

West of Scotland Cancer Network



**Haemato-oncology
Managed Clinical Network**

Lymphoma

Regional Follow-up Guideline

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Issue date:	March 2026
Review date:	August 2027
Version:	V5.1 (replaces v5.0 August 2024)

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1. Introduction

The purpose of the Lymphoma Regional Follow-up Guideline is to promote consistency of practice across the West of Scotland (WoS) and to ensure that patients who have a high chance of cure from their underlying lymphoma receive appropriate follow-up care. This follow-up guideline has been developed for those patients with curable lymphomas eg Hodgkin lymphoma, diffuse large B cell lymphoma (DLBCL) and Burkitt lymphoma who achieve complete remission with initial therapy.

This follow-up guideline does not apply to patients who have received CAR T therapy for DLBCL or Mantle Cell lymphoma. These patients should be followed up as per the BMTU Shared Care SOP.

The principles of any revision to the follow-up guideline will continue to ensure that management of patients after initial treatment for lymphoma is:

- Patient-centred;
- Aligned to recognised current best practice;
- Equitable across the region;
- Clinically safe and effective; and
- Efficiently delivered.

The guideline continues to be developed on the basis that the key aims underpinning the purpose of follow-up are to:

- Manage and treat symptoms and complications;
- Encourage healthy lifestyle habits;
- Detect and treat recurrent disease; and
- Provide information to support person-centred care, best delivered in the form of a holistic needs assessment and care plan, and a treatment summary.

Follow-up practice has to be patient-centred and, ideally, supported by empirical evidence of improved outcomes and survival. In the absence of good quality evidence, care should be tailored to the needs and preference of patients. The construction of appropriate follow-up guidance requires balancing perceived patient needs with effective utilisation of resources.

