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 4.1: July 2022

To be used in conjunction with:

1. Acute Leukaemia QPI Final Publication (Latest Published Version)
2. Acute Leukaemia QPI Validations (Latest Published Version)
3. Acute Leukaemia Measurability of Quality Performance Indicators (Latest Published Version)
# Document Control Sheet

## Key Information

<table>
<thead>
<tr>
<th>Title</th>
<th>Acute Leukaemia – Data Definitions for Minimum Core Dataset for Quality Performance Indicators (QPIs)</th>
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<td>Date Published/Issued</td>
<td>July 2022</td>
</tr>
<tr>
<td>Date Effective From</td>
<td>1&lt;sup&gt;st&lt;/sup&gt; July 2021</td>
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<td>Version/Issue Number</td>
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<td>Document Type</td>
<td>Guidance</td>
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<td>Document Status</td>
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<td>Standard Audience</td>
<td>NHS staff involved in implementing and recording Acute Leukaemia Quality Performance Indicators.</td>
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| Cross References | Acute Leukaemia Quality Performance Indicators  
Acute Leukaemia Measurability of Quality Performance Indicators |
| Author | Public Health Scotland (PHS) |

## Revision History

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<td>Oct 2014</td>
<td>Changes agreed out with review to support data collection.</td>
<td>Jane Garrett</td>
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| V3.3    | Feb 2021   | Rebranding Updates  
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*Data Definitions for the National Minimum Core Dataset for Acute Leukaemia.*
*Developed by ISD Scotland*
*1st July 2014*
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 2021 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

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

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

Revisions to dataset changes outwith review (July 2022)

Cytogenetic Analysis Performed (CYTOANALYSIS) – notes for user updated 'It's possible to have cytogenetics performed but the risk group not specifically reported, especially for cases with normal karyotype'.

Revisions to Dataset from Formal review (Nov 2021)

Database Specification

Date Tissue Typing Sample Taken (at Diagnosis) - add new Data item, Field Name: TTSAMPDATE, Field Type: Date (DD/MM/CCYY), Field Length: 10

Criteria for Inclusion of Patients in Audit
add “Patients, at date of diagnosis, under 16 years of age i.e. up to 15 years 364 days” to the exclusion criteria of patients in audit

Dataset

Final Diagnosis Notes for Users - amend ‘QPI(s): 1, 5, 12, 13’ to ‘QPI(s): 1, 5, 9, 12, 13’

Molecular Marker Analysis Performed Notes for Users - amend ‘Required for national analysis’ to ‘Required for QPI(s): 1 and for national analysis’, add ‘This must include Flt-3 and NPM-1 as a minimum requirement for patients with AML.’

Date Tissue Typing Sample Taken (at Diagnosis) - Add new data item, implement from July 2021

Tissue Typing Sample Taken (at Diagnosis)
Notes for Users - remove ‘Tissue typing sample can be taken at time of or within one week of diagnosis.’
Related Data Items – add ‘Date Tissue Typing Sample Taken (at diagnosis)’

Intent of Treatment (Acute Leukaemia) Notes for Users – amend ‘QPI(s): 1, 5, 7, 8, 9, 11, 12’ to ‘QPI(s): 1, 5, 7, 8, 9’

Type of Treatment 1-4
Notes for Users – amend ‘QPI(s): 5, 7, 10, 11, 12’ to ‘QPI(s): 5, 7, 10, 12’
Notes for Users – add ‘Remission Inducing SACT includes regimens which are not classed as intensive chemotherapy, although still aimed at remission induction. These include (but are not limited to):

• Daunorubicin/ cytarabine +/- gemtuzumab, ozogamicin or midostaurin
• Midostaurin maintenance
• FLAG-Ida, Mini FLAG-Ida, FLAG
• Any regimen with venetoclax (azacitidine/ venetoclax, low-dose cytarabine/ venetoclax, FLAG-Ida/ venetoclax), LDAC/ venetoclax.
• CPX-351/ Vyxeos
• High/ Intermediate dose cytarabine

Palliative SACT regimens include (but are not limited to):

• Azacitidine/ decitabine alone
• Low dose cytarabine alone
• Small molecule inhibitor alone - e.g. gilteritinib, enasidinib/ ivosidenib

If it is unclear whether the regimen is remission inducing or palliative please seek clarification from a relevant clinician.’

