

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2023 / 45
Date of Issue:	14 th November 2023

Ministerial / Official Letter: TBC	Subject: Suspected Cancer Pathway – Core
Sponsor: Olivia Shorrocks, Head of Major Conditions, Delivery and Performance, Health and Social services Group, Welsh Government	
Implementation Date: 14th November 2023	

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 October 2023.

WISB Reference: ISRN 2023 / 027

Summary:

To update the existing Suspected Cancer Pathway - Core data set to update the Primary Cancer Site Description (Sub Site) from a Free Text box to a standardised list.

Data sets / returns affected:

- Existing patient level data set:
- Suspected Cancer Pathway - Core

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

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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

All patients suspected of having a new primary cancer will be put on the Suspected Cancer Pathway regardless of their entry point onto the pathway. This includes patients who have had a previous cancer and are now suspected of having a different primary (a new) cancer.

The progress of this standard has involved a long period of engagement and development work within the cancer community to support and implement the SCP across Wales. The standard outlined the requirements for reporting against the SCP through utilising the patient level data set and the agreed suite of supplementary measures. The new reporting approach replaces the existing Urgent Suspected Cancer (USC) and non-Urgent Suspected Cancer (nUSC) standards.

Since February 2021, Welsh Government no longer report cancer performance against the USC and nUSC (however, Health Boards have been asked to continue to submit aggregate returns alongside the new SCP data set until the new process for SCP reporting is fully embedded). Welsh Government need this information to ensure that the new reporting method is correct, and as an indication of demand changes over time for activity planning.

The original data set was limited to closed pathways only, thus limiting the picture of suspected cancer activity in services in Wales. This change widens the scope of the data set to include active pathways for all new referrals onto the SCP, whatever the source of that referral. The primary care referral information is used to show the volume of patients coming into the system through primary care and the data highlighting patients entering from other sources is essential to track the impact of early diagnosis amongst others. There is now a requirement to include all new active patient pathways in the data set returns to maintain the flow of this information.

All patients who receive their first definitive treatment within Wales should be included. Patients referred by secondary care for treatment outside of NHS Wales are also included in the SCP reporting.

Effective Date

This data standard is effective from the date of publication.

Description of Change

To update the existing Suspected Cancer Pathway - Core data set to update the Primary Cancer Site Description and to update the Primary Cancer Site Description (Sub Site) from a Free Text box to a standardised list.

Changes to the previous publication are highlighted as follows:

- **Blue** – new text
- **Grey** – existing text
- **Strikethrough** – text deletions

Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.18 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.19 of the NHS Wales Data Dictionary.

Actions Required

Actions for Local Health Boards NDR infrastructure (WelshPAS):

- Ensure that the NDR has access to each WelshPAS Health Board instance to enable data to be extracted and transferred to the NDR data stores.

Actions for Local Health Boards infrastructure (non-WelshPAS or Multiple PAS):

- Ensure that the local warehouse infrastructure is set up to enable data to be extracted via a SQL-to-SQL view from the Local Health Board data warehouse or delivered via CSV file format into the NDR data stores.
- Ensure that the local data warehouse infrastructure complies with the specifications outlined in the Suspected Cancer Pathway – Core data set technical implementation.
- Data relating to all patients on a closed pathway within the previous month to be made available in the following month e.g., patients whose pathway closed between 1st September to 30th September are to be made available on 31st October.
- Data relating to all patients not included in the closed pathway submission and are on an active pathway that started in the previous month are to be made available in the following month e.g., patients on an active pathway between 1st September to 30th September to be made available on 31st October.

Actions for all Local Health Boards (regardless of system):

- Data must be validated and made available to DHCW in the November 2021 submission (for September 2021 data).
- For each patient, all columns must be included in the output and named/typed as per the table in Appendix B.
- Where health boards are unable to provide data for optional data items within the data set, these are to be left blank. All mandatory data items must be provided.
- Data will be validated and made available monthly by the last working day of each month.

Actions for the NDR infrastructure:

- Develop and deliver the functionality necessary to enable the implementation of the Suspected Cancer Pathway.
- Ensure that processes are in place to extract the data via methods outlined above into the data stores.

Actions for DHCW Data Standards

- Ensure that development within WelshPAS is in place for the Wales Cancer Tracking Module to accommodate the data items in this Standard.
- Ensure processes are in place to analyse and report on the data for Welsh Government.
- Implement data quality standards and validation methods.
- Ensure processes are in place for local sign off of the data for all Health Boards.

Welsh Government Delivery & Performance Division:

- Notify Digital Health and Care Wales of any changes to Suspected Cancer Pathway measures.

