



Thames Valley Cancer Network

# GUIDELINES FOR THE REFERRAL OF CHILDREN AND YOUNG PEOPLE WITH SUSPECTED CANCER

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## 1. Background & Scope (11-7A-113)

This document has been developed in order to ensure that all children within the Thames Valley Cancer Network with cancer or suspected cancer are referred promptly to the appropriate clinical team for assessment and diagnosis. In this context **children and young people are those patients aged 0 until their 19<sup>th</sup> birthday.**

This policy should be followed by the following groups:

- Primary Care Practitioners
- Paediatricians
- Surgeons who treat children
- Accident and Emergency Departments

The first section in this document offers guidance for when to suspect childhood cancer. It is in line with, and builds upon, the recommendations made in the National Institute for Health and Clinical Excellence (NICE) HSC2000/013 "Referral Guidelines for Suspected Cancer" (June 2005). The rest of this document covers how to refer into the TVCN Oxford Principle Treatment Centre for Childhood Cancer with details of the services that are provided and the available facilities.

*\* The geographical area which makes up the Thames Valley Cancer Network) has been defined by the South Central Specialised Commissioning Group. Please refer to **Appendix 1** for further details. Any practitioners who are within the catchment areas of the Trusts listed in Appendix 1 should apply this policy to all children in their care.*

## 2. Criteria for Referral

### 2.1. General and Unexplained Symptoms Requiring Referral

#### Consider referral

Consider referral when a child or young presents with **persistent back pain** (an examination is needed and a full blood count and blood film).

**Persistent parental anxiety** is sufficient reason for referral, even where a benign cause is considered most likely. Take into account parental insight and knowledge when considering urgent referral.

#### Urgent referral

Refer urgently **when a child or young person presents several times** (for example, three or more times) with the same problem, but no clear diagnosis has been made (investigations should also be carried out).

There are associations between Down's syndrome and leukaemia, between neurofibromatosis and CNS tumours, and between other rare syndromes and some cancers. Be alert to the potential significance of unexplained symptoms in children with such syndromes.

### 2.2. Suspected Leukaemia

#### Immediate referral

Refer immediately children or young people with either **unexplained petechiae**, or **hepatosplenomegaly**.

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**Investigations:**

Investigate with full blood count and blood film one or more of the following symptoms and signs:

- pallor
- fatigue
- unexplained irritability
- unexplained fever
- persistent/recurrent upper respiratory tract infections
- generalised lymphadenopathy
- persistent or unexplained bone pain
- unexplained bruising

If the blood film or full blood count indicates leukaemia, make an urgent referral.

**2.3. Suspected Lymphoma**

<b>Immediate referral</b>
Refer immediately children and young people with either <b>hepatosplenomegaly</b> , or <b>mediastinal or hilar mass</b> on chest x-ray

<b>Urgent referral</b>
Refer urgently children or young people with <b>one or more of the following</b> (particularly if there is no evidence of local infection): <ul style="list-style-type: none"> <li>Non-tender, firm or hard lymph nodes</li> <li>Lymph nodes greater than 2 cm in size</li> <li>Lymph nodes progressively enlarging</li> <li>Other features of general ill-health, fever or weight loss</li> <li>Axillary node involvement (in the absence of local infection or dermatitis)</li> <li>Supraclavicular node involvement</li> <li>Shortness of breath and unexplained petechiae or hepatosplenomegaly (particularly if not responding to bronchodilators)</li> </ul> <p><b>Please note:</b> New respiratory symptoms or changes in pattern of symptoms in known asthmatics should prompt consideration of lymphoma/leukaemia and therefore referral for chest X-ray before embarking on treatment with steroids.</p>

**2.4. Suspected Brain and CNS Tumours**

<b>Immediate referral</b>
Refer immediately children or young people with <b>either of the following</b> : <ul style="list-style-type: none"> <li>A reduced level of consciousness</li> <li>Headache and vomiting that cause early morning waking or occur on waking as these are classical signs of raised intracranial pressure.</li> </ul>

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Refer urgently or immediately children with **any of the following neurological symptoms and signs:**

- New-onset seizures
- Cranial nerve abnormalities
- Visual disturbances
- Gait abnormalities
- Motor or sensory signs
- Unexplained deteriorating school performance or developmental milestones
- Unexplained behavioural and/or mood changes

Refer immediately **children aged younger than 2 years with any of the following symptoms:**

- New-onset seizures
- Bulging fontanelle
- Extensor attacks
- Persistent vomiting

### Urgent referral

Refer urgently children aged 2 years and older, and young people, with a **persistent headache** where you cannot carry out an adequate neurological examination in primary care.

