Guideline for the Referral to Secondary\Tertiary Care for Suspected Children’s Cancer (age 0-16 years)

Version History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date Issued</th>
<th>Brief Summary of Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>05.08.10</td>
<td>Version 1 approved by the West Midlands Children's Cancer Network Co-ordinating Group) August 2010.</td>
</tr>
<tr>
<td>1.0</td>
<td>07.04.11</td>
<td>Reformatted for consistency with Pan Birmingham Cancer Network documents by Rachel Loveless (RL). Sent to Jeanette Hawkins (JH) and Gail Fortes-Mayer for information and agreement.</td>
</tr>
<tr>
<td>1.1</td>
<td>12.04.11</td>
<td>Slight modification by Dave Hobin and flow chart revised</td>
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<tr>
<td>1.2</td>
<td>13.04.11</td>
<td>Page 7, table 2 Coventry Clinic changed from Tuesday to Thursday by Nigel Coad</td>
</tr>
<tr>
<td>1.3</td>
<td>16.04.11</td>
<td>Slight modification by Deepak Kalra. Renumbering of section 4</td>
</tr>
<tr>
<td>1.4</td>
<td>14.06.11</td>
<td>Clinical Governance Sub Group for information – modifications suggested.</td>
</tr>
<tr>
<td>1.5</td>
<td>15.06.11</td>
<td>Re written by RL with input from JH</td>
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<tr>
<td>1.6</td>
<td>19.07.11</td>
<td>Rachel Loveless Incorporated comments from Mark Velangi, Dave Hobin, Bruce Morland and Martin English with Headsmart info.</td>
</tr>
<tr>
<td>1.7</td>
<td>19.07.11</td>
<td>JH confirmed POSCU and non-POSCU pathways</td>
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<tr>
<td>1.8</td>
<td>25.07.11</td>
<td>Reviewed and updated by Lara Barnish (LB)</td>
</tr>
<tr>
<td>1.9</td>
<td>28.07.11</td>
<td>Review and update by LB following comment from Jeanette Hawkins and Alison Rowe comments added by RL.</td>
</tr>
<tr>
<td>1.10</td>
<td>08.08.11</td>
<td>Sent to JH for review and questions</td>
</tr>
<tr>
<td>1.11</td>
<td>09.08.11</td>
<td>With final comments from JH. For the addition of updated referral forms.</td>
</tr>
<tr>
<td>1.12</td>
<td>31.08.11</td>
<td>Reviewed by LB for submission to the governance sub group</td>
</tr>
<tr>
<td>2.0</td>
<td>20.09.11</td>
<td>Reviewed and endorsed by Guidelines Sub Group</td>
</tr>
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Date Approved by Network Governance | September 2011

Date for Review | September 2014

Changes between version 1 and 2

1. Many general content changes.
This protocol should be distributed within the West Midlands to all:

a) primary care practitioners  
b) paediatricians  
c) surgeons who treat children  
d) accident and emergency departments

1. **Scope of the guideline**

This guideline has been produced to support clinicians in primary and secondary care with the following:

- The referral of children with suspected cancer for assessment and diagnosis.  
- The referral of children with a diagnosis of cancer.

2. **Guideline background**

2.1 The Principal Treatment Centre (PTC) for all childhood cancer within the West Midlands is **Birmingham Children’s Hospital (BCH)**

<table>
<thead>
<tr>
<th>Telephone</th>
<th>Haematology Fax (BCH)</th>
<th>Oncology Fax (BCH)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0121 333 9999</td>
<td>0121 333 9841</td>
<td>0121 333 8241</td>
</tr>
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</table>

2.2 The care of all children referred to BCH is overseen by consultants in oncology and haematology (Table 1 – page 7).

2.3 The West Midlands has a formal network of Paediatric Oncology Shared Care Units (POSCUs) and each has a lead clinician, nurse and a link BCH consultant (see Table 2 – page 8).

2.4 The West Midlands Children’s Cancer Network Coordinating Group has overall responsibility for coordination of children’s cancer services across the West Midlands. The group is chaired by the West Midlands Specialised Commissioning Group, and is hosted by Pan Birmingham Cancer Network.

**Guideline statements**

3. **All suspected cancer referrals in children <16years**

3.1 All referrals of suspected or diagnosed cancer in children aged 0-16 years are considered urgent: some require immediate referral, the others within a 2 week timeframe. The referral process is determined by referrer and disease type. Each is described below and can be found in the flow chart on page 6.
3.2 NICE referral guidance is attached in appendix 1, referral forms in appendix 2, and patient information on referral in appendix 3.

