



**Scottish Cancer Taskforce
National Cancer Quality Steering Group**

**Lymphoma
Clinical Quality Performance Indicators**

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June 2021 (v4.1)

The following statement has been updated:

Please note that this version of the Lymphoma QPI Document applies to cases diagnosed from 1st October 2019 onwards. Where amended or new QPIs require new data items for measurement, this will apply for patients diagnosed from 1st October 2020.

May 2021 (v4.0)

This document was updated following formal review (2nd cycle) of the Lymphoma Quality Performance Indicators (QPIs) which took place following analysis of year 6 of the Lymphoma QPI data.

The following QPIs have been updated:

- QPI 1 – Radiological Staging
- QPI 2 – Treatment Response
- QPI 3 – Positron Emission Tomography (PET CT) Staging
- QPI 4 – Cytogenetic Testing
- QPI 5 – Lymphoma MDT
- QPI 11 – Hepatitis and HIV Status
- QPI 12 – Treatment Response in Hodgkin Lymphoma

The following QPIs have been archived:

- QPI 6 – Treatment for Follicular Lymphoma and Diffuse Large B-Cell Lymphoma
- QPI 10 – Primary Cutaneous Lymphoma
- QPI 13 – Maintenance Therapy in Follicular Lymphoma

As a result of the changes above, the contents page and page numbering differ from earlier versions of this document. Sections 1 – 10 and the appendices have also been updated.

Please note that this version of the Lymphoma QPI Document applies to cases diagnosed from 1st October 2019 onwards. Where amended or new QPIs require new data items for measurement, this will apply for patients diagnosed from 1st October 2020.

Previous Updates:

October 2017 (v3.0)

This document was updated following formal review of the Lymphoma Cancer Quality Performance Indicators (QPIs) which took place following analysis of year 3 of the lymphoma QPI data.

The following QPIs have been updated:

- QPI 1 – Radiological Staging
- QPI 3 – Positron Emission Tomography (PET CT) Staging
- QPI 4 – Cytogenetic Testing
- QPI 5 – Lymphoma MDT
- QPI 6 – Treatment for Follicular Lymphoma and Diffuse Large B-Cell Lymphoma

- QPI 11 – Hepatitis and HIV Status

The following QPIs have been archived:

- QPI 7 - Treatment of Grade 3b Follicular Lymphoma
- QPI 8 - Treatment for Stage 1a Diffuse Large B Cell Lymphoma
- QPI 9 - Treatment for Classical Hodgkin Lymphoma

The following new QPIs have been added:

- QPI 12 - Treatment Response in Hodgkin Lymphoma
- QPI 13 - Maintenance Therapy for Follicular Lymphoma

Please note the revised Clinical Trials Access QPI has now been added into each tumour specific QPI document (see QPI 14: Clinical Trials).

As a result of the changes above, the contents page and page numbering differ from earlier version of this document. Sections 1 - 10 and the appendices have also been updated.

Please note that this version of the Lymphoma QPI Document applies to cases diagnosed from 1st October 2016 onwards. Where amended or new QPIs require new data items for measurement, this will apply for patients diagnosed from 1st October 2017.

September 2015 (v2.0)

This document was updated following baseline review of the Lymphoma QPIs which took place following analysis of year 1 of the lymphoma QPI data. As a result, the following QPIs have been updated:

- QPI 1 - Radiological Staging
- QPI 2 – Treatment Response
- QPI 3 – Positron Emission Tomography (PET CT) Staging
- QPI 4 – Cytogenetic Testing
- QPI 7 – Treatment of Grade 3b Follicular Lymphoma
- QPI 8 – Treatment for Stage 1a Diffuse Large B Cell Lymphoma
- QPI 9 – Treatment of Classical Hodgkin Lymphoma

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1. National Cancer Quality Programme

Better Cancer: Ambition and Action (2016)¹ details a commitment to delivering the national cancer quality programme across NHSScotland, with a recognised need for national cancer QPIs to support a culture of continuous quality improvement. Addressing variation in the quality of cancer services is pivotal to delivering improvements in quality of care. This is best achieved if there is consensus and clear indicators for what good cancer care looks like.

Small sets of cancer specific outcome focussed, evidence based indicators are in place for 19 different tumour types. These are underpinned by patient experience QPIs that are applicable to all, irrespective of tumour type. These QPIs ensure that activity is focused on those areas that are most important in terms of improving survival and individual care experience whilst reducing variation and supporting the most effective and efficient delivery of care for people with cancer. QPIs are kept under regular review and are responsive to changes in clinical practice and emerging evidence.

A programme to review and update the QPIs in line with evolving evidence is in place as well as a robust mechanism by which additional QPIs will be developed over the coming years.

1.1 Quality Assurance and Continuous Quality Improvement

The ultimate aim of the programme is to develop a framework, and foster a culture of, continuous quality improvement, whereby real time data is reviewed regularly at an individual Multi-Disciplinary Team (MDT)/Unit level and findings actioned to deliver continual improvements in the quality of cancer care. This is underpinned and supported by a programme of regional and national comparative reporting and review.

NHS Boards will be required to report against QPIs as part of a mandatory, publicly reported, programme at a national level. A rolling programme of reporting is in place, with approximately three national tumour specific summary reports published annually. These reports highlight the publication of the QPIs in the Cancer QPI Dashboard which includes comparative reporting of performance against QPIs at MDT/Unit level across NHSScotland, trend analysis and survival. This approach helps to overcome existing issues relating to the reporting of small volumes in any one year.

In the intervening years tumour specific QPIs are monitored on an annual basis through established Regional Cancer Networks and local governance processes, with analysed data submitted to Public Health Scotland (PHS) (previously ISD Scotland) for inclusion in the Cancer QPI Dashboard and subsequent national summary reports. This approach ensures that timely action is taken in response to any issues that may be identified through comparative reporting and systematic review.

2. Quality Performance Indicator Development Process

The QPI development process was designed to ensure that indicators are developed in an open, transparent and timely way. The development process can be found in appendix 1.

The Lymphoma QPI Development Group was convened in March 2012, chaired by Mr Matthew Barber, Consultant Surgeon, NHS Lothian. Membership of this group included clinical representatives drawn from the three regional cancer networks, Healthcare Improvement Scotland, ISD and patient/carer representatives. Membership of the development group can be found in appendix 2.

3. QPI Formal Review Process

As part of the National Cancer Quality Programme a systematic national review process has been developed, whereby all tumour specific QPIs published are subject to formal review following 3 years analysis of comparative QPI data.

