Pan Birmingham NHS
Cancer Network

Guideline for the referral to the Late Effects Multi Disciplinary Team

Version History

Version	Date	Summary of Change\Process
0.1	July 2010	Reviewed and approved by West Midlands Children's Cancer Network Co-ordinating Group
1.0	August 2010	Approved by Guidelines Sub Group
1.1	July 2011	Appendices amended to include leukaemia, retinoblastoma and end of treatment summary sheets
1.2	July 2011	Reviewed and updated by Network Guidelines Sub Group
1.3	10.10.11	Following discussion with Jeanette Hawkins and the addition of http://www.cclg.org.uk/guidelines reference re approved by the Chair of the CCNCG
2.0	October 2011	Reviewed and endorsed by Network Guidelines Sub Group

Date Approved by Network Governance	**October 2011**

Date for Review	**October 2014**

Changes between version one and version 2

- Appendices amended to include leukaemia, retinoblastoma and end of treatment summary sheets
- Clarity over the referral process added
- Reference to National clinical follow-up guidance added http://www.cclg.org.uk/guidelines

This policy has been reviewed and approved by the Chair of the West Midlands Children's Cancer Network Co-ordinating Group

Gail Fortes-Mayer
Chair of the West Midlands Children's Cancer Network Co-ordinating Group
October 2011

1 Scope of the Guideline

This guidance has been produced to support the long term follow-up of survivors of childhood cancer in line with measure 09-7A-124 to ensure that the multi-disciplinary teams from the Paediatric Oncology Shared Care Unit (POSCU) and Principal Treatment Centre (PTC) operate consistently and to the same standard of care**.**

2. Guideline Background

2.1 As treatment for cancer improves in children and adolescents, increasing numbers are surviving. There is now an expectation that overall survival for this group of patients is in excess of 70%. Currently around 200 new patients are accepted annually at Birmingham Children's Hospital NHS Foundation Trust (BCH). One third have leukaemia, one quarter Central Nervous System tumours and the rest a range of 'solid' tumours, mostly of embryonal type. The majority of these survivors need on-going follow up to monitor for any late effects of treatment and it is essential to ensure that the quality and consistency of this follow-up is equal across the Network, with care shared seamlessly between POSCU and PTC, and eventually on to adult services.

2.2 The West Midlands Children's Cancer Network Co-ordinating Group (WMCCNC) have agreed to follow the attached guideline and end of treatment summary proformas. See appendix 1 - pages 4-17. The guideline statements below are a summary of this.

3. Guideline Statements

3.1 All patients completing treatment for childhood cancer should have an "end of treatment summary" (see appendix 2 – page 8) completed within 6 months of completing their treatment.

3.2 The end of treatment summary should include cumulative doses of chemotherapy and of radiotherapy, and details of surgery. Also it should indicate the investigations required for disease surveillance and late effects monitoring along with the frequency of these tests and where they will be performed.

3.3 The end of treatment summary should be forwarded to the late effects team within 6 months of the end of treatment.

3.4 Patients will continue to be monitored by their treatment team for a period of 2-3 years from the end of their treatment.

3.5 At the end of clinical follow-up patients should be referred to the late effects team at BCH, or, if 16 years or over, the transition service at University Hospital Birmingham.

3.6 The details for late effects surveillance will be planned individually, based on National guidance published by Childhood Cancer and Leukaemia Group http://www.cclg.org.uk/guidelines

4. Clinical Trials

4.1 Wherever possible, patients who are eligible should be offered the opportunity to participate in National Institute for Health Research portfolio clinical trials and other well designed studies.

4.2 Where a study is only open at one Trust in the Network, patients should be referred for trial entry. A list of studies available at each Trust is available from Pan Birmingham Cancer Research Network.
Email: PBCRN@westmidlands.nhs.uk .

4.3 Patients who have been recruited into a clinical trial will be followed up as defined in the protocol.

Monitoring of the Guideline

Implementation of the guidance will be considered as a topic for audit by the NSSG in 2012

Authors

Dr Helen Jenkinson	Late Effects Multi Disciplinary Team Lead Clinician Birmingham Children's Hospital NHS Foundation Trust
Dr Mark Velangi	Lead Cancer Clinician Birmingham Children's Hospital NHS Foundation Trust

Approval Signatures

Pan Birmingham Cancer Network Governance Committee Chair

Name: Doug Wulff

Signature:  Date October 2011

Pan Birmingham Cancer Network Manager

Name: Karen Metcalf

Signature:  Date: October 2011

Network Site Specific Group Clinical Chair

Name: Gail Fortes-Mayer

Signature:  Date: October 2011

Appendix 1 – Late Effects Protocol

1.0 Introduction

This protocol outlines the process for follow up and late effects monitoring to ensure that the multi-disciplinary teams from the Paediatric Oncology Shared Care Unit (POSCU) and Principal Treatment Centre (PTC) operate consistently and meet agreed standards that reflect a high quality of care.