3.3 Suspected cancer can be referred to a POSCU or the PTC, but confirmation of diagnosis can only happen at the PTC.

4.1 Patients presenting to their GP or other primary health care provider (i.e. dentist/optician) with suspected cancer

4.1.1 All children presenting with a suspected cancer in primary care must be discussed with a paediatrician in oncology or haematology; either at the PTC (BCH), or the local POSCU, prior to completing the urgent fax referral form. This is to ensure that urgency of referral, and destination of referral is correctly assessed. (See appendix 1 [NICE guidance] for a list of symptoms suggestive of cancer).

4.1.2 Referrals to BCH should be made via the hospital switch board to the duty haematology or oncology middle grade doctor or consultant and should be followed up with a fax referral form for the appropriate suspected cancer. (See appendix 2 for referral forms).

4.1.3 Referrals to POSCUs should be made by phone and followed up with a fax referral form for the appropriate suspected cancer. See appendix 2 for referral forms and list of local POSCU contact numbers.

4.2 Patients with suspected bone cancers

4.2.1 Referral for suspected bone cancers can be made directly to BCH or to the Royal Orthopaedic Hospital (ROH). If a diagnosis of bone cancer is confirmed at the ROH, these patients will be discussed and jointly managed with the oncology team at BCH.

4.2.2 Referrals to the ROH should be made by phone and followed up with a fax referral form for the appropriate suspected cancer.

4.2.3 Referral to Birmingham Children’s Hospital NHS Foundation Trust is via the hospital switch board to the duty haematology or oncology middle grade doctor or consultant and should be followed up with a fax referral form for the appropriate suspected cancer. (See appendix 2 for referral forms).

4.3 Patients with a suspected brain tumour

4.3.1 A primary healthcare professional who has a high index of suspicion regarding a possible brain tumour in a child / teenager should discuss their concerns with a secondary healthcare paediatrician the same day, on one of the numbers provided on the "urgent referral child 0-16 suspected brain / CNS tumour form" (see appendix 2).
4.3.2 A child / teenager referred from primary care in which the differential diagnosis includes a possible space occupying lesion should be seen in secondary care within 2 weeks.

4.3.3 The following are all associated with an increased risk of childhood brain tumours. Their presence may lower the threshold for referral:

   a) personal or family history of a brain tumour
   b) leukaemia
   c) sarcoma
   d) early onset breast cancer
   e) personal history of prior therapeutic CNS irradiation
   f) neurofibromatosis 1 and 2
   g) tuberous sclerosis 1 and 2
   h) other familial genetic syndromes

4.3.4 More detailed signs and symptoms can be found in the HEADSMART guidelines page 90-95 [www.headsmart.org.uk](http://www.headsmart.org.uk)

5 Children in a secondary care hospital where a new suspicion of cancer emerges

5.1 All children presenting to a local hospital (DGH), for example via the emergency department, outpatient clinic, general paediatrics or surgery, where a suspicion of cancer is subsequently raised must be discussed via telephone with a paediatrician specialising in paediatric oncology / haematology.

5.2 If the DGH has POSCU status this will be an internal conversation with the POSCU oncology paediatrician, followed up with an urgent referral form.

5.3 If the DGH does not have POSCU status this will be a telephone discussion with the oncology or haematology team at the PTC (BCH), followed up with an urgent referral form. This will ensure that the urgency of the referral and appropriate destination for referral has been correctly assessed.

5.4 Referrals to BCH should be made via the hospital switch board to the duty haematology or oncology middle grade doctor or consultant, and should be followed up with a fax referral form for the appropriate suspected cancer.

6 Internal referrals

Referred inpatients will either be transferred from the referring hospital to an inpatient bed in BCH or will be seen in the haematology/oncology outpatient clinic at BCH.

ENDORESED BY GOVERNANCE COMMITTEE
7 Patients referred from primary care to a POSCU with a suspected cancer following telephone discussion and urgent referral form

7.1 The POSCU oncology paediatrician(s) will undertake further investigations following the West Midlands Children’s Cancer Network Coordinating Group ‘Diagnosis & Staging Protocol’ to confirm or exclude suspicion of cancer.

7.2 Where the suspicion of cancer remains after preliminary investigations, the POSCU paediatrician will discuss the patient with the duty oncologist/haematologist at BCH and arrange a transfer; for confirmation of diagnosis, for consent to available and eligible clinical trials, and for treatment planning. This will happen within the 2 week wait timeframe.

