

NHS Data Model and Dictionary



Type:	Change Request
Reference:	1917
Version No:	1.0
Subject:	Cancer Outcomes and Services Data Set Version 10 and Pathology version 5 Update
Effective Date:	1 April 2024
Reason for Change:	Change to Information Standards
Publication Date:	25 March 2024

Background:

The Cancer Outcomes and Services Data Set version 10 and Pathology version 5 were approved by the Data Alliance Partnership Board (DAPB) as [DAPB1521: Cancer Outcomes and Services Data set](#).

Since the data sets were published, amendments have been made to the following Cancer Outcomes and Services Data Sets:

- Haematological
- Lung.

Additional changes have also been made to the formatting of some items in the XML Schemas for both data sets. The updated XML Schemas can be found at: [Cancer Outcomes and Services Data Set XML Schema](#).

A short demonstration is available which describes "How to Read an NHS Data Model and Dictionary Change Request", in an easy to understand screen capture including a voice over and readable captions. This demonstration can be viewed at: https://datadictionary.nhs.uk/elearning/change_request/index.html.

Note: if the web page does not open, please copy the link and paste into the web browser. A guide to how to use the demonstration can be found at: [Demonstrations](#).

Summary of changes:

Data Set

[CANCER OUTCOMES AND SERVICES DATA SET - HAEMATOLOGICAL](#)

Changed Description

[CANCER OUTCOMES AND SERVICES DATA SET - LUNG](#)

Changed Description

Attribute Definitions

[BRONCHOSCOPY PERFORMED TYPE FOR LUNG CANCER](#)

Changed Description

Date: 25 March 2024

Sponsor: Dr Brian Rous, Director of Tumour Classification, National Disease Registration Service, NHS England

Note: New text is shown with a blue background. Deleted text is crossed out. Retired text is shown in grey. Within the Diagrams deleted classes and relationships are red, changed items are blue and new items are green.

CANCER OUTCOMES AND SERVICES DATA SET - HAEMATOLOGICAL

Change to Data Set: Changed Description

CANCER CARE PLAN CHOICE - HAEMATOLOGICAL

One of the following Cancer Care Plan Sections MUST be provided per Core Cancer Care Plan

CHOICE 1 - CHRONIC MYELOID LEUKAEMIA (CML)

To carry cancer care plan details specific to Chronic Myeloid Leukaemia (CML) for Haematological cancer.

One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.

M/R	Data Set Data Elements
M	CHRONIC MYELOID LEUKAEMIA INDEX SCORE (SOKAL)

OR

CHOICE 2 - MYELODYSPLASIA

To carry cancer care plan details specific to Myelodysplasia for Haematological cancer.

One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.

M/R	Data Set Data Elements
-----	------------------------

M	REVISED INTERNATIONAL PROGNOSTIC SCORING SYSTEM SCORE
---	---

OR

CHOICE 3 - FOLLICULAR LYMPHOMA	
To carry cancer care plan details specific to Follicular Lymphoma for Haematological cancer. One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	
M/R	Data Set Data Elements
M	FOLLICULAR LYMPHOMA INTERNATIONAL PROGNOSTIC INDEX 2 SCORE

OR

CHOICE 4 - DIFFUSE LARGE B-CELL LYMPHOMA (DLBCL)	
To carry cancer care plan details specific to Diffuse Large B-Cell Lymphoma (DLBCL) for Haematological cancer. One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	
M/R	Data Set Data Elements
R	PRIMARY EXTRANODAL CANCER SITE
R	NUMBER OF EXTRANODAL SITES CODE
R	REVISED INTERNATIONAL PROGNOSTIC INDEX SCORE

OR

CHOICE 5 - HODGKIN LYMPHOMA	
To carry cancer care plan details specific to Hodgkin Lymphoma for Haematological cancer. One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	
M/R	Data Set Data Elements
R	NUMBER OF ABNORMAL NODAL AREAS
R	HASENCLEVER INDEX SCORE

