

# **Coversheet for Network Site Specific Group Agreed Documentation**

Document Title	Clinical Management Protocol – Retinoblastoma		
Document Date	July 2010		
Document Purpose	The document aims to inform both clinical practice and commissioning. It identifies;		
	Modalities of treatment or available multi-centre trials		
	The roles of the Principal Treatment Centre and Paediatric Oncology Shared Care Units and their linked services, e.g. Radiotherapy Centre, Community Teams.		
	Indications for referral outside the catchment area where relevant.		
	<ul> <li>Identification of relevant MDTs</li> </ul>		
Authors	Dr. Bruce Morland, Consultant Paediatric Oncologist & Solid Tumour MDT Lead, Birmingham Children's Hospital NHS Foundation Trust		
	Carol Hitchcott, Retinoblastoma Clinical Nurse Specialist Birmingham Children's Hospital NHS Foundation Trust		
References	<ol> <li>DH National Cancer Action Team (2008) National Cancer Peer Review Program Manual for Cancer Services 2008; Children's Cancer Measures</li> <li>National Institute for Health &amp; Clinical Excellence (2005) Referral guidelines for suspected cancer: Section - Cancer in Children &amp; Young People.</li> </ol>		
Consultation Process	Consultation was with the Solid Tumour MDT at Birmingham Children's Hospital (BCH), Cancer Locality Group (BCH) and the West Midlands Paediatric Oncology Supra Network Group		
Review Date (must be within three years)	July 2013		
Approval Signatures:  Network Site Specific Group Clinical Chair	Bal		
Date Approved by Netw	Date Approved by Network Governance Committee 26 / 07 / 2010		

## **Version History**

Version	Date	Summary of change/ process
Draft V1	15.01.0	Draft developed Carol Hitchcott RB CNS, Dr Morland RB MDT
		Lead & Jeanette Hawkins Lead Cancer Nurse.
Draft V2	29.01.10	Cover sheet for PBCN Documents added. Amendments to
		Clinical Trial entry information. Signed off at Rb MDT

Date: July 2010

Approval Date of Network Site Specific Group Date: July 2010

**Approval Date of the Governance Committee**Date: July 2010

**Approval Signatures** 

**Pan Birmingham Cancer Network Governance Committee Chair** 

Name: Doug Wulff

Signature:

**Pan Birmingham Cancer Network Manager** 

Name: Karen Metcalf

Signature: Date: July 2010

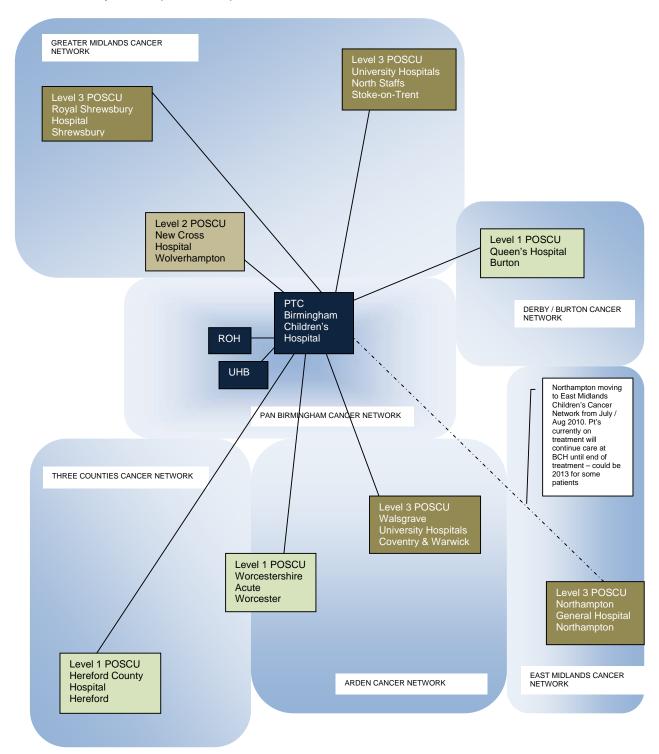
**Network Site Specific Group Clinical Chair** 

