after CD138 plasma cell purification.	Code List	1	Stage I - ISS Stage 1 and standard-risk chromosomal abnormalities by iFISH and normal LDH	M	R-ISS Stage for Myeloma (HA9100)
			2	Stage II - Not R-ISS Stage I or III		
			3	Stage III - ISS Stage 3 and either high-risk chromosomal abnormalities by iFISH or high LDH		
MRI Outcome		Code List	1	Normal	R	N/A

	Specific outcome results following MRI recorded at diagnosis/pre-treatment		2	Focal lesions (more than 1 >0.5 cm)		
			3	Signal Change		
			4	Extramedullary disease		
			9	Not done		
PET-CT Outcome	Specific outcome results following PET-CT recorded at diagnosis/pre-treatment	Code List	1	Normal	R	N/A
			2	Focal lesions (more than 1 >0.5 cm)		
			3	Extramedullary disease		
			9	Not done		
Bone Disease on CT/Plain Film	Specific outcome results of bone disease following CT scan or plain films recorded at diagnosis/pre-treatment	Code List	1	Lytic	R	N/A
			2	Fracture		
			3	Plasmacytoma		
			0	None		
Treatment Response	To indicate the patients best/maximum response to treatment	Code List	01	CR - Complete Response	R	N/A
			03	VGPR - Very Good Partial Response		
			18	PR - Partial Response		
			05	SD - Stable Disease		
			19	PP - Plateau Phase		
			06	PD - Progressive Disease		
			99	NE - Non Evaluable		
Mixed Phenotype Acute Leukaemia Data Items. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
Primary Induction Failure	Did the patient fail to achieve morphological remission after induction chemotherapy	Code List	Y	Yes	R	Primary Induction Failure (CT7110)
			N	No		
			9	Not known		
		Code List	1	Hepatomegaly	R	

Mixed Phenotype Symptoms (at Diagnosis)	Record if any of the associated symptoms were present at diagnosis		2	Splenomegaly		Mixed Phenotype Symptoms (at Diagnosis) (CT7200)
			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		
Stem Cell Transplantation. Record if *Patient Eligibility Status for Stem Cell Transplantation* is recorded as *Eligible*						
Stem Cell Infusion Source *	Source of stem cells for infusion **Note:** This data item is also in the Core standard, however, is included here as it is a requirement for the Haematology site-specific standard if *Patient Eligibility Status for Stem Cell Transplantation* is recorded as *Eligible*	Code List	B	Bone Marrow	R	Stem Cell Infusion Source (CR8600)
			P	Peripheral Blood		
			C	Cord		
			9	Not Known		
Stem Cell Infusion Donor *	Donor for stem cell infusion. **Note:** This data item is also in the Core standard, however, is included here as it is a requirement for the Haematology site-specific standard if *Patient Eligibility Status for Stem Cell Transplantation* is recorded as *Eligible*	Code List	1	Autologous	R	Stem Cell Infusion Donor (CR8610)
			2	Allogeneic - Sibling		
			3	Allogeneic - Haplo		
			4	Allogeneic - Unrelated		
			9	Not Known		
Conditioning Regimen *	Record the Stem Cell Transplant Conditioning Regimen **Note:** This data item is also in the Core standard, however, is included here as it is a requirement for the Haematology site-specific standard if *Patient Eligibility Status*	Code List	1	Myeloablative	R	Conditioning Regimen (CR8620)
			2	Reduced Intensity		

	for Stem Cell Transplantation is recorded as *Eligible*		3	Minimal Intensity		
Polycythaemia Vera. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
JAK2 Status	To indicate the JAK2 Status for the patient **Note:** Required to derive the PV Prognostic Score	Code List	1	Positive	M	N/A
			2	Negative		
PV Prognostic Score	Prognostic Score for Thrombosis **Note:** This is a derived data item from Vascular Occlusion, marrow fibrosis at diagnosis, JAK2 status, CALR Status, CALR Type, MPL status and Spleen size.	Code List	1	Very Low Risk	D	N/A
			2	Low Risk		
			3	Intermediate Risk		
			4	High Risk		
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			14	HI - Hematologic Improvement		
			91	NR - No Response		
			05	SD - Stable Disease		
			15	Prog from Hi - Progression from Hematologic Improvement		
			16	Rel from CR - Relapse from Complete Response		
Essential Thrombocythemia. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
JAK2 Status	To indicate the JAK2 Status for the patient **Note:** Required to derive the R-IPSET Score	Code List	1	Positive	M	N/A
			2	Negative		