Appendix A: Table reflecting areas that are impacted as a result of this DSCN

The following table shows where there are changes to the scope and/or definitions of applicable data sets, data items, terms and other associated areas that are linked with the changes documented within this DSCN.

Each data definition type is listed in alphabetical order and is shown in the sequence in which it appears in this DSCN.

Data Definition Type	Name	New/Retired/Changed	Page Number
Patient Level Data Set	Suspected Cancer Pathway Core	Changed	7
Data Item	Primary Cancer Site Description	Changed	9
Data Item	Primary Cancer Site Description (Sub Site)	Changed	10

Appendix B: Highlighted changes to be made to the NHS Wales Data Dictionary

Changes to the NHS Wales Data Dictionary are detailed below, with new text being highlighted in **blue** and deletions are shown with a ~~strikethrough~~. The text shaded in **grey** shows existing text copied from the NHS Wales Data Dictionary.

a) Changes to be made to 'Patient Level Data Set'

Scope

All cancer patients should be tracked from point of suspicion to treatment within 62 days regardless of their entry point onto the pathway. The Suspected Cancer Pathway will not include adjustments – the real wait will be reported (currently pathways can be adjusted when a patient takes a holiday, is unable to attend their appointment or needs stabilising treatment. These will not be included in the reporting so the waits reported will reflect the real wait that the patient experienced).

Health boards are required to enter all patients suspected of having a new primary cancer onto the SCP. This includes patients who have had a previous cancer and are now suspected of having a different primary (a new) cancer. This also includes all Squamous Cell Skin Cancer (SCC). For SCP, the clock start point for all patients is the point of suspicion. The main entry points onto the pathway are defined in the "single suspected cancer pathway definitions" document.

Health boards are required to report on all patients referred into services they provide following a suspicion of cancer for SCP, as per previous reporting requirements for nUSC/USC defined in Welsh Health Circular 2004 (067)1 and subsequent guidance. Health boards are required to report on active and closed pathways. All patients who receive their first definitive treatment within Wales should be included in these figures. Patients who are referred by secondary care for treatment outside of NHS Wales will be included in the SCP reporting, however, those that enter directly or are referred from primary care directly to services outside of Wales will not.

Return Submission Details

Data is to be extracted from the source WelshPAS system instance for each Local Health Board. There will be a requirement that traditional DSCN data feed methods will have to continue for some Health Boards where non-WelshPAS systems or multiple PAS systems are in place and these will either be provided through a CSV file format or a SQL-to-SQL transfer. In both instances, the data will be transported into the NDR controlled data stores for dissemination.

Data Set Structure

Rating 1 = Mandatory 2 = Optional 3 =Mandatory where 'Reason for Pathway Close' is 'Treated'	Data Items Relating to Patient Sensitive Data	Column Header	Format
1	Patient's Name (Surname)	Surname	35 character alpha-numeric
1	Patient's Name (Forename)	Forename	35 character alpha-numeric
1	NHS Number	NHSNumber	10 digit numeric
1	NHS Number Status Indicator	NHSNumberStatusIndicator	2 digit numeric
1	Local Patient Identifier	LocalPatientIdentifier	10 character alpha- numeric
1	Patient's Address	Address	175 character alpha- numeric
1	Patient's Postcode	Postcode	8 character alpha- numeric
1	Code of Registered GP Practice	GPPracticeCode	6 character alpha- numeric
1	Birth Date	BirthDate	8 digit numeric (ccyymmdd)
2	Death Date	DeathDate	8 digit numeric (ccyymmdd)
1	Sex (at birth)	Sex	1 digit numeric
1	Ethnic Group	EthnicGroup	2 character alpha- numeric
	Data Items Relating to Local Health Board Data		
1	Organisation Code (Code of Provider)	ProviderOrgCode	5 character alpha- numeric
	Data Items Relating to Pathway Type		
1	Unique Pathway Identifier	UniquePathwayIdentifier	24 character alpha- numeric
1	Pathway Start Date (Point of Suspicion of Cancer)	PathwayStartDate	8 digit numeric (ccyymmdd)
1	Source of Suspicion	SuspicionSource	2 character alpha- numeric
1	Source of Cancer Referral	ReferralSource	2 character alpha- numeric
	Data Items Relating to Tumour Identification		
1	Primary Cancer Site Description	PrimaryCancerSiteDescription	2 character alpha-numeric
2	Primary Cancer Site Description (Sub Site)	PrimaryCancerSubSiteDescription	100 character alpha-numeric 3 digit numeric
	Data Items Relating to Component Waits		

