NNHLA
National Non-Hodgkin Lymphoma Audit

NATCAN
National Cancer Audit Collaborating Centre

National Non-Hodgkin Lymphoma Audit State of the Nation Report 2024

An audit of care received by people diagnosed with non-Hodgkin lymphoma in England (2020-2021) and Wales (2022)

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NNHLA

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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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NDRS
NATIONAL DISEASE REGISTRATION SERVICE

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. For patients diagnosed in England, the data is collated, maintained and quality assured by the National Disease Registration Service (NDRS), which is part of NHS England. Access to the data was facilitated by the NHS England Data Access Request Service.

GIG CYMRU NHS WALES
Rhwydwaith Canser Cymru
Wales Cancer Network

NHS Wales is implementing a new cancer informatics system. As a result, the quality and completeness of data from Wales is likely to have been impacted due to implementation of this new system across multiple NHS organisations (Health Boards), which has resulted in data being supplied by both old and new systems. Additionally, and reflecting the uncertainty of data quality, the data submitted to the audit may not have undergone routine clinical validation prior to submission to the Wales Cancer Network (WCN), Public Health Wales.

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1. Introduction

The National Non-Hodgkin Lymphoma Audit (NNHLA) aims to evaluate patterns of care and outcomes for people diagnosed with non-Hodgkin lymphoma (NHL) in England and Wales in line with its Quality Improvement Plan. The NNHLA Quality Improvement Plan set out the scope, care pathway, five quality improvement goals and 11 performance indicators that will be utilised to measure progress against these goals.

The NNHLA is one of ten national cancer audits within the National Cancer Audit Collaborating Centre (NATCAN), which is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government. The aim of NATCAN is to provide regular information on patterns and variation in delivery of cancer care from diagnosis to treatment. It aims to use this information to improve access to treatment and facilitate quality improvement initiatives, with a view to improving outcomes nationally.

The NNHLA assesses current clinical practice against standards set out in national guidelines. It reports on performance indicators that have been drawn from extensive review of existing literature and review of UK-specific guidelines relevant to NHL; produced by National Institute for Health and Care Excellence (NICE), NHS England, as well as guidelines on diffuse large B-cell lymphoma (DLBCL) and follicular lymphoma (FL) from the British Society of Haematology (BSH).

This State of the Nation report provides a national perspective on the patterns of NHL care and outcomes across England and Wales. This year it includes people diagnosed with NHL from January 2020 to December 2021 in England, and January 2022 to December 2022 in Wales. It reports on 6 out of the 11 performance indicators for England, and 4 out of the 11 performance indicators for Wales outlined in the NNHLA Quality Improvement Plan (Table 1). The report describes the national picture and variation between hospitals and NHS trusts in England/hospitals in Wales. The cancer care described for the period 2020-2021 in England reflects changes introduced during the COVID-19 pandemic and can be “atypical” to some degree.

Further development work and/or additional data is required to report on all 11 indicators for both nations. Findings in the report have led to 5 recommendations to drive improvements in the quality of NHL care. The State of the Nation report will be published annually. In future years the NNHLA will work to align the reporting periods in England and Wales, and to provide more timely reporting. In England this will require the use of Rapid Cancer Registration Data (RCRD) as well as ‘gold standard’ National Cancer Registration Data (NCRD), and development work is needed to ensure the RCRD is of sufficient data quality. Future reports will evaluate change in care and outcomes over time, as well as variation between organisations.

The NNHLA also provides timely quarterly reports to NHS trusts in England. Data quality reports provide a local perspective on the completeness of data available on people with NHL at individual NHS organisations, and shine a spotlight on areas where improvements to data collection are needed. Good quality data is essential for the audit to produce reliable and robust information. The most recent data quality report was on data spanning January 2023 to December 2023, and reports are updated every three months.

The NNHLA will shortly begin quarterly reporting of performance indicators for NHS trusts in England (expected October 2024). These will be updated every three months and will provide timely reports on the performance indicators outlined in the NNHLA Quality Improvement Plan. The intended audience is NHS trusts; supporting them to track progress alongside local quality improvement initiatives.

A summary of this report for people diagnosed with NHL and the public will be made available on the audit’s webpages. Details of the methods are available in the NNHLA Methodology document and a glossary is provided of terminology in this report. Further results accompanying this report are provided (Supplementary Tables and Trust Results) and an Action Plan template to support local quality improvement. Further information about the outlier process can be found in the FAQs for NATCAN (point 17).

