



Lymphoma

Data Definitions for the National Minimum Core Dataset to support the Introduction of Lymphoma Quality Performance Indicators

Definitions developed by ISD Scotland in collaboration with the Lymphoma Quality Performance Indicator Development Group

Version 2.2: January 2016

To be used in conjunction with:

1. Lymphoma Clinical Quality Performance Indicators V1.0 (September 2013)
2. Lymphoma QPI Dataset Validations (Latest published version).
3. Lymphoma Measurability of Quality Performance Indicators (Latest published version)

DOCUMENT CONTROL SHEET

Key Information

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Revision History

Version	Date	Summary of Changes	Name	Changes Marked
1.1	31/12/13	Changes agreed out with review to support data collection.	David Early ISD	See page iii.
1.2	30/06/14	Changes agreed out with review to support data collection.	Jane Garrett ISD	See page iii.
2.0	09/09/14	Changes agreed at 9 month review	Jane Garrett ISD	See page iii.
2.1	06/02/15	Changes agreed after QA of validation documents	Jane Garrett ISD	See page iii.
2.2	001/2016	Changes agreed at Baseline Review and changes agreed outwith review	Jane Garrett ISD	See page iii.

CONTENTS

PREFACE	i
NOTES FOR IMPLEMENTATION OF CHANGES	ii
CONVENTIONS	ii
REVISIONS TO DATASET	iii
CRITERIA FOR INCLUSION OF PATIENTS IN AUDIT	vii
DATABASE SPECIFICATION	viii
Section 1: Demographic Items	1
Person Family Name	2
Person Given Name	3
Patient Postcode at Diagnosis {Cancer}	4
Date of Birth	5
Person Sex at Birth	6
CHI Number	7
Section 2: Pre-treatment Imaging & Staging Investigations	9
Radiological Staging Investigations Complete {Lymphoma}	10
Date Radiological Staging Investigations Completed {Lymphoma}	11
Date of Radiology Request	12
FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	13
Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	14
Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	15
Date MYC Testing Reported [DLBCL/Burkitts Lymphoma]	16
MYC Testing Result [DLBCL/Burkitts Lymphoma]	17
Location of Diagnosis {Cancer}	18
Date of Diagnosis {Cancer}	19
Virological Testing (1-3)	20
Date of Virological Testing (1-3)	21
Date Discussed by Haematology Care Team (MDT)	22
Date Discussed by Specialist MDT [Primary Cutaneous Lymphoma]	23
WHO/ ECOG Performance Status	24
Treatment Intent	25
Type of First Cancer Treatment {Lymphoma}	26
Date of First Cancer Treatment {Lymphoma}	27
Section 3: Pathology	28
Morphology of Tumour {Lymphoma}	29
Number of Nodal Sites {Lymphoma}	32
Number of Extranodal Sites {Lymphoma}	33
Serum LDH	34
Haemoglobin	35
Albumin at Diagnosis	36
WBC Total	37
WBC Differential – Lymphocytes	38
Section 4: Classification	39
IPI {Lymphoma}	40
FLIPI {Lymphoma}	41
Hasenclever Index for Hodgkin's Disease {Lymphoma}	42
Cotswold Clinical Stage {Lymphoma}	43
B Symptoms {Lymphoma}	44
Manchester Stage {Lymphoma}	45
Bulk Disease	46
Section 5: Oncology Treatment	47
Location Code {Oncology Treatment}	48
Radiotherapy {Lymphoma}	49
Date Treatment Started {Cancer} (Radiotherapy)	50
Date Treatment Completed {Cancer} (Radiotherapy)	51
Type of Systemic Anti-Cancer Therapy (SACT)	52
Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT)	53
Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT)	54
Rituximab {Lymphoma}	55

Rituximab + CHOP {Lymphoma}	55
Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}.....	57
Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}.....	58
Bone Marrow Transplant.....	59
Date of Radiological Imaging Post Treatment Completed {Lymphoma}	60
Section 6: Clinical Trial Entry	61
Patient Entered into Clinical Trial {Lymphoma}	62
Section 7: Follow-up	63
Response Post First Treatment	64
Post-Treatment Assessment Date	65
Follow-up Status	66
Follow-up Date/Date of Relapse/Progression.....	67
Transformation to High Grade	68
Section 8: Death Details.....	69
Date of Death	70

PREFACE

Following the publication of Better Cancer Care: An Action Plan in October 2008, the Scottish Government established the Scottish Cancer Taskforce to oversee its implementation. The NHS Scotland Healthcare Quality Strategy in 2010 expands on this by articulating quality ambitions. A quality measurement framework has been developed setting out measures and targets which will be used to monitor, challenge, manage and report progress. Part of this strategy is the development of quality performance indicators (QPIs) to drive quality improvement in cancer care throughout NHS Scotland.

As high quality data are required to enable comparisons over time and between regions, it is important that national data definitions are used to facilitate consistent data collection. National data definitions already in use have been used as much as possible to allow electronic data capture, thereby minimising duplication of data collection. Where national data definitions do not already exist, definitions used in other systems have been incorporated.

To ensure that findings are comparable across Scotland, the national dataset and data definitions in conjunction with the final quality performance indicators were agreed through public engagement and are now ready for implementation for patients diagnosed from 1 October 2014.

NOTES FOR IMPLEMENTATION OF CHANGES

The following changes should be implemented for all patients who are diagnosed with Lymphoma cancer on or after 1 October 2014 who are eligible for inclusion in the Lymphoma cancer audit.

Changes to definitions fall into the following categories:

- to address problems with ongoing audit and standardise data definitions, where feasible, between different cancer sites
- to address problems with existing definitions
- to allow Quality Improvement Indicators to be measured and reported against

Please email NSS.ISDCANCERAUDIT@nhs.net for enquiries regarding definitions and collection of the minimum core dataset.

CONVENTIONS

In the following definitions the layout for each item is standard. Two conventions have been used in the document as follows:

- {curly brackets} - definition relates to one specific named data set
- 'described elsewhere' - indicates there is a definition for the named item within this document

REVISIONS TO DATASET

REVISIONS TO DATASET (January 2016)

The following changes have been made to facilitate the recording of data. Changes to take effect for patients diagnosed from 01/10/2014

Specification:

WBC Differential – Lymphocytes - field length 6 field type numbers (nnn.nn)

Dataset:

Radiological Staging Investigations Complete {Lymphoma} - Add in Notes for Users 'Separate codes to identify complete CT scans with / without CT neck are required to inform clinical debate.'

Date Radiological Staging Investigations Completed {Lymphoma} - In Definition, delete 'of the chest, abdomen and pelvis ± neck' In Notes for users delete 'Complete staging is CT of chest, abdomen and pelvis ± neck (and no other combination).'

FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment) - In Definition, delete 'of Hodgkin's Lymphoma'. In Notes for Users add Required for QPI (s): 1, 3

Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment) - In Notes for Users: Add Required for QPI (s): 1, 3

Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment) - In Notes for Users add Required for QPI (s): 1, 3. In Notes for Users: delete 'or patient has None Hodgkins Lymphoma,'

Virological Testing (1-3) - In Notes for Users add 'virological tests recorded should be those undertaken as part of the diagnostic process.'

Treatment Intent - In Notes for Users add Required for QPI (s): 1, 2, 3, 4

Morphology of Tumour {Lymphoma} –In Notes for Users add 'Code 98233, Small B-cell Lymphocytic Lymphoma, is also utilised for CLL. However patients with CLL should not be recorded in this dataset.' Delete Morphology Code 97613D – Waldenström Macroglobulinaemia and amend code for Lymphoplasmacytic Lymphoma from 96713C to 96713. Add 98233 – Small B-cell Lymphocytic Lymphoma.

WBC Differential – Lymphocytes - field length 6 field type numbers (nnn.nn), change to 999.99 (Not recorded).

IPI {Lymphoma} – add to Notes for Users 'All Hodgkin lymphoma patients, or those with known distant metastasis who would not require this prognostic index calculated code as Not applicable' and

Non - Hodgkin lymphoma with known distant metastasis or where not recorded in clinical notes code as Not known.

Location Code {Oncology Treatment} - In Notes for Users replace last para. With 'If oncological treatment has not been performed or the patient has refused, record the hospital where clinic was attended.

Radiotherapy {Lymphoma} – In Notes for Users add 'Treatment received for initial management and not treatment of recurrence or relapse. If the patients type of first treatment was 'supportive care only' or 'watchful waiting' then subsequently proceeds to active treatment at a later date, only record if treatment occurs within 6 months of diagnosis.'

Date Treatment Completed {Cancer} (Radiotherapy) – In Notes for Users add 'Required for QPI (s): 2.'

Type of Systemic Anti-Cancer Therapy (SACT) (1-3) - In Notes for Users add 'Treatment received for initial management and not treatment of recurrence or relapse. If the patients type of first treatment was 'supportive care only' or 'watchful waiting' then

subsequently proceeds to active treatment at a later date, only record if treatment occurs within 6 months of diagnosis.'

Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT) – In Notes for Users delete as follows 'Required for QPI(s): 2, 8

Date of Radiological Imaging Post Treatment Completed {Lymphoma} – In Definition add 'or PET CT'

In Notes for Users add 'or PET CT.'

At end of Notes for Users add paragraph. 'If patient dies during treatment record as 08/08/1900.'

REVISIONS TO DATASET (February 2015)

Database Specification:

Virological Testing (1-3) incorrect field name change to HEPC

Date of First Cancer Treatment change to Date (DD/MM/CCYY)

Haemoglobin incorrect field name change to HAEMOGLOB

Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT) incorrect field length change to 4

Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT) incorrect field name change to SACTCYC1

Dataset:

FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment) – '99' (Not recorded)

MYC Testing Result [DLBCL/Burkitts Lymphoma - '99' (Not recorded)

Virological Testing (1-3) - '99' (Not recorded)

WHO/ ECOG Performance Status - '99' (Not recorded)

Rituximab {Lymphoma} - '99' (Not recorded)

Rituximab + CHOP {Lymphoma} - '99' (Not recorded)

Follow-up Status - '99' (Not recorded)

WBC Total - field length 5

WBC Differential – Lymphocytes - field length 5

REVISIONS TO DATASET AT 9 MONTH REVIEW (September 2014)

Dataset:

Radiological Staging Investigations Complete {Lymphoma}

Add in explanatory notes for code '96' – patient not for treatment or further investigation.

MYC Testing Result [DLBCL/Burkitts Lymphoma]

Add the following 2 codes - code '03' failed and code '04' indeterminate.

Add to explanatory notes for negative – 'normal' and for positive – 'rearranged'

Location of Diagnosis {Cancer}

Add to Notes for Users - Must be a valid hospital code listed in the national reference file and if location is unknown record as X9999

Treatment intent

Add to Notes for Users – All patient with low grade Lymphoma being treated with the intention of reaching durable remission should be recorded as curative for the purposes of QPI reporting.

Type of First Cancer Treatment {Lymphoma}

New data item added

Date of First Cancer Treatment {Lymphoma}

New data item added

Morphology of Tumour {Lymphoma}

Remove from Notes for Users codes 1111/1 and 8888/8

Number of Nodal Sites {Lymphoma}

Add to Notes for Users – Number Nodal Sites should be stated by Clinician/MDT record as '99' if not recorded.

Number of Extranodal Sites {Lymphoma}

Add to Notes for Users – Number Extranodal Sites should be stated by Clinician/MDT record as '99' if not recorded.

Serum LDH

Amendment to Notes for Users – Record the last available result prior to starting treatment.

WBC Total

Delete code 1010 (not known)

Amend code 9999 (not recorded) to code 999.9

WBC Differential

Delete code 1010 (not known)

Amend code 9999 (not recorded) to code 99.99

IPI {Lymphoma}

Amendment to Notes for Users – If result is unclear please seek clarification from Clinician.

FLIPI {Lymphoma}

Amendment to Notes for Users – If result is unclear please seek clarification from Clinician.

B Symptoms {Lymphoma}

Remove code '96' – not applicable

Radiotherapy {Lymphoma}

Remove code '96' – not applicable

Type of Systemic Anti-Cancer Therapy (SACT) (1-3)

Remove SACT2 and SACT3

Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT) (1-3)

Remove PLSACTCYC2 and PLSACTCYC3

Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT) (1-3)

Remove SACTCYC2 and SACTCYC3

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer} (1-3)

Remove SACTDATE2 and SACTDATE3

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer} (1-3)

Remove SACTENDATE2 and SACTENDATE3

Database Specification:

Type of First Cancer Treatment {Lymphoma} data item added: Field Name: FIRSTTREATTYPE, Field Type: Integer, Field Length 2.

Date of First Cancer Treatment {Lymphoma} data item added: Field Name: FIRSTTREATDATE, Field Type: Date, Field Length: 10.

The following changes have been made to facilitate the recording of data. Changes to take effect for patients diagnosed from 01/10/2014.

Dataset:

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer} 1-3:

Amended notes for users from 'This is the last dose of the last cycle of a course of chemotherapy or immunotherapy e.g. day 1 of final cycle should be recorded, the date the final treatment was actually delivered to the patient, irrespective if this was planned completion or not.' to 'This is the first day of the last cycle of a course of SACT'.

REVISIONS TO DATASET OUT-WITH REVIEW (June 2014)

Dataset:

Systemic Therapy Agent {Lymphoma} (1-3)

Data item delete

Patient Entered into clinical Trial {Lymphoma}

Amended code '96' - Not applicable and added code '95' – Patient refused clinical trial.

WBC Total

Amended 'Field Type' to number. (nnn.n)

WBC Differential

Amended 'Field Type' to number (nn.nn)

Radiotherapy {Lymphoma}

Removed explanatory notes against 'Code 96 not applicable' – No radiotherapy given

Type of Systemic Anti-Cancer Therapy (SACT) (1-3)

Added code '06' - Single Agent Immunotherapy.

Rituximab {Lymphoma}

Data item added

R-CHOP {Lymphoma}

Data item added

CRITERIA FOR INCLUSION OF PATIENTS IN AUDIT

To facilitate national comparisons the same patients must be audited throughout Scotland. It is therefore important to document the patient eligibility criteria for each national cancer audit data set.

Include:

- All patients with a confirmed new primary lymphoma (see page 32 for morphology inclusion codes)
- Including all patients who have had a previous primary malignancy of any site or a concurrent primary malignancy of another site.

Exclude:

- Patients with recurrent disease (as opposed to a new primary) including patients with DLBCL transformed from low grade disorders.
- Patients, at date of diagnosis, under 16 years of age i.e. up to 15 years 364 days.
- Patients where the only record of their cancer is from a death certificate (DCO).
- Patients with normal residence outwith Scotland.
- Patients whose definitive cancer treatment was privately funded or undertaken outwith NHS Scotland.

DATABASE SPECIFICATION

DOWNLOAD FORMAT

To assist with downloading data to ISD for the National Quality Assurance Programme and other agreed activities, all sites should be able export data according to the following specification.

Data Item	Field Name	Field Type	Size	Page
Section 1: Demographic Items				1
Person Family Name	PATSNM	Characters	35	2
Person Given Name	PATFNAM	Characters	35	3
Patient Postcode at Diagnosis {Cancer}	PATPCODE	Characters	8	4
Date of Birth	DOB	Date (DD/MM/CCYY)	10	5
Person Sex at Birth	SEX	Integer	2	6
CHI Number	CHINUM	Characters	10	7
Section 2: Pre-treatment Imaging & Staging Investigations				9
Radiological Staging Investigations Complete {Lymphoma}	SINVEST	Integer	2	10
Date Radiological Staging Investigations Completed {Lymphoma}	SINVESTDATE	Date (DD/MM/CCYY)	10	11
Date of Radiology Request	RADREQDATE	Date (DD/MM/CCYY)	10	12
FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	PETSCAN	Integer	2	13
Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	PETREQDATE	Date (DD/MM/CCYY)	10	14
Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)	PETDATE	Date (DD/MM/CCYY)	10	15
Date MYC Testing Reported [DLBCL/Burkitts Lymphoma]	MYCDATE	Date (DD/MM/CCYY)	10	16
MYC Testing Result [DLBCL/Burkitts Lymphoma]	MYCRESULT	Integer	2	17
Location of Diagnosis {Cancer}	HOSP	Characters	5	18
Date of Diagnosis {Cancer}	DIAGDATE	Date (DD/MM/CCYY)	10	19
Virological Testing (1-3)	HEPB	Integer	2	20
Virological Testing (1-3)	HEPC	Integer	2	20
Virological Testing (1-3)	HIV	Integer	2	20
Date of Virological Testing (1-3)	HEPBDATE	Date (DD/MM/CCYY)	10	21
Date of Virological Testing (1-3)	HEPCDATE	Date (DD/MM/CCYY)	10	21
Date of Virological Testing (1-3)	HIVDATE	Date (DD/MM/CCYY)	10	21
Date Discussed by Haematology Care Team (MDT)	MDTDATE	Date (DD/MM/CCYY)	10	22
Date Discussed by Specialist MDT [Primary Cutaneous Lymphoma]	SPECMDTDATE	Date (DD/MM/CCYY)	10	23
WHO/ ECOG Performance Status	PSTATUS	Integer	1	24