R-IPSET Score	International Prognostic Score for Thrombosis in Essential Thrombocythemia (ET). **Note:** This is a derived data item from Vascular Occlusion, marrow fibrosis at diagnosis, JAK2 status, CALR Status, CALR Type, MPL status and Spleen size. For information on the methodology see http://bloodref.com/myeloid/mpd/ipset-thrombosis	Code List	1	Low Risk	D	N/A
			2	Intermediate Risk		
			3	High Risk		
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			14	HI - Hematologic Improvement		
			91	NR - No Response		
			05	SD - Stable Disease		
			15	Prog from Hi - Progression from Hematologic Improvement		
			16	Rel from CR - Relapse from Complete Response		
Myelofibrosis. Record in addition to the Core Haematopoietic and Lymphoid Data Items & Lymphoma Core Data Items						
JAK2 Status	To indicate the JAK2 Status for the patient **Note:** Required to derive the IWG-MRT prognostic score	Code List	1	Positive	M	N/A
			2	Negative		
IWG-MRT Score	International Working Group (IWG) consensus criteria for treatment response in myelofibrosis with myeloid metaplasia, for the IWG for Myelofibrosis Research and Treatment (IWG-MRT) score. **Note:** This is a derived data item from Vascular Occlusion, marrow fibrosis at diagnosis, JAK2 status, CALR Status, CALR	Code List	1	Low Risk	D	N/A
			2	Intermediate Risk -1		

	Type, MPL status and Spleen size. For information on the methodology see: http://bloodref.com/myeloid/mpd/myelofibrosis-prognosis		3	Intermediate Risk -2		
			4	High Risk		
DIPSS (Dynamic International Prognostic Scoring System)	Record the DIPSS score for the patient. This estimates survival in patients with myelofibrosis. **Note:** This is a derived data item from Age, Constitutional Symptoms, White Cell count, Hb, Peripheral Blood Blasts. For information on the methodology see: https://www.mdcalc.com/dipss-dynamic-international-prognostic-scoring-system-myelofibrosis The score has a range of 0-5 and corresponds with the adjacent values as follows: Score 0 = Low risk Score 1-2 = Intermediate Risk 1 Score 3-4 = Intermediate Risk 2 Score 5 or more = High Risk	Code List	1	Low Risk	D	N/A
			2	Intermediate Risk -1		
			3	Intermediate Risk -2		
			4	High Risk		
DIPPS Plus (Dynamic International Prognostic Score System Plus)	Record the DIPSS Plus score for the patient. This estimates the prognosis in patients with myelofibrosis. **Note:** This is a derived data item from Age,	Code List	1	Low Risk	D	N/A

	Constitutional Symptoms, White Cell count, Hb, PB Blast, Karyotype, Transfusion Dependent, Platelets. For information on the methodology see: https://qxmd.com/calculate/calculator_315/dipss-plus-score-for-prognosis-in-myelofibrosis The score has a range of 0-4 and corresponds with the adjacent values as follows: Score 0 - Low Risk Score 1 - Intermediate Risk 1 Score 2-3 = Intermediate Risk 2 Score 4 or more = High Risk					
			2	Intermediate Risk -1		
			3	Intermediate Risk -2		
			4	High Risk		
Treatment Response	To indicate the patient's response to treatment	Code List	01	CR - Complete Response	R	N/A
			14	HI - Hematologic Improvement		
			91	NR - No Response		
			05	SD - Stable Disease		
			15	Prog from Hi - Progression from Hematologic Improvement		
			16	Rel from CR - Relapse from Complete Response		