

Thames Valley Cancer Network
Paediatric Haematology and Oncology
Referral Guidelines
Audit

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Outline

- Overview of guidelines (Dr Wheeler)
- Background
- Audit results
- Discussion points

Background of audit

Thames Valley Cancer Network (Berkshire, Buckinghamshire, Oxfordshire, Swindon)



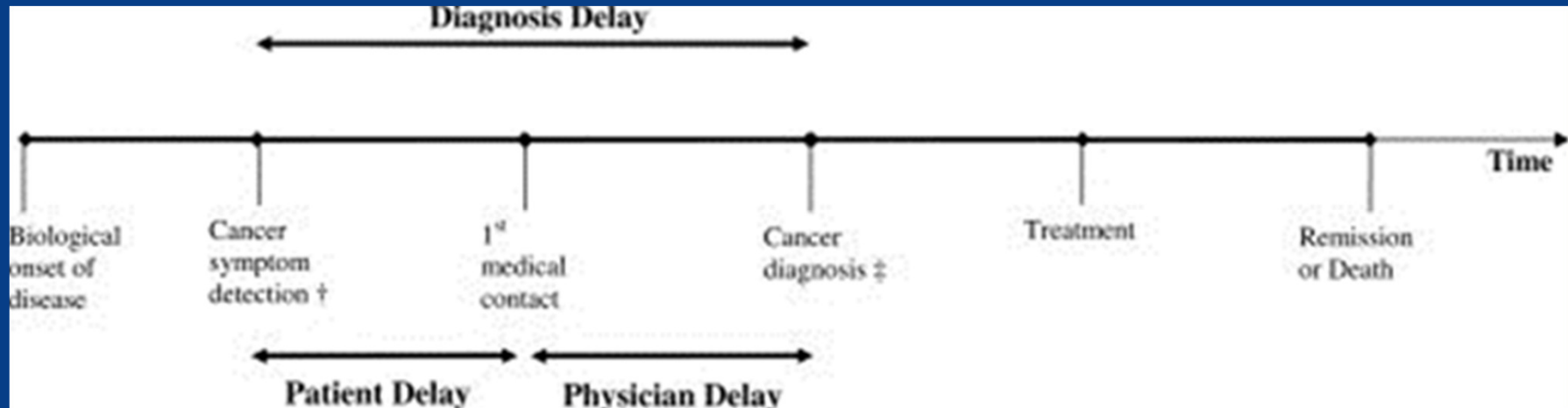
Fig.1 TVCN¹

‘Guidelines for the referral of children and young people with suspected cancer’ (June 2011)

- In line with NICE ‘Referral Guidelines for Suspected Cancer’ (June 2005)

Benefit of guidelines

- To ensure children & young people (0-19y) with cancer or suspected cancer are referred promptly for assessment and diagnosis



[Fig2. Diagnosis delay in the Cancer Care Pathway \(Dang-Tan et al\)](#)

- Structured approach to assessment
- Clear criteria for immediate and urgent referral

Aim of audit

- To investigate **adherence to** *Thames Valley Cancer Network 'Guidelines for the referral of children and young people with suspected cancer' (June 2011)*
- To investigate **awareness of** the above guidelines targeted for
 - Primary Care Practitioners
 - Paediatricians
 - Surgeons who treat children
 - Accident and Emergency Departments

Methods

- Retrospective review of medical notes
- Recently diagnosed patients from each of the following groups selected Jan 2011
 - CNS tumours 10 patients
 - Solid tumours 5 patients
 - Leukaemia/Lymphoma 5 patients
- Events surrounding referral audited

Results

| CNS | Pt1 7y | Pt2 9y | Pt3 9y | Pt4 15m | Pt5 5y |
|--|--|--|---|--|---|
| Referral pathway First symptoms to tertiary service | Dx OMS 2005 Paed Neu asked parents to attend Paed A&E (ND if GP involved) | Dx DI 2009 Routine MRI under Paed Endocrinol. | GP referral to Paeds MRI Eastbourne 4cm solid mass L1 | Same day GP referral to GWH Paeds | Seen Paeds Horton 2x Ref NS post CT. 10/7 prior GP+paeds->viral/dioral. |
| PC | 4/12 vertigo & vomiting | None | 8/12 back pain, nocturnal enuresis | 4/7 imbalance Head tilt Falling to R | Early am vomiting lethargy Weight loss |
| Abnormal Neurology | Vertical gaze abnormality Unsteady ↓coordination | None | | | lethargy |
| 1 st sympt. to JR HaemOnc | 16 weeks | N/A | 32 weeks | 4 days | 2weeks |
| Diagnosis | Atypical teratoid rhabdoid tumour | Germinoma | Gr 2 Ependymoma | Non-metastatic medulloblastoma | Post. Fossa anaplastic ependymoma |

