NNHLA
National Non-Hodgkin Lymphoma Audit

NATCAN
National Cancer Audit Collaborating Centre

National Non-Hodgkin Lymphoma Audit

Quality Improvement Plan – September 2024

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HQIP
Healthcare Quality Improvement Partnership

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 and the Royal College of Nursing. 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. https://www.hqip.org.uk/national-programmes

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Executive Summary

The National Non-Hodgkin Lymphoma Cancer Audit (NNHLA) has been commissioned to evaluate Non-Hodgkin Lymphoma (NHL) care delivered in NHS hospitals across England and Wales. It aims to help NHS organisations to benchmark their NHL care against measurable standards, to identify unwarranted variation in care, and to provide tools to help services improve quality of care for people with NHL.

The NNHLA Quality Improvement Plan sets out the scope, care pathway, five quality improvement goals and eleven performance indicators for the NNHLA.

The NNHLA team carried out an extensive review of both peer-reviewed and grey literature which highlighted the most important areas of focus for quality improvement. The performance indicators which were identified, were selected in close consultation with the audit's Clinical Reference Group (CRG).

The following quality improvement goals have been identified for the NNHLA:

1. Improving timely diagnosis and treatment

2. Treatment appropriate to the subtype of NHL

3. Improving safety and reducing toxicity of NHL therapy

4. Improving overall survival

5. Reducing variation in NHL management among NHS providers.

The NNHLA has identified eleven performance indicators, which are mapped to these five quality improvement goals and clinical guidelines. It sets out improvement methods, improvement activities and approaches to evaluation of the Quality Improvement Plan.

1. Introduction

1.1 Aim and objectives of the Quality Improvement Plan

The National Non-Hodgkin Lymphoma Audit's (NNHLA) Quality Improvement Plan builds on the previous Scoping Document, which set out the scope and care pathway of the NNHLA and identified five key quality improvement goals.

The Quality Improvement Plan defines eleven performance indicators, and how they map to the NNHLA quality improvement goals, national guidelines and standards. These performance indicators will be used by the NNHLA to monitor progress towards its quality improvement goals and to stimulate improvements in Non-Hodgkin Lymphoma (NHL) care.

The Quality Improvement Plan describes the approach taken to develop the NNHLA's quality improvement goals and performance indicators. In addition, it aims to set out the improvement methods and activities that will support implementation of the plan, including strategies for reporting and disseminating results, in addition to describing the approaches to evaluation.

The NNHLA's Quality Improvement Plan was developed in consultation with key stakeholders, including people with lived experience of NHL and will be reviewed on an annual basis.

1.2 The National Cancer Audit Collaborating Centre

The 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 1st October 2022 to deliver six new national cancer audits, including kidney, ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. The centre is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government.

The aim of the ten NATCAN 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.

Further information about NATCAN and key features of its approach to audit can be found in Appendix 1.

2. Background on Non-Hodgkin Lymphoma

2.1 Main issues in Non-Hodgkin Lymphoma care and outcomes

NHL is the sixth most common cancer in the UK accounting for 4% of all new cancer cases between 2016 and 2018[1]. On average, 14,200 people were diagnosed with 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 people with NHL.

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; people 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 people who achieve remission remain cured[2]. Prognosis for people with NHL 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 impact quality of life[2].

As well as being a heterogeneous disease, NHL care is changing rapidly, with new treatments being developed,

[1] Cancer Research UK. Non-Hodgkin lymphoma statistics: incidence. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statatics-by-cancertype/non-hodgkin-lymphoma#heading-Zero.
[2] National Institute for Health and Care Excellence. NICE guideline NG52 Non-Hodgkin's lymphoma: diagnosis and management (2016). https://www.nice.org.uk/guidance/ng52
[3] Cancer Research UK. Non-Hodgkin lymphoma statistics: survival. https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancertype/non-hodgkin-lymphoma#heading-Two.

advances in biomarker and genomic testing, and new technologies on the horizon.

2.2 Care pathways

The management of NHL involves a variable sequence of treatments depending on the characteristics of the individual, and care is provided through a mix of centralised and decentralised services.

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

Within the 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 people with relapsed/refractory DLBCL[4]. CAR-T therapy is also commissioned as third line therapy by NHS England for other people with relapsed DLBCL and some other forms of NHL[5].
- "Watch and wait" or "active monitoring" approaches may be recommended for low grade NHL (e.g., follicular lymphoma).

