

West of Scotland Cancer Network



**Haemato-oncology
Managed Clinical Network**

Acute Leukaemia

Regional Follow-up Guideline

Prepared by:	Dr N Heaney
Approved by:	Haemato-oncology MCN/Regional Cancer Clinical Leads Group/Regional Cancer Advisory Group
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1. Introduction

The purpose of a regional follow-up guideline is to promote consistency of practice across the West of Scotland (WoS) and to ensure that patients who have received curative treatment for a diagnosis of acute leukaemia receive appropriate follow-up care.

This follow-up guideline has been developed for those patients with Acute Lymphoblastic Leukaemia (ALL) or Acute Myeloid Leukaemia (AML) who have received treatment with curative intent and achieved complete remission with initial intensive therapy. Patients who have received a haemopoietic stem cell transplant, will be followed up as per the WoS Haemato-oncology MCN guideline 'Recommended Screening and Preventative Practices for Adult Long-term Survivors after Allogeneic Haemopoietic Stem Cell Transplant (HCT) and Total Body Irradiation (TBI) Autografts'.

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

- detect recurrent disease;
- monitor for late effects of treatment;
- modify other life style risk factors;
- provide holistic needs assessment and care plan; and
- provide information, best delivered in the form of a treatment summary.

2. Background

There has been an improvement in survival rates following treatment for acute leukaemia over recent decades. This is particularly evident in the treatment of childhood ALL. As a consequence of this, there are an increasing number of leukaemia survivors. With time, the risk of relapse declines and there may be a shift in focus from early detection of relapse to monitoring for late effects. A late effect is considered to be a complication related to therapy that has developed subsequent to completion of treatment and that is not related to relapse of disease. Acute treatment related toxicities, such as osteonecrosis, portal hypertension and pancreatitis may have a long-term impact on quality of life after treatment, though are not considered late effects and are not detailed in this guideline.

The treatments for ALL and AML are separated in this guideline. There are, however, common themes to the follow-up of each condition.

Much of the literature for follow-up guidance applies to survivors of paediatric and adolescent cancer e.g. Children's Oncology Group (COG) [1], Children's Cancer and Leukaemia Group (CCLG) [2] and Scottish Intercollegiate Guidelines Network (SIGN) [3]. These guidelines do, however, contain advice relevant to the population group as a whole and are referred to here.

2.1 Transition Care

There may be patients referred to adult haematology clinics who were treated as children for leukaemia. For those attending for the first time to adult services, it is important to understand the follow-up process they and their parents will have been used to. At completion of treatment in the Royal Hospital for Children (RHC) Glasgow, patients are monitored in a specific late effects clinic, with transition to adult services occurring from aged 16 years. However many patients choose to remain in paediatric services until they finish school at 18 years. RHC patients have the option to transfer to the Teenager and Young Adult (TYA) late effects clinic at the Beatson until aged 25 years or to be referred directly to local services. Within the paediatric

late effects service they will have blood taken (by finger prick) for full blood count (FBC) and will have height and weight monitored with results entered onto a growth chart. Issues of fertility, cardiovascular disease and second malignancies will have been discussed – though often these discussions are with parents rather than patients. It should be expected that the team within the adult sector accepting patients who transition from paediatric services will be provided with a complete treatment summary. This should include guidance on any expected long term effects.

2.2 Holistic Assessment

Any cancer experience, whether it is as a child, teenager or adult may have an impact on future well being. This may manifest in a number of ways including educational difficulties, lack of employment and/or psychiatric conditions such as depression. A general assessment of holistic needs (see Appendix 1 for example) may enable detection, whilst the associated discussion and care plan will determine if a low level intervention such as buddying, support group or group exercise class is appropriate, or whether more formal interventions such as counselling, psychology, cognitive rehabilitation etc. are required. It is recommended that a HNA and care plan is completed at the end of initial treatment / start of the follow-up pathway, with information given to the patient regarding organisations that support health and wellbeing.

3. Acute Lymphoblastic Leukaemia (ALL)

ALL is predominantly a disease of children, teenagers and young adults with approximately two-thirds younger than 25 years at diagnosis and children aged 1-5 years comprising the most frequent age-group affected. For this reason many adult patients undergoing late effects monitoring following ALL therapy were treated as children.

3.1 Early Detection of Relapse

Published evidence demonstrates that relapse of ALL is more likely to occur within 5 years however very late relapses (>10 years) are reported to occur [4]. Relapse of ALL may present with bone marrow failure and/or extramedullary disease. For this reason it is reasonable to monitor FBC in those patients attending for review up to 5 years. Note should be taken of any new reported symptoms such as headache and clinical signs such as lymphadenopathy or testicular swelling. Routine radiological investigations are not necessary in the absence of new symptoms or signs.