| CNS | Pt6 5y | Pt7 7y | Pt8 13m | Pt9 14y | Pt10 4y |
|--|--|--|--|--|--|
| Referral pathway First symptoms to tertiary service | Paeds WPH to neurosurgery Post-CT | Known NF1 Paeds WPH to neurosurgery post-MRI | Parents self-ref to Paeds A&E, seen by Paeds Cons. Same day ref. Paed Neu. Prev seen GP Dx Viral | Paed OPD WPH 18/12 treated as H. Pylori. Referred to NS post MRI head | Paeds RBH to Neurosurg post-CT |
| PC | 6/12 vomiting unsteady gait Right eye squint | 3/12 nausea, vomiting, headaches 2/52 double vision | Head tilt to L L. Eye blinking Unsteadiness | 18/12 headaches, abdo pain vomiting then several week hx imbalance | 6/52 ↓appetite Neck pain Head tilt to R vomiting unsteadiness |
| Abnormal Neurology | Ataxia Broad based gait Papilloedema | Bilat CNVI palsies Papilloedema | Roving eye mvt Failure R. eye abduction Falls to left | Ataxia Diplopia lateral gaze Papilloedema | Drowsy Papilloedema |
| 1 st sympt. to JR HaemOnc | 24 weeks | 12 weeks | 2 weeks | 72 weeks | 6 weeks |
| Diagnosis | Grade 1 pilocytic astrocytoma | Right cerebellar lesion | Brainstem primitive neuroectodermal tumour | Grade 1 choroid plexus papilloma | Ependymoma |

| SOLIDS | Pt1 5y | Pt2 3y | Pt3 13m | Pt4 16m | Pt5 11y |
|--|--|--|---|--|---|
| Referral pathway First symptoms to tertiary service | GP referral to rapid access clinic D6. Seen by Paed Cons D9 discharged with eye drops, f/u phone D12. Re-presented A&E D14 | RBH Paeds (ND if referred by GP) | Parents brought to WPH Paeds A&E | GP to Paed Warwick with 2/7 urinary retention & constipation Ref JR neu in view of ocular albinism & conj. Nystagmus | Out of hours GP to JR Paeds A&E Prev seen ED 3/52 prior after tripping XRAY nad, f/u #clinic, discharged |
| PC | 14/7 Right eye swelling | 3/52 Abdominal pain Weight loss Bruising | 3/52 R. neck mass Dev. regression Not using lower limbs | 3/52 Urinary retention Constipation | 3/52 Posterior right thigh & buttock pain Decreased ROM hip flex |
| 1 st sympt. to JR HaemOnc | 14 days | 3 weeks | 3 weeks | 3 weeks | 3 weeks |
| Diagnosis | Right orbit embryonal RMS | Stage 4 Neuroblastoma | Neuroblastoma | Prostatic embryonal RMS | Ewing's Sarcoma |

| Leukaemia/ Lymphoma | Pt1 13m | Pt2 14y | Pt3 5y | Pt4 21m | Pt5 13y |
|--|---|---|---|---|---|
| Referral pathway First symptoms to tertiary service | GP referral to JR Paeds A&E initially treated as meningitis | GP referral to Paeds Eastbourne | Self-referral to RBH A&E, referred by RBH Paeds | Referred by SMH Paeds (ND if ref by GP) | GP referral to ENT; ENT referral to Haem-Onc post biopsy |
| PC | Reduced GCS Petechial rash | 3/52 epistaxis Lethargy GP did FBC: high WCC, low plt, blasts on film | 1/52 pallor, bruising, epistaxis, lethargy, ↓appetite | Fever ↓appetite pallor Petechiae Bruising | 2/12 R neck swelling – lymphadenitis Rx Abx Assoc Fever & URTI sympt. |
| 1 st sympt. to JR HaemOnc | 1 day | 3 weeks | 1 week | 1 day | 8 weeks |
| Diagnosis | AML | ALL | ALL | ALL | Hogkin's lymphoma Stage B |

