WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020/30
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 – Acute Oncology Service (AOS)

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 / 033

Summary:

To introduce a new standard for cancer minimum reporting requirements for Acute Oncology Service (AOS).

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 cancer minimum reporting requirements for Acute Oncology Service (AOS). 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 Acute Oncology Service (AOS) 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. It should be completed for all acute oncology patients that present within the hospital or health board setting, each time of presentation. Explicitly, information within this Standard would be required where the Core data item *Acute Oncology Assessment Date* is populated with a date and reflects that an acute oncology assessment has taken place.

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 – Acute Oncology Service (AOS) and their equivalent labels in COSD V9.0, where there is an equivalent, are listed below.

This Standard should be completed for all acute oncology patients that present within the hospital or health board setting, each time of presentation. Explicitly, information within this Standard would be required where the Core data item *Acute Oncology Assessment Date* is populated with a date and reflects that an acute oncology assessment has taken place.

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.

National Cancer Data Standards for Wales – Acute Oncology Service (AOS)

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
Presentation Details. To be completed for all, in conjunction with one or more presentation types						
Organisation Code (Initial Acute Presentation)	An identifier code to identify the Health Board or Trust of where the patient's initial acute presentation occurred	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	R	N/A
Organisation Site Code (Initial Acute Presentation)	An identifier site code to identify the organisation within the Health Board/Trust of where the patient's initial acute presentation occurred	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	R	N/A
Date of Initial Acute Presentation	Record the date that the initial acute presentation to the Health Board/Trust occurred	ccyymmdd	N/A	N/A	R	N/A

Time of Initial Acute Presentation	Record the time that the initial acute presentation to the Health Board/Trust occurred	24 hr hh:mm	N/A	N/A	R	N/A
Acute Oncology Presentation Type	Record the presentation type for the patient (Multiple options can be chosen)	Code List	01	Complication of Cancer	R	N/A
			02	Complication of Cancer Treatment		
			03	New Diagnosis of Cancer		
			04	Unrelated to Cancer Diagnosis		
Patient Type*	Record the type each patient presentation is grouped within. (Multiple options can be chosen) **Note**: i. Of the adjacent codes, *MUO/CUP (Malignancy Unknown Origin/Cancer Unknown Primary)*, *Treatment Complication - Immunotherapy Toxicity Details* and *Treatment Complication - Other* are not present in Core. These have been added here to provide greater granularity. ii. The information recorded here will determine the collection of additional information in proceeding sections as follows: Sepsis Details will be required if	Code List	01	New Presentation	R	Patient Type (CR8730)
			03	Suspected or Confirmed Neutropenic Sepsis		
			04	Cancer Complication		
			05	Cancer Recurrence/Progression (Local or Regional)		
			06	Cancer Recurrence/Progression (Distant)		
			07	Cancer Transformation		

	Suspected or Confirmed Neutropenic Sepsis is selected. Metastatic Spinal Cord Compression (MSCC) Details will be required if *Suspected or Confirmed Metastatic Spinal Cord Compression (MSCC)* is selected. Malignancy of Undefined Primary Origin (MUO)/Carcinoma Unknown Primary (CUP) Details will be required if *MUO/CUP (Malignancy Unknown Origin/Cancer Unknown Primary)* is selected. Immunotherapy Toxicity Details will be required if *Treatment Complication - Immunotherapy Toxicity* is selected Other Disease Complications Details will be required where *Cancer Complication, Cancer Recurrence/Progression (Local or Regional)*, *Cancer Recurrence/Progression (Distant)*, *Cancer Transformation*, *Comorbidity Complications* or *Other* are selected.		08	Suspected or Confirmed Metastatic Spinal Cord Compression (MSCC)		
			09	Comorbidity Complications		
			81	MUO/CUP (Malignancy Unknown Origin/Cancer Unknown Primary)		
			82	Treatment Complication - Immunotherapy Toxicity		
			83	Treatment Complication - Other		
			98	Other		
Sepsis Details						
Date of recognition of suspected sepsis	Record the date of onset of the recognition of suspected sepsis This is at point of triage/first set of observations	ccyymmdd	N/A	N/A	R	N/A
Time of recognition of suspected sepsis	Record the time of the onset of the recognition of suspected sepsis This is the time the patient was assessed within triage/first set of observations taken	24 hr hh:mm	N/A	N/A	R	N/A

