Acute Leukaemia

Data Definitions for the National Minimum Core Dataset to support the introduction of Acute Leukaemia Quality Performance Indicators

Definitions developed by ISD Scotland in Collaboration with the Acute Leukaemia Quality Performance Indicator Development Group

Version 2.2: February 2017

To be used in conjunction with:

1. Acute Leukaemia QPI Final Publication v1.0 (14th March 2014)
2. Acute Leukaemia QPI Validations (Latest Published Version)
3. Acute Leukaemia Measurability of Quality Performance Indicators (Latest Published Version)

DOCUMENT CONTROL SHEET

Key Information

Title	**Acute Leukaemia – Data Definitions for Minimum Core Dataset for Quality Performance Indicators (QPIs)**
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Cross References	**Acute Leukaemia Quality Performance Indicators Acute Leukaemia Measurability of Quality Performance Indicators**
Author	**Information Services Division of NHS National Services Scotland**

Revision History

Version	Date	Summary of Changes	Name	Changes Marked
1.1	**07/10/14**	**Changes agreed out with review to support data collection.**	**Jane Garrett ISD**	**See page iii.**
2.0	**05/05/15**	**New version following 9 month review**	**Charlotte Anthony ISD**	**See page iii.**
2.1	**21/12/15**	**Changes agreed out with review to support data collection**	**Charlotte Anthony ISD**	**See page iii.**
2.2	**02/2017**	**Changes outwith review**	**Charlotte Anthony ISD**	**See page iii**

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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 1st July 2014.

NOTES FOR IMPLEMENTATION OF CHANGES

The following changes should be implemented for all patients who are diagnosed with Acute Leukaemia on or after 1st July 2015 who are eligible for inclusion in the Acute Leukaemia 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 Performance Indicators to be measured and reported against

If you have difficulties in using individual definitions within this document please contact

General Enquiries on the Collection of the Minimum Core Data Set
If you have any comments on the attached data definitions ISD would welcome your feedback. Please contact:

NSS.ISDCANCERAUDIT@NHS.NET

CONVENTIONS

The layout for each item is standard as shown below where it is applicable:

Common Name(s):
Main Source of Data Item Standard:
Definition:
Field Name:
Field Type:
Field Length:
Notes for Users:
Codes and Values:
Related Data Item(s):

In addition the following two conventions have been used in the document:

- {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 OUT WITH REVIEW – February 2017

Amended CHI Number fieldname in the Data Specification from CHI to CHINUM

REVISIONS TO DATASET OUT WITH REVIEW – December 2015

The following changes have been made to facilitate the recording of data. Changes to take effect for patients diagnosed from 1st July 2015.

Dataset :

Type of Treatment (1-4) – (Query 1117) inserted code and value 96 – Not applicable.

VERSION 2 PUBLISHED FOLLOWING PRECEDENT RE : 9 MONTH REVIEW – NO CHANGES MADE.

REVISIONS TO DATASET OUTWITH REVIEW – May 2015

Location of Diagnosis {Acute Leukaemia} – removed X1010 – Not applicable

REVISIONS TO DATASET

The following changes have been made to facilitate the recording of data. Changes to take effect for patients diagnosed from 1st July 2014.

Dataset:

Cytogentic/Molecular Risk Group:

i. Changes to Codes and Values

CRITERIA FOR INCLUSION OF PATIENTS IN AUDIT

To facilitate national comparisons the same patients must be audited throughout Scotland. The following eligibility criteria have been documented for this purpose.

Include:

- All patients with a confirmed new primary Acute Myeloid Leukaemia or Acute Lymphoblastic Leukaemia.
- Including all patients who have had a previous primary malignancy of any site (including myelodysplastic syndrome or myeloproliferative neoplasm) or a concurrent primary malignancy of another site.

Exclude:

- Patients with recurrent disease (as opposed to a new primary).
- Patients with blast crisis chronic myeloid leukaemia.
- 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.

NB:

- Only treatments as part of the initial treatment plan should be recorded.

- Patients treated within 6 months of a patient initially refusing further investigation or whose initial treatment is 'Watch and Wait' can also be recorded.

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.