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Table 1. Performance Indicators (PIs) included in this report		
PI	**Included in this report for English data (2020-2021)?**	**Included in this report for Welsh data (2022)?**
1. Proportion of people diagnosed with NHL discussed at a lymphoma/ haematology multidisciplinary team (MDT) meeting within 4 weeks of diagnosis.	Yes	No
2. Proportion of people with high-grade lymphoma (Burkitt lymphoma (BL), DLBCL or high-grade T-cell) who start chemotherapy within 62 days of referral.	Yes	Yes
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.	Yes	No. Regimen-level chemotherapy data for Wales not provided
4. Proportion of people diagnosed with NHL seen by a clinical nurse specialist (CNS)	Yes	Yes
5. Proportion of people with NHL receiving radiotherapy, reported by sub-type.	Yes	Yes
6. Proportion of people diagnosed with BL or DLBCL undergoing treatment who have MYC testing.	No. Development work needed	No. Molecular data for Wales not provided
7. First-line chemotherapy treatment regimens received by people with high-grade lymphoma (BL, DLBCL or high-grade T-cell lymphoma).	No. Development work needed	No. Regimen-level chemotherapy data for Wales not provided
8. Time to treatment for relapse of follicular lymphoma, other B-cell lymphomas (incl. chronic lymphocytic leukaemia (CLL), marginal zone lymphoma) and T-cell lymphomas which are not high-grade.	No. Development work needed	No. Development work needed
9. Proportion of people diagnosed with NHL with severe acute toxicity after SACT, reported by sub-type.	No. Development work needed	No. Development work needed
10. Proportion of people diagnosed with NHL who are consented for a clinical trial/research study, reported by sub-type.	No. Development work needed	No. Development work needed
11. Overall 2-year survival of people with high-grade lymphoma (BL, DLBCL, mantle cell or high-grade T-cell).	Yes. One-year survival reported by sub-type nationally	Yes. One-year survival reported by sub-type nationally

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2. Infographic

NNHLA
National Non-Hodgkin Lymphoma Audit

Summary of results for people diagnosed with Non-Hodgkin Lymphoma (NHL) in England (2020-2021) and Wales (2022).

Data completeness

	Age	Sex	Ethnicity	Deprivation	Performance status	Staging (Ann Arbor)	Staging (Binet)	Clinical Nurse Specialist (CNS)	Multi-Disciplinary Team meeting (MDT)
England 2020-2021	100%	100%	93.6%	100%	48.8%	73.2%	29.2%	36.9%	72.8%
Wales 2022	100%	87.6%	45.7%	90.1%	60.3%	29.2%	10.2%	69.1%	No data on MDT discussion was provided for Wales

Diagnosis and staging

Diagnoses per year

England
14,099 diagnosed in 2020
14,973 diagnosed in 2021

Wales
619 diagnosed in 2022

69 years — **Mean age** at diagnosis for both England & Wales

Grade of lymphoma

England 2020-2021
high-grade 51%, low-grade 47%, not classified 1%

Wales 2022
high-grade 49%, low-grade 51%, not classified 0.2%

Clinical Nurse Specialist (CNS) seen, where recorded

82% of people diagnosed with NHL seen by a CNS in **England** (2020 & 2021) and 96% in **Wales**.
CNS information was recorded in only 37% of people diagnosed with NHL in **England** and 69% in **Wales**.

MDT discussion within 4 weeks of diagnosis, where recorded

England 2020 - 69%, (high-grade 74.5%, low-grade 61.8%)

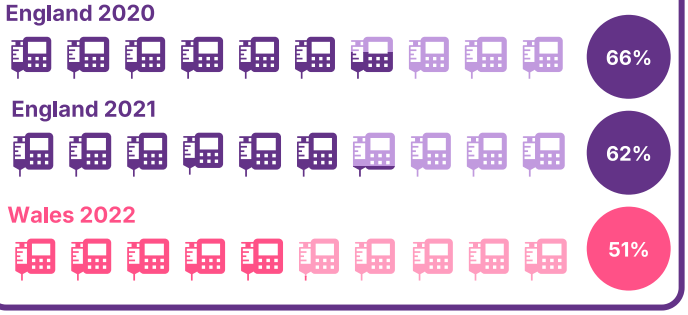
England 2021 - 63.5%, (high-grade 68.6%, low-grade 57.3%)

No data on MDT discussion was provided for Wales

Treatment

Chemotherapy treatment

Percentage of people diagnosed with high grade lymphoma, who received chemotherapy within 62 days of referral.



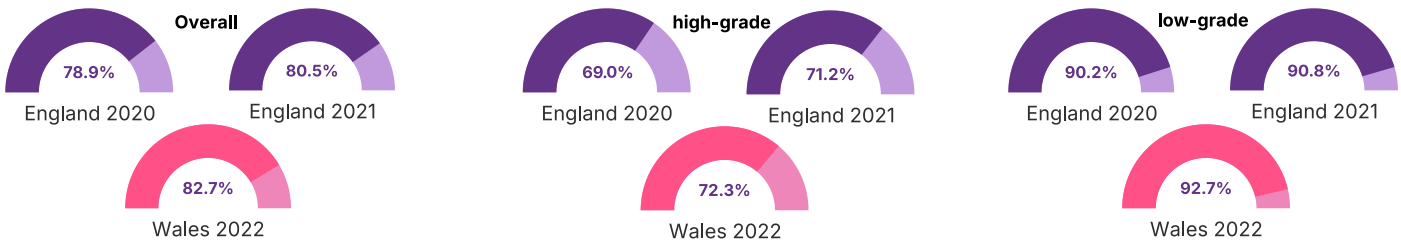
Radiotherapy treatment

Percentage of people diagnosed with high-grade lymphoma,who received radiotherapy within 8 weeks of end of first line chemotherapy.