7.5 Patients may be admitted to BCH or may attend BCH as an outpatient and return to the POSCU for treatment according to clinical need and designated level of POSCU service.

8 All patients

8.1 The urgency for inpatient admissions will be assessed by the POSCU or BCH team and the referring consultant advised appropriately.

8.2 If transfer cannot be arranged in the timeframe recommended by BCH, the referring hospital will be advised by the BCH team to refer the patient to an out of region PTC.

8.3 Patients requiring an outpatient appointment will be reviewed in an appropriate clinic within 2 weeks or referral.
Patient reports symptoms of suspected cancer at either:

- **Assessment in Primary Care**
  (Either at patients’ GP, dentist or optician)

- **Assessment at the Principal Treatment Centre (BCH)**
  (Either in the Emergency Department, OPD, or through a surgical or general paediatric admission).

- **Assessment at a NON-POSCU DGH**
  (Either in the Emergency Department, OPD, or through a surgical or general paediatric admission).

- **Assessment at a POSCU designated DGH**
  (Either in the Emergency Department, OPD, or through a surgical or general paediatric admission).

Discuss with POSCU oncology paediatrician and admit to POSCU

- Refer via phone to local POSCU or duty Oncologist/Haematologist at BCH
- Refer via phone to duty Oncologist/Haematologist at BCH
- Refer via phone to duty Oncologist/Haematologist at BCH
- Refer via phone to duty Oncologist/Haematologist at BCH

Follow up with fax referral form for the appropriate suspected cancer
<table>
<thead>
<tr>
<th>Table 1</th>
<th>BCH CONSULTANT TEAM</th>
</tr>
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<tbody>
<tr>
<td><strong>Oncology</strong></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Secretary contact</td>
</tr>
<tr>
<td>Dr Martin English</td>
<td>0121 333 8412</td>
</tr>
<tr>
<td>Dr Andrew Peet</td>
<td>0121 333 8412</td>
</tr>
<tr>
<td>Dr Pam Kearns</td>
<td>0121 333 8234</td>
</tr>
<tr>
<td>Dr Dave Hobin</td>
<td>0121 333 8233</td>
</tr>
<tr>
<td>Dr Helen Jenkinson</td>
<td>0121 333 8233</td>
</tr>
<tr>
<td>Dr Bruce Morland</td>
<td>0121 333 8234</td>
</tr>
<tr>
<td><strong>Haematology</strong></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Secretary contact</td>
</tr>
<tr>
<td>Dr Phil Darbyshire</td>
<td>0121 3339844</td>
</tr>
<tr>
<td>Dr Jayashree Motwani</td>
<td>0121 3339842</td>
</tr>
<tr>
<td>Dr Mike Williams</td>
<td>0121 3339843</td>
</tr>
<tr>
<td>Dr Sarah Lawson</td>
<td>0121 3339848</td>
</tr>
<tr>
<td>Dr Mark Velangi</td>
<td>0121 3339842</td>
</tr>
<tr>
<td>Table 2</td>
<td>POSCU NETWORK</td>
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<tr>
<td>---------</td>
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</tr>
<tr>
<td>Unit</td>
<td>Lead Clinician</td>
</tr>
<tr>
<td>Burton Hospitals NHS Trust</td>
<td>Jacob Samuel</td>
</tr>
<tr>
<td>Hereford Hospitals NHS Trust</td>
<td>Simon Meyrick</td>
</tr>
<tr>
<td>Royal Wolverhampton Hospitals NHS Trust</td>
<td>Deepak Kalra</td>
</tr>
<tr>
<td>Shrewsbury and Telford Hospitals NHS Trust (SATH)</td>
<td>Andrew Cowley</td>
</tr>
<tr>
<td>University Hospitals Coventry and Warwickshire NHS Trust</td>
<td>Nigel Coad</td>
</tr>
<tr>
<td>University Hospital of North Staffordshire NHS Trust</td>
<td>Sarah Thompson</td>
</tr>
<tr>
<td>Worcestershire Acute Hospitals NHS Trust</td>
<td>Baylon Kamalarajan</td>
</tr>
</tbody>
</table>
Monitoring

Monitoring will be via BCH Cancer Locality Group quarterly review of cancer waiting times, breaches and investigation of inappropriate referral patterns.