**Type of Treatment 1-4** Codes and Values table – remove codes ‘1A Chemotherapy – Intensive’ and ‘1B Chemotherapy – Low dose’, add code ‘16 Remission Inducing SACT’ with explanatory note ‘Aimed at remission induction’, add code ‘17 Palliative SACT’

**Date Treatment Completed 1-4** Notes for Users – amend ‘If the date treatment started is unknown, record as 09/09/1900 (Not recorded).’ to ‘If the date treatment completed is unknown, record as 09/09/1900 (Not recorded).’

**Patient Entered into Clinical Trial** Notes from Users – amend ‘QPI(s): 8, 10,11’ to ‘QPI(s): 8, 10’

**Date of Referral** - Notes for user updated – see table

**Rebranding Updates (February 2021)**

Key Information – Author amended from Information Services Division (ISD) to Public Health Scotland (PHS)

**Revisions to Dataset Outwith Review (February 2021)**

**Dataset**

**Final Diagnosis** – codes and values table add 9835/3 Acute Lymphoblastic Leukaemia

**Addition to dataset during COVID 19 Pandemic (June 2020)**

**Database Specification**

**Date of Referral** - add new Data item, Field Name: REFERDATE, Field Type: Date (DD/MM/CCYY), Field Length: 10
COVID 19 Impact - add new Data item, Field Name: COVID, Field Type: Integer, Field Length: 2

Dataset

Date of Referral - add new data item - implement from 1 March 2020

COVID 19 Impact - add new Data item – implemented from 1 July 2019

Revisions to Dataset Outwith Review (June 2020)

Person Sex at Birth Codes and Values table remove leading ‘0’

Secondary Acute Myeloid Leukaemia Codes and Values table remove leading ‘0’

Immunophenotyping Performed Codes and Values table remove leading ‘0’

Cytogenetic Analysis Performed Codes and Values table remove leading ‘0’

Cytogenetic/Molecular Risk Group Codes and Values table remove leading ‘0’

Molecular Marker Analysis Performed Codes and Values table remove leading ‘0’

Genetic Material Stored Codes and Values table remove leading ‘0’

Assessment of Minimal Residual Disease Marker (at Diagnosis) Codes and Values table remove leading ‘0’

Tissue Typing Sample Taken (at Diagnosis) Codes and Values table remove leading ‘0’

Intent of Treatment {Acute Leukaemia} Codes and Values table remove leading ‘0’

Type of Treatment 1-4 Codes and Values table remove leading ‘0’

Patient Entered into Clinical Trial Codes and Values table remove leading ‘0’

Remission Status Codes and Values table remove leading ‘0’

First Complete Remission Status Maintained at Time of Death Codes and Values table remove leading ‘0’
Update to Dataset due to WHO4 classification implemented from 1 July 2019

**Final Diagnosis** – Update Codes and Values table

**Assessment of Minimal Residual Disease Marker (at Diagnosis)** – Update Codes and Values table

Revisions to Dataset Outwith Review (April 2019)

**Date of First Diagnosis** {Acute Leukaemia} – Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’

**Final Diagnosis** – Codes and Values table add 9835/3 Acute Lymphoblastic Leukaemia.

**Date Discussed by Care Team** - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’; amend ‘10/10/1010’ to ‘10/10/1900’

**Date Treatment Started (1-4)** - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’; amend ‘10/10/1010’ to ‘10/10/1900’

**Date Treatment Completed (1-4)** - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’; amend ‘10/10/1010’ to ‘10/10/1900’

**Date First Complete Remission** - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’; amend ‘10/10/1010’ to ‘10/10/1900’

**Date of Death** - Notes for Users amend ‘09/09/0909’ to ‘09/09/1900’; amend ‘10/10/1010’ to ‘10/10/1900’

Revisions to Dataset from Formal review (October 2018)

