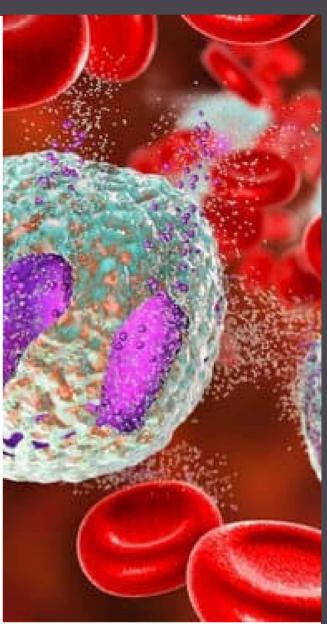


National Non-Hodgkin Lymphoma **Audit**

Scoping Document

November 2023





























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National Non-Hodgkin Lymphoma Audit (NNHLA) Scoping Document 2023

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The National Cancer Audit Collaborating Centre (NATCAN) is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). NATCAN delivers national cancer audits in non-Hodgkin lymphoma, bowel, breast (primary and metastatic), oesophago-gastric, ovarian, kidney, lung, pancreatic and prostate cancers. HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes, and in particular, to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical, and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies.

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Executive summary

The National Non-Hodgkin Lymphoma Audit (NNHLA) has been commissioned to evaluate the care received by patients diagnosed with Non-Hodgkin lymphoma at NHS hospitals within England and Wales. It aims to

- 1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
- 2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
- 3. Stimulate improvements in cancer detection, treatment and outcomes for patients, including survival rates.

To develop the scope of the audit and identify priority areas for quality improvement, the NNHLA project team started by carrying out a review of the existing literature relevant to Non-Hodgkin Lymphoma care. This informed the *proposed* NNHLA scope and healthcare improvement goals, guided the data request for England and Wales, and helped to identify any potential challenges in the design and delivery of the NNHLA. The NNHLA project team then consulted with stakeholders on the *proposed* NNHLA scope and healthcare improvement goals. Feedback received from stakeholders was used to refine the final scope and healthcare improvement goals that are presented in this document.

Based on this work, the scope of the NNHLA will include all adults diagnosed with NHL who received diagnostic and therapeutic services offered through secondary and tertiary care providers within the National Health Service in England or Wales.

The following healthcare improvement goals were identified:

- 1. Improving timely diagnosis and treatment
- 2. Treatment appropriate to the subtype of Non-Hodgkin Lymphoma
- 3. Improving safety and reducing toxicity of Non-Hodgkin Lymphoma therapy
- 4. Improving overall survival
- 5. Reducing variation in Non-Hodgkin Lymphoma management among NHS providers.

These healthcare improvement goals set out priorities that will inform the development of the NNHLA Healthcare Improvement Plan, which is the next phase of work for the NNHLA project team.

The healthcare improvement plan will build on this scoping document to include an outline of the ten key performance indicators (KPI) to be reported by the NNHLA. It will also outline how the KPI map to the healthcare improvement goals and national guidelines. In addition, further detail will be provided on the strategies for reporting and disseminating results from the NNHLA.

1 Aim of audit scope

The aim of the audit scope is to define the following:

- 1. Patient inclusion criteria: which patients are to be included in the audit.
- 2. Care pathway coverage: which parts of the care pathway are to be covered by the audit.
- 3. Healthcare improvement goals: what aspects of care have been identified as priority areas for the audit to support quality improvement.

Given this is the first national audit of non-Hodgkin lymphoma in England and Wales, the scope of the audit is expected to evolve over subsequent years.

2 Background

2.1 Overview the National Cancer Audit Collaborating Centre (NATCAN).

The National Non-Hodgkin Lymphoma Audit (NNHLA) is part of the National Cancer Audit Collaborating Centre (NATCAN), a new national centre of excellence to strengthen NHS cancer services by looking at treatments and patient outcomes across the country. It was set up on 1 October 2022 to deliver six new national cancer audits, including the NNHLA. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government, with funding for an initial period of three years.

NATCAN is based within the Clinical Effectiveness Unit (CEU), the academic partnership between the Royal College of Surgeons of England (RCS Eng) and the London School of Hygiene & Tropical Medicine (LSHTM). The CEU is recognised as a national centre of expertise in analytic methodology and the development of administrative and logistic infrastructure for collating and handling large-scale data for assessment of health-care performance.

Prior to the launch of NATCAN, the <u>CEU</u> was already the sole provider of national cancer audits in the NHS in England and Wales, incorporating audits in <u>prostate</u>, <u>lung</u>, <u>bowel</u>, and <u>oesophago-gastric</u> cancers, and recently completed an audit of <u>breast cancer in older patients</u>. These audits have helped provide a wider understanding of cancer treatments across England and Wales and have improved services and infrastructure leading to improved outcomes for patients. By consistently placing quality improvement (QI) at the centre of all audits, initiatives which promote QI within NHS cancer services have been developed and areas of best practice identified.

Alongside the NNHLA, NATCAN delivers four other cancer audits, including ovarian, pancreatic and breast (two separate audits in primary and metastatic disease). The aim of these audits is to:

- 1. Provide regular and timely evidence to cancer services of where patterns of care in England and Wales may vary.
- 2. Support NHS services to increase the consistency of access to treatments and help guide quality improvement initiatives.
- 3. Stimulate improvements in cancer detection, treatment and outcomes for patients, including survival rates.

The audits which the CEU already provided have joined NATCAN (bowel, oesophago-gastric and prostate) or will, in the near future (lung), bringing the number of NATCAN audits to ten. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

Further information on the organisational structure of NATCAN and key features of its approach to audit can be found in the appendix (section 8.1 and section 8.3 respectively).

2.2 Overview of the National Non-Hodgkin Lymphoma Audit (NNHLA)

The aim of the NNHLA is to evaluate the care received by patients diagnosed with Non-Hodgkin lymphoma at NHS hospitals within England and Wales.

The NNHLA will consider the following possible reasons for variation in Non-Hodgkin lymphoma care and outcomes:

- 1. Variations in the uptake of, and inequalities in access to, new technologies and treatment techniques e.g., hospitals participating in clinical trials, geographical location, deprivation, ethnicity.
- 2. Differences in the nature and extent of disease, notably the distinct tumour subtypes given their distinct patterns of care and prognosis.
- 3. Differences in patient frailty and prevalence of comorbidities that may contraindicate certain treatment modalities.

Audit development and delivery is the responsibility of the NNHLA Project Team. The Project Team works in partnership to deliver the objectives of the audit and is responsible for the day-to-day running of the audit and producing the deliverables. It will lead on the audit design, data collection, data quality monitoring, data analysis and reporting. Further information on organisation of the NNHLA project team and its membership can be found in the appendix (section 8.1 and section 8.3 respectively).

Clinical leadership of the NNHLA is provided by representatives from the British Society of Haematology and the Royal College of Radiologists.

The NNHLA will be supported by twice-yearly meetings of stakeholders in the NNHLA Clinical Reference Group (CRG), which will include clinicians involved with care across the patient pathway, patient representatives, commissioners, and funder representatives. Further information on organisation of the NNHLA CRG and its membership can be found in the appendix (section 8.1 and section 8.4 respectively).

The NNHLA Patient and Public Involvement (PPI) forum will provide advisory support and ensure the voice of patients is central to the direction and delivery of the Audit. A key activity of the PPI Forums will be to actively participate in the production of patient-focussed audit outputs (including patient and public information, patient summaries of reports, infographics and design and function of the NATCAN website), guiding on how to make this information accessible. Further information on organisation of the NNHLA PPI forum can be found in the appendix (section 8.1).

3 Non-Hodgkin lymphoma

3.1 Main issues in non-Hodgkin lymphoma care and outcomes

Non-Hodgkin lymphoma (NHL) is the sixth most common cancer in the UK and accounted for 4% of all new cancer cases between 2016 and 2018.¹ On average, there were 14,200 new cases of NHL each year in the UK between 2016 and 2018.¹ Since the early 1990s, NHL incidence rates have increased by approximately 38% in the UK.¹

NHL is a heterogeneous disease comprising over 30 subtypes, which are all linked by their origin within the lymphoid tissues but have markedly different clinical courses and requirements for therapy.² Personalised medicine is therefore a core principle that underpins the care of NHL patients.