References


Authors

Jeanette Hawkins  Lead Cancer Nurse
Birmingham Children’s Hospital NHS Foundation Trust

Rachel Loveless  Project Lead
Pan Birmingham Cancer Network

Approval Signatures

Pan Birmingham Cancer Network Clinical Governance Committee Chair

Name: Doug Wulff
Signature  Date  September 2011

Pan Birmingham Cancer Network Manager

Name: Karen Metcalf
Signature  Date  September 2011

Network Site Specific Group Clinical Chair

Name: Gail Fortes-Mayer
Signature  Date  September 2011
N.I.C.E. (2005) Extract from REFERRAL GUIDELINES FOR SUSPECTED CANCER IN ADULTS AND CHILDREN: June 2005

Children’s Cancer

General Recommendations

1. Children and young people who present with symptoms and signs of cancer should be referred to a paediatrician or a specialist children’s cancer service, if appropriate.

2. Childhood cancer is rare and may present initially with symptoms and signs associated with common conditions. Therefore, in the case of a child or young person presenting several times (for example, three or more times) with the same problem, but with no clear diagnosis, urgent referral should be made.

3. The parent is usually the best observer of the child’s or young person’s symptoms. The primary healthcare professional should take note of parental insight and knowledge when considering urgent referral.

4. Persistent parental anxiety should be a sufficient reason for referral of a child or young person, even when the primary healthcare professional considers that the symptoms are most likely to have a benign cause.

5. Persistent back pain in a child or young person can be a symptom of cancer and is indication for an examination, investigation with a full blood count and blood film, and consideration of referral.

6. There are associations between Down syndrome and leukaemia, neurofibromatosis and CNS tumours, and between other rare syndromes and some cancers. The primary healthcare professional should be alert to the potential significance of unexplained symptoms in children or young people with such syndromes.

7. The primary healthcare professional should convey information to the parents and child/young person about the reason for referral and which service the child/young person is being referred to so that they know what to do and what will happen next.

8. The primary healthcare professional should establish good communication with the parents and child/young person in order to develop the supportive relationship that will be required during the further management if the child/young person is found to have cancer.
Specific Recommendations

**Leukaemia (children of all ages)**

9 Leukaemia usually presents with a relatively short history of weeks rather than months. The presence of one or more of the following symptoms and signs requires investigation with full blood count and blood film:
- pallor
- fatigue
- unexplained irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- persistent or unexplained bone pain
- unexplained bruising.

If the blood film or full blood count indicates leukaemia then an urgent referral should be made.

10 The presence of either of the following signs in a child or young person requires immediate referral:
- unexplained petechiae
- hepatospleno-omegalgy.

**Lymphomas**

Hodgkin’s lymphoma presents typically with non tender cervical and/or supraclavicular lymphadenopathy. Lymphadenopathy can also present at other sites. The natural history is long (months). Only a minority of patients have systemic symptoms (itching, night sweats, fever). Non Hodgkin’s lymphoma typically shows a more rapid progression of symptoms, and may present with lymphadenopathy, breathlessness, SVC obstruction, abdominal distension

11 Lymphadenopathy is more frequently benign in younger children but urgent referral is advised if one or more of the following characteristics are present, particularly if
- there is no evidence of local infection:
- lymph nodes are non-tender, firm or hard
- lymph nodes are greater than 2 cm in size
- lymph nodes are progressively enlarging
- other features of general ill-health, fever or weight loss
- the axillary nodes are involved (in the absence of local infection or dermatitis)
- the supraclavicular nodes are involved.

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12 The presence of hepatosplenomegaly requires immediate referral.

13 Shortness of breath is a symptom that can indicate chest involvement but may be confused with other conditions such as asthma. Shortness of breath in association with the above signs (recommendation 1.14.11), particularly if not responding to bronchodilators, is an indication for urgent referral.

14 A child or young person with a mediastinal or hilar mass on chest X-ray should be referred immediately.

Brain & CNS Tumours

a. Children 2 years and older and young people

15 Persistent headache in a child or young person requires a neurological examination by the primary healthcare professional. An urgent referral should be made if the primary healthcare professional is unable to undertake an adequate examination.

16 Headache and vomiting that cause early morning waking or occur on waking are classical signs of raised intracranial pressure, and an immediate referral should be made.

17 The presence of any of the following neurological symptoms and signs should prompt urgent or immediate referral:

- 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.

18 A child or young person with a reduced level of consciousness requires emergency admission.
a. Children < 2 years

In children aged younger than 2 years, any of the following symptoms may suggest a CNS tumour, and referral (as indicated below) is required.

- Immediate referral:
  - new onset seizures
  - bulging fontanelle
  - extensor attacks
  - persistent vomiting.