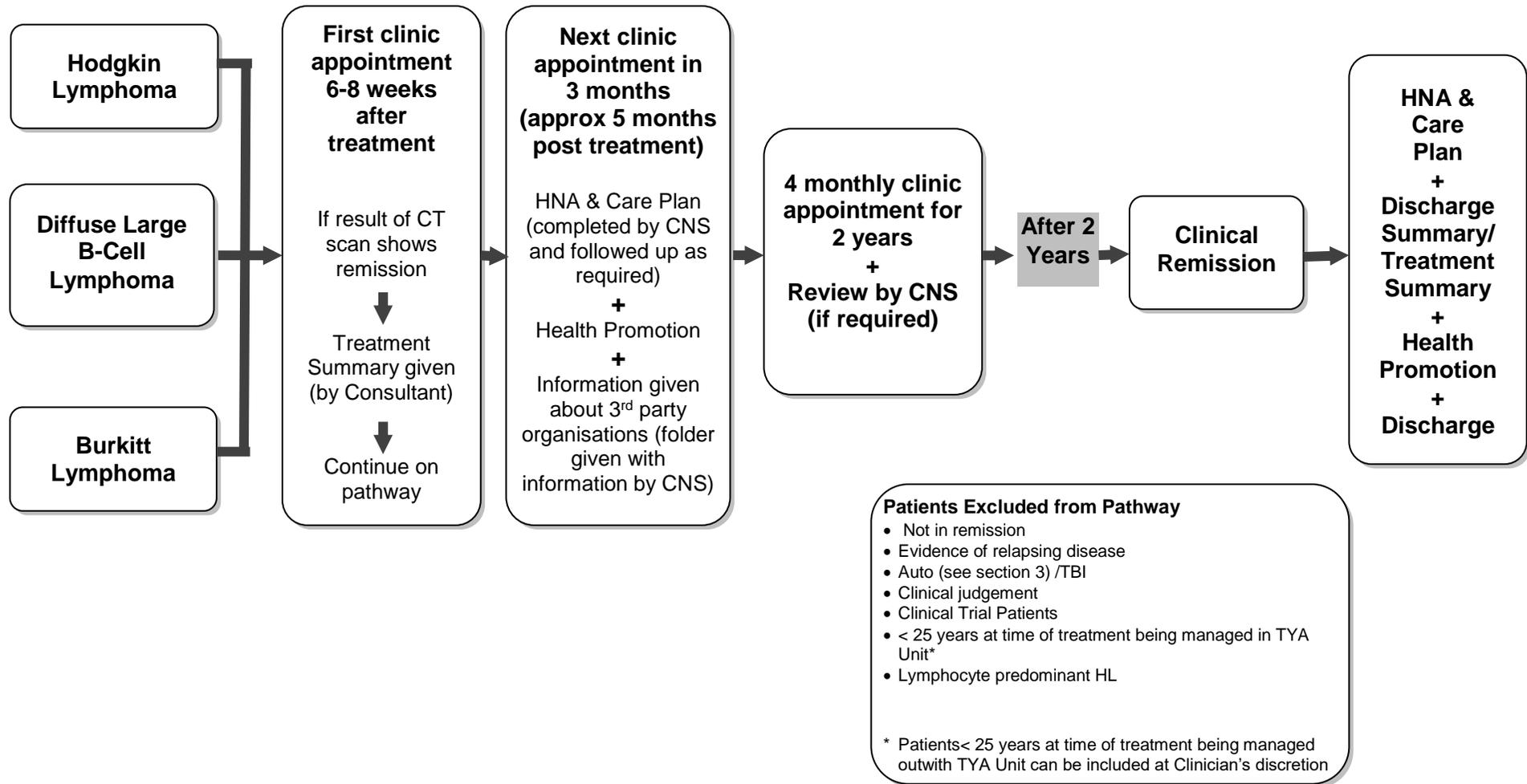
2. Risk Stratified Follow-up Pathway

The follow-up pathway is detailed in Figure 1. Supporting documents (HNA/Care plan - Appendix 1 and Treatment Summary - Appendix 2 or local IT supported system) are completed at specific time points on the patient pathway. Completed documents are given to the patient and copied to the patient's GP and case notes. All patients should have full re-staging evaluation on completion of first line therapy to confirm remission status and a post therapy check up at 6-8 weeks to ensure that all acute toxicity has subsided. Patients who receive radiotherapy should also be reviewed by Clinical Oncology at the end of treatment to assess recovery from any acute toxicity. These patients will be referred back to haematology for subsequent follow-up. All patients in complete remission after first line treatment should follow the pathway. Patients who obtain complete remission after BEAM autologous peripheral stem cell transplant follow a modified pathway (see section 3 and Figure 2).

A checklist has been provided to facilitate patient review at follow-up clinic appointments (Appendix 3). This is not proscriptive. After 2 years of follow-up, patients who remain in remission may be discharged from the clinic (Appendix 4 or local IT supported system). Particular points to note at discharge:

- Hodgkin Lymphoma patients should be aware that if a blood transfusion is required in the future they should receive irradiated blood and blood components. This is a lifelong requirement.
- All female patients who received mediastinal radiotherapy < 36 years of age should undergo breast screening to commence at age 25 years if treated < 17 years or 8 years post treatment if treated between 17 and 35 years. Pathway for referral to breast screening to be agreed at local Board level.

Figure 1: Risk stratified follow-up pathway for curative lymphoma patients who obtain complete remission with initial therapy