OR

CHOICE 6 - INTERNATIONAL PROGNOSTIC SCORE INDEX	
To carry cancer care plan details specific to Diffuse Large B-Cell Lymphoma (DLBCL), Nodal T-Cell and Mantle Cell lymphoma for Haematological cancer. One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	
CHOICE 6 - NODAL T CELL LYMPHOMA	
To carry cancer care plan details specific to Nodal T-Cell Lymphoma for Haematological cancer. One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	

M/R	Data Set Data Elements
R	REVISED INTERNATIONAL PROGNOSTIC INDEX SCORE
R	INTERNATIONAL PROGNOSTIC INDEX SCORE

OR

CHOICE 7 - MANTLE CELL LYMPHOMA	
To carry cancer care plan details specific to Mantel Cell lymphoma for Haematological cancer.	
One occurrence of this group is required per Core Cancer Care Plan if selected as the choice.	
M/R	Data Set Data Elements
R	MANTLE CELL INTERNATIONAL PROGNOSTIC INDEX SCORE

SITE SPECIFIC STAGING - HAEMATOLOGICAL

One of the following Site Specific Staging Sections MUST be provided per Core Site Specific Staging

CHOICE 1 - ANN ARBOR	
To carry Ann Arbor site specific staging details for various haematological diseases for Haematological cancer.	
One occurrence of this group is required per Core Site Specific Staging if selected as the choice.	
M/R	Data Set Data Elements
M	ANN ARBOR STAGE

OR

CHOICE 2 - CHRONIC LYMPHOID LEUKAEMIA (CLL)	
To carry Chronic Lymphoid Leukaemia (CLL) staging details for Haematological cancer.	
One occurrence of this group is required per Core Site Specific Staging if selected as the choice.	
M/R	Data Set Data Elements
M	BINET STAGE

OR

CHOICE 3 - MYELOMA	
To carry Myeloma staging details for Haematological cancer.	
One occurrence of this group is permitted per Core Site Specific Staging if selected as the choice.	
M/R	Data Set Data Elements
M	

[REVISED INTERNATIONAL STAGING SYSTEM STAGE FOR MULTIPLE MYELOMA](#)

OR

CHOICE 4 - NON HODGKIN LYMPHOMA (NHL)

To carry Non Hodgkin Lymphoma (NHL) staging details for Haematological cancer. One occurrence of this group is required per Core Site Specific Staging if selected as the choice.

M/R	Data Set Data Elements
M	MURPHY ST JUDE STAGE

OR

CHOICE 5 - ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)

To carry Acute Lymphoblastic Leukaemia (ALL) staging details for Haematological cancer. One occurrence of this group is permitted per Core Site Specific Staging if selected as the choice.

M/R	Data Set Data Elements
M	CHILDRENS ONCOLOGY GROUP STAGING SYSTEM STAGE

OR

CHOICE 6 - ACUTE MYELOID LEUKAEMIA (AML)

To carry Acute Myeloid Leukaemia (AML) staging details for Haematological cancer. One occurrence of this group is required per Core Site Specific Staging if selected as the choice.

M/R	Data Set Data Elements
M	HAEMATOLOGICAL CENTRAL NERVOUS SYSTEM INVOLVEMENT STATUS

ANN ARBOR: EXTENSIONS - HAEMATOLOGICAL

To carry supporting Ann Arbor staging details for various haematological diseases as specified for Haematological cancer. One occurrence of this group is permitted.

M/R	Data Set Data Elements
R	ANN ARBOR SYMPTOMS INDICATION CODE
R	ANN ARBOR EXTRANODALITY INDICATION CODE
R	ANN ARBOR BULKY DISEASE INDICATION CODE
R	ANN ARBOR SPLENIC INDICATION CODE

LABORATORY RESULTS CHOICE - HAEMATOLOGICAL

**One occurrence of this group is required per Core Laboratory Results
One of the following Laboratory Results MUST be provided per Core Laboratory Results**

CHOICE 1 - VARIOUS HAEMATOLOGICAL DISEASES: CHILDREN, TEENAGERS AND YOUNG ADULTS (CTYA).