DATABASE SPECIFICATION

Data Item	Field Name	Field Type	Size	Page
Section 1: Demographic Items				**1**
Person Family Name (at Diagnosis)	PATSNAME	Characters	35	2
Person Given Name	PATFNAME	Characters	35	3
Patient Postcode (at Diagnosis)	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: Investigations and Diagnosis				8
Location of Diagnosis {Acute Leukaemia}	HOSP	Characters	5	9
Date of First Diagnosis {Acute Leukaemia}	DIAGDATE	Date (DD/MM/CCYY)	10	10
Final Diagnosis	FINALDIAG	Characters	6	11
Secondary Acute Myeloid Leukaemia	SAML	Integer	2	13
WHO/ ECOG Performance Status	PSTATUS	Integer	1	14
Date Discussed by Care Team (MDT)	MDTDATE	Date (DD/MM/CCYY)	10	15
Immunophenotyping Performed	IMMUNOTYPE	Integer	2	16
Cytogenetic Analysis Performed	CYTOANALYSIS	Integer	2	17
Cytogenetic/Molecular Risk Group	ADVERCYTO	Integer	2	18
Molecular Marker Analysis Performed	MOLANALYSIS	Integer	2	19
Genetic Material Stored	GENMATSTOR	Integer	2	20
Assessment of Minimal Residual Disease Marker (at Diagnosis)	MRDMARK	Integer	2	21
Tissue Typing Sample Taken (at Diagnosis)	TTSAMP	Integer	2	22
Bone Marrow % Blasts	BMBLAST	Integer	4	23
WCC – Peripheral Blood	WCC	Number (nnn.n)	5	24
Section 3: Treatment				25
Location of Treatment {Acute Leukaemia}	HOSPTREAT	Characters	5	26
Intent of Treatment {Acute Leukaemia}	INTENT	Integer	2	27
Type of Treatment 1-4	MODE1	Characters	3	28
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Date Treatment Started 1- 4	TREATDATE1	Date (DD/MM/CCYY)	10	29
Date Treatment Started 1- 4	TREATDATE2	Date	10	29

		(DD/MM/CCYY)		
Date Treatment Started 1- 4	TREATDATE3	Date (DD/MM/CCYY)	10	29
Date Treatment Started 1- 4	TREATDATE4	Date (DD/MM/CCYY)	10	29
Date Treatment Completed 1-4	TREATENDATE1	Date (DD/MM/CCYY)	10	30
Date Treatment Completed 1-4	TREATENDATE2	Date (DD/MM/CCYY)	10	30
Date Treatment Completed 1-4	TREATENDATE3	Date (DD/MM/CCYY)	10	30
Date Treatment Completed 1-4	TREATENDATE4	Date (DD/MM/CCYY)	10	30
Section 4: Clinical Trials				31
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Section 5: Remission and Death Details				33
Remission Status	REMISSTAT	Integer	2	34
Date First Complete Remission	DREMISSION	Date (DD/MM/CCYY)	10	35
Date of Death	DOD	Date (DD/MM/CCYY)	10	36
First Complete Remission Maintained at Time of Death	DEATHRS	Integer	2	37

Section 1: Demographic Items

Person Family Name (at Diagnosis)

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:
Main Source of Standard: Government Data Standards Catalogue

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

Notes by Users:

Person Given Name

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

Main Source of Data Item Standard of 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:
Main Source of Standard: Government Data Standards Catalogue

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.

Notes by Users:

Patient Postcode (at Diagnosis)

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

Related Data Item(s):
Date of Diagnosis

Notes by Users:

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.

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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.

Related Data Item(s):
CHI Number

Notes by Users:

Person Sex at Birth

Common Name(s): Sex at Birth

Main Source of Data Item Standard of 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 Item(s):
CHI Number

Notes by Users:

CHI Number

Main Source of Data Item Standard of 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.

Related Data Item(s):
Date of Birth
Person Sex at Birth

Notes by Users:

Section 2: Investigations and Diagnosis

Location of Diagnosis {Acute Leukaemia}

Main Source of Data Item Standard: The National Audit Cancer 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 analysis purposes and clarifying responsibility for data collection.

Details of location codes for hospitals can be found in the "Definitions and Codes for the NHS in Scotland" manual produced by ISD Scotland.