**Dataset**

**Person Family Name (at Diagnosis)** – link updated

**Person Given Name** – link updated

**Patient Postcode at Diagnosis** {Cancer} – link updated

**Date of Birth** – link updated

**Date of first Diagnosis** {Acute leukaemia} – Notes for Users amend ‘QPI 1’ to ‘QPI 1 -13’

**Final Diagnosis** – Notes for Users amend ‘QPI 1 - 12’ to ‘QPI 1, 5, 12, 13’
Assessment of Minimal Residual disease Marker (at Diagnosis) – Notes for Users removed ‘required for QPI 4’

Bone Marrow % Blasts - Notes for Users Updated to add “If a range is stated e.g. 50-60% then the highest percentage should be recorded i.e. 60%.

Location of Treatment {Acute leukaemia} – (Query 1670) Notes for Users updated to include ‘The hospital in which the patient received the majority of SACT Treatment.’

Intent of Treatment {Acute leukaemia} – Notes for Users remove QPI 4 from required QPI’s.

Type of Treatment 1-4 – Notes for Users amend ‘QPI 1,2,4,5,6,7,8,9,10,11, 12’ to ‘QPI 5,7,10,11, 12’

Date Treatment Started 1-4 – Notes for Users amend ‘QPI 3,6’ to ‘QPI 5,’

Date Treatment Completed 1-4 – Notes for Users removed ‘required for QPI 5’ text amend ‘Only record if occurring within 12 months of diagnosis.’ To ‘Only record if occurs within 12 months of diagnosis.’

Patient Entered into Clinical Trial – Query(1740) code 96 not applicable added (patient died before treatment) added.

Remission Status – Notes for Users text amend ‘Only record if occurring within 12 months of diagnosis.’ To ‘Only record if occurs within 12 months of diagnosis.’

Date of Death – Notes for Users amend ‘QPI 3,5,7’ to ‘QPI 5,7,13’ text amend ‘Only record if occurring within 12 months of diagnosis.’ To ‘Only record if occurs within 12 months of diagnosis.’

First Complete Remission Maintained at Time of Death – Notes for Users text amend ‘Only record if occurring within 12 months of diagnosis.’ To ‘Only record if occurs within 12 months of diagnosis.’

Revisions to Dataset Outwith Review (February 2017)

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

Revisions to Dataset Outwith 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.
- Patients, at date of diagnosis, under 16 years of age i.e. up to 15 years 364 days.

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 PHS for the National Quality Assurance Programme and other agreed activities, all sites should be able to export data according to the following specification.

DATABASE SPECIFICATION

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Data Definitions for the National Minimum Core Dataset for Acute Leukaemia.
Developed by ISD Scotland
1st July 2014
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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.

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:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>09</td>
<td>Not specified/Indeterminate</td>
<td>Where it has not been possible to determine if the person is male or female at birth, e.g. intersex / hermaphrodite.</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**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. (PHS, 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:**

*Data Definitions for the National Minimum Core Dataset for Acute Leukaemia.*  
*Developed by ISD Scotland*  
*1st July 2014*
Section 2: Investigations and Diagnosis
Date of Referral

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

Definition: The date on which the patient referral to secondary care for the investigation and / or treatment of Acute Leukaemia cancer was received.