2.3 Service provision

Treatment decision making, imaging, chemotherapy, and radiotherapy are all decentralised services, whereas genomic testing, stem cell therapy and CAR-T therapy are all centralised to specialist centres/laboratories.

2.4 Guidelines on the management of Non-Hodgkin Lymphoma

There are several UK-specific guidelines relevant to NHL, which were reviewed as part of the development of the audit's Scoping Document and which have been considered in developing the audit's performance indicators. These include:

- NICE guideline NG52 Non-Hodgkin's lymphoma: diagnosis and management
- NICE quality standard for haematological cancer (QS150)
- British Society of Haematology (BSH) guideline for the management of newly diagnosed large B-cell lymphoma
- BSH guideline on the investigation and management of follicular lymphoma

3. Approach to developing the Quality Improvement Plan

This NNHLA's Quality Improvement Plan builds on the NNHLA Scoping Document which set out the inclusion criteria and care pathway (Section 4) as well as five quality improvement goals for the NNHLA (Section 5). This Quality Improvement Plan outlines eleven performance indicators that have been mapped to clinical guidelines and the five quality improvement goals (Section 5).

In Sections 6 and 7, the quality improvement framework and improvement activities are outlined. Finally, Section 8 sets out the approaches to evaluation of the Quality Improvement Plan. Given that this is the first national audit of NHL in England and Wales, the Quality Improvement Plan is expected to evolve over subsequent years.

3.1 Approach to developing the audit scope

The NNHLA carried out an extensive review of existing literature and guidelines in order to develop the proposed NNHLA scope and quality 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 Clinical Reference Group (CRG) meeting, the NNHLA project team consulted with stakeholders on the proposed NNHLA scope and quality improvement goals. Following stakeholder consultation, all comments and responses were used to refine the final scope and quality improvement goals.

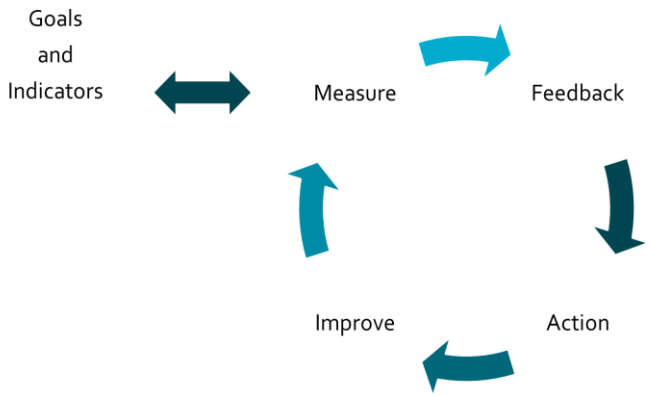
[4] National Institute for Health and Care Excellence. Axicabtagene ciloleucel for treating relapsed or refractory diffuse large B-cell lymphoma after first-line chemoimmunotherapy: NICE final appraisal document. 2023. https://www.nice.org.uk/guidance/ta895

[5] National Institute for Health and Care Excellence. Axicabtagene ciloleucel for treating diffuse large B-cell lymphoma and primary mediastinal large B-cell lymphoma after 2 or more systemic therapies. https://www.nice.org.uk/guidance/ta872

3.2 Approach to developing the quality improvement goals and indicators

Clinical Performance Feedback Intervention Theory (CP-FIT)[6] states that developing improvement goals and performance indicators are the first steps in the audit and feedback cycle (Figure 1).

Figure 1: The audit and feedback cycle



Using the five quality improvement goals outlined in its Scoping Document, the NNHLA developed a list of 148 candidate indicators for the performance of NHS providers. These were drawn from an extensive review of existing literature and guidelines. Prioritisation of eleven indicators from this list of candidates was informed by the following set of key principles.

The audit and feedback cycle is only as strong as its weakest link: to enhance the NNHLA's ability to inform improvements in care, its performance indicators must have three properties:

- **Measurable** so that they can be the basis of credible feedback about performance. This property means that the indicators can be defined with available data in a valid, reliable, and fair manner that allows performance to be attributed to a specific unit.[7]
- **Actionable** so that feedback translates into action to improve care. Indicators should therefore be important and address a specific pathway of care that is clear to all stakeholders. Stakeholders should understand the drivers of variation in performance within this pathway and control the levers for change (see example Driver Diagram in Appendix 5). These changes should be evidence-based and address policy priorities.
- **Improvable** so that actions have the desired effect on patient care. There should therefore be clear scope for improvement (low baseline levels or large unwarranted variation) in a large population and a receptive context, with no unintended consequences. Some interventions may have demonstrated improvements to certain indicators in existing literature.