Location codes for hospitals are five character codes maintained by ISD Scotland and the General Register Office (Scotland). 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
X9999=Not recorded

If a patient was provisionally diagnosed at one hospital but transferred to another for confirmation of the diagnosis only e.g. biopsy, then returns to the original hospital, the first hospital should be recorded as the Location of diagnosis.

Codes and Values:

Related Data Items:
Date of First Diagnosis {Acute Leukaemia}

Notes by Users:

Date of First Diagnosis {Acute Leukaemia}

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

Definition: The date of diagnosis is the date on which there was first confirmation of the diagnosis of acute leukaemia whether by morphology, histology, flow cytometry or other methods.

Field Name: DIAGDATE
Field Type: Date (DD/MM/CCYY)
Field length: 10

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

The date recorded is the date of the first investigative procedure that confirms a diagnosis of acute leukaemia.

Where a suspected diagnosis is made using a blood sample and later confirmed by a bone marrow sample then the bone marrow sample date should be recorded.

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.

Codes and Values:

Related Data Items:
Location of Diagnosis {Acute Leukaemia}
Assessment of Minimal Residual Disease Marker (at Diagnosis)
Tissue Typing Sample Taken (at Diagnosis)

Notes by Users:

Final Diagnosis

Main Source of Data Item Standard: WHO Classification of Tumours of Haematopoietic and Lymphoid Tissue, 4th Edition.

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

Field Name: FINALDIAG
Field Type: Characters
Field Length: 6

Notes for Users: Required for QPI(s): 1 to 12

This is the final diagnosis once all testing is complete (e.g. cytogenetics, immunology, flow cytometry etc).

The morphology terms have five-digit code numbers which run from 8000/0 to 9989/1; the first four digits indicate the specific histologic terms and the fifth digit, after the slash, is a behaviour code.

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.
Codes and Values:

Code	Description
Acute Myeloid Leukaemia's with recurrent cytogenetic abnormalities	
9896/3	AML with t(8;21)(q22;q22);(RUNX1-RUNX1T1)
9871/3	AML with inv(16)(p13.1q22) or t(16;16)(p13.1;q22)};(*CBFβ/MYH11*)
9866/3	Acute promyelocytic leukaemia (AML with t(15;17)(q22;q12); (*PML-RARA*)
9897/3	Acute myeloid leukaemia with T(9;11)(P22;Q23);MLLT3-MLL
9865/3	Acute Myeloid Leukaemia with t(6;9)(p23;q34);DEK-NUP214
9869/3	Acute Myeloid Leukaemia with INV(3)(q21q26.2) or t(3;3)(q21;q26.2);RPN1-EV11
9911/3	Acute Myeloid Leukaemia (Megakaryoblastic) with t(1;22)(p13;q13);RBM15-MKL1
9861/3	Acute Myeloid Leukaemia not otherwise specified / with Mutated CEBPA / with Mutated NMP1 (from scan list)
Acute Myeloid Leukaemia with Myelodysplasia-related Changes	
9895/3	AML with Myelodysplasia-related Changes
Therapy Related Myeloid Neoplasm's	
9920/3	AML – therapy-related
Acute Myeloid Leukaemia Not Otherwise Specified	
9872/3	AML – with minimal differentiation
9873/3	AML – without maturation
9874/3	AML – with maturation
9867/3	Acute myelomonocytic leukaemia
9891/3	Acute monoblastic and monocytic leukaemia
9840/3	Acute erythroid leukaemia
9910/3	Acute megakaryoblastic leukaemia
9870/3	Acute basophilic leukaemia