3.2 Monitoring for Late Effects

Conventional ALL therapy is multi-agent and will include exposure to steroid, anthracycline, alkylating agent, vinka alkaloid, asparaginase, thiopurine, methotrexate (including intra-theal) and cytosine arabinoside. Modern non-stem-cell transplant protocols do not expose patients to prophylactic cranial radiotherapy.

3.2.1 Cardiovascular disease

There is evidence that anthracyclines are a cause of cardiac toxicity which may manifest during treatment (early) or after treatment is completed (late cardiotoxicity). Late cardiotoxicity may be symptomatic (e.g. cardiomyopathy, arrhythmias) or asymptomatic. There is evidence that early toxicity and asymptomatic late toxicity are risk factors for symptomatic late toxicity. The cumulative dose of anthracycline to which the patient has been exposed is important, though there are confounding factors to many of the studies that support this [5,6]. SIGN adopts the statement that those receiving a cumulative dose of $\geq 250\text{mg/m}^2$ are considered at high risk which equates to a 5.2-fold excess risk of future symptomatic disease [3].

- Transthoracic echocardiogram (ECHO) is an appropriate modality to use as screening for late cardiotoxicity.
- Patients who were exposed to anthracyclines as a child (<18 years) should be screened for cardiac dysfunction. The screening frequency recommended by SIGN 132 is 5-yearly as a minimum.
- Patients treated for adult onset leukaemia should be considered for screening for cardiac dysfunction. Particular groups in whom this may be beneficial include women of child-bearing potential, patients receiving higher cumulative doses of anthracycline

(>250mg/m²) and patients with other risk factors for cardiovascular disease. An appropriate screening time would be at time of completion of therapy and then 5 years later.

- Patients with asymptomatic or symptomatic cardiac dysfunction should have ECHO surveillance tailored to the clinical scenario with advice being sought from a cardiologist.
- Patients treated with anthracyclines who become pregnant should have an ECHO performed during pregnancy.

It is considered good practice to modify other known risk factors for cardiac dysfunction for example control of hypertension, diabetes, obesity, hypercholesterolaemia, smoking cessation and discouraging a sedentary lifestyle [3].

3.2.2 Metabolic syndrome

Some studies indicate that there is an increased risk of developing metabolic syndrome in those treated as children for ALL. This risk is highest (though not restricted to) in those patients who have received a stem cell transplant (SCT) and/or cranial irradiation [3].

Patients should have annual assessment of blood pressure and recording of the body mass index (BMI). Fasting glucose and lipids should be performed in overweight patients every 2 years (every 5 years in those with a healthy BMI). Management of metabolic syndrome should follow guidance for the general population and is best delivered through primary care [3].

3.2.3 Fertility

The cumulative chemotherapy exposure for ALL in both adults and children is not considered a high risk for infertility. An exception to this is patients who receive testicular or cranial irradiation or who undergo SCT. Few patients will have had the opportunity to undergo fertility preserving procedures prior to commencing therapy.

- Male patients should be offered the opportunity to have their fertility assessed following completion of therapy. Serum FSH provides an indirect measure of spermatogenesis; serum LH and testosterone a measure of Leydig cell function. However, sperm analysis delivered through local fertility services will provide a more direct assessment of fertility.
- Female patients who continue to menstruate following completion of therapy should be reassured that they are likely to have maintained fertility. The fertility window may however be shorter than had they not had chemotherapy, with menopause occurring at an earlier age. All female patients of child-bearing age should therefore be offered the opportunity for fertility assessment at their local specialist gynaecology service. Patients who may particularly benefit from this are those from families where there is a history of early menopause.
- Female patients who were pre-menopausal prior to treatment and who do not restart menstruation within 6 months of completing therapy should be offered referral to a specialist clinic.
- All patients who have received testicular radiation and/or cranial irradiation are at risk of future endocrine late effects and should be referred for assessment at their local endocrinology clinic. This referral should include details of radiotherapy site and dose received.

3.2.4 Vaccinations

Patients treated as children should have undergone a standard childhood re-vaccination protocol at 6 months following completion of treatment. Vaccinations will have been delivered through primary care. For patients treated as adults who have not undergone SCT routine re-vaccination is not recommended, other than engagement with the national annual flu-vaccination programme.