- Urgent referral:
  - 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.

- Urgency contingent on other factors:
  - squint.

**Neuroblastoma (all ages)**

The majority of children 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.

The presence of the following symptoms and signs requires investigation with FBC:

- persistent or unexplained bone pain (and X–ray)
- pallor
- fatigue
- unexplained irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- unexplained bruising.
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21 Other symptoms which should raise concern about neuroblastoma and prompt urgent referral include:

- proptosis
- unexplained back pain
- leg weakness
- unexplained urinary retention.

22 In children or young people with symptoms that could be explained by neuroblastoma, an abdominal examination (and/or urgent abdominal ultrasound) should be undertaken, and a chest X-ray and full blood count considered. If any mass is identified, an urgent referral should be made.

23 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, an immediate referral should be made.

Wilms’ tumour (all ages)

24 Wilms’ tumour most commonly presents with a painless abdominal mass. Persistent or progressive abdominal distension should prompt abdominal examination, and if a mass is found an immediate referral be made. If the child or young person is uncooperative and abdominal examination is not possible, referral for an urgent abdominal ultrasound should be considered.

25 Haematuria in a child or young person, although a rarer presentation of a Wilms’ tumour, merits urgent referral.

Soft tissue sarcoma (all ages)

26 A soft tissue sarcoma should be suspected and an urgent referral should be made for a child or young person with an unexplained mass at almost any 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
- >2 cm in diameter in size.
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27 A soft tissue mass in an unusual location may give rise to misleading local and persistent unexplained symptoms and signs, and the possibility of sarcoma should be considered. These symptoms and signs include:

- head and neck sarcomas:
  - 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

**Bone sarcomas (osteosarcoma and Ewing's sarcoma) (all ages)**

28 Limbs are the most common site for bone tumours, especially around the knee in the case of osteosarcoma. Persistent localised bone pain and/or swelling requires an X-ray. If a bone tumour is suspected, an urgent referral should be made to the Supraregional Bone Sarcoma Service based at the Royal Orthopaedic Hospital.

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

30 Rest pain, back pain and unexplained limp may all point to a bone tumour and require discussion with a paediatrician, referral or X-ray.

**Retinoblastoma (mostly children aged under 2 years)**

31 In a child with a white pupillary reflex (leukocoria) noted by the parents, identified in photographs or found on examination, an urgent referral should be made. The primary healthcare professional should pay careful attention to the report by a parent of noticing an odd appearance in their child’s eye.

32 A child with a new squint or change in visual acuity should be referred. If cancer is suspected, referral should be urgent, but otherwise referral should be non-urgent.

33 A family history of retinoblastoma should alert the primary healthcare professional to the possibility of retinoblastoma in a child who presents with visual problems.

Offspring of a parent who has had retinoblastoma, or siblings of an affected child, should undergo screening soon after birth.

**ENDORESED BY GOVERNANCE COMMITTEE**
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Investigations

34  When cancer is suspected in children and young people, imaging is often required. This may be best performed by a paediatrician, following urgent or immediate referral by the primary healthcare professional.

35  The presence of any of the following symptoms and signs requires investigation with full blood count:

- pallor
- fatigue
- irritability
- unexplained fever
- persistent or recurrent upper respiratory tract infections
- generalised lymphadenopathy
- persistent or unexplained bone pain (and X-ray)
- unexplained bruising
**URGENT REFERRAL FOR SUSPECTED BRAIN & CNS CANCER**  
**CHILD 0-16 years**  
(Version 1.0) If you wish to include an accompanying letter, please do so.  
PHONE FOR ADVICE & FAX completed form to a number on page 3.

A fax only is an inadequate referral. All referrals MUST be discussed with the relevant medical team (see below).

These forms should only be used for suspected cancer and in conjunction with the NICE Referral Guidelines for Suspected Cancer, June 2005 & HEADSMART Brain Tumour Awareness Guidelines 2011.