Treatment Intent	INTENT	Integer	2	25
Type of First Cancer Treatment	FIRSTTREATTYPE	Integer	2	26
Date of First Cancer Treatment	FIRSTTREATDATE	Date (DD/MM/CCYY)	10	27
Section 3: Pathology				28
Morphology of Tumour {Lymphoma}	MORPHOL	Characters	6	29
Number of Nodal Sites {Lymphoma}	NONODAL	Integer	2	32
Number of Extranodal Sites {Lymphoma}	EXNODAL	Integer	2	33
Serum LDH	SERLDH	Integer	2	34
Haemoglobin	HAEMOGLOB	Integer	4	35
Albumin at Diagnosis	ALBUMIN	Integer	4	36
WBC Total	WBCTOT	Number	5	37
WBC Differential – Lymphocytes	WBCLYMPHO	Number (nnn.nn)	6	38
Section 4: Classification				39
IPI {Lymphoma}	IPI	Integer	2	40
FLIPI {Lymphoma}	FLIPI	Integer	2	41
Hasenclever Index for Hodgkin's Disease {Lymphoma}	HASENINDEX	Integer	2	42
Cotswold Clinical Stage {Lymphoma}	COTSWOLD	Integer	2	43
B Symptoms {Lymphoma}	BSYMPATOM	Integer	2	44
Manchester Stage {Lymphoma}	MANCHESTER	Integer	2	45
Bulk Disease	BULKDISEASE	Integer	2	46
Section 5: Oncology Treatment				47
Location Code {Oncology Treatment}	HOSPNONSURG	Characters	5	48
Radiotherapy {Lymphoma}	RADIOTYPE1	Integer	2	49
Date Treatment Started {Cancer} (Radiotherapy)	RSRTDATE1	Date (DD/MM/CCYY)	10	50
Date Treatment Completed {Cancer} (Radiotherapy)	RCOMPDATE1	Date (DD/MM/CCYY)	10	51
Type of Systemic Anti-Cancer Therapy (SACT)	SACT1	Integer	2	52
Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT)	PLSACTCYC1	Integer	4	53
Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT)	SACTCYC1	Integer	4	54
Rituximab {Lymphoma}	RITUXIMAB	Integer	2	55
Rituximab + CHOP {Lymphoma}	RCHOP	Integer	2	55
Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}	SACTDATE1	Date (DD/MM/CCYY)	10	57
Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}	SACTENDATE1	Date (DD/MM/CCYY)	10	58
Bone Marrow Transplant	BONETR	Integer	2	59
Date of Radiological Imaging Post Treatment Completed {Lymphoma}	POSTIMAGDATE	Date (DD/MM/CCYY)	10	60
Section 6: Clinical Trial Entry				61
Patient Entered into Clinical Trial {Lymphoma}	TRIAL	Integer	2	62
Section 7: Follow-up				63

Response Post First Treatment	FTRESPONS	Integer	2	64
Post-Treatment Assessment Date	POSTTREATDATE	Date (DD/MM/CCYY)	10	65
Follow-up Status	FUSTATUS	Integer	2	66
Follow-up Date/Date of Relapse/Progression	FUDATE	Date (DD/MM/CCYY)	10	67
Transformation to High Grade	TRANS	Integer	2	68
Section 8: Death Details				69
Date of Death	DOD	Date (DD/MM/CCYY)	10	70

Section 1: Demographic Items

Person Family Name

Common Name(s): Surname, Family name

Main Source of Data Item Standard: [Government Data Standards Catalogue](#)

Definition:

That part of a person's name which is used to describe family, clan, tribal group, or marital association at the time of diagnosis.

Field Name: PATSNAME

Field Type: Characters

Field Length: 35

Notes for Users:

The surname of a person represents that part of the name of a person indicating the family group of which the person is part.

It should be noted that in Western culture this is normally the latter part of the name of a person. However, this is not necessarily true of all cultures. This will, of course, give rise to some problems in the representation of the name. This is resolved by including the data item Name Element Position in the structured name indicating the order of the name elements.

From SMR Definitions and Codes

Codes and Values:

Related Data Items:

Person Given Name

Common Name(s): Forename, Given Name, Personal Name

Main Source of Data Item Standard: [Government Data Standards Catalogue](#)

Definition:

The forename or given name of a person.

Field Name: PATFNAME

Field Type: Characters

Field Length: 35

Notes for Users:

The first forename of a person represents that part of the name of a person which after the surname is the principal identifier of a person.

Where the person's preferred forename is not the first forename, the related data item 'Preferred Forename' should be used to indicate this.

Codes and Values:

Related Data Items:

Patient Postcode at Diagnosis {Cancer}

Main Source of Data Item Standard: [Government Data Standards Catalogue](#)

Definition:

Postcode of patient's usual place of residence on the date of diagnosis

Field Name: PATPCODE

Field Type: Characters

Field Length: Maximum 8

Notes for Users:

Postcode is included in BS7666 Address (GDSC) but there is also a separate Post Code standard which will be populated from BS7666 Address Post Code.

This item can be derived from the date of diagnosis and patient address at that time

Codes and Values: N/A

Related Data Items:

Date of Diagnosis {Cancer}

Date of Birth

Main Source of Data Item Standard: [Government Data Standards Catalogue](#)

Definition:

The date on which a person was born or is officially deemed to have been born, as recorded on the Birth Certificate.

Field Name: DOB

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users:

If the patient's date of birth is recorded differently on different occasions, the most frequently used or latest date should be recorded.

The patient's full date of birth inclusive of the century should be recorded. The format should be DD/MM/CCYY e.g. 01/02/2011.

Codes and Values: N/A

Related Data Items:

CHI Number

Person Sex at Birth

Common Name(s): Sex at Birth

Main Source of Data Item Standard: Derived from the nearest equivalent Government Data Standards Catalogue standard 'Person Gender at Registration'

Definition: This is a factual statement, as far as is known, about the phenotypic (biological) sex of the person at birth

Field Name: SEX

Field Type: Integer

Field Length: 2

Notes for Users:

A person's sex has clinical implications, both in terms of the individual's health and the health care provided to them.

In the majority of cases, the phenotypic (biological) sex and genotypic sex are the same and the phenotypic sex is usually easily determined. In a small number of cases, accurate determination of genotype may be required

Codes and Values:

Code	Value	Explanatory Notes
01	Male	
02	Female	
09	Not specified/Indeterminate	Where it has not been possible to determine if the person is male or female at birth, e.g. intersex / hermaphrodite.
99	Not recorded	

Related Data Items:

CHI Number

CHI Number

Main Source of Data Item Standard: Scottish Executive Health Department.

Definition:

The Community Health Index (CHI) is a population register, which is used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.

Field Name: CHINUM

Field Type: Characters

Field Length: 10

Notes for Users:

The Community Health Index (CHI) is a computer based population index whose main function at present is to support primary care services. CHI contains details of all Scottish residents registered with a General Practitioner and was originally envisaged and implemented as a population-based index to help assess the success of immunisation and screening programmes. It is therefore closely integrated with systems for child health, cervical cytology and breast screening call and recall...It is intended that this number, the Scottish equivalent of the new NHS number in England and Wales, should become the Unique Patient Identifier throughout the NHS in Scotland.

From Designed to Care - Scottish Office

The CHI number is a unique numeric identifier, allocated to each patient on first registration with the system. The CHI number is a 10-character code consisting of the 6-digit date of birth (DDMMYY), two digits, a 9th digit which is always even for females and odd for males and an arithmetical check digit.

(ISD, Information Services, NHS National Services Scotland)

The CHI number should always be used to identify a patient. However, Health record identifiers, such as hospital numbers in Patient Administration Systems (PAS), may be used locally, in conjunction with the CHI number or in the absence of the CHI number, to track patients and their records.

Although there may be no number when a patient presents for treatment, there must be an allocation at some point in the episode of care as CHI is mandatory on all clinical communications.

Non-Scottish patients and other temporary residents can have a CHI number allocated if required but it is envisaged that future development may allow the identifying number used in other UK countries to be used in Scotland.

Codes and values: N/A

Related Data Items:

Date of Birth

Person Sex at Birth

Section 2: Pre-treatment Imaging & Staging Investigations

Radiological Staging Investigations Complete {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: A record if radiological staging investigations were completed by Computed Tomography (CT) of the chest, abdomen and pelvis ± neck.

Field Name: SINVEST

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI(s): 1

Staging investigations may be done separately but should be completed.

Complete staging is CT of the chest, abdomen and pelvis ± neck.

Separate codes to identify complete CT scans with / without CT neck are required to inform clinical debate.

Codes and Values:

Code	Value	Explanatory Notes
01	Complete – CT Chest, Abdomen and Pelvis	
02	Complete – CT Chest, Neck, Abdomen and Pelvis	
03	Incomplete	e.g. no imaging or part imaging
95	Patient refused investigation	
96	Not applicable	e.g. patient not for treatment or further investigation
99	Not recorded	

Related Data Item(s):

Date Radiological Staging Investigations Completed {Lymphoma}

Date Radiological Staging Investigations Completed {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: The date that radiological staging investigations were completed by CT

Field Name: SINVESTDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 1

Record the date that ALL items are complete, e.g. if done on separate days then record the final date.

If staging investigations were not completed, record as inapplicable (10/10/1010).

If the exact date is not documented, record as (09/09/0909).

Related Data Item(s):

Radiological Staging Investigations Complete {Lymphoma}

Date of Radiology Request

Date of Radiology Request

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: The date a CT scan was requested by a Clinician and sent to radiology for CT of chest, abdomen and pelvis ± neck.

Field Name: RADREQDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 1

If more than one CT scan undertaken the final CT scan date should be recorded to align with date of investigation.

If radiology request not required, record as 10/10/1010 (Not applicable).