End date for 1st line chemotherapy was not provided for Wales so this indicator could not be measured.

Survival

One-year survival outcomes



3. Recommendations

Recommendation	Audience	Report Findings	Quality Improvement Goal	National guidance/standards/resources
1. **Identify and address factors delaying people with NHL being discussed at a haematology or lymphoma MDT including referral pathways, staging investigations and record keeping.**	England Cancer Alliances working with trusts Wales Health boards	**Proportion of people with NHL discussed at a haematology or lymphoma an MDT within 4 weeks of diagnosis (%) (and % amongst high-grade cases):** Data completeness: 73.0% England 2020: 69.0% discussed in 4 weeks (74.5% amongst high-grade) England 2021: 63.5% discussed in 4 weeks (68.6% amongst high-grade) Wales 2022: Not available	Improving timely diagnosis and treatment	BSH guidelines for DLBCL and Follicular Lymphoma and NICE guideline for improving the outcomes of haematological cancers (NG47): recommendation 1.3.4
2. **Identify pathway factors contributing to delays in people with high-grade NHL starting chemotherapy within 62 days of referral to develop strategies for process improvement**	England Cancer Alliances working with trusts Wales Health boards	**Proportion of people with NHL starting chemotherapy within the 62 day target:** England 2020: 66.1% England 2021: 62.0% Wales 2022: 51.2%	Improving timely diagnosis and treatment	NHS England (2023) Changes to cancer waiting times standards from 1 Oct 2023.
3. **Identify patient and hospital factors contributing to delays in radiotherapy delivery since last administered dose of chemotherapy**	England Cancer Alliances working with trusts Wales Health boards	**Proportion of people with NHL receiving radiotherapy within 8 weeks of last administered dose of chemotherapy:** England 2020 and 2021: 43.3-44.2%40.9-41.0% Wales 2022: Not available	Improving timely diagnosis and treatment	No national guidance set. Recommendation agreed by the NNHLA Clinical Reference Group

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Recommendation	Audience	Report Findings	Quality Improvement Goal	National guidance/standards/resources
4. **Ensure adequate resource allocation for data provision.** **They should support hospitals/trusts/ health boards in England and Wales with coding, data entry, and quality assurance to improve quality and completeness of data submitted. Data items of focus include:** • **Cancer staging (Ann Arbor and Binet)** • **Prognostic indices for NHL**	England Integrated Care Boards (ICBs) working with trusts Wales Health boards	**Completeness of data for staging as follows (Binet – CLL, Ann Arbor – All other NHL):** England 2020: 76.0% (Ann Arbor), 32.4% (Binet) England 2021: 70.3% (Ann Arbor), 25.9% (Binet) Wales 2022: 60.0% (Ann Arbor), 10.2% (Binet) **Completeness of data for International Prognostic Indices (IPI) and FLIPI (follicular lymphoma IPI):** England 2020-2021: 9.2-11.4% Wales 2022: Not available	N/A	NHS organisations have an obligation to submit accurate and timely data to the English National Disease Registration Service (NDRS) and Wales Cancer Network (WCN). The Cancer Outcome and Services Data set (COSD) has been the national standard for reporting cancer in the NHS in England since January 2013. Feedback reports for the data submitted are available through the CancerStats website. COSD is the main source for the rapid cancer registration dataset. Improved completeness of this dataset is required to ensure quarterly reporting. The Welsh Health Circular (NHS Wales) mandates high quality data submissions for the national cancer audits.
5. **Deliver more comprehensive cancer data in Wales, with particular focus on:** • **Chemotherapy regimens and delivery** • **Radiotherapy regimes and delivery** **This is in the process of being developed with introduction of National Data Resource (NDR) as part of the newly established Digital Health and Care Wales (DHCW) as part of the "Digital Strategy for Wales"**	Wales Health boards working with DHCW	**Detailed chemotherapy and radiotherapy information is not currently available for Wales**	N/A	NHS organisations have an obligation to submit accurate and timely data to the Wales Cancer Network (WCN). The Welsh Health Circular (NHS Wales) mandates high quality data submissions for the national cancer audits. The Digital and Data Strategy for Health and Social Care in Wales aims to enhance modern health and care services through technology and data utilisation. The availability of more comprehensive data is anticipated with the introduction of the National Data Resource (NDR) as part of the newly established Digital Health and Care Wales (DHCW).

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4. Results for England (2020,2021) and Wales (2022)

4.1 Data Completeness

Key Message: NHS trusts and MDTs should ensure key data items are submitted to cancer registries for all people diagnosed with NHL. Particular attention should be given to documentation of staging/prognostic indices, MDT records and CNS involvement in both England and Wales.

