

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2019 / 09
Date of Issue:	25 th July 2025

Welsh Health Circular/Official Letter: N/A	Subject: National Cancer Data Standards for Wales – Core – Banked Tissue (AMD)
Sponsor: Anthony Davies, Welsh Government	
Standard Type: Operational Standards	
Implementation Date: 3 rd March 2025	

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 17th July 2025.

WISB Reference: ISRN 2018 / 018

Summary:

Amendment to the information specification in the current National Cancer Data Standards for Wales – Core. Changes have been made to the information specification specifically in the collection on Banked Tissue adding three new data items and three new codes.

Applies to:

There are no data sets affected by this change.

Please address enquiries about this Data Standards Change Notice to the Data Standards Team in Digital Health and Care Wales

E-mail: data.standards@wales.nhs.uk

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:

https://nhswales365.sharepoint.com/sites/DHC_DST/Lists/Information%20Standards%20Assurance%20Submission%20Log/AllItems.aspx

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 Data Standards Change Notices.

This Notice encompasses the cancer minimum reporting requirements for Core. This should be used in conjunction with National Cancer Data Standards for Wales – Core (DSCN 2019/09).

Due to the decommissioning of Canisc, new requirements from Biobank relating to banked tissue are required. These changes will be made to the core cancer e-form only. The core national cancer data standards will remain with no change.

The current National Cancer Data Standards will not be impacted; the only change will be to the form to enable the Wales Cancer Biobank (WCB) to capture the withdrawal of consent and additional values for tissue type and data from consenting patients.

These proposed amendments are intended to facilitate this process for WCB users that include:

- To incorporate banked tissue in collaboration with the Wales Cancer Biobank (WCB) and is part of WCB reporting requirement.
- The amendment and subsequent reporting requirement are exclusively for WCB and has no impact on any other organisation.
- The intention behind these proposed amendments is to facilitate users of the Wales Cancer Biobank (WCB) in capturing patient consent, obtaining bio samples, and processing data for consenting patients.
- Part of the requirement is to also allow for the selection of multiple types of samples.
- These proposed amendments are designed to enhance the governance of data access and to facilitate the capturing of structured data.

Description of Change

The proposed amendments to the Data Standards Change Notice (DSCN) under the heading 'Banked Tissue at Diagnosis' including adding new values such as:

- Patient Withdrawn Consent
- Ascites
- Pleural Fluid

Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.25 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.26 of the NHS Wales Data Dictionary

Actions Required

Digital Health and Care Wales:

- Ensure that all national systems have been updated to comply with the standard set out in the Information Specification within this DSCN.
- Maintain the DSCN as Operational and Clinical Practices evolve.

Banked Tissue - Core Diagnosis (One Occurrence Per Tumour)

Scope

The amendment has been requested specifically for Biobank that have requested changes to the e-form to facilitate this transition, ensuring business continuity. These new data values will enable WCB users to safely capture patient consent for banked tissue samples.

Additionally, the proposed changes will help ISD colleagues safeguard patient data if a patient withdraws their consent. Biobank is required to capture and report against these data items that have been added as amendments to the information specification linked to the DSCN.

Information Specification

The following information lists the Data Items, corresponding definitions and values that make up the information standard mandated by this DSCN:

The data items required for National Cancer Data Standards for Wales – Site Specific – Core 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 Standard and users should refer to National Cancer Data Standards for Wales – (DSCN 2019/09)([National Cancer Data Standards](#)) for a list of Core requirements please look at the core excel worksheet tab. 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.

Please refer to row 209 in the information specification for the complete table.

Just to note: *Changes made to the Information Specification are highlighted in the colour blue.*

Reporting Data Item	Definition	Format	Code List (Code)	Code List (Text)	Status	NHS Wales DD	Data display format	COSD
Banked Tissue - Core Diagnosis (One Occurrence Per Tumour)								
Banked Tissue Status (At Diagnosis)	Indicates whether any tissue was banked at diagnosis	Code List	1	Patient approached, consented	R	Banked Tissue at Diagnosis	Single select	Banked Tissue at Diagnosis
			2	Patient approached, but declined				
			3	Patient not approached				
			4	Patient withdrawn consent				
			9	Not Known (Not Recorded)				
Type Of Tissue Banked (At Diagnosis)	Type of Tissue Banked (At Diagnosis)	Code List	1	Tumour	R	Type of Tissue Banked at Diagnosis	Multi-select	Type of Tissue Banked at Diagnosis
			2	Blood				
			3	CSF				
			4	Bone Marrow				
			5	Urine				
			6	Other				
			7	Ascites				
			8	Pleural fluid				
Other - Type Of Tissue Banked (At Diagnosis)	If Other is chosen in type of tissue banked, specify the other type	an50	N/A	N/A	R	N/A	N/A	N/A



Llywodraeth Cymru
Welsh Government

Appendix

Information Specification original link

[National Cancer Data Set - Full list DSCNs information Specifications.xlsx](#)