Formal review of the Lymphoma QPIs was undertaken for the first time in May 2017. A Formal Review Group was convened, chaired by Mr Matthew Barber, Consultant Surgeon. Membership of this group included Clinical Leads from the three Regional Cancer Networks and can be found in appendix 3.

The 2nd Cycle of Formal Review commenced in September 2020 following reporting of 6 years of QPI data. This cycle of review is more selective and focussed on ensuring the ongoing clinical relevance of the QPIs. A Formal Review Group was convened with Mr Khaver Qureshi, Consultant Urological Surgeon, WoSCAN appointed as Clinical Advisor/Chair to the group. Membership of this group can be found in appendix 4.

The formal review process is clinically driven with proposals for change sought from specialty specific representatives in each of the Regional Cancer Networks. Formal Review meetings to discuss proposals will be arranged where deemed necessary. The review builds on existing evidence using expert clinical opinion to identify where new evidence is available, and a full public engagement exercise will take place where significant revisions have been made or new QPIs developed.

During formal review QPIs may be archived and replaced with new QPIs. Triggers for doing so include significant change to clinical practice, targets being consistently met by all Boards and publication of new evidence. Where QPIs have been archived, for those indicators which remain clinically relevant, data will continue to be collected to allow local / regional analysis of performance as required.

Any new QPIs have been developed in line with the following criteria:

- **Overall importance** – does the indicator address an area of clinical importance that would significantly impact on the quality and outcome of care delivered?
- **Evidence based** – is the indicator based on high quality clinical evidence?
- **Measurability** – is the indicator measurable i.e. are there explicit requirements for data measurement and are the required data items accessible and available for collection?

4. Format of the Quality Performance Indicators

QPIs are designed to be clear and measurable, based on sound clinical evidence whilst also taking into account other recognised standards and guidelines.

- Each QPI has a **short title** which will be utilised in reports as well as a fuller **description** which explains exactly what the indicator is measuring.
- This is followed by a brief overview of the **evidence base and rationale** which explains why the development of this indicator was important.
- The measurability **specifications** are then detailed; these highlight how the indicator will actually be measured in practice to allow for comparison across NHSScotland.

- Finally a **target** is indicated, this dictates the level which each unit should be aiming to achieve against each indicator.

In order to ensure that the chosen target levels are the most appropriate and drive continuous quality improvement as intended they will be kept under review and revised as necessary, if further evidence or data becomes available.

Rather than utilising multiple exclusions, a tolerance level has been built into the QPIs. It is very difficult to accurately measure patient choice, co-morbidities and patient fitness therefore target levels have been set to account for these factors. Further detail is noted within QPIs where there are other factors which influenced the target level.

Where 'less than' (<) target levels have been set the rationale has been detailed within the relevant QPI. All other target levels should be interpreted as 'greater than' (>) levels.

5. Supporting Documentation

A national minimum core dataset and a measurability specification document have been developed in parallel with the indicators to support the monitoring and reporting of Lymphoma QPIs. The updated document will be implemented for patients diagnosed with lymphoma on, or after, 1st October 2020.

6. Quality Performance Indicators for Lymphoma

QPI 1 – Radiological Staging

QPI Title:	Patients with lymphoma should be evaluated with appropriate imaging to detect the extent of disease, with timely reports available to guide treatment decision making.
Description:	Proportion of patients with lymphoma undergoing treatment with curative intent who undergo Computed Tomography (CT) of the chest, abdomen and pelvis or PET CT scanning prior to treatment, where the report is available within 3 weeks of radiology request.
Rationale and Evidence:	<p>Accurate staging is important to ensure appropriate treatment is delivered and futile interventions avoided.</p> <p>CT is recommended as the initial imaging investigation for all patients with lymphoma to detect extent of disease and guide treatment decision making. This should include CT of the chest, abdomen and pelvis. CT neck should also be undertaken where clinically appropriate. Intravenous contrast should be utilised unless contraindicated².</p>
Specifications	<p>Numerator: Number of patients with lymphoma undergoing treatment with curative intent who undergo CT of chest, abdomen and pelvis or PET CT scanning prior to treatment where the report is available within 3 weeks of radiology request.</p> <p>Denominator: All patients with lymphoma undergoing treatment with curative intent who undergo CT of chest, abdomen and pelvis or PET CT scanning prior to treatment.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • None.
Target:	<p>90%</p> <p>The tolerance within this target is designed to account for situations where imaging may be delayed due to factors of patient fitness or patient choice.</p>

QPI 2 – Treatment Response

QPI Title:	Patients with Diffuse Large B Cell Lymphoma (DLBCL) who are treated with curative intent should have their response to treatment evaluated with appropriate imaging.
Description:	Proportion of patients with DLBCL who are undergoing chemotherapy treatment with curative intent, who have their response to treatment evaluated with Computed Tomography (CT) scan of the chest, abdomen and pelvis or PET CT scan.
Rationale and Evidence:	<p>CT scanning is recommended as the most appropriate method of response assessment following chemotherapy for DLBCL² as treatment response may not be clinically obvious.</p> <p>Evidence suggests that mid-treatment evaluation is best practice, unless there is a good clinical response to treatment². Measurement of this is however not specifically included within this QPI.</p>
Specification:	<p>Numerator: Number of patients with DLBCL who are undergoing chemotherapy treatment with curative intent who undergo CT of chest, abdomen and pelvis or PET CT at end of chemotherapy treatment*.</p> <p>Denominator: All patients with DLBCL who are undergoing chemotherapy treatment with curative intent.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • Patients who died during treatment. • Patients with Primary Central Nervous System (CNS) Lymphoma.
Target:	<p>90%</p> <p>The tolerance within this target is designed to account for the fact that some patients will have a good clinical response to chemotherapy and will therefore not require an end of treatment scan. It also accounts for those patients who may not complete chemotherapy treatment due to factors of fitness.</p>

* Within the measurement of this QPI, CT scans within 6 weeks of the last day of the final cycle of chemotherapy, or within 3 months of final fraction of radiotherapy in patients undergoing combined modality treatment, will be classified as an end of treatment scan.