To carry laboratory results for various haematological diseases for Children Teenagers and Young Adults (CTYA) Haematological cancer.

One occurrence of this group is required per Core Laboratory Results if selected as the choice.

M/R	Data Set Data Elements
R	BONE MARROW BLAST CELLS PERCENTAGE
R	CYTOGENETIC FINDINGS COMMENT

OR

CHOICE 2 - PAEDIATRIC MYELODYSPLASIA

To carry Paediatric Myelodysplasia laboratory result details for Haematological cancer. One occurrence of this group is required per Core Laboratory Results if selected as the choice.

M/R	Data Set Data Elements
R	CELLULARITY PERCENTAGE
R	DIEPOXYBUTANE TEST RESULT
R	DYSPLASTIC HAEMOPOIESIS TYPE

OR

CHOICE 3 - ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)

To carry Acute Lymphoblastic Leukaemia (ALL) laboratory result details for Haematological cancer.

One occurrence of this group is required per Core Laboratory Results if selected as the choice.

M/R	Data Set Data Elements
R	WHITE BLOOD CELL COUNT (HIGHEST PRETREATMENT)

OR

CHOICE 4 - ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) - RESPONSE

To carry Acute Lymphoblastic Leukaemia (ALL) Response laboratory result details for Haematological cancer.

One occurrence of this group is required per Core Laboratory Results if selected as the choice.

M/R	Data Set Data Elements
M	LEUKAEMIC CELLS PRESENT POST MINIMAL RESIDUAL DISEASE INDUCTION PERCENTAGE CODE

DIAGNOSIS CHOICE - HAEMATOLOGICAL

One of the following can be provided per Core Diagnosis

CHOICE 1 - MIXED PHENOTYPE ACUTE LEUKAEMIA (MPAL)

To carry diagnostic Mixed Phenotype Acute Leukaemia (MPAL) details for Haematological cancer.

One occurrence of this group is required per Core Diagnosis if selected as the choice.

M/R	Data Set Data Elements
R	MIXED PHENOTYPE ACUTE LEUKAEMIA SYMPTOMS (AT DIAGNOSIS) Multiple occurrences of this item are permitted
R	EUROPEAN GROUP FOR THE IMMUNOLOGICAL CLASSIFICATION OF LEUKAEMIA SCORING SYSTEM SCORE

OR

CHOICE 2 - ACUTE MYELOID LEUKAEMIA (AML)

To carry diagnostic Acute Myeloid Leukaemia (AML) details for Haematological cancer.

One occurrence of this group is required per Core Diagnosis if selected as the choice.

M/R	Data Set Data Elements
R	CYTOGENETIC RISK GROUP (PAEDIATRIC MOLECULAR GENETIC ABNORMALITIES)
R	ACUTE MYELOID LEUKAEMIA RISK FACTORS (AT DIAGNOSIS)

OR

CHOICE 3 - PAEDIATRIC MYELOYDYSPLASIA

To carry diagnostic Paediatric Myelodysplasia details for Haematological cancer.

One occurrence of this group is required per Core Diagnosis if selected as the choice.

M/R	Data Set Data Elements
R	PAEDIATRIC MYELOYDYSPLASIA CLINICAL FINDINGS (AT DIAGNOSIS) Multiple occurrences of this item are permitted
R	UNDERLYING DISEASE ASSOCIATED WITH MYELOYDYSPLASIA (AT DIAGNOSIS) Multiple occurrences of this item are permitted
R	CONGENITAL ANOMALIES COMMENT
R	OTHER MYELOYDYSPLASIA SYMPTOMS AT DIAGNOSIS Multiple occurrences of this item are permitted

ACUTE LEUKAEMIAS - HAEMATOLOGICAL

To carry treatment details for Acute Leukaemias for Haematological cancer.
One occurrence of this group is permitted per Core Treatment.