From a patient's perspective the Multi Disciplinary Team (MDT) is that group of professionals who meet together at a given time and place, to make decisions regarding treatment of individual patients. The DH Children's Cancer Measures (2009) address the patient's interaction with the team up to and including what is termed the 'multidisciplinary treatment planning decision'.

The Late Effects MDT is based at Birmingham Children's Hospital Foundation NHS Trust (BCH). BCH is the PTC for children's cancers within the West Midlands as specified in the NICE 2005 Improving Outcomes Guidance for Children and Young People with Cancer (CYP IOG). Some patients may receive a significant amount of their treatment/supportive care in the POSCU.

The MDTs are committed to collaborative working relationships with all Trusts across the West Midlands Children's Cancer Network and each ensures their team is represented at at least two thirds of the Cancer Network meetings.

2.0 Objectives of this Protocol

To ensure that designated specialists work efficiently together in teams such that decisions regarding all aspects of the long term follow up care of individual patients are based on a multidisciplinary decision.

To ensure that care is based on agreed national or Supra-Regional Network-wide clinical guidelines.

To improve communication and enhance the professional skills and knowledge between MDT members.

To identify service gaps/breakdowns in co-ordination so that they can be rectified.

3.0 End of Treatment Summary

Oncology/Haematology End-of-Treatment summaries, for which each MDT has a disease-appropriate proforma (Appendix 1) must be completed by the PTC for every patient within six months of completion of treatment for childhood cancer. The responsibility to complete this summary sheet lies with each individual treatment MDT and the lead clinician will identify the responsible person within each MDT. A copy of the completed summary sheet is sent to the POSCU if one has been involved.

The end-of-treatment summary includes:

- Details of treatment received
- End-of-treatment investigations required
- Date when re-immunisations due and confirmation that GP has been informed
- Investigations required for **disease surveillance** to monitor for disease relapse, frequency of surveillance and where this will be carried out (i.e. PTC or POSCU)
- Anticipated **late effects of treatment**, surveillance investigations required to monitor for each late effect and frequency of each investigation
- Evidence that follow up plan has been discussed with patient / parent.
- Review date

4.0 Out Patient Follow-up Frequency and Location

Some patients may receive a significant amount of their treatment/supportive care in the POSCU. On completion of treatment, the frequency of out patient follow-up appointments will be decided by the treatment MDT at the PTC. However, these appointments are likely to be shared between PTC and POSCU. The timing and frequency of appointments between PTC and POSCU will vary between patients and will be dependent upon medical, geographical and social factors determined individually for each patient following consultation between the PTC treatment MDT, POSCU MDT and patient/parent. The plan for each individual patient will be clearly documented in the end-of-treatment summary.

5.0 Role of the PTC Late effects MDT

Follow-up of patients after completion of therapy remains the responsibility of the PTC treatment MDT and POSCU MDT until the patient is eligible for referral to the Late Effects service when their role ends.

Patients under the care of the Leukaemia MDT are eligible for transfer to the Nurse-Led follow-up clinic at the PTC when they are:

- 5 years from diagnosis of standard or low risk ALL and
- 3 years after completion of treatment

Patients under the care of solid tumour, retinoblastoma and neuro-oncology MDTs are eligible for transfer to the Late Effects service at 16 years of age when they will be seen in the Young Adult Transition clinic held monthly at the PTC.

6.0 Informing the Patient's GP Following Discussion of Long Term Follow-up Plan

The Department of Health Cancer Reform Strategy 2007 emphasizes the need for good communication between health professionals and patients, both for delivering high quality care and for empowering people to be involved in decisions about their own care. The patient's GP will be informed in writing once the long term plan for follow-up and disease and late effects surveillance has been discussed with the patient/parent.

7.0 Offering Patients a Permanent Record of the "End of Treatment" Summary at Which Long Term Follow-up Plans Were Discussed

The patient is offered a permanent record or summary of the plan. If the patient declines a record of the consultation, this is documented on the proforma and filed in the patient's records.