QPI 3 – Positron Emission Tomography (PET CT) Staging

QPI Title:	Patients with Classical Hodgkin Lymphoma (CHL) should be evaluated with PET CT scanning to detect the extent of disease, with timely reports available to guide treatment decision making.
Description:	Proportion of patients with Classical Hodgkin Lymphoma undergoing treatment with curative intent who undergo PET CT scan prior to first treatment, where the report is available within 3 weeks of radiology request.
Rationale and Evidence:	<p>Accurate staging is important to ensure appropriate treatment is delivered and futile interventions avoided.</p> <p>All newly diagnosed patients with CHL being considered for curative therapy should have a baseline PET CT scan³.</p> <p>A whole body PET CT scan is recommended for the diagnosis of CHL to assess the extent of disease and therefore identify the most appropriate treatment option⁴.</p>
Specifications:	<p>Numerator: Number of patients with CHL undergoing treatment with curative intent who undergo PET CT prior to first treatment where the report is available within 3 weeks of radiology request.</p> <p>Denominator: All patients with CHL undergoing treatment with curative intent who undergo PET CT prior to first treatment.</p> <p>Exclusions:</p> <ul style="list-style-type: none"> • None.
Target:	<p>95%</p> <p>The tolerance within this target is designed to account for situations where imaging may be delayed due to factors of patient fitness or patient choice.</p>

QPI 4 – Cytogenetic Testing

QPI Title:	Patients with Burkitt Lymphoma or Diffuse Large B-Cell Lymphoma (DLBCL) should have MYC testing (and BCL2/BCL6 testing where appropriate) as part of the diagnostic process.
Description:	<p>Proportion of patients with Burkitt Lymphoma or DLBCL undergoing treatment with curative intent who have MYC testing (and BCL2 / BCL6 testing where appropriate) as part of the diagnostic process.</p> <p>Please note: The specifications of this QPI are separated to ensure clear measurement of the following:</p> <ul style="list-style-type: none"> (i) Patients with Burkitt Lymphoma or DLBCL undergoing chemotherapy treatment with curative intent who have MYC testing; and (ii) Patients with DLBCL MYC rearrangement identified on FISH analysis undergoing chemotherapy treatment with curative intent who have BCL2/BCL6 testing with results reported within 3 weeks of commencing treatment.
Rationale and Evidence:	<p>Classical cytogenetic or Fluorescence in Situ Hybridization (FISH) analysis is essential for the diagnosis of Burkitt lymphoma⁵.</p> <p>Rearrangements of MYC in DLBCL are a strong prognostic factor and will guide treatment options and provide important information to help inform patients and carers about the nature of the disease and prognosis⁶.</p> <p>Deregulation of MYC in DLBCL, as occurs in translocations involving the long arm of chromosome 8, is highly associated with aggressive disease and a poor prognosis. Detection of such a translocation by FISH is an important prognostic factor and will often lead to a change in management⁶.</p> <p>Cases approaching 100% ki67 and with deregulation of p53 (p53+ p21-) need to be investigated for MYC rearrangements to exclude Burkitt lymphoma⁷. Rearrangements of MYC, particularly in association with t(14;18) remain a strong prognostic factor in DLBCL⁶.</p> <p>DLBCL should be tested for MYC rearrangement by FISH and, if detected, further testing should be performed for BCL2 and BCL6 rearrangements⁸.</p>
Specification (i):	<p>Numerator: Number of patients with Burkitt Lymphoma or DLBCL undergoing chemotherapy treatment with curative intent who have MYC testing.</p> <p>Denominator: All patients with Burkitt Lymphoma or DLBCL undergoing chemotherapy treatment with curative intent.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • No exclusions.

(Continued overleaf)

QPI 4 – Cytogenetic Testing (continued)

Specification (ii):	<p>Numerator: Number of patients with DLBCL MYC rearrangement identified on FISH analysis undergoing chemotherapy treatment with curative intent who have BCL2/BCL6 testing with results reported within 3 weeks of commencing treatment.</p> <p>Denominator: All patients with DLBCL MYC rearrangement identified on FISH analysis undergoing chemotherapy treatment with curative intent.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • No exclusions.
Target:	<p>Specifications (i) and (ii): 90%</p> <p>The tolerance within this target accounts for situations where there is no fresh tissue for cytogenetic analysis and there is insufficient tissue for FISH studies. Furthermore, MYC testing may not be appropriate if patients are not suitable for more intensive treatment, i.e. for factors of fitness or due to co-morbidities.</p>

QPI 5 – Lymphoma MDT

QPI Title:	Patients with lymphoma should be discussed by a multidisciplinary team following diagnosis.
Description:	Proportion of patients with lymphoma who are discussed at MDT meeting within 8 weeks of the pathology report being issued.
Rationale and Evidence:	<p>Evidence suggests that patients with cancer managed by a multi-disciplinary team have a better outcome. There is also evidence that the multidisciplinary management of patients increases their overall satisfaction with their care⁹.</p> <p>Discussion prior to definitive treatment decisions being made provides reassurance that patients are being managed appropriately.</p> <p>The QPI Group agreed that, due to the complex referral and diagnostic pathway for patients with lymphoma, an 8 week timeframe from diagnosis (when the pathology report is issued) is the most appropriate time period in which patients should be discussed at MDT.</p>
Specifications:	<p>Numerator: Number of patients with lymphoma discussed at the MDT within 8 weeks of the pathology report being issued.</p> <p>Denominator: All patients with lymphoma.</p> <p>Exclusions:</p> <ul style="list-style-type: none"> • Patients who died before first treatment. • Patients with primary cutaneous lymphoma.
Target:	<p>90%</p> <p>The tolerance within this target is designed to account for situations where additional complex diagnostic testing requires to be undertaken.</p>

QPI 11 – Hepatitis and HIV Status

QPI Title:	Virological testing for Human Immunodeficiency Virus (HIV), hepatitis B and C should be undertaken for patients undergoing systemic anti-cancer therapy (SACT).
Description:	Proportion of patients with lymphoma undergoing SACT who have hepatitis B [core antibody (anti-HBcAB) and surface antigen (HB-sAG)], hepatitis C and HIV status checked prior to treatment.
Rationale and Evidence:	<p>Clinical assessment and virological testing for HIV, hepatitis B and C should be undertaken for all patients as part of the diagnostic process and in all patients considered at risk of virus reactivation^{2,4}.</p> <p>All patients who are found to be hepatitis B should receive the appropriate anti-viral prophylaxis and those found to be HIV positive should receive appropriate anti-retroviral treatment before commencing treatment.</p>
Specifications:	<p>Numerator: Number of patients with lymphoma undergoing SACT who have hepatitis B [core antibody (anti-HBcAB) and surface antigen (HB-sAG)], C and HIV status checked prior to treatment.</p> <p>Denominator: All patients with lymphoma undergoing SACT.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • No exclusions.
Target:	<p>95%</p> <p>The tolerance within this target accounts for situations where patients undergo other treatments prior to systemic anti-cancer therapy (SACT).</p>

