WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2020/25
Date of Issue:	5th November 2020

Ministerial / Official Letter: N/A	**Subject:** National Cancer Data Standards for Wales – Patient Group Specific – Teenage Young Adult (TYA)[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 22nd October 2020

WISB Reference: ISRN 2020 / 030

Summary:

To introduce a new standard for patient group specific cancer minimum reporting requirements for Teenage Young Adult (TYA).

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 Teenage Young Adult (TYA). This should be used in conjunction with National Cancer Data Standards for Wales – Core (DSCN 2019/09) and any 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).

Description of Change

This Standard covers the data items for Teenage Young Adult (TYA), 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.

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[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 – Teenage Young Adult (TYA) 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.

National Cancer Data Standards – Teenage Young Adult (TYA)

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	COSD
MDT Details						
MDT Referral from Local MDT Team to TYA MDT	Record if a MDT referral from the Health Board MDT team to the TYA MDT was made	Code List	01	Yes	R	N/A
			02	No		
MDT Specialty Referring to the TYA MDT*****	Record the MDT site specialty referring the patient for discussion at the TYA MDT This could be determined by the MDT meeting type	Code List		Any code from the Core list of codes for *Multidisciplinary Team Meeting Type (CR3190), excluding 0407 - Teenage and Young Adult MDT*	R	Multidisciplinary Team Meeting Type (CR3190)
Discussed at TYA MDT where treatment plan confirmed	Record if the patient was discussed at the TYA MDT Meeting where the Treatment Plan was Confirmed **Note:** This data item is only required where *MDT Meeting Identifier (MDT Meeting Type)* (in Core) is recorded as *Teenage and Young Adult MDT*	Code List	01	Yes	R	N/A
			02	No		
TYA Clinical Trial Availability Assessment Undertaken	Record if a TYA clinical trial assessment has been undertaken for the patient To ensure that specific TYA/Paediatric/Adult clinical trials are considered if available	Code List	01	Yes	R	N/A
			02	No		
TYA/Paediatric/Adult Trial Available	Following the clinical trial assessment, was a TYA/Paediatric/Adult trial available for the patient	Code List	01	Yes	R	N/A
			02	No		
Treatment (One occurrence per treatment submission/multiple treatments through pathway)						

TYA Principal Treatment Centre Status	An indication of the status of whether a patient has been offered treatment (SACT/Supportive Care) within the TYA Principal Treatment Centre	Code List	01	Offered and Accepted Treatment within the PTC	R	N/A
			02	Offered and Declined Treatment within the PTC		
			09	Not Known (Not Recorded)		
Place of Care Chosen	Record the patient's choice of where to receive care and treatment	Code List	7A4	PTC - Cardiff & Vale UHB	R	N/A
			317	Treatment locally in TYA designated hospital and not at a PTC		
			318	Treatment locally but NOT in a TYA designated hospital and not at a PTC		
			RRK02	University Hospitals Birmingham NHS Foundation Trust		
			RBV01	The Christie NHS Foundation Trust		
			REN20	The Clatterbridge Cancer Centre NHS Foundation Trust		
			09	Not Known		
Organisation Site Identifier	Record the organisation where SACT and/or Supportive Care treatment was provided by a local organisation **Note:** This data item is only required where *Place of Care Chosen* is recorded as *Treatment locally in TYA designated hospital and not at a PTC* or *Treatment locally but NOT in a TYA*	See NHS Wales Data Dictionary - Terms (Organisation Code - LHB/Trust Site Code)	N/A	N/A	R	N/A

	designated hospital and not at a PTC					
Teenage Young Adult (TYA) Principal Treatment Centre	Record the patient's nominated TYA principal treatment centre (PTC), whether they have chosen to have treatment at the PTC. If the service is integrated between two PTCs, record both. Multiples can be chosen **Note:** Only those centres applicable to Wales are listed here	Code List	7A4	Cardiff and Vale University Health Board	R	Teenage Young Adult (TYA) Principal Treatment Centre (CT7610)
			RRK02	University Hospitals Birmingham NHS Foundation Trust		
			RBV01	The Christie NHS Foundation Trust		
			REN20	The Clatterbridge Cancer Centre NHS Foundation Trust		
			REM	Liverpool University Hospitals NHS Foundation Trust		
			RBS01	Alder Hey Children's NHS Foundation Trust		
Keyworker (Multiples can be added through Pathway)						
Staff Role Carrying out the Keyworker Role	Record the role of the individual carrying out the role of Keyworker	Code List	01	Cancer Nurse Specialist	R	N/A
			07	Cancer Nurse Specialist - Tumour Site Specific		
			10	Cancer Nurse Specialist - TYA Specific		
			02	Other Nurse		