Some of these properties are difficult to know in advance of selecting and investigating a performance indicator (such as existing levels of performance, the drivers of low performance, or interventions that can improve care). In addition, clinical practice and its context may change over time so that properties of indicators also change (such as whether they relate to a policy priority). Therefore, the NNHLA's goals and performance indicators are likely to evolve over time too. Recommendations will also evolve and become more focused as the NNHLA learns through the audit and feedback cycle.

3.3 Data provision

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. Further details on data acquisition can be found in Appendix 2.

3.4 Data limitations

For accurate and timely benchmarking, it is essential that data used by the NNHLA.

1. Includes all 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.

For people treated in England, Rapid Cancer Registration Data (RCRD) linked to other national healthcare datasets, will be used for quarterly reporting. This dataset is mainly compiled from Cancer Outcomes and Services Dataset (COSD) records and is made available more quickly than the gold standard National Cancer Registration Data (NCRD). 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. For people treated in Wales, no equivalent of RCRD is currently available.

3.5 Stakeholder involvement

NNHLA is provided through a partnership that combines clinical leadership, methodological expertise, project management and a secure environment for data analysis, representing the following organisations: Royal College of

[6] Brown B, Gude WT, Blakeman T, van der Veer SN, Ivers N, Francis JJ, et al. Clinical Performance Feedback Intervention Theory (CP-FIT): a new theory for designing, implementing, and evaluating feedback in health care based on a systematic review and meta-synthesis of qualitative research. Implement Sci 2019;14:40.

[7] Geary RS, Knight HE, Carroll FE, Gurol-Urganci I, Morris E, Cromwell DA, van der Meulen JH. A step-wise approach to developing indicators to compare the performance of maternity units using hospital administrative data. BJOG 2018;125:857-65.

Radiologists (RCR), British Society of Haematology (BSH), and NATCAN.

The audit team is supported by twice-yearly meetings of stakeholders in its Clinical Reference Group (CRG), which includes clinicians from across the patient pathway, patient representatives, commissioners, funders, and representatives from Blood Cancer UK and Lymphoma Action. NNHLA has also established a Patient and Public Involvement (PPI) Forum that meets twice a year, whose members represent people with lived experience of NHL and representatives from Lymphoma Action and Blood Cancer UK.

4. Audit scope

4.1. Patient inclusion criteria

The NNHLA includes all people aged 18 years and over who meet the following inclusion criteria:

- Have a diagnosis of NHL, as documented by the International Classification of Diseases codes (ICD-10: C82-C86, C88 or C91.1 or ICD-03 included subtypes in Appendix 3). Note that diagnoses based on death certificate only are excluded.
- Have received care provided by the National Health Service in England or Wales.

The ICD-10 diagnostic codes for NHL were identified through the review of existing literature and align with those reported by NICE guidance[2], Public Health Scotland[8], and the Office for National Statistics[9]. ICD-O3 codes were identified using guidance from the Haematological Malignancy Research Network (HMRN)[10] and are used to increase the granularity of NHL subtypes reported by the NNHLA.

It is 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). People diagnosed with SLL are often treated in a similar way to low grade NHL and by the same clinicians, therefore we include people with SLL in the scope of the NNHLA.

4.2. Care pathway

The NNHLA will cover the patient pathway from diagnostic and therapeutic services offered in secondary and tertiary care providers to short- and longer-term outcomes.

[8] Public Health Scotland. Cancer incidence and prevalence in Scotland to December 2018. https://www.publichealthscotland.scot/publications/cancer-incidence-in-scotland/cancerincidence-in-scotland-cancer-incidence-and-prevalence-in-scotland-to-december-2018/ (2018).

9 Office for National Statistics. Cancer survival in England: Patients diagnosed between 2010 and 2014 and followed up to 2015. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancersurvivalinenglandadultsdiagnosed/2010and2014andfollowedupto20 15 (2016).