Refer urgently children aged younger than 2 years with **any of the following symptoms** suggestive of CNS cancer:

- Abnormal increase in head size
- Arrest or regression of motor development
- Altered behaviour
- Abnormal eye movements
- Lack of visual following
- Poor feeding/failure to thrive
- Squint, urgency dependant on other factors

## June 2011

A new campaign Head Smart be brain tumour aware has been launched by the Royal College of Paediatrics and Child Health [www.rcpch.ac.uk](http://www.rcpch.ac.uk), the Samantha Dickson Brain Tumour Trust <http://braintumourtrust.co.uk/> and the Children's Brain Tumour Research Centre at the University of Nottingham <http://www.nottingham.ac.uk/cbtrc/index.aspx>. Evidence based best practice guidelines *The Diagnosis of Brain Tumour in Children*, endorsed by Royal College of Paediatrics and Child Health (RCPCH), for the referral of children with suspected brain tumours have been developed and are available from <http://www.rcpch.ac.uk> and [www.HeadSmart.org.uk](http://www.HeadSmart.org.uk). The pocket sized symptom card is in Appendix 3.

## 2.5. Suspected Neuroblastoma

Many children and young people with neuroblastoma have symptoms of metastatic disease which may be general in nature (malaise, pallor, bone pain, irritability, fever or respiratory symptoms), and may resemble those of acute leukaemia.

### Investigations:

Investigate with a full blood count any of the following symptoms and signs:

- Persistent or unexplained bone pain (X-ray also needed)
- Pallor

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- Fatigue
- Unexplained irritability
- Unexplained fever
- Persistent or recurrent upper respiratory tract infections
- Generalised lymphadenopathy
- Unexplained bruising

If neuroblastoma is suspected carry out an abdominal examination and consider chest X-ray and full blood count. Refer urgently if a mass is found or if there is any uncertainty which would warrant urgent ultrasound.

Infants aged younger than 1 year may have localised abdominal or thoracic masses, and in infants younger than 6 months of age there may also be rapidly progressive intra-abdominal disease. Some babies may present with skin nodules. If any such mass is identified, refer immediately.

Remember neuroblastoma can present with signs of spinal cord compression from an intra spinal component of a para spinal mass.

**Urgent referral**

Refer urgently children with **any of the following**:

- Proptosis
- Unexplained back pain
- Leg weakness
- Unexplained urinary retention

**2.6. Suspected Wilms' tumour**

Wilms' tumour most commonly presents with a painless abdominal mass.

**Investigations:**

Persistent or progressive **abdominal distension** should prompt abdominal examination.

If mass found, refer immediately.

If child or young person is uncooperative and abdominal examination is not possible, consider referral for an urgent abdominal ultrasound.

**Urgent referral**

Refer urgently a child or young person presenting with **haematuria**.

**2.7. Suspected Soft Tissue Sarcomas**

A soft tissue mass in an unusual location may give rise to misleading local and persistent unexplained symptoms and signs, and sarcoma should be considered. These include:

- Head and Neck
- Proptosis
- Persistent unexplained unilateral nasal obstruction with or without discharge and/or bleeding.
- Aural polyps/discharge
- Genitourinary tract
- Urinary retention
- Scrotal swelling
- Bloodstained vaginal discharge

**Urgent referral**

Refer urgently a child or young person presenting with **an unexplained mass at almost any**

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**site that has one or more of the following features.** The mass is:

- Deep to the fascia
- Non-tender
- Progressively enlarging
- Associated with a regional lymph node that is enlarging
- Greater than 2 cm in diameter in size

## 2.8. Suspected Bone Sarcomas (Osteosarcoma and Ewing's Sarcoma)

History of an injury should not be assumed to exclude the possibility of a bone sarcoma.

### Referral

Refer children or young people with **either of the following**:

- Rest pain, back pain and unexplained limp (a discussion with a paediatrician or X-ray should be considered before or as well as referral)
- Persistent localised bone pain and/or swelling, and X-ray showing signs of cancer. In this case refer urgently

## 2.9. Suspected Retinoblastoma

This would most likely apply to children less than 2 years old.

