‘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

Dr Rachel Dommett
Why TYA?
Cancer incidence by age
Disease spectrum

Late onset childrens cancers

Typical TYA cancers

Early onset adult cancers
Average number of new cases per year
15-24y UK 2000-2009

Diagram showing the average number of new cases per year for different diagnostic groups, with separate bars for male and female. The groups include:
- Lymphomas
- Carcinomas
- Germ Cell Tumours
- Brain, Other CNS & Intracranial Tumours
- Malignant Melanoma
- Leukaemias
- Bone Tumours
- Soft Tissue Sarcomas
- Other and Unspecified
GP Consultation Rates

GP consultation rates per registered patient for males and females

NOTE: Analysis by calendar years
copyright QRESEARCH 2003-2009 (Database version 22)
What do young people tell us?

National Cancer Patient Experience Survey

“should have been seen a lot sooner”

Teenage Cancer Trust 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?

Symptom → Consult a doctor → 

- Tests
- Referral
- Specialist visit
- Diagnosis
- Treatment
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
The diagnostic pathway

- Symptom
- Consult a doctor
- Tests
- Referral
- Specialist visit
- Diagnosis
- Treatment
Aims of ‘Too young to get cancer?’

- 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**

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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

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<th>Room For Improvement</th>
<th>Less Than Satisfactory</th>
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Recruitment

- $n = 105$
- Overall response rate 63%
- 68% 19y+
Every experience is different
Total interval in days (median)

1\textsuperscript{st} 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)  
1\textsuperscript{st} presentation to start of treatment
Total interval, individual data
First presentation

85%

A&E
Primary Care
Other
Unknown
### Cancer suspicion at first presentation

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Primary care interval (days, median)  
1\textsuperscript{st} presentation to 1\textsuperscript{st} referral

- Bone Sarcoma
- Brain/CNS
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Malignant Melanoma
- Soft Tissue Sarcoma
Route to diagnosis

- Emergency Presentation: 38
- GP Referral: 6
- TWW: 45
- Other Outpatient: 11
- Screen Detected: 1
Route to diagnosis

- Bone Sarcoma
- Brain/CNS
- Carcinoma
- Germ Cell Tumour
- Leukaemia
- Lymphoma
- Malignant Melanoma
- Soft Tissue Sarcoma
- Other

Legend:
- Unknown
- Screen Detected
- Other Outpatient
- TWW
- GP Referral
- Emergency Presentation
What is happening in secondary care?

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

- Secondary Care Interval
- Specialist Care Interval
- Treatment Interval
Mapping the pathway and qualitative outcomes

- Diagnostic Assessment
- Diagnostic Follow Up
- Tests
- System Communication
- System Targets
- System Capacity
- Disease
- Patient Experience
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19 year old male
Ewings sarcoma
- 2yr back pain
- 6mth groin lump
- Drug use
- Use of Out of Hours
Referral made at first consult for MRI

Multiple contacts
  6 contacts in 8 days

Multiple GPs

Use of Out of Hours
  Frequent caller

Escalating analgesia requirements

Reliance on secondary care
Secondary Care

- MSK clinic - Double gate keeping
- Non urgent onward referral
- Xray reported as normal
- Supraregional referral
### Clinical Bottom Line

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<tr>
<th>Category</th>
<th>Percentage</th>
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<td>44%</td>
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<td>Less Than Satisfactory</td>
<td>16%</td>
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TYAs may have difficulty in describing their symptoms

Naïve healthcare seeking behaviour

Different priorities Life Vs Health

Ongoing role of the parent as their advocate

Vague symptoms and who to refer to

Is a different safety netting approach required

Consider a “3 hits and you’re in” principle
Typical symptoms but too young??
- Ovarian
- Colorectal cancer

Musculoskeletal symptoms
- Back pain
- Pain at night
- Escalating analgesia requirements
Total interval, individual data
Primary care contacts from 1\textsuperscript{st} presentation to start of treatment
Primary care contacts from 1\textsuperscript{st} presentation to start of treatment

Patients are consulting primary care for support after specialist referral
Conclusions

- Every experience is different
- Route to diagnosis ≠ diagnostic pathway
- 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
What next?

- Patient experience
- Earlier access to TYA support
- 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
- UH Bristol 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