ACE ‘Too young to get cancer?’

Understanding the challenge of achieving a timely diagnosis for Teenagers and Young Adults (TYA) in the South West of England


What do young people tell us?

National Cancer Patient Experience Survey

“should have been seen a lot sooner”

Teenage Cancer Trust
FYSOT Survey

61% diagnosis could have been quicker
24% visited GP at least 4 times before referral
21% not referred to a specialist at all
What do young people tell us?

Features Of Cancer In Teenagers And Young Adults In Primary Care: A Population-Based Nested Case-Control Study. **Dommett** et al. Br J Cancer. 2013

- In the 3 months before diagnosis
  - 42.9% cases consulted ≥4 times (11.5% controls)
  - Predictive value of symptoms and consultation frequency v low
The diagnostic pathway

Symptom → Consult a doctor → Tests → Referral → Specialist visit → Diagnosis → Treatment
Aims

- Map the diagnostic pathway
- To better understand the referral pathways across the network
- To define and inform the design of interventions to improve Time To Diagnosis (TTD) and patient experience in TYA cancer

Bespoke database to capture every healthcare contact
### Route Map

<table>
<thead>
<tr>
<th>Day</th>
<th>Date</th>
<th>Patient Factors</th>
<th>Self-Primary Care</th>
<th>Primary Care</th>
<th>Investigation</th>
<th>A&amp;E</th>
<th>Consultation</th>
<th>Cancer Ix</th>
<th>Biopsy</th>
<th>MDT</th>
<th>Treatment</th>
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### Multiprofessional Panel

To identify:

- Key Events
- Good Practice
- Missed Opportunities
- Potential Interventions
Panel Aims

To identify:
- Key Events
- Good Practice
- Missed Opportunities
- Potential Interventions

A. 1st Presentation Relating to Cancer Diagnosis (Patient)
B. 1st Presentation/Clinical Appearance
C. 1st Investigation
D. 1st Referral
E. 1st Specialist Visit
F. Diagnosis
G. Start of Treatment

Clinical Bottom Line

<table>
<thead>
<tr>
<th></th>
<th>Good Practice</th>
<th>Room For Improvement</th>
<th>Less Than Satisfactory</th>
<th>Insufficient Data</th>
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Recruitment

- n= 105
- Overall response rate 63%
- 68% 19y+

Cancer diagnosis

- Lymphoma: 29
- Carcinoma: 21
- Leukaemia: 18
- Germ Cell Tumour: 10
- Bone Sarcoma: 7
- Brain/CNS Tumour: 7
- Soft Tissue Sarcoma: 6
- Malignant Melanoma: 5
- Other: 1
Every experience is different

Total interval in days (median)
1st presentation to start of treatment

- Bone Sarcoma
- Brain/CNS
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Malignant Melanoma
- Soft Tissue Sarcoma
- Other
Total interval (median, range)  
1st presentation to start of treatment

Total interval, individual data
Primary care contacts from 1st presentation to start of treatment

First presentation

- Bone: 7%
- Brain: 85%
- Carcinoma: 4%
- GCT: 4%
- Leukaemia: 10%
- Lymphoma: 10%
- Melanoma: 10%
- STS: 10%

A&E: 4%
Primary Care: 4%
Other: 7%
Unknown: 85%
Cancer suspicion at first presentation

- GCT (n=9)
- Malignant Melanoma (n=5)
- Lymphoma (n=27)
- Leukaemia (n=18)
- Soft Tissue Sarcoma (n=6)
- Carcinoma (n=19)
- Brain/CNS (n=7)
- Bone Sarcoma (n=7)
- Other (n=1)

Primary care interval (days, median)
1st presentation to 1st referral

- Bone Sarcoma
- Brain/CNS
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Malignant Melanoma
- Soft Tissue Sarcoma
Route to diagnosis
What is happening in secondary care?

- Bone Sarcoma
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Soft Tissue Sarcoma

What is really happening in secondary care?

- Referral interval

- Bone Sarcoma
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Soft Tissue Sarcoma
Specialist care interval = specialist visit to treatment
Treatment interval = biopsy to treatment

Mapping the pathway and qualitative outcomes

- Diagnostic Assessment
- Diagnostic Follow Up
- Tests
- System Communication
- System Targets
- System Capacity
- Disease
- Patient Experience

Time to biopsy
19 year old male
Ewings sarcoma

### Clinical Bottom Line

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Good Practice</td>
<td>40%</td>
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<tr>
<td>Room For Improvement</td>
<td>44%</td>
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<tr>
<td>Less Than Satisfactory</td>
<td>16%</td>
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Conclusions

- Every experience is different
- This study readjusts our understanding of where difficulties arise
- There should be as much focus in secondary care as primary care

What next?

- Streamline pathways
  - Referral guidance
  - TYA health services
  - Secondary Care Pathway Interventions
  - Pathway coordinator
What next?

- Patient experience
- Debrief exercise
- Early re-engagement with primary care

Never Too young to get cancer
Thank you

- Young people
- Paul Beynon
- Primary care
- Cancer Managers
- TYA CNS team
- UHBristol NHS Foundation Trust

- North Bristol NHS Trust
- Royal Cornwall Hospitals NHS Trust
- Plymouth Hospitals NHS Trust
- Royal Devon and Exeter NHS Foundation Trust
- Taunton and Somerset NHS Foundation Trust
- Weston Area Health NHS Trust
- Yeovil District Hospital NHS Foundation Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Royal United Hospitals Bath NHS Foundation Trust