### Urgent referral

Refer urgently children with **any of the following**:

- A white papillary reflex (leukocoria). Pay attention to parents reporting an odd appearance in their child's eye.
- A new squint or change in visual acuity if cancer is suspected (refer non-urgently if cancer is not suspected).
- A family history of retinoblastoma and visual problems (screening should be offered soon after birth).

### Investigations:

Imaging may be best done by a paediatrician, following referral.

Any of the following symptoms and signs requires a full blood count:

- Pallor
- Fatigue
- Irritability
- Unexplained fever
- Persistent or recurrent upper respiratory tract infections
- Generalised lymphadenopathy
- Persistent or unexplained bone pain (X-ray also needed)
- Unexplained bruising

## 3. Referral Procedure

When childhood or teenage cancer is suspected in any patient up to the age of 19 years who is in full time education within the TVCN they should be referred directly into the TVCN Oxford Paediatric Haematology and Oncology Principle Treatment Centre (PTC).

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If a primary bone tumour is suspected they can be referred either as above or to the bone tumour service at the Nuffield Orthopaedic Centre, these patients will then be discussed and managed by both teams.

When a brain tumour is suspected the initial referral should be made directly into the Oxford Paediatric Neurosurgical Unit.

### **3.1. New Patients Living Outside the ORH Catchment Area who Present in Primary Care, A&E or Within Any Hospital Team Outside of Paediatrics**

All these patients should be discussed with and referred to the consultant paediatrician on call at their relevant local Paediatric Oncology Shared Care Unit (POSCU). Which hospital is contacted will depend on where the patient lives. There are 5 POSCUs in the TVCN: Royal Berkshire Hospital, Wexham Park Hospital, Great Western Hospital, Stoke Mandeville Hospital and Wycombe General Hospital and Milton Keynes Hospital.

The relevant POSCU main hospital switchboard should be called and the paediatric consultant on call should be contacted. POSCU paediatricians are encouraged to discuss new cases or suspected new cases with their local hospital lead for children's cancer. These cases should then be referred by telephone to the OXFORD paediatric haematology or oncology consultant of the week or, if out of hours, the on call consultant, and when a brain tumour is suspected to the on call paediatric neurosurgeon. An immediate management plan can then be made with a timely transfer to the Oxford unit.

When making a referral, the parents and child or young person should be informed about the reason for referral and about which service they are going to attend so that they know what to do and what will happen next. It is important to establish initial good communication with the patient and family so that a supportive relationship with the local POSCU can develop if cancer is subsequently diagnosed.

#### **POSCU switchboard numbers**

Great Western Hospital, Swindon 01793 604020

Milton Keynes Hospital 01908 660033

Royal Berkshire Hospital, Reading 0118 322 5111

Bucks, Stoke Mandeville Hospital 01296 315000

Bucks, Wycombe General Hospital 01494 526161

Wexham Park Hospital, Slough 01753 633000

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### 3.2. Referral of Patients into the TVCN Oxford Paediatric Haematology and Oncology Principle Treatment Centre (PTC)

#### Paediatric Haematology and Oncology

After an initial telephone conversation with the paediatric haematology or oncology consultant of the week a prompt referral letter should be sent electronically and/or faxed to the appropriate senior member of the Paediatric Haematology and Oncology Team: Dr Chris Mitchell, Dr Kate Wheeler or Dr Sheila Lane (Paediatric Oncologists) or Dr Georgina Hall or Dr Amrana Qureshi (Locum) (Paediatric Haematologists). If a consultant cannot immediately be found the specialist registrar in paediatric haematology/oncology should be contacted.

When a patient is referred to the Oxford Unit all relevant imaging and histopathological specimens from the referring hospital must accompany the patient. Imaging can usually be electronically transferred.

#### CNS Tumour

When a brain tumour is suspected the on call consultant paediatric neurosurgeon should be contacted.

#### Bone Tumour

If a bone tumour is suspected the on call paediatric orthopaedic consultant at the Nuffield Orthopaedic Centre or the paediatric haematology/oncology consultant of the week should be contacted.

#### Benign Haematology

Referrals can be made directly to one of the paediatric haematology consultants with a referral letter.

Cases can also be referred into our service via the 2 week wait bureau. However this is not necessary as a direct telephone call to a member of the Oxford team will result in an almost immediate outpatient review.

All patients referred with a possible diagnosis of cancer will be seen within 2 weeks with an aim to start treatment within a month of referral. In practice, most patients are seen within two days of referral.