Date of first clinical review	Record the date the first clinical review by a Senior Practitioner took place within the Health Board/Organisation	ccyymmdd	N/A	N/A	R	N/A
Time of first clinical review	Record the time the first clinical review by a Senior Practitioner took place within the Health Board/Organisation	24 hr hh:mm	N/A	N/A	R	N/A
Date IV Antibiotics administered	Record the date the iv antibiotics were administered	ccyymmdd	N/A	N/A	R	N/A
Time IV Antibiotics were administered	Record the time the iv antibiotics were administered	24 hr hh:mm	N/A	N/A	R	N/A
Lactate Undertaken	Has a Lactate test been undertaken	Code List	01	Yes	R	N/A
			02	No		
Lactate Undertaken within 1 Hour	Has the Lactate test been undertaken within 1 hour from the time of recognition of suspected sepsis	Code List	01	Yes	R	N/A
			02	No		
Blood Cultures Undertaken	Has all Blood Cultures been undertaken	Code List	01	Yes	R	N/A
			02	No		
Antibiotics Prescribed as per Sepsis Policy	Record if antibiotics were prescribed in line with the sepsis policy	Code List	01	Yes	R	N/A
			02	No		
Neutropenic Sepsis Confirmed	Record if neutropenic sepsis was confirmed	Code List	01	Yes	R	N/A
			02	No		
Mortality from Sepsis within 30 days	Record if death occurred from sepsis within 30 days	Code List	01	Yes	R	N/A
			02	No		
Compliance with Sepsis 6 Actions within 1 hour	Record if compliant with Sepsis 6 actions within one hour as per guidelines Sepsis 6 consists of three diagnostic and three therapeutic	Code List	01	Yes	R	N/A

	steps all to be delivered within one hour of the initial diagnosis of sepsis: (1) Tritrate oxygen to a saturation target of 94% (2) Take blood cultures and consider source control (3) Administer empiric intravenous antibiotics (4) Measure serial serum lactates (5) Start intravenous fluid resuscitation (6) Commence accurate urine output measurements		02	No		
			08	Not appropriate		
Metastatic Spinal Cord Compression (MSCC) Details						
Date of suspicion of MSCC	Record the date of onset of suspected MSCC This is the date of the first clinical documentation of suspicion	ccyymmdd	N/A	N/A	R	N/A
Time of suspicion of MSCC	Record the time of the onset of suspected MSCC This is the time of the first clinical documentation of suspicion	24 hr hh:mm	N/A	N/A	R	N/A
Date of Whole Spine MRI	Record the date of the whole spine MRI following the suspicion of MSCC	ccyymmdd	N/A	N/A	R	N/A
Time of Whole Spine MRI	Record the time of the whole spine MRI following the suspicion of MSCC	24 hr hh:mm	N/A	N/A	R	N/A
Date Whole Spine MRI Reported	Record the date the whole spine MRI was reported	ccyymmdd	N/A	N/A	R	N/A
Time Whole Spine MRI Reported	Record the time the whole spine MRI was reported, if available	24 hr hh:mm	N/A	N/A	O	N/A
		Code List	01	MSCC confirmed	R	N/A

Whole Spine MRI Result	Record the result of the whole spine MRI.		02	MSCC not confirmed		
			03	Spinal Mets		
			04	Neither (No MSCC or Spinal Mets confirmed)		
Steroids Commenced	Record if the patient was commenced on steroids. If the patient was commenced on steroids select *Yes*. Where the patient was not commenced on steroids, provide the reason for that by selecting *Contra-indicated for Medical Reasons*, *Lymphoma*, *Not Considered by Medical/Clinical Team* or *Patient Declined*	Code List	01	Yes	R	N/A
			02	No - Contra-indicated for Medical Reasons		
			03	No - Lymphoma		
			04	No - Not Considered by Medical/Clinical Team		
			05	No - Patient Declined		
Low Molecular Weight Heparin (LMWH) Commenced	Record if the patient was commenced on Low Molecular Weight Heparin (LMWH)	Code List	01	Yes	R	N/A
			02	No		
			08	Not Appropriate		
Date referred to Physiotherapy	Record the date the patient was referred to Physiotherapy	ccyymmdd	N/A	N/A	R	N/A
Date seen by Physiotherapy	Record the date the patient was seen by Physiotherapy	ccyymmdd	N/A	N/A	R	N/A
Tokuhashi Score	Specify the Tokuhashi Prognostic Score range	Code List	01	0-8; Survival <6 months	R	N/A
			02	9-11; Survival 6-12 months		
			03	12-15; >1 year		
Date of Treatment Plan	Record the date of the treatment plan, determined by a member of the MDT	ccyymmdd	N/A	N/A	R	N/A
Time of Treatment Plan	Record the time of the treatment plan, determined by a member of the MDT	24 hr hh:mm	N/A	N/A	R	N/A
Treatment Plan		Code List	01	Surgery	R	N/A