If the exact date is not documented, record as 09/09/0909 (Not recorded).

Related Data Item(s):

Radiological Staging Investigations Complete {Lymphoma}

Date Radiological Staging Investigations Completed {Lymphoma}

FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record if a FDG-PET/CT (PET/CT) scan was performed for staging and assessment.

Field Name: PETSCAN

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI(s): 1, 3

All newly diagnosed patients with Classical Hodgkin's Lymphoma being considered for curative therapy should have a baseline PET CT scan

Codes and Values:

Code	Value
01	Yes
02	No
95	Patient refused investigation
96	Not applicable
99	Not recorded

Related Data Items:

Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: The date a PET/CT scan was requested by a Clinician and sent to radiology.

Field Name: PETREQDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 1, 3

Scan should be undertaken within 2 weeks of radiology request.

If radiology request not required, record as 10/10/1010 (Not applicable).

If the exact date is not documented, record as 09/09/0909 (Not recorded).

Related Data Item(s):

Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Date of Integrated FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the date of computed tomography the integrated FDG-PET/CT (PET/CT) scan was performed for staging and assessment.

Field Name: PETDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 1, 3

Scan should be undertaken within 2 weeks of radiology request

If the patient has more than one PET/CT scan the date of the first procedure is recorded.

If the exact date of the PET/CT Scan is not documented, record as 09/09/0909 (Not recorded).

If PET/CT scan was not performed record as 10/10/1010 (not applicable).

Related Data Items:

Date of Radiology Request for FDG-PET/CT (PET/CT) Scan {Lymphoma} (Pre-treatment)

Date MYC Testing Reported [DLBCL/Burkitts Lymphoma]

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This date MYC testing was reported using classical cytogenetics or Fluorescence in Situ Hybridization (FISH).

Field Name: MYCDATE

Field Type: Date (DD/MM/CCYY)

Field Length:10

Notes for Users: Required for QPI(s): 4

Classical cytogenetic or Fluorescence in Situ Hybridization (FISH) analysis is essential for the diagnosis of Burkitt lymphoma.

Rearrangements of MYC in DLBCL/Burkitts are a strong prognostic factor and will guide treatment options and provide important information to help inform patients and carers about the nature of the disease and prognosis.

If the date of the MYC report is unknown record as 09/09/0909 (Not Recorded)

If MYC testing is not required, record as 10/10/1010 (Not applicable).

Related Data Items:

MYC Testing Result [DLBCL/Burkitts Lymphoma]

MYC Testing Result [DLBCL/Burkitts Lymphoma]

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The result of the MYC testing as reported using classical cytogenetics or Fluorescence in Situ Hybridization (FISH).

Field Name: MYCRESULT

Field Type: Integer

Field Length: 2

Notes for Users:

Classical cytogenetic or Fluorescence in Situ Hybridization (FISH) analysis is essential for the diagnosis of Burkitt lymphoma.

Rearrangements of MYC in DLBCL/Burkitts are a strong prognostic factor and will guide treatment options and provide important information to help inform patients and carers about the nature of the disease and prognosis.

Codes and Values:

Code	Value	Explanatory Notes
01	Positive	e.g. rearranged
02	Negative	e.g. normal
03	Failed	
04	Indeterminate	
89	Test not done	
96	Not applicable	
99	Not recorded	

Related Data Items:

Date MYC Testing Reported [DLBCL/Burkitts Lymphoma]

Location of Diagnosis {Cancer}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The patient's hospital of investigation in which the diagnosis of cancer was first made

Field Name: HOSP

Field Type: Characters

Field Length: 5

Notes for Users: Required for clarifying responsibility for data collection and national comparative analysis.

Must be a valid hospital code listed in the national reference file.

Location codes for hospitals are five character codes maintained by ISD and the General Register Office (Scotland). <http://www.natref.scot.nhs.uk/>

Location must be viewed as an address and not a code. If any new locations arise where NHS healthcare is delivered/administered, please ensure that the Reference Files Team at ISD is informed using form LOC-NEW (which can be downloaded from the website below) so that a new code may be issued as appropriate. <http://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/>

The first character denotes the health board, the next three are assigned and the fifth denotes the type of location (H=hospital) e.g.

A111H=Crosshouse Hospital

G107H=Glasgow Royal Infirmary

If a patient was diagnosed through imaging at one hospital but transferred to another for confirmation of the diagnosis, the first hospital should be recorded as the Location of diagnosis.

If location is unknown record as X9999

Related Data Item(s):

Date of Diagnosis {Cancer}

Date of Diagnosis {Cancer}

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date on which lymphoma was first diagnosed whether by histology, cytology, immunology or cytogenetics.

Field Name: DIAGDATE

Field Type: Date (DD/MM/CCYY)

Field length: 10

Notes for Users: Required for national survival analysis and national comparative analysis.

Diagnosis of lymphoma is usually determined by histology.

If the exact date is not documented, record as 09/09/0909.

The date recorded is the date the procedure was performed, not the date the report was issued.

Related Data Item(s):

Location of Diagnosis {Cancer}

Virological Testing (1-3)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record of the result of virological testing for, hepatitis B, hepatitis C and HIV.

Field Name: HEPB
HEPC
HIV

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI(s): 11

Virological tests recorded should be those undertaken as part of the diagnostic process.

Hepatitis B includes core and surface.

Results for all 3 blood tests should be recorded separately.

Codes and Values:

Code	Value	Explanatory Notes
01	Positive	
02	Negative	
89	Test not done	
95	Patient refused investigation	
96	Not applicable	Patient not undergoing rituximab treatment
99	Not recorded	

Related Data Items:

Date of Virological Testing (1-3)

Date of Virological Testing (1-3)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record of the date that virological testing, hepatitis B, hepatitis C and HIV was carried out.

Field Name: HEPBDATE
HEPCDATE
HIVDATE

Field Type: Date (DD/MM/CCYY)

Field length: 10

Notes for Users: Required for QPI(s): 11

Dates for each individual blood test should be recorded separately.

If the date of the test is unknown record as 09/09/0909. If test is not carried out record as Not Applicable 10/10/1010.

Related Data Items:

Virological Testing

Date Discussed by Haematology Care Team (MDT)

Common name: Date discussed by multidisciplinary team (MDT)

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the date the Haematology care team meeting (also known as the multidisciplinary team) was held to discuss the management of the patient's care.

Field Name: MDTDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI: 5

A cancer multidisciplinary care team may include surgeons, oncologists, haemato-oncologists, radiologists, pathologists, nurses, physiotherapists and others relevant to the treatment of a specific cancer. The team meets on a regular basis to discuss optimal patient management. Documentation of the discussion should be included in the case-note or other formal documentation.

The first MDT meeting should be recorded.

If the date of the MDT meeting is unknown record as 09/09/0909 or if the patient has not been discussed by the MDT, record as Not applicable 10/10/1010.

Related Data Item(s):

Date Discussed by Specialist MDT [Primary Cutaneous Lymphoma]

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the date the specialist MDT meeting which included representation from pathology, dermatology, oncology ± haemato-oncology was held to discuss the management of the patient's primary cutaneous lymphoma.

Field Name: SPECMDTDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI 10

A specialist MDT for patients with primary cutaneous lymphoma facilitates clinico-pathological correlation, which is very important in this group of conditions where treatment is multi-faceted. Furthermore it allows for consolidation of expertise in this rare condition which will help develop robust diagnosis and management.

The first specialist MDT meeting should be recorded.

If the date of the MDT meeting is unknown record as 09/09/0909 or if the patient has not been discussed by the MDT, record as Not applicable 10/10/1010.

Related Data Item(s):

WHO/ ECOG Performance Status

Main Source of Data Item Standard: WHO (World Health Organisation) and ECOG (Eastern Cooperative Oncology Group)

Definition: An overall assessment of the functional/physical performance of the patient.

Field Name: PSTATUS

Field Type: Integer

Field length: 1

Notes for Users: Required for survival analysis

The WHO/ECOG performance status is a grade on a five point scale (range 0 to 4) at the time of investigation in which '0' denotes normal activity and '4' a patient who is 100% bedridden. If it is not documented do not deduce from other information and record as 'Not recorded'.

This item may occur more than once throughout a patient's record.

This field relates to pre-treatment performance status i.e. at the time of the MDT closest to actual treatment.

If the performance status falls between two scores, record the higher value i.e. the worst performance status.

Codes and values:

Code	Value
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work
2	Ambulatory and capable of self care but unable to carry out any work activities: up and about more than 50% of waking hours
3	Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4	Completely disabled, cannot carry on any self care, totally confined to bed or chair
9	Not recorded

Treatment Intent

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services

Definition: This is intent of treatment that was carried out.

Field Name: INTENT

Field Type: Integer

Field length: 2

Notes for Users: Required for QPI(s): 1, 2, 3, 4

This information should be recorded at MDT, clinical letter or within electronic prescribing systems, this should not be deduced.

All patients with low grade lymphoma being treated with the intention of reaching durable remission should be recorded as curative for the purposes of QPI reporting.