			03	Allied Health Professional		
			04	Support Worker/Care Navigator/Cancer Information & Support co-ordinator		
			05	Psychologist or other mental health professional		
			06	Consultant/Medical Team		
			11	TYA Social Care Professional		
			12	TYA Social Worker		
			13	TYA Youth Worker		
			08	Other		
			09	Not Known		
Additional Patient Care Details - Fertility (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	R	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		
			06	GnRH analogue injection		
Psychosocial Care Details (Multiples can be added through pathway)						
Psychosocial Support Status	An indication of the status of whether a patient has been offered psychosocial support	Code List	01	Offered and Accepted	R	N/A
			02	Offered and Declined		
			09	Not Known (Not Recorded)		
Psychosocial Support Place	An indication of the place that provided the psychosocial support services, if accepted (multiples responses)	Code List	01	Principal Treatment Centre (PTC)	R	N/A
			02	Local Service provided within Health Board		
			03	Third Sector Support Services		
			09	Not Known (Not Recorded)		
		Code List	01	At Diagnosis	R	N/A

			02	During treatment		
			03	End of Definitive Treatment		
Psychosocial - Point in Pathway	The point in the pathway when psychosocial support was offered		04	During Long Term Follow Up		
			05	Relapse/Recurrence		
			06	During Palliative Care		
			07	Bereavement		
			98	Other		
Psychology Services Care Details (Multiples can be added through pathway)						
Psychology Services Referral	Record if the patient was referred to Psychology Services	Code List	01	Yes	R	N/A
			02	No		
Date of Psychology Services Referral	Record the date a Psychology Services Referral was made	ccyymmdd	N/A	N/A	R	N/A
Psychology Services Referral - Point in Pathway	The point in the pathway when a psychology services referral was made	Code List	01	At Diagnosis	R	N/A
			02	During treatment		
			03	End of Definitive Treatment		
			04	During Long Term Follow Up		
			05	Relapse/Recurrence		
			06	During Palliative Care		
			07	Bereavement		
			98	Other		
Allied Health Professional (AHP) Services Care Details (Multiples can be added through pathway) (Repeating data items as could be referred to more than one AHP service)						
AHP Services Referral	Record if the patient was referred to an AHP Service	Code List	01	Yes	R	N/A
			02	No		
Start of Repeating Data Items						
AHP Service Referred To	Record the AHP service the patient was referred to	Code List	01	Physiotherapy	R	N/A
			02	Occupational Therapy		

			03	Speech and Language Therapy (SALT)		
			04	Dietician		
			05	Complementary Therapy		
Date of AHP Service Referral	Record the date the AHP Service Referral was made	ccyymmdd	N/A	N/A	R	N/A
AHP Services Referral - Point in Pathway	The point in the pathway when the AHP services referral was made	Code List	01	At Diagnosis	R	N/A
			02	During treatment		
			03	End of Definitive Treatment		
			04	During Long Term Follow Up		
			05	Relapse/Recurrence		
			06	During Palliative Care		
			07	Bereavement		
			98	Other		
End of Repeating Data Items						
Rehabilitation - Recovery Package (Multiples can be added through pathway)						
Recovery Package Offered	An indication of whether a patient has been offered a recovery package post treatment	Code List	01	Offered and Undecided	R	N/A
			02	Offered and Declined		
			03	Offered and Accepted		
			04	Not Offered		
			05	Offered but patient unable to complete		
Date Recovery Package Offered	Record the date the Recovery Package is offered	ccyymmdd	N/A	N/A	R	N/A
Recovery Package Completed Date	Record the date Recovery Package is completed	ccyymmdd	N/A	N/A	R	N/A