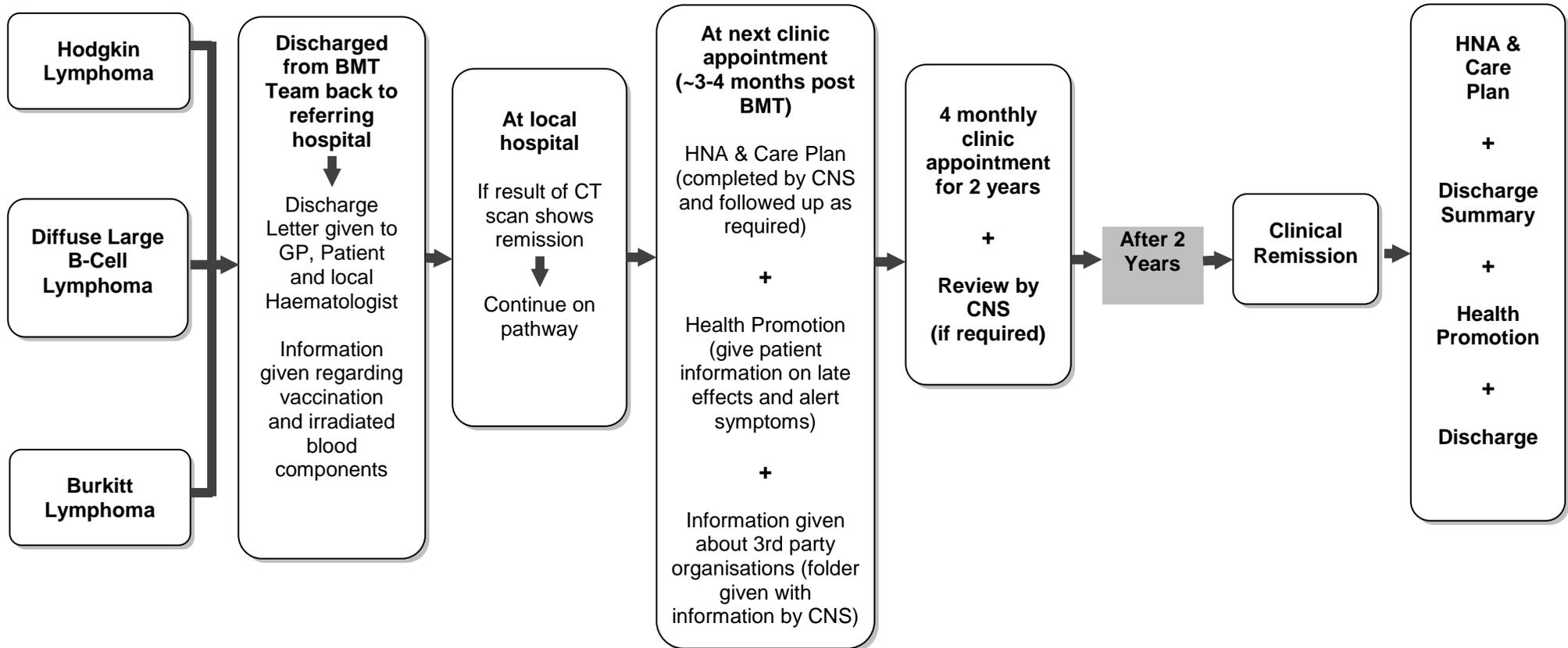


3. Follow-up Pathway Post BEAM Autologous Peripheral Blood Stem Cell Transplant

A separate follow-up pathway has been developed for curative lymphoma patients who obtain a complete remission after BEAM autologous peripheral blood stem cell transplant (Figure 2). These patients no longer attend a bone marrow transplant clinic post transplant and are discharged back to the referring hospital for ongoing follow-up. A discharge letter is given to the Patient, GP and local Haematologist regarding their treatment and information is given regarding vaccination and irradiated blood components. Patients will undergo CT scanning at their local hospital to confirm remission status. All patients in complete remission will follow the pathway. HNA/Care plans are completed at specific time points on the patient pathway (Appendix 1) and a discharge summary will be completed at the end of 2 year follow-up (Appendix 5).

Completed documents are given to the patient and copied to the patient's GP and case notes.

Figure 2: Risk stratified follow-up pathway for curative lymphoma patients who obtain complete remission after BEAM autologous peripheral blood stem cell transplant



Identifying your concerns

Discussed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

I have questions about my diagnosis/treatment that I would like to discuss.

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating or appetite
- Indigestion
- Sore or dry mouth
- Nausea or vomiting
- Sleep problems/nightmares
- Tired/exhausted or fatigued
- Swollen tummy or limb
- High temperature or fever
- Getting around (walking)
- Tingling in hands/feet
- Pain
- Hot flushes/sweating
- Dry, itchy or sore skin
- Wound care after surgery
- Changes in weight
- Memory or concentration
- Taste/sight/hearing
- Speech problems
- My appearance
- Sex/intimacy/fertility

Practical concerns

- Caring responsibilities
- Work and education
- Money or housing
- Insurance and travel
- Transport or parking
- Contact/communication with NHS staff
- Laundry/housework
- Washing and dressing
- Preparing meals/drinks
- Grocery shopping