Codes and Values:

Code	Value	Explanatory Note
01	Curative	Treatment given with the potential for cure (radical treatment). E.g. radical chemotherapy such as R-CHOP and ABVD.
02	Palliative	Any treatment given for the control of symptoms resulting from the cancer e.g. surgery, radiotherapy, or Systemic Anti-Cancer Therapy (SACT).
03	Supportive care only	Care aimed at symptom control and sustaining the patients and/or carers ability to cope with a medical condition.
04	Watch and Wait	
94	Patient died before treatment	
95	Patient refused treatment	
99	Not recorded	

Type of First Cancer Treatment {Lymphoma}

Common name: Mode of first treatment

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the first specific treatment modality administered to a patient.

Field Name: FIRSTTREATTYPE

Field Type: Integer

Field length: 2

Notes for Users: Required for QPI(s): 5

For any particular modality it is the first treatment and not specifically the definitive treatment i.e. this does not include purely diagnostic biopsies such as incisional biopsies, needle biopsies or core biopsies.

Record patients as having 'supportive care only' if a decision was taken not to give the patient any active treatment as part of their primary therapy.

No active treatment includes watchful waiting and supportive care but not palliative chemotherapy and/or radiotherapy.

Steroids etc should not be recorded as first treatment if more substantive treatment such as radiotherapy, chemotherapy or surgery is given. If no further treatment is given, then record as supportive care

Codes and Values:

Code	Description	Explanatory notes
01	Surgery	
02	Radiotherapy	
03	Chemotherapy	
05	Endoscopic	
06	Hormone therapy	
07	Supportive care	No active treatment
11	Other therapy	
12	Watchful waiting	No active treatment
15	Chemoradiotherapy	
18	Chemoimmunotherapy	
19	Immunotherapy	
94	Patient died before treatment	
95	Patient refused all therapies	
99	Not recorded	

Related Data Item(s):

Date of First Cancer Treatment

Date of First Cancer Treatment {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the date the type of first cancer treatment was given to the patient.

Field Name: FIRSTTREATDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users:

This field should be recorded for all patients including those with supportive care only ('No active treatment') (see below).

If type of first cancer treatment is 'supportive care only', the date recorded should be the first date the decision was taken not to give the patient treatment as part of their primary therapy. The aim of this date is to distinguish between patients who have initially had no treatment but receive some therapy when symptoms develop.

The date recorded should be that of the first type of cancer treatment.

If the exact date is not documented, record as 09/09/0909 (Not recorded).

If the patient died before treatment or the patient refused treatment, record as 10/10/1010 (Not applicable).

Related Data Item(s):

Type of First Cancer Treatment

Section 3: Pathology

Morphology of Tumour {Lymphoma}

Main Source of Data Item Standard: WHO Histological Classification of Tumours (4th Edition).

Definition: This is the morphology of the tumour according to the International Classification of Diseases for Oncology (ICD-O(3)).

Field Name: MORPHOL

Field Type: Characters

Field Length: 6

Notes for Users: Required for QPI 1-11

If not recorded, record as 9999/9 (Not recorded).

Morphology codes are shown below. This list is not exhaustive and if a code is not on the list please contact <mailto:NSS.isdCANCERAUDIT@nhs.net> for advice.

ICD-O(3) code '96983' has been subdivided into 'A' (Follicular Lymphoma Grade 3A) and 'B' (Follicular Lymphoma Grade 3B) to meet QPI requirements.

Code 98233, Small B-cell Lymphocytic Lymphoma, is also utilised for CLL. However patients with CLL should not be recorded in this dataset.

Lymphoma Morphology Codes

Mature B-cell Neoplasms

Code	Description
96893	Splenic B-cell Marginal Zone Lymphoma
95913A	Splenic B-cell Lymphoma/Leukaemia, Unclassifiable
95913B	Splenic Diffuse Red Pulp Small B-cell Lymphoma
96713	Lymphoplasmacytic Lymphoma
96993A	Extranodal Marginal Zone Lymphoma of Mucosa-Associated Lymphoid Tissue (MALT-Lymphoma)
96993B	Nodal Marginal Zone Lymphoma
96903	Follicular Lymphoma
96913	Follicular Lymphoma Grade 2
96953	Follicular Lymphoma Grade 1
96983A	Follicular Lymphoma Grade 3A
96983B	Follicular Lymphoma Grade 3B
95973	Primary Cutaneous Follicle Centre Lymphoma
96733	Mantle Cell Lymphoma
96803A	Diffuse Large B-cell Lymphoma NOS
96883	T-cell Histiocyte-rich Large B-cell Lymphoma
96803B	Primary Diffuse Large B-cell Lymphoma of the CNS
96803C	Primary Cutaneous DLBCL, Leg Type
96803D	EBV Positive Diffuse Large B-cell Lymphoma of the Elderly

Code	Description
96803E	DLBCL Associated with Chronic Inflammation
97661	Lymphomatoid Granulomatosis
96793	Primary Mediastinal (Thymic) Large B-cell Lymphoma
97123	Intravascular Large B-cell Lymphoma
97373	ALK-Positive Large B-Cell Lymphoma
97353	Plasmablastic Lymphoma
97383	Large B-cell Lymphoma Arising in HHV8-associated Multicentric Castleman Disease
96783	Primary Effusion Lymphoma
96873	Burkitt Lymphoma
96803F	B-cell Lymphoma, Unclassifiable, with Features Indeterminate between Diffuse Large B-cell Lymphoma and Burkitt Lymphoma
95963	B-cell Lymphoma, Unclassifiable with Features Indeterminate between Large B-cell Lymphoma and Classical Hodgkin Lymphoma
98233	Small B-cell Lymphocytic Lymphoma

B-cell Proliferations of Uncertain Malignant Potential

Code	Description
99701	Post-transplant Lymphoproliferative Disorder, Polymorphic

T-Cell and NK-Cell Neoplasms

Code	Description
Other Extranodal	
97193	Extranodal NK/T Cell Lymphoma, Nasal Type
97173	Enteropathy-associated T-cell Lymphoma
97163	Hepatosplenic T-cell Lymphoma
97083	Subcutaneous Panniculitis-like T-cell Lymphoma
Cutaneous	
97003	Mycosis Fungoides
97013	Sezary Syndrome

Primary Cutaneous CD30-positive T-cell Lymphoproliferative Disorders

Code	Description
97183	Primary Cutaneous Anaplastic Large Cell Lymphoma (C-ALCL)
97263	Primary Cutaneous Gamma-delta T-cell Lymphoma
97093A	Primary Cutaneous CD8-positive Aggressive Epidermotropic Cytotoxic T-cell Lymphoma
97093B	Primary Cutaneous CD4-positive /small/Medium T-cell Lymphoma

Nodal

Code	Description
97023	Peripheral T-cell Lymphoma, Unspecified
97053	Angioimmunoblastic T-cell Lymphoma
97143	Anaplastic Large Cell Lymphoma, (ALCL) ALK Positive
97023	Anaplastic Large Cell Lymphoma, ALK Negative

Uncertain if B or T cell

Code	Description
95903	Malignant Lymphoma, Not Otherwise Specified
95913	Malignant Lymphoma, Non-Hodgkin, Not Otherwise Specified
95963	Composite Hodgkin and Non-Hodgkin Lymphoma

Hodgkin Lymphoma

Code	Description
96593	Nodular Lymphocyte Predominant Hodgkin Lymphoma
96503	Classical Hodgkin Lymphoma
96633A	Nodular Sclerosis Classical Hodgkin Lymphoma
96653	Nodular Sclerosis Classical Hodgkin Lymphoma, Grade 1
96673	Nodular Sclerosis Classical Hodgkin Lymphoma, Grade 2
96633B	Nodular Sclerosis Classical Hodgkin Lymphoma, Cellular Phase
96523	Mixed Cellularity Classical Hodgkin Lymphoma
96513	Lymphocyte-rich Classical Hodgkin Lymphoma
96533A	Lymphocyte-depleted Classical Hodgkin Lymphoma
96533B	Lymphocyte-depleted Classical Hodgkin Lymphoma, Diffuse Fibrosis
96533C	Lymphocyte-depleted Classical Hodgkin Lymphoma, Reticular

Number of Nodal Sites {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The number of nodal sites involved with disease

Field Name: NONODAL

Field Type: Integer

Field Length: 2

Notes for Users: Required for survival analysis.

Number of nodal sites should be stated by Clinician/ MDT.

If the number of nodal sites is unknown record as 99 (Not Recorded).

If number of nodal sites is not required, record as 96 (Not applicable).

Codes and Values:

Code	Value	Explanatory Notes
01	0	
02	1-4	
03	≥ 5	
96	Not applicable/not assessed	not staged
99	Not recorded	

List of Nodal Sites:

CERVICAL	COELIAC
PRE-AURICULAR	PARA-AORTIC
POST-AURICULAR	PORTA HEPATIS
PAROTID	MESENTERIC
SUBMANDIBULAR	RETROPERITONEAL
SUBMAXILLARY	ILIAC
OCCIPITAL	INGUINAL
SUBMENTAL	FEMORAL
SUPRACLAVICULAR	EPITROCHLEAR / BRACHIAL
INFRACLAVICULAR	OTHER NODAL
AXILLARY	THYMUS
PECTORAL	MEDIASTINUM
INTERCOSTAL	NASOPHARYNX
LUNG HILAR	WALDEYERS RING
RETROCRURAL	SPLEEN
SPLENIC HILAR	

Number of Extranodal Sites {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The number of extranodal sites involved with disease

Field Name: EXNODAL

Field Type: Integer

Field Length: 2

Notes for Users: Required for survival analysis.