The most common subtypes are diffuse large B cell lymphoma (DLBCL), which is an aggressive or high-grade lymphoma, and follicular lymphoma, which is an indolent (non-aggressive) or low-grade lymphoma.²

NHL symptoms can be variable, depending on the subtype and where it is in the body; patients with NHL can therefore seek healthcare for a range of different reasons and the pathway to being diagnosed can vary accordingly. Low grade NHL progresses slowly, can be induced into remission but has a high rate of relapse.² In contrast, high grade NHL progresses rapidly but the majority of patients who achieve remission remain cured.² Prognosis for NHL patients overall is relatively good, with 55% of people diagnosed with NHL in England surviving their disease for ten years or more.³ However, side effects of treatment such as toxicity remain a key challenge to quality of life.²

As well as being a heterogeneous disease, NHL care is changing rapidly, with new treatments being developed, advances in biomarker and genomic testing, and new technologies on the horizon.

3.2 Diagnostic and therapeutic pathways

NHL is categorised into subtypes according to morphological, molecular and immunophenotypic characteristics. The resulting diagnostic information for each individual patient allows therapeutic pathways to be tailored according to the diagnosed subtype and therefore personalised for each patient.

Within the UK National Health System (NHS), the following treatment modalities are used to manage NHL:

- Systemic anti-cancer therapy the mainstay of NHL treatment.
- Radiation therapy can be given alone or in combination with chemotherapy for early-stage disease, as well as for enhanced disease control and palliative purposes for advanced stage disease.
- Stem cell rescue or transplant may be required following high-dose chemotherapy, as this treatment can deplete the bone marrow.
- Chimeric antigen receptor T-cell (CAR-T) therapy recently recommended for use within the Cancer Drugs Fund as second line therapy for patients with relapsed/refractory DLBCL.⁴ CAR-T

therapy is also commissioned as third line therapy by NHS England for other patients with relapsed DLBCL and some other forms of NHL.⁵

• "Watch and wait" or "active monitoring" approach may be recommended for low grade NHL (e.g., follicular lymphoma).

3.3 Service provision

NHL care is provided through a mix of centralised and decentralised services. Treatment decision-making, imaging, chemotherapy, and radiotherapy are all decentralised services, whereas genomic testing, stem cell therapy and chimeric antigen receptor T-cell therapy are all centralised to specialist centres/laboratories.

4 Process for development of NNHLA scope

The NNHLA carried out a review of existing literature in order to develop the *proposed* NNHLA scope and healthcare improvement goals, as well as to guide the data request for England and Wales, and to identify potential challenges in the design and delivery of the NNHLA.

During the first NNHLA CRG meeting, the NNHLA project team consulted with stakeholders on the *proposed* NNHLA scope and healthcare improvement goals. Following stakeholder consultation, all comments and responses were used to refine the final scope and healthcare improvement goals.

4.1 Review of existing literature

4.1.1 NICE guidelines

The National Institute for Health and Care Excellence (NICE) published guidelines on the diagnosis and management of NHL (NG52) in 2016.² These address several areas where there is uncertainty or variation in clinical practice, in relation to diagnosing NHL and management of certain subtypes.² Topics include the best type of biopsy for diagnosis, genetic testing, the role of fluorodeoxyglucose positron emission tomography/computerised tomography (FDG-PET-CT) imaging in staging, patient information needs and survivorship.² The scope is limited to management of the more common subtypes, specifically follicular lymphoma, mucosal associated lymphoid tissue (MALT) lymphoma, mantle cell lymphoma, diffuse large B-cell lymphoma, Burkitt lymphoma and peripheral T-cell lymphoma.²

NICE guidelines on the recognition and referral of suspected cancer in primary care were last updated in 2023 (NG12).⁶ For NHL, recommendations are made on which patients should be referred on a suspected cancer pathway referral (for an appointment within 2 weeks).

NICE guidelines on improving outcomes in haematological cancers (NG47), published in 2016, aims to improve care for people with suspected or diagnosed cancer by promoting best practice on the organisation of haematological cancer services.⁷ It covers integrated diagnostic reporting for diagnosing haematological cancer, staffing, facilities (levels of care) and multidisciplinary teams needed.

4.1.2 NICE quality standards

NICE quality standards for haematological cancers (QS150), published in 2017, cover diagnostic reporting, the organisation of haematological cancer services, managing haematological cancers and consists of a set of specific and measurable statements.⁸

Topics highlighted in these statements include integrated reporting from a haematological malignancy diagnostic service, PET-CT scanning for certain NHL sub-types, radiotherapy as first-line treatment for certain localised NHL subtypes and an end-of-treatment summary plan to be discussed at treatment completion.⁸

4.1.3 Other relevant literature

The British Society of Haematology (BSH) produces evidence-based guidelines on the diagnosis and treatment of haematological diseases. The BSH haemato-oncology task force has produced several guidelines for specific subtypes of NHL.

Clinical quality performance indicators for lymphoma have been published by Healthcare Improvement Scotland.¹⁰ These will be reviewed as part of future work to develop performance indicators for the NNHLA.

4.2 Data sources

The NNHLA will use information from routine national health care datasets. These capture details on the diagnosis, management and treatment of every patient newly diagnosed with NHL in England and Wales. The following sections provide a summary of data requested and further details on data acquisition can be found in the appendix (section 8.5).

4.2.1 Data requested for England.

For patients with NHL treated in England, the NNHLA will receive data (via a NATCAN data request) from the National Cancer Registration and Analysis Service (NCRAS). NCRAS collects patient-level data from all NHS acute providers on patients with cancer using a range of national data-feeds. The NNHLA will receive Cancer Registry data annually and quarterly extracts of Rapid Cancer Registration Data (RCRD), linked at patient level to items of several routinely collected datasets, including the Cancer Outcomes and Services Dataset (COSD), the Hospital Episode Statistics (HES) data sets, the Radiotherapy Data Set (RTDS), the Systemic Anti-Cancer Treatment (SACT) data set, the Cancer Waiting Times data set, the Office for National Statistics (ONS) data set and data from the National Cancer Patient Experience Survey (CPES). There are limitations with the representativeness of patients captured in CPES because the survey is only carried out during a three-month window each year and is distributed to patients with NHL accessing hospital care who can be anywhere in their care trajectory.

4.2.2 Data requested for Wales.

For patients with NHL treated in Wales, the NNHLA will receive data from the Wales Cancer Network (WCN), Public Health Wales. Welsh cancer registration data is captured through a national system, Cancer Network Information System Cymru (CaNISC), which is in the process of being replaced by a

new Cancer Information System for Wales. As the replacement work is ongoing, it is unclear exactly what data will be available, or how frequent and timely it will be. The Welsh registration records will be linked to records from the Patient Episode Database for Wales (PEDW), which contains data describing all inpatient and day case activity undertaken within the NHS.

4.3 Data limitations

Performance indicators need to be accurate and reliable at the chosen level of reporting (e.g., hospital, trust / local health board, or region / Cancer Alliance). For accurate and timely benchmarking, it is essential that NCRAS and Welsh cancer data that is being used by NNHLA:

- 1. Includes all the data items required to measure and risk-adjust performance indicators.
- 2. Is timely.
- 3. Has a high-level of case-ascertainment.
- 4. Has high levels of data completeness.
- 5. Is accurate.

4.3.1 Rapid vs. gold standard cancer registration datasets

For patients treated in England, the NNHLA will be provided with data from the Rapid Cancer Registration Dataset (RCRD) for quarterly reporting. This dataset is compiled mainly from COSD records and is made available more quickly than gold standard cancer registration datasets. The RCRD will be linked to other national health care datasets. The speed of production means that case ascertainment and data completeness are lower, and the range of data items in the RCRD is limited. This may restrict the extent to which risk adjustment can be applied to performance indicators used for quarterly reporting.

A particular issue for the NNHLA is that, in the RCRD, ICD-03 codes are unavailable and the ICD-10 codes only have three characters. This is likely to mean that some patients in the RCRD with NHL may not be included or that they may shift between diagnostic sub-types/categories when the gold standard cancer registration data becomes available. The extent to which this is an issue will be investigated by comparing patients identified using gold standard cancer registry data and RCRD.

4.4 Stakeholder consultation

The first CRG meeting took place on 7th September 2023 and was designated as a stakeholder consultation meeting. The aim of this meeting was to collect the views of key stakeholders on the *proposed* scope of the NNHLA and to identify potential challenges in its design and delivery. Written feedback was invited from CRG members unable to attend this meeting.