It is important to note that data was provided for different calendar years for England ('Gold standard' Cancer Registry data for 2020 and 2021) compared to Wales (Cancer Network Information System Cymru (CaNISC) data for 2022). Therefore, as the data reporting periods were different, the data for England was obtained during the peak of the COVID-19 pandemic. This may have contributed to poorer data quality and completeness compared to Wales, where the data was collected later. The following databases were also used to gather data for England (2020-2021): Cancer Outcomes and Services Dataset (COSD), Hospital Episode Statistics (HES), Systemic Anti-Cancer Therapy (SACT), Radiotherapy Dataset (RTDS) and Cancer Waiting Times (CWT). The following databases were also used to gather data for Wales (2022): Lower Super Output Area (LSOA), Office of National Statistics mortality data (ONS) and Patient Episode Database for Wales (PEDW).

The audits in NATCAN do not 'collect' clinical data. The cancer audits utilise the nationally mandated flows of data from hospitals to the National Disease Registration Service (NDRS) in NHSE and the Wales Cancer Network in Public Health Wales, thereby minimising the burden of data collection on provider teams.

Descriptive Data

Complete information on key data items is important to report on variation in healthcare delivery and outcomes, and to make fair comparisons between trusts/hospitals and groups of people diagnosed with NHL.

Overall in England, data completeness of age, sex, ethnicity and deprivation was excellent (over 90%). In Wales, data completeness of age and deprivation was also excellent (over 90%). However, levels of data completeness for sex (87.6%) and in particular ethnicity (45.7%) were lower. Completeness of data for performance status was poor; with 47.9% and 49.7% completeness respectively in 2020 and 2021 for England, and 60.3% in 2022 for Wales. Completeness of Charlson Comorbidity Index was also low due to incomplete linkage to Hospital Episode Statistics data in England and Patient Episode Data for Wales; 69.5% in England 2020, 67.3% in England 2021 and 59.8% in Wales 2022 (Supplementary Table 1).

There was excellent data completeness for grade of NHL (around 99%) in both England and Wales (Table 3). In England, Ann Arbor staging was documented for 76.0% of people diagnosed in 2020 and 70.3% in 2021. Binet staging, pertaining only to people diagnosed with CLL, was recorded for only 32.4% of cases in 2020 and 25.9% in 2021. Staging data in Wales in 2022 was more incomplete; data completeness of Ann Arbor staging was 60%, and of Binet staging was 10.2% (Table 2). There was poor overall completeness of data for prognostic indices. Data completeness for both IPI (International Prognostic Index for DLBCL) and FLIPI (Follicular Lymphoma International Prognostic Index) was 11% and 9% in 2020 and 2021 in England respectively. No data on prognostic indices was available for Wales (Table 4).

Data

Record keeping for MDT discussions within 4 weeks of diagnosis was poor in England in 2020 and 2021 (73% and 72.6% respectively). No data on MDT discussion was provided for Wales.

The proportion of people diagnosed with NHL, seen by a clinical nurse specialist was recorded in less than 40% of cases in England in 2020 and 2021, and less than 70% of cases in Wales in 2022.

With regards to treatment delivery, for this State of the Nation report no data was available on regimen-level chemotherapy and limited data was available on radiotherapy delivery for Wales. A new cancer informatics system is being developed in Wales and work is ongoing to provide more detailed chemotherapy and radiotherapy data for Wales.

4.2 Characteristics of people with NHL

'Gold standard' Cancer Registration data (England) identified 14,099 people diagnosed with non-Hodgkin lymphoma in 2020, and 14,973 people diagnosed in 2021, across 133 English NHS trusts. CaNISC data identified 619 people diagnosed with NHL in Wales in 2022 across 17 Welsh hospitals. Supplementary Tables 1 and 2 as well as Table 2 to 4, summarise the characteristics of people with NHL and their tumours, separately for these three cohorts of people with NHL.

Across all three cohorts there was a similar mean age of 69 years and on average, a higher number of male individuals diagnosed with NHL (57 to 60% male).

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Most people diagnosed with NHL in England and Wales were white British, although a large volume of people were missing ethnicity information in the Welsh data. A higher proportion of people diagnosed lived in the least deprived quintiles in England and Wales (23% in least deprived quintile compared to 15% in most deprived quintile for England; similarly, 24% in least deprived quintile compared to 14% in most deprived quintile for Wales).

Most people included in the audit with a recorded performance status, were performance status 0-1 (fully active or able to carry out light work); with 82% and 81% of people in England (2020 and 2021 respectively), and 79% in Wales (2022).

More than three-quarters of people with NHL who had a Charlson comorbidity index available (through linkage to HES or PEDW data) had zero or one comorbidities in England (2020-2021) and Wales (2022). However, drawing any conclusions is difficult as 30-40% of data was missing for this data item.