The patient/family should be offered the following written information:-

1. A record the end-of-treatment summary consultation
2. Details of the plan for long term follow up, disease surveillance and late effects monitoring.

8.0 Patient Centred Care

Written information is available to the patient at all stages of the care pathway, this reinforces all information given verbally (**7B-219)**. The majority of the patient information has been written and produced locally by trust workgroups, CCLG, Macmillan and the Network, offering appropriate updated generic information on specific late effects. Also available is information on local service provision, offering psychological/social/cultural support networks. This ensures continuity and parity of information given to all patients in all Trust across the West Midlands Children's Cancer Network. Patients also have access to a wide range of information from recognised groups and internet access.

Appendix 2

END OF TREATMENT SUMMARIES FOR EACH MDT

1. SOLID TUMOUR AND NEURO-ONCOLOGY
2. ACUTE LYMPHOBLASTIC LEUKAEMIA
3. ACUTE MYELOID LEUKAEMIA
4. RETINOBLASTOMA

1. Solid Tumour / Neuro-oncology MDT End of Treatment Summary Sheet (To be kept in plastic pocket at front of patient notes and copy to POSCU)

Name:	DOB:
Reg No:	Date of Diagnosis:
DIAGNOSIS:	**Consultant:**
Protocol:	Date Treatment completed:

Chemotherapy (inc cumulative doses of anthracyclines, alkylating agents, etoposide)

Chemotherapy drug	**Cumulative dose (mg/ m2)**

Surgery

Date:	**Details**:

Radiotherapy

Date:	**Site:**	**Dose:**	**Fractions:**

Was treatment completed as planned?	**Yes/No**	If no, please state reasons:	
What was the extent of measurable disease at completion?			

Additional Information (Including relapse information)

DATE	EVENT	DATE INACTIVE

End of Treatment Investigations

Investigation	Date	Result

Re-immunisation

Date due	Letter sent to GP

Out patient follow up

Years from completion of treatment	Frequency	Place of follow up PTC / POSCU / both

Disease Surveillance

Investigation required	Frequency	Where will this be carried out i.e.PTC / POSCU

Late Effects Monitoring

Anticipated Late Effect	Surveillance investigation	Frequency

1. End-of-treatment summary & follow up plan discussed with patient / parent

Signed _____ Date _____

Copy sent to GP ☐ Date _____ Copy sent to POSCU ☐ Date _____

2. Plan for Long term follow up review at _____ years from diagnosis

3. Refer to Late Effects Service at 16 years of age

2. LEUKAEMIA MDT

ACUTE LYMPHOBLASTIC LEUKAEMIA ALL2003 END OF TREATMENT SUMMARY

(To be kept in plastic pocket at front of patient notes and copy to POSCU)

Name:	DOB:
Reg No:	Date of Diagnosis:
Diagnosis: ALL	Consultant:

Chemotherapy

	Please indicate relevant regime	Anthracycline mg/m^2 (doxo equivalents)					Cyclophosphamide (mg/m^2)
		Ind	Cons	DI 1	DI 2	Total	Total
Regimen A DI 1		-	-	75	-	**75**	1000
Regimen A DI 2		-	-	75	75	**150**	2000
Regimen B DI 1		83	-	75	-	**158**	1000
Regimen B DI 2		83	-	75	75	**233**	1000
Regimen A>C (SER/cyto)		75	-	75	75	**225**	4000
Regimen B>C (SER/cyto)		83	-	75	75	**233**	4000
Regimen A>C (day 28)		0	-	75	75	**150**	4000
Regimen B>C (day 28)		83	-	75	75	**233**	4000

*Use formulas below to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose:
Doxorubicin – multiply total dose x 1 **Daunorubicin** – multiply total dose x 0.833 **Epirubicin** - multiply total dose x 0.67
Idarubicin - multiply total dose x 5 **Mitoxantrone** - multiply total dose x 4
Note: There is a paucity of literature to support isotoxic dose conversion; however, the above conversion factors may be used for convenience in order to gauge screening frequency. Clinical judgment should ultimately be used to determine indicated screening for individual patients.