### Patient Details

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forename</th>
<th>D.O.B.</th>
<th>Address</th>
<th>Postcode</th>
<th>Telephone</th>
<th>NHS No</th>
<th>Hospital No</th>
<th>Interpreter?</th>
<th>First Language</th>
<th>Gender</th>
<th>Fax No:</th>
</tr>
</thead>
</table>

### GP Details (inc Fax Number)

<table>
<thead>
<tr>
<th>Date of Decision to Refer</th>
<th>Date of Referral</th>
<th>GP Signature</th>
</tr>
</thead>
</table>

### Relevant information: (Tick if present) **CNS Symptoms (For suspected brain tumour in a child 0-16 years)**

- Persistent / recurrent vomiting
- Persistent / recurrent headache
- Deteriorating vision
- Balance / co-ordination / walking problems
- Abnormal head position such as wry neck, head tilt or stiff neck
- Abnormal eye movements
- Blurred or double vision
- Fits or seizures (Not febrile fits under 5)
- Behaviour change, (especially lethargy <5)
- Delayed or arrested puberty, slow growth (especially 12-18years)

### Referral (HEADSMART GUIDELINES)

1. A primary healthcare professional who has a high index of suspicion regarding a possible brain tumour in a child / teenager should discuss their concerns with a secondary healthcare professional the same day on one of the numbers provided.
2. A child / teenager referred from primary care in which the differential diagnosis includes a possible space occupying lesion should be seen within 2 weeks.
3. The following are all associated with an increased risk of childhood brain tumours. Presence may lower the threshold for referral: Personal or family history of a brain tumour, leukaemia, sarcoma, and early onset breast cancer; personal history of prior therapeutic CNS irradiation; Neurofibromatosis 1 and 2; Tuberous sclerosis 1 and 2; other familial genetic syndromes.
4. More detailed signs and symptoms can be found in the HEADSMART guidelines page 90-95.  
   [www.headsmart.org.uk](http://www.headsmart.org.uk)
**Clinical Details:** History/Examination/Investigations

**Medication:**

What have the parents / carers and child been told?
CHILDREN’S BRAIN & CNS CANCER SERVICES WITH RAPID ACCESS FACILITIES (West Midlands Region)

Place of phone discussion & fax referral should take into account urgency of signs and symptoms, geographical location & patient (carer) choice

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Tel</th>
<th>Fax</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Birmingham Children’s Hospital NHS Foundation Trust</strong> <em>(West Midlands Children’s Cancer Principal Treatment Centre)</em></td>
<td>0121 333 9999</td>
<td>0121 333 8241</td>
<td></td>
</tr>
<tr>
<td>Ask for Oncology Middle Grade or Consultant Oncologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Burton Hospitals NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 1)</em></td>
<td>01283 566333</td>
<td>01283 593031</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Jacob Samuels or designated cover (Paediatrics)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hereford Hospitals NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 1)</em></td>
<td>01432 355444</td>
<td>01432 364036</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Simon Meyrick or designated cover (Paediatrics)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Shrewsbury and Telford Hospitals NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 3)</em></td>
<td>01743 492452</td>
<td>01743 261333</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Andrew Cowley or designated cover (Paediatrics)</td>
<td></td>
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</tr>
<tr>
<td><strong>The Royal Wolverhampton Hospitals NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 2)</em></td>
<td>01902 307999</td>
<td>01902 695616</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Deepak Kalra or designated cover (Paediatrics)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>University Hospital of North Staffordshire NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 3)</em></td>
<td>01782 715444</td>
<td>01782</td>
<td></td>
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<tr>
<td>Ask for Dr Sarah Thompson or designated cover (Paediatrics)</td>
<td></td>
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</tr>
<tr>
<td><strong>University Hospitals Coventry and Warwickshire NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 3)</em></td>
<td>02746 964000</td>
<td>02476 538894</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Nigel Coad or designated cover (Paediatrics)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Worcestershire Acute Hospitals NHS Trust</strong> <em>(Paediatric Oncology Shared Care Unit – Level 1)</em></td>
<td>01905 763333</td>
<td>01905 760584</td>
<td></td>
</tr>
<tr>
<td>Ask for Dr Baylon Kamalarajan or designated cover (paediatrics)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**For Hospital Use**

<table>
<thead>
<tr>
<th>Appointment Date</th>
<th>Clinic Attending</th>
<th>Was the referral appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>

(if no please give reason) ____________________________________________

**ENDORESED BY GOVERNANCE COMMITTEE**
URGENT REFERRAL FOR SUSPECTED HAEMATOLOGY CANCER
CHILD 0-16 years

Panel Birmingham Cancer Network

ENDORSE BY GOVERNANCE COMMITTEE

S:\Cancer Network\Guidelines\Guidelines And Pathways By Speciality\Paediatric\Current Approved Versions (Word & PDF)\Guideline For The Referral To Secondary Care For Children With Suspected Cancer - Version 2.Doc

Page 20 of 26
Clinical Details: History/Examination/Investigations

Medication:

What have the parents / carers and child been told?
CHILDREN’S HAEMATOLOGY CANCER SERVICES WITH RAPID ACCESS FACILITIES (West Midlands Region)

Place of phone discussion & fax referral should take into account urgency of signs and symptoms, geographical location & patient (carer) choice

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Tel</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birmingham Children’s Hospital NHS Foundation Trust (West Midlands Children’s Cancer Principal Treatment Centre)</td>
<td>0121 333 9999</td>
<td>0121 333 9841</td>
</tr>
<tr>
<td>Ask for Haematology Specialist Registrar or Consultant on call</td>
<td></td>
<td>FAO: Paediatric Haematology Consultants</td>
</tr>
<tr>
<td>Burton Hospitals NHS Trust (Paediatric Oncology Shared Care Unit – Level 1)</td>
<td>01283 566333</td>
<td>01283 593031</td>
</tr>
<tr>
<td>Ask for Dr Jacob Samuels or designated cover (Paediatrics)</td>
<td></td>
<td>FAO: Dr Samuels</td>
</tr>
<tr>
<td>Hereford Hospitals NHS Trust (Paediatric Oncology Shared Care Unit – Level 1)</td>
<td>01432 355444</td>
<td>01432 364036</td>
</tr>
<tr>
<td>Ask for Dr Simon Meyrick or designated cover (Paediatrics)</td>
<td></td>
<td>FAO: Dr Meyrick</td>
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<tr>
<td>Shrewsbury and Telford Hospitals NHS Trust (Paediatric Oncology Shared Care Unit – Level 3)</td>
<td>01743 492452</td>
<td>01743 261333</td>
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<tr>
<td>Ask for Dr Andrew Cowley or designated cover (Paediatrics)</td>
<td></td>
<td>FAO: Dr Cowley</td>
</tr>
<tr>
<td>The Royal Wolverhampton Hospitals NHS Trust (Paediatric Oncology Shared Care Unit – Level 2)</td>
<td>01902 307999</td>
<td>01902 695616</td>
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<tr>
<td>Ask for Dr Deepak Kalra or designated cover (Paediatrics)</td>
<td></td>
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<td>01782 715444</td>
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</tr>
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<td>01782 553171 Dr Thompson</td>
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For Hospital Use
Appointment Date Clinic Attending
Was the referral appropriate Yes No (if no please give reason)
**URGENT REFERRAL FOR SUSPECTED SOLID TUMOUR (non-CNS)**

CHILD 0-16 years (Version 1.0) If you wish to include an accompanying letter, please do so.

**PHONE FOR ADVICE & FAX completed form to a number on page 3.**

A fax only is an inadequate referral. All referrals MUST be discussed with the relevant medical team (see below).

These forms should only be used for suspected cancer and in conjunction with the NICE Referral Guidelines for Suspected Cancer, June 2005

### Patient Details

<table>
<thead>
<tr>
<th>Surname</th>
<th>Forename</th>
<th>D.O.B.</th>
<th>Address</th>
<th>Postcode</th>
<th>Telephone</th>
<th>NHS No</th>
<th>Hospital No</th>
<th>Interpreter?</th>
<th>GP Details (inc Fax Number)</th>
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<td>Date of Decision to Refer</td>
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<td>Date of Referral</td>
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<td></td>
<td>GP Signature</td>
</tr>
</tbody>
</table>

### Diagnosis Suspected:

- Lymphoma
- Neuroblastoma
- Wilm's Tumour
- Soft Tissue Sarcoma
- Bone Tumour
- Retinoblastoma
- Hepatoblastoma
- Skin cancer
- Germ Cell Tumour
- Uncertain / other

### Relevant Information: (Check as appropriate)

#### Symptoms/Signs in child 0-16:

- Pallor
- Bruising / Petechiae
- Fatigue
- Unexplained fever
- Swelling / mass
- Unexplained Weight Loss
- Recurrent infections
- Breathlessness
- Mediastinal mass
- Lymphadenopathy Large >2cm, painless, persistent >4weeks or earlier if increasing in size or clinical suspicion of malignancy
- Neurological signs
- Headache
- Back Pain
- Bone Pain
- Other pain
- Unexplained irritability
- Night Sweats
- Itching
- Hepatomegally
- Persistent unexplained splenomegaly
- Abdominal discomfort
- Bowel symptoms
- Bladder / urinary symptoms
- Scrotal swelling
- Unexplained vaginal discharge
- White pupillary reflex Leukocoria
- Proptosis
- Visual problems / squint
- Unexplained aural discharge
- Unexplained nasal obstruction or discharge

### Additional Features:

4. There are associations between some rare syndromes and childhood cancers. Be alert to the potential significance of unexplained symptoms in children with such syndromes.