9931/3	Acute panmyelosis with myelofibrosis
Myeloid Sarcoma	
9930/3	Myeloid sarcoma
Myeloid Proliferations Related to Down Syndrome	
9898/3	Myeloid Leukaemia associated with Down Syndrome
Blastic Plasmacytoid Dendritic Cell Neoplasm	
9727/3	Blastic Plasmacytoid Dendritic Cell Neoplasm
Acute Leukaemia of Ambiguous Lineage	
9801/3	Undifferentiated acute leukaemia
9806/3	Mixed Phenotype Acute Leukaemia with t(9;22)(q34;q11.2);BCR-ABL1
9807/3	Mixed Phenotype Acute Leukaemia with t(v;11q23);MLL Rearranged
9808/3	Mixed Phenotype Acute Leukaemia, B/Myeloid NOS
9809/3	Mixed Phenotype Acute Leukaemia, T/Myeloid NOS
Lymphoid Lineage	
Precursor Lymphoid Neoplasm	
9811/3	B Lymphoblastic Leukaemia/Lymphoma, Not Otherwise Specified
B Lymphoblastic Leukaemia/Lymphoma with Recurrent Genetic Abnormalities	
9812/3	B Lymphoblastic Leukaemia/Lymphoma with t(9;22)(q34;q11.2);BCR-ABL1
9813/3	B Lymphoblastic Leukaemia/Lymphoma with t(v;11q23);MLL Rearranged
9814/3	B Lymphoblastic Leukaemia/Lymphoma with t(12;21)(p13;q22);TEL-AML1(ETV6-
9815/3	B Lymphoblastic Leukaemia/Lymphoma with Hyperdiploidy
9816/3	B Lymphoblastic Leukaemia/Lymphoma with Hypodiploidy
9817/3	B Lymphoblastic Leukaemia/Lymphoma with t(5;14)(q31;q32);IL3-IGH
9818/3	B Lymphoblastic Leukaemia/Lymphoma with t(1;19)(q23;p13.3);E2A-PBX1(TCF3-PBX1)
T-Cell and NK-Cell Neoplasm's	
Precursor T-cell Neoplasm's	
9837/3	T Lymphoblastic Leukaemia / Lymphoma
1111/1	Not assessable
9999/9	Not recorded

Related Data Items:

Secondary Acute Myeloid Leukaemia

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

Definition: Denotes whether the diagnosed Acute Myeloid Leukaemia has developed as a secondary AML.

Field Name: SAML
Field Type: 2
Field length: Integer

Notes for Users: Required for national analysis.

Secondary Acute leukaemia is a term used to denote disease arising (usually AML) in patients with pre-existing Haematological Disorders such as Myelodysplasia, Myeloproliferative Disease (Essential thrombocythaemia, polycythaemia or Myelofibrosis), Aplastic Anaemia or Paroxysmal Nocturnal haemoglobinuria. It does not relate to AML arising from previous chemo-radiotherapy for an unrelated tumour (where the classification "Therapy Related Myeloid Neoplasm " should be used).

It should not be confused with acute leukaemia that occurs as a second primary cancer.

This will be documented at the MDT.

Codes and values:

Code	Value	Explanatory Notes
01	Yes	
02	No	AML developed through de novo (primary) process
99	Not recorded	

Related Data Items:

Notes by Users:

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 and QPI(s): 10

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

Related Data Items:

Notes by Users:

Date Discussed by Care Team (MDT)

Common name: Date discussed by multidisciplinary team (MDT) {Cancer}

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 care team meeting 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(s): 3

A cancer multidisciplinary care team may include surgeons, oncologists, radiologists, pathologists, nurses, speech language therapists, 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 date will be recorded.

If the patient has not been discussed by the MDT record as 10/10/1010 (Not applicable).

If the date of the MDT meeting is unknown record as 09/09/0909 (Not recorded)

Related data Item(s):

Immunophenotyping Performed

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

Definition: This indicates whether immunophenotyping was performed at the time the patient was investigated for cancer.

Field Name: IMMUNOTYPE
Field Type: Integer
Field Length: 2

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

Immunophenotyping is a technique used to study the protein expressed by cells. This can be done on tissue section (fresh or fixed tissue), cell suspension, etc. An example is the detection of tumour marker, such as in the diagnosis of leukaemia. It involves the labelling of white blood cells with antibodies directed against surface proteins on their membrane. By choosing appropriate antibodies, the differentiation of leukaemic cells can be accurately determined.

Results from this test should be documented by the laboratory or MDT.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not applicable	E.g. Supportive care only
98	Failed	E.g. No results due to technical failure
99	Not recorded	

Related Data Items:
Final Diagnosis
Cytogenetic Analysis Performed
Molecular Marker Analysis Performed
Genetic Material Stored

Cytogenetic Analysis Performed

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

Definition: This indicates whether a cytogenetic test was performed at the time the patient was investigated for cancer.