Field Name: REFERDATE
Field Type: Date (DD/MM/CCYY)
Field Length: 10

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

See Table Overleaf:
<table>
<thead>
<tr>
<th>Referral Mode</th>
<th>Guidance on date of referral</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care clinician (Dentist, GP, Nurse practitioner)</strong></td>
<td>Record the date on which the patient referral to secondary care for the investigation and / or treatment of cancer was received.</td>
</tr>
<tr>
<td><strong>Screening service</strong></td>
<td>The referral date is the date that the letter for the assessment centre is generated to request recall to an assessment centre for further diagnostic intervention.</td>
</tr>
<tr>
<td><strong>Incidental finding / Secondary Care</strong></td>
<td>For patients who are incidentally found or suspected of having a cancer (and a new cancer is subsequently confirmed), the date the patient was referred to a specialist for further investigation and treatment should be used. If no referral is required, the date of the investigation that led to the suspicion of cancer should be used. For example, if a patient was having a mammogram for follow up of a previously diagnosed breast cancer, and a new breast cancer is picked up, an onward referral may not be necessary and the date of the mammogram should be used.</td>
</tr>
<tr>
<td><strong>Review clinic</strong></td>
<td>For patients who attend for routine review either for follow up of a previous cancer (and a new cancer is found) or, patients who attend for follow up for benign disease (and a new cancer is found), the date the patient was referred to a specialist for further investigation and treatment should be used. If no referral is required, the date of the investigation that led to the suspicion of cancer should be used. For example, if a patient was having a mammogram for follow up of a previously diagnosed breast cancer, and a new breast cancer is picked up, an onward referral may not be necessary and the date of the mammogram should be used.</td>
</tr>
<tr>
<td><strong>Cancer genetic clinic</strong></td>
<td>Record the date the referral for the investigation and / or treatment of cancer was received.</td>
</tr>
<tr>
<td><strong>Self-referral to A&amp;E</strong></td>
<td>Record the date the patient self presents to A&amp;E.</td>
</tr>
<tr>
<td><strong>GP referral directly to hospital</strong></td>
<td>Record the date the patient presents to hospital (A&amp;E or other) following referral by their GP (usually the same date as referral).</td>
</tr>
<tr>
<td><strong>Previous GP referral but subsequently admitted to hospital</strong></td>
<td>If the previous GP referral was made due to the same or similar symptoms that led to the patient presenting at A&amp;E, record the date the initial GP referral was received. If the previous referral made by the GP was due to different symptoms, record the patient as self-referral to A&amp;E or GP referral directly to hospital, whichever is appropriate.</td>
</tr>
<tr>
<td><strong>Primary care clinician (dental)</strong></td>
<td>Record the date on which the patient referral to secondary care for the investigation and / or treatment of cancer was received.</td>
</tr>
<tr>
<td><strong>Referral from private healthcare</strong></td>
<td>Record the date on which the patient referral from a private healthcare provider for the investigation and / or treatment of cancer was received by the NHS hospital.</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>Record the date on which the patient referral to secondary care for the investigation and / or treatment of cancer was received.</td>
</tr>
<tr>
<td><strong>Not recorded</strong></td>
<td>If the exact date is not documented, record as 09/09/1900.</td>
</tr>
</tbody>
</table>

**Notes by Users:**

*Data Definitions for the National Minimum Core Dataset for Acute Leukaemia.*
*Developed by ISD Scotland*
*1st July 2014*
Location of Diagnosis {Acute Leukaemia}

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

**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 PHS.

Location codes for hospitals are five character codes maintained by PHS 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=Crowhouse 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 PHS.

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): 1 to 13

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 09/09/1900.