1	Date of Receipt of Cancer Referral	CancerReferralReceiptDate	8 digit numeric (ccyymmdd)
2	Date of First Appointment Taken	FirstAppointmentTakenDate	8 digit numeric (ccyymmdd)
2	Date of First Diagnostic Test Undertaken	FirstDiagnosticTestUndertakenDate	8 digit numeric (ccyymmdd)
2	Date of First Diagnostic Test Reported	FirstDiagnosticTestReportedDate	8 digit numeric (ccyymmdd)
2	Date of Last Diagnostic Test Undertaken before Date of Decision to Treat (DDTT)	LastDiagnosticTestBeforeDDTTDate	8 digit numeric (ccyymmdd)
2	Date of Last Diagnostic Test Reported before Date of Decision to Treat (DDTT) or Treatment Start	LastDiagnosticTestBeforeDDTTorTreatmentStartDate	8 digit numeric (ccyymmdd)
3	Date Patient Informed of Diagnosis	PatientInformedofDiagnosisDate	8 digit numeric (ccyymmdd)
2	Multi Disciplinary Team (MDT) Meeting Date (First Meeting)	MDTFirstMeetingDate	8 digit numeric (ccyymmdd)
2	Multi Disciplinary Team (MDT) Meeting Date (Last Meeting)	MDTLastMeetingDate	8 digit numeric (ccyymmdd)
3	Date of Primary Diagnosis – Clinically Agreed	PrimaryCancerDiagnosisDate	8 digit numeric (ccyymmdd)
1	Outcome of Investigations	InvestigationsOutcome	1 digit numeric
3	Date of Decision to Treat CWT (DDTT)	DDTTDecisionDate	8 digit numeric (ccyymmdd)
2	Date Referred to Tertiary Centre	TertiaryCentreReferralDate	8 digit numeric (ccyymmdd)
2	Tertiary Centre of Treatment	TreatmentTertiaryCentre	5 character alpha-numeric
	Data Items Relating to End Point		
1	Date of SCP Clock Stop	SCPClockStopDate	8 digit numeric (ccyymmdd)
3	Cancer Treatment Modality	CancerTreatmentModality	2 character alpha-numeric
1	SCP Target Date	SCPTargetUnadjustedDate	8 digit numeric (ccyymmdd)
1	Pathway Status	PathwayStatus	1 digit numeric

b) Changes to Existing Data Items

Primary Cancer Site Description

This data item is / was included in the following data sets / collections between the dates shown:

Data Set / Collection	Valid From	Valid To
SCPC ds	1 st January 2021	

The site of the primary cancer for which the patient is receiving care.

Format: 2 character alpha-numeric

Value	Meaning
01	Head and Neck
02	Upper GI
03	Lower GI
04	Lung
05	Sarcoma
06	Skin (exc BCC)
07	Brain/CNS
08	Breast
09	Gynaecological
10	Urological
11	Haematological (exc Acute Leukaemia)
12	Acute Leukaemia
13	Children's
14	Unknown Primary
98	Other

Primary Cancer Site Description (Sub Site)

This data item is / was included in the following data sets / collections between the dates shown:

Data Set / Collection	Valid From	Valid To
SCPC ds	1 st January 2021	

The more granular and free-text 'sub-site' of the primary cancer for which the patient is receiving care.

Format: 100 character alpha-numeric

The more granular list of 'sub site' of the primary cancer for which the patient is receiving care.

Format: n3

Primary site Value	Primary site	Sub site value	Sub site
01	Head & Neck	010	Head & Neck
		011	Thyroid
		099	Unknown
02	Upper GI	020	Pancreas
		021	Stomach

		022	Oesophagus
		023	Liver
		024	Small Intestine
		025	Biliary Tract
		098	Other
		099	Unknown
03	Lower GI	030	Anal
		031	Colon
		032	Rectum
		098	Other
		099	Unknown
04	Lung	040	Lung
		041	Mesothelioma
		098	Other
		099	Unknown
05	Sarcoma	000	Sarcoma (No split)
06	Skin (exc BCC)	050	Melanoma
		051	SCC
		098	Other
		099	Unknown
07	Brain/CNS	000	Brain (No split)
08	Breast	000	Breast (No split)
09	Gynaecological	060	Endometrium
		061	Cervix
		062	Ovary/Primary Peritoneal
		063	Vulva
		098	Other
		099	Unknown
10	Urological	070	Prostate
		071	Bladder
		072	Renal
		073	Testis
		074	Penile
		098	Other
		099	Unknown
11	Haematological (exc Acute Leukaemia)	080	Leukaemia
		081	Lymphoma
		082	Myeloma
		098	Other
		099	Unknown
12	Acute Leukaemia	000	Acute Leukaemia
13	Children's	000	Children's
14	Unknown Primary	000	Unknown Primary
98	Other	000	Other