[10] https://hmrn.org/resources/icdo3

5. Quality Improvement Goals & Performance indicators

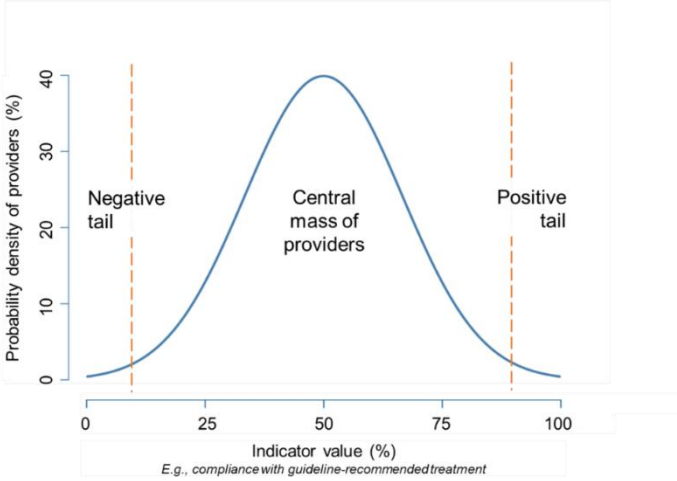
Quality improvement goal	Performance indicators*	National Guidance/standards
Improving timely diagnosis and treatment	1. Proportion of people diagnosed with NHL discussed at a lymphoma/haematology MDT within 4 weeks of diagnosis.	BSH guidelines for DLBCL and Follicular Lymphoma and NICE guideline for improving the outcomes of haematological cancers (NG47): recommendation 1.3.4
	2. Proportion of people with high-grade lymphoma (Burkitt Lymphoma (BL), DLBCL or high grade T-cell lymphoma) who start chemotherapy within 62 days of referral	https://www.england.nhs.uk/long-read/changes-to-cancer-waiting-times-standards-from-1-october-2023/
	3. Proportion of people with high-grade lymphoma (BL, DLBCL or high grade T-cell) who start radiotherapy within 8 weeks of end of first line chemotherapy.	https://www.england.nhs.uk/long-read/changes-to-cancer-waiting-times-standards-from-1-october-2023/
Reducing variation in NHL management among NHS providers	4. Proportion of people diagnosed with NHL seen by a clinical nurse specialist	NICE guideline for improving the outcomes of haematological cancers (NG47): recommendation 1.3.15
	5. Proportion of people with NHL receiving radiotherapy, reported by sub-type.	Aligns with the NICE quality standard for haematological cancer (QS150). NICE guideline for the diagnosis and management of NHL (NG52): recommendations 1.3.1, 1.6.1, 1.7.1, and 1.8.1
Treatment appropriate to the subtype of NHL	6. Proportion of people with BL or DLBCL undergoing treatment who have MYC testing.	NICE guideline for the diagnosis and management of NHL (NG52): recommendations 1.1.5 and 1.1.6
	7. First-line chemotherapy treatment regimens received by people with high-grade lymphoma (BL, DLBCL or high grade T-cell lymphoma).	NICE guideline for the diagnosis and management of NHL (NG52): recommendations 1.6, 1.7 and 1.8
	8. Time to treatment for relapse amongst follicular lymphoma, other B-cell lymphomas (incl. chronic lymphocytic leukaemia (CLL), marginal zone lymphoma) and T-cell lymphomas which are not high grade.	N/A
Improving safety and reducing toxicity of NHL therapy	9. Proportion of people diagnosed with NHL with severe acute toxicity after SACT, reported by sub-type.	NICE guideline for the diagnosis and management of NHL (NG52): Recommendations 1.9.1, 1.11.1 and 1.11.2)
Improving overall survival	10. Proportion of people diagnosed with NHL who are consented for a clinical trial/research study, reported by sub-type	BSH guidelines for Follicular Lymphoma and DLBCL
	11. Overall 2-year survival of people with high grade lymphoma (BL, DLBCL or high grade T-cell).	N/A

* Not all 11 indicators can be reported initially. More indicators will be reported when data availability allows and after completion of robust, methodological development work including appropriate risk-adjustment models.

6. Quality Improvement Framework

The figure below shows a hypothetical example of how a performance indicator may be distributed across NHS providers nationally at a single time point. This distribution can be separated into three domains: the negative tail (suggestive of worse performance), the central mass (centred on the national average, for example), and the positive tail (suggestive of better performance).