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


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, 5, 9, 12, 13

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 phs.canceraudit@phs.scot for advice.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>9896/3</td>
<td>AML with t(8;21)(q22;q22.1); (RUNX1-RUNX1T1)</td>
</tr>
<tr>
<td>9871/3</td>
<td>AML with inv(16)(p13.1q22) or t(16;16)(p13.1;q22); (CBFβ/MYH11)</td>
</tr>
<tr>
<td>9866/3</td>
<td>Acute promyelocytic leukaemia with PML-RARA</td>
</tr>
<tr>
<td>9897/3</td>
<td>AML with t(9;11) (p21.3;q23.3); KMT2A-MLLT3</td>
</tr>
<tr>
<td>9865/3</td>
<td>AML with t(6;9) (p23;q34.1); DEK-NUP214</td>
</tr>
<tr>
<td>9869/3</td>
<td>AML with inv(3) (q21.3q26.2) or t(3;3)(q21.3;q26.2); GATA2, MECOM</td>
</tr>
<tr>
<td>9911/3</td>
<td>AML (megakaryoblastic) with t(1;22) (p13.3;q13.1); RBM15-MKL1</td>
</tr>
<tr>
<td>9912/3</td>
<td>AML with BCR-ABL1</td>
</tr>
<tr>
<td>9877/3</td>
<td>AML with mutated NPM1</td>
</tr>
<tr>
<td>9878/3</td>
<td>AML with biallelic mutation of CEBPA</td>
</tr>
<tr>
<td>9879/3</td>
<td>AML with mutated RUNX1</td>
</tr>
<tr>
<td>9861/3</td>
<td>Acute Myeloid Leukaemia NOS</td>
</tr>
<tr>
<td>Acute Myeloid Leukaemia with Myelodysplasia-related Changes</td>
<td></td>
</tr>
<tr>
<td>9895/3</td>
<td>AML with Myelodysplasia-related Changes</td>
</tr>
<tr>
<td>Therapy Related Myeloid Neoplasm’s</td>
<td></td>
</tr>
<tr>
<td>9920/3</td>
<td>AML – therapy-related</td>
</tr>
<tr>
<td>Code</td>
<td>Description</td>
</tr>
<tr>
<td>--------</td>
<td>-------------</td>
</tr>
<tr>
<td>9872/3</td>
<td>Acute Myeloid Leukaemia Not Otherwise Specified</td>
</tr>
<tr>
<td>9873/3</td>
<td>AML – without maturation</td>
</tr>
<tr>
<td>9874/3</td>
<td>AML – with maturation</td>
</tr>
<tr>
<td>9867/3</td>
<td>Acute myelomonocytic leukaemia</td>
</tr>
<tr>
<td>9891/3</td>
<td>Acute monoblastic and monocytic leukaemia</td>
</tr>
<tr>
<td>9840/3</td>
<td>Pure erythroid leukaemia</td>
</tr>
<tr>
<td>9910/3</td>
<td>Acute megakaryoblastic leukaemia</td>
</tr>
<tr>
<td>9870/3</td>
<td>Acute basophilic leukaemia</td>
</tr>
<tr>
<td>9931/3</td>
<td>Acute panmyelosis with myelofibrosis</td>
</tr>
<tr>
<td>9930/3</td>
<td>Myeloid Sarcoma</td>
</tr>
<tr>
<td>9989/3</td>
<td>Myeloid Leukaemia associated with Down Syndrome</td>
</tr>
<tr>
<td>9727/3</td>
<td>Blastic Plasmacytoid Dendritic Cell Neoplasm</td>
</tr>
<tr>
<td>9801/3</td>
<td>Acute undifferentiated Leukaemia</td>
</tr>
<tr>
<td>9806/3</td>
<td>Mixed-phenotype acute leukaemia with t(9;22) (q34.1;q11.2); BCR-ABL1</td>
</tr>
<tr>
<td>9807/3</td>
<td>Mixed-phenotype acute leukaemia with t(v;11q23.3); KMT2A-rearranged</td>
</tr>
<tr>
<td>9808/3</td>
<td>Mixed Phenotype Acute Leukaemia, B/Myeloid NOS</td>
</tr>
<tr>
<td>9809/3</td>
<td>Mixed Phenotype Acute Leukaemia, T/Myeloid NOS</td>
</tr>
<tr>
<td>9811/3</td>
<td>Precursor Lymphoid Neoplasm</td>
</tr>
<tr>
<td>9812/3</td>
<td>B-lymphoblastic leukaemia/lymphoma with iAMP21</td>
</tr>
<tr>
<td>9813/3</td>
<td>B-lymphoblastic leukaemia/lymphoma with t(9;22)(q34.1;q11.2); BCR-ABL1</td>
</tr>
<tr>
<td>9814/3</td>
<td>B-lymphoblastic leukaemia/lymphoma with t(12;21) (p13.2;q22.1); ETV6-RUNX1</td>
</tr>
<tr>
<td>9815/3</td>
<td>B Lymphoblastic Leukaemia/Lymphoma with Hyperdiploidy</td>
</tr>
<tr>
<td>9816/3</td>
<td>B-lymphoblastic leukaemia/lymphoma with hypodiploidy (hypodiploid ALL)</td>
</tr>
<tr>
<td>9817/3</td>
<td>B-lymphoblastic leukaemia/lymphoma with t(5;14)(q31.1;q32.1); TCF3-PBX1</td>
</tr>
<tr>
<td>9819/3</td>
<td>B-lymphoblastic leukaemia/lymphoma BCR-ABL1-like</td>
</tr>
<tr>
<td>9835/3</td>
<td>Acute Lymphoblastic Leukaemia</td>
</tr>
<tr>
<td>9837/3</td>
<td>T Lymphoblastic Leukaemia / Lymphoma</td>
</tr>
<tr>
<td>1111/1</td>
<td>Not assessable</td>
</tr>
<tr>
<td>9999/9</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>
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 PHS.