3.2.5 Bone health

Children who have received ALL therapy are at risk of future low bone mineral density. Groups at particular risk are females, those >10 years at diagnosis and those exposed to

cranial irradiation and/or SCT. Low levels of physical activity, reduced vitamin D levels, poor nutrition and obesity are contributing factors [3].

- Young patients transitioning to adult follow-up within 2 years of completion of ALL therapy should have bone mineral density evaluation.
- Routine evaluation of bone mineral density in adult patients is not required unless the clinical scenario is of concern (e.g. recurrent fractures).
- Patients with reduced bone mineral density should be referred to endocrine services.
- Patients should be encouraged to eat a healthy diet, perform regular exercise and to maintain a healthy BMI.
- Patients should have vitamin D levels assessed annually in the first 2 years following treatment completion with vitamin D supplementation prescribed if levels suboptimal.

3.3 Detection of Subsequent Primary Cancers

Chemotherapy exposure is associated with an increased risk of subsequent primary cancers. In particular this risk is associated with cumulative exposure to alkylating agents and epipodophyllotoxins. The risk is higher in those exposed to radiotherapy, where most subsequent cancers will occur in the radiotherapy field [3,7].

- Healthcare professionals should adopt a high index of suspicion of subsequent primary cancers when assessing patients who have received prior chemotherapy.
- In the absence of radiotherapy exposure, no routine additional cancer screening is required other than that which is applied to the general population.
- Patients should be discouraged from smoking and should adopt safe practice in the sun.
- Patients who had cranial irradiation for childhood ALL are at increased risk of meningioma.

4. Acute Myeloid Leukaemia (AML)

AML is predominantly a disease of older adults with approximately two thirds of patients being older than 65 years at diagnosis. The majority of patients are likely to have additional co-morbidities that precede the diagnosis of AML.

4.1 Early Detection of Relapse

Published evidence demonstrates that the risk of relapse of AML in those achieving remission declines significantly after 2 years and is very rare after 5 years from achievement of complete remission (CR) [8].

Relapse of AML is most likely to present with bone marrow failure. For this reason it is appropriate to monitor FBC in those patients attending clinic for review, particularly in the first 2 years from CR. The frequency of attendances in the first 2 years is likely to be individually determined dependent on the perceived risk of relapse for each patient, taking into account cytogenetics, molecular information and chemotherapy delivered.

4.2 Monitoring for Late Effects

4.2.1 Cardiovascular disease

Patients receiving treatment for AML will have been exposed to anthracyclines. The justification for the guidance is as summarised in section 3.2.1.

- Transthoracic ECHO is an appropriate modality to use as screening for late cardiotoxicity.
- Patients who were exposed to anthracyclines as a child (<18y) should be screened for cardiac dysfunction. The screening frequency recommended by SIGN 132 is 5-yearly as a minimum.
- Patients treated for adult onset leukaemia should be considered for screening for cardiac dysfunction. Particular groups in whom this may be beneficial include women of child-bearing potential, patients receiving higher cumulative doses of anthracycline

(>250mg/m²) and patients with other risk factors for cardiovascular disease. An appropriate screening time would be at 1 and 5 years following completion of therapy.

- Patients with asymptomatic or symptomatic cardiac dysfunction should have ECHO surveillance tailored to the clinical scenario with advice should be sought from a cardiologist.
- Patients treated with anthracyclines who become pregnant should have an ECHO performed during pregnancy.

It is considered good practice to modify other known risk factors for cardiac dysfunction for example control of hypertension, diabetes, obesity, hypercholesterolaemia, smoking cessation and discouraging a sedentary lifestyle.

There is not clear evidence that non-SCT treatment for AML is a risk factor for metabolic syndrome and so screening, in addition to that which would be applied to the general population, is not recommended.

4.2.2 Fertility

The cumulative chemotherapy exposure for AML in both adults and children is not considered a high risk for infertility. An exception to this is patients who undergo SCT. Few patients will have had the opportunity to undergo fertility preserving procedures prior to commencing therapy.

- Male patients should be offered the opportunity to have their fertility assessed following completion of therapy. Serum FSH provides an indirect measure of spermatogenesis; serum LH and testosterone a measure of Leydig cell function. However, sperm analysis delivered through local fertility services will provide a more direct assessment of fertility.
- Female patients who continue to menstruate following completion of therapy should be reassured that they are likely to have maintained fertility. The fertility window may however be shorter than had they not had chemotherapy, with menopause occurring at an earlier age. All female patients of child-bearing age should therefore be offered the opportunity for fertility assessment at their local specialist gynaecology service. Patients who may particularly benefit from this are those from families where there is a history of early menopause.
- Female patients who do not restart menstruation within 6 months of completing therapy should be offered referral to a specialist clinic.