Family/relationship concerns

- Partner
- Children
- Other relatives/friends

Emotional concerns

- Difficulty making plans
- Loss of interest/activities
- Unable to express feelings
- Anger or frustration
- Guilt
- Hopelessness
- Loneliness or isolation
- Sadness or depression
- Worry, fear or anxiety

Spiritual or religious concerns

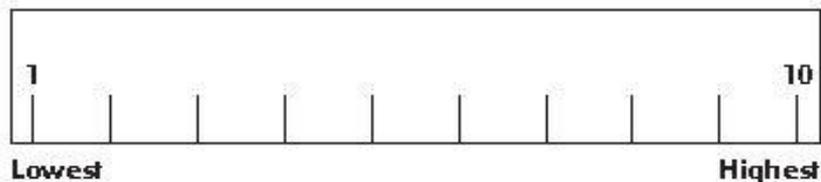
- Loss of faith or other spiritual concerns
- Loss of meaning or purpose of life
- Not being at peace with or feeling regret about the past

Lifestyle or information needs

- Support groups
- Complementary therapies
- Diet and nutrition
- Exercise and activity
- Smoking
- Alcohol or drugs
- Sun protection
- Hobbies
- Staying in/returning to work and education
- Making a will
- Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



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Care plan

Completed by: _____
 Date: _____
 Designation: _____
 Contact details: _____

Patient's name or label

Level 1: Score 0–3 Mild concerns

Discuss sources of concern with the patient, include information, contact details and monitor.

Level 2: Score 4–6 Moderate concerns

As above for level 1 and provide information and discuss with a colleague if necessary and signpost to support. Use second level assessment tool if appropriate e.g. HADs.

Level 3: Score 7–10 Significant concerns

As above in Level 1 and 2 and use second level assessment tool if appropriate e.g. HADs and refer to specialist services if required.

Overall score on the scale: _____

Main concerns	Score	Description of concern	Plan of action

Copies sent to: GP Patient

Next review due: _____



NHS Improvement

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Appendix 2: Treatment Summary (excluding BEAM auto)



TREATMENT SUMMARY

We have summarised your diagnosis, treatment and ongoing management plan below. It includes symptoms that you should be aware of and who to contact. Your GP will also receive a copy of this summary.

Section 1: Patient Details

CHI:	Surname:	First name(s):
Consultant:	Hospital:	
Diagnosis:	Date of completion of treatment:	
Date of Diagnosis:		

Section 2: Summary of Treatment

Chemotherapy regimen:	No. of courses:	Total Anthracycline Dose: mg/m ² (If applicable)
Radiotherapy area treated:	Dose:	Date of completion:
Any problems related to treatment (include current toxicities and long term problems from treatment):		
Treatment Aim: Curative	Current medications (ongoing hospital initiated drugs only):	
Pre-existing relevant co-morbidities:		

**Possible Treatment Toxicities/Late Effects
(Rare possibilities which Patient and GP should be aware of)**

- Infertility/Menopause
- Cardiac – long term cardiovascular risk
(Important to avoid risk factors, eg smoking; high blood pressure; diabetes)
- Hypothyroidism
(If received radiotherapy to neck or chest area)
- Secondary Cancers
(common cancers: breast;lung;skin – important to engage in available NHS screening programmes)
- Infectious Complications
(If you have had a splenectomy or radiotherapy to spleen)
- Lung Complications, including pulmonary fibrosis, interstitial pneumonitis and acute respiratory distress syndrome (if exposed to Bleomycin) – see section 8

These may be managed within primary care or trigger a referral to a specialist team when necessary.

Section 3: Secondary Care ongoing management plan

Reviewed every 4 months at Haematology Clinic for 2 years then discharged.

Add any further relevant follow-up information:

Alert Symptoms that Require Referral back to Specialist Team:

- B-symptoms
(fevers/drenching night sweats and/or unexplained weight loss)
- New unexplained widespread itch
- New lymph gland swelling
- Falling blood counts (GP reference)
- Rising LDH (GP reference)

Section 4: Contact for re-referrals or queries

First Contact: CNS (insert name and telephone number):

Second Contact: Haematology Secretary telephone number:

Section 5: Referrals made to other services

Please list:

Section 6: Required GP actions

Annual flu vaccination as per GP vaccination programme.