The patients referring clinician and GP will be notified of the patient's diagnosis within 24 hours of making the diagnosis, usually by telephone followed by written communication.

### 3.3. Outpatient referrals

Non urgent patients can be referred directly to one of the consultants with a request for an outpatient clinic consultation.

### 3.4. Contact Numbers for all referrals to the Oxford PTC

All the relevant contact details for referral are listed below and are also available in the comprehensive Oxford Paediatric Cancer Services Directory which is available on the Oxnet intranet site and the TVCN web site.

#### Oxford PTC

Children's Hospital 01865 741166 ask for:

Paediatric Haematology or Oncology Consultant of the week or  
Paediatric Haematology or Oncology Specialist Registrar Bleep 1805  
Paediatric Haematology or Oncology Secretaries Fax 01865 234199  
Secretaries email  
[paed.oncology@orh.nhs.uk](mailto:paed.oncology@orh.nhs.uk); [paed.haem@orh.nhs.uk](mailto:paed.haem@orh.nhs.uk)

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When a **Bone tumour** is suspected refer as above or contact the Nuffield Orthopaedic Centre 01865 741155 and ask for the on call consultant paediatric orthopaedic surgeon.

When a **CNS tumour** is suspected ask the John Radcliffe Hospital switchboard 01865 741166 for the on call consultant paediatric neurosurgeon. If they are not available ask for the paediatric neurosurgical registrar.

**Kamran's Ward (Paediatric Haematology/Oncology Ward):**

01865 234068/234069  
Fax: 01865 231683

**Robin's Ward (Paediatric Neurosurgery Ward):**

01865 231255

Dr Chris Mitchell	Consultant Paediatric Oncologist CHOX Neuro Onc MDT Chair	01865 234196 (secretary)
Dr Kate Wheeler	Consultant Paediatric Oncologist CHOX	01865 234199 (secretary)
Dr Sheila Lane	Consultant Paediatric Oncologist CHOX MDT chair solid tumour	01865 234199 (secretary)
Dr Georgina Hall	Consultant Paediatric Haematologist CHOX	01865 234188 (secretary)
Dr Amrana Qureshi	Consultant Paediatric Haematologist CHOX MDT Chair Haematology MDT	01865 234188 (secretary)
Dr Tina Foord	Consultant Oncologist Churchill Hospital MDT chair Late effects	01865 235211 (secretary)
Dr Elaine Sugden	Consultant Oncologist Churchill Hospital	01865 235201 ( secretary)
Mr Jay Jayamohan	Consultant Paediatric Neurosurgeon	01865 741166 (switch)
Mr Peter Richards	Consultant Paediatric Neurosurgeon	01865 741166 (switch)
Mr Shailendra Magdum	Consultant Paediatric Neurosurgeon	01865 741166 (switch)
Mr Andy Wainwright	Consultant Paediatric Orthopaedic Surgeon NOC	01865 741155 ( switch)
Mr Tim Theologis	Consultant Paediatric Orthopaedic Surgeon NOC	01865 741155 ( switch)
Ms Kokila Lakhoo	Consultant Paediatric Surgeon	01865 234197 (secretary)

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## 4. Oxford Paediatric Haematology and Oncology PTC Service

### 4.1. General

The Paediatric Oncology and Haematology Department at the Oxford Children's Hospital (CHOX) is one of 14 Principal Treatment Centres (PTC) in England which provides diagnosis, treatment and management for children and young adults (0-19 years) presenting with solid tumours and haematological malignancies in the Thames Valley Cancer Network (TVCN) catchment area which services a population of about 2.5 million with 0.6 million 0-19 year olds. The service is configured as a hub and spoke model with Oxford as the Principal Treatment Centre, (PTC) associated with 5 Paediatric Oncology Shared Care Units (POSCUs).

The 5 POSCUs in the TVCN, are Royal Berkshire Hospital (Reading), Wexham Park Hospital (Slough), Great Western Hospital (Swindon), Stoke Mandeville Hospital, Wycombe General Hospital and Milton Keynes Hospital. Each shared care hospital has a lead Consultant and a local MDT structure.

On average 90-100 new local and regional referrals are accepted into the Unit annually. All patients have an initial assessment, diagnosis and treatment plan at the Oxford Regional Unit, following which an active shared-care policy operates for most patients within the TVCN encouraging supportive care management and some of the less complex day case chemotherapy treatments for appropriate patients to be delivered at their POSCU. Patients living within the ORH catchment area have all their treatment (chemotherapy and all supportive care) provided by the Oxford PTC service.