**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-radiation therapy 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:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td>AML developed through de novo (primary) process</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**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)


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:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>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</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of self care but unable to carry out any work activities: up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled, cannot carry on any self care, totally confined to bed or chair</td>
</tr>
<tr>
<td>9</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

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 PHS.

**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 10/10/1900 (Not applicable).

If the date of the MDT meeting is unknown record as 09/09/1900 (Not recorded)

**Related data Item(s):**
COVID 19 Impact

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

Definition: A record of whether COVID 19 has impacted on treatment decisions.

Field Name: COVID
Field Type: Integer
Field Length: 2

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

The COVID 19 pandemic will have an impact on the patient pathways of some patients, potentially affecting the treatment they will receive. This may affect treatment decisions from the outset or plans may change part way through treatment. MDTs will record when the recommendations of the MDT for management are made on the basis of emergency COVID 19 management guideline and differ from what would otherwise be advised.

Where there is a record of a patients treatment being amended due to the emergency COVID 19 management guidelines elsewhere, for example amendments to treatment after MDT discussion, then this can also be recorded under ‘Yes – other’, however it is acknowledged that this information may not be complete.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes - plan developed by MDT</td>
<td>MDT record treatment as determined by emergency COVID 19 management guidelines from the outset</td>
</tr>
<tr>
<td>2</td>
<td>Yes - plan amended by MDT</td>
<td>MDT record amendment to existing treatment plan due to emergency COVID 19 management guidelines</td>
</tr>
<tr>
<td>3</td>
<td>Yes – Other</td>
<td>Other record of amendment to treatment due to emergency COVID 19 management guidelines e.g. clinic letter about alteration of treatment plan</td>
</tr>
<tr>
<td>4</td>
<td>No</td>
<td>No evidence of patient treatment being affected by COVID 19</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td>Where documentation of part of the patient pathway is unavailable, e.g. for patients diagnosed outwith NHS Scotland, or where the patient moves away while treatment is still ongoing</td>
</tr>
</tbody>
</table>
Immunophenotyping Performed

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

**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:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care only</td>
</tr>
<tr>
<td>98</td>
<td>Failed</td>
<td>E.g. No results due to technical failure</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**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 PHS.

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.

It’s possible to have cytogenetics performed but the risk group not specifically reported, especially for cases with normal karyotype

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care only</td>
</tr>
<tr>
<td>98</td>
<td>Failed</td>
<td>E.g. No results due to technical failure</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

**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:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Favourable / Good</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Intermediate / Standard</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Adverse</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care only</td>
</tr>
<tr>
<td>98</td>
<td>Failed cytogenetics</td>
<td>E.g. No results due to technical failure</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**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 PHS.