	Specify the plan of treatment for the patient, determined by a member of the MDT		02	Radiotherapy		
			03	Best Supportive Care		
Date Referred for Surgical Opinion	Record the date the patient was referred for Surgical Opinion **Note:** Only for completion when *Treatment Plan* is recorded as *Surgery*	ccyymmdd	N/A	N/A	R	N/A
Time Referred for Surgical Opinion	Record the time the patient was referred for Surgical Opinion **Note:** Only for completion when *Treatment Plan* is recorded as *Surgery*	24 hr hh:mm	N/A	N/A	R	N/A
Date Surgical Opinion Given	Record the date the Surgical Opinion was given **Note:** Only for completion when *Treatment Plan* is recorded as *Surgery*	ccyymmdd	N/A	N/A	R	N/A
Time Surgical Opinion Given	Record the time the Surgical Opinion was given **Note:** Only for completion when *Treatment Plan* is recorded as *Surgery*	24 hr hh:mm	N/A	N/A	R	N/A
Date Of Surgery	Record the date the Surgery was undertaken **Note:** Only for completion when *Treatment Plan* is recorded as *Surgery*	ccyymmdd	N/A	N/A	R	N/A
Date Of Radiotherapy	Record the date the Radiotherapy commenced **Note:** Only for completion when *Treatment Plan* is recorded as *Radiotherapy*	ccyymmdd	N/A	N/A	R	N/A

Date Of Best Supportive Care	Record the date that the treatment of Best Supportive Care (BSC) commenced **Note:** Only for completion when *Treatment Plan* is recorded as *Best Supportive Care*	ccyymmdd	N/A	N/A	R	N/A
Treatment within 24 hours	Record if treatment commenced within 24 hours of MSCC being confirmed. **Note:** i. Only for completion when *Whole Spine MRI Result* is recorded as *MSCC Confirmed* ii. The response will be based on the time difference between the information recorded for *Date Whole Spine MRI Reported/Time Whole Spine MRI Reported* and *Date of Treatment Plan/Time of Treatment Plan*. As time information may not always be available, the *Yes* response may reflect an approximate 24 hrs calculation where it is based on date information only.	Code List	01	Yes	R	N/A
			02	No		
Malignancy of Undefined Primary Origin (MUO)/Carcinoma Unknown Primary (CUP) Details						
Date of suspicion of MUO/CUP	Record the date of suspected MUO/CUP	ccyymmdd	N/A	N/A	R	N/A
Was the patient discussed at a Multi-disciplinary meeting (MDT)?	Specify if the patient was discussed at a MDT meeting?	Code List	01	Yes	R	N/A
			02	No		
			08	Not Appropriate		

Date of First MDT Discussion	Specify the date the patient was first discussed at a MDT meeting **Note:** Only for completion when *Was the patient discussed at a Multi-disciplinary meeting (MDT)?* Is recorded as *Yes*	ccyymmdd	N/A	N/A	R	N/A
Number of different MDT specialties that patient discussed in	Specify the number of different MDT specialties that the patient was discussed in, this includes specific MUO/CUP MDTs. E.g. if discussed at a Breast MDT, Gynae MDT and MUO MDT, then this should be recorded as 3 **Note:** Only for completion when *Was the patient discussed at a Multi-disciplinary meeting (MDT)?* Is recorded as *Yes*	max an2	N/A	N/A	R	N/A
Diagnosis	Specify the confirmed diagnosis **Note:** If the patient dies before a clear diagnosis is made it remains an MUO	Code List	01	Benign	R	N/A
			02	MUO (Malignancy of Undefined Primary Origin) - No Biopsy Available		
			03	Confirmed CUP (cCUP - Confirmed Carcinoma Unknown Primary)		
			04	Tumour Site Identified (Solid Tumours) - Site Specific Origin Confirmed		