QPI 12 – Treatment Response in Hodgkin Lymphoma

QPI Title:	Patients with advanced Hodgkin Lymphoma who receive treatment with ABVD, BEACOPP or BEACOPDac [†] chemotherapy should have early assessment of response by appropriate imaging.
Description:	<p>Proportion of patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment, that have their treatment evaluated with PET CT scan after 2[‡] cycles of chemotherapy, and where the report is available within 3 working days.</p> <p>Please note: The specifications of this QPI are separated to ensure clear measurement of the following:</p> <ul style="list-style-type: none"> (i) Patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment that undergo PET CT scan after 2 cycles of chemotherapy. (ii) Patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment that undergo PET CT scan after 2 cycles of chemotherapy where the report is available within 3 working days.
Rationale and Evidence:	<p>PET CT demonstrates a higher level of accuracy compared with contrast CT scan and is therefore the most appropriate method of response assessment following chemotherapy in lymphoma patients⁹.</p> <p>Interim PET CT is recommended for patients with advanced Hodgkin Lymphoma undergoing treatment with ABVD chemotherapy or escalated BEACOPP/BEACOPDac as this is an indicator of predicted treatment success when continuing treatment^{8,10}.</p> <p>Evidence suggests that the optimal timing for PET CT to be carried out is following 2 cycles of ABVD or escalated BEACOPP/BEACOPDac chemotherapy⁸. It is important that the PET CT is reported in a timely manner to ensure there is no treatment delay.</p>
Specification (i):	<p>Numerator: Number of patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment that undergo PET CT scan after 2 cycles of chemotherapy.</p> <p>Denominator: All patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • Patients who die during treatment.

(Continued overleaf.....)

[†] ABVD, BEACOPP and BEACOPDac are chemotherapy regimens which include the following:
 ABVD - Doxorubicin, Bleomycin, Vinblastine and Dacarbazine.

BEACOPP - Bleomycin, Etoposide, Doxorubicin, Cyclophosphamide, Vincristine, Procarbazine and Prednisolone.

BEACOPDac - Bleomycin, Cyclophosphamide, Dacarbazine, Doxorubicin, Etoposide, Prednisolone and Vincristine

[‡] PET CT Scans should be carried out up to 7 days prior to the commencement of day 1 of the 3rd cycle of chemotherapy treatment.

QPI 12 – Treatment Response in Hodgkin Lymphoma (continued)

Specification (ii):	<p>Numerator: Number of patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment that undergo PET CT scan after 2 cycles of chemotherapy where the report is available within 3 working days.</p> <p>Denominator: All patients with advanced Hodgkin Lymphoma (stage 2B and above) who receive ABVD, BEACOPP or BEACOPDac chemotherapy treatment that undergo PET CT scan after 2 cycles of chemotherapy.</p> <p>Exclusions</p> <ul style="list-style-type: none"> • None
Target:	<p>80%</p> <p>The tolerance within this target is designed to account for those patients who may not complete chemotherapy treatment due to factors of fitness. It also accounts for those patients where PET CT may not be appropriate as the result will not alter management due to co-morbidities or fitness.</p>

QPI 14 – Clinical Trial and Research Study Access

QPI Title:	All patients should be considered for participation in available clinical trials/research studies, wherever eligible.
Description:	Proportion of patients diagnosed with lymphoma who are consented [§] for a clinical trial/research study.
Rationale and Evidence:	<p>Clinical trials are necessary to demonstrate the efficacy of new therapies and other interventions⁹. Evidence suggests improved patient outcomes when hospitals are actively recruiting patients into clinical trials¹¹.</p> <p>Clinicians are therefore encouraged to enter patients into well-designed trials and to collect longer-term follow-up data.</p> <p>High accrual activity into clinical trials is used as a goal of an exemplary clinical research site.</p> <p>The measurement of this QPI focuses on those patients who have consented in order to reflect the intent to join a clinical trial and demonstrate the commitment to recruit patients. Often patients can be prevented from enrolling within a trial due to stratification of studies and precise inclusion criteria identified during the screening process.</p>
Specifications:	<p>Numerator: Number of patients diagnosed with lymphoma consented for a clinical trial/research study.</p> <p>Denominator: All patients diagnosed with lymphoma.</p> <p>Exclusions:</p> <ul style="list-style-type: none"> • No exclusions.
Target:	15%

Please note:

The Clinical Trials and Research Study Access QPI is measured utilising SCRN data and PHS incidence data, as is the methodology currently utilised by the Chief Scientist Office (CSO) and NCRI. The principal benefit of this approach is that this data is already collected utilising a robust mechanism.

Utilising SCRN data allows for comparison with CSO published data and ensures capture of all eligible clinical trials and research studies, not solely first line treatment trials, as contained in the clinical audit data. Given that a significant proportion of clinical trials and research studies are for relapsed disease this is felt to be particularly important in driving quality improvement. This methodology utilises incidence as a proxy for all patients with cancer. This may slightly over, or underestimate, performance levels, however this is an established approach currently utilised by NHSScotland.

For further details of definitions, inclusion criteria and methodology used, please see the full Clinical Trials and Research Study Access QPI. This can be found at:

[Healthcare Improvement Scotland - Cancer Quality Performance Indicators](#)

[§] Consented is defined as patients who have given consent to participate in a clinical trial / research study subject to study specific screening for eligibility.

7. Survival

Improving survival forms an integral part of the national cancer quality improvement programme. Lymphoma survival analysis will be reported and analysed on a 3 yearly basis by Public Health Scotland (PHS). The specific issues which will be addressed will be identified by an expert group ahead of any analysis being undertaken, as per the agreed national cancer quality governance and improvement framework.

The Lymphoma QPI Group has identified, during the QPI development process, the following issues for survival analysis:

- 2 and 5 year overall survival

To ensure consistent application of survival analysis, it has been agreed that a single analyst on behalf of all three regional cancer networks undertakes this work. Survival analysis will be scheduled as per the national survival analysis and reporting timetable, agreed with the National Cancer Quality Steering Group and Scottish Cancer Taskforce. This reflects the requirement for record linkage and the more technical requirements of survival analyses which would make it difficult for individual Boards to undertake routinely and in a nationally consistent manner.

8. Areas for Future Consideration

The Lymphoma QPI Groups have not been able to identify sufficient evidence, or determine appropriate measurability specifications, to address all areas felt to be of key importance in the treatment of lymphoma, and therefore in improving the quality of care for patients affected by lymphoma.