4.3 Diagnosis and Staging

Key Message: Improved staging should be prioritised as complete staging data will allow risk-adjusted comparisons between groups of people diagnosed with NHL and trusts/ MDTs. There is highly complete recording of sub-type based on diagnostic and morphology coding (92%).

14,099 people were diagnosed with NHL in England in 2020, which slightly increased to 14,973 in England 2021. This may be due to delays in diagnosis in 2020 due to the COVID-19 pandemic. 619 people were diagnosed in Wales in 2022.

The three most common sub-types were large B-cell lymphoma, chronic lymphocytic leukaemia and follicular lymphoma (Supplementary Table 2). The incidence of low-grade and high-grade disease was similar across England and Wales (Table 3).

People included in the audit, tend to present with a late stage at diagnosis in all cohorts; this is likely due to the aggressive nature of some sub-types but may also be due to patient factors (delayed presentation due to non-specific nature of symptoms), delays in diagnosis due to capacity issues and unclear diagnostic pathways in primary and secondary care. In England in 2020 and 2021, 71.1% and 71.4% (respectively) of individuals with recorded stage presented at Ann Arbor Stage 3 or 4 (Table 2). In Wales in 2022, 70.1% of individuals with recorded stage presented at Ann Arbor Stage 3 or 4 disease. Conversely with CLL, the pattern suggested that people in all cohorts were more likely to present at an earlier stage; this may be in keeping with a slower trajectory of the disease, rather than faster diagnosis pathways (Table 2).

It is difficult to make definitive conclusions as there was a large amount of missing data in all cohorts (range 24%-90%).

Table 2. Tumour characteristics (stage) in England (2020 and 2021) and Wales (2022)

	Jan - Dec 2020 England		Jan - Dec 2021 England		Jan - Dec 2022 Wales	
	N	%	N	%	N	%
Total	14,099	100	14,973	100	619	100
Ann Arbor staging						
Total	11,007	100	11,606	100	462	100
1	1,420	17.0	1,398	17.1	44	15.9
2	998	11.9	933	11.4	39	14.1
3	1,571	18.8	1,526	18.7	70	25.3
4	4,379	52.3	4,303	52.7	124	44.8
Missing (% of total)	2,639 (24.0)		3,446 (29.7)		185 (40.0)	
Binet staging (CLL)						
Total	3,092	100	3,367	100	157	100
A	793	79.1	732	84.0	10	62.5
B	129	12.9	88	10.1	<5	<30
C	80	8.0	51	5.9	<5	<15
Missing (% of total)	2,090 (67.6)		2,496 (74.1)		141 (89.8)	

NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

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Table 3. Tumour characteristics (grade) in England (2020 and 2021) and Wales (2022)						
	Jan - Dec 2020 England		**Jan - Dec 2021 England**		**Jan - Dec 2022 Wales**	
	N	**%**	**N**	**%**	**N**	**%**
Total	14,099	100	14,973	100	619	100
NHL grade**						
High	7,340	52.1	7,605	50.8	~300*	~49.0
Low	6,594	46.8	7,201	48.1	~320*	~51.0
Not classified	165	1.2	167	1.1	<5*	<0.8
**** Coded according to ICD-10.**						

* Exact numbers suppressed to protect people's confidentiality
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

Table 4. Tumour characteristics (prognostic indices) in England (2020 and 2021). International Prognostic Index (IPI) (for DLBCL) and FLIPI (for follicular lymphoma)				
	Jan - Dec 2020 England		**Jan - Dec 2021 England**	
	N	**%**	**N**	**%**
IPI for DLBCL				
Total DLBCL	4,100	100	4,017	100
Recorded	454	11.1	371	9.2
Missing	3,646	88.9	3,646	90.8
FLIPI for follicular lymphoma				
Total FL	2,097	100	2,287	100
Recorded	239	11.4	211	9.2
Missing	1,858	88.6	2,076	90.8

NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

4.4 Diagnosis to Treatment Pathway

PI 1: Proportion of people diagnosed with NHL discussed at a lymphoma/haematology MDT within 4 weeks of diagnosis

Key Message: Improvement at trust/MDT level is needed regarding MDT discussion documentation and ensuring timely MDT discussions for all people diagnosed, particularly for high-grade NHL.

Data completeness for MDT discussion of people diagnosed in England in 2020 and 2021 was 73%. Where data is available for this item, less than 70% were discussed in a lymphoma MDT (or general haematology MDT if no specific lymphoma MDT available) within 4 weeks of diagnosis; the proportion was lower in 2021 compared to 2020.

People with high-grade NHL were more likely to be discussed within this time-period, reflecting the urgency in treatment decision-making with high-grade tumours. There was also wide variation between trusts/hospitals regarding MDT discussion within 4 weeks (Table 5, Supplementary Table 3).

Further analysis (Supplementary Table 4) demonstrates, where recorded, just under 90% of cases were discussed at an MDT within 8 weeks of diagnosis, 91-93% of these were high grade cases.

No data on MDT discussion was available for analysis for Wales.

