



Llywodraeth Cymru
Welsh Government

WELSH INFORMATION STANDARDS BOARD

	DSC Notice: DSCN 2020/29
	Date of Issue: 10 th December 2020
Ministerial / Official Letter: N/A	Subject: National Cancer Data Standards for Wales – Patient Group Specific – Childhood 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	
<p>A Data Standards Change Notice (DSCN) is an information mandate for a new or revised information standard.</p> <p>This DSCN was approved by the Welsh Information Standards Board (WISB) at its meeting on 19th November 2020</p> <p>WISB Reference: ISRN 2020 / 030</p>	
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) <https://dhw.nhs.wales/information-services/information-standards/data-standards/data-standards-files/data-standard-change-notices-docs/national-cancer-standards-spec/1-national-cancer-data-set-full-list-dscns-xlsx/> **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 comparability², 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 ccyyymmdd.

Where *D* is denoted in Status, this indicates that the information should be derived from another data item. This typically occurs with data items that are simply text representations of their code counterparts. Other Status codes are *M* (Mandatory), *R* (Required) – the data item should be recorded where applicable and *O* (Optional).

Appendix

National Cancer Data List - Data Standard Specification

<https://dhw.nhs.wales/information-services/information-standards/data-standards/data-standards-files/data-standard-change-notices-docs/national-cancer-standards-spec/1-national-cancer-data-set-full-list-dscns-xlsx/>