Key topics raised by stakeholders as important for the NNHLA included:

- 1. Routes to, and delays in, diagnosis.
- 2. Palliative care and end of life care.
- 3. Health inequalities, such as by ethnicity and deprivation.
- 4. NHL subtypes.
- 5. Treatment toxicity.

- 6. Patient age.
- 7. Relapsed/recurrent disease.
- 8. Clinical trial participation.
- 9. Dissemination of audit results.

Following stakeholder consultation, the *proposed* scope and healthcare improvement goals were revised in light of feedback received.

CRG membership is outlined in section 8.4.

5 The NNHLA scope

5.1 Patient inclusion criteria

The NNHLA will include all patients aged 18 years and over who meet the following proposed inclusion criteria:

- 1. Have a diagnosis of NHL, as documented by International Classification of Diseases codes (ICD-10 or ICD-03 codes, as listed in section 8.6 and 8.7 respectively).
- 2. Have received care provided by the National Health Service in England or Wales.

The ICD-10 codes proposed to be used to include patients with NHL were identified through the review of existing literature and align with those reported by NICE guidance², Public Health Scotland¹¹, and the Office for National Statistics.¹² ICD-O3 codes will be used to increase the granularity of NHL subtypes.

It was recognised that some diagnoses of potential interest exist within the chronic lymphocytic leukaemia (CLL) spectrum, where the lymphoma variant is known as small lymphocytic lymphoma (SLL). Patients diagnosed with SLL are often treated in a similar way to low grade NHL and by the same clinicians, therefore we propose to include patients with SLL in the scope of the NNHLA.

5.2 Care pathway coverage

The NNHLA scope will include diagnostic and therapeutic services offered through secondary and tertiary care providers within the National Health Service.

5.3 Healthcare improvement goals

Table 1 summarises the healthcare improvement goals for the NNHLA.

5.4 Topics for future consideration

The following topics were discussed during stakeholder consultation and identified as important areas for future consideration but outside of the current audit scope. Working with the data sources outlined in section 4.2, the NNHLA is not currently positioned to measure performance indicators related to these aspects of NHL care. However, given this is the first national audit of non-Hodgkin lymphoma in England and Wales, the scope of the audit is expected to evolve over subsequent years.

- 1. **Disease recurrence**: stakeholders discussed whether it would be possible to include patients with recurrent/relapsed disease. At present, the data sources outlined in section 4.2 do not capture these patients reliably and so they remain outside of the current audit scope. However, methods to identify such patients in routine datasets is an active area of research.
- 2. Primary care: stakeholders discussed that patients with NHL can attend primary care providers several times before referral to secondary/tertiary care and a diagnosis is subsequently made. Expanding future audit scope to cover primary care services would enable these early stages of the NHL care pathway to be captured, however lack of a nationally comprehensive primary care data set that can be linked to the national cancer data is a current limitation.
- 3. **Palliative care**: stakeholders discussed the importance of palliative care but acknowledged that end of life care is often provided in the community and by third sector providers (e.g., hospices), which are not captured in data sources available to the audit and therefore outside of the current audit scope. However, end of life care provided within secondary and tertiary care is within audit scope.
- 4. Patients aged <18 years old: stakeholders discussed that services for teenagers and young adults (TYA) can span those aged 16-25 years old. However, current information governance limits the audit scope to evaluating care for patients aged 18 years and over. Expanding the age range of patients included in the audit could enable more comprehensive coverage of TYA services.</p>

Table 1: Healthcare improvement goals for the National Non-Hodgkin Lymphoma Audit

| Healthcare Improvement Goal | | Alignment with NICE guidance |
|-----------------------------|---|---|
| 1. | Improving timely diagnosis and treatment. | The NHS long-term plan aims to improve cancer survival through earlier cancer diagnosis and sets a target for 75% of cancers to be diagnosed at stages one and two by 2028. ¹³ |
| 2. | Treatment appropriate to the subtype of NHL. | Aligns with the NICE quality standard for haematological cancer (QS150). ⁸ Reflects recommendations in the NICE guideline for the diagnosis and management of NHL (NG52). ² |
| 3. | Improving safety and reducing toxicity of NHL therapy. | Aligns with the NICE quality standard for haematological cancer (QS150).8 |
| 4. | Improving overall survival. | Aligns with the NICE quality standard for haematological cancer (QS150).8 |
| 5. | Reducing variation in NHL management among NHS providers. | Aligns with the NICE guideline for the diagnosis and management of NHL (NG52). ² |

Abbreviations: NHL: non-Hodgkin lymphoma

6 Next steps

6.1 Development of performance indicators

Following publication of the NNHLA scope, the next step will be to develop ten performance indicators and map these to the NNHLA healthcare improvement goals. These key performance indicators will be used to support the audit's objectives and to monitor progress towards its healthcare improvement goals. This work will begin once NATCAN has received the requested datasets outlined in section 4.2; at this point, the feasibility of deriving each performance indicator from the available data will be evaluated.

6.2 Healthcare improvement plan

The healthcare improvement plan will build on this scoping document to include an outline of the ten key performance indicators to be reported by the NNHLA and how they map to the healthcare improvement goals and national guidelines. In addition, further detail will be provided on the strategies for reporting and disseminating results from the NNHLA.

The two principal strategies for reporting NNHLA results include:

- 1. A short (ten-page) "state of the nation" report for NHS Trusts/Health Boards within England and Wales.
 - These reports will focus on reporting the ten key performance indicators (outlined in the healthcare improvement plan) and highlight where services should focus quality improvement activities.
 - The PPI Forum will actively participate in the production of a patient summary of the "state of the nation" reports, guiding on how to make this information accessible.
- 2. An indicator dashboard on the NNHLA website containing NHS organisational-level results.
 - These dashboard indicators will facilitate benchmarking and timely monitoring of performance at regular intervals so improvements in performance can be tracked.
 - The dashboard will also present a broader range of indicators, as required, to provide further context for interpreting the ten key performance indicators outlined in the healthcare improvement plan.

These outputs will be accompanied by a range of healthcare improvement tools that will support their use by national, regional, and local stakeholders. Details of healthcare improvement tools, methods and activities will be outlined in the healthcare improvement plan.

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8 Appendices

8.1 Organisational structure of NATCAN

Centre Board

NATCAN has a multi-layered organisational structure. <u>NATCAN's Board</u> provides top-level governance and oversees all aspects of the delivery of the contract, ensuring that all audit deliverables are produced on time and within budget and meet the required quality criteria. The Board also provides the escalation route for key risks and issues. It will also consider NATCAN's strategic direction. The Board will meet at 6-monthly intervals and will receive regular strategic updates, programme plans, and progress reports for sign-off. Risks and issues will be reported to the NATCAN Board for discussion and advice.

Executive Team

NATCAN's Executive Team is chaired by the Director of Operations (Dr Julie Nossiter) and includes the Clinical Director (Dr Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Dr Kate Walker), and the Senior Clinical Epidemiologist (Prof Jan van der Meulen) with support provided by NATCAN's project manager (Ms Verity Walker). This Executive Team is responsible for developing and implementing NATCAN's strategic direction, overseeing its day-to-day running, and coordinating all activities within each of cancer audits. This group meets monthly. The Executive Team will provide 6-monthly updates to NATCAN's Board.

Advisory groups

The Executive Team will be supported by two external groups. First, the Technical Advisory Group including external senior data scientists, statisticians, and epidemiologists as well as representatives of the data providers (NDRS, NHSD and WCN, PHW), co-chaired by NATCAN's Senior Statistician and Senior Epidemiologist, will advise on national cancer data collection, statistical methodology, development of relevant and robust performance indicators to stimulate QI, and communication to practitioners and lay audiences.

Second, the Quality Improvement Team includes national and international experts who have extensive experience in QI and implementation research. This team will provide guidance on the optimal approaches to change professional and organisational behaviour. It will be chaired by NATCAN's Clinical Director and managed by the Director of Operations.

This set up will provide a transparent and responsive management structure allowing each audit to cater for the individual attributes of the different cancer types, while also providing an integrated and consistent approach across the NATCAN audits. The integrated approach will result in efficient production of results through sharing of skills and methods, a common "family" feel for users of audit outputs, and a shared framework for policy decisions and, project management.