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Table 5. MDT discussion within 4 weeks of diagnosis for high-grade and low-grade NHL in England. Percentages are amongst people with MDT status available.

Denominator*	England 2020	Variation 2020**	England 2021	Variation 2021**
All NHL	69.0%	Range: 0-100% Median (IQR***): 70% (57-76%)	63.5%	Range: 0-100% Median (IQR): 65% (51-72%)
High-grade lymphoma	74.5%	Range: 0-100% Median (IQR): 74% (64-83%)	68.6%	Range: 0-100% Median (IQR): 70% (58-79%)
Low-grade lymphoma	61.8%	Range: 0-100% Median (IQR): 63% (47-71%)	57.3%	Range: 0-100% Median (IQR): 57% (47-69%)

* Denominator is number of people (with NHL) with MDT status available. Available in 73.0% and 72.6% for England in 2020 and 2021, respectively.
**Variation between trusts in England.
*** Interquartile range (IQR).
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

PI 4: Proportion of people diagnosed with NHL seen by a clinical nurse specialist

Key Message: Improvement at trust/ Health Board level regarding record of, and involvement of CNS teams, particularly in England, is key to ensuring consistent support to people with NHL.

In cases where CNS information was available 96% of people with NHL in Wales were seen by a CNS, however this only applied to 82% of cases in England. Active CNS contact was noted to be higher in high-grade lymphoma cases compared to low-grade lymphoma cases across all cohorts. Variation was also noted between trusts/hospitals, though poor data completeness (less than 40% in England and less than 70% in Wales) makes it difficult to draw conclusions on the consistency of support by providers (Table 6).

Table 6. Percentage of people diagnosed with NHL seen by CNS in England (2020 and 2021) and Wales (2022). Percentages are amongst people with CNS information available.

Denominator	England 2020	Variation 2020 ****	England 2021	Variation 2021 ****	Wales 2022	Variation 2022^
People with NHL with CNS information available *	81.5%	Range: 0-100% Median (IQR): 92% (78-100%)	82.2%	Range: 0-100% Median (IQR): 93% (82-100%)	96.0%	Range: 60-100% Median (IQR): 99% (86-100%)
People with high-grade NHL with CNS information available **	85.8%	Range: 0-100% Median (IQR): 96% (82-100%)	86.6%	Range: 0-100% Median (IQR): 95% (87-100%)	98.2%	Range: 82-100% Median (IQR): 100% (100-100%)
People with low-grade NHL with CNS information available ***	76.0%	Range: 0-100% Median (IQR): 92% (68-100%)	77.2%	Range: 0-100% Median (IQR): 91% (74-100%)	93.9%	Range: 33-100% Median (IQR): 100% (78-100%)

* Data completeness for CNS records in all people with NHL: 35.6% in 2020 and 38.2% in 2021 for England; 69.1% in 2022 for Wales
** Data completeness for CNS records in all people with high-grade NHL: 37.1% in 2020 and 39.3% in 2021 with CNS record for England; 71.3% in 2022 for Wales.
*** Data completeness for CNS records in all people with low-grade NHL: 34.2% in 2020 and 37.0% in 2021 for England; 67.3% in 2022 for Wales.
****Variation between trusts in England
^Variation between hospitals in Wales
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

PI 2: Proportion of people with high-grade lymphoma (Burkitt lymphoma, DLBCL or high-grade T-cell) who start chemotherapy within 62 days of referral

Key Message: Less than 67% of people with high-grade NHL in England and 50% of people with high-grade NHL in Wales receive chemotherapy within 62 days of referral.

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Many people with high-grade lymphoma do not receive first line chemotherapy within the target of 62 days across both England and Wales; notably only half of people diagnosed in Wales are meeting these targets (Table 7). There is wide variation between hospitals/NHS trusts suggestive of potential issues in the referral pathway, access to specialist care and resource availability that will require further development and exploration of the data in future analyses.

Table 7. Percentage of people with high-grade lymphoma who received chemotherapy within 62 day referral targets in England and Wales

Denominator	England 2020	Variation 2020*	England 2021	Variation 2021*	Wales 2022	Variation 2022**
People with high-grade lymphoma who had chemotherapy and with referral date recorded	66.1%	Range: 0-100% Median (IQR): 65% (54-76%)	62.0%	Range: 0-100% Median (IQR): 63% (53-71%)	51.2%	Range: 0-100% Median (IQR): 50% (26-67%)

* Variation between trusts in England
** Variation between hospitals in Wales
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

4.5 Treatment

PI 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

Key Message: Less than 44% of people with high-grade lymphoma start their radiotherapy within 8 weeks of the end of first line chemotherapy and there is wide variation between trusts.

For this year's State of the Nation report no data was provided on chemotherapy regimens in Wales so it was not possible to report radiotherapy delivery following chemotherapy for Wales.