The Unit accepts children and adolescents aged between 0-19 years. Patients in the older age range are always discussed thoroughly within the MDT and the POSCU consultant (if relevant) to establish that it is appropriate for them to be treated within the team (rather than in an adult centred team). The final decision is dependent on the cancer type (whether a paediatric or adult cancer), whether they are at school and their families preference. All these cases must be treated in a principal treatment centre.

All patients are discussed in one of the appropriate IOG compliant MDTs, solid tumour (lead Dr Sheila lane), neuroncology (lead Dr Chris Mitchell) or haematology (lead Dr Amrana Qureshi) with appropriate specialist radiology and pathology input. Bone tumours and other appropriate sarcoma cases are also discussed at the sarcoma MDT (Churchill Hospital). All cases aged 16-19 years are also discussed in the Teenage and Young Adult MDT

There are TVCN agreed paediatric psychosocial assessment guidelines available on the Oxnet and TVCN website.

The Long Term Follow-up MDT is an area of development. At present there is a comprehensive long-term follow up service for all appropriate patients provided by a variety of clinics, the Young Adult Clinic for patients over the age of 16 years who have had radiotherapy, a combined paediatric haematology and oncology/endocrine clinic, and clinics with the patients lead consultant either in Oxford or at the relevant POSCU.

### 4.2. Medical Staffing (11-7B-122 to 11-7B-123)

The Paediatric Haematology/Oncology service in Oxford is provided by a team of 5 paediatric haematology and oncology consultants supported by a full MDT structure.

The 5 consultants all provide inpatient care as part of their timetable during normal working hours and provide 24 /7 cover for:

- In patient care
- 24 hour advice and availability to the PTC and
- 24 hour advice to enquiring clinicians or nurses about any patient managed in the CCN (in POSCUs or in the community)

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There is 24/7 resident on call cover from paediatric medical staff by paediatric trainees at ST3 minimum level of seniority.

**4.3. Cover from PTC (11-7A-125/11-7B-124)**

The Oxford PTC will provide specialist medical cover for a POSCU if required when the POSCU lead and deputy lead clinician are absent. This should preferably be pre arranged and during this time if necessary the patients can have scheduled assessments and treatment provided by the Oxford team in Oxford.

**4.4. 24 Hour Service (11-7B-128)**

The PTC provides a 24 hour telephone advice service for patient’s with childhood cancer and their carers with a single contact point of the telephone on Kamran’s ward. Full documentation about this service is on Oxnet and the TVCN website.

**Kamran’s Ward 01865 234068/234069**

**4.5. Radiotherapy (11-7A-139 to 11-7A-140)**

Radiotherapy (radical treatment and palliative) for all paediatric patients within the TVCN is provided at the Churchill Hospital (1 mile away from the JR site). When the radiotherapy is being delivered these patients will be under the care of Dr Elaine Sugden and Dr Tina Foord, Clinical Oncologists, who are both members of the PTC diagnostic and treatment MDT. Dawn-Marie Davies is the lead paediatric radiographer. There is access to specialist play therapy support as required.

There is provision for radiotherapy to be given at the Churchill Hospital under a general anaesthetic if/when necessary. Dr Simon Berg consultant paediatric anaesthetist is the lead for children’s anaesthesia and is responsible for coordinating this.

If specialist Radiotherapy such as MIBG treatment, IMRT or proton therapy is appropriate patients will be referred outside the region to centres offering these modalities of treatment.

**4.6. Specialist surgery referrals within the extended Oxford PTC (11-7B-169-172)**

There is a comprehensive service for patients with brain tumours. All these patients are admitted to Robin’s Ward or Melanie’s Ward at the Oxford Children’s Hospital. There are 3 consultant paediatric neurosurgeons. After surgery all the patients are discussed in the full neuro-oncology MDT that takes place every 2 weeks when a final treatment plan is confirmed.

When patients with a bone tumour are discussed at the sarcoma MDT the surgical lead consultant is identified. The Lead Paediatric Orthopaedic Surgeons are Mr Tim Theologis and Mr Andy Wainwright.

The surgery for soft tissue sarcoma cases is discussed at the paediatric solid tumour MDT and an appropriate referral for surgery is then made depending on the site of the tumour.