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 QPI(s): 1 and for national analysis

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

This must include Flt-3 and NPM-1 as a minimum requirement for patients with AML.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td>E.g. Flt-3, NPM-1, CEBPA, BCR-ABL, PML-RARA, PCR for 8:21 translocation</td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care only</td>
</tr>
<tr>
<td>98</td>
<td>Failed</td>
<td>E.g. No results due to technical failure</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

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:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care only</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

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:

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 -

<table>
<thead>
<tr>
<th>Precursor Lymphoid Neoplasm</th>
</tr>
</thead>
<tbody>
<tr>
<td>9811/3 B Lymphoblastic Leukaemia/Lymphoma, Not Otherwise Specified</td>
</tr>
<tr>
<td>9812/3 B-lymphoblastic leukaemia/lymphoma with iAMP21</td>
</tr>
<tr>
<td>9813/3 B-lymphoblastic leukaemia/lymphoma with (9;22)(q34.1;q11.2); BCR-</td>
</tr>
<tr>
<td>9814/3 B-lymphoblastic leukaemia/lymphoma with t(12;21) (p13.2;q22.1);</td>
</tr>
<tr>
<td>9815/3 B Lymphoblastic Leukaemia/Lymphoma with Hyperdiploidy</td>
</tr>
<tr>
<td>9816/3 B-lymphoblastic leukaemia/lymphoma with hypodiploidy (hypodiploid</td>
</tr>
<tr>
<td>9817/3 B-lymphoblastic leukaemia/lymphoma with t(5;14)(q31.1;q32.1);</td>
</tr>
<tr>
<td>9818/3 B-lymphoblastic leukaemia/lymphoma with t(1;19)(q23;p13.3); TCF3-</td>
</tr>
<tr>
<td>9819/3 B-lymphoblastic leukaemia/lymphoma BCR-ABL1-like</td>
</tr>
<tr>
<td>9837/3 T Lymphoblastic Leukaemia / Lymphoma</td>
</tr>
<tr>
<td>9837/3 Early T cell precursor lymphoblastic leukaemia</td>
</tr>
</tbody>
</table>

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Aged 25 and over</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

**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).

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

**Codes and Values:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Patients receiving low-dose chemotherapy, low intensity chemotherapy, Supportive care only</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**Related Data Items:**
- Date of First Diagnosis {Acute Leukaemia}
- Date Tissue Typing Sample Taken (at diagnosis)
**Date 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 PHS.

**Definition:** This denotes the date the sample was taken for tissue typing.

**Field Name:** TTSAMPDATE  
**Field Type:** Date (DD/MM/CCYY)  
**Field Length:** 10

**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).

The date the sample was taken should be recorded and not when this was received by the laboratory.

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

If a sample has not been taken for tissue typing record as 10/10/1900 (Not applicable).

If the date the tissue typing sample was taken is unknown record as 09/09/1900 (Not recorded).

**Related Data Items:**  
Date of First Diagnosis {Acute Leukaemia}  
Tissue Typing Sample Taken (at diagnosis)
Bone Marrow % Blasts

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

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 a range is stated e.g. 50 - 60% then the highest percentage should be recorded i.e. 60%.

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 PHS.

**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 PHS.

**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.

The hospital in which the patient received the majority of SACT Treatment. Details of location codes for hospitals can be found in the "Definitions and Codes for the NHS in Scotland" manual produced by PHS.

Location codes for hospitals are five character codes maintained by PHS 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 PHS.

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, 5, 7, 8, 9,

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Curative</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Non-curative</td>
<td>Includes: palliative treatment and supportive care</td>
</tr>
<tr>
<td>94</td>
<td>Patient died before treatment</td>
<td></td>
</tr>
<tr>
<td>95</td>
<td>Patient refused treatment</td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

**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): 5, 7, 10, 12

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

Remission Inducing SACT includes regimens which are not classed as intensive chemotherapy, although still aimed at remission induction. These include (but are not limited to):

- Daunorubicin/ cytarabine +/- gemtuzumab, ozogamicin or midostaurin
- Midostaurin maintenance
- FLAG-Lda, Mini FLAG-Lda, FLAG
- Any regimen with venetoclax (azacitidine/ venetoclax, low-dose cytarabine/ venetoclax, FLAG-Lda/ venetoclax), LDAC/ venetoclax.
- CPX-351/ Vyxeos
- High/ Intermediate dose cytarabine

Palliative SACT regimens include (but are not limited to):

- Azacitidine/ decitabine alone
- Low dose cytarabine alone
- Small molecule inhibitor alone - e.g. gilteritinib, enasidinib/ ivosidenib

If it is unclear whether the regimen is remission inducing or palliative please seek clarification from a relevant clinician.