Overall, 43-44% of people included in this audit in England commenced radiotherapy within 8 weeks of the end of first line chemotherapy, with wide variation between NHS trusts/hospitals (Table 8). This was calculated with the denominator defined as all people with high-grade lymphoma who received radiotherapy within 6 months of the end of first line chemotherapy. Further development and exploration of the data will be carried out by the NNHLA to understand whether this is because of extent of response to first line treatment, sub-type, location of disease involvement at presentation, baseline fitness and suitability of radiotherapy, or due to issues with access to care.

Table 8. Percentage of people with high-grade lymphoma receiving radiotherapy within 8 weeks of completion of first line chemotherapy in England and Wales

Denominator	England 2020	Variation 2020*	England 2021	Variation 2021*	Wales 2022	Variation 2022
People with high-grade lymphoma who completed one chemotherapy regimen before radiotherapy	44.2%	Range: 0-100% Median (IQR): 33% (10-56%)	43.3%	Range: 0-100% Median (IQR): 33% (0-50%)	Not available this year	Not available this year

* Variation between trusts in England.
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

PI 5: Proportion of people diagnosed with NHL receiving radiotherapy by sub-type

Key Message: Further analysis of variation in care across NHS hospitals is required to understand the use and delivery of radiotherapy for varying sub-types.

Consistent with observed clinical practice, the sub-types most likely to receive radiotherapy at any point were DLBCL, follicular lymphoma and marginal zone lymphoma (Supplementary Table 5). Due to current difficulties in radiotherapy capture with existing databases in Wales, only limited conclusions can be drawn from the current data provided for Wales; this may explain lower proportions of radiotherapy delivery in Wales compared to England.

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Radiotherapy by sub-type was further analysed within 1 year and 2 years of diagnosis (Table 9, Supplementary Table 6). In order to capture initial treatments and to provide more comparable results for England and Wales, radiotherapy starting within 1 year of diagnosis was included (Table 9). Radiotherapy information was available up to 30 June 2023 in England and up to 21 September 2023 in Wales. Therefore, all people diagnosed in England had full follow-up, and people diagnosed in Wales had at least 8 months of follow-up, with three-quarters of people having full follow-up (Table 9).

The most common sub-types receiving radiotherapy within 1 year of diagnosis were DLBCL, cutaneous T-cell lymphoma and marginal zone lymphoma, although numbers of people were still low across all cohorts. Similar results were also seen within 2 years of diagnosis (Supplementary Table 6). The absence in follicular lymphoma in the top 3 most common sub-types being treated with radiotherapy within 1 to 2 years of diagnosis may be explained by the "watch and wait" approach and slow growing nature of follicular lymphoma, with radiotherapy often only offered when an individual is symptomatic.

Further analysis on indications for radiotherapy delivery and future analyses exploring variations in radiotherapy delivery at a trust and hospital level, as well as the structure of radiotherapy referral pathways/tertiary referral centres services, will increase our understanding of differences in care delivery across England and Wales.

Table 9. Proportion of people diagnosed with NHL receiving radiotherapy within 1 year of diagnosis, reported by sub-type in England (2020 and 2021) and Wales 2022

Denominator	England 2020	Variation 2020*	England 2021	Variation 2021*	Wales 2022	Variation 2022**
All people with NHL	14.0%	Range: 0-62% Median (IQR): 13% (10-18%)	13.2%	Range: 0-75% Median (IQR): 12% (8-17%)	6.0%	Range: 0-50% Median (IQR): 6% (4-8%)
Burkitt lymphoma	12.2%	Range: 0-100% Median (IQR): 0% (0-0%)	12.4%	Range: 0-100% Median (IQR): 0% (0-0%)	0%	Range: 0-0% Median (IQR): 0% (0-0%)
Chronic lymphocytic leukaemia	0.5%	Range: 0-14% Median (IQR): 0% (0-0%)	0.4%	Range: 0-8% Median (IQR): 0% (0-0%)	0%	Range: 0-0% Median (IQR): 0% (0-0%)
Follicular lymphoma	18.6%	Range: 0-70% Median (IQR): 17% (9-25%)	18.1%	Range: 0-100% Median (IQR): 18% (9-24%)	4.3%	Range: 0-17% Median (IQR): 0% (0-5%)
Large B-cell lymphomas	24.0%	Range: 0-100% Median (IQR): 24% (16-32%)	22.7%	Range: 0-100% Median (IQR): 23% (14-31%)	9.0%	Range: 0-50% Median (IQR): 11% (3-15%)
Mantle cell lymphoma	5.6%	Range: 0-100% Median (IQR): 0% (0-0%)	8.4%	Range: 0-100% Median (IQR): 0% (0-14%)	3.7%	Range: 0-25% Median (IQR): 0% (0-0%)
Marginal zone lymphoma	19.7%	Range: 0-100% Median (IQR): 17% (0-33%)	20.0%	Range: 0-100% Median (IQR): 17% (0-29%)	0%	Range: 0-0% Median (IQR): 0% (0-0%)
NHL, NOS	9.8%	Range: 0-51% Median (IQR): 0% (0-12%)	9.0%	Range: 0-50% Median (IQR): 0% (0-14%)	9.1%	Range: 0-50% Median (IQR): 0% (0-8%)
Peripheral T-cell lymphomas	12.0%	Range: 0-100% Median (IQR): 0% (0-20%)	12.5%	Range: 0-100% Median (IQR): 0% (0-20%)	11.1%	Range: 0-100% Median (IQR): 0% (0-0%)
Cutaneous T-cell lymphomas	22.8%	Range: 0-100% Median (IQR): 0% (0-41%)	22.5%	Range: 0-100% Median (IQR): 0% (0-38%)	13.3%	Range: 0-33% Median (IQR): 0% (0-13%)
Other	3.8%	Range: 0-100% Median (IQR): 0% (0-2%)	3.4%	Range: 0-67% Median (IQR): 0% (0-0%)	18.8%	Range: 0-100% Median (IQR): 0% (0-25%)