The named leads for specialist paediatric cancer surgery are Ms Kokila Lakhoo (lead), Mr Hugh Grant and Ms Silke Wagener. They provide in and out patient care for paediatric surgical oncology patients. There are weekly surgical lists dedicated for cancer surgery and provision for extra surgical lists if needed. All the surgical lists are covered by consultant paediatric anaesthetists who work in the Children’s Hospital with dedicated DCC PAs for this activity. These theatre sessions are covered by Paediatric ODP’s.

There is a weekly general anaesthetic intervention list for diagnostics and central venous line insertions held in the paediatric radiology department. The paediatric radiologists (lead Dr Ash Chakrobarty) are responsible for these biopsies and central venous line insertions and the lead anaesthetist is Dr Sumit Das.

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#### 4.7. Extended paediatric services offered on the Oxford PTC

- a) Intensive Care
- b) Surgery
- c) Anaesthetic service
- d) Neurosurgery
- e) Neurology
- f) Cardiology
- g) Endocrinology
- h) Respiratory Medicine
- i) Nephrology
- j) Gastroenterology
- k) Infectious Diseases
- l) Orthopaedics (provided at the Nuffield Orthopaedic Centre)
- m) ENT, Ophthalmology and Plastic Surgery
- n) Clinical Genetics (Churchill Hospital)

These are all tertiary services apart from Nephrology. When a specialised renal opinion is needed the consultant in charge of the patient needs to discuss the case with Dr Janet Craze (the Oxford Paediatrician with a special interest in renal medicine). If needed the case is then discussed with Dr Van't Hoff (Specialist in Paediatric Renal Disease, Great Ormond Street Hospital, London with an Honorary Consultant post at Oxford). If necessary the child is transferred to GOSH for appropriate treatment.

#### 4.8. The following services are not provided within the Oxford PTC and these patients will be referred by their lead consultant for supraregional management as follows:

- a) Allogeneic Bone marrow transplantation for children < 16 years – referred to Bristol Children's Hospital or in the case of very young children <1 year, or children with highly complex cases, to Great Ormond Street Hospital, London. After the BMT the child returns to Oxford for further management and treatment
- b) Liver Surgery/transplantation – all cases <10 years that need liver surgery or a liver transplant are referred to the Paediatric Liver Unit, Birmingham. After the liver surgery the child will return to Oxford for further treatment/management.
- c) Retinoblastoma – these cases are referred into the Retinoblastoma Service in Birmingham, Children's Hospital or The London Hospital for their initial treatment plan and surgical management. Chemotherapy and supportive care for these patients is always administered in Oxford. These cases of retinoblastoma are also discussed with the Oxford Eye Department who may be involved in some aspects of their ocular care, eg prosthetics.

## 5. Oxford Paediatric Haematology and Oncology PTC Facilities

### 5.1. Wards

The paediatric haematology and oncology patients are cared for on Kamran's Ward. They are admitted to this ward under the care of the paediatric haematologists and oncologists in preference to other wards as the agreed part of the ward's regular activity. Kamran's Ward has 8 in-patient beds, 5 of which are cubicles, 2 with laminar flow facilities and a day care area with 5 beds. Melanie's Ward is an adjacent but separate adolescent unit with 16 inpatient beds for the whole paediatric department which does admit haematology and oncology patients for investigations, surgical procedures and

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occasionally supportive care but never for chemotherapy. Tom's ward accommodates surgical patients and Robin's ward accommodates the neurosurgical patients.

Day care is either provided on the Kamran's Ward day care (including all cases needing chemotherapy administration) or on the general paediatric day care unit on level 1 for non chemotherapy patients including day cases having radiology investigations needing sedation.

## 5.2. Facilities for Psychosocial Support

Facilities for the psychosocial support of children, parents and siblings include a playroom, outdoor play area, schoolroom, parents' accommodation, sitting room and kitchen. The accommodation for families of children is provided either in on site rooms in the Ronald McDonald Unit or in a house CLIC Court which is just outside the hospital grounds with 5 bedrooms.