4.2.3 Vaccinations

Patients treated as children should have undergone a standard childhood re-vaccination protocol at 6 months following completion of treatment. Vaccinations will have been delivered through primary care. For patients treated as adults who have not undergone SCT routine re-vaccination is not recommended, other than engagement with the national annual flu-vaccination programme.

4.3 Detection of Subsequent Primary Cancers

Chemotherapy exposure is associated with an increased risk of subsequent primary cancers. In particular this risk is associated with cumulative exposure to alkylating agents and epipodophyllotoxins.

- Healthcare professionals should adopt a high index of suspicion of subsequent primary cancers when assessing patients who have received prior chemotherapy.
- In the absence of radiotherapy exposure, no routine additional cancer screening is required other than that which is applied to the general population.
- Patients should be discouraged from smoking and should adopt safe practice in the sun.

5. Protocol for Follow-up of Patients with ALL/AML

5.1 Frequency of Follow-up

The frequency of follow-up is not mandated as there will be factors specific to particular patients which may influence this such as risk of early relapse, presence of significant treatment related toxicities. As a minimum it is recommended that follow up occurs:

- Year 1 : every 3 months
- Year 2 : every 4 months
- Year 3 : every 6 months then annually thereafter

Patients who are ≥ 2 years post treatment may be referred by the Consultant Haematologist to a Nurse Led follow-up clinic (if available). This relates to the reduced risk of relapse occurring after this time.

As mentioned in section 2.2, it is recommended that a treatment summary is completed at the start of the follow-up pathway, summarising the diagnosis, treatment and ongoing management plan. A copy should be given to both the patient and GP (Appendix 2).

After 5 years of follow-up, patients who were treated as adults and who remain in remission may be discharged from the clinic. The discharge letter prepared for the GP and patient should detail the risks of future health problems related to treatment such as late onset cardiotoxicity, subsequent primary cancers, infertility and metabolic syndrome. This information is best delivered in the form of a discharge summary (Appendix 3).

For patients treated as children the SIGN recommendation is for life-long follow-up. However for those treated without SCT or radiotherapy this follow-up may be nurse or primary-care led. As with patients treated as adults, the discharge letter prepared for the GP and patient/parent should detail potential future risks to the health of the patient and any need for ongoing screening e.g. Transthoracic ECHO, monitoring of BMI.

For all patients, any ongoing clinical issues related to the leukaemia or the treatment received should be discussed with a Consultant Haematologist prior to discharge to ensure appropriate follow-up is arranged.

5.2 Checklist for each Visit

Follow-up clinic checklists are detailed in Appendix 4. These are primarily aimed at follow-up clinic nurses and junior doctors however may also be a useful aide memoire for experienced consultants.

General assessment

- Ask about general well being and new symptoms, particularly bruising, infections, headaches (ALL) and testicular swelling (ALL).
- Record WHO performance status.
- Ask about current medications.
- Examine for peripheral lymphadenopathy, hepatomegaly, splenomegaly and abdominal masses.
- Check FBC and biochemical profile. Consider vitamin D assessment in patients with previous ALL (see section 3.2.5).
- Record any new diagnoses, including subsequent primary malignancy, occurring since previous visit.

Fertility / Endocrine

- Enquire about menstruation and menopausal symptoms – if troublesome symptoms consider referral to gynaecology.

- Ensure patients who have received cranial irradiation >30Gy have been referred to an endocrinologist for assessment of hypothalamic-pituitary axis

Cardiovascular Disease

- Ensure patients >45 years who received anthracycline drugs are attending their GP for monitoring of blood pressure, cholesterol and glucose at least annually.
- Echocardiogram – for all patients receiving anthracycline treatment as a child at 5 yearly intervals as a minimum. Consider for adult patients considered at increased risk of cardiovascular disease - see section on cardiovascular disease (3.2.1 / 4.2.1).

Subsequent Primary Cancers

- Advise on smoking cessation and avoidance of sunburn. Investigate any suspicious skin lesions promptly.
- Ensure uptake of all screening programmes offered by GP e.g. cervical, breast, colorectal.