			05	Non-Epithelial or Haematological Malignancy (e.g., Sarcoma, Lymphoma, Germ Cell Tumour etc)		
Discussed at MUO/CUP MDT	Record if the patient was discussed in a specific MUO/CUP MDT?	Code List	01	Yes	R	N/A
			02	No		
Staff Role Carrying out the Keyworker Role	Record the type of Keyworker assigned to the patient	Code List	01	AOS Nurse Practitioner	R	N/A
			02	CUP Specialist Nurse		
Immunotherapy Toxicity Details. This section relates to Checkpoint Inhibitors Only						
Date immunotherapy treatment complication suspected (onset of immunotherapy complication)	Record the date of the suspected/onset of the immunotherapy complication	ccyymmdd	N/A	N/A	R	N/A
Start of Repeating Data Items. Multiple occurrences of this item are permitted. Record the date, grade and complication experienced for the following data items e.g., if 3 complications experienced need to record date, grade and complication for each one separately						
Date of Immunotherapy Toxicity	Record the date the Immunotherapy toxicity experienced is clinically recorded	ccyymmdd	N/A	N/A	R	
Grade of Immunotherapy Toxicity	Record the grade of the Immunotherapy toxicity **Note:** Only for completion where *Date of Immunotherapy Toxicity* is recorded	Code List	1	Grade I	R	N/A
			2	Grade II		
			3	Grade III		
			4	Grade IV		
Immunotherapy Complication	Specify the immunotherapy complication experienced	Code List	01	Diarrhoea/Colitis	R	N/A
			02	Hepatitis		

	Note: Only for completion where *Date of Immunotherapy Toxicity* is recorded		03	Endocrine		
			04	Dermatitis		
			05	Pneumonitis		
			06	Nephritis		
			07	Neurological		
			08	Cardiac		
			97	Other		
Immunotherapy Complication - Other	Provide detail of the 'other' immunotherapy complication experienced. **Note:** Only for completion when *Immunotherapy Complication* is recorded as *Other*	max an50	N/A	N/A	R	N/A
End of Repeating Data Items						
Start of Repeating Data Items. Multiple occurrences of this item are permitted						
Was the patient referred to a Non-Cancer Specialist	Specify if the patient was referred to a Non-Cancer Specialist	Code List	01	Yes	R	N/A
			02	No		
			08	Not Appropriate		
Specialty Type of Non-Cancer Specialist Referred to	Specify the specialty type of the non cancer specialist the patient was referred to **Note:** Only required for completion where *Was the patient referred to a Non-Cancer Specialist* recorded as *Yes*	Code List	01	Gastroenterology	R	N/A
			02	Respiratory		
			03	Endocrinology		
			04	Dermatology		
			05	Other		

Date referred to Non-Cancer Specialist	Record the date referred to the Non-Cancer Specialist **Note:** Only required for completion where *Was the patient referred to a Non-Cancer Specialist* recorded as *Yes*	ccyymmdd	N/A	N/A	O	N/A
Date toxicity related treatment started	Record the date that the treatment for the immunotherapy toxicity/complication started	ccyymmdd	N/A	N/A	R	N/A
End of Repeating Data Items						
Other Disease Complications Details						
Start of Repeating Data Items. Multiple occurrences of this item are permitted. Add each Disease Complication separately						
Disease Complication that resulted in Presentation	Specify the complication/toxicity that caused the reason for presentation	Code List	01	AKI	R	N/A
			02	Anaemia		
			03	Ascites		
			04	Bleeding		
			05	Brain Mets		
			06	Cancer Associated Thrombosis (CAT)		
			07	Disease Progression		
			08	Dyspnoea		
			09	Fatigue/Frailty/Generally Unwell		
			10	Fall		
			11	Fracture		
			12	Infection		
			13	GI Symptoms (inc bowel obstruction)		
			14	Hypercalcaemia		

			15	Jaundice		
			16	Neurosensory		
			17	Pain		
			18	Pleural Effusion		
			19	Social		
			20	Supra Vena Cava Obstruction (SVCO)		
			97	Other		
Disease Complication that resulted in Presentation - Other	If Other is recorded, specify the other type of disease complication that caused the reason for presentation	max an50	N/A	N/A	R	N/A
End of Repeating Data Items						