Significant clinical events (past/ongoing/radiotherapy/relapse/treatment omissions)

Date	Event

End of Treatment Investigations

Investigation	Date	Result
End of treatment BM		-
Reimmunisation letter to GP		-
End of treatment echocardiogram		

1. End-of-treatment summary & follow up plan discussed with patient / parent

Signed _____ **Date** _____

Copy sent to GP ☐ Date _____ **Copy sent to POSCU ☐ Date** _____

2. Plan for Long term follow up review at _____ **years from diagnosis**

3. Refer to Late Effects Service at 16years of age

3. LEUKAEMIA MDT

ACUTE MYELOID LEUKAEMIA END OF TREATMENT SUMMARY

(To be kept in plastic pocket at front of patient notes and copy to POSCU)

Name:	DOB:
Reg No:	Date of Diagnosis:
Diagnosis:	Treatment regime:
Consultant:	

Chemotherapy

	Please indicate number of courses	Anthracycline mg/m^2 (doxo equivalents) per course	Cyclo (mg/m^2)	Etoposide (mg/m^2)
ADE		124	-	500
FLAG/FLA		-	-	-
FLAG-Ida			-	-
MiDac		200	-	-
MACE		-	-	500
hIdAC		-	-	-
Clofarabine/Cyclo/VP16		-		

*Use formulas below to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose:
Doxorubicin – multiply total dose x 1 **Daunorubicin** – multiply total dose x 0.833 **Epirubicin** - multiply total dose x 0.67
Idarubicin - multiply total dose x 5 **Mitoxantrone** - multiply total dose x 4
Note: There is a paucity of literature to support isotoxic dose conversion; however, the above conversion factors may be used for convenience in order to gauge screening frequency. Clinical judgment should ultimately be used to determine indicated screening for individual patients.

Significant clinical events (past/ongoing/radiotherapy/relapse/treatment omissions)

Date	Event

End of Treatment Investigations

Investigation	Date	Result
End of treatment BM		-
Reimmunisation letter to GP		-
Recent echocardiogram		

1. End-of-treatment summary & follow up plan discussed with patient / parent

Signed _____ Date _____

Copy sent to GP ☐ Date _____ Copy sent to POSCU ☐ Date _____

2. Plan for Long term follow up review at _____ years from diagnosis

3. Refer to Late Effects Service at 16years of age

4. RETINOBLASTOMA MDT END OF TREATMENT SUMMARY

Name	Date of Birth	Hospital No
Diagnosis	Date Diagnosed	Family History
Genetic Yes No	Mutation identified	

Chemotherapy received with dose and completion dates.

Drug	Cumulative Dose (mg / m2)	Completion date

Radiotherapy

EBRT	Date	Dose	Fractions
Plaque	Date	Dose	Eye
Plaque	Date	Dose	Eye

Surgery

Date	Operation detail

Significant clinical events (past/ongoing/radiotherapy/relapse/treatment omissions)

Date	Event

RETINOBLASTOMA MDT
LATE EFFECTS FOLLOW-UP CARE PLAN

Investigations at every clinic visit

Height
Weight
Blood pressure
Urinalysis

Tests	Dates					
Review immunisation status. Six months after chemo						
Growth and Pubertal staging All patients particularly post EBRT						
FOLLOWING JOE CHEMOTHERAPY						
Hearing Test End of treatment						
Serum U&Es / creatinine, Mg, Ca Urine (Pr / Cr ratio) I month post **carboplatin** then 5 yearly or as indicated						
GFR Only if creat raised						
FOLLOWING IVAD CHEMOTHERAPY						
Serum U&Es, creatinine, bicarb, Cl, Ca, Po4, alk phos Urine: phosphate, creatinine and Pr / Cr ratio 1-year post **ifosfamide** then 5 yearly or as indicated						
GFR Only if creat raised						
Echo 1 month after completion then 5yrly (unless clinically indicated)						

Parental height	Father	Mother

RETINOBLASTOMA MDT
OPHTHALMOGICAL FOLLOW-UP CARE PLAN

During treatment

During Chemotherapy or local therapy – every 4 weeks (every 2-3 weeks if focal treatment limited by tumour size)

Following enucleation – 1-2 week socket check in clinic
Unilateral - 6 week EUA followed by artificial eye fitting
Bilateral - 4 week EUA followed by artificial eye fitting 6 weeks post op.

Following successful treatment – EUA/Eye examination in clinic depending on co-operation

Unilateral – every 2 months for 6 months
every 3 months for 12 months
every 4 months for 12 months
every 6 months to age 10
Transfer for local follow up after 12 months disease free

Bilateral - every 2 months for 12 months
every 3 months for 12 months
every 4 months for 12 months
every 6 months to age 16
Transfer for local follow up after 24 months disease free