Field Name: CYTOANALYSIS
Field Type: Integer
Field Length: 2

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

Results from this test should be documented by the laboratory or MDT.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not applicable	E.g. Supportive care only
98	Failed	E.g. No results due to technical failure
99	Not recorded	

Related Data Items:
Final Diagnosis
Immunophenotyping Performed
Molecular Marker Analysis Performed
Genetic Material Stored

Cytogenetic/Molecular Risk Group

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

Definition: This indicates the prognostic risk result as determined by cytogenetic and/or molecular marker analysis.

Field Name: ADVERCYTO
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 12

Risk group should be documented on a laboratory report or at MDT. If this is not documented then discuss with the relevant clinician, this should not be deduced by audit staff.

Codes and Values:

Code	Value	Explanatory Notes
01	Favourable / Good	
02	Intermediate / Standard	
03	Adverse	
96	Not applicable	E.g. Supportive care only
98	Failed cytogenetics	E.g. No results due to technical failure
99	Not recorded	

Related Data Items:
Cytogenetic Analysis Performed

Molecular Marker Analysis Performed

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

Definition: This indicates whether a molecular marker test was performed at the time the patient was investigated for cancer.

Field Name: MOLANALYSIS
Field Type: Integer
Field Length: 2

Notes for Users: Required for national analysis

Results from this test should be documented by the laboratory or MDT.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	E.g. Flt-3, NPM-1, CEBPA, BCR-ABL, PML-RARA, PCR for 8:21 translocation
02	No	
96	Not applicable	E.g. Supportive care only
98	Failed	E.g. No results due to technical failure
99	Not recorded	

Related Data Items:
Final Diagnosis
Immunophenotyping Performed
Cytogenetic Analysis Performed
Genetic Material Stored

Genetic Material Stored

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

Definition: This indicates whether diagnostic material was obtained and stored prior to the patient commencing treatment.

Field Name: GENMATSTOR
Field Type: Integer
Field Length: 2

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

This is the storage of DNA or RNA obtained from blood or bone marrow. This is for routine diagnostic testing and not for research purposes.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not applicable	E.g. Supportive care only
99	Not recorded	

Related Data Items:
Final Diagnosis
Immunophenotyping Performed
Cytogenetic Analysis Performed
Molecular Marker Analysis Performed

Assessment of Minimal Residual Disease Marker (at Diagnosis)

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

Definition: This indicates whether the patient was assessed for the presence of Minimal Residual Disease (MRD) marker at diagnosis.

Field Name: MRDMARK
Field Type: Integer
Field Length: 2

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

Identification of the MRD marker must be done at diagnosis to allow later measurement of disease levels.

Only applicable to patients under 25 years of age (at diagnosis) with Acute Lymphoblastic Leukaemia, i.e. patients with the following morphology -

Lymphoid Lineage	
Precursor Lymphoid Neoplasm	
9811/3	B Lymphoblastic Leukaemia/Lymphoma, Not Otherwise Specified
B Lymphoblastic Leukaemia/Lymphoma with Recurrent Genetic Abnormalities	
9812/3	B Lymphoblastic Leukaemia/Lymphoma with t(9;22)(q34;q11.2);BCR-ABL1
9813/3	B Lymphoblastic Leukaemia/Lymphoma with t(v;11q23);MLL Rearranged
9814/3	B Lymphoblastic Leukaemia/Lymphoma with t(12;21)(p13;q22);TEL-AML1(ETV6-
9815/3	B Lymphoblastic Leukaemia/Lymphoma with Hyperdiploidy
9816/3	B Lymphoblastic Leukaemia/Lymphoma with Hypodiploidy
9817/3	B Lymphoblastic Leukaemia/Lymphoma with t(5;14)(q31;q32);IL3-IGH
9818/3	B Lymphoblastic Leukaemia/Lymphoma with t(1;19)(q23;p13.3);E2A-PBX1(TCF3-PBX1)
T-Cell and NK-Cell Neoplasm's	
Precursor T-cell Neoplasm's	
9837/3	T Lymphoblastic Leukaemia / Lymphoma

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not applicable	E.g. Aged 25 and over
99	Not recorded	

Related Data Items:
Date of First Diagnosis {Acute Leukaemia}

Tissue Typing Sample Taken (at Diagnosis)

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

Definition: This indicates whether a specimen was sent to the lab for tissue typing at diagnosis.