Number of extranodal sites should be stated by Clinician/ MDT.

If the number of extranodal sites is unknown record as 99 (Not Recorded).

If number of extranodal sites is not required, record as 96 (Not applicable).

Codes and Values:

Code	Value	Explanatory Notes
01	0	
02	1	
03	>1	
96	Not applicable/not assessed	not staged
99	Not recorded	

List of Extranodal Sites:

BONE	THYROID	PERITONEUM
BRAIN	SINUS	LIVER
SPINAL CORD	NOSE	PANCREAS
SKIN	TONGUE	GALLBLADDER
SUBCUTANEOUS	OROPHARYNX	ADRENAL
CERVIX	PALATE	PAROTID SALIVARY GLAND
OVARY	GUM	OMENTUM
VAGINA	BUCCAL	MUSCLE
LABIA	LARYNX	BLOOD BONE MARROW
TESTIS	TRACHEA	EXTRA NODAL
UTERUS	BRONCHUS	SUBMANDIBULAR SALIVARY GLAND
PROSTATE	LUNG	ORBIT
BLADDER	PLEURA	EYELID
KIDNEY	BREAST	
OESOPHAGUS	CARDIAC	
STOMACH	CHEST WALL	
SMALL BOWEL	EAR	
LARGE BOWEL	EXTRADURAL	
RECTUM	LACRIMAL	

Serum LDH

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The level of lactate dehydrogenase (LDH) as measured at the time the patient was investigated for cancer.

Field Name: SERLDH

Field Type: Integer

Field Length: 2

Notes for Users: Required for survival analysis

Record the last available result prior to starting treatment.

This information should be available in the MDT notes.

Codes and Values:

Code	Value
01	Normal or Below
02	Raised
03	Not performed
99	Not recorded

Haemoglobin

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The level of haemoglobin (Hb) detected in the patient's blood when they were investigated for cancer.

Field Name: HAEMOGLOB

Field Type: Integer

Field Length: 4

Notes for Users: Required for survival analysis

Hb should be recorded in g/l.

The level recorded should normally be the first result after referral and before treatment. This information should be available in the MDT notes.

If the test was not performed, record as 1010 (Not applicable)

If no level is recorded then record as 9999 (Not recorded).

Albumin at Diagnosis

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The serum level of albumin at the time the patient was investigated for cancer.

Field Name: ALBUMIN

Field Type: Integer

Field Length: 4

Notes for Users: Required for survival analysis

Albumin should be recorded in g/l.

The level recorded should normally be the first result after referral and before treatment. This information should be available in the MDT notes.

If the test was not performed, record as 1010 (Not applicable)

If no level is recorded then record as 9999 (Not recorded).

WBC Total

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The total white blood cell count in the patient's blood when they were first investigated for cancer.

Field Name: WBCTOT

Field Type: Number (nnn.n)

Field Length: 5

Notes for Users: Required for survival analysis

The level recorded should normally be the first result after referral and before treatment. This information should be available in the MDT notes.

WBC total should be recorded in $10^9/l$.

If no blood count is recorded then record as 999.9 (Not recorded).

WBC Differential – Lymphocytes

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The lymphocyte count in the patient's blood when they were first investigated for cancer.

Field Name: WBCLYMPHO

Field Type: Number (nnn.nn)

Field Length: 6

Notes for Users: Required for survival analysis

A WBC differential is a measure of an individual component (lymphocytes) of the total white blood cell count.

The level recorded should normally be the first result after referral and before treatment.

Lymphocytes should be recorded in $10^9/l$.

If no blood count is recorded then record as 999.99 (Not recorded).

Section 4: Classification

IPI {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The International Prognostic Index (IPI) is for patients with high grade non-Hodgkin's lymphoma.

Field Name: IPI

Field Type: Integer

Field Length: 2

Notes for Users: Required for survival analysis

The background to this index is detailed in: The International Non-Hodgkin's Lymphoma Prognostic Factors Project. A predictive model for aggressive Non-Hodgkin's lymphoma. NEJM (1993) 329:987.

It is calculated as follows:

Age	>60years
WHO/ECOG	>=2
Cotswold	III, IV (Ann Arbor)
Extranodal Disease	> 1 site
LDH	Raised

Score 1 for each of the above factors.

Cotswold staging will be utilised to determine IPI.

IPI is a calculated field. This should ensure no interpretation of clinical information by audit staff and provides background data for sub-analysis.

All Hodgkin lymphoma patients, or those with known distant metastasis who would not require this prognostic index calculated code as Not applicable
Non - Hodgkin lymphoma with known distant metastasis or where not recorded in clinical notes code as Not known.

If result is unclear please seek clarification from Clinician.
Record the calculated value.

Codes and Values:

Code	Value	Explanatory Notes
01	0-1	Low Risk
02	2	Intermediate/Low treatment Distant metastases
03	3	Intermediate/High
04	4-5	High Risk treatment Distant metastases
96	Not applicable treatment Distant metastases	Patient does not have high grade follicular NHL
99	Not recorded treatment Distant metastases	

FLIPI {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is a 5 factor prognostic index for patients with low grade follicular non-Hodgkin's lymphoma.

Field Name: FLIPI

Field Type: Integer

Field Length: 2

Notes for Users:

FLIPI is calculated as follows:

Age	>=60 years
Clinical Stage	III, IV
LDH	Raised
Hb	<120g/l
Number of Nodal Sites	>=5

Score 1 for each of the above factors.

FLIPI is a calculated field. This should ensure no interpretation of clinical information by audit staff and provides background data for sub-analysis.

If result is unclear please seek clarification from Clinician.

Record the calculated value.

Codes and Values:

Code	Value	Explanatory Notes
01	0-1	Good
02	2	Intermediate
03	>=3	Intermediate/High
96	Not applicable treatment Distant metastases	Patient does not have low grade follicular NHL
99	Not recorded treatment Distant metastases	Insufficient details

Hasenclever Index for Hodgkin's Disease {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is a prognostic index for patients with advanced Hodgkin's disease.

Field Name: HASENINDEX

Field Type: Integer

Field Length: 2

Notes for Users:

This is a prognostic score for advanced Hodgkin's Disease (The New England Journal of Medicine: 1998;339:1506-14).

Factors required for calculation:

- Serum albumin <40g/l (serum)
- Haemoglobin <105 g/l
- Male sex
- Stage IV disease
- Age \geq 45 yrs
- White cell count \geq 15,000/mm³ (\geq 15 x 10⁹/l)
- Lymphocyte count <600/mm³ (<0.6x10⁹/l)

Score 1 for each of the above factors.

Stage IV indicates diffuse or disseminated involvement of one or more extralymphatic organs, including any involvement of the liver, bone marrow, or nodular involvement of the lungs.

This is a calculated field. This should ensure no interpretation of clinical information and provides background data for sub-analysis.

Record the calculated value.

If any of the elements of the score are missing the index cannot be calculated and should be recorded as 'Not recorded' (99).

If the patient does not have Hodgkin's Disease, record as 'Not applicable' (96).

Cotswold Clinical Stage {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the clinical stage of the patient prior to the start of their treatment for lymphoma according to the Cotswold classification.

Field Name: COTSWOLD

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI 8, 9

The Cotswold Staging Classification is also known as the Ann Arbor Staging Classification, or the Revised Ann Arbor System.

Treatment depends both on the stage of the disease and whether or not symptoms are present. Stages are labelled with an A if no symptoms are present. If symptoms are present, drenching sweats, unexplained weight loss and fatigue, the stage is labelled with a B.

This information should be recorded at MDT.

Codes and Values:

Code	Value	Explanatory Notes
01	I	The disease is confined to one lymph node area (eg cervical, axillary, mediastinal) or lymphoid structure (eg spleen, Waldeyer's ring).
02	IE	The disease extends from the one lymph node area to adjacent regions. Single extra lymphatic site as only site of disease
03	II	The disease is in two or more lymph node areas on one side of the diaphragm (the muscle below the lungs) eg bihilar disease.
04	IIE	The disease extends to adjacent regions of at least one of these nodes Extra nodal site which is contiguous or proximal to a known site.
05	III	The disease is in lymph node areas on both sides of the diaphragm .
06	IIIE	The disease extends into adjacent areas or organs.
07	IIISE	The disease extends into adjacent areas or organs and/or the spleen.
08	IV	The disease has spread from the lymphatic system to one or more other organs, such as the bone marrow or liver.
96	Not applicable	Not staged / Not applicable for Primary Cutaneous Lymphoma.
99	Not recorded	

Related Data Item(s):

IPI {Lymphoma}

B Symptoms {Lymphoma}

B Symptoms {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The presence of one or more B symptoms in the patient at presentation for investigation of the cancer.