* Variation between trusts in England
** Variation between hospitals in Wales
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

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4.6 Survival/Outcomes

PI 11: Overall 2-year survival of people diagnosed with high-grade lymphoma (BL, DLBCL or high-grade T-cell)

Measure: 1 year survival data presented in lieu of 2-year survival due to data available.

Key message: High 1 year survival of around 90% for people with low-grade lymphoma, and around 70% for people with high-grade lymphoma, with similar results reported for England and Wales.

In this State of the Nation Report 1-year survival was reported to allow results to be presented for 2020 and 2021 in England and for 2022 in Wales. In the next State of the Nation Report 2-year survival will be reported. 1-year survival was almost 20% higher in absolute terms for people with low-grade lymphoma compared to people with high-grade lymphoma in England and Wales. Overall survival was similar across nations and years, with overlapping confidence intervals (Table 10, Supplementary Table 7 (for survival reported by sub-type)).

Table 10. One year survival for all people diagnosed with NHL in England (2020 and 2021) and Wales (2022)

Denominator	England 2020		England 2021		Wales 2022	
	%	95% CI*	%	95% CI	%	95% CI
All people diagnosed with NHL	78.9%	78.2-80.0%	80.5%	79.8-81.1%	82.7%	79.5-85.6%
People with high-grade lymphoma	69.0%	67.9-70.0%	71.2%	70.2-72.2%	72.3%	66.9-77.2%
People with low-grade lymphoma	90.2%	89.5-90.9%	90.8%	90.1-91.4%	92.7%	89.2-95.3%

*confidence interval (CI)
**97.5% CI (1-sided)
NOTE: Data were impacted by the COVID-19 pandemic and so will be atypical to some degree during 2020-2021

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5. Commentary

This is the first State of the Nation report outlining the patterns of care received by people with a diagnosis of non-Hodgkin lymphoma in England (2020-2021) and Wales (2022). Results are also provided by trust diagnosis (Trust Results). It is important to note that substantial variation is noted across trusts/hospitals in the diagnostic and treatment pathway. To provide meaningful data at a trust level to guide change, it is important that commissioners support trusts to improve coding, data entry, and quality assurance for the cancer registration data. Particular focus on data completeness should be targeted towards staging and prognostic indices in order to facilitate future risk-adjusted comparisons between trusts/hospitals, regions and groups of people with a diagnosis of NHL, in order to report on, and understand variation and inequality in care, and outcomes. This will build on the outlined NNHLA Quality Improvement Plan.

We note that the gaps in Welsh data on treatment delivery are being addressed and this is a focus for NHS Wales in the coming years, with ongoing work to provide national data on chemotherapy and radiotherapy care.

Improved data completeness will also help to provide a more complete picture of delays in MDT discussions and chemotherapy/radiotherapy treatments. We encourage local Cancer Alliances to review and monitor local practice pertaining to pathways between diagnosis and treatment delivery.

Data collected and presented in this report provides an initial understanding of treatment pathways and suggests areas of delay and variation in care delivery nationally. It is important to note definitive comparisons between England and Wales outcomes cannot be made due to the different reporting periods for the two nations. It is also unclear at this point, the impact of the COVID-19 pandemic on patterns in delivery of care which may account for delays in diagnosis and presentation at later stages, delays in delivery of treatment and poor uptake of chemotherapy and radiotherapy. It is particularly important as the data collection period for England (2020-2021) coincides with the height of the COVID-19 pandemic where hospitals and trusts were faced with significant staffing and resource pressures which may have limited data collection. Data may therefore not be representative of standard current practice.

Next steps:

Quarterly reports for English NHS trusts will be published on more timely data, providing a regular review of the outcomes of the PIs outlined, facilitating local intervention and quality improvement. The performance indicators will be presented in the quarterly report due to be published in October 2024. The focus for the coming 12 months should be improving data completeness and more complete data provision to better understand variations in care and facilitate change to improve care and outcomes as part of the NNHLA's Quality Improvement Plan.

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