Results - summary

- Time from first symptom to referral (mean)
 - **CNS tumours: 129.6 days (18weeks)** [9 patients]
 - **Solids: 19.6 days**
 - **Leukaemia/Lymphoma: 17.2 days**
- Shortest time to referral: Leukaemia/Lymphoma
- Longest time to referral: CNS tumours

Conclusions

- Delayed referral to tertiary services in some cases of childhood cancer
 - Longer symptoms interval assoc. declining survival rates
 - RMS/Ewing family tumours (Ferrari et al.);
 - Osteosarcoma (Kim et al)
 - Well documented delays with CNS tumours (Wilne et al)
 - 26 weeks average Time to diagnosis with CNS tumours (Fajardo-Gutierrez et al)
- Would an increased awareness of these referral guidelines & criteria for urgent referral improve this?
- If so how can this be achieved?
 - Headsmart Project 'to enhance the awareness of symptoms of brain tumours in children and young people'
- Re-audit

Limitations of audit

- Small patient sample
 - Targeted towards local services
- Retrospective review of notes
 - Referral pathway often poorly documented
 - Difficulty getting full details in retrospect within shared care service



Fig 3³

Suggested discussion points

- **Challenges in suspecting childhood cancer and making timely and appropriate referrals** (Goyder)
 - **Identifying 'Alert' symptoms**
 - Often vague and depend on type of cancer present (Dang-Tan et al)
 - Uncommon: 4% of all consultations 15-24y by GPs (Fern et al)
 - **Few cases seen by GPs**
 - 'a single GP in Yorkshire will see a child diagnosed with cancer once every 20 years on average' (Feltbower et al, 2004)
 - **Parents to identify symptoms and make medical contact**
 - Increased challenges in view of nature of tumour, capacity for **rapid growth of tumour and progression of symptoms** (Dang-Tan et al)
 - increased morbidity particularly with bone tumours

References

- Fig. 1 TVCN <http://www.tvcn.nhs.uk/about-us/>
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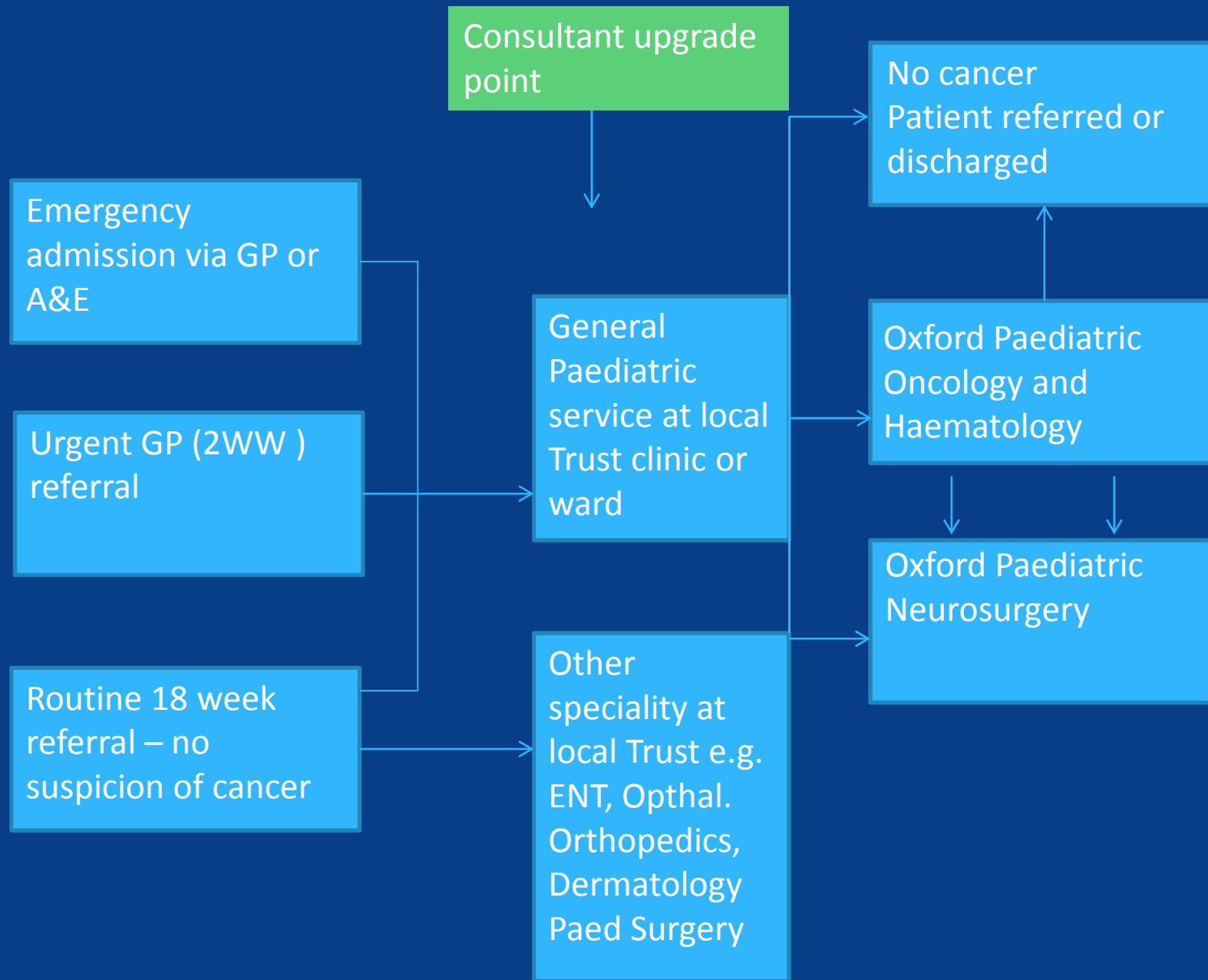