Audit Project Teams

Audit development and delivery is the responsibility of each Project Team. The Project Team works in partnership to deliver the objectives of the audit and is responsible for the day-to-day running of the audit and producing the deliverables. It will lead on the audit design, data collection, data quality monitoring, data analysis and reporting.

Each cancer audit Project Team is jointly led by two Clinical Leads representing the most relevant professional organisations, and senior academics with a track record in health services research, statistics, data science and clinical epidemiology, affiliated to the London School of Hygiene and Tropical Medicine. In addition, each audit will have a clinical fellow, who contributes to all aspects of the audits, reinforcing the audits' clinical orientation and contributing to capacity building.

The delivery of the audit is coordinated by an audit manager who is supported by NATCAN's wider infrastructure. Data scientists with experience in data management and statistics and methodologists with experience in performance assessment and QI work across audits.

Audit Clinical Reference Groups

Each audit has a Clinical Reference Group representing a wide range of stakeholders. This group will act as a consultative group to the Project Team on clinical issues related to setting audit priorities, study methodology, interpretation of audit results, reporting, QI, and implementation of recommendations.

Effective collaboration within the centre and across audits facilitates the sharing of expertise and skills in all aspects of the delivery process, notably: designing the audits, meeting information governance requirements, managing and analysing complex national cancer data to produce webbased indicator dashboards / state of the nation reports, and supporting quality improvement.

This organisation creates "critical mass" and audit capacity that is able to respond to the requirements of the funders (NHS England and Welsh Government) and the wider stakeholder "family".

Audit PPI Forums

Patients and patient charities are involved in all aspects of the delivery of the cancer audits. Each audit will also have a standalone Patient and Public Involvement (PPI) Forum to provide insight from a patient perspective on strategic aims and specific audit priorities. This will include shaping the development of each audit's quality improvement initiatives by ensuring this work is relevant from a patient perspective. A key activity of the PPI Forums will be to actively participate in the production of patient-focussed audit outputs (including patient and public information, patient summaries of reports, infographics and design and function of the NATCAN website), guiding on how to make this information accessible.

8.2 Key features of NATCAN's audit approach

The design and delivery of the audits in NATCAN has been informed by the CEU's experience delivering national audits, built up since its inception in 1998. Key features of all audit projects within the CEU include:

- Close clinical-methodological collaboration
- Use of national existing linked datasets as much as possible
- Close collaboration with data providers in England (National Disease Registration Service [NDRS], NHS Digital [NHSD]) and Wales (Wales Cancer Network [WCN], Public Health Wales [PHW])
- A clinical epidemiological approach, informing quality improvement activities.
- "Audit" informed by "research".

All these features will support NATCAN's focus on the three "Rs", ensuring that all its activities are clinically relevant, methodologically robust, and technically rigorous.

8.3 NNHLA project team membership

- David Cutter Clinical Lead (Oncology) representing the Royal College of Radiologists; MBBChir DPhil MRCP FRCR, Consultant Clinical Oncologist, Oxford University Hospitals and Associate Professor, University of Oxford
- 2. Cathy Burton Clinical Lead (Haematology) representing the British Society of Haematology; MBBChir MA MD FRCP FRCPath Consultant Haematologist, St James's University Hospital, Leeds.
- 3. Kate Walker Senior Methodologist, Royal College of Surgeons of England, London.
- 4. Ella Barber Data scientist, Royal College of Surgeons of England, London.
- 5. Vikki Hart Audit Manager, Royal College of Surgeons of England, London.

8.4 NNHLA clinical reference group membership (as of 29 September 2023)

- 1. NHS England
- 2. NHS Wales
- 3. UK Lymphoma Radiotherapy Group
- 4. National Cancer Registration & Analysis Service (NCRAS)
- 5. National Disease Registration Service (NDRS)
- 6. National Cancer Research Institute (NCRI) Lymphoma Group
- 7. Haematological Malignancy Research Network
- 8. British Society for Haematology
- 9. Oxford University Hospitals NHS Foundation Trust
- 10. Blood Cancer UK
- 11. Lymphoma Action
- 12. Healthcare Quality Improvement Partnership (HQIP)
- 13. British Society for Blood & Marrow Transplantation
- 14. Royal College of Radiologists

Specialities which are represented within the clinical reference group include: haematology, radiology, pathology, palliative care and primary care.

8.5 Data acquisition

The NATCAN Executive Team is working closely with data providers in England (National Disease Registry Service, NHSE) and in Wales (Wales Cancer Network, PHW) to establish efficient "common data channels" for timely and frequent access to datasets, combining data needs for all cancers into a

single request in each Nation and only using routinely collected data, thereby minimising the burden of data collection on provider teams.

Annual and quarterly data

NATCAN will utilise two types of routinely collected data in England. First, an annual "gold-standard" cancer registration dataset, released on an annual basis with a considerable delay between the last recorded episode and the data being available for analysis, and second, a "rapid" cancer registration dataset (RCRD), released at least quarterly with much shorter delays (3 months following diagnosis). The CEU's recent experience with English rapid cancer registration data, in response to the COVID pandemic has demonstrated the latter's huge potential, despite a slightly lower case ascertainment and less complete staging information.

NATCAN will utilise these data across all cancers linked to administrative hospital data (Hospital Episode Statistics/Systemic Anti-Cancer Therapy/Radiotherapy Data Set/Office National Statistics among other routinely collected datasets, see Figure 1) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

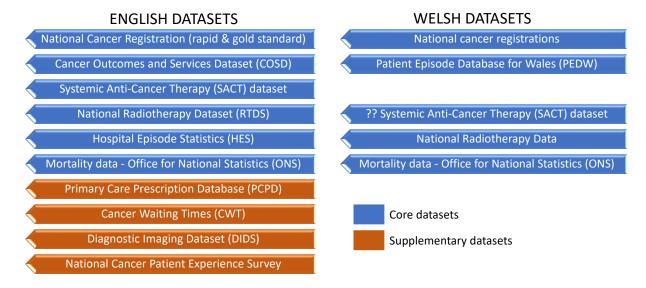


Figure 1: National datasets available to NATCAN.

An equivalent data request will be made to the Wales Cancer Network (WCN)/Public Health Wales (PHW).

Information governance

NATCAN will comply with legislation and good practice principles to ensure data security and patient confidentiality. The patient-level information received and managed by NATCAN is treated as confidential. When analysing data to produce information on patient care and outcomes, NATCAN audit teams use de-identified data and so individual patients are not identifiable.

HQIP and NHSE are joint data controller for the linked de-identified dataset that is supplied to NATCAN for analysis.

8.6 ICD-10 codes for defining non-Hodgkin lymphoma.

Table 2: ICD-10 codes for defining non-Hodgkin lymphoma¹⁵

| ICD-10 code | Cancer types / Description |
|-------------|---|
| C82 | Follicular lymphoma |
| C83 | Non-follicular lymphoma |
| C84 | Mature T/NK-cell lymphomas |
| C85 | Other and unspecified types of non-Hodgkin lymphoma |
| C86 | Other specified types of T/NK-cell lymphoma |
| C88 | Malignant immunoproliferative diseases |
| C91.1 | Chronic lymphocytic leukaemia of B-cell type |

C82 Follicular lymphoma

Incl.:

1. Follicular lymphoma with or without diffuse areas

Excl.:

1. Mature T/NK-cell lymphoma (C84.-)

Table 3: ICD-10 codes for Follicular lymphoma¹⁵

| ICD-10 | Description |
|--------|--|
| C82.0 | Follicular lymphoma grade I |
| C82.1 | Follicular lymphoma grade II |
| C82.2 | Follicular lymphoma grade III, unspecified |
| C82.3 | Follicular lymphoma grade IIIa |
| C82.4 | Follicular lymphoma grade IIIb |

| ICD-10 | Description |
|--------|--|
| C82.5 | Diffuse follicle centre lymphoma |
| C82.6 | Cutaneous follicle centre lymphoma |
| C82.7 | Other types of follicular lymphoma |
| C82.9 | Follicular lymphoma, unspecified Nodular lymphoma NOS |