Complete as required and note that patient will be reviewed at clinic in the first 2 years.

Please list any GP actions:

Section 7: Summary of information given to patient about their cancer and future progress

Holistic Needs Assessment (HNA) to be completed at next clinic appointment and information will be given regarding 3rd party organisations and health and wellbeing.

Please add details of any further information given to the patient:

Section 8: Additional information including issues relating to lifestyle and support needs

Educate patient on avoidance of sunburn and use of skin protection (SPF30 or above). Attend GP if new skin lesions develop.

For patients exposed to bleomycin there is a small risk of future lung complications. These include pulmonary fibrosis, interstitial pneumonitis and acute respiratory distress syndrome. Risk factors for these are thought to include smoking, inhaled toxic compounds, radiotherapy to lung tissue (including total body irradiation) and inhalation of high concentrations of oxygen for prolonged periods of time (several hours). Inhaled oxygen will be used by anaesthetists and so patients should inform their surgical team about previous bleomycin exposure if an operation is planned. In addition patients are advised not to SCUBA dive unless reviewed by an accredited doctor as part of a fitness to dive assessment. If the occupation of a patient includes the use of breathing apparatus then this should be discussed with their work occupational health team.

Add any relevant information, e.g. special transfusion requirements:

Irradiated blood and blood components for Hodgkin Lymphoma patients
(This is a lifelong requirement)

Consultant Name:

Signature: *Physical Signature
Required*

Date:

Copy to GP and Patient
Copy in case notes

Appendix 3: Clinic Visit Checklist

Symptoms	<ul style="list-style-type: none"> • Ask about general well being and new symptoms, particularly B symptoms. • Other investigations should be arranged in response to new symptoms/signs of disease, abnormal routine investigations or in the context of trial protocols. • Encourage patient to make earlier appointment if new problems arise.
Medicines	Ask about current medications.
Examination	Examine for peripheral lymphadenopathy, hepatomegaly, splenomegaly and abdominal masses
WHO Performance	Record WHO performance status
FBC,BIO, LDH	Check FBC and biochemical profile, including LDH
TFT	Check thyroid function tests annually if previous radiotherapy to neck or mediastinum.
Fertility/Menses	<ul style="list-style-type: none"> • Enquire about menstruation and menopausal symptoms – if troublesome symptoms consider referral to gynaecology. • Check baseline FSH/LH in women who are >35 yrs when receiving chemotherapy if periods not returned within 3-6 months. • Patients who have had orchidectomy and irradiation of contralateral testis are likely to develop low testosterone levels within 3-6 months of completion of treatment and many will already be hypogonadal prior to irradiation. It is recommended that baseline serum LH and testosterone be checked at the end of chemotherapy, and referral made to endocrinology after completion of all treatment.
New Diagnoses	Record any new diagnoses, including second malignancy, occurring since previous visit
Cardiovascular Risks	<p>Ensure patients >45 years who received anthracycline drugs and/or mediastinal radiotherapy are attending their GP for monitoring of blood pressure, cholesterol and glucose at least annually. Consider referral to cardiology if patient has clinically concerning symptoms.</p> <p>Echocardiogram</p> <ul style="list-style-type: none"> • Consider if clinical suspicion of cardiotoxicity in patients treated with anthracycline or mediastinal radiotherapy. • Consider repeating prior to discharge if base line pre-chemotherapy echocardiogram showed abnormalities and patient received anthracycline-containing chemotherapy.
Vaccines (GP)	<ul style="list-style-type: none"> • Ensure all patients receive GP recommended vaccines. • Post transplant patients may need additional vaccines – refer to policy. • Patients post splenectomy or radiotherapy to the spleen require appropriate vaccinations eg pneumovax, haemophilus influenza and meningococcal vaccines.
Lifestyle	Advise on smoking cessation, exercise, avoidance of sunburn (investigate any suspicious skin lesions promptly).
NHS Screening	<ul style="list-style-type: none"> • Ensure uptake of all NHS screening programmes e.g. cervical, breast, colorectal. • Encourage all females to examine their breasts regularly.
Dental Health	Ensure patients are receiving careful dental follow-up, especially those who had previous neck or oropharyngeal irradiation

Appendix 4: Clinic Discharge Summary (excluding BEAM Auto)



CLINIC DISCHARGE SUMMARY

The treatment you have had for your lymphoma has gone very well and you no longer need to attend a clinic on a regular basis.