Name: Deepak Kalra

Signature: Date: July 2010

### West Midlands Paediatric Oncology Supra Network

- PTC Principal Treatment Centre
- POSCU Paediatric Oncology Shared Care Unit
- Levels of shared care Specified on pages 28 to 29 National Cancer Action Team <u>Manual</u> for Cancer Services 2008: Children's cancer Measures 2009
- University Hospitals Birmingham UHB Radiotherapy and Young Adult Services
- Royal Orthopaedic Hospital ROH Bone Tumour Service



#### Clinical Management Protocol "Retinoblastoma"

Carers present child / Y.P. <16yrs with symptoms Leukocoria, squint, red / painful eye, or other to: GP / Health Visitor Emergency Dept @ DGH, Eye Hospital, POSCU or PTC Optician Tumour identified at routine screening for genetic Rb Absent red reflex at birth / 6 week check Abnormality detected during any other eye examination No suspicion of cancer – referral to Suspicion of cancer – **URGENT cancer referral** paediatric ophthalmologist at DGH or Referral to national Rb service Birmingham secondary care Children's Hospital NHS Foundation Trust (BCH) Urgent telephone referral to Retinoblastoma team preferred 0121 333 9999 And follow up with urgent cancer referral form (fax) BCH 0121 333 8241 Cancer Day case admission to BCH for examination under anaesthetic within 7 days of referral Diagnosis not Diagnostic investigations – as per Pathway confirmed Diagnosis confirmed move to other Grouping by international classification appropriate referral pathway Treatment plan discussed at MDT on the day & relayed back to parents / carers on the day for involvement in treatment plan Key worker assigned RETINOBLASTOMA TREATMENT – See detailed care pathway Treatment according to group as per national guidelines **CURRENT AVAILABLE GUIDELINES** Central line / portacath insertion under anaesthetic if required. CCLG Retinoblastoma working group Surgical Day Care at BCH or MODALITIES of TREATMENT according to group & MDT discussion refer to local CCLG centre. Timing dependant on disease, treatment Local disease therapy - cryotherapy or laser therapy at BCH only requirements and individual patient Chemotherapy - at BCH and level 3 West Mids POSCUs or other CCLG access centres via National Shared care Enucleation - BCH only Specialist Paediatric Ophthalmology Surgeons Intra-arterial chemotherapy at BCH only Febrile neutropenia admissions and / or Day Case blood product support - packed red cells and /or platelets Complications Admit / transfer BCH Haem West Midlands patients - admit BCH or POSCU L1,2 or 3 (Stoke, Onc ward only Shrewsbury, Wolverhampton, Burton, Coventry, Worcester, Hereford) - dependent on diagnosis, post code, patient choice, severity / complications. May include PICU when necessary transfer back to BCH from POSCU if patient develops complications & on rarer occasions requires PICU retrieval team. Urgent End-of-life care on Out of region national referrals – admit to local nationally treatment for minority (Rare for designated children's cancer Principal Treatment Centre or their this tumour group) designated POSCU

# End of treatment assessments as per guidelines at BCH

- Removal of central venous access device if fitted – surgical admission
- Follow-up plan shared with parents / carers, patient, local POSCU or national PTC/POSCU & GP

#### Long Term Follow Up (LTFU) and Transitional Care / Survivorship Programme

- Transfer to LTFU MDT or discharge at 16 years as per CCLG Guidelines
- Stratification of type of follow-up according to NCSI project linked to local policy
- Commence Transitional Care Programme at age 13yrs
- Transfer to Selly Oak LTFU Clinic at 16yrs for those stratified to adult Long Term Follow-up clinics or recommend follow-up strategy for implementation in other national PTC
- Survivorship & rehabilitation
- Screening of off-spring

Relapse / progression on or after primary treatment / refractory disease

Treatment at BCH. Continue use of CCLG Retinoblastoma Working Group Guidelines

#### MODALITIES OF TREATMENT

As previous according to second line therapy guidelines and agreed MDT discussion Addition of options for Plaque Radiotherapy

Plaque Radiotherapy
External Beam Radiotherapy
Intra-arterial chemotherapy

Intra-arterial chemotherapy
To include referral to specialist Clinical Oncologist
with expertise in Paediatric Clinical Oncology at QEH

Further progression of disease Consider eligibility for phase I / II Clinical Trials if

May include transfer to palliative care pathway

Self referral back into system (S.O.S. plan) for any patient off treatment with concerns at any time.