Other

- Vaccinations – ensure all patients are offered annual flu vaccination.
- Dental health – ensure all patients attend the dentist regularly (6-monthly).
- Ophthalmic assessment – patients exposed to steroids and/or cranial irradiation are at increased risk of developing cataracts. Such patients should be advised to attend an optician every 2 years.
- Encourage patient to make earlier appointment if new problems arise.
- Other investigations should be arranged in response to new symptoms/signs of disease, abnormal routine investigations or in the context of trial protocols.

5.3 Final Discharge Summary

After 5 years of follow-up, patients who remain in remission may be discharged from the clinic. If there are any outstanding issues, these should be discussed with a Consultant Haematologist prior to discharge. Patients who have received fludarabine should be aware that if a blood transfusion is required in the future they should receive irradiated blood. It is recommended that the patient be given a discharge summary including information on their diagnosis and treatment received and contact details if concerned about relapse (Appendix 3).

6. References

1. Children's Oncology Group and long term follow-up guidelines for survivors of childhood, adolescent and young adult cancers version 4.0, 2013. www-survivorshipguidelines.org
2. UK CCLG Therapy Based Long Term Follow Up 2nd edition. 2005. www.cclg.org/uk
3. SIGN 132. Long term follow up of survivors of childhood cancer. 2013. www.sign.ac.uk
4. Late relapsing childhood lymphoblastic leukaemia. Vora A et al. Blood 1998 102(2);439-43
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7. Population-based risks of CNS tumours in survivors of childhood cancer: The British Childhood Cancer Survivor Study. Taylor AJ et al. JCO 2010; 28:5287-93
8. Younger adults with AML in remission for ≥ 3 years have a high likelihood of cure: The ECOG experience in over 1200 patients. Watts JM et al Leuk Res 2014;38(8); 901-6

Appendix 1: HNA and Care Plan

Concerns Checklist – identifying your concerns

Patient's name or label

Key worker: _____

Date: _____

Contact number: _____

This self assessment is optional. It has been designed to help us support you by identifying any concerns you may have and information you may require.

What do I need to do?

Select any areas that may have caused you concern recently and you would like to discuss with your key worker.

When selecting please score each concern between 1-10, with 1 being low level of concern and 10 the highest.

Physical concerns

- Breathing difficulties
- Passing urine
- Constipation
- Diarrhoea
- Eating, appetite or taste
- Indigestion
- Swallowing
- Cough
- Sore or dry mouth or ulcers
- Nausea or vomiting
- Tired, exhausted or fatigued
- Swelling
- High temperature or fever
- Moving around (walking)
- Tingling in hands or feet
- Pain or discomfort
- Hot flushes or sweating
- Dry, itchy or sore skin
- Changes in weight
- Wound care
- Memory or concentration
- Sight or hearing
- Speech or voice problems
- My appearance
- Sleep problems
- Sex, intimacy or fertility
- Other medical conditions

I have questions about my diagnosis, treatments or effects

Practical concerns

- Taking care of others
- Work or education
- Money or finance
- Travel
- Housing
- Transport or parking
- Talking or being understood
- Laundry or housework
- Grocery shopping
- Washing and dressing
- Preparing meals or drinks
- Pets
- Difficulty making plans
- Smoking cessation
- Problems with alcohol or drugs
- My medication

Emotional concerns

- Uncertainty
- Loss of interest in activities
- Unable to express feelings
- Thinking about the future
- Regret about the past
- Anger or frustration
- Loneliness or isolation
- Sadness or depression
- Hopelessness
- Guilt

- Worry, fear or anxiety
- Independence

Family or relationship concerns

- Partner
- Children
- Other relatives or friends
- Person who looks after me
- Person who I look after

Spiritual concerns

- Faith or spirituality
- Meaning or purpose of life
- Feeling at odds with my culture, beliefs or values

Information or support

- Exercise and activity
- Diet and nutrition
- Complementary therapies
- Planning for my future priorities
- Making a will or legal advice
- Health and wellbeing
- Patient or carer's support group
- Managing my symptoms
- Sun protection

Key worker to complete

Copy given to patient

Copy to be sent to GP

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Care and Support Plan

Patient's name or label

Key worker: _____

Key worker to complete

Copy given to patient

Date of Care and Support Plan: _____

Copy to be sent to GP

Contact number: _____

Next review date: _____

**WE ARE
MACMILLAN.
CANCER SUPPORT**

Main concerns	Plan of action
Score 1-10 (10 being highest) <input type="checkbox"/>	Patient action
	Key worker action
Score 1-10 (10 being highest) <input type="checkbox"/>	Patient action
	Key worker action
Score 1-10 (10 being highest) <input type="checkbox"/>	Patient action
	Key worker action

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Appendix 2: Treatment Summary



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:	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)**

- Metabolic Syndrome (in those treated as children for ALL)
- Infertility/Menopause
- Cardiac – long term cardiovascular risk
(Important to avoid risk factors, eg smoking; high blood pressure; diabetes)
- Secondary Cancers
(common cancers: breast;lung;skin – important to engage in available NHS screening programmes)

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

Section 3: Secondary Care ongoing management plan

Patients are regularly reviewed at Haematology Clinic:

Year 1: every 3 months

Year 2: every 4 months

Year 3: every 6 months and annually thereafter.