Field Name: TTSAMP
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 9

Specimen taken for Human Leukocyte Antigen (HLA) typing (high-resolution molecular typing of classes I and II).

Tissue typing sample can be taken at time of or within one week of diagnosis.

This should be documented in a report by the tissue typing lab and/or by the MDT.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	
02	No	
96	Not applicable	E.g. Patients receiving low-dose chemotherapy, low intensity chemotherapy, Supportive care only
99	Not recorded	

Related Data Items:
Date of First Diagnosis {Acute Leukaemia}

Bone Marrow % Blasts

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

Definition: This records the percentage of blasts measured in a sample from bone marrow aspirate when the patient is investigated for acute leukaemia.

Field Name: BMBLAST
Field Type: Integer
Field Length: 4

Notes for Users: Required for national analysis.

This test should have been performed between the date of referral and the date of diagnosis for acute leukaemia. If more than one is taken, use the report from what appears to be the definitive sample. If a bone marrow blast count cannot be obtained from the aspirate the percentage from the trephine should be used.

If >X% is documented then record this as X (%), e.g. if >90% is documented then record this as 90 (%).

If no specific percentage is recorded (e.g. mainly blasts noted in report) seek clarification from haematologist.

Record as not recorded (9999) if no bone marrow sample result is available (aspirate or trephine).

Notes by Users:

Related Data Items:

WCC – Peripheral Blood

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

Definition: This records the white cell count measured in a peripheral blood sample when the patient is investigated for acute leukaemia.

Field Name: WCC
Field Type: Number (nnn.n)
Field Length: 5

Notes for Users: Required for national analysis.

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

WCC should be recorded in 10^9/l. If no blood count is recorded then record as 999.9.

Notes by Users:

Related Data Items:

Section 3: Treatment

Location of Treatment {Acute Leukaemia}

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

Definition: This is the hospital where the patient's cancer treatment took place.

Field Name: HOSPTREAT
Field Type: Characters
Field Length: 5

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

Details of location codes for hospitals can be found in the "Definitions and Codes for the NHS in Scotland" manual produced by ISD Scotland.

Location codes for hospitals are five character codes maintained by ISD Scotland and the General Register Office (Scotland). 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
X1010=Not applicable
X9999=Not recorded

Notes by Users:

Related Data Items:
Date Treatment Started 1- 4
Type of Treatment 1-4

Intent of Treatment {Acute Leukaemia}

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

Definition: Final assessment of intent of treatment as defined by the Multidisciplinary Team (MDT).

Field Name: INTENT
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 1, 4, 5, 7, 8, 9, 11, 12

Codes and Values:

Code	Value	Explanatory Notes
01	Curative	
02	Non-curative	Includes: palliative treatment and supportive care
94	Patient died before treatment	
95	Patient refused treatment	
99	Not recorded	

Related Data Items:

Type of Treatment 1-4

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 specific treatment modality administered to a patient.

Field Name: MODE1
MODE2
MODE3
MODE4
Field Type: Characters
Field length: 3

Notes for Users: Required for QPI(s): 1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12

Treatment must be received for initial management and not treatment for recurrence or relapse.

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

Codes and Values:

Code	Description	Explanatory notes
01A	Chemotherapy - Intensive	Aimed at remission induction
01B	Chemotherapy - Low dose	Palliative chemotherapy (including cytarabine, azacitidine etc)
04A	Biological Therapy - Other	E.g. Imatinib (Glivec), nilotinib (Tasigna), dasatinib (Sprycell)
04B	Biological Therapy - All Trans-Retinoic Acid (ATRA)	Tretinoin, Vesanoid
07A	Transplant - Autologous	Self
07B	Transplant - Allogenic	Other person
14	Supportive Care Only	Blood transfusion, analgesia, antibiotics, hydroxycarbamide
94	Patient died before treatment	
95	Patient refused all therapies	
96	Not applicable	
99	Not recorded	

Related Data Item(s):
Date Treatment Started 1- 4
Date Treatment Completed 1-4

Date Treatment Started 1- 4

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 commenced.

Field Name: TREATDATE1
TREATDATE2
TREATDATE3
TREATDATE4
Field Type: Date (DD/MM/CCYY)
Field length: 10

Notes for Users: Required for QPI(s): 3, 6

For patients treatment with chemotherapy this is the first dose of the first cycle of a course of chemotherapy or biological therapy.

For patients undergoing stem cell transplant this is date of transplant.

If type of 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.

If the date treatment started is unknown, record as 09/09/0909 (Not recorded).

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

Related data items:
Type of Treatment 1-4
Date Treatment Completed 1-4

Date Treatment Completed 1-4

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: TREATENDATE1
TREATENDATE2
TREATENDATE3
TREATENDATE4
Field Type: Date (DD/MM/CCYY)
Field length: 10

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

For patients undergoing chemotherapy/biological treatment this is first day of the last cycle of a course of chemotherapy, or biological therapy.

For patients undergoing stem cell transplant or supportive care only record as 10/10/1010 (Not Applicable).

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

If the date treatment started completed is unknown, record as 09/09/0909 (Not recorded).

If treatment has not been given or the patient has refused treatment, record as 10/10/1010 (Not applicable).

Only record if occurring within 12-months of diagnosis.

Codes and values:

Related data items:
Type of Treatment 1-4
Date Treatment Started 1- 4

Section 4: Clinical Trials

Patient Entered into Clinical Trial

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(s): 8, 10, 11

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 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	
99	Not recorded	

Related data items:

Section 5: Remission and Death Details

Remission Status

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

Definition: This defines whether the patient has achieved first complete remission (CR).

Field Name: REMISSTAT
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 7

Within the measurement of this QPI complete remission as confirmed by morphology will be utilised.

Remission status should not be deduced by audit staff and should be documented at MDT based on the post-treatment marrow pathology.

Only record if occurring within 12-months of diagnosis.

Codes and Values:

Code	Value	Explanatory Notes
01	Complete Remission (CR)	The bone marrow is regenerating normal haemopoietic cells and contains <5% blast cells by morphology in an aspirate sample with at least 200 nucleated cells. Additionally there is an absolute neutrophil count of more than 1.0 x 10^9/l and platelet count of at least 100 x 10^9/l
02	Complete Remission with incomplete recovery (CRi)	Fulfilling all criteria for CR except for residual neutropenia (≤1.0 x 10^9/l) or thrombocytopenia (<100 x 10^9/l)
03	Partial Remission (PR)	The bone marrow is regenerating normal haemopoietic cells and blast count has reduced by at least half, to a value between 5 and 15% leukaemic cells
04	Resistant Disease (RD)	The bone marrow shows persistent AML or ALL
96	Not applicable	E.g. Supportive care, patient died before treatment
99	Not recorded	

Related Data Item(s):
Date First Complete Remission

Date First Complete Remission

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

Definition: This defines the date which the patient has achieved **first** complete remission (CR).

Field Name: DREMISSION
Field Type: Date (DD/MM/YYY)
Field Length: 10

Notes for Users: Required for QPI(s): 7

This date is not necessarily related to remission status, rather is the date of first remission.

This information can be obtained from the bone marrow report.

If remission date is unknown, record as 09/09/0909 (Not recorded).

If patient is not in remission, record as 10/10/1010 (Not applicable).

Related Data Item(s):
Remission Status

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 QPI(s): 3, 5, 7

Only record if occurring within 12-months of diagnosis.

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

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

First Complete Remission Maintained at Time 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 defines the patients first complete remission had been maintained at the time of their death

Field Name: DEATHRS
Field Type: Integer
Field Length: 2

Notes for Users: Required for QPI(s): 7

Only record if occurring within 12-months of diagnosis.

Codes and Values:

Code	Value	Explanatory Notes
01	Yes	Patient was still in 1st CR or CRi
02	No	Patient had relapsed
96	Not applicable	E.g. Supportive care only, patient died before treatment
99	Not recorded	

Related Data Item(s):