The following areas for future consideration have been raised across the lifetime of the Lymphoma QPIs:

- Histology minimum panels for diagnosis of lymphoma.
- Production of final integrated report for all patients with lymphoma before treatment
- Access to a specific cancer nurse specialist.
- PET-CT scanning in patients with Diffuse Large B cell Lymphoma (DLBCL).
- Fertility preservation

9. Governance and Scrutiny

A national and regional governance framework to assure the quality of cancer services in NHSScotland has been developed; key roles and responsibilities within this are set out below. Appendices 5 and 6 provide an overview of these governance arrangements diagrammatically. The importance of ensuring robust local governance processes are in place is recognised and it is essential that NHS Boards ensure that cancer clinical audit is fully embedded within established processes.

9.1 *National*

- Scottish Cancer Taskforce
 - Accountable for overall national cancer quality programme and overseeing the quality of cancer care across NHSScotland.

- Healthcare Improvement Scotland
 - Proportionate scrutiny of performance.
 - Support performance improvement.
 - Quality assurance: ensure robust action plans are in place and being progressed via regions/Boards to address any issues identified.
- Public Health Scotland (PHS) (previously Information Services Division (ISD))
 - Publish national comparative report on tumour specific QPIs and survival for three tumour types per annum and specified generic QPIs as part of the rolling programme of reporting.

9.2 Regional – Regional Cancer Networks

- Annual regional comparative analysis and reporting against tumour specific QPIs.
- Support national comparative reporting of specified generic QPIs.
- Identification of regional and local actions required and development of an action plan to address regional issues identified.
- Performance review and monitoring of progress against agreed actions.
- Provide assurance to NHS Board Chief Executive Officers that any issues identified have been adequately and timeously progressed.

9.3 Local – NHS Boards

- Collect and submit data for regional comparative analysis and reporting in line with agreed measurability and reporting schedule (generic and tumour specific QPIs).
- Utilise local governance structures to review performance, develop local action plans and monitor delivery.
- Demonstrate continual improvements in quality of care through on-going review, analysis and feedback of clinical audit data at an individual multidisciplinary team (MDT) or unit level.

10. References

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11. Appendices

Appendix 1: QPI Development Process

Preparatory Work and Scoping

The preparatory work involved the development of a structured briefing paper by Healthcare Improvement Scotland. This paper took account of existing, high quality, clinical guidance and provided a basis for the development of QPIs.

The scope for development of Lymphoma QPIs and a search narrative were defined and agreed by the Lymphoma QPI Development Group. The table below shows the final search criteria used in the literature search.

Inclusion	Exclusion
<p>Topics (population/patient):</p> <ul style="list-style-type: none"> Hodgkin's Lymphoma, primary cutaneous lymphoma and non-Hodgkin's Lymphoma. <p>Topics (intervention):</p> <ul style="list-style-type: none"> Diagnosis Staging Imaging CNS prophylaxis Treatment of disease (including treatment with curative and non-curative intent) <p>Follow up management of disease Adults only (16 years of age or over)</p> <p>Date: 2005 to present day Language: English only</p>	<p>Topics: prevention, screening, communication, information sharing and support and palliative/end of life care.</p>

Table 1 – Lymphoma Search Criteria

A systematic search was carried out by Healthcare Improvement Scotland using selected websites and two primary medical databases to identify national and international guidelines.

Thirteen guidelines were appraised for quality using the AGREE II instrument¹². The instrument assesses the methodological rigour and precision used when developing a guideline. Two of the guidelines were not recommended for use. Of the remaining eleven guidelines, all were recommended for use.

Indicator Development

The Lymphoma QPI Development group defined evidence based, measurable indicators with a clear focus on improving the quality and outcome of care provided.

The Group developed QPIs using the clinical recommendations set out in the briefing paper as a base, ensuring all indicators met the following criteria:

- Overall importance** – does the indicator address an area of clinical importance that would significantly impact on the quality and outcome of care delivered?
- Evidence based** – is the indicator based on high quality clinical evidence?

- **Measurability** – is the indicator measurable i.e. are there explicit requirements for data measurement and are the required data items accessible and available for collection?

Engagement Process

A wide clinical and public engagement exercise was undertaken as part of development in May 2013 where the Lymphoma QPIs, along with accompanying draft minimum core dataset and measurability specifications, were made available on the Scottish Government website. During the engagement period clinical and management colleagues from across NHSScotland, patients affected by lymphoma cancer and the wider public were given the opportunity to influence the development of Lymphoma QPIs.

Draft documentation was circulated widely to professional groups, health service staff, voluntary organisations and individuals for comment and feedback.

Following the engagement period all comments and responses received were reviewed by the Lymphoma Cancer QPI Development Group and used to produce and refine the final indicators.

Appendix 2: Lymphoma QPI Development Group Membership (2012)

Name	Designation	Cancer Network/Base
Matthew Barber	Consultant Breast Surgeon (CHAIR)	SCAN
Iain Andrews	Consultant Radiologist	WoSCAN (Gartnavel General Hospital, Glasgow)
Kathy Burton	Cancer Audit Manager	SCAN (Queen Margaret Hospital, Fife)
Dominic Culligan	Consultant Haematologist	NOSCAN (Aberdeen Royal Infirmary)
Susan Cumming	Haematology Audit/ MDT Co-ordinator	NOSCAN (Raigmore Hospital, Inverness)
Cathy Dowdle	Advanced Nurse Practitioner	WoSCAN (Beatson West of Scotland Cancer Centre)
John Good	Patient Representative	
John Goodlad	Consultant Pathologist	SCAN (Western General Hospital, Edinburgh)
Bob Jackson	Consultant Pathologist	WoSCAN (Southern General Hospital, Glasgow)
Simon Jackson	Consultant Radiologist	SCAN (Western General Hospital, Edinburgh)
Neil Kernohan	Consultant Pathologist	NOSCAN (Ninewells Hospital, Dundee)
Mike Leach	Consultant Haematologist	WoSCAN (Beatson West of Scotland Cancer Centre)
Graham Macdonald	Consultant Clinical Oncologist	NOSCAN (Aberdeen Royal Infirmary)
Jean MacKenzie	Patient Representative	
Pam McKay	Consultant Haematologist	WoSCAN (Beatson West of Scotland Cancer Centre)
Jean McKnight	Haematology Research Nurse	SCAN (Western General Hospital, Edinburgh)
David Meiklejohn	Consultant Haematologist	NOSCAN (Ninewells Hospital, Dundee)
Brian Murray	Principal Information Development Manager	ISD
Noelle O'Rourke	Consultant Clinical Oncologist	WoSCAN (Beatson West of Scotland Cancer Centre)
Norman Pratt	Head of Laboratory Services, Human Genetics Unit	NOSCAN (Ninewells Hospital, Dundee)
Iona Scott	Project Manager	WoSCAN
Fiona Scott	Consultant Haematologist	SCAN (Western General Hospital, Edinburgh)
Evelyn Thomson	Regional Manager (Cancer)	WoSCAN
Heather Whately	Charge Nurse - Haematology	NOSCAN (Ninewells Hospital, Dundee)
Heather Wotherspoon	MCN Manager/Audit Facilitator	WoSCAN