Patients treated as adults and who remain in remission after 5 years of follow-up may be discharged from the clinic.

Patients treated as children, SIGN recommendation for life-long follow-up (for those treated without SCT or radiotherapy, this follow-up may be nurse or primary-care led.

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 lymph gland swelling
- Falling blood counts (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.

Please list any GP actions:

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

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

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

Avoid sunburn and use skin protection (SPF30 or above). Attend GP if new skin lesions develop.

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

Irradiated blood products if patient received a purine analogue
(This is a lifelong requirement)

Consultant Name:

Signature: *Physical Signature
Required*

Date:

Copy to GP and Patient
Copy in case notes

Appendix 3: Clinic Discharge Summary



CLINIC DISCHARGE SUMMARY

The treatment you have had for your acute leukaemia 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:	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)**

- Metabolic Syndrome (in those treated as children for ALL)
- Infertility/Menopause
- Cardiac – long term cardiovascular risk (Important to avoid risk factors, eg smoking; high blood pressure; diabetes)
- Secondary Cancers (common cancers: breast;lung;skin – important to engage in available NHS screening programmes)

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 lymph gland swelling
- Falling blood counts (For GP reference)

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

- Health Promotion (Smoking cessation; weight control; exercise)
- 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. 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.

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

Avoid sunburn and use skin protection (SPF 30 or above). Attend GP if new skin lesions develop.

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

Irradiated blood products if patient received a purine analogue

(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:

Consultant Name:

Signature: *Physical Signature
Required*

Date:

CNS Name:

Signature: *Physical Signature
Required*

Date:

Copy to GP and Patient
Copy in case notes

Appendix 4: Clinic Checklists

Acute Lymphoblastic Leukaemia (ALL) Follow-up Clinic:

	3	6	9	12	16	20	24	30	36	48	60
Symptoms	x	x	x	x	x	x	x	x	x	x	x
Medicines	x	x	x	x	x	x	x	x	x	x	x
Examination	x	x	x	x	x	x	x	x	x	x	x
BMI				x			x		x	x	x
WHO Performance Status	x	x	x	x	x	x	x	x	x	x	x
FBC, BIO	x	x	x	x	x	x	x	x	x	x	x
Fertility/Menses	x			x			x		x	x	x
New Diagnoses	x	x	x	x	x	x	x	x	x	x	x
Cardiovascular Risks*	x			x			x		x	x	x
Blood Pressure				x			x		x	x	x
Lipids, fasting glucose#							x			x	
Vaccines (GP)				x			x		x	x	x
Dental Health	x			x			x		x	x	x
Optician review							x			x	
Lifestyle	x	x	x	x	x	x	x	x	x	x	x
NHS Screening	x			x			x		x	x	x

*Refer to text for recommendation on ECHO screening

#Annual if obese (by BMI)

Acute Myeloid Leukaemia (AML) Follow-up Clinic:

	3	6	9	12	16	20	24	30	36	48	60
Symptoms	x	x	x	x	x	x	x	x	x	x	x
Medicines	x	x	x	x	x	x	x	x	x	x	x
Examination	x	x	x	x	x	x	x	x	x	x	x
BMI				x			x		x	x	x
WHO Performance Status	x	x	x	x	x	x	x	x	x	x	x
FBC, BIO, LDH	x	x	x	x	x	x	x	x	x	x	x
Fertility/Menses	x			x			x		x	x	x
New Diagnoses	x	x	x	x	x	x	x	x	x	x	x
Cardiovascular Risks*	x			x			x		x	x	x
Blood Pressure				x			x		x	x	x
Lipids, fasting glucose#							x			x	
Vaccines (GP)				x			x		x	x	x
Dental Health	x			x			x		x	x	x
Lifestyle	x	x	x	x	x	x	x	x	x	x	x
NHS Screening	x			x			x		x	x	x

*Refer to text for recommendation on ECHO screening

#Annual if obese (by BMI)