Figure 2: Hypothetical distribution of performance indictor across NHS providers



Each domain is associated with a different set of methods for improving healthcare:

Negative tail

Example methods: Regulation and public reporting of outliers

- Clinical audit has traditionally focused on the negative tail to improve healthcare. This approach implies that some NHS providers are doing something systematically wrong that can be resolved through direct intervention. Such intervention may be necessary to assure minimum standards of care and to reduce inequality between the best and worst performing NHS providers. Cancer Audits that pre-date NATCAN have formally reported negative outliers (see Appendix 4).

Central mass

Example methods: Statistical process control and iterative testing of interventions

Most providers exist in the central mass of the distribution (by definition) which may present the greatest scope for improving average levels of care nationally. Methods in this domain suggest that all providers can improve their performance, regardless of baseline levels. Longitudinal monitoring provides feedback about whether improvements occur or not.

Positive tail

Example methods: Positive deviance

- Some NHS providers perform exceptionally well despite similar constraints to others, which presents opportunities to learn how this is achieved. 'Positive deviance' approaches assert that generalisable solutions to better performance already exist within the system. Such solutions are therefore more likely to be acceptable and sustainable within existing resources. These approaches aim to identify local innovations and spread them to other settings (see Appendix 4).
- The NNHLA will select which methods to implement to improve NHL care after investigating the distributions of its performance indicators (outlined in section 5). This includes the distribution of performance indicators between providers at a given time point and within providers over time. It also includes investigation of variation at the patient, hospital, and regional levels to see where most variation exists and which variables help to explain it (see Appendix 4 for more detail).

7. Improvement activities

Improvement activities and outputs of the NNHLA will be aligned to the Quality Improvement Plan. The NNHLA will:

(1) engage in key collaborations, (2) align with other initiatives in NHL cancer care, and (3) provide outputs to support quality improvement at the national, regional and local level.

The two principal strategies for reporting NNHLA results include:

- A short 'State of the Nation' (SotN) report for NHS Trusts/Health Boards within England and Wales. This annual report publishes five key recommendations highlighting where services should focus quality improvement activities. These recommendations will be at the Cancer Alliance level where applicable and be formed between audit teams, clinical reference groups and major national stakeholders.

- A quarterly dashboard will facilitate benchmarking and the monitoring of performance at regular intervals so improvements can be tracked over time.

7.1 National and Regional

The NNHLA undertakes various activities that directly support national stakeholders and regional NHS organisations to tackle system-wide aspects related to the delivery of high-quality NHL cancer services:

Stakeholder	NNHLA activity
NATIONAL	
NHS England and Wales	Identify issues and make recommendations on the organisation and delivery of NHL services, which might involve national leadership. Recommendations published in audit's State of the Nation reports.
Professional organisations	Identify issues and make recommendations regarding the delivery of NHL care that fall within the remit of the professional organisations.
REGIONAL	
Cancer Networks / Alliances / Vanguards	Support the monitoring role of Welsh Cancer Networks and the English Cancer Alliances / Integrated Care Boards by publishing results for their region/area.

At a national level, the NNHLA team will also provide the National Cancer Registration and Analysis Service (NCRAS) Data Improvement Leads (in England), and the Wales Cancer Network with information to help them support their NHS organisations to improve the quality of their routine data submissions.

7.2 Local

The NNHLA supports local NHS cancer services in their care of people diagnosed with NHL in the following ways:

NNHLA feedback activity	**Description**
Annual "State of the Nation" Reports	State of the Nation reports that allow NHS organisations in England and Wales to benchmark themselves against clinical guideline recommendations and the performance of their peers.
Web-based dashboard	Presents results for individual NHS organisations that allows the user to compare the results of a selected provider against a peer organisation.
Local Action Plan template	Allows NHS organisations to document how they will respond to the State of the Nation Report recommendations.
Outlier reporting	In the future, the NNHLA will report NHS provider values that are more than three standard deviations from the expected level of performance (i.e. deemed a potential outlier). The NNHLA will support outliers to identify areas for improvement.
Improvement Case Studies	Examples of different approaches used by NHS trusts to improve care quality or recommendations identified from review of processes at positive or negative outliers, with a specific focus on the pathway of care (see actionable earlier)
Interventions	This will include possible interventions that have been identified in the literature linked to the performance indicators assessed by the audit or include interventions developed by Trusts/Health Boards/Alliances in the NHS.
Materials supplementary to the State of the Nation Report	Including tools for improving data completeness.