C83 Non-follicular lymphoma

Table 4: ICD-10 codes for non-follicular lymphoma¹⁵

| ICD-10 | Description |
|--------|--|
| C83.0 | Small cell B-cell lymphoma: 1. Lymphoplasmacytic lymphoma 2. Nodal marginal zone lymphoma 3. Non-leukaemic variant of B-CLL 4. Splenic marginal zone lymphoma Excl.: 1. Chronic lymphocytic leukaemia (C91.1) 2. Waldenström macroglobulinaemia (C88.0) 3. Mature T/NK-cell lymphomas (C84) |
| C83.1 | Mantle cell lymphoma 1. Centrocytic lymphoma 2. Malignant lymphomatous polyposis |
| C83.3 | Diffuse large B-cell lymphoma 1. Anaplastic 2. CD30-positive 3. Centroblastic 4. Plasmablastic 5. Immunoblastic 6. Subtype not specified |

| ICD-10 | Description |
|--------|--|
| | 7. T-cell rich |
| | Excl.: |
| | Mediastinal (thymic) large B-cell lymphoma (C85.2) Mature T/NK-cell lymphomas (C84) |
| | Lymphoblastic (diffuse) lymphoma |
| C83.5 | B-cell precursor lymphoma Lymphoblastic B-cell lymphoma Lymphoblastic lymphoma NOS Lymphoblastic T-cell lymphoma T-cell precursor lymphoma |
| | Burkitt lymphoma |
| C83.7 | Atypical Burkitt lymphoma "Burkitt-like" lymphoma |
| | Excl.: |
| | 1. Mature B-cell leukaemia Burkitt-type (C91.8) |
| | Other non-follicular lymphoma |
| C83.8 | Primary effusion B-cell lymphoma Intravascular large B-cell lymphoma Lymphoid granulomatosis |
| | Excl.: |
| | Mediastinal (thymic) large B-cell lymphoma (C85.2) T-cell rich B-cell lymphoma (C83.3) |
| C83.9 | Non-follicular (diffuse) lymphoma, unspecified |

C84 Mature T/NK-cell lymphomas

Table 5: ICD-10 codes for mature T/NK-cell lymphomas¹⁵

| ICD-10 | Description |
|--------|-------------|
| | |

| C84.0 | Mycosis fungoides |
|-------|---|
| C84.1 | Sézary disease |
| C84.4 | Peripheral T-cell lymphoma, not elsewhere classified 1. Lennert's lymphoma 2. Lymphoepithelioid lymphoma |
| C84.5 | Other mature T/NK-cell lymphomas Note: If T-cell lineage or involvement is mentioned in conjunction with a specific lymphoma, code to the more specific description. Excl.: 1. Angioimmunoblastic T-cell lymphoma (C86.5) 2. Blastic NK-cell lymphoma (C86.4) 3. Enteropathy-type T-cell lymphoma (C86.2) 4. Extranodal NK-cell lymphoma, nasal type (C86.0) 5. Hepatosplenic T-cell lymphoma (C86.1) 6. Primary cutaneous CD30-positive T-cell proliferations (C86.6) 7. Subcutaneous panniculitis-like T-cell lymphoma (C86.3) 8. T-cell leukaemia (C91) |
| C84.6 | Anaplastic large cell lymphoma, ALK-positive 1. Anaplastic large cell lymphoma, CD30-positive |
| C84.7 | Anaplastic large cell lymphoma, ALK-negative Excl.: 1. Primary cutaneous CD30-positive T-cell proliferations (C86.6) |
| C84.8 | Cutaneous T-cell lymphoma, unspecified |
| C84.9 | Mature T/NK-cell lymphoma, unspecified 1. NK/T cell lymphoma NOS Excl.: 1. Mature T-cell lymphoma, not elsewhere classified (C84.4) |

C85 Other and unspecified types of non-Hodgkin lymphoma

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Table 6: ICD-10 codes for other and unspecified types of non-Hodgkin lymphoma¹⁵

| ICD-10 | Description |
|--------|---|
| C85.1 | B-cell lymphoma, unspecified Note: If B-cell lineage or involvement is mentioned in conjunction with a specific lymphoma, code to the more specific description. |
| C85.2 | Mediastinal (thymic) large B-cell lymphoma |
| C85.7 | Other specified types of non-Hodgkin lymphoma |
| C85.9 | Non-Hodgkin lymphoma, unspecified 1. Lymphoma NOS 2. Malignant lymphoma NOS 3. Non-Hodgkin lymphoma NOS |

C86 Other specified types of T/NK-cell lymphoma

Excl.:

- 1. Anaplastic large cell lymphoma, ALK negative (C84.7)
- 2. Anaplastic large cell lymphoma, ALK positive (C84.6)

Table 7: ICD-10 codes for other specified types of T/NK-cell lymphoma¹⁵

| ICD-10 | Description |
|--------|--|
| C86.0 | Extranodal NK/T-cell lymphoma, nasal type |
| C86.1 | Hepatosplenic T-cell lymphoma 1. Alpha-beta and gamma-delta types |
| C86.2 | Enteropathy-type (intestinal) T-cell lymphoma 1. Enteropathy associated T-cell lymphoma |
| C86.3 | Subcutaneous panniculitis-like T-cell lymphoma |

| ICD-10 | Description |
|--------|---|
| C86.4 | Blastic NK-cell lymphoma |
| C86.5 | Angioimmunoblastic T-cell lymphoma 1. Angioimmunoblastic lymphadenopathy with dysproteinaemia [AILD] |
| C86.6 | Primary cutaneous CD30-positive T-cell proliferations 1. Lymphomatoid papulosis 2. Primary cutaneous anaplastic large-cell lymphoma 3. Primary cutaneous CD30-positive large T-cell lymphoma |

C88 Malignant immunoproliferative diseases

Table 8: ICD-10 codes for malignant immunoproliferative diseases¹⁵

| ICD-10 | Description |
|--------|--|
| | Waldenström macroglobulinaemia |
| C88.0 | Lymphoplasmacytic lymphoma with lgM-production Macroglobulinaemia (primary)(idiopathic) |
| | Excl.: |
| | 1. Small cell B-cell lymphoma (C83.0) |
| C88.2 | Other heavy chain disease |
| | 1. Franklin disease |
| | 2. Gamma heavy chain disease |
| | 3. Mu (μ) heavy chain disease |
| C00.2 | Immunoproliferative small intestinal disease |
| C88.3 | Alpha heavy chain disease Mediterranean lymphoma |
| | Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid |
| C88.4 | tissue [MALT-lymphoma] |
| C00.4 | Note: Use additional code (C83.3) if desired, to specify transition to high malignant (diffuse large cell) lymphoma |

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| ICD-10 | Description |
|--------|---|
| | Lymphoma of skin-associated lymphoid tissue (SALT-lymphoma) Lymphoma of bronchial-associated lymphoid tissue (BALT-lymphoma) |
| C88.7 | Other malignant immunoproliferative diseases |
| C88.9 | Malignant immunoproliferative disease, unspecified |
| | 1. Immunoproliferative disease NOS |

C91.1 Chronic lymphocytic leukaemia of B-cell type

Note: C91 Lymphoid leukaemia

Table 9: ICD-10 code for chronic lymphocytic leukaemia of B-cell type¹⁵

| ICD-10 | Description |
|--------|---|
| C91.1 | Chronic lymphocytic leukaemia of B-cell type 1. Lymphoplasmacytic leukaemia 2. Richter syndrome Excl.: 1. lymphoplasmacytic lymphoma (C83.0) |

8.7 ICD-O3 codes for defining non-Hodgkin lymphoma.

Table 10: ICD-O3.2 codes for defining non-Hodgkin lymphoma.