Appendix 3: Lymphoma QPI Formal Review Group Membership (2017)

Name	Designation	Cancer Network/Base
Matthew Barber	Consultant Breast Surgeon (CHAIR)	SCAN
Jennifer Doherty	Project Co-ordinator	National Cancer Quality Programme
Carol Marshall	Information Manager	WoSCAN
David Meiklejohn	Clinical Lead	NOSCAN
Pam McKay	Clinical Lead	WoSCAN
Fiona Scott	Clinical Lead	SCAN
Lorraine Stirling	Project Officer	National Cancer Quality Programme

Formal review of the Lymphoma QPIs has been undertaken in consultation with various other clinical specialties e.g. oncology and pathology.

SCAN - South East Scotland Cancer Network
 NOSCAN - North of Scotland Cancer Network
 WoSCAN - West of Scotland Cancer Network

Appendix 4: Lymphoma QPI Formal Review Group Membership (2020)

Name	Designation	Cancer Network/Base
Khaver Qureshi	Consultant Urological Surgeon (CHAIR)	WoSCAN
Dominic Culligan	Clinical Lead	NCA
Jennifer Doherty	Project Co-ordinator	National Cancer Quality Programme
Peter Forsyth	Consultant Haematologist	NCA
Anne-Marie Hobkirk	Health Intelligence Senior Analyst	NCA
David Meiklejohn	Consultant Haematologist	NCA
Pam McKay	Consultant Haematologist	WoSCAN
Grant McQuaker	Clinical Lead	WoSCAN
Fiona Scott	Clinical Lead	SCAN
Lorraine Stirling	Project Officer	National Cancer Quality Programme
Christine Urquhart	Information Analyst	WoSCAN
Heather Wotherspoon	MCN Manager	WoSCAN

Formal review of the Lymphoma QPIs has been undertaken in consultation with various other clinical specialties.

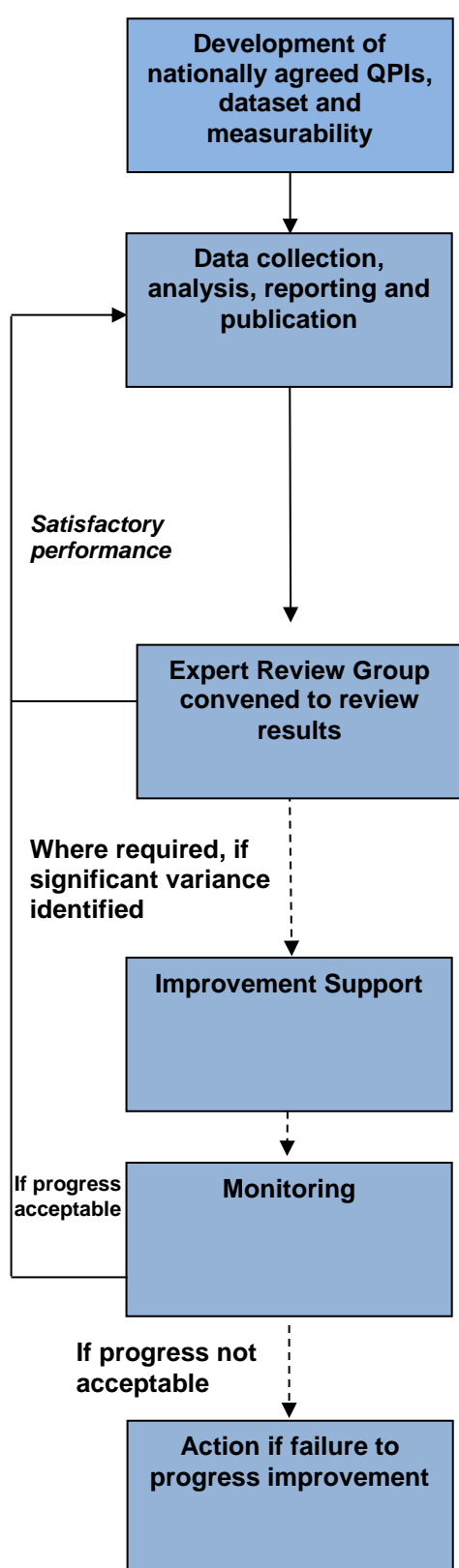
SCAN - South East Scotland Cancer Network

NCA - North Cancer Alliance

WoSCAN - West of Scotland Cancer Network

Appendix 5: 3 Yearly National Governance Process & Improvement Framework for Cancer Care

This process is underpinned by the annual regional reporting and governance framework (see appendix 6).



1. National QPI Development Stage

- QPIs developed by QPI development groups, which include representation from Regional Cancer Networks, Healthcare Improvement Scotland, ISD, patient representatives and the Cancer Coalition.

2. Data Analysis Stage:

- NHS Boards and Regional Cancer Advisory Groups (RCAGs)* collect data and analyse on yearly basis using nationally agreed measurability criteria and produce action plans to address areas of variance, see appendix 6.
- Submit yearly reports to ISD for collation and publication every 3 years.
- National comparative report approved by NHS Boards and RCAGs.
- ISD produce comparative, publicly available, national report consisting of trend analysis of 3 years data and survival analysis.

3. Expert Review Group Stage (for 3 tumour types per year):

- Expert group, hosted by Healthcare Improvement Scotland, review comparative national results.
- Write to RCAGs highlighting areas of good practice and variances.
- Where required NHS Boards requested to submit improvement plans for any outstanding unresolved issues with timescales for improvement to expert group.
- Improvement plans ratified by expert group and Scottish Cancer Taskforce.

4. Improvement Support Stage:

- Where required Healthcare Improvement Scotland provide expertise on improvement methodologies and support.