Fig 4. Referral Pathway to Tertiary services

CNS tumours: Signs and Symptoms between onset and diagnosis

| Symptomatology | At onset | At diagnosis |
|-----------------------|----------|--------------|
| Visual system | 17% | 70% |
| Motor abnormality | 22% | 67% |
| Cranial nerve palsies | 17% | 54% |
| Behavioural change | 3% | 40% |
| Nausea and Vomiting | 28% | 63% |
| Headache | 40% | 58% |
| Endocrine / Growth | 7% | 25% |

Table 1: Top 7 symptoms in rank order of percentage increase (Wilne et al, www.headsmart.org.uk)

CNS Tumours – Referral criteria < 2years

- **Immediate Referral**
 - New-onset seizures
 - Bulging fontanelle
 - Extensor attacks
 - Persistent vomiting

CNS Tumours – Referral criteria > 2 years

- **Immediate Referral Criteria >2yrs**
 - Reduced level of consciousness
 - Headache and vomiting that cause early morning waking or occur on waking (signs of raised ICP)
 - Neurological symptoms
 - New onset seizures
 - CN abnormalities
 - Gait Abnormalities
 - Motor /sensory signs
 - Unexplained deteriorating school performance/developmental milestones
 - Unexplained behavioural and/or mood changes

CNS Tumours – Urgent Referral criteria

- **Urgent Referral >2yrs**
 - Persistent headache & unable to carry out adequate neurological exam in Primary Care
- **Urgent referral <2 yrs**
 - Abnormal increase in head size
 - Arrest/regression of motor development
 - Altered behaviour
 - Abnormal eye movements
 - Lack of visual following
 - Poor feeding/failure to thrive
 - Squint, urgency dependant on other factors

Solid Tumours – Neuroblastoma

- Urgent referral:
 - Proptosis
 - Unexplained back pain
 - Leg weakness
 - Unexplained urinary retention

Solid Tumours - Soft tissue Sarcomas

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

Leukaemia

- **Immediate referral**
 - Unexplained petechiae
 - Hepatosplenomegaly
- **Investigations (FBC, Blood film) if:**
 - Pallor. Fatigue
 - Unexplained irritability/fever
 - Persistent/recurrent URTIs
 - Generalised lymphadenopathy
 - Persistent/unexplained bone pain
 - Unexplained bruising

Lymphoma

- **Immediate referral**
 - Hepatosplenomegaly
 - Mediastinal/hilar mass on CXR
- **Urgent referral**
 - Non-tender, firm, hard LNs
 - LN >2cm
 - Progressively enlarging LN
 - General ill health, fever, weight loss
 - Axillary node involvement (in absence of local infection/dermatitis)
 - Supraclavicular node involvement
 - Shortness of breath, Unexplained petechiae, hepatoplenomegaly