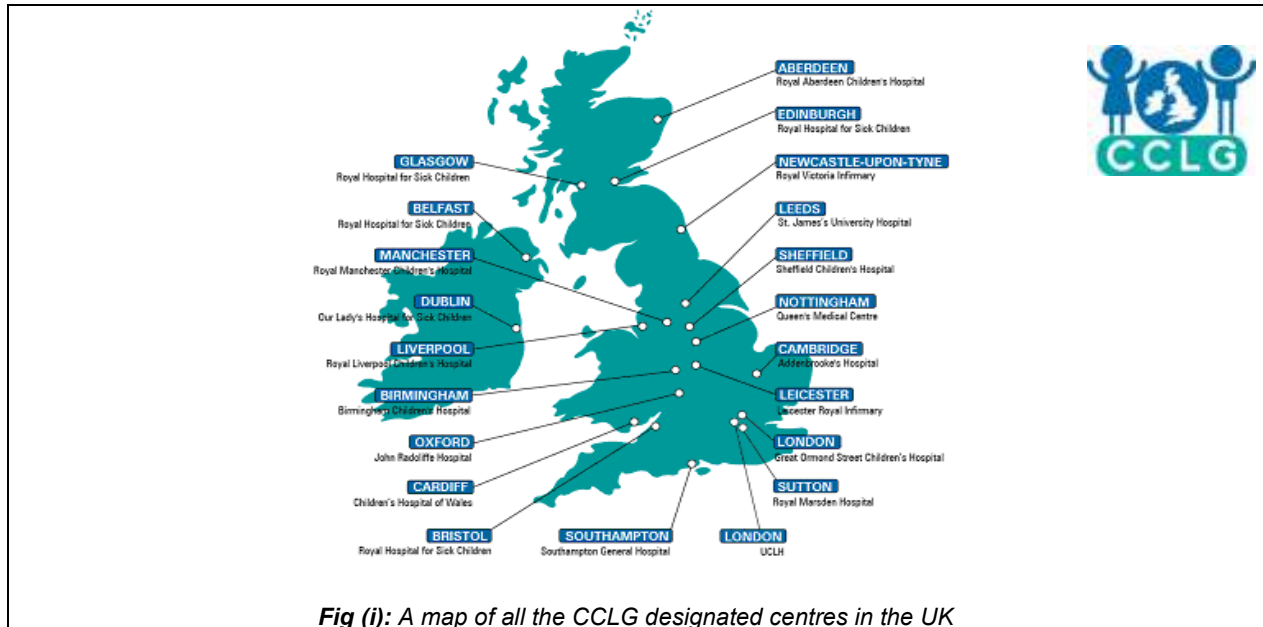
## 5.3. Outpatient Clinics

All outpatient clinics (for patients off treatment) are accommodated in the main Paediatric Outpatient Department. All the PTC consultants have regular clinics dedicated to paediatric haematology and oncology patients. The young adult (over 16 years) long-term follow up clinic takes place in the Churchill Hospital as does the haemophilia clinic.

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## 6. Appendix 1: Thames Valley Children’s Cancer Network

The provision of paediatric oncology care in the UK is divided by the Children’s Cancer and Leukaemia Group (CCLG) among 21 centres. The Oxford Children’s Hospital is the specialist centre which co-ordinates care for the **Oxford Region** and it has also been designated by the Specialised Commissioning Group (SCG) as the **TVCN Primary Treatment Centre (PTC)** for Paediatric Haematology and Oncology.



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Within the TVCN, a proportion of patient care can be provided closer to their home in one of 5 named hospitals. In this context they are referred to as the **Paediatric Oncology Shared Care Units (POSCUs)**.

- **Royal Berkshire Hospital, Reading**
- **Stoke Mandeville Hospital , Bucks**
- **Wycombe General, Bucks**
- **Wexham Park, Slough**
- **Great Western Hospital, Swindon**
- **Milton Keynes Hospital, Bucks**



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## 7. Appendix 2: Abbreviations

### List of Abbreviations

CCLG	Children's Cancer and Leukaemia Group
CHOX	Children's Hospital Oxford
CE	Chief Executive
D and T MDT	Diagnostic and Treatment Multidisciplinary Team
DCC	Direct clinical care
ENB	English Nursing Board (now disbanded)
EQA	External quality assurance
HDU	High dependency unit
ITC	Intrathecal chemotherapy
ITU	Intensive therapy unit
MAC	Medicine Advisory Committee
MDT	Multidisciplinary team
NSCG	National Specialist Commissioning Group
ODP	Operating department practitioner
ORH	Oxford Radcliffe Hospital
PCG	Paediatric Chemotherapy Group
PA	Programmed activity
PCT	Primary care trust
POSCU	Children's Haematology/Oncology shared care unit
PTC	Principal Treatment centre
PTCCG	Principal Treatment Centre Chemotherapy Group
RCN	Royal College of Nursing
RN	Registered nurse
RSCN	Registered sick children's nurse
SCG	Specialist commissioning group
SC-C&TYA	South Central SHA C&TYA Steering Group
SLA	Service level agreement
SOP	Standard Operating Policy
ST3	Specialist trainee (level 3)
TYA	Teenage and young adults
TVCN	Thames Valley Cancer Network
TVCCN	Thames Valley Children's Cancer Network
TVCCN-CG	Thames Valley Children's Cancer Network Co-ordinating Group
TVCRN	Thames Valley Cancer Research Network
TYACN	Teenage and Young Adults Cancer Network
TYACU	Teenage and Young Adults Cancer Unit
WTE	Whole time equivalent