We have summarised your diagnosis, treatment and on-going management plan below. It includes symptoms that you should be aware of and who to contact. Your GP will also receive a copy of this summary.

We may want to contact you in the future to ask how you are. If you are happy for us to do this, please let the secretaries know if you change address. Their telephone number is:

Section 1: Patient Details

CHI:	Surname:	First name(s):
Consultant:	Hospital:	
Diagnosis:	Date of completion of treatment:	
Date of Diagnosis:		

Section 2: Summary of Treatment

Chemotherapy regimen:	No. of courses:	Total Anthracycline Dose: mg/m ² (If applicable)
Radiotherapy area treated:	Dose:	Date of completion:
Any problems related to treatment:		
Treatment aim: Curative	Current medications (ongoing hospital initiated drugs only):	
Pre-existing relevant co-morbidities:		

**Possible Treatment Toxicities / Late Effects
(Rare possibilities which Patient and GP should
be aware of)**

- Infertility/Menopause
- Cardiac – long term cardiovascular risk
(Important to avoid risk factors, e.g. smoking; high BP; diabetes)
- Hypothyroidism
(If received radiotherapy to neck or chest area)
- Secondary cancers
(common cancers: breast; lung; skin – important to engage in available NHS screening programmes)
- Infectious complications
(If you have had a splenectomy or radiotherapy to spleen)
- Lung complications, including pulmonary fibrosis, interstitial pneumonitis and acute respiratory distress syndrome (If exposed to Bleomycin) – see section 4

These may be managed within Primary Care or trigger a referral to a specialist team when necessary.

Alert Symptoms that require referral back to Specialist Team

- B-symptoms
(fevers/drenching night sweats and/or unexplained weight loss)
- New unexplained widespread itch
- New lymph gland swelling
- Falling blood counts (For GP reference)
- Rising LDH (For GP reference)

Section 3: Recommendations for GP in addition to GP Cancer Care Review

- Health Promotion
(Smoking cessation; weight control; exercise)
- Thyroid Function Test Annually Yes No
(at risk of developing hypothyroidism)
- Any swelling/lymphadenopathy should be discussed with Haematologist and consider re-referral for investigation
- BP, cholesterol/glucose monitoring annually from age of >45years old if received anthracycline chemotherapy and/or mediastinal radiotherapy. Consider referral to cardiology if patient has clinically concerning symptoms.
- Health protection measures – annual flu vaccination as per GP vaccination programme. Routine dental check-up. Advice on skin protection.
- Cancer screening – breast, bowel, cervical as per NHS screening programmes.
- Breast screening for patients receiving mediastinal radiotherapy <36 years of age
(Check with patient that they have received an appointment regarding this)

• Has the patient had: Splenectomy: Yes No

Has the patient had: Radiotherapy to Spleen: Yes No

If 'Yes', patient requires Pneumovax, Haemophilus Influenza and Meningococcal vaccines

Section 4: Additional information including issues relating to lifestyle and support needs

Educate patient on avoidance of sunburn and use of skin protection (SPF 30 or above). To attend GP if new skin lesions develop.

For patients exposed to bleomycin there is a small risk of future lung complications. These include pulmonary fibrosis, interstitial pneumonitis and acute respiratory distress syndrome. Risk factors for these are thought to include smoking, inhaled toxic compounds, radiotherapy to lung tissue (including total body irradiation) and inhalation of high concentrations of oxygen for prolonged periods of time (several hours). Inhaled oxygen will be used by anaesthetists and so patients should inform their surgical team about previous bleomycin exposure if an operation is planned. In addition patients are advised not to SCUBA dive unless reviewed by an accredited doctor as part of a fitness to dive assessment. If the occupation of a patient includes the use of breathing apparatus then this should be discussed with their work occupational health team.