M/R	Data Set Data Elements
R	PRIMARY INDUCTION CHEMOTHERAPY FAILURE INDICATOR

CANCER OUTCOMES AND SERVICES DATA SET - LUNG

Change to Data Set: Changed Description

DIAGNOSTIC PROCEDURES CHOICE - LUNG

One of the following may be provided per Diagnostic Procedure

CHOICE 1 - DIFFUSION CAPACITY

To carry Diffusion Capacity details for the National Lung Cancer Audit (NLCA), to be captured once only for each care pathway for Lung cancer. One occurrence of this group is required per Core Diagnostic Procedures if selected as the choice.

M/R	Data Set Data Elements
M	DIFFUSION CAPACITY TEST RESULT

OR

CHOICE 2 - FEV1

To carry FORCED EXPIRATORY VOLUME1 details for the National Lung Cancer Audit (NLCA), to be captured once only for each care pathway for Lung cancer. One occurrence of this group is required per Core Diagnostic Procedures if selected as the choice.

M/R	Data Set Data Elements
R	FORCED EXPIRATORY VOLUME IN 1 SECOND (PERCENTAGE)
R	FORCED EXPIRATORY VOLUME IN 1 SECOND (ABSOLUTE AMOUNT)

OR

CHOICE 3 - BRONCHOSCOPY

To carry bronchoscopy details for Lung cancer. One occurrence of this group is required per Core Diagnostic Procedures if selected as the choice.

M/R	Data Set Data Elements
M	BRONCHOSCOPY PERFORMED TYPE (LUNG CANCER)

DIAGNOSTIC PROCEDURES - LUNG



To carry bronchoscopy details for Lung cancer.

One occurrence of this group is permitted.

M/R	Data Set Data Elements
M	BRONCHOSCOPY PERFORMED TYPE (LUNG CANCER)

MEDIASTINAL SAMPLING - LUNG

To carry Mediastinal Sampling details for the National Lung Cancer Audit (NLCA), to be captured once only for each care pathway for Lung cancer.

One occurrence of this group is permitted.

M/R	Data Set Data Elements
R	MEDIASTINAL SAMPLING INDICATOR (LUNG CANCER)

TREATMENT - SURGERY: LUNG CANCER CONSULTANT OUTCOME PUBLICATION (LCCOP) - LUNG

To carry surgery details for the Lung Cancer Consultant Outcome Publication (LCCOP) for Lung cancer.

One occurrence of this group is permitted per Core Treatment Surgery.

M/R	Data Set Data Elements
R	REGIONAL ANAESTHETIC TECHNIQUE (LUNG CANCER)

HEALTH CHECK - LUNG

To carry screening details required for the Targeted Lung Health Checks (TLHC) Programme for Lung cancer.

One occurrence of this group is permitted.

M/R	Data Set Data Elements
R	LUNG HEALTH CHECK APPOINTMENT STATUS

BRONCHOSCOPY PERFORMED TYPE FOR LUNG CANCER

Change to Attribute: Changed Description

The type of [Bronchoscopy](#) performed on the [PATIENT](#) with lung cancer during a [Lung Cancer Care Spell](#).

For further guidance on recording of this item, see the [National Disease Registration Service](#) website at: [Cancer Outcomes and Services Data Set User Guide](#).

National Codes:

- 1 Flexible [Bronchoscopy](#)
- 2 Rigid [Bronchoscopy](#)
- 3 Endobronchial Ultrasound (EBUS) - Diagnostic
- 4 Endobronchial Ultrasound (EBUS) - Staging
- 5 [Bronchoscopy](#) not performed

For enquiries about this Change Request, please email information.standards@nhs.net