7.3 Improvement tools

The NATCAN website includes a Quality Improvement Resources page with links to the RCSEng website and other web-based material that direct healthcare providers to various quality improvement tools including:

- 'How to' guides including quality improvement methodology
- Links to existing resources
- Links to training courses for quality improvement
- Good practice repository with contact information where possible.

7.4 Improvement workshops

The NNHLA will organise quality improvement workshops, where possible aligning with annual meetings of the professional organisations.

7.5 Designing a National Quality Improvement Initiative

Using rapid cancer registry data, the NNHLA will design a national Quality Improvement initiative aiming "to close the

audit cycle" following an approach, commonly referred to as the "plan-do-study-act" method.[11]

This will involve the identification of priority areas for quality improvement and working with stakeholders to develop appropriate design and methodology to underpin the initiative.

Further details about the initiative design and consultation process will be published in a future audit output.

7.6 Patient and Public Involvement

Patient representatives will be regularly consulted on the design of the audit and the communication of its results, via the NNHLA Patient and Public Involvement (PPI) Forum. The chair of the PPI Forum also acts as a patient representative on the Clinical Reference Group to advise on audit priorities and participate in the development and review of key audit outputs. The PPI forum will:

- Undertake a key advisory role in developing the design and function of the audit web pages to ensure that patients and the public can easily access the information they are seeking,
- Contribute to the design and content of patient information materials and NNHLA reports for the public,
- Provide input into the development of the audit's quality improvement goals, activities and outputs to ensure they reflect priorities from the patient perspective, and
- Help to disseminate and publicise NNHLA and its outputs via their networks.

7.7 Communication & dissemination activities

The NNHLA communicates regularly with stakeholders, providers, patients and the public in several ways, including:

- Regular posts and interactions with the NHL community on social media platforms
- Quarterly distribution of newsletters
- Contribution of items for newsletters created by patient associations
- Presentations at national conferences such as the BSH Annual Scientific Meeting or the Lymphoma Action National Conference
- Publication of articles in medical journals and other media

8. Evaluation

The NNHLA will report year-on-year progress against improvement goals to the audit's Clinical Reference Group and in the SotN reports on an annual basis. This will focus on describing how values of performance indicators have changed over time at a national level.

To evaluate the impact of specific NNHLA or other national interventions on the performance of NHS providers, quasi-experimental methods (when allocation of providers to certain groups cannot be controlled) or trial-based methods (when group allocation can be controlled) will be used.

The NNHLA will examine the opportunities for, and strengths and limitations of, quasi-experimental and trial-based evaluation methods once it is more fully established.

[11] Taylor MJ, McNicholas C, Nicolay C, Darzi A, Bell D, Reed JE. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. BMJ Qual Saf. 2014 Apr;23(4):290-8. doi: 10.1136/bmjqs-2013-001862.

Appendix

1. National Cancer Audit Collaborating Centre (NATCAN)

NNHLA is part of the National Cancer Audit Collaborating Centre (NATCAN), a national centre of excellence launched on 1st October 2022 to strengthen NHS cancer services by looking at treatments and patient outcomes in multiple cancer types across the country. The centre was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government with funding in place 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. 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.

NATCAN was set up on 1st October 2022 to deliver six new national cancer audits, including kidney, ovarian, pancreatic, breast (two separate audits in primary and metastatic disease) and non-Hodgkin Lymphoma. Existing audits in prostate, lung, bowel, and oesophago-gastric cancers moved into NATCAN in 2023. This critical mass of knowledge and expertise enable it to respond to the requirements of the funders and stakeholders.

The aim of the ten NATCAN 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.

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, NHSE] 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.

Organisational structure of NATCAN

Centre Board

NATCAN has a multi-layered organisational structure. NATCAN's Board 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 (Prof Ajay Aggarwal), the Director of the CEU (Prof David Cromwell), the Senior Statistician (Prof 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 web-based performance 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 has 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.