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 959 | 3 | Malignant lymphomas, NOS or diffuse |
| 9590/3 | Preferred | Malignant lymphoma, NOS |
| 9590/3 | Synonym | Lymphoma, NOS |
| 9590/3 | Synonym | Microglioma |
| 9591/1 | Preferred | Monoclonal B-cell lymphocytosis, NOS |
| 9591/1 | Related | Monoclonal B-cell lymphocytosis, non-CLL type |
| 9591/3 | Preferred | Malignant lymphoma, non-Hodgkin, NOS |
| 9591/3 | Synonym | Non-Hodgkin lymphoma, NOS |
| 9591/3 | Related | B-cell lymphoma, NOS |
| 9591/3 | Related | Lymphosarcoma, NOS |
| 9591/3 | Synonym | Lymphosarcoma, diffuse |
| 9591/3 | Related | Malignant lymphoma, diffuse, NOS |
| 9591/3 | Related | Malignant lymphoma, non-cleaved cell, NOS |
| 9591/3 | Related | Reticulum cell sarcoma, NOS |
| 9591/3 | Synonym | Reticulosarcoma, NOS |
| 9591/3 | Synonym | Reticulum cell sarcoma, diffuse |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9591/3 | Synonym | Reticulosarcoma, diffuse |
| 9591/3 | Related | Hairy cell leukemia variant |
| 9591/3 | Related | Malignant lymphoma, lymphocytic, intermediate differentiation, nodular |
| 9591/3 | Related | Malignant lymphoma, lymphocytic, poorly differentiated, diffuse |
| 9591/3 | Synonym | Malignant lymphoma, cleaved cell, NOS |
| 9591/3 | Synonym | Malignant lymphoma, small cleaved cell, NOS |
| 9591/3 | Related | Malignant lymphoma, small cell, noncleaved, diffuse |
| 9591/3 | Synonym | Malignant lymphoma, undifferentiated cell type, NOS |
| 9591/3 | Synonym | Malignant lymphoma, undifferentiated cell, non-Burkitt |
| 9591/3 | Related | Malignant lymphoma, small cleaved cell, diffuse |
| 9591/3 | Related | Splenic B-cell lymphoma/leukemia, unclassifiable |
| 9591/3 | Related | Splenic diffuse red pulp small B-cell lymphoma |
| 9596/3 | Preferred | Composite Hodgkin and non-Hodgkin lymphoma |
| 9596/3 | Related | B-cell lymphoma, unclassifiable, with features intermediate between diffuse large B-cell lymphoma and classical Hodgkin lymphoma |
| 9597/3 | Preferred | Primary cutaneous follicle center lymphoma |
| 967-969 | 3 | Mature B-cell lymphomas |
| 9671/3 | Preferred | Lymphoplasmacytic lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9671/3 | Synonym | Malignant lymphoma, lymphoplasmacytoid |
| 9671/3 | Related | Immunocytoma |
| 9671/3 | Related | Malignant lymphoma, plasmacytoid |
| 9671/3 | Related | Plasmacytic lymphoma |
| 9673/1 | Preferred | In situ mantle cell neoplasia |
| 9673/1 | Synonym | In situ mantle cell lymphoma |
| 9673/3 | Preferred | Mantle cell lymphoma |
| 9673/3 | Synonym | Malignant lymphoma, centrocytic |
| 9673/3 | Synonym | Malignant lymphoma, lymphocytic, intermediate differentiation, diffuse |
| 9673/3 | Synonym | Malignant lymphomatous polyposis |
| 9673/3 | Synonym | Mantle zone lymphoma |
| 9675/3 | Preferred | Malignant lymphoma, mixed small and large cell, diffuse |
| 9675/3 | Synonym | Malignant lymphoma, centroblastic-centrocytic, NOS |
| 9675/3 | Synonym | Malignant lymphoma, centroblastic-centrocytic, diffuse |
| 9675/3 | Synonym | Malignant lymphoma, mixed cell type, diffuse |
| 9675/3 | Synonym | Malignant lymphoma, mixed lymphocytic-histiocytic, diffuse |
| 9678/3 | Preferred | Primary effusion lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9679/3 | Preferred | Mediastinal large B-cell lymphoma |
| 9679/3 | Synonym | Thymic large B-cell lymphoma |
| 9680/1 | Preferred | EBV positive mucocutaneous ulcer |
| 9680/3 | Preferred | Diffuse large B-cell lymphoma, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large B-cell, diffuse, NOS |
| 9680/3 | Synonym | Malignant lymphoma, histiocytic, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large B-cell, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large B-cell, diffuse, centroblastic, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large cell, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large cell, cleaved, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large cell, diffuse, NOS |
| 9680/3 | Synonym | Malignant lymphoma, large cell, noncleaved, NOS |
| 9680/3 | Synonym | Malignant lymphoma, noncleaved, NOS |
| 9680/3 | Synonym | Malignant lymphoma, noncleaved, diffuse, NOS |
| 9680/3 | Synonym | Malignant lymphoma, histiocytic, diffuse |
| 9680/3 | Synonym | Malignant lymphoma, large cell, cleaved and noncleaved |
| 9680/3 | Synonym | Malignant lymphoma, large cell, cleaved, diffuse |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9680/3 | Synonym | Malignant lymphoma, large cell, noncleaved, diffuse |
| 9680/3 | Related | Malignant lymphoma, centroblastic, NOS |
| 9680/3 | Related | Diffuse large B-cell lymphoma, germinal center B-cell subtype |
| 9680/3 | Related | Diffuse large B-cell lymphoma, activated B-cell subtype |
| 9680/3 | Related | Malignant lymphoma, centroblastic, diffuse |
| 9680/3 | Related | Anaplastic large B-cell lymphoma |
| 9680/3 | Related | B-cell lymphoma, unclassifiable, with features intermediate between diffuse large B-cell lymphoma and Burkitt lymphoma |
| 9680/3 | Related | Diffuse large B-cell lymphoma associated with chronic inflammation |
| 9680/3 | Related | EBV positive diffuse large B-cell lymphoma |
| 9680/3 | Related | Primary cutaneous diffuse large B-cell lymphoma, leg type |
| 9680/3 | Related | Primary diffuse large B-cell lymphoma of CNS |
| 9680/3 | Related | High grade B-cell lymphoma, NOS |
| 9680/3 | Related | High grade B-cell lymphoma with MYC and BCL2 and/or BCL6 rearrangements |
| 9680/3 | Related | Vitreoretinal lymphoma |
| 9684/3 | Preferred | Malignant lymphoma, large B-cell, diffuse, immunoblastic, NOS |
| 9684/3 | Synonym | Malignant lymphoma, immunoblastic, NOS |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9684/3 | Synonym | Immunoblastic sarcoma |
| 9684/3 | Synonym | Malignant lymphoma, large cell, immunoblastic |
| 9687/3 | Preferred | Burkitt lymphoma, NOS |
| 9687/3 | Synonym | Burkitt tumor |
| 9687/3 | Synonym | Malignant lymphoma, small noncleaved, Burkitt type |
| 9687/3 | Synonym | Malignant lymphoma, undifferentiated, Burkitt type |
| 9687/3 | Related | Burkitt-like lymphoma, NOS |
| 9687/3 | Related | Burkitt-like lymphoma with 11q aberration |
| 9687/3 | Synonym | Burkitt cell leukemia |
| 9687/3 | Synonym | Acute leukemia, Burkitt type |
| 9687/3 | Synonym | Acute lymphoblastic leukemia, mature B-cell type |
| 9687/3 | Synonym | B-ALL |
| 9687/3 | Synonym | FAB L3 |
| 9688/3 | Preferred | T-cell/histiocyte rich large B-cell lymphoma |
| 9688/3 | Synonym | T-cell rich large B-cell lymphoma |
| 9688/3 | Synonym | Histiocyte-rich large B-cell lymphoma |
| 9689/3 | Preferred | Splenic marginal zone B-cell lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9689/3 | Synonym | Splenic marginal zone lymphoma, NOS |
| 9689/3 | Synonym | Splenic lymphoma with villous lymphocytes |
| 9690/3 | Preferred | Follicular lymphoma, NOS |
| 9690/3 | Synonym | Malignant lymphoma, follicle center, NOS |
| 9690/3 | Synonym | Malignant lymphoma, follicular, NOS |
| 9690/3 | Synonym | Malignant lymphoma, lymphocytic, nodular, NOS |
| 9690/3 | Synonym | Malignant lymphoma, nodular, NOS |
| 9690/3 | Synonym | Malignant lymphoma, centroblastic-centrocytic, follicular |
| 9690/3 | Synonym | Malignant lymphoma, follicle center, follicular |
| 9690/3 | Related | Follicular lymphoma, pediatric type |
| 9691/3 | Preferred | Follicular lymphoma, grade 2 |
| 9691/3 | Synonym | Malignant lymphoma, mixed cell type, follicular |
| 9691/3 | Synonym | Malignant lymphoma, mixed cell type, nodular |
| 9691/3 | Synonym | Malignant lymphoma, mixed lymphocytic-histiocytic, nodular |
| 9691/3 | Synonym | Malignant lymphoma, mixed small cleaved and large cell, follicular |
| 9695/1 | Preferred | In situ follicular neoplasia |
| 9695/1 | Synonym | In situ follicular lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9695/3 | Preferred | Follicular lymphoma, grade 1 |
| 9695/3 | Synonym | Follicular lymphoma, small cleaved cell |
| 9695/3 | Synonym | Malignant lymphoma, lymphocytic, poorly differentiated, nodular |
| 9695/3 | Synonym | Malignant lymphoma, small cleaved cell, follicular |
| 9695/3 | Related | Follicular lymphoma, duodenal type |
| 9698/3 | Preferred | Follicular lymphoma, grade 3 |
| 9698/3 | Synonym | Malignant lymphoma, large cell, follicular, NOS |
| 9698/3 | Synonym | Malignant lymphoma, noncleaved cell, follicular, NOS |
| 9698/3 | Synonym | Follicular lymphoma, grade 3A |
| 9698/3 | Synonym | Follicular lymphoma, grade 3B |
| 9698/3 | Synonym | Malignant lymphoma, centroblastic, follicular |
| 9698/3 | Synonym | Malignant lymphoma, histiocytic, nodular |
| 9698/3 | Synonym | Malignant lymphoma, large cell, noncleaved, follicular |
| 9698/3 | Synonym | Malignant lymphoma, large cleaved cell, follicular |
| 9698/3 | Synonym | Malignant lymphoma, lymphocytic, well differentiated, nodular |
| 9698/3 | Related | Large B-cell lymphoma with IRF4 rearrangement |
| 9699/3 | Preferred | Marginal zone B-cell lymphoma, NOS |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9699/3 | Synonym | Marginal zone lymphoma, NOS |
| 9699/3 | Synonym | BALT lymphoma |
| 9699/3 | Synonym | Bronchus-associated lymphoid tissue lymphoma |
| 9699/3 | Synonym | MALT lymphoma |
| 9699/3 | Synonym | Monocytoid B-cell lymphoma |
| 9699/3 | Synonym | Mucosa-associated lymphoid tissue lymphoma |
| 9699/3 | Synonym | Nodal marginal zone lymphoma |
| 9699/3 | Synonym | SALT lymphoma |
| 9699/3 | Synonym | Skin-associated lymphoid tissue lymphoma |
| 9699/3 | Related | Extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue |
| 9699/3 | Related | Primary choroidal lymphoma |
| 970-971 | 3 | Mature T- and NK-cell lymphomas |
| 9700/3 | Preferred | Mycosis fungoides |
| 9700/3 | Synonym | Pagetoid reticulosis |
| 9700/3 | Related | Granulomatous slack skin |
| 9701/3 | Preferred | Sezary syndrome |
| 9701/3 | Synonym | Sezary disease |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9702/1 | Preferred | Indolent T-cell lymphoproliferative disorder of gastrointestinal tract |
| 9702/3 | Preferred | Mature T-cell lymphoma, NOS |
| 9702/3 | Synonym | Peripheral T-cell lymphoma, NOS |
| 9702/3 | Synonym | T-cell lymphoma, NOS |
| 9702/3 | Synonym | Peripheral T-cell lymphoma, large cell |
| 9702/3 | Synonym | Peripheral T-cell lymphoma, pleomorphic medium and large cell |
| 9702/3 | Synonym | Peripheral T-cell lymphoma, pleomorphic small cell |
| 9702/3 | Synonym | T-zone lymphoma |
| 9702/3 | Related | Lymphoepithelioid lymphoma |
| 9702/3 | Synonym | Lennert lymphoma |
| 9702/3 | Related | Follicular T-cell lymphoma |
| 9702/3 | Related | Nodal peripheral T-cell lymphoma with T follicular helper phenotype |
| 9705/3 | Preferred | Angioimmunoblastic T-cell lymphoma |
| 9705/3 | Synonym | Angioimmunoblastic lymphoma |
| 9705/3 | Synonym | Peripheral T-cell lymphoma, AILD (Angioimmunoblastic Lymphadenopathy with Dysproteinemia) |
| 9708/3 | Preferred | Subcutaneous panniculitis-like T-cell lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9709/1 | Preferred | Primary cutaneous CD4 positive small/medium T-cell lymphoproliferative disorder |
| 9709/1 | Related | Primary cutaneous CD4 positive small/medium T-cell lymphoma |
| 9709/3 | Preferred | Cutaneous T-cell lymphoma, NOS |
| 9709/3 | Synonym | Cutaneous lymphoma, NOS |
| 9709/3 | Related | Primary cutaneous CD8 positive aggressive epidermotropic cytotoxic T-cell lymphoma |
| 9709/3 | Related | Primary cutaneous acral CD8 positive T-cell lymphoma |
| 9712/3 | Preferred | Intravascular large B-cell lymphoma |
| 9712/3 | Synonym | Intravascular B-cell lymphoma |
| 9712/3 | Synonym | Angioendotheliomatosis |
| 9712/3 | Synonym | Angiotropic lymphoma |
| 9714/3 | Preferred | Anaplastic large cell lymphoma, T-cell and Null-cell type |
| 9714/3 | Synonym | Large cell (Ki-1 positive) lymphoma |
| 9714/3 | Related | Anaplastic large cell lymphoma, NOS |
| 9714/3 | Synonym | Anaplastic large cell lymphoma, CD30 positive |
| 9714/3 | Related | Anaplastic large cell lymphoma, ALK positive |
| 9715/3 | Preferred | Anaplastic large cell lymphoma, ALK negative |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9715/3 | Related | Breast implant-associated anaplastic large cell lymphoma |
| 9716/3 | Preferred | Hepatosplenic T-cell lymphoma |
| 9716/3 | Synonym | Hepatosplenic gamma-delta cell lymphoma |
| 9717/3 | Preferred | Intestinal T-cell lymphoma |
| 9717/3 | Synonym | Enteropathy-associated T-cell lymphoma |
| 9717/3 | Synonym | Enteropathy type intestinal T-cell lymphoma |
| 9717/3 | Related | Monomorphic epitheliotropic intestinal T-cell lymphoma |
| 9718/1 | Preferred | Primary cutaneous CD30 positive T-cell lymphoproliferative disorder |
| 9718/1 | Synonym | Lymphomatoid papulosis |
| 9718/3 | Preferred | Primary cutaneous anaplastic large cell lymphoma |
| 9718/3 | Synonym | Primary cutaneous CD30 positive large T-cell lymphoma |
| 9719/3 | Preferred | NK/T-cell lymphoma, nasal and nasal type |
| 9719/3 | Synonym | Malignant reticulosis, NOS |
| 9719/3 | Synonym | Angiocentric T-cell lymphoma |
| 9719/3 | Synonym | Extranodal NK/T-cell lymphoma, nasal type |
| 9719/3 | Synonym | Malignant midline reticulosis |
| 9719/3 | Synonym | Polymorphic reticulosis |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9719/3 | Synonym | T/NK-cell lymphoma |
| 972 | 3 | Precursor cell lymphoblastic lymphomas |
| 9724/3 | Preferred | Systemic EBV positive T-cell lymphoproliferative disease of childhood |
| 9725/1 | Preferred | Hydroa vacciniforme-like lymphoproliferative disorder |
| 9725/1 | Synonym | Hydroa vacciniforme-like lymphoma |
| 9726/3 | Preferred | Primary cutaneous gamma-delta T-cell lymphoma |
| 9727/3 | Preferred | Precursor cell lymphoblastic lymphoma, NOS |
| 9727/3 | Synonym | Malignant lymphoma, lymphoblastic, NOS |
| 9727/3 | Synonym | Lymphoblastoma |
| 9727/3 | Synonym | Malignant lymphoma, convoluted cell |
| 9727/3 | Related | Blastic NK-cell lymphoma |
| 9727/3 | Related | Blastic plasmacytoid dendritic cell neoplasm |
| 976 | 2 | Immunoproliferative diseases |
| 9760/3 | Preferred | Immunoproliferative disease, NOS |
| 9761/1 | Preferred | IgM monoclonal gammopathy of undetermined significance |
| 9761/3 | Preferred | Waldenstrom macroglobulinemia |
| 9762/3 | Preferred | Heavy chain disease, NOS |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9762/3 | Related | Alpha heavy chain disease |
| 9762/3 | Related | Gamma heavy chain disease |
| 9762/3 | Synonym | Franklin disease |
| 9762/3 | Related | Mu heavy chain disease |
| 9764/3 | Preferred | Immunoproliferative small intestinal disease |
| 9764/3 | Synonym | Mediterranean lymphoma |
| 9765/1 | Preferred | Monoclonal gammopathy of undetermined significance, NOS |
| 9765/1 | Synonym | MGUS |
| 9765/1 | Synonym | Monoclonal gammopathy, NOS |
| 9766/1 | Preferred | Angiocentric immunoproliferative lesion |
| 9766/1 | Related | Lymphomatoid granulomatosis, NOS |
| 9766/1 | Related | Lymphomatoid granulomatosis, grade 1 |
| 9766/1 | Related | Lymphomatoid granulomatosis, grade 2 |
| 9766/3 | Preferred | Lymphomatoid granulomatosis, grade 3 |
| 9767/1 | Preferred | Angioimmunoblastic lymphadenopathy (AIL) |
| 9767/1 | Synonym | Immunoblastic lymphadenopathy (IBL) |
| 9768/1 | Preferred | T-gamma lymphoproliferative disease |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9769/1 | Preferred | Immunoglobulin deposition disease |
| 9769/1 | Synonym | Primary amyloidosis |
| 9769/1 | Synonym | Systemic light chain disease |
| 981-983 | 3 | Lymphoid leukemias |
| 9811/3 | Preferred | B lymphoblastic leukemia/lymphoma, NOS |
| 9811/3 | Synonym | c-ALL |
| 9811/3 | Synonym | Common ALL |
| 9811/3 | Synonym | Common precursor B ALL |
| 9811/3 | Synonym | Pre-B ALL |
| 9811/3 | Synonym | Pre-pre-B ALL |
| 9811/3 | Synonym | Pro-B ALL |
| 9811/3 | Synonym | Precursor B-cell lymphoblastic lymphoma |
| 9811/3 | Synonym | Precursor B-cell lymphoblastic leukemia |
| 9811/3 | Related | B lymphoblastic leukemia/lymphoma with iAMP21 |
| 9812/3 | Preferred | B lymphoblastic leukemia/lymphoma with t(9;22)(q34;q11.2); BCR-ABL1 |
| 9813/3 | Preferred | B lymphoblastic leukemia/lymphoma with t(v;11q23); MLL rearranged |
| 9814/3 | Preferred | B lymphoblastic leukemia/lymphoma with t(12;21)(p13;q22); TEL-AML1 (ETV6-RUNX1) |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9815/3 | Preferred | B lymphoblastic leukemia/lymphoma with hyperdiploidy |
| 9816/3 | Preferred | B lymphoblastic leukemia/lymphoma with hypodiploidy (Hypodiploid ALL) |
| 9817/3 | Preferred | B lymphoblastic leukemia/lymphoma with t(5;14)(q31;q32); IL3-IGH |
| 9818/3 | Preferred | B lymphoblastic leukemia/lymphoma with t(1;19)(q23;p13.3); E2A-PBX1 (TCF3-PBX1) |
| 9819/3 | Preferred | B lymphoblastic leukemia/lymphoma, BCR-ABL1-like |
| 9820/3 | Preferred | Lymphoid leukemia, NOS |
| 9820/3 | Related | Lymphatic leukemia, NOS |
| 9820/3 | Related | Lymphocytic leukemia, NOS |
| 9820/3 | Related | Aleukemic lymphoid leukemia |
| 9820/3 | Synonym | Aleukemic lymphatic leukemia |
| 9820/3 | Synonym | Aleukemic lymphocytic leukemia |
| 9820/3 | Related | Lymphosarcoma cell leukemia |
| 9820/3 | Related | Subacute lymphoid leukemia |
| 9820/3 | Synonym | Subacute lymphatic leukemia |
| 9820/3 | Synonym | Subacute lymphocytic leukemia |
| 9823/1 | Preferred | Monoclonal B-cell lymphocytosis, CLL type |
| 9823/3 | Preferred | B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma |

| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9823/3 | Synonym | Chronic lymphatic leukemia |
| 9823/3 | Synonym | Chronic lymphocytic leukemia |
| 9823/3 | Synonym | Chronic lymphocytic leukemia, B-cell type |
| 9823/3 | Synonym | Chronic lymphoid leukemia |
| 9823/3 | Synonym | Malignant lymphoma, small B lymphocytic, NOS |
| 9823/3 | Synonym | Malignant lymphoma, lymphocytic, NOS |
| 9823/3 | Synonym | Malignant lymphoma, lymphocytic, diffuse, NOS |
| 9823/3 | Synonym | Malignant lymphoma, small cell, NOS |
| 9823/3 | Synonym | Malignant lymphoma, small lymphocytic, NOS |
| 9823/3 | Synonym | Malignant lymphoma, lymphocytic, well differentiated, diffuse |
| 9823/3 | Synonym | Malignant lymphoma, small cell diffuse |
| 9823/3 | Synonym | Malignant lymphoma, small lymphocytic, diffuse |
| 9827/3 | Preferred | Adult T-cell leukemia/lymphoma (HTLV-1 positive) |
| 9827/3 | Synonym | Adult T-cell leukemia |
| 9827/3 | Synonym | Adult T-cell lymphoma |
| 9827/3 | Synonym | Adult T-cell lymphoma/leukemia |
| 9831/3 | Preferred | T-cell large granular lymphocytic leukemia |