Field Name: BSYMPTOM

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI 8, 9

The following symptoms are classified as 'B' Symptoms:

- **Night sweats** - should be drenching
- **Weight loss** - should exceed 10% body weight in the last 6 months
- **Fever** - requires careful history and, ideally, confirmation by thermometry

Alcohol pain and itch are not 'B' symptoms.

Codes and Values:

Code	Value
01	Yes
02	No
99	Not recorded

Related Data Item(s):

Manchester Stage {Lymphoma}

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This denotes the clinical stage of the patients with gastrointestinal lymphoma prior to the start of their treatment.

Field Name: MANCHESTER

Field Type: Integer

Field Length: 2

Notes for Users: Required for survival analysis

Gastrointestinal lymphomas are defined as tumours originating in the stomach, small or large intestine.

Codes and Values:

Code	Value	Explanatory Notes
01	Ia	Tumour confined to one area of the gastrointestinal tract without penetration of the serosa.
02	Ib	Multiple tumours confined to the gastrointestinal tract without penetration of the serosa.
03	IIa	Tumour with local nodes radiologically/histologically involved (gastric or mesenteric).
04	IIb	Tumour with perforation and/or adherence to adjacent structures.
05	IIc	Tumour with perforation and peritonitis.
06	III	Tumour with widespread nodal involvement (para-aortic or more distant nodes).
07	IV	Disseminated disease involving extra-lymphatic tissues not adjacent to the tumour (eg liver, bone marrow, bone, lung etc).
96	Not applicable	Lymphoma not gastrointestinal
98	Not staged	
99	Not recorded	

Bulk Disease

Main source of data standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This indicates whether bulk disease was present at the time the patient was investigated for cancer.

Field Name: BULKDISEASE

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI 8

This should have been assessed after referral and before treatment for cancer.

Bulk disease is defined as by Cotswold criteria (Lister et al, 1989).

The bulk of palpable lymph nodes will be defined by the largest dimension (cm) of a single node or conglomerate nodal mass in each region of involvement, using CT, MRI, lymphography, or ultrasonography. A node or nodal mass must be 10cm or greater to be recorded as 'bulky'.

The overall amount of disease in the spleen will not be quantitatively assessed using imaging procedures. Lesions within the liver or spleen may be measured for assessment or response but the measurements will not be recorded for staging purposes.

Codes and Values:

Code	Value
01	Yes (≥ 10 cm)
02	No Bulk Disease
96	Not applicable
98	Not assessed
99	Not recorded

Section 5: Oncology Treatment

Location Code {Oncology Treatment}

Common Name(s): Location

Main Source of Data Item Standard: Derived from SMR data standards.

Definition: This is the reference number of any building or set of buildings where events pertinent to NHS Scotland take place. Locations include hospitals, health centres, GP surgeries, clinics, NHS board offices, nursing homes, schools and patient/client's home.

Field Name: HOSPNONSURG

Field Type: Characters

Field Length: 5

Notes for Users: Required for regional/national analysis

The hospital in which the patient received the majority of SACT Treatment.

Location codes for hospitals are five character codes maintained by ISD and the General Register Office (Scotland). <http://www.natref.scot.nhs.uk/>

Location must be viewed as an address and not a code. If any new locations arise where NHS healthcare is delivered/administered, please ensure that the Reference Files Team at ISD is informed using form LOC-NEW (which can be downloaded from the website below) so that a new code may be issued as appropriate.

<http://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/National-Reference-Files/>

The first character denotes the health board, the next three are assigned and the fifth denotes the type of location (H=hospital) e.g.

A111H=Crosshouse Hospital

G107H=Glasgow Royal Infirmary

Information about location should be electronically stored, managed and transferred using the relevant location code. IT systems should allow the recording and display of locations on the user interface as the relevant location name and associated address, etc.

If the location code is not documented, record as X9999.

If oncological treatment has not been performed or the patient has refused, record the hospital where clinic was attended.

Radiotherapy {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record if external beam radiotherapy has been administered for the treatment of the cancer.

Field Name: RADIOTYPE1

Field Type: Integer

Field length: 2

Notes for Users: Required for QPI(s): 5, 8 & 9

Combined treatments may be administered concurrently/synchronously e.g. chemotherapy and radiotherapy.

All treatments given as part of the initial treatment plan should be recorded, including consolidation radiotherapy.

Treatment received for initial management and not treatment of recurrence or relapse. If the patients type of first treatment was 'supportive care only' or 'watchful waiting' then subsequently proceeds to active treatment at a later date, only record if treatment occurs within 6 months of diagnosis.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
93	Patient contraindicated in treatment	
94	Patient died before treatment	
95	Patient refused treatment	
99	Not recorded	

Related Data Items:

Location Code {Oncology Treatment}

Date Treatment Started {Cancer} (Radiotherapy)

Date Treatment Completed {Cancer} (Radiotherapy)

Date Treatment Started {Cancer} (Radiotherapy)

Main Source of Data Item Standard: The National Audit Cancer Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date cancer treatment course commenced.

Field Name: RSRTDATE1

Field Type: Date (DD/MM/CCYY)

Field length: 10

Notes for Users:

This is the first fraction of a course of radiotherapy.

For the purposes of national audit, only radiotherapy given as part of the primary treatment plan should be recorded. Palliative radiotherapy to other (metastatic) sites is only recorded if part of the initial treatment plan.

If the date radiotherapy started is unknown, record as 09/09/0909.

If radiotherapy has not been given or the patient has refused radiotherapy, record as not applicable, 10/10/1010.

Related Data Items:

Location Code {Oncology Treatment}

Radiotherapy {Lymphoma}

Date Treatment Completed {Cancer} (Radiotherapy)

Date Treatment Completed {Cancer} (Radiotherapy)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services

Definition:

The date cancer treatment course ended.

Field Name: RCOMPDATE1

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 2

This is the last fraction of a course of radiotherapy.

It should be noted this can be the same day as the day the therapy started.

If the date treatment completed is unknown, record as 09/09/0909.

If treatment has not been given, record as not applicable, 10/10/1010.

Related Data Item(s):

Location Code {Oncology Treatment}

Radiotherapy {Lymphoma}

Date Treatment Started {Cancer} (Radiotherapy)

Type of Systemic Anti-Cancer Therapy (SACT)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The type of course of cytotoxic or biological drugs administered for the treatment of the cancer. Cytotoxic drugs are drugs which destroy cells.

Field Name: SACT1

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI(s): 2, 5, 6, 7, 8 & 9

Treatment given as part of initial/first line treatment should be recorded, i.e. treatment for relapsed or recurrent disease should not be recorded.

If patient is receiving chemotherapy in combination with radiotherapy, record as option 1 and detail radiotherapy information in relevant radiotherapy field.

Treatment received for initial management and not treatment of recurrence or relapse. If the patients type of first treatment was 'supportive care only' or 'watchful waiting' then subsequently proceeds to active treatment at a later date, only record if treatment occurs within 6 months of diagnosis.

Follicular Lymphoma only: rituximab for 2 years post chemotherapy. Maintenance immunotherapy occurs immediately after chemotherapy for a period of up to 2 years. At present Rituximab is the only immunotherapy agent which will be given in this indication.

Codes and Values:

Code	Value	Explanatory Notes
01	Chemotherapy	Chemotherapy treatment may be given in combination with radiotherapy or alone.
02	Chemoimmunotherapy	Chemotherapy given in combination with immunotherapy, e.g. R-CHOP Chemoimmunotherapy will include any combination of chemotherapy and Rituximab.(Systemic Therapy Agent codes 3,7,8a,9a,10,11,13,14,15,19,21a,27, 29)
03	Maintenance Immunotherapy	Follicular Lymphoma only
06	Single Agent Immunotherapy	
94	Patient died before SACT treatment	i.e. Patient who died before receiving planned SACT treatment
95	Patient refused SACT treatment	
96	Not applicable	e.g. Systemic therapy not given.
99	Not recorded	

Related Data Items:

Location Code {Oncology Treatment}

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The planned total number of cycles of SACT treatment to be given to the patient, regardless of the number of cycles the patient receives.

Field Name: PLSACTCYC1

Field Type: Integer

Field Length: 4

Notes for Users: Required for survival analysis

This is for all chemotherapy regimens.

There is no requirement to complete this field for maintenance immunotherapy.

If systemic therapy not given record as '1010' (Not applicable).

If number of cycles has not been recorded or unknown, record as '9999' (Not recorded).

Related Data Item(s):

Location Code {Oncology Treatment}

Type of Systemic Anti-Cancer Therapy (SACT)

Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT)

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Total Number of Systemic Anti-Cancer Therapy Cycles Given (SACT)

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record of the total number of cycles of SACT treatment given to the patient.

Field Name: SACTCYC1

Field Type: Integer

Field Length: 4

Notes for Users: Required for QPI(s): 8

There is no requirement to complete this field for maintenance immunotherapy.