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## 8. Appendix 3: Symptom Card

This card is designed to help you know and spot the signs and symptoms of brain tumours in children and young people.

Fortunately brain tumours in children and young people are rare, but they happen.

- ❑ A quarter of childhood cancers occur in the brain
- ❑ Early detection of brain tumours can improve the outcome
- ❑ If you are worried you / your child has a brain tumour **SEE** this to your doctor
- ❑ The website [www.headsmart.org.uk](http://www.headsmart.org.uk) can provide further information, support and reassurance

If you are worried **make** an appointment with your doctor. Please remember any young person needing urgent medical help should be taken to the nearest emergency department or dial 999.



Any child with symptoms that are unusual for him or her, or are persistent or unexplained, should be seen by a GP. Please remember that any child needing urgent medical help should be taken to the nearest emergency department.  
**In an emergency dial 999.**

The HeadSmart Campaign is run by a partnership between the Children's Brain Tumour Research Centre (CBTRC) at the University of Nottingham, the Royal College of Paediatrics and Child Health (RCPCH) and Samantha Dickson Brain Tumour Trust (SDBTT), and has been funded by The Health Foundation and SDBTT.

If you would like to talk to someone about brain tumours, or have been affected by the brain tumour symptoms campaign, please contact the support line at SDBTT on **0845 130 9733** or [email: support.info@headsmart.org.uk](mailto:support.info@headsmart.org.uk)

RCPCH Registered Charity no: 1057744  
SDBTT Registered Charity no: 1128214  
and Company Limited by Guarantee no: 05403995  
CBTRC Charitable Status Inland Revenue Number: 875294  
Health Foundation Reg Charity no: 280987  
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**HEADSMART**  
be brain tumour aware

**This card will give you all the information you need to be brain tumour aware.**

[www.headsmart.org.uk](http://www.headsmart.org.uk)



**Brain tumours happen...**  
**Symptoms include:**

- ❑ Persistent / recurrent vomiting
- ❑ Balance / co-ordination / walking problems
- ❑ Abnormal eye movements
- ❑ Behaviour change, particularly lethargy
- ❑ Fits or seizures (not with a fever)
- ❑ Abnormal head position such as wry neck, head tilt or stiff neck

*If your child has one of these, see your doctor  
If two or more, ask for an "urgent referral"*



**Brain tumours happen...**  
**Symptoms include:**

- ❑ Persistent / recurrent headache
- ❑ Persistent / recurrent vomiting
- ❑ Balance / co-ordination / walking problems
- ❑ Abnormal eye movements
- ❑ Blurred or double vision
- ❑ Behaviour change
- ❑ Fits or seizures
- ❑ Abnormal head position such as wry neck, head tilt or stiff neck

*If your child has one of these, see your doctor  
If two or more, ask for an "urgent referral"*



**Brain tumours happen...**  
**Symptoms include:**

- ❑ Persistent / recurrent headache
- ❑ Persistent / recurrent vomiting
- ❑ Balance / co-ordination / walking problems
- ❑ Abnormal eye movements
- ❑ Blurred or double vision
- ❑ Behaviour change
- ❑ Fits or seizures
- ❑ Delayed or arrested puberty, slow growth

*If your child has one of these, see your doctor  
If two or more, ask for an "urgent referral"  
Especially if growth or puberty is slow*

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## 9. Evidence of Agreement

This Guideline has been agreed by:

Lead Clinician Oxford PTC: Dr Kate Wheeler
Head of Service for Chemotherapy Oxford PTC: Dr Sheila Lane

## 10. Review of Protocol

This document will be reviewed annually within the TVCN Oxford Paediatric TSSG Meeting.

### Disclaimer

It is **your** responsibility to check against the electronic library that this printed out copy is the most recent issue of this document.

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