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:

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Explanatory notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>4A</td>
<td>Biological Therapy - Other</td>
<td>E.g. Imatinib (Glivec), nilotinib (Tasigna), dasatinib (Sprycell)</td>
</tr>
<tr>
<td>4B</td>
<td>Biological Therapy - All Trans-Retinoic Acid (ATRA)</td>
<td>Tretinoin, Vesanoid</td>
</tr>
<tr>
<td>7A</td>
<td>Transplant - Autologous</td>
<td>Self</td>
</tr>
<tr>
<td>7B</td>
<td>Transplant - Allogenic</td>
<td>Other person</td>
</tr>
<tr>
<td>14</td>
<td>Supportive Care Only</td>
<td>Blood transfusion, analgesia, antibiotics, hydroxycarbamide</td>
</tr>
<tr>
<td>16</td>
<td>Remission Inducing SACT</td>
<td>Aimed at remission induction</td>
</tr>
<tr>
<td>17</td>
<td>Palliative SACT</td>
<td></td>
</tr>
<tr>
<td>94</td>
<td>Patient died before treatment</td>
<td></td>
</tr>
<tr>
<td>95</td>
<td>Patient refused all therapies</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td></td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

### 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 PHS.

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): 5

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 09/09/1900 (Not recorded).

If treatment has not been given or the patient has refused treatment, record as 10/10/1900 (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 PHS.

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:

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 completed is unknown, record as 09/09/1900 (Not recorded).

If treatment has not been given or the patient has refused treatment, record as 10/10/1900 (Not applicable).

Only record if occurs 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 PHS.

**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

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:**

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No trial available</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>No trial offered</td>
<td>Trial available but not offered to patient</td>
</tr>
<tr>
<td>4</td>
<td>Not eligible for trial</td>
<td></td>
</tr>
<tr>
<td>95</td>
<td>Patient refused</td>
<td></td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>Patient died before treatment</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

**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 PHS.

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 occurs within 12 months of diagnosis.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Complete Remission (CR)</td>
<td>The bone marrow is regenerating normal haemopoietic cells and contains &lt;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</td>
</tr>
<tr>
<td>2</td>
<td>Complete Remission with incomplete recovery (CRi)</td>
<td>Fulfilling all criteria for CR except for residual neutropenia (&lt;1.0 x 10^9/l) or thrombocytopenia (&lt;100 x 10^9/l)</td>
</tr>
<tr>
<td>3</td>
<td>Partial Remission (PR)</td>
<td>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</td>
</tr>
<tr>
<td>4</td>
<td>Resistant Disease (RD)</td>
<td>The bone marrow shows persistent AML or ALL</td>
</tr>
<tr>
<td>96</td>
<td>Not applicable</td>
<td>E.g. Supportive care, patient died before treatment</td>
</tr>
<tr>
<td>99</td>
<td>Not recorded</td>
<td></td>
</tr>
</tbody>
</table>

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 PHS.

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

**Field Name:** DREMISSION  
**Field Type:** Date (DD/MM/YYYY)  
**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 09/09/1900 (Not recorded).

If patient is not in remission, record as 10/10/1900 (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 PHS.

**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): 5, 7, 13

Only record if occurs within 12-months of diagnosis.

If the exact date is not documented, record as 09/09/1900 (Not recorded).

If the patient is alive use the code 10/10/1900 (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 PHS.

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 occurs within 12 months of diagnosis.

Codes and Values:

<table>
<thead>
<tr>
<th>Code</th>
<th>Value</th>
<th>Explanatory Notes</th>
</tr>
</thead>
</table>
| 1    | Yes    | Patient was still in 1
st CR or CRi                                         |
| 2    | No     | Patient had relapsed                                    |
| 96   | Not applicable | E.g. Supportive care only, patient died before treatment |
| 99   | Not recorded                                      |

Related Data Item(s):