If systemic therapy not given record as '1010' (Not applicable).

If number of cycles has not been recorded or unknown, record as '9999' (Not recorded).

Related Data Item(s):

Location Code {Oncology Treatment}

Type of Systemic Anti-Cancer Therapy (SACT)

Total Number of Systemic Anti-Cancer Therapy Cycles Planned (SACT)

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Rituximab {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The type of chemotherapy or biological therapy used either alone or in combination to treat lymphoma containing rituximab.

Field Name: RITUXIMAB

Field Type: Integer

Field length: 2

Notes for Users: Required for QPIs 6 & 11

Chemotherapy drugs can be given in or outwith the context of a clinical trial.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
99	Not recorded	

List of SACT regimens containing Rituximab (includes but is not limited to) :

Rituximab
Bendamustine, rituximab
R-CODOX-M (Rituximab + CODOX-M)
R-CODOX-M/IVAC (Rituximab + CODOX-M/IVAC)
Fludarabine, rituximab
Fludarabine, Cyclophosphamide and Rituximab (FCR)
Rituximab/CVP
Rituximab/EPOCH
Rituximab/hyper CVAD
R-CEOP
R-GCVP
R-ESHAP (Rituximab + ESHAP)
Rituximab maintenance
R-DHAP (Rituximab + DHAP)
R-IVE (Rituximab + IVE)
R-CHOP (Rituximab + CHOP)

Related Data Items:

Type of Systemic Anti-Cancer Therapy (SACT)

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Rituximab + CHOP {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: Rituximab and CHOP (R-CHOP) used in combination to treat lymphoma.

Field Name: RCHOP

Field Type: Integer

Field length: 2

Notes for Users: Required for QPIs 6, 7 & 11

Chemotherapy drugs can be given in or outwith the context of a clinical trial.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
99	Not recorded	

Related Data Items:

Type of Systemic Anti-Cancer Therapy (SACT)

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date systemic anti cancer therapy course commenced.

Field Name: SACTDATE1

Field Type: Date (DD/MM/CCYY)

Field length: 10

Notes for Users: Required for QPI(s), 4, 5, 11

This is the first dose of the first cycle of a course of chemotherapy or immunotherapy.

Up to three courses may be recorded.

If the date SACT started is unknown, record as 09/09/0909.

If SACT has not been given or the patient has refused SACT, record as not applicable, 10/10/1010.

Related Data Items:

Location Code {Oncology Treatment}

Type of Systemic Anti-Cancer Therapy (SACT)

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Date Completed Systemic Anti-Cancer Therapy (SACT) {Cancer}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date cancer treatment course ended.

Field Name: SACTENDATE1

Field Type: Date (DD/MM/CCYY)

Field length: 10

Notes for Users: Required for QPI 2

This is the first day of the last cycle of a course of SACT.

It should be noted this can be the same day as the day the therapy started.

There is no requirement to complete this field for maintenance immunotherapy.

If the date treatment started is unknown, record as 09/09/0909.

If SACT has not been given or the patient has refused SACT, record as not applicable, 10/10/1010.

Related Data Items:

Location Code {Oncology Treatment}

Type of Systemic Anti-Cancer Therapy (SACT)

Date Started Systemic Anti-Cancer Therapy (SACT) {Cancer}

Bone Marrow Transplant

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record if the patient received a bone marrow transplant as first line of treatment.

Field Name: BONETR

Field Type: Integer

Field Length: 2

Notes for Users:

Bone marrow transplant for first line treatment is rare.

Only record if treatment was first line.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	e.g. Bone marrow transplant not given
96	Not applicable	
99	Not recorded	

Related Data Items:

Date of Radiological Imaging Post Treatment Completed {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by the Information Services.

Definition: The date that radiological imaging was completed by CT of the chest, abdomen and pelvis \pm neck, or PET CT, at the end of treatment.

Field Name: POSTIMAGDATE

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPI(s): 2

Completed at the end of induction treatment.

CT scans within 6 weeks of the last day of the final cycle of chemotherapy or within 3 months of radiotherapy will be classified as an end of treatment scan. Date should be recorded.

Complete imaging is of the CT of chest, abdomen and pelvis \pm neck (and no other combination), or PET CT,

If imaging was not completed or not done, record as 10/10/1010 (Not applicable).

If the exact date is not documented, record as 09/09/0909 (not recorded)

If patient dies during treatment record as 08/08/1900

Related Data Item(s):

Section 6: Clinical Trial Entry

Patient Entered into Clinical Trial {Lymphoma}

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition:

An indication of whether or not the patient received treatment within the context of a clinical trial.

Field Name: TRIAL

Field Type: Integer

Field Length: 2

Notes for Users: Required for QPI 6, 7, 8, 9

This relates only to participation in clinical trials which may be national or international multi-centred trials.

The majority of non-commercial multi-centred trials available in Scotland are National Cancer Research Network (NCRN) badged or equivalent.

Some academic and university units may have ongoing local trials which should not be included here. These can be recorded on local trials databases.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No trial available	
03	No trial offered	Trial available but not offered to patient
04	Not eligible for trial	
95	Patient refused clinical trial	
96	Not applicable	Patient died before treatment
99	Not recorded	

Related Data Items:

Section 7: Follow-up

Response Post First Treatment

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: A record of what the patient's best response was as determined by the clinician at the post treatment assessment.

Field Name: FTRESPONS

Field Type: Integer

Field length: 2

Notes for Users: Required for survival analysis

Codes and Values:

Code	Value	Explanatory Notes
01	Complete remission (CR)/ Complete Remission Unconfirmed (CRU)	No signs or symptoms of disease
02	Partial Remission (PR)	50% decrease in tumour size
03	Stable Disease	Neither partial response nor progressive disease
04	Progressive Disease/Refractory Disease	50% increase in disease
96	Not applicable	e.g. Watch & wait / Patient died before treatment
99	Not recorded	

Related Data Item(s):

Post-Treatment Assessment Date

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date on which the patient had their post-treatment assessment.

Field Name: POSTTREATDATE

Field Type: Date (DD/MM/CCYY).

Field Length: 10

Notes for Users: Required for survival analysis

If patient did not have a post-treatment assessment, record as 10/10/1010 (not applicable).

Post treatment assessment date should be the date of radiological evidence i.e. date of CT post primary therapy whether chemo/radiotherapy etc., if no radiology undertaken/available the date of the clinic appointment should be recorded.

If the exact date is not documented, record as 09/09/0909 (Not recorded).

Related Data Item(s):

Follow-up Status

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: An indicator of the patient's vital status as determined by the clinician at follow-up.

Field Name: FUSTATUS

Field Type: Integer

Field length: 2

Notes for Users: Required for survival analysis

It is essential that follow-status has a follow-up date recorded, without which time to relapse cannot be assessed.

Codes and Values:

Code	Value	Explanatory Notes
01	Continued first remission	
02	Stable Disease	e.g. Watch & wait
03	Relapsed Disease	Includes watch & wait with progressive disease
04	Moved away	
05	Patient deceased	
99	Not recorded	

Related Data Item(s):

Follow-up Date/Date of Relapse/Progression

Follow-up Date/Date of Relapse/Progression

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: The date on which the patient was last seen at follow-up for patients with continued first remission or stable disease, or date of relapse/progression, for patients with relapsed/progressive disease.

Field Name: FUDATE

Field Type: Date (DD/MM/CCYY).

Field Length: 10

Notes for Users: Required for survival analysis

This should be collected annually for a minimum of 5 years.

The follow-up period is calculated from the date of diagnosis to the date of follow-up.

If patient has relapsed/progressive disease the date of relapse/progression should be recorded rather than follow up date.

If the exact date is not documented, or data are required for reporting within the year, record as 09/09/0909 (Not recorded).

If the patient was not seen for follow up, record as 10/10/1010

Related Data Item(s):

Follow-up Status

Date of Diagnosis {Cancer}

Transformation to High Grade

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: An indicator as to whether a patient's lymphoma, if relapsed, has transformed from low to high grade lymphoma.

Field Name: TRANS

Field Type: Integer

Field length: 2

Notes for Users:

In low grade lymphomas the cancerous lymphocytes multiply slowly. This kind of lymphoma therefore accumulates at a slow rate over time. This is in contrast to high-grade lymphomas, in which the cells are multiplying very quickly and the lymphoma accumulates rapidly over a matter of weeks.

Transformation can happen with any low grade lymphoma.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not Applicable	Already high grade disease e.g. DLBCL

Related Data Item(s):

Section 8: Death Details

Date of Death

Main Source of Data Item Standard: The National Cancer Audit Datasets developed by the regional Cancer Networks supported by Information Services.

Definition: This is the certified date of death as recorded by the General Register Office (Scotland) (GRO(S)).

Field Name: DOD

Field Type: Date (DD/MM/CCYY)

Field Length: 10

Notes for Users: Required for QPIs: 4, 7, 10

If the exact date is not documented, record as 09/09/0909.

If the patient is alive use the code 10/10/1010 (Not applicable).

Codes and Values: N/A

Related Data Items: