

WELSH INFORMATION STANDARDS BOARD

DSC Notice:	DSCN 2021 / 23 (AMD)
Date of Issue:	22 nd October 2021

Ministerial / Official Letter: TBC	Subject: Suspected Cancer Pathway – Core (AMD)
Sponsor: Olivia Shorrocks, Head of Major Conditions, Delivery and Performance, Health and Social services Group, Welsh Government	
Implementation Date: 1 st November 2021 (September 2021 data to be published in November 2021).	

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 21st October 2021.

WISB Reference: ISRN 2021 / 020

Summary:

To update the existing Suspected Cancer Pathway - Core data set to include active pathways and to remove USC and nUSC reporting requirements.

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

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

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.

Description of Change

To update the existing Suspected Cancer Pathway - Core data set to include active pathways and to remove USC and nUSC reporting requirements.

Data Dictionary Version

Where applicable, this DSCN reflects changes introduced by DSCN and/or DDCN since the release of version 4.14 of the NHS Wales Data Dictionary.

The changes introduced by such DSCNs will be published in version 4.15 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	5
Data Item	Source of Cancer Referral	Changed	9
Data Item	SCP Target Date	Changed	10
Data Item	Reason for Pathway Close	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
	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

Source of Cancer Referral

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

Data Set / Collection	Valid From	Valid To
National Cancer Ds - Core		
SCPC ds	1 st January 2021	

This is a classification used to identify the source of referral where the recording guidelines (See Definitions document for pathway start date definitions <http://www.walescanet.wales.nhs.uk/scp-key-documents>) advise that the point of suspicion for recording is different to that of the first clinical suspicion of cancer e.g. Receiving clinician suspects cancer in a referral (on vetting) not originally referred as 'suspected cancer' - the date and source proposed by the guidelines would be for the original referral from primary care. Source of Referral is how the patient entered the pathway, and Source of Suspicion is what triggered the suspicion of cancer. Subsequently the Source of Suspicion and Source of Referral (Cancer Wait Times) can differ but in most cases will be the same.

Format: 2 character alpha-numeric

Value ¹	Meaning
Initiated by the Consultant or Independent Nurse responsible for the Out-Patient Episode	
01	Following an emergency admission
02	Following a domiciliary visit
10	Following an Accident and Emergency attendance (including Minor Injuries Units and Walk-In Centres)
11	Other – initiated by the Consultant responsible for the Consultant Out-Patient Episode
Not initiated by the Consultant or Independent Nurse responsible for the Out-Patient Episode	
03	Referral from a General Medical Practitioner
04	Referral from A&E Department (including Minor Injuries Unit and Walk-In Centres)
05	Referral from a Consultant or Independent Nurse, other than in an A&E department
06	Self-referral
07	Referral from Prosthetist
12	Referral from a General Practitioner with a Special Interest (GPwSI) or Dentist with a Special Interest (DwSI)
13	Referral from a Specialist Nurse (Secondary Care)
14	Referral from an Allied Health Professional (AHP)
15	Referral from Optometrist
16	Referral from an Orthoptist
17	Referral from a National Screening Programme

92	General Dental Practitioner
93	Community Dental Service
97	Other – not initiated by the Consultant responsible for the Consultant Out-Patient Episode

¹ A number of values included in the Core Data Standards (see <http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20191210-DSCN%202019%2009-National%20Cancer%20Data%20Standards%20for%20Wales%20-%20Core-v1-0.pdf>) will not be utilised in the SCP data set for this data item as they relate to Source of Suspicion and are therefore listed for the Source of Suspicion data item.

SCP Target Date

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	

Target date of SCP pathway. This is an unadjusted target date which will be incorporated with pathway resets. The pathway reset will move the unadjusted target date forwards and will retain the original suspicion date.

Format: 8 digit numeric, CCYMMDD

Pathway Status

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	

Indicates the status of the patient's pathway. Active represents that the pathway is open with the suspicion date within that being the start point. The other values for pathway status detail why the pathway was closed.

Format: 1 digit numeric

Value	Meaning	Valid From	Valid To
1	Downgraded	1 st January 2021	
2	Treated	1 st January 2021	
3	Deceased	1 st January 2021	
4	Other	1 st January 2021	
5	Active	1 st November 2021	

Examples of 'Other' could include instances such as:

- Metastasis

- Recording error
- Patient opted to be managed privately
- Patient treated outside of Wales
- Patient refused investigations/treatment
- Uncertain episode
- Recurrent
- Duplicate record
- Inappropriate referral

Addendum

As a result of the publication of the Single Cancer Pathway standard, the new reporting approach consequently replaces the Urgent Suspected Cancer (USC) and non-Urgent Suspected Cancer (nUSC) standards. The term *Single* was originally used for this standard to identify this pathway against the other pathways. As this will now be the only pathway going forward, the name of this standard has been amended to *Suspected Cancer Pathway*. The amended terminology is aligned with the latest release of the [Welsh Health Circular](#) (WHC) and [Cancer Waiting Times](#) (CWT) guidance, in which this standard will be referred to as *Suspected Cancer Pathway* as of February 2021.

To ensure all Health Boards have a mutual understanding of the definitions outlined in the DSCN, please refer to the scenarios developed between DHCW and Health Boards here: <https://dhcw.nhs.wales/information-services/information-standards/data-standards/data-standards-files/scp-scenarios-pdf/>