Add any relevant information, e.g. special transfusion requirements:

Irradiated blood and blood components for Hodgkin Lymphoma patients

(This is a lifelong requirement)

Section 5: Referrals made to other services

Please list:

Section 6: Secondary Care ongoing management plan

Discharged from Haematology clinic. Quick access back into system if required.

Contact for re-referrals or queries:

GP first contact (insert name/telephone number):

Haematology contact telephone number:

Section 7: Summary of information given to patient about their cancer and future progress

Please add any relevant details including written information given to patient:

Holistic Needs Assessment (HNA) completed Yes No

If yes, please send copy of HNA and Care Plan to GP.

Consultant Name:

Signature: *Physical Signature
Required*

Date:

CNS Name:

Signature: *Physical Signature
Required*

Date:

Copy to GP and Patient
Copy in case notes

Appendix 5: Clinic Discharge Summary – BEAM Auto



CLINIC DISCHARGE SUMMARY

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Section 1: Patient Details

CHI:	Surname:	First name(s):
Consultant:	Hospital:	
Diagnosis:	Date of completion of treatment:	
Date of Diagnosis:		

Section 2: Summary of Treatment

Chemotherapy regimen:	No. of courses:	Total Anthracycline Dose: mg/m^2 (If applicable)
Radiotherapy area treated:	Dose:	Date of completion:
Transplant: Autologous Peripheral Blood Stem Cell Transplant	Conditioning chemotherapy: BEAM (Carmustine, Etoposide, Cytarabine, Melphalan)	Date of transplant:
Any problems related to treatment:		
Treatment aim: Curative	Current medications (ongoing hospital initiated drugs only):	
Pre-existing relevant co-morbidities:		

**Possible Treatment Toxicities / Late Effects
(Rare possibilities which Patient and GP
should be aware of)**

- Infertility/Menopause
- Cardiac – long term cardiovascular risk
(Important to avoid risk factors, e.g. smoking;
high BP; diabetes)
- Hypothyroidism
(If received radiotherapy to neck or chest
area)
- Secondary cancers
(common cancers: breast; lung; skin –
important to engage in available NHS
screening programmes)
- Infectious complications
(If you have had a splenectomy or
radiotherapy to spleen)
- Lung complications, including pulmonary
fibrosis, interstitial pneumonitis and acute
respiratory distress syndrome (If exposed to
Bleomycin) – see section 4

**These may be managed within Primary Care
or trigger a referral to a specialist team when
necessary.**

**Alert Symptoms that require referral back to
Specialist Team**

- B-symptoms
(fevers/drenching night sweats and/or
unexplained weight loss)
- New unexplained widespread itch
- New lymph gland swelling
- Falling blood counts (For GP reference)
- Rising LDH (For GP reference)

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(Smoking cessation; weight control; exercise)
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(at risk of developing hypothyroidism)
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- BP, cholesterol/glucose monitoring annually from age of >45years old if received anthracycline chemotherapy and/or mediastinal radiotherapy. Consider referral to cardiology if patient has clinically concerning symptoms.
- Health protection measures – annual flu vaccination as per GP vaccination programme. Routine dental check-up. Advice on skin protection.
- Cancer screening – breast, bowel, cervical as per NHS screening programmes
- Breast screening for patients receiving mediastinal radiotherapy <36 years of age
(Check with patient that they have received an appointment regarding this)
- Has the patient had: Splenectomy: Yes No
Has the patient had: Radiotherapy to Spleen: Yes No

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GP first contact (insert name/telephone number):

Haematology contact telephone number:

Section 7: Summary of information given to patient about their cancer and future progress

Please add any relevant details including written information given to patient:

Holistic Needs Assessment (HNA) completed Yes No

If yes, please send copy of HNA and Care Plan to GP.

Consultant Name:

Signature: *Physical Signature
Required*

Date:

CNS Name:

Signature: *Physical Signature
Required*

Date:

Copy to GP and Patient
Copy in case notes