


Coversheet for Network Site Specific Group Agreed Documentation

Document Title	Clinical Management Protocol – Retinoblastoma
Document Date	July 2010
Document Purpose	<p>The document aims to inform both clinical practice and commissioning. It identifies;</p> <ul style="list-style-type: none"> ▪ 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. ▪ Identification of relevant MDTs
Authors	<p>Dr. Bruce Morland, Consultant Paediatric Oncologist & Solid Tumour MDT Lead, Birmingham Children's Hospital NHS Foundation Trust</p> <p>Carol Hitchcott, Retinoblastoma Clinical Nurse Specialist Birmingham Children's Hospital NHS Foundation Trust</p>
References	<ol style="list-style-type: none"> 1. DH National Cancer Action Team (2008) National Cancer Peer Review Program Manual for Cancer Services 2008; Children's Cancer Measures 2. National Institute for Health & Clinical Excellence (2005) Referral guidelines for suspected cancer: Section - Cancer in Children & Young People.
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	
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

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:

Date: July 2010

Pan Birmingham Cancer Network Manager

Name: Karen Metcalf



Signature:

Date: July 2010

Network Site Specific Group Clinical Chair

Name: Deepak Kalra

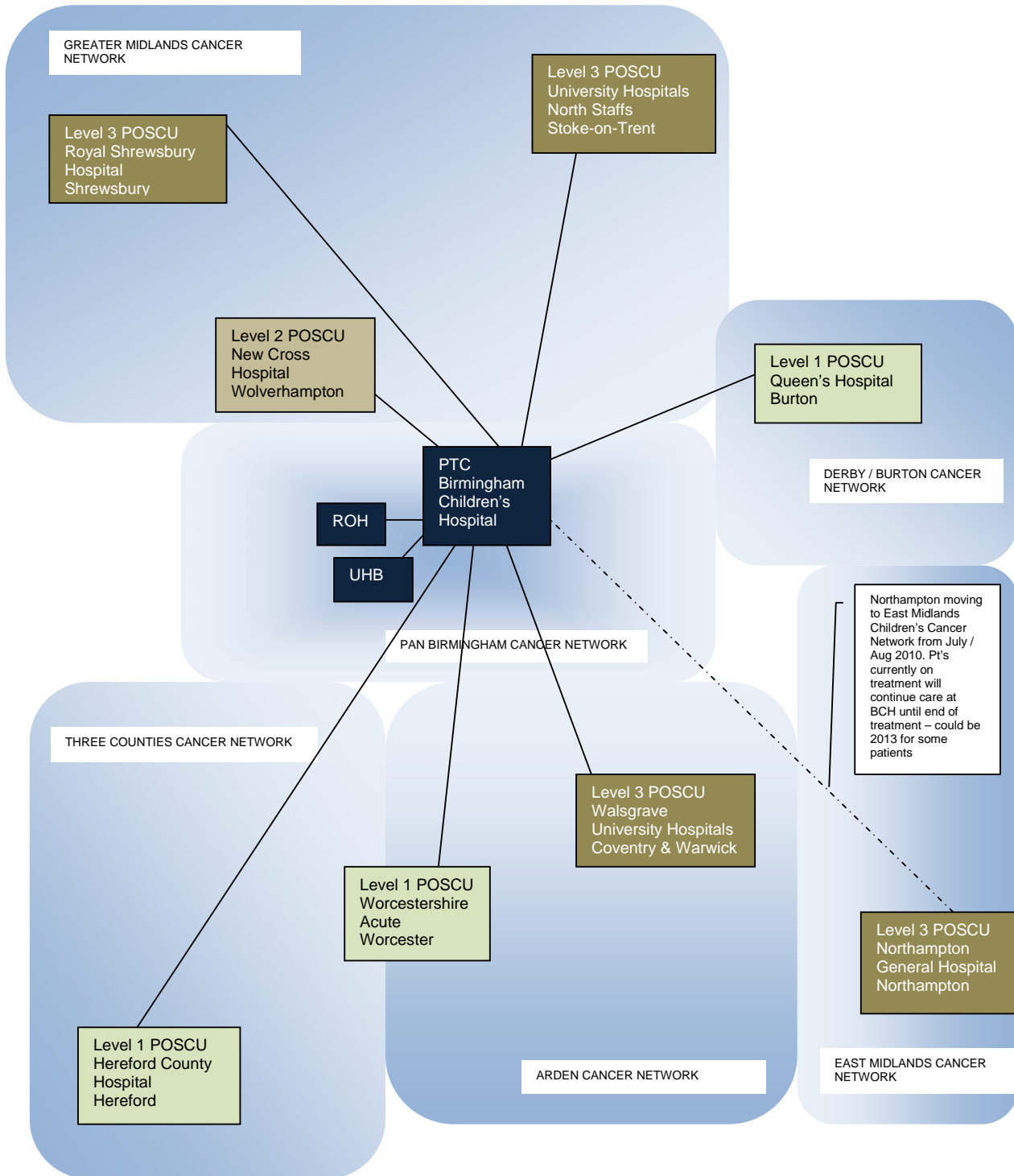


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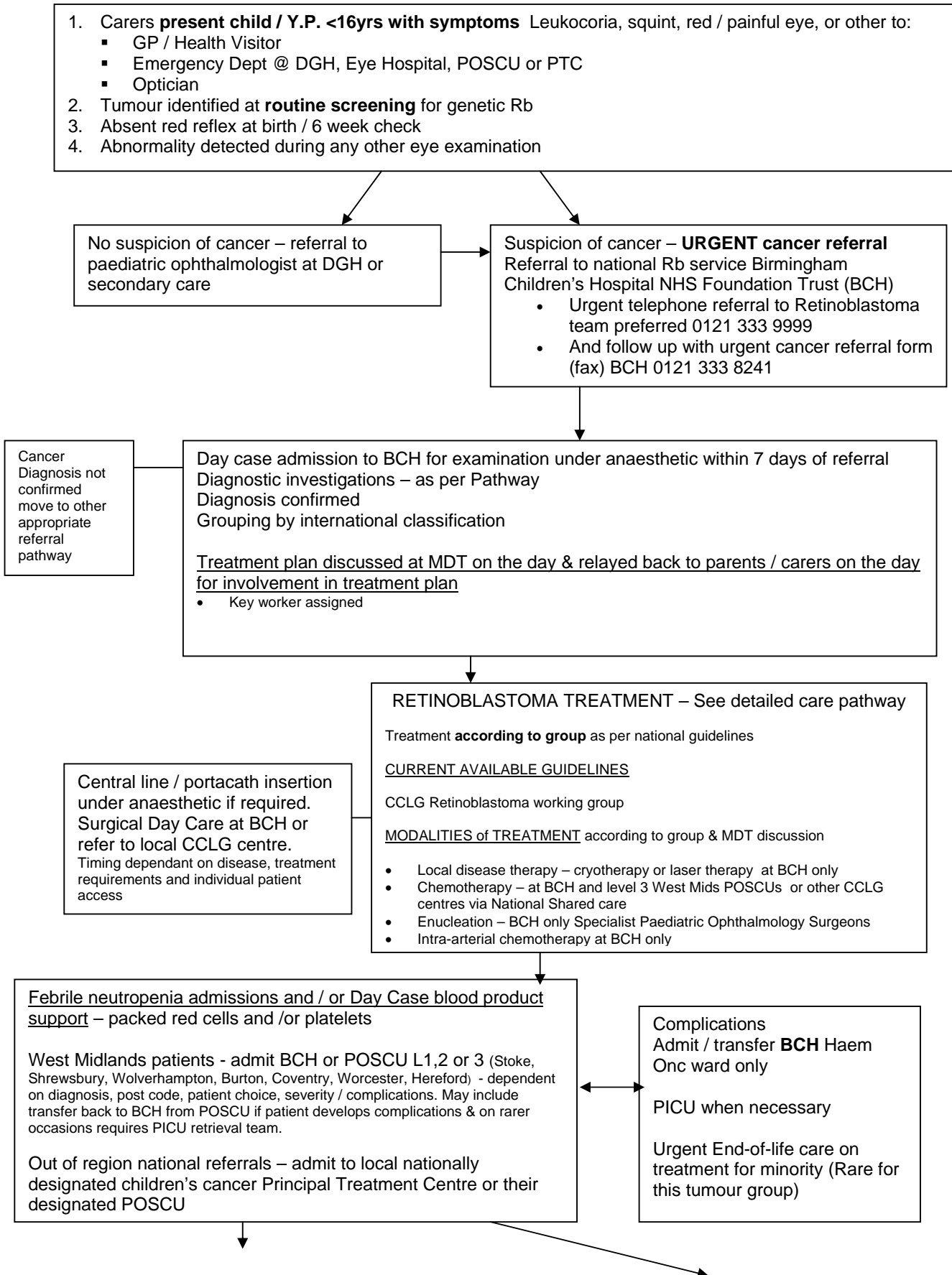
Date: July 2010

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 Manual 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”



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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

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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
 External Beam Radiotherapy
 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 available

May include transfer to palliative care pathway

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

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