2. Data provision

The NATCAN Executive Team has worked closely with data providers in England (NDRS, NHSE) and in Wales (WCN, 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

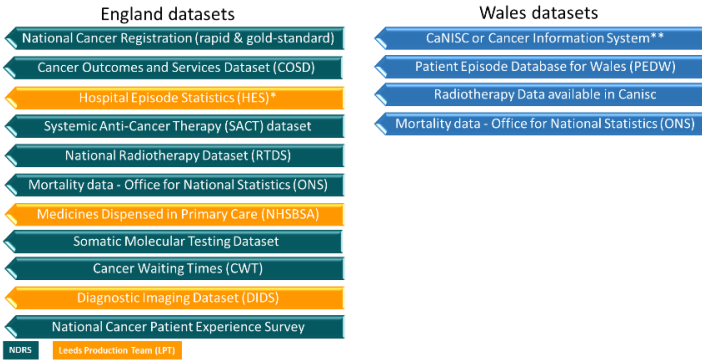
NATCAN will utilise two types of routinely collected data in England. First, an annual "gold-standard" cancer registration dataset, released on an annual basis with a considerable delay between the last recorded episode and the data being available for analysis, and second, a "rapid" cancer registration 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,[12] 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 for National Statistics among other routinely collected datasets, see Figure 1) for describing diagnostic pathway patterns, treatments received and clinical outcomes.

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

[12] Nossiter J, Morris M, Parry MG, Sujenthiran A, Cathcart P, van der Meulen J, Aggarwal A, Payne H, Clarke NW. Impact of the Covid-19 pandemic on the diagnosis and treatment of men with prostate cancer. BJU Int. 2022; doi: 10.1111/bju.15699

Figure 3: National datasets available to NATCAN



* Includes inpatient and outpatient data and Emergency care Dataset (ECDS).

** NHS Wales will use Welsh registry information for the initial years data for the audit. NATCAN submitted a request for historical data from the Welsh Cancer Registry in Q4 2023 (not received to date). From 2022 data submissions will be from either Canisc or the new cancer dataset forms.

3. ICD-10 and ICD-O3 codes for inclusion

ICD-10 codes for defining Non-Hodgkin Lymphoma.

ICD-10	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

ICD-O3 codes for defining Non-Hodgkin Lymphoma.

ICD-O-3	NHL sub-type
9687/3	Burkitt lymphoma
9823/3	Chronic lymphocytic leukaemia
9597/3, 9690/3, 9695/3, 9698/3	Follicular lymphoma
9679/3, 9680/3, 9688/3, 9698/3, 9712/3, 9735/3	Large B-cell lymphomas
9673/3	Mantle cell lymphoma
9689/3, 9699/3	Marginal zone lymphoma
9591/3	NHL, not otherwise specified
9700/3, 9701/3, 9709/3, 9718/3, 9726/3	Cutaneous T-cell lymphomas
9702/3, 9705/3, 9714/3, 9716/3, 9717/3, 9719/3, 9827/3	Peripheral T-cell lymphomas

4. Quality Improvement Framework – Supplementary information

Negative tail

Regulation and public reporting of outliers

National cancer audits that pre-date NATCAN have used a formal process for reporting outliers publicly. This process includes contacting outliers before publication to: (1) verify the data, (2) identify the reasons for the low level of performance identified, and (3) determine what corrective interventions have been put in place. The findings are reported publicly and may inform care practices in other NHS Trusts.

Central mass

Statistical process control and iterative testing of interventions

Most providers exist in the central mass of the distribution (by definition). Just because something is common it does not mean that it is alright: performance may be systematically below an achievable standard nationally for example (such as 75% of eligible patients receiving a particular treatment). We recommend that individual providers verify their performance data and undertake internal audits to assess areas for improvement and consider evaluation of their processes of care.

Positive tail

Positive deviance

Positive deviants may perform consistently better than comparators over time or demonstrate a clear upward trend in performance between two time points. It may be possible to learn from these providers to identify practices of care that have driven high levels of performance. This could include care protocols or factors related to system organisation which may inform quality improvement amongst providers in the negative tail and central mass of performance.

Determinants of variation

To support targeting of improvement interventions and recommendations, the audit will analyse particular patient, hospital and regional factors associated with variation in processes and outcomes of care. For example, for the utilisation of a particular evidence-based treatment, factors associated with utilisation may include advanced age, social deprivation and frailty, clinician preferences, and regional policies. Findings may be reported at an aggregated national or regional (alliance) level and can support NHS Trusts to target interventions or evaluation at particular patient populations.

5. Example driver diagram

Driver diagram for severe acute toxicity after chemotherapy, adapted from work in the National Bowel Cancer Audit[13].

[13] Boyle JM, et al. Development and validation of a coding framework to identify severe acute toxicity from systemic anti-cancer therapy using hospital administrative data. Cancer Epidemiol. 2022. doi: 10.1016/j.canep.2022.102096.