| ICD-03.2 | Level | Term |
|----------|-----------|--|
| 9831/3 | Synonym | Large granular lymphocytosis, NOS |
| 9831/3 | Synonym | NK-cell large granular lymphocytic leukemia |
| 9831/3 | Synonym | T-cell large granular lymphocytosis |
| 9831/3 | Related | Chronic lymphoproliferative disorder of NK cells |
| 9832/3 | Preferred | Prolymphocytic leukemia, NOS |
| 9833/3 | Preferred | Prolymphocytic leukemia, B-cell type |
| 9834/3 | Preferred | Prolymphocytic leukemia, T-cell type |
| 9835/3 | Preferred | Precursor cell lymphoblastic leukemia, NOS |
| 9835/3 | Synonym | Acute lymphoblastic leukemia, NOS |
| 9835/3 | Synonym | Acute lymphoblastic leukemia, L2 type, NOS |
| 9835/3 | Synonym | Acute lymphoblastic leukemia-lymphoma, NOS |
| 9835/3 | Synonym | Lymphoblastic leukemia, NOS |
| 9835/3 | Synonym | Acute lymphatic leukemia |
| 9835/3 | Synonym | Acute lymphocytic leukemia |
| 9835/3 | Synonym | Acute lymphoid leukemia |
| 9835/3 | Synonym | FAB L1 |
| 9835/3 | Synonym | FAB L2 |

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| ICD-03.2 | Level | Term |
|----------|-----------|---|
| 9835/3 | Synonym | Precursor cell lymphoblastic leukemia, not phenotyped |
| 9835/3 | Synonym | Acute lymphoblastic leukemia, precursor-cell type |
| 9837/3 | Preferred | Precursor T-cell lymphoblastic leukemia |
| 9837/3 | Synonym | Cortical T ALL |
| 9837/3 | Synonym | Mature T ALL |
| 9837/3 | Synonym | Pre-T ALL |
| 9837/3 | Synonym | Pro-T ALL |
| 9837/3 | Synonym | Precursor T-cell lymphoblastic lymphoma |
| 9837/3 | Related | T lymphoblastic leukemia/lymphoma |
| 9837/3 | Related | Early T-cell precursor acute lymphoblastic leukemia |

8.8 NICE quality standards for haematological cancers

Quality statements:

- 1. People with haematological cancer have an integrated report produced by a specialist integrated haematological malignancy diagnostic service (SIHMDS) that is shared with the haemato-oncology multidisciplinary team (MDT).⁸
- 2. Young people and adults with specific subtypes of non-Hodgkin lymphoma have staging using fluorodeoxyglucose-positron emission tomography-CT (FDG-PET-CT).⁸
- 3. Young people and adults with localised stage IIA follicular lymphoma have local radiotherapy as first-line treatment.⁸
- 4. Young people and adults who have completed their treatment for non-Hodgkin lymphoma have a discussion about their end-of-treatment summary plan.⁸

This quality standard is expected to contribute to improvements in the following outcomes:

- 1. Overall survival of haematological cancers.8
- 2. Treatment-related morbidity of haematological cancers.8
- 3. Quality of life of people with haematological cancers.8
- 4. Patient management of haematological cancers.8