5. Urgent referral for children 0-16 with petechiae, hepatosplenomegaly, respiratory distress, spinal cord compression symptoms, proptosis, or other compression-like symptoms, reduced consciousness, headache with vomiting, focal neurology.


7. Bone pain with no history of sports / play injury needs investigating – be cautious of phrase "growing pains”

### For Hospital Use

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Was the referral appropriate

Yes No (if no please give reason)

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**ENDORESED BY GOVERNANCE COMMITTEE**

S:\Cancer Network\Guidelines\Guidelines And Pathways By Specialty\Paediatric\Current Approved Versions (Word & PDF)\Guideline For The Referral To Secondary Care For Children With Suspected Cancer - Version 2.Doc

Page 23 of 26
**Referral Guidance:**
1. The West Midlands offers a hub and spoke model of Children’s Cancer Services. The Principal Treatment Centre (PTC) is Birmingham Children’s Hospital, which “shares care” with 7 designated Paediatric Oncology Shared Care Units (POSCUs) across the West Midlands (see next page for details).
2. Children with urgent or distressing signs and symptoms should be referred to the Principal Treatment Centre following telephone discussion.
3. For less urgent or uncertain suspicion refer through local paediatricians to any of the services below by phone. Birmingham Children's Hospital provides both secondary & tertiary care. Follow with fax referral with patient details to provide accurate details for referral and 2 week wait monitoring.
4. Avoid referral to adult surgeons if childhood cancer is a consideration.
5. Do not biopsy locally. Do the minimum of investigations prior to referral.
6. Be open with parents/children. Use appropriate language. If you don’t know what to say, ask us. Don’t be scared to say “cancer.” If referring to an oncologist tell the family this is a cancer specialist.

**Clinical Details:** History/Examination/Investigations

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**CHILDREN’S SUSPECTED SOLID TUMOUR (non-CNS) CANCER SERVICES WITH RAPID ACCESS FACILITIES (West Midlands Region)**

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<td>FAO: Paediatric Oncology Consultants</td>
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Why has my child been given a ‘Two Week Wait’ hospital appointment?

What is a ‘two week wait’ appointment?
The ‘two week wait’ or ‘urgent’ appointment was introduced so that a specialist would see any patient with symptoms that might indicate cancer as quickly as possible. The two week wait appointment has been requested either by your child’s GP or dentist.

Why has our GP referred my child?
GPs diagnose and treat many illnesses but sometimes they need to arrange for your child to see a specialist hospital doctor. This could be for a number of reasons such as:

- The treatment already given by your GP for your child’s symptoms has not worked.
- Your symptoms need further investigation.
- Investigations arranged by your GP have shown some abnormal results.
- Your GP suspects cancer.

Does this mean my child has cancer?
Most of the time, it doesn’t. Even though you are being referred to a specialist, this does not necessarily mean that your child has cancer. More than 70% of patients referred with a ‘two week wait’ appointment do not have cancer.

What symptoms might need a ‘two week wait’ appointment?

- A lump that does not go away.
- A change in the size, shape or colour of a mole.
- Abnormal bleeding.
- A change in bowel or bladder habits.
- Continuous tiredness and/or unexplained weight loss.
- Other unexplained symptoms.

What should I do if my child is unable to attend an appointment in the next two weeks?
This is an important referral. Let your GP know immediately (or the hospital when they contact you) if you are unable to attend a hospital appointment within the next two weeks.

What do I need to do now?

- Make sure that your GP has your correct address and telephone number, including your mobile phone number.
- The hospital will try to contact you by telephone to arrange an appointment. If they are not able to make telephone contact, an appointment letter will be sent to you by post.
- Inform your GP surgery if you have not been contacted by the hospital within three working days of the appointment with your GP.
- You will receive further information about your appointment before you go to the hospital. It is important you read this information and follow the instructions.
- Please feel free to bring someone with you to your appointment at the hospital.

It is important to remember that even though you will receive a ‘two week wait’ appointment, being referred to a specialist does not necessarily mean that you have cancer. Remember, 7 out of 10 patients referred this way do not have cancer.

©Pan Birmingham Cancer Network 2011
Publication date: July 2011 Review date: July 2015
Patient Information adapted from Harrow Primary Care Trust