5. Monitoring Stage:

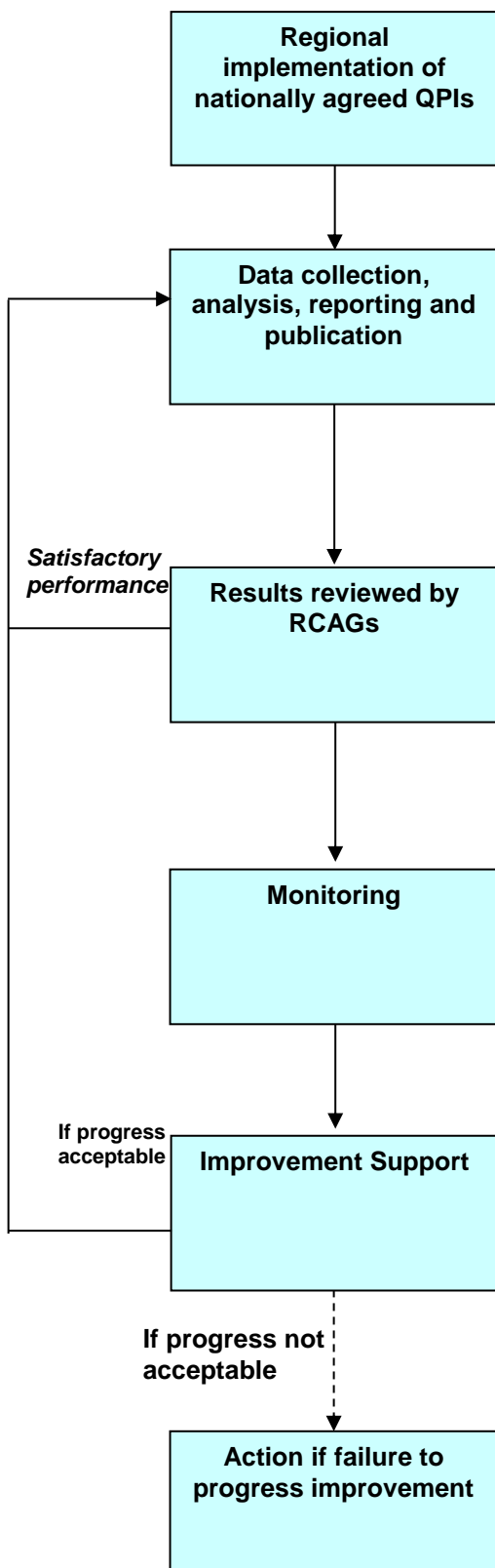
- RCAGs work with Boards to progress outstanding actions, monitor improvement plans and submit progress report to Healthcare Improvement Scotland.
- Healthcare Improvement Scotland report to Scottish Cancer Taskforce as to whether progress is acceptable.

6. Escalation Stage:

- If progress not acceptable, Healthcare Improvement Scotland will visit the service concerned and work with the RCAG and Board to address issues.
- Report submitted to Scottish Cancer Taskforce and escalation with a proposal to take forward to Scottish Government Health Department.

* The Regional Cancer Planning Group (South and East of Scotland) and the North Cancer Clinical Leadership Group (North Cancer Alliance) are equivalent to the Regional Cancer Advisory Group (RCAG) in the West of Scotland.

Appendix 6: Regional Annual Governance Process and Improvement Framework for Cancer Care



1. Regional QPI Implementation Stage:

- National cancer QPIs and associated national minimum core dataset and measurability specifications, developed by QPI development groups.
- Regional implementation of nationally agreed dataset to enable reporting of QPIs.

2. Data Analysis Stage:

- NHS Boards collect data and data is analysed on a yearly basis using nationally agreed measurability criteria at local/ regional level.
- Data/results validated by Boards and annual regional comparative report produced by Regional Networks.
- Areas of best practice and variance across the region highlighted.
- Yearly regional reports submitted to ISD for collation and presentation in national report every 3 years.

3. Regional Performance Review Stage:

- RCAGs* review regional comparative report.
- Regional or local NHS Board action plans to address areas of variance developed.
- Appropriate leads identified to progress each action.
- Action plans ratified by RCAGs.

4. Monitoring Stage:

- Where required, NHS Boards monitor progress with action plans and submit progress reports to RCAGs.
- RCAGs review and monitor regional improvement.

5. Improvement Support Stage:

- Where required Healthcare Improvement Scotland maybe requested to provide expertise to NHS Boards/RCAGs on improvement methodologies and support.

6. Escalation Stage:

- If progress not acceptable, RCAGs will escalate any issues to relevant Board Chief Executives. If progress remains unacceptable RCAGs will escalate any relevant issues to Healthcare Improvement Scotland.

* The Regional Cancer Planning Group (South and East of Scotland) and the North Cancer Clinical Leadership Group (North Cancer Alliance) are equivalent to the Regional Cancer Advisory Group (RCAG) in the West of Scotland.

Appendix 7: Glossary of Terms

Asymptomatic	Having no symptoms. You are considered asymptomatic if you: <ul style="list-style-type: none"> • Have recovered from an illness or condition and no longer have symptoms. • Have an illness or condition (such as early stage high blood pressure or glaucoma) but do not have symptoms.
BCL2/BCL6	BCL2 and BCL6 (B-cell chronic lymphocytic leukaemia/lymphoma) are genes that influence the behaviour of a B-cell lymphoma.
Burkitt Lymphoma	An aggressive (fast-growing) type of B-cell non-Hodgkin lymphoma that occurs most often in children and young adults. The disease may affect the jaw, central nervous system, bowel, kidneys, ovaries, or other organs. There are three main types of Burkitt lymphoma (sporadic, endemic, and immunodeficiency related).
Central Nervous System (CNS)	The brain and spinal cord.
Chemotherapy	The use of drugs that kill cancer cells, or prevent or slow their growth.
Chromosome	Part of a cell that contains genetic information.
Classical Hodgkin Lymphoma (CHL)	The most common type of Hodgkin lymphoma.
Clinical Trials	A type of research study that tests how well new medical approaches or medicines work. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.
CNS prophylaxis	Treatment given to prevent spread of disease to the central nervous system.
Combined modality treatment	The treatment of a disease or condition by several different means simultaneously or sequentially.
Co-morbidity	The condition of having two or more diseases at the same time.
Computed Tomography (CT)	An x-ray imaging technique, which allows detailed investigation of the internal organ of the body.
Contraindication/Contraindicated	A symptom or medical condition that makes a particular treatment or procedure inadvisable because a person is likely to have a bad reaction.
Curative intent	Treatment which is given with the aim of curing the cancer.
Cytogenetics	The study of chromosomes and chromosomal abnormalities.
Cytotoxic	Toxic to cells. This term is used to describe drugs which kill cancer cells or slow their growth.
Dermatology	A branch of medicine concerned with the study and treatment of disorders of the skin.
Diagnosis	The process of identifying a disease, such as cancer, from its signs and symptoms.
Diffuse Large B-Cell lymphoma (DLBCL)	A type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually aggressive (fast-growing). It is the most common type of non-Hodgkin lymphoma, and is marked by rapidly growing tumours in the lymph nodes, spleen, liver, bone marrow, or other organs.
Fluorescence in situ hybridization (FISH)	Provides researchers with a way to visualize and map the genetic material in an individual's cells, including specific genes or portions of genes. This is important for understanding a variety of chromosomal abnormalities and other genetic mutations.
Follicular Lymphoma	A type of non-Hodgkin lymphoma that is usually indolent (slow-growing) divided into 3 separate grades (1, 2 and 3).
Grading	The degree of malignancy of a tumour, i.e. how closely the cancer

	cells look like normal cells.
Haemato-oncology	A branch of medicine concerned with the study and treatment of cancers of the blood and blood-forming tissues.
Hepatitis B	A virus that causes hepatitis (inflammation of the liver). It is carried and passed to others through the blood and other body fluids.
Hepatitis C	A virus that causes hepatitis (inflammation of the liver). It is carried and passed to others through the blood and other body fluids. Although patients who are infected with hepatitis C virus may not have symptoms, long-term infection may lead to cirrhosis (scarring of the liver) and liver cancer. These patients may also have an increased risk for certain types of non-Hodgkin lymphoma.
Hickman line	A fine plastic cannula inserted under the skin of your chest into a vein to allow administration of drugs and repeated blood samples.
Hodgkin Lymphoma	Cancer of the lymphatic system. There are 2 main types of Hodgkin lymphoma; classical Hodgkin lymphoma and nodular lymphocyte predominant Hodgkin lymphoma.
Human Immunodeficiency Virus (HIV)	The cause of acquired immunodeficiency syndrome (AIDS).
Imaging	Medical imaging is process used to create images of the body for clinical purposes.
Immunohistochemistry (IHC)	A technique used to identify specific molecules in different kinds of tissue. The tissue is treated with antibodies that bind the specific molecule. These are made visible under a microscope by using a colour reaction, a radioisotope, colloidal gold, or a fluorescent dye. Immunohistochemistry is used to help diagnose diseases, such as cancer, and to detect the presence of micro-organisms. It is also used in basic research to understand how cells grow and differentiate (become more specialized).
Intravenous contrast	A substance administered directly into the bloodstream to enhance the visibility of structures on imaging.
Lymphatic system	Complex network of tubes (lymphatic vessels), glands (lymph nodes) and other organs including the spleen.
Lymphoma	Cancer of the lymphatic system. There are two main types of lymphoma – Hodgkin Lymphoma and non-Hodgkin Lymphoma.
Mediastinal	Relating to the mediastinum, the space in the chest cavity between the 2 pleural sacs.
Multi-disciplinary team meeting (MDT)	A meeting which is held on a regular basis, which is made up of participants from various disciplines appropriate to the disease area, where diagnosis, management, and appropriate treatment of patients is discussed and decided.
MYC	MYC is a regulator gene located on chromosome 8. Deregulation of MYC in diffuse large B-cell lymphoma, as occurs in translocations involving the long arm of chromosome 8, is highly associated with aggressive disease and a poor prognosis. Detection of such a translocation by Fluorescent in-situ hybridisation (FISH) is an important prognostic factor and will often lead to a change in management.
Nodal	Relating to lymph nodes.
Non-Hodgkin Lymphoma	Cancer of the lymphatic system. There are two main groups – high grade which are aggressive and fast growing and low grade which are slow growing. High grade lymphomas include: Diffuse Large B Cell Lymphoma (DLBCL), Peripheral T-cell Lymphoma, Burkitt's Lymphoma, Mantle Cell Lymphoma and AIDS-related

lymphoma. Low grade or indolent lymphomas include: Follicular Lymphomas, Waldenstrom's Lymphoma and Marginal Zone Lymphomas.

Oncology	The study of the biology and physical and chemical features of cancers. Also the study of the causes and treatment of cancers.
Pathology/Pathological	The study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of fluid and tissues obtained from the living patient by various methods, or at post mortem.
Positron Emission Tomography - Computed Tomography (PET-CT)	A highly specialised imaging technique used to produce a computerised image of metabolic activity of body tissues. It may be used to diagnose a cancer, show what stage it is, or see how well you are responding to treatment.
Primary cutaneous lymphoma	A rare type of non-Hodgkin lymphoma that presents in the skin with no evidence of extra cutaneous disease at the time of diagnosis.
Prognosis	An assessment of the expected future course and outcome of a person's disease.
Prognostic Factors	Factors, such as staging, tumour type or deprivation that may influence treatment effectiveness and outcomes.
Prophylaxis	An intervention used to prevent an unwanted outcome.
Radiological	The use of imaging technologies (such as ultrasound and magnetic resonance imaging) to diagnose or treat disease.
Radiotherapy	The use of radiation to treat disease.
Rituximab	Rituximab belongs to a group of cancer drugs known as monoclonal antibodies. Monoclonal antibodies recognise and lock on to specific proteins on the surface of cancer cells. This helps the body's immune system recognise the cancer cells and destroy them. Monoclonal antibodies are sometimes called targeted therapies because they target cancer cells.
Scottish Medicines Consortium (SMC)	The purpose of the SMC is to accept for use those newly licensed drugs that clearly represent good value for money to NHSScotland. SMC analyses information supplied by the drug manufacturer on the health benefits of the drug and justification of its price.
Staging	Process of describing to what degree cancer has spread from its original site to another part of the body. Staging involves clinical, surgical and pathology assessments.
Survival	The percentage of people in a study or treatment group who are alive for a certain period of time after they were diagnosed with or treated for a disease, such as cancer.
Symptomatic	Having to do with symptoms, which are signs of a condition or disease.
Systemic Anti-Cancer Therapy (SACT)	Treatment of cancer using drugs which prevent the replication or growth of cancer cells. This encompasses biological therapies and cytotoxic chemotherapy.
Translocation	A genetic change in which a piece of one chromosome breaks off and attaches to another chromosome. Sometimes pieces from two different chromosomes will trade places with each other.
Virological Testing	Used to diagnose infection, and most importantly guide treatment